Empowerment in Epilepsy Services: A ‘Soft Systems’ study referenced to Critical Social Theory and a Specialist Epilepsy Service in Ireland.

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Declaration

I, Louise Bennett declare that this thesis is submitted in partial fulfilment of the requirement of the degree in Doctor of Philosophy (PhD) and is entirely my own work except where otherwise accredited. It has not at any time, either whole or in part been submitted for any other educational award.

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Abstract

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Empowerment is an integral component of holistic practice and service design in health care, particularly as it relates to the improvement of quality of life for people with chronic illnesses. However, the literature suggests that empowerment is a neglected and poorly understood concept by service users and providers. This study explores the concept and dimensions of empowerment within an Irish epilepsy service using a ‘Soft Systems’ methodology (Checkland 1981) referenced to Critical Social Theory (CST).

The study adopted a three phase mixed methods design to promote data analytical triangulation. The first phase involved a survey of people with epilepsy on their views of their service needs in relation to design and delivery. The second phase involved in depth interviews with people with epilepsy and service providers with reference to service user and clinician empowerment. This analysis was further informed by a non- participatory observation of services within one Irish epilepsy specialist service in Ireland. The final phase involved a focus group with people with epilepsy and service providers to identify desirable and feasible changes needed to facilitate empowerment within Irish epilepsy services.

A situational analysis and conceptual model of empowerment within one Irish epilepsy specialist service is presented. Findings suggest that considerable improvements in terms of epilepsy services and care provision, communication, education, resources, empowerment strategies and supports are needed. The conceptual model of the service is compared to its service operation and wider inferences for the development and operationalization of epilepsy policy and practice within Irish epilepsy services is presented. Overall, the findings of this study contribute to the understanding and the literature relating to CST, empowerment and epilepsy health care.

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I dedicate this thesis to the memory of my late father Paddy Bennett, who will never be forgotten and always missed.

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Glossary and Acronyms

A&E:	Accident & Emergency
AEDs:	Anti-Epileptic Drugs
ANP:	Advanced Nurse Practitioner
ANPc’s:	Advanced Nurse Practitioner candidates
ASAP:	Alcohol and Substance Abuse Prevention
CATWOE:	Customer, Actor, Transformation, Weltanschauung Ownership, Environment
CAQDAS:	Computer Assisted Qualitative Data Analysis Software
CBD:	Cannabidiol
CCM:	Chronic Care Model
CDM:	Chronic Disease Management
CINAHL:	Cumulative Index to Nursing and Allied Health Literature
CNS’s:	Clinical Nurse Specialist’s
CWEQ-II:	Conditions of Work Effectiveness Questionnaire-II
CST:	Critical Social Theory
CUH:	Cork University Hospital
DoH:	Department of Health
DoHC:	Department of Health and Children
DoN:	Director of Nursing
ECG:	Electro-Cardio-Gram
ED:	Emergency Department
EI:	Epilepsy Ireland
ELSC:	European Life Science Circle
EPiC:	Epilepsy Partnership in Care
EPR’s:	Electronic Patient Records
ESN:	Epilepsy Specialist Nurse
EU:	European Union
EUFSH:	European Union’s Financial Stability Fund
EUWTD:	European Union Working Time Directive
GCAE:	Global Campaign Against Epilepsy
GDMS:	General Decision Making Style scale
GP:	General Practitioner

GUH:	Galway University Hospital
HAS:	Human Activity System
HSE:	Health Services Executive
IBE:	International Bureau for Epilepsy
IBE:	International Bureau for Epilepsy
ICT:	Integrated Communication Technology
ID:	Intellectual Disability
ILAE:	International League Against Epilepsy
IMF:	International Monetary Fund
IOM:	Institute of Medicine
IT:	Information Technology
KPIs:	Key Performance Indicators
LoS:	Length of Stay
LUH:	Limerick University Hospital
MDT:	Multidisciplinary Team
MHC:	Mental Health Commission
MOP’s:	Management Operating Procedures
MOSES:	Modular Service Package Epilepsy
NECP:	The National Epilepsy Care Programme.
NHS:	National Health Service
NICE:	National Institute of Health and Clinical Excellence
OPTION:	Observing Patient Involvement
OPD:	Out Patient Department
PAC:	Patient Advisory Committee
PAR:	Particapatory Action Research
PCC:	Patient/Person Centred Care
PEQ:	Psychological Empowerment Questionnaire
PRISMA:	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROMs:	Patient Reported Outcome Measures
PCHR:	Personally Controlled Health Records
PubMED:	Public/Publisher MEDLINE
PWE:	People with Epilepsy
PWE F:	Person with epilepsy: Female
PWE M:	Person with epilepsy: Male

QoL:	Quality of Life
RAC:	Rapid Access Clinic
RANPs:	Registered Advanced Nurse Practitioner’s
RCSI:	Royal College of Surgeon in Ireland
RCT:	Random Control Trial
RGN:	Registered General Nurse
RMN:	Registered Mental Nurse
RO:	Research Objective
SCT:	Social Cognitive Theory
SD:	Specialist Doctor
SE:	Status Epilepticus
SEE:	Seizure and Epilepsy Education
SENsE:	Specialist Epilepsy Nurse(s) Evaluation
SIGN:	Scottish Intercollegiate Guidelines Network
SJH:	St James’s Hospital
SOP’s:	Standard Operating Procedures
SP: F:	Service Provider: Female
SP: M:	Service Provider: Male
SPSS:	Statistical Package for Social Sciences
SSM:	Soft Systems Methodology
SUDEP:	Sudden Unexplained Death in Epilepsy
UK:	United Kingdom
US:	United States
VPA:	Valproic Acid
VNS:	Vagal or Vagus Nerve Stimulation
WebEase:	Epilepsy Awareness Support and Education
WHO:	World Health Organisation
WIT:	Waterford Institute of Technology

CHAPTER ONE

Introduction: Focus, Catalyst and Structure

1.1 Introduction

Since 2001 the Irish Government has promoted the concept empowerment of both service users and providers of healthcare (DoHC 2001). This study explores empowerment within Irish epilepsy services by using one specialist service as an exemplar. Empowerment is now seen as an integral component of holistic practice and service design in health care, particularly as it relates to the improvement of quality of life for people with epilepsy (Wagner 1998, Baker and Jacoby 2000, Living Well with Epilepsy 2004, Jacoby *et al.* 2009). However, the literature suggests that empowerment is a neglected and poorly understood concept by service users and providers alike within epilepsy services (England *et al.* 2012, Fitzsimons *et al.* 2012). Following a concept analysis of empowerment and epilepsy healthcare a working definition of empowerment within epilepsy services was developed (see Chapter 2).

> '*Empowerment within epilepsy services is a subjective process or outcome for service users and providers arising from a transformation of consciousness and an access to power from within. This facilitates an experience of personal and social change, enabling service users and providers to take action in order to achieve influence over the organisations and institutions which affect their lives and the communities in which they live'*.

Whilst there is a body of research which points to a lack of empowerment for people with chronic conditions, such as people with epilepsy (Varley *et al.* 2011), research exploring organisational structures within which service providers function and how they are supported in practice to facilitate empowerment for people is lacking. The Living Well with Epilepsy II conference (2004) recommends that systems and models of care foster empowerment and independence for people with epilepsy and support their efforts towards improved seizure control and an improved quality of life. Furthermore, chronic care models emphasise patient-centeredness and the need for both community and health care systems to work together to achieve desired outcomes (Austin *et al.* 2000). This study, therefore, explores and critically analyses organisational issues and human factors on service provision that support or hinder empowerment within one Irish epilepsy specialist service using a '*soft systems'* approach (Checkland 1981) referenced to Critical Social Theory (CST) (Habermas 1971; 1978; 1984; 1987; 1988; 1990, Freire 1970; 1972; 1990; 1993; 1997; 1998; 2000; 2004).

This chapter provides an introduction to the study. Section 1.2 outlines the incidence and prevalence of epilepsy. In section 1.3 the impact of epilepsy on the person with epilepsy, their family and carer is described. Section 1.4 outlines both national and international concerns as they relate to empowerment within epilepsy healthcare as the rationale for this study. In section 1.5 the catalyst for this study is discussed and section 1.6 explores the theoretical understandings of empowerment that exist within the literature, with particular emphasis on CST. In section 1.7 an overview of the structure and content of this thesis is presented. The novel contributions of this soft systems study is acknowledged in section 1.8. Finally, section 1.9 describes the relationship between published peer reviewed papers arising from this study with the chapters in this thesis.

1.2 Epilepsy: Overview of incidence and prevalence

Epilepsy is a chronic neurological disorder characterised by recurrent unprovoked seizures and is the most common serious neurological condition after stroke (Hadjikoutis and Smith 2005). The World Health Organisation (WHO) (2006) projects a rise in the number of epilepsy cases in Europe from approximately 40 million in 2005 to more than 50 million by 2030. Such a rise has economic implications as more than €15 billion is spent annually on the treatment of epilepsy in Europe; a financial burden comparable to that of lung and breast cancer combined (Puglatti *et al.* 2007).

Internationally the overall incidence of epilepsy has been reported as 67.77 cases per 100,000 persons per year while the lifetime prevalence has been reported as 7.60 cases per 1,000 persons (Fiest *et al.* 2017). Specific to Ireland, lifetime prevalence of epilepsy among those aged 18 years and older has been reported as 10 per 1,000 persons (n=31,000), with 8.3-9 per 1,000 persons (approximately 33,000-37,000) aged 5 years and older having epilepsy, which is in line with other industrialised nations (Linehan *et al.* 2010).

Of the 40,000 people with epilepsy in Ireland (10,000 of whom are under 16 years), 70% are well controlled on medication (Linehan *et al.* 2010). This leaves approximately 12-15,000 people who have breakthrough seizures, and who are in regular contact with secondary and tertiary hospital services (Linehan *et al*. 2010).

1.3 Impact of epilepsy on the person with epilepsy, their carer and family

For people with epilepsy the burden of this disorder is substantial and complex, compromising biological, psychological and social challenges. Adults and children with epilepsy have an increased rate of mortality which is about 2-3 times higher than that of the general population, with a conservative estimate of 111 people dying per year due to Sudden Unexplained Death in Epilepsy (SUDEP) or the complications of prolonged uncontrolled convulsive activity, also known as Status Epilepticus (SE) (Health Service Executive (HSE) 2014). Also, higher rates of co-morbidity are reported in people with epilepsy compared to the general population (Elliott *et al.* 2009). Epilepsy is associated with particular vulnerable groups of people including people with an Intellectual Disability (ID), whose prevalence rate has been reported thirty times higher than the general population (Forsgren *et al.* 2005). Epilepsy in adults with ID has a worse prognosis than epilepsy in the general population, and have higher rates of morbidity (McGrother *et al.* 2006) and mortality, including sudden unexplained death in epilepsy (Hitiris *et al.* 2007).

Empirical literature highlights that the medical features of epilepsy are the least disabling aspect of life compared to psycho-social and structural difficulties that people with epilepsy confront (Fisher *et al.* 2000, Varley *et al.* 2011). A potential significant issue for people with epilepsy is co-morbid psychiatric disorder, for example depression and schizophrenia. Compared to the general population, people with epilepsy are up to 50% more likely to suffer from depression and have an 8-fold increased risk of developing a mental health issue (Kanner 2003, Clancy *et al.* 2014). Lifestyle, driving, work, self-confidence/self-esteem, academic life, family life are but a few areas highlighted (Fisher *et al.* 2000, Varley *et al.* 2011). For example, in Ireland, people with epilepsy must be free of seizures with loss of awareness for at least one year before being allowed to drive. Consequently there can be significant implications for the level of burden experienced by people with epilepsy, dependents and family (Zarocostas 2010).

Stigma, myth, fear and discrimination still exist in relation to a diagnosis of epilepsy and leads to poor self-esteem and exclusions; restrictions; overprotection and social isolation (Weatherby-Fell 2011). Consequently, health-related quality of life is significantly poorer (Chubon 1995, Hermann *et al.* 1996). Bearing all of these issues in mind, Fisher *et al*.

(2000) states that even for people with well controlled epilepsy, there is a need for ongoing medical and psychosocial support.

1.4 Rationale for this study

A Cochrane review reports that an optimum system of care for people with epilepsy has not yet been empirically determined (Bradley and Lindsay 2008). Indeed, recent data suggest that people with epilepsy play a passive role in their healthcare (Varley *et al.* 2011) which reinforces the necessity for direct patient participation as a priority for service planning and delivery. Supporting people with epilepsy to develop the attributes and skills required to function as equal partners with clinical and social services, be empowered to make informed decisions and competently self-manage with regards to their healthcare is warranted if they are to manage effectively the day-to-day challenges they face in their lives (Fitzsimons *et al.* 2012). However, research to date exploring service user's and service provider's perspectives on empowerment in relation to epilepsy care is lacking despite health policy advocating a partnership approach (Department of Health and Children (DoHC 2008).

In this context, a challenge facing modern health care systems is to develop and implement new models of service that delivers a high-quality, more cost-effective service that significantly improves the lives of people with epilepsy (Westbrook *et al.* 2009). This is reflected in recent Irish health care policy, which challenges traditional models of service delivery and cost structures with a move towards models of care that require service reconfiguration, reform and greater productivity (HSE 2011). Improving quality of life for people with epilepsy is the main goal of national and international policy (D0HC 2008, HSE 2011). However, national data highlight that the implementation of empowerment from theory to practice is not always straightforward (Corbally *et al.* 2007). For instance, it is claimed that there is a lack of a service model that is sensitive to the needs of the service user affecting the quality of service provision (Mental Health Commission (MHC) 2006). Arguably, what is required is an epilepsy service that is guided by empowerment policy with more meaningful engagement of people with epilepsy, and service providers.

While current Irish healthcare policy addresses the principle of partnership and patient centeredness (DoHC 2008), it still does not explicitly deal with facilitating empowerment within Irish epilepsy services. Moreover, while chronic disease management strategies recommend that patients be empowered to self-manage their healthcare, the importance of empowerment for healthcare policy and service provision needs to be more explicitly recognised and the need to reformulate debate within an empowered perspective advanced. Arguably, a move towards developing an empowering health policy and service provision requires a stronger awareness of the macro, meso and micro levels for policy development.

1.5 Catalyst for this study

This study was prompted by the HSE following a number of meetings with the Irish Epilepsy Services in which clinicians expressed a desire for a study on how the service could better meet the needs of service users and, specifically whether services effectively engaged with service users as partners in their care and support. It was this that informed the development of the research questions, aim and objectives. Clinicians in this particular service, that is the focus of this study, felt that people with epilepsy largely play a passive role with regards to their health care but were not clear why this situation was ongoing. In this context, it was important that this study explore the views of both people with epilepsy and members of the Epilepsy service in relation to empowerment within this service and what lessons could be learned more broadly about empowerment within Irish epilepsy services. Therefore this study uses one epilepsy service as an exemplar to explore wider issues. Thus the research questions, aim and objectives posed in this study were as follows:

1.5.1 Research Questions

1. What do people with epilepsy and service providers' understand by empowerment?
2. What are the organisational issues and human factors within the service that support or hinder empowerment of people with epilepsy?
3. What are the organisation and human factors within the service that support or hinder empowerment of clinicians within the service?

1.5.2 Aim and Objectives

To explore and analyse the epilepsy service as a system with reference to dimensions of empowerment using CST. It encompasses the following objectives:

(1) To utilise CST to analyse and define the concept of empowerment in the Irish health service.

(2) To develop a situational analysis and conceptual model of the service utilising 'soft systems' methods with reference to the NECP.
(3) To explore and critically analyse organisational issues and human factors in service provision that support or hinder empowerment.
(4) To compare the conceptual model of the service with its service operation.
(5) To draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland as this relates to empowerment.

I applied to do a full time PhD in relation to this project in 2012 at Waterford Institute of Technology (WIT). I transferred to the part time register in 2014 as I was appointed a lecturer in Nursing at WIT. A number of personal and professional beliefs and experiences provided the motivation to embark on this study.

At a professional level, I worked as a Registered General Nurse (RGN) in both national and international hospitals from 1997 to 2013. During this period it became apparent to me that various levels of empowerment exist for both service users and providers within healthcare. Consequently, such factors challenged me both personally and professionally with regards to my own empowerment and the facilitation of empowerment for service users within my care.

During my years in clinical practice, I pursued a part time post graduate Diploma in Perioperative Nursing, a Master's of Science in Nursing, a Certificate in Nurse/ Midwife Prescribing and a Postgraduate Diploma in Clinical Health Science in Education. This raised my philosophical, sociological and political awareness about issues in relation to empowerment within healthcare for both service users and providers. This led me to further question the concept and meaning of empowerment within healthcare, and indeed whether or not it was in fact a '*buzz word'*. Thus, I discovered the meaning of powerlessness and the urgent need for empowerment. Such awareness shaped my subsequent thoughts with regard to the current study (O Gorman and Bennett 2014).

Empowerment was often discussed during my years in clinical practice and on reflection, raised many questions and concerns by colleagues. For instance, on the one hand, much literature has promoted the concept of empowerment, whilst on the other hand, service users remain ignored during the decision-making process. Nonetheless, it seems that some service users do not always want to make decisions. Therefore, many questions have crossed my mind over the years and thus, I consider it necessary to clarify and explore the concept of empowerment within epilepsy healthcare.

Empowerment has been shown to affect both job satisfaction and improved quality care (Manojlovich and Laschinger 2002). Therefore, in relation to the climate of austerity in Ireland, care needs to be taken that strategies are put in place that prioritise the empowerment of service providers also and ensure their visibility within the organisation (Scott *et al*. 2013). Therefore, the catalyst for this study was a combination of reactive elements over time involving my professional experience, on-going education, research interests relating to my clinical practice and also issues identified by the working committee of the NECP. As a result this study is a *'systems'* study that explores empowerment in epilepsy services referenced to CST and a specialist epilepsy service in Ireland.

1.6 Theoretical understandings of empowerment

Theoretically empowerment is viewed from many vantage points such as (1) organisational/structural (Kuokkanen and Leino-Kilpi 2000); (2) psychological (Kuokkanen and Leino-Kilpi 2000); (3) post-structuralism and (4) CST (Kuokkanen and Leino-Kilpi 2000). These theoretical positions are now explored.

1.6.1 Organisational/Structural Theory

Organisational empowerment is a much researched topic within the management and business arena and acknowledged as access to organisational structures in the work environment through lines of communication, support, information, and resources, offering workers opportunities to share in decision making processes and assist in control of resources (Conger and Kanungo 1988, Kanter 1993, Mills and Ungson 2003). Much of this research emanates from Kanter's Theory of Structural Power and Laschinger's Work Empowerment theory and both are now explored.

Rosabeth Kanter (1977) outlines a structural theory of organisational behaviours, which evolved from her qualitative study of work environments in a large American corporation. According to Kanter (1977), employee work behaviours and attitudes are shaped in response to work conditions and situations, rather than inherent personal characteristics. Hence, the structural aspects of a job are more important in influencing effectiveness and success of an individual within an organisation. Kanter's model was used to explore and measure empowerment (Chandler 1992, Laschinger and Havens 1996, Laschinger 2008).

According to Kanter (1977) power is the critical structural element that affects behaviours in organisations, and formal and informal power in the workplace provides access to organisational structures that empower workers. She defines the structure of power as organisational attributes that enable workers to mobilise resources (Kanter 1993 p.166) and asserts that structural power comes from three organisational sources that include: (1) information; (2) support; and (3) resources. Information is recognised as the necessary knowledge and communication essential to the work of the organisation. This includes technical knowledge and expertise related to the core roles of employees, as well as information concerning what is going on in the larger organisation. Resources are the necessary people, money, equipment and supplies that enable the worker to perform work effectively. Support is feedback, coaching and assistance that one receives from management, peers and others. Positive feedback from superiors in an organisation, as well as support for exercising discretion in one's job are important components of this source of power.

Kanter (1977) maintains that opportunity within the workforce is a key influence on employees' overall mode of work involvement. Individuals in high-opportunity jobs are more likely to be highly motivated and committed and actively participate in change and innovation. Indeed, Kanter (1977) claims that employee's work behaviours are not due to individual power personal traits, but instead are responses to work conditions and situations. Therefore, arguably management must create conditions for work effectiveness by ensuring that employees have access to empowerment structures of information, support and resources to achieve organisational goals and opportunity for development (Kanter 1979). Consequently, employees who have access to these structures are more productive, experience less burnout and have higher levels of organisational commitment. As a counterpoint, individuals who have limited access to these structures are powerless and develop feelings of helplessness, insignificance, frustration and failure which in turn decreases their ambition, commitment and work effectiveness (Kanter 1977, Brown and Kanter 1982, Laschinger 1996).

As outlined, Kanter's (1979) theory acknowledges that access to information, support and resources creates an empowering work force and environment. However, it is argued that a critical component of empowerment is interpersonal relationships (Chandler 1992). Consequently, Laschinger *et al*. (2001; 2004) broadened Kanter’s (1979) interpretation of empowerment, supporting the relationship between organisational and psychological empowerment. Indeed psychological empowerment has a mediating effect on organisational empowerment. With this in mind, organisational empowerment refers to organisational efforts that generate psychological empowerment among members and organisational effectiveness needed for goal achievement (Peterson and Zimmermann 2004).

According to Laschinger (1996) structural empowerment is assumed to directly influence psychological empowerment. The higher structural empowerment is, the higher the level of psychological empowerment. With this in mind, Laschinger’s Work Empowerment theory expanded Kanter’s model to include Spreitzer’s concept of psychological empowerment. Indeed, access to empowering structures in work environments results in higher levels of psychological empowerment (Kanter 1993, Laschinger *et al.* 2010). Consequently, empowered individuals are more likely to share power with others (Kanter 1979). Indeed, service users have highlighted higher levels of satisfaction with healthcare provision and improved quality of care as a result of empowering work conditions (Laschinger *et al.* 2001, Donahue *et al.* 2008, Laschinger 2008).

1.6.1.1 Concluding comments on organisational/structural theory

Kanter’s (1993) central argument is that structural factors within an organisation are more important for empowerment than individual qualities. Kanter (1993) proposed four conditions for empowerment: (1) opportunity for advancement; (2) access to information; (3) access to support; and (4) access to resources. The environment provides relatively more or less empowerment, depending on how many of the four structures are present (Manojlovich and Laschinger 2007). From this perspective, power is the ability to get things performed and empowerment is the opportunity to execute a certain course of action successfully (Kuokkanen and Leino-Kilpi 2000, Suominen *et al.* 2006). Considering power within organisations, then, is a useful way of understanding how to empower people. However, organisational theory does not account for oppressed groups, but rather is concerned with the distribution of power in organisations and particularly how this occurs from the top-down (Kuokkanen and Leino-Kilpi 2000). The following section describes psychological theory.

1.6.2 Psychological theory

Psychological empowerment is a much researched topic and amongst the theorists include: Zimmerman (1995); Conger and Kanungo (1988); Thomas and Velthouse (1990); and Spreitzer (1995, 1997). A brief description of their work is now outlined.

Psychological empowerment is acknowledged as a process through which individuals gain control (Rappaport 1981, Zimmerman 1995, Peterson and Zimmerman 2004). Zimmerman (1995) asserts that psychological empowerment is comprised of the individual's interaction with their environment and intrapersonal perception of empowerment. Within the psychological model the assumption is that power is a personal attribute that can be fostered through a humanistic discourse. For example, personal growth encourages personal power and therefore empowerment (Katz 1984, Gilbert 1995, Ryles 1999) is linked to concepts such as self-esteem and personal control (Rissel *et al.* 1996). This has the potential to transform individuals so that they are able to critically analyse their situations and have the confidence to act upon their analyses (Gibson 1991, Townsend 1998, Ghaye 2000). It is a series of experiences in which individuals learn to see a closer relationship between their goals and a sense of how to achieve them; gain greater access to and control over resources; and in which people, organisations, and communities gain mastery over their lives (Zimmerman 2000).

Zimmerman (1995) suggests that individual's psychological empowerment operates through intrapersonal; interactional; and behavioral components. Firstly, at an intrapersonal component, empowerment addresses the manner in which individuals think about themselves and includes concepts of perceived control, self-efficacy, motivations to control, and perceived competence. Secondly, the interaction component of psychological empowerment assesses how people understand and relate to their social environment. Interactional characteristics address one's ability to develop a critical understanding of the forces that shape their environment and knowledge of the resources required and methods to access those resources to produce social change. Interactional characteristics include management skills, problem solving, and critical awareness. Finally, the behavioral component of psychological empowerment includes actions that address needs in a specific context.

Conger and Kanungo (1988) and Thomas and Velthouse (1990) were among the first to work on psychological theory in the development of empowerment. Conger and Kanungo (1988) suggested that empowerment viewed as a purely organisational concept was inadequate unless the individual employee was considered. Subsequently, Thomas and Velthouse (1990) further developed a model of empowerment describing three necessary stages of human existence and these include: belief systems; assessment; and enactment processes.

Spreitzer's theory of psychological empowerment is a motivational construct demonstrated by meaning, competence, self-determination and impact (Spreitzer 1995; 1997). A measurement scale known as the Psychological Empowerment Questionnaire (PEQ) was devised by Spreitzer (1995) to measure each of these constructs and has been used extensively internationally (Laschinger *et al.* 2004, Li *et al.* 2008, Uner and Turan 2010, Ibrahim 2011, Nasiripour and Siadati 2011).

1.6.2.1 Concluding comments on psychological theory

To summarise, psychological theory of empowerment supports the influence of the individuals' response to their environment in relation to meaning, competence, self-determination, and impact and is a personal attribute or quality. This would suggest that the environment, while important, interplays with the individual creating the empowered individual. However, for a social critique to be liberating, it must reveal the hidden relations of domination and power inherent in society's fundamental structures and ideologies (Fay 1987). The following section outlines poststructuralism.

1.6.3 Poststructuralism

Poststructuralism is usually associated with the work of Michel Foucault. Foucault's conception of power is that it takes a capillary form and *'reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives*' (Foucault 1980 p. 39). Foucault's suggests that power should be studied from the bottom up rather than the top-down. Two core elements of Foucault's work include: disciplinary power; and knowledge/power relationships.

Disciplinary power is marked by meticulous control of the body and subtle coercion, resulting in a relation of docility-utility (Foucault 1995). According to Ryles (1999) disciplinary power is exercised through three processes: (1) hierarchical observation; (2) normalising judgement and (3) examination.

Firstly, hierarchical observation is about being watched and been subject to a constant ‘gaze’ (Gilbert 1995). For Foucault, this observation (gaze) takes two main forms: indiscreet and discreet. Secondly, normalising judgement is concerned with being judged and compared with particular norms (Gilbert 1995, Hardin 2001). According to Hui and Stickley (2007) different roles and responsibilities become ascribed and gradually they become the norm. In this context, a post-structural approach involves exploring how these norms have been constructed, for whom, and for what purpose (Hardin 2001). Finally, the examination combines the techniques of hierarchical observation and normalising judgement and is a surveillance ‘*that makes it possible to qualify, to classify and to punish’* (Foucault 1995 p.184). According to Bradbury-Jones *et al.* (2007) a feature of the examination is its permanency-the normalising gaze is not merely a fleeting glance.

The link between power and knowledge was addressed comprehensively by Foucault. Those in powerful positions are able to exert their version of ‘truth’ (Hui and Stickley 2007), and discourses construct a particular version of something as if it were real (Carabine 2001).

1.6.3.1 Concluding comments on poststructuralism

Power is central to understanding epilepsy healthcare provision and, if claims of empowerment are to be credible, they need to be based on an understanding of the way power operates within certain social contexts. A post-structural approach offers a means of challenging what is self-evident and hierarchical observation, normalising judgement, the examination and knowledge/power relationships need to be considered. However, Foucault does not discuss empowerment as such; indeed he may have questioned how empowerment can exist in a world where power is everywhere (Appelbaum *et al.* 1999). With this in mind, the following section outlines CST.

1.6.4 Critical Social Theory

CST is based on the premise that certain groups in society maintain subordinate positions. The origins of CST can be traced to the Institute of Social Research at the University of Frankfurt in the 1920's (Creswell 1998). Pioneering critical theorists at the Frankfurt School included Max Horkheimer, Theodor Adorno, and Herbert Marcuse, whom were largely influenced by the philosophical tradition of Marx, Kant, Hegel and Weber.

Recently however, the philosophical basis of CST has been largely linked with the German philosopher Jürgen Habermas[1], and Paulo Friere. Habermas chose to revisit the Marxian origin of critical theory and he posited a distinction between the core of Marx's social theory of labour as instrumental action, thus concentrating on economic relations and social interaction as communicative action (Habermas 1971, Crotty 1998, Miles 2005). In addition, Freire, a Brazilian educator in the 1950's dedicated his life and his teaching to the struggle of aiding oppressed and marginalised communities to achieve liberation.

According to Kuokkanen and Leino-Kilpi (2000) oppression is maintained by social institutions in order to control people, their resources and finances and can decrease a person's self-esteem and autonomy. CST is one way of generating knowledge that is based on a critical reflection of the power relations which are embedded in the structures and functions of society (Stevens 1989). A central assumption of CST is that society is structured by meanings, rules, convictions or habits adhered to by social beings (Allen *et al.* 1986). CST can provide direction, questioning the oppressive structures service users and providers confront in their everyday lives. According to Fay (1987 p.29) CST can:

> '*Redress a situation in which a group is suffering as a result of the way their lives are arranged and to overturn these arrangements and put into place another set in which people can relate and act in fuller more satisfying ways.'*

CST is also concerned with issues of politics, power and justice and the ways that society, education, religion, gender, race, sexuality, social discourses, organisations and cultural situations interact to create a social system (Kincheloe and McLaren 2005). Bearing this in mind, it aims not only to study and understand society, but to critique and change society, raising consciousness and affecting the balance of power in favour of those less powerful or oppressed (Patton 2002). It influences personal as

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[1] See Chapter 5, Section 5.3 and Habermas's (1984; 1987) distinctive features of CST.

well as group choices, recognizing that many of life's options are influenced by social attitudes (Owen-Mills 1995). Thus social attitude or norms may control many options for people with chronic illnesses such as lifestyle, school, and employment. Therefore, the aim of CST is to expose oppressions that may place constraints on individuals or social freedom (Browne 2000)[2].

The power relations that exist within the health care system are all that service users and providers have known and are taken for granted, and therefore appear normal to them (Hughes 2008). A CST framework has been utilised by nurse researchers to explore oppressive health care systems and their effect on service users. For example, Dickinson (1999) acknowledged that adolescents with diabetes displayed oppressed group behaviour because of negative judgements made by service providers and recommends the use of a research method informed by CST to facilitate empowerment for adolescents with diabetes. Mohammed (2006) also recommends the use of CST in order to improve formation of partnerships between service providers and adolescents with diabetes.

1.6.4.1 Concluding comments on CST

CST offers a way forward to achieve change in health care practice that is congruent with critical thinking that leads to challenging existing political, economic and social perspectives and that may result in empowerment, emancipation and enlightenment for service users and providers within epilepsy services. From a CST perspective, oppressed individuals are viewed as striving for liberation from oppression which is imposed through historical legacy and culture. Arguably, when empowerment is viewed using CST, many aspects of healthcare culture and socialisation within epilepsy services are acknowledged that are excluded from organisational/structural theory, psychological theory and poststructuralism.

1.6.5 Concluding comments on theoretical understandings of empowerment

Empowerment can be viewed from an organisational, psychological, poststructuralism and a critical social theoretical approach and each offers potential for healthcare research and practice. However, arguably CST is more relevant to this study of empowerment within epilepsy healthcare, insofar as it provides a mechanism to

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[2] See Chapter 5, Section 5.4 and the potential of CST for the study of empowerment and epilepsy healthcare.

analyse oppressive conditions (Manias and Street 2000) and uncover the constraints and conditions that prevent un-coerced or rational communication (Sokoly and Dokecki 1992). Moreover, it offers a framework that can explore empowerment within epilepsy services, through a critical self-reflection, one that examines the micro and macro levels of power[3].

1.7 'CST principles, soft systems methods and their relationship to the research questions, aim and objectives in this study

A Soft Systems Methodology (SSM) using a mixed method approach, informed by principles of CST, was employed in this study to explore and analyse one Irish epilepsy service as a system with reference to dimensions of empowerment.

CST is a meta-theoretical framework (Morrow and Brown 1994). Its realist ontology advocates for an improved approach to social existence (Morrow and Brown 1994); one that is free of domination, power inequities and oppression (Browne 2000). It offers a historical framework, which proposes that what is seen as real has been shaped by social, political, cultural, economic, gender and ethnic values (Carreiro 2002). It challenges the theoretical or ideological underpinnings of everyday practice and uses stakeholders' perspectives of and experiences with those practices to develop new ways for understanding their meaning and purpose in society (Lather 1986). Epistemologically, CST is transactional and subjective where:

> '*the investigator and the investigated object are assumed to be interactively linked, with the values of the investigator inevitably influencing the enquiry'* (Guba and Lincoln 1994 p.110).

In other words, the epistemology of CST is based on interactions of the researcher and the researched and subjectivity (these principles are further elaborated in Chapter 5).

SSM adopts a research approach to focus on creating change rather than simply describing the problem. This is achieved by developing models of relevance to the 'real world' or practice situation. These models are then compared against perceptions of the 'real world', which initiate an iterative process, a debate that leads to a decision about purposeful action (these principles are further elaborated in Chapter 5).

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[3] See Chapter 2, Section 2.10 and the formulation of hypothesis.

People’s experiences are now central to assessing performance of health care services as they relate to quality of care, patient engagement and enhanced accountability of clinical services to local communities (Luxford 2012). The person with a chronic condition, such as epilepsy is likely to have a life-long engagement with clinical services (Ralston *et al.* 2004, Tinetti *et al.* 2012) and therefore identifying and incorporating their experience must be seen as central to effective service design and delivery. However, to date there is a lack of research internationally that explores the views of people with epilepsy in relation to design and delivery, in particular people with epilepsy’ satisfaction with care they recieve. With this in mind, the first phase of this study involved a cross-sectional descriptive survey and examines the views of people with epilepsy with regards to health service delivery in Ireland. This survey provides a basis for an evaluation of current practice and identifies opportunities for future service reconfiguration in order to improve the quality and efficiency of epilepsy services and care provision. The findings of this survey were presented to service providers within the service and this provided a useful insight into factors that may support or hinder empowerment within the Irish epilepsy service. The findings can also be of relevance to other chronic conditions and to service development outside of Ireland.

Empowering people with epilepsy and the promotion of self-care, requires service providers to understand and appropriately deliver their role in the healthcare process (Varley *et al.* 2011). It is argued that emancipatory knowledge can be produced when service providers and users are together prepared to question the assumptions underlying the conduct of clinical practice (Edwards and Elwyn 2004). In this context, exploring empowerment from the service users and providers perspective is required in order to inform how to best facilitate empowerment within the epilepsy service. The second phase of this study involved a non-participatory observation of practice within one epilepsy service in Ireland and one-to-one interviews of people with epilepsy and their service providers of their views in relation to empowerment. Whilst a paucity of literature exists in relation to empowerment and epilepsy healthcare, the second phase of this study provides an understanding of the current operation of the Irish epilepsy service as a system and particularly the degree to which it supports or hinders empowerment of service users and providers. By utilising a soft systems approach the findings of phase 2 of this research study was presented to service users and providers as a ‘rich picture’.

Finally, the third phase of this research involved the conduction of a focus group with service users and providers to identify desirable and feasible changes needed in order to facilitate empowerment within Irish epilepsy services. This allowed service users and providers within one specialist epilepsy service to appreciate and understand each other's perspectives in relation to empowerment, service design and delivery. Arguably these findings have significant implications for practice, policy, education and research relating to empowerment within Irish epilepsy services (see Chapter 11).

1.8 Outline of study

This thesis is divided into three sections. Section One consists of three Chapters and is entitled '*Metatheory, Empowerment and Epilepsy Health Care*. The theoretical and empirical literature in relation to the research questions, aims and objectives of this study are reviewed. Chapter 2 outlines a concept analysis of empowerment and an examination of people with epilepsy and service providers within Irish epilepsy services. In this regard, empowerment is referenced to CST. An eclectic methodological framework based on aspects of Norris's (1982) and Rodgers (2000) view of concept analysis is described. This Chapter provides an operational definition and model of empowerment within epilepsy services. It describes empowerment of service users and providers and its relationship to epilepsy services. Results indicate that a critical reflection on the 'micro' and 'macro' levels of power that exist within epilepsy services is warranted with reference to theoretical principles. In this context although the map is not the terrain, this Chapter argues that an educational intervention guided by CST principles has the potential to encourage an understanding of empowerment and 'holds the key' to future advances for its implementation within epilepsy services.

Chapter 3 presents a critical appraisal of the literature in relation to empowerment and epilepsy healthcare. However, due to the relative lack of empirical studies specifically relating to empowerment and epilepsy healthcare, the search was broadened to include chronic illness. Studies conducted internationally and nationally from the perspectives of service users and providers is presented. This Chapter highlights the necessity for this current study and aims to address this gap in the literature by exploring empowerment in one specialist epilepsy service in Ireland using a soft systems methodology and CST.

Chapter 4 explores the relationship between empowerment, health policy and epilepsy care provision. Firstly, it explores key theoretical perspectives and their significance for epilepsy policy. This chapter also describes national and international epilepsy guidelines and model of care and outlines possible explanations for the absence of an empowered perspective. The importance of empowerment for policy development and service provision is recognised, and the need to reformulate debate within an empowered perspective explored. This chapter suggests a stronger awareness and connections between content, context, processes and actors for policy development.

Section Two of the thesis consists of 2 Chapters and is entitled '*The Research Journey'* and describes the process of investigation. Chapter 5 is divided into three sections. Firstly, the philosophical principles of CST are explored in relation to empowerment and epilepsy healthcare. This argument is developed using Habermas's distinctive features of CST. This chapter suggests that CST offers a philosophical framework for the study of empowerment and epilepsy care without dismissing that which is already known either from a positivist or constructivist understanding. It offers a framework that can explore empowerment within epilepsy healthcare, through critical self-reflection that examines and challenges the liberal ideological basis of inquiry, knowledge, theory development and practice. Secondly, this Chapter present's systems theory as a social ontology and Checkland's 'Soft System Methodology' (SSM) as the methodological approach for this study of empowerment and epilepsy healthcare. The philosophical underpinnings of research paradigms and how systems theory relates to CST is outlined. It also presents a critical debate of SSM and its suitability for the study of empowerment within epilepsy health care. This chapter suggests the use of systems theory and SSM has the potential to provide an opportunity to engage with macro, meso and micro levels of power within this study and facilitate empowerment for all stakeholders within the epilepsy service. The final section of this Chapter describes the methodological approach for the study and the mixed methods approach that was adopted with a focus on why these approaches were used in this study. In particular, emphasis in relation to the research setting, sampling, data collection, ethical considerations, and rigour are explored. In this context, this chapter provides a reflective section that provides insight into my thoughts and feelings during this stage of the process.

Chapter 6 describes the process of data analysis which occurred sequentially in two phases (in which the quantitative analysis phase preceded the qualitative analysis phase)

(Onwuegbuzie and Teddlie 2003). The five stages of Ritchie and Spencer's (1994) Framework Analysis/Approach are detailed. This chapter reflects on the experience of using a Computer Assisted Qualitative Data Analysis Software (CAQDAS) programme, NVivo 10, when used in conjunction with the Frameworks approach. This chapter concludes by outlining some benefits for using a CAQDAS programme. Arguably NVivo 10 in conjunction with a framework approach assists rich qualitative analysis and advances the rigor of qualitative research.

Section Three consists of four Chapters and is entitled '*Data, Soft Systems Analysis and Discussion'.* Chapter 7 presents the quantitative findings arising from this study. It reports the results of a survey of people with epilepsy in Ireland on their views of their service needs in relation to design and delivery. This Chapter ascertains the satisfaction of people with epilepsy with regards to service delivery and explores the views of people with epilepsy in relation to how health care provision could be improved. The actual and preferred sources of epilepsy care for people with epilepsy are outlined and the level of information provision for people with epilepsy presented. Findings acknowledge that despite high levels of satisfaction with hospital and primary care, participants offered several suggestions to improve healthcare delivery, such as: less delay in accessing specialist care and hospital appointments; better communication; and easier access to investigatory services. Findings demonstrate that for people with epilepsy the burden of the disorder is substantial and complex encompassing social, psychological and structural difficulties. Poor information provision particularly among women is reported. Furthermore, a lack of empowerment in people with epilepsy is highlighted.

Chapter 8 describes and analyses the perspectives of people with epilepsy and service providers in relation to empowerment within one specialist epilepsy service in Ireland. In depth interviews with people with epilepsy and service providers with reference to service user and provider empowerment was undertaken. This analysis was further informed by data generated from a non-participatory observation of service. The concept of empowerment within Irish epilepsy services is analysed and defined. Whilst some people with epilepsy lacked an understanding of empowerment the majority of service users and providers acknowledged empowerment as a subjective process and outcome and an access to 'power from within'. The findings also suggest that considerable improvement in terms of services and care provision is required in terms of access to services;

investigations and information provision. It highlights the need to fully understand the social, psychological, structural and educational concerns of people with epilepsy. An imbalance of power is reported within Irish epilepsy services with service providers unwilling to surrender control. Indeed, considerable improvement in terms of service user-provider interactions are required. Findings also demonstrate that poor communication amongst stakeholders is distorting the service experience. Whilst a lack of empowerment in people with epilepsy is highlighted, findings recognise that service providers cannot facilitate empowerment in part due to lack of training and service pressures. Moreover, a number of antecedents to empowerment within epilepsy services were identified as significant for service providers.

Chapter 9 presents the findings of a focus group (n=8) with people with epilepsy (n=4) and service providers (n=4) conducted within one specialist epilepsy service in Ireland. The aim of the focus group was to share findings of the data collected from the previous two data collection phases and explore with the participants potential service improvements and desirable and feasible changes that are needed to facilitate empowerment within the Irish epilepsy service. The five themes reported include: (1) improvements in communication and collaboration within the Irish epilepsy service; (2) involvement of people with epilepsy in the design and delivery of the service; (3) development of an ambassador program to promote understanding, social inclusion, and foster empowerment related to epilepsy; (4) provision of an empowerment curriculum for service providers and finally (5) legalising medicinal cannabis for people with epilepsy

Chapter 10 presents a softs systems analysis and describes stages 1-7 of Checkland's (2000) SSM. A situational analysis of empowerment within one Irish epilepsy specialist service is described and a rich picture presented. This Chapter provides a conceptual model describing the activities that must take place in order to understand and facilitate empowerment within the Irish epilepsy service. Findings suggest that considerable improvements in terms of epilepsy services, care provision, supports, communication, education, resources and empowerment strategies are needed. This Chapter compares the conceptual model of the service to its service operation. Finally, this Chapter translates these suggested changes into planned service objectives.

Chapter 11 critically describes the key findings of this study in relation to issues discussed in Section One of this thesis. It critiques CST and Checkland's (2000) SSM as a methodological approach and its application to this study and considers any further limitations of this study. Findings suggest that the current structure of epilepsy care in Ireland does not facilitate empowerment and requires policies, structures and financial incentives to be made available to support people with epilepsy and service providers in working together. This Chapter draws relevant conclusions and recommendations for practice, education, policy and research and reviews the contributions of this piece of research to theory and knowledge.

1.9 Author's notes of peer-reviewed publications arising from this study to date

This section describes the relationship between published peer reviewed papers arising from this study to date with the chapters in this thesis (Box 1.2). In accordance with WIT's guidelines, copies of these papers (Appendix A) are included with the thesis. This section also describes the relationship between conference papers presented nationally arising from this study with the chapters in this thesis (Box 1.1).

Box 1.1: Peer reviewed oral presentations

Chapter 7 to 10 informed Bennett L., Bergin M., Wells J.S.G. (2016) Empowerment within one Irish specialist epilepsy service: An exploratory analysis. Oral presentation. 17th Annual interdisciplinary research conference, Trinity College Dublin, Ireland.

Chapter 7 informed Bennett L., Bergin M., Wells J.S.G. (2015) Epilepsy services in Ireland: ‘A survey of people with epilepsy in relation to satisfaction, preferences and information provision’. 5th Annual Research Day. Connect, Innovate, Inspire. Waterford Institute of Technology, Waterford, Ireland. Oral presentation.

Chapter 7 informed Bennett L, Bergin M, Wells J.S.G. (2014) Patients’ perspectives of epilepsy services: A survey of patient satisfaction, preferences and information provision in people with epilepsy. 33rd Annual International Nursing & Midwifery Research Conference, RCSI Dublin, Ireland. Oral presentation.

Chapters 8 and 11 informed: Bennett L., Bergin M., Wells J.S.G. (2014) The potential of Friere’s Critical Social Theory as an approach for the study of education and people with epilepsy. 14th Annual interdisciplinary research conference, Trinity College Dublin, Ireland. Oral presentation.

Chapter 5 informed: Bennett L., Bergin M., Wells J.S.G. (2013) The potential of Critical Social Theory as a philosophical framework for the study of empowerment and epilepsy care. 13thAnnual interdisciplinary research conference, Trinity College, Dublin, Ireland. Oral presentation

Chapter 1 informed: Bennett L., Bergin M., Wells J.S.G. (2013) Empowerment in epilepsy services: A Soft Systems study referenced to CST and one specialist epilepsy service in Ireland. 4th Annual Research Day Waterford Institute of Technology, Waterford, Ireland. Poster presentation.

Box 1.2: Peer reviewed published paper

Chapter 2 informed Bennett L., Bergin M., Wells J.S.G (2016b) The social space of empowerment within epilepsy services: The map is not the terrain'. *Epilepsy & Behavior* 56: 139-148.

Chapter 8 and 11 informed: Bennett L., Bergin M., Wells J.S.G (2016a) The potential of critical social theory as an educational framework for people with epilepsy. *Epilepsy & Behavior* 43:80-87.

Chapter 7 informed Bennett L., Bergin M., Wells J.S.G (2015) Epilepsy services in Ireland: A survey of people with epilepsy in relation to satisfaction, preferences and information provision. *Epilepsy Research* 113:11-18.

1.10 Chapter summary

This Chapter has provided an introduction to this study. It has outlined the aim of this study to explore empowerment within epilepsy services using a soft systems approach referenced to CST and one specialist epilepsy service in Ireland. This Chapter provides detail in relation to the rationale and catalysts for this study. Moreover, the theoretical underpinnings of empowerment are described with particular emphasis on CST. Additionally, the contributions that this research has made to the literature are outlined. Finally, this Chapter concludes with an overview of the sections and summary of the remaining Chapters.

SECTION 1

Metatheory, Empowerment and Epilepsy Health Care

CHAPTER TWO

The Social Space of Empowerment within Epilepsy Services: The Map is not the Terrain

2.1 Introduction

Section one of this thesis consists of three Chapters. This Chapter undertakes a concept analysis and explores theoretical and empirical literature in relation to empowerment and epilepsy healthcare, referenced to CST. Chapter 3 outlines a literature review and provides a critical synthesis of existing studies in relation to empowerment and epilepsy health care from the perspective of services users and providers. Chapter 4 explores the relationship between empowerment, health policy and care provision.

Research undertaken for the purpose of knowledge development should begin with exploring existing knowledge in order to develop a conceptual and theoretical understanding of the concept to be researched (Kvale 1996). Indeed, without a clear conceptual foundation, the quality of research and theory construction is weakened and its maturity compromised (Weaver and Mitcham 2008). Bearing this in mind, a clear definition of empowerment is needed in order to adopt and evaluate epilepsy services in ways that realistically recognise, encourage and prioritise empowerment.

In section 2.2, the methodological framework based on a synthesis of Norris's (1982) and Rodgers (2000) method of concept analysis is described. The eight stages of this hybrid concept analysis methodology are outlined in sections 2.3 through to 2.10. In section 2.11 the empowerment of service users and providers and what its relationship to epilepsy services is discussed. The chapter concludes with a discussion as to whether CST has the potential to empower service providers and people with epilepsy within epilepsy healthcare.

2.2 A concept analysis of empowerment and epilepsy healthcare

Concept analysis is a method or approach by which concepts that are of interest to disciplines are examined in order to explicate their characteristics or attributes. It entails synthesising existing views of a concept and distinguishing it from other concepts with the aim of resolving gaps or variations in the knowledge base of the discipline (Knafl and Deatrick 2000). It includes a number of approaches that, on the surface, appear similar but possess significant philosophical differences (Rodgers 2000). Many concept analysis methods exist and these include: (1) Walker and Avant (1983); (2) Norris's (1982) method of concept analysis; (3) an evolutionary concept analysis (Rodgers 1989); (4) simultaneous concept analysis (Haase *et al.* 1992); (5) utility method (Morse 2000); (6) principle-based method of concept analysis (Penrod and Hupeey 2005); (7) and a hybrid model of concept development (Schwarz-Barcott and Kim 1993).

For the purpose of this study, an eclectic methodological framework based on aspects of Norris's (1982) and Rodgers (2000) approach of concept analysis was undertaken. Norris‘s (1982) framework was chosen because it is systematic, with a focus on clear-cut phases during the analysis process, and contributes to clarifying, describing and explaining concepts (Tofthagen and Fagerstrom 2010). The five steps outlined in Norris's (1982) method include: (1) identification of the concept of interest from within the discipline as well as from the viewpoint of other disciplines; (2) observation of the concept and repeated descriptions of the concept to provide a systematised description of the concept (look for patterns and sequences); (3) deciding on an operational definition of the concept; (4) development of a model, which illustrates the concept; and (5) formulation of hypothesis. All five stages are included in this concept analysis.

The seven stages outlined in Rodgers (2000) method include: (1) identify and name the concept of interest; (2) identify surrogate terms and relevant uses of the concept; (3) identify and select an appropriate realm (sample)for data collection; (4) identify the attributes of the concept; (5) identify the references, antecedents, and consequences of the concept, if possible; (6) identify concepts that are related to the concept of interest; (7) identify a model case of the concept. Rodgers (2000) stage of antecedents and consequences will be included in this analysis. Box 2.1 highlights a synthesis of Norris's (1982) and Rodgers (2000) method of concept analysis that was utilised.

An empowerment definition within research depends both on the specific people and context involved (Bailey 1992). Using a hybrid concept analysis methodology this section aims to clarify the ambiguities of empowerment in order to promote its adoption by service users and providers as an integral part of epilepsy service in Ireland.

Box 2.1: A synthesis of Norris's (1982) and Rodgers (2000) method of concept analysis

- Identify and select an appropriate realm (sample) for data collection (methods).
- Identification of the concept of interest from within the discipline as well as from the viewpoint of other disciplines.
- Observation of the concept and repeated descriptions of the concept to provide a systematised description of the concept.
- Identify concepts that are related to the concept of interest.
- Antecedent and consequential occurrences.
- Deciding on an operational definition of the concept.
- Development of a model, which illustrates the concept.
- Formulation of hypothesis

2.3 Identify and select an appropriate realm (sample) for data collection (methods)

The databases Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Public/Publisher MEDLINE (PubMED) were searched using the keywords 'empowerment', 'healthcare', 'epilepsy' and 'epilepsy services' both separately and together. Literature published in English from January 1990-July 2017 was included. I examined all the abstracts and the full texts of the articles deemed eligible for the review. Reference lists from identified articles were manually screened. The criterion for inclusion of a paper in the review was the presence of empowerment (with or without people with epilepsy). The list of references of eligible articles was examined in search of additional books and reports. A total of 391 articles were identified as potentially eligible after abstract review. Two hundred and thirty four (n=234) articles were excluded because they did not address the concept for review. The final yield was one hundred and fifty seven (n=157) paper and books. Ten concept analyses are identified to help clarify the core dimensions of empowerment which focus on empowerment from the perspective of (1) service users; (2) service providers and (3) service user-service provider relationships (Gibson 1991, Hawks 1992, Rodwell 1996, Ellis-Stoll *et al.* 1998, Ryles 1999, Finfgeld 2004, Aujoulat *et al*. 2007, McCarthy and Holbrook 2008, Holmstrom and Roing 2010, Dowling *et al.* 2011).

2.4 Identification of the concept of interest from within the discipline as well as from the viewpoint of other discipline

The first task of this concept analysis was to identify empowerment from within the discipline and from other disciplines. The results of this stage of analysis identify: (1) the origins of empowerment; (2) the historical debate with regards to healthcare empowerment and finally (3) an examination of empowerment from within the discipline and other disciplines. These are now explored.

2.4.1 The origins of empowerment

The origins of empowerment can be traced to: (1) Paulo Freire's work on CST (2) Beatrice Wright's work on discrimination and stereotypical attitudes towards people with disabilities; (3) Wolf Wolfensberger (1934-2011) a German-American academic who influenced disability policy and practice through his development of North American Normalisation; (4) John Kosciulek, who introduced the Consumer-Directed Theory of Empowerment to the field of rehabilitation; (5) Michael Wehmeyer and his contributions of the functional theory of self-determination, and finally (6) Michael Rosenbaum's (1983) contribution on learned resourcefulness among people with epilepsy.

Freire (2000) developed his theory of oppression after studying in South America. He suggested that the oppressed are fearful of change in power structures, as the oppressed grow dependent on their oppressors. Freire (1970 p.44) defined oppression as '*a concrete historical fact not a given destiny but the result of unjust order'*. Oppression or unequal power decreases a person's self-esteem and autonomy (Wittmann-Price 2004). Freire (1972) advocated sharing power with the oppressed, rather than doing things for them. At a later date social movements promoted the rights of ethnic and sexual minorities and women further developed the concept of empowerment.

Wright's (1960; 1983) most enduring contributions to an understanding of the disability experience was her attention to values and their transformation during the disability adjustment process. According to Wright (1983) mechanisms employed by self-accepting disabled persons include: (1) the enlargement of their scope of values, accomplished by developing interest in attainable goals; (2) the subordination of the values of body appearance and performance, to qualities of human worth that are still within grasp, such as personality attributes; (3) the 'containment' of disability effects to prevent the perceived ‘spread’ of limitation to the entire self; and finally (4) the transformation of comparative-status values, the assessment of ones qualities in comparison to the qualities of others or cultural norms.

Much of Wolfensberger’s work has been concerned with ideologies, structures and planning patterns of human service systems, concerning people with intellectual disabilities who are often rejected and socially excluded from mainstream society. According to Wolfensberger (1987) normalisation implies the use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people. During his research in the United States (US), Wolfensberger succeeded his work on normalisation through his concept of social role valorisation (Wolfensberger 1998). He suggested that poor attitudes towards people with learning disabilities could be countered through inclusion and creating opportunities to take on valued social roles. Indeed, both stigma reduction/prevention and societal attitude changing can be achieved by: (1) the enhancement of the social image of a person or group; (2) the enhancement of the competence of the person or group, including bodily, sensory, intellectual and social performance, and (3) the practice of valued skills and habit (Wolfensberger and Tullman 1982).

Within the disability movement, empowerment has been used to reflect a changed understanding of the self and one's place in society. Kosciulek (1999 p.197) defined empowerment as:

> ‘*the process by which people who have been rendered powerless or marginalised develop the skills to take control of their lives and their environment*’

He argues that consumers of rehabilitation services should gain power over the services they receive and, in the process, gain or regain control over their lives (Kosciulek 1999). With this in mind, self-determination has become part of the demands by people with disabilities in the self-advocacy movement and these ideas have been incorporated into the disability rights and empowerment movement. Thus, Wehmeyer *et al.* (1996) proposes a functional theory of self-determination and identifies four essential characteristics of self-determined actions: (1) the person acts autonomously; (2) the behaviour is self-regulated; (3) the person initiates and responds to the event(s) in a psychologically empowered manner; and (4) the person acts in a self-realising manner.

Rosenbaum (1990) suggested that individuals may differ in the extent to which they are able and willing to self-regulate internal responses (such as emotions, pain, and cognitions). This general repertoire of self-control skills is identified as learned resourcefulness (Rosenbaum 1983) and is a basic behavioural repertoire (Staats 1975) that is learned from the moment of birth and serves as a basis for coping with stressful situations. Bearing this in mind, Rosenbaum and Palmon (1984) illustrated that participant's psychological adjustment to epilepsy is a joint function of their perceived repertoire of self-control skills (i.e., their learned resourcefulness) and of the extent to which they were exposed to uncontrollable seizures.

2.4.2 The historical debate with regards to healthcare empowerment

The historical debate with regards to healthcare empowerment first appeared as a foundation for health promotion in the WHO Ottawa Charter (Ottawa 1986), with social justice and equity recorded among fundamental conditions for health. During the 1980's and 1990's empowerment was adopted politically as part of the 'new right' ideology of consumerism within health and social care (Masterson and Owen 2006).

2.4.3 An examination of empowerment from within the discipline and other disciplines

Empowerment is explored in a wide range of contexts within healthcare such as professional empowerment (Powers 2003, Daiski 2004, Finlay 2005, Corbally *et al.* 2007), mental health (Ryles 1999, Finfgeld 2004, Lloyd 2007), older people (Faulkner 2001, Roberts 2004), chronic illness (Paterson 2001, Dowling *et al.* 2011), nursing education (Hawks 1992, Espeland and Shanta 2001), nursing management (Manojlovich and Laschinger 2007), from a service user-service provider perspective (Gibson 1991, Rodwell 1996, Ellis-Stoll & Popkess-Vawter 1998, Aujoulat *et al.* 2007, McCarthy and Holbrook 2008, Holmstrom and Roing 2010) and finally family empowerment (Hulme 1999, Espezel and Canam 2003, Coyne 2007, Jolley and Shields 2009). From other disciplines empowerment is explored in psychology, sociology, and economics (Wallerstein and Bernstein 1994, Aujoulat *et al.* 2007). Once the concept of empowerment has been identified, Norris 2nd stage of concept analysis includes observation and description of the concept and is now explored.

2.5 Observation and description of empowerment

An observation and description of empowerment is required in order to provide a systematised discovery of patterns and sequences. The result of this stage of analysis observes and describes empowerment as: (1) a process; (2) an outcome; (3) an understanding of power; (4) different levels of empowerment; (5) theoretical underpinnings of empowerment; and (6) related terms with regards to empowerment. These are now explored.

2.5.1 Empowerment as a process

The literature identifies empowerment as a process with varying functions and understandings. They include: (1) a social process of recognizing, promoting and enhancing people's abilities to meet their own needs, solve their own problems, and mobilise the necessary resources in order to feel in control of their own lives (Gibson 1991); (2) an enabling process or a product arising from a mutual sharing of resources and opportunities which improves decision making to achieve change (Rodwell 1996); (3) a helping process (Rodwell 1996, Holmstom and Roing 2010); (4) a dynamic process associated with growth and development where competency is enhanced (Kuokkanen and Leino-Kilpi 2000); (5) an interactive process through which people experience personal and social change, enabling them to take action to achieve influence over the organisations and institutions which affect their lives and the communities in which they live and finally (6) a transactional process where there is a sharing of power between people to achieve mutually beneficial interactions (Gibson 1991). This process involves micro factors (intrapersonal, self-esteem and efficacy), mediating structures (group membership and involvement) and macro-factors (social and political activities (Kieffer 1984).

2.5.2 Empowerment as an outcome

On the other hand, empowerment is described as an outcome such as: (1) an active involvement in health care issues (2) the negotiation of healthcare goals (Chang *et al.* 2004); and (3) an enhanced sense of self-efficacy as a result of empowerment (Wallerstein and Bernstein 1988, Rissel 1994, Ryles 1999, Dilirio *et al.* 1992, Dilirio *et al.* 2006).

Chronic disease management strategies recommend that patients be empowered to self-manage their health care[4]. Therefore, arguably a need for a more collaborative approach between people with epilepsy and service providers so that shared expectations can be established and decisions jointly made in striving to achieve realistic and desired outcomes is required.

2.5.3 An understanding of power

The literature argues that an understanding of power is essential in order to recognise empowerment (Rowlands 1997). Although a myriad of often conflicting power theories exist, the most influential theories include those of Max Weber, Steven Lukes and Michael Foucault. Weber defines power as being a finite commodity to be seized or bestowed. This is relevant to epilepsy healthcare because in order to empower people with epilepsy and service providers, those who possess power, such as service providers, service managers and policymakers, must necessarily surrender some of their own power. However, this can be argued as a disincentive to those in power and a reason to resist genuine service user empowerment (McDougall 1997, Kumar 2000).

Central to Foucault’s work is a relationship between knowledge, truth, and power, which come together to control people within modern society. This is achieved through disciplines, such as psychology, medicine and social work, which are grounded in specific knowledge. Such disciplines use discourses, and dominant discourses will form socially accepted ways of viewing reality, and may be established so successfully that they are accepted as being self-evident. Foucault argued that disciplinary discourses have a strong social control function. This can be said to have occurred with the discourse of epilepsy healthcare. However, Foucault is criticised for an over emphasis on external power influences; he does not account for an internal autonomy that may also exert power (Gillespie 2000).

Power is described in different ways such as power over; power to; power with; and power from within. Firstly, *power over* is controlling power, which refers to ‘the capacity of some actors to override the agency of others’ (Kabeer 2005 p.14). *Power to* refers to the ability of an individual to increase own choices and act on them without

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[4] See Chapter 4, Section 4.4: Evidence Based Models of care for people with epilepsy

weakening the power of another. *Power with* refers to a collective action by a group (Rowland 1997, Mosedale 2005) and finally, *power from within* refers to a person's sense of self-worth and self-knowledge. It includes an ability to recognise individual differences while respecting others. Power within is the capacity to imagine and have hope and affirms the common human search for dignity and fulfilment (VeneKlasen and Miller 2002).

Lukes (2005) described power as having three dimensions: (1) overt; (2) covert; and (3) institutionalised. Covert power can perhaps explain why people with epilepsy play a passive role within their own healthcare and lack empowerment (Varley *et al.* 2011). Institutionalised power is not maintained by single acts, but rather through socially-constructed norms of the institution. Therefore, those in subordinated positions become accustomed to, and socialised in, the ways of the institution. For example, service provider's lack autonomy and control with regards to organisation change and feel that their voices are not listened to. Control and autonomy are concepts associated with job satisfaction, and are viewed as contributing to the overall efficacy of a service provider's role (Ellefsen and Hamilton 2000). Spreitzer (1995) maintained that factors such as self-esteem, impact, and job satisfaction are all part of empowerment. This further demonstrates the connection between power and empowerment, and the extent to which both concepts are inextricably linked.

It is evident therefore, that power and empowerment can be viewed as having a close relationship, whether interdependent or connected. Historically, power relations exist between service providers and people with epilepsy. For example, mothers of children with neurological disabilities reported difficulty in experiencing a sense of power in settings where the hierarchical medical model predominated (Gibson 1991). They also described situations where service providers were unwilling to share their power and failed to listen to the mothers' concerns and viewpoints. It is argued that to achieve empowerment, access to and control of power is required (Rowlands 1997, Kabeer 2005). Empowerment involves a sharing or transferring of power (Ryles 1999, Kuokkanen and Leino-Kilpi 2000, McCarthy and Holbrook 2008). This requires structural change and 'top-down' transference of power within services (Masterson and Owen 2006). Hawks (1992) claims that one can empower others if one can empower themselves. Bearing this in mind, as power relations exist between service providers and service users, arguably power from within is warranted with regards to empowerment of all stakeholders within epilepsy services.

2.5.4 Different levels of empowerment

The literature links empowerment to different levels and these include individual, organisational and community levels (Rappaport 1981, Tveiten and Severinsson 2005). Firstly, an individual level often termed the ‘micro level’ of empowerment is linked to personal power and is concerned with ideologies of self-care, self-responsibility, self-determination, and personal control (Ghaye 2000). At this level, individuals can accept ownership and responsibility for their own health and social situation, rather than be dependent on service providers (Gibson 1991). Secondly, a group level often termed the ‘macro level’ of empowerment is linked to the individual level but manifests itself through collective action, such as voluntary groups and social networks (Schulz *et al.* 1995).

Finally, a community level also termed the ‘macro level’ of empowerment is linked with political action (Segal *et al.*1995). Bearing this in mind, we argue for the need to concentrate on the interface between the ‘macro’ and ‘micro levels’ ofempowerment. For instance, changes are necessary not only in personal behaviour, but also in social situations and organisations that influence individual lives (Feste and Anderson 1995).

2.5.5 Theoretical underpinnings of empowerment

Theoretically empowerment is viewed from many vantage points such as (1) psychological theories (Kuokkanen and Leino-Kilpi 2000); (2) organisational theory/ structural theory (Kuokkanen and Leino-Kilpi 2000); (3) poststructuralism (Foucault 1980) and (4) CST (Kuokkanen and Leino-Kilpi 2000) as described in Chapter 1[5].

2.5.6 Concluding comments

In summary, this section describes empowerment as a process and/or outcome arising from a power from within. By considering an interface between the macro and micro levels of empowerment of all stakeholders within epilepsy services there is a potential to define how individual empowerment can contribute to group empowerment, and how the increase of a group’s power can enhance the functioning of its individual

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[5] See Chapter 1, Section 1.7 and theoretical understandings of empowerment.

members (Gould 1987). With this in mind, concepts that are related to empowerment are now explored.

2.6 Identify concepts that are related to the concept of interest

The literature suggests that empowerment lacks clarity and several related terms identified in the literature add to this lack of clarity. Amongst these related terms of empowerment include self-management (Helgeson *et al.* 1990, Dilorio 1997, Buelow 2001, Reid *et al.* 2001, DiIorio 2009a, DiIorio 2009b), self-determination of health and treatment-related goals through participation and negotiation (McCann and Weinman 1996, Paterson 2001, Gunter *et al.* 2004), self-efficacy regarding disease and treatment-related behaviours (Dilirio *et al.* 1992, McCann & Weinman 1996, Dilirio *et al.* 1996), enablement (Chandler 1992, Hudon *et al.* 2011) and a change of consciousness (Deveaux 1994).

According to Austin and de Boer (1997), self-management refers to the adaptive health behaviours and activities that a person with epilepsy can perform to promote seizure control and enhance well-being. Although a number of recent self-management techniques and programmes for people with epilepsy are described in the literature (Helgeson *et al.* 1990, Dilorio 1997, Buelow 2001, Reid *et al.* 2001, DiIorio 2009a, DiIorio 2009b), a Cochrane review reported that only two met the definition of epilepsy self-management. It is argued that participant drop out and attrition in self-management studies is due to a lack of patient-centred planning (Johnson *et al.* 2012). Comparing service providers and people with epilepsy's self-management needs, findings of a study by Johnson *et al.* (2012) illustrated consistent dissonance in the views of service providers and people with epilepsy. This indicates the need to consider the person with epilepsy's input in self-management programs. Thus, the need for the development, evaluation, and expansion of epilepsy self-management has been suggested (IOM 2012).

The literature reports that the quality of life of people with epilepsy can be severely compromised by statutory conditions on driving and employment (Schneider and Conrad 1983, Elwers *et al.* 1991, Living Well with Epilepsy 2004). In this regards, self-determination is the product of both the person and the environment insofar as the person utilises the skills, knowledge, and beliefs at his/her disposal to act on the environment with the goal of obtaining valued and desired outcomes (Wehmeyer and Abery 2013).
Empowerment is also associated with the term enablement throughout the literature. The

attributes of enablement in healthcare include: (1) contribution to the therapeutic relationship; (2) consideration of the person as a whole; (3) the facilitation of learning; (4) valorisation of the person's strength's and (5) supporting decision making (Hudson *et al.* 2010). Indeed service user empowerment is described as a process whereby nurses enable individuals to be effective (Chandler 1992).

Moreover, empowered individuals often exhibit various self-regulatory qualities such as high self-efficacy perceptions and a sense of agency or personal control (Cleary and Zimmerman 2004). Self-efficacy is a central and ongoing individual mechanism (which operates by means of cognitive, motivational and affective processes) which is comprised of a person's perceived belief in one's capability to exercise control over events (Bandura 1989). Self-efficacy is positively associated with self-management (Dilorio *et al.* 1992, Dilorio *et al.* 1994, Dilorio *et al.* 1994). However, the high levels of perceived stigma for people with epilepsy results in lower levels of self-efficacy to manage epilepsy (Dilorio *et al.* 2003).

Empowerment is acknowledged as a change in consciousness that results from the influence of internal and external factors (Deveaux 1994). For example, internal factors considered to be significant in advocating health-relevant behaviours include: (1) knowledge about risk factors and risk reduction; (2) attitudes, beliefs and core values; (3) social and life adaptation skills; (4) psychological disposition such as self-efficacy and (5) physiology**.** On the other hand, external factors include: (1) social support; (2) media, for example, public service announcements; (3) socio-cultural, economic and political factors; (4) biologic; (5) health care system; (6) environmental stressors and (7) societal laws and regulations (Cole *et al.* 1992).

Other related terms of empowerment identified in the literature include: mutual decision making (Rodwell 1996, Holmstom and Roing 2010, Nygardh *et al*. 2011), participation (Hokanson Hawks 1992, Ellis-Stoll and Popkess-Vawter 1998, Finfgeld 2004, Dowling *et al*. 2011), individualised knowledge acquisition (Ellis-Stoll and Popkess-Vawter 1998, McCarthy and Holbrook 2008, Holmstom and Roing 2010, Nygardh *et al.* 2011), goal setting (Hokanson Hawks 1992, Bulsara *et al.* 2004), autonomy (Rodwell 1996, Finfgeld 2004, McCarthy and Holbrook 2008, Holmstom and Roing 2010), negotiation (Finfgeld 2004), active listening (Ellis-Stoll and Popkess-Vawter 1998, Holmstom and Roing 2010, Nygardh *et al.* 2011), open communication (Hokanson Hawks 1992, Dowling *et al.*

2011), support (Bulsara *et al.* 2004, Finfgeld 2004), greater access to financial or intangible resources (McCarthy and Holbrook 2008), respect (Nygardh *et al*. 2011), acceptance (Bulsara *et al.* 2004, coping strategies (Bulsara *et al.* 2004) and trust (Nygardh *et al.* 2011). The antecedents and consequences of empowerment are now explored.

2.7 Antecedents and consequences

The identification of antecedents and consequences further clarify the concept of interest (Rodgers 2000). This section now explores antecedents and consequences from both service users and providers perspective in relation to empowerment.

2.7.1 Antecedents from a service user's perspective

The antecedents to empowerment identified from the perspective of service users include: a loss of power and control; a transformation of consciousness; motivation; active participation; and competencies. Arguably a loss of power and control is required for empowerment to occur (Gibson 1991, Ryles 1999). This loss of power and control can relate to both a hierarchical, power-based relation of a healthcare service, and a diagnosis of epilepsy and seizure disorders. At the service organisation and delivery level, people with epilepsy are poorly informed and often poorly consulted.

Indeed, epilepsy is a disorder characterised by loss of control (Baker *et al.* 1996). For instance, seizures may occur at any time with little or no warning. Bearing this in mind, studies have reported that people with epilepsy have a more external locus of control compared to people with other medical conditions (Matthews *et al.* 1982, Shagena *et al.* 1988, Asadi-Pooya *et al.* 2007). Moreover, stigma continues to contribute significantly to the loss of power and control in people with epilepsy. Internalised stigma ('felt sigma') refers to beliefs and fears within a person with epilepsy whereas interpersonal stigma refers to discrimination from others. On the other hand, institutional stigma refers to society's position on epilepsy (Muhlbauer 2002). Indeed, it is identified that people with epilepsy often internalise societal perceptions and consequently feel disempowered (Dell 1986). Conversely, personal empowerment has long been considered the opposite of 'felt stigma' (Corrigan 2002).

An awareness that one's life chances are being undermined by politics, economics, and disenfranchisement is required (Ryles 1999), insofar as people with epilepsy still experience serious limitations in economic, social and cultural rights. For example, many people with epilepsy have unmet needs in areas such as civil rights, education, employment, residential and community services, and access to appropriate healthcare (de Boer 2010). This can lead to social isolation and dependency on others especially when it prevents people from driving or working (Beran 1999).

Service users need significant power over their own future to feel empowered (Tones 2010) and arguably must be willing to take responsibility, and participate in goal setting (Hawks 1992, Ryles 1999). Service users desire to change is central to the empowerment process (Ellis Stoll and Popkess-Vawter 1998, Shearer and Reed 2004). However, according to Dilorio *et al.* (1992) people with epilepsy are less committed to the process of improving the management of their disease because of uncontrolled seizures, a lack of knowledge and educational resources and insufficient social support. Consequently, people with epilepsy become discouraged and unmotivated to change their behaviours. However, motivation is vital in the empowerment process (Gibson 1991, Rodwell 1996, Ellis-Stoll and Popkess Vawter 1998, Holmstrom and Roing 2010) and even more so in the reality of powerlessness and oppression (Prilleltensky and Gonick 1996). Bearing this in mind, service users need to be active participants (Brody 1980, Ballard-Reisch 1990, Gibson 1991, Hawks 1992, Hage and Lorensen 2005) and be willing to work alongside service providers. This requires service users to be actively involved in the decision making process (Harris 1998, Ehrenberger 2001) and be equipped with the knowledge, skills, attitudes and self- belief to modify aspects of their lives (Bandura 1986).

The literature suggests that a loss of power and control is a necessary antecedent to empowerment for service users. However, on the other hand, a transformation of consciousness; motivation; active participation; and competencies is also required.

2.7.2 Antecedents from a service provider's perspective

The antecedents to empowerment identified from the perspective of service providers include: surrendering the need to control; to feel empowered; possession of professional skills; and a transformation of consciousness. For empowerment to transpire, service providers need to surrender control (Gibson 1991, Aujoulat *et al.* 2007, McCarthy and Holbrook 2008, Holmstrom and Roing 2010, Dowling *et al.* 2011). However, the literature suggests that service providers view service users as objects or bodies that need surveillance and monitoring (Henderson 1994, Manias and Street 2000). Indeed, empowerment has been claimed as a ‘double edged sword’ disguising and justifying paternalistic practices (Opie 1998). Furthermore, research demonstrates that service providers discount the expertise knowledge of service users and do not provide the resources necessary to make informed decisions despite intentions to foster participatory decision making (Gray *et al.* 1992, Turton and Cooke 2000, Paterson 2001, Henderson 2003). With this in mind, service providers need to embrace service user’s decision making (Nyatanga and Dann 2002).

As previously stated, service providers must themselves be empowered in order to empower service users (Dowling *et al.* 2011). However, a dilemma facing service providers with regard to empowerment is that they are expected to engage in processes that are empowering for service users often without consideration as to whether they themselves are empowered practitioners (Ryan *et al.* 2006). According to Chavasse (1992) no-one can value others unless they value themselves. As a counter point Skelton, (1994) argues that the idea of nurses empowering themselves in order to empower others is a little naïve.

Furthermore, a personal capacity for growth and a desire for autonomy and self-determination is an essential antecedent for empowerment (McCarthy and Holbrook 2008). Gibson (1991) argues that nurses can help service users empower themselves by using resources that will foster a sense of control and self-efficacy. However, if service providers adopt the discourse of empowerment, without critical review, a false sense of security that all people with a chronic disease are able to participate fully may evolve. This has been described as the ‘myth of empowerment’ (Paterson 2001). Therefore, empowerment involves a process of helping people develop a critical awareness of the causes of their problems and a readiness to act on this awareness (Kuokkanen and Leino-Kilpi 2000).

Empowering people with epilepsy and the promotion of self-care requires service providers to understand and appropriately deliver their role in the healthcare process (Varley *et al.* 2011). Arguably, embracing empowerment requires a paradigm shift from the traditional approach to healthcare to a more holistic approach (Anderson and Funnell 2010). It is suggested that an alternative paradigm has the potential to increase awareness of power issues among service providers and create an urge for empowering practices (Thesen 2005)**.**

Overall, therefore it is suggested that the antecedents from a service providers' perspective include surrendering the need to control; to feel empowered; and possession of professional skills. Likewise to the results identified for antecedents to service user empowerment, a transformation of consciousness is also a necessary antecedent to empowerment for service providers.

2.7.3 Context antecedent from both a service users and service provider's perspective

The person with epilepsy is likely to have a life-long engagement with clinical services (Tinetti *et al*. 2012). With this in mind, the literature identifies that a nurturing, caring and supportive environment is required (Hawks 1992, Dowling *et al*. 2011), based upon mutual trust, honesty, genuineness, shared vision, and respect are necessary antecedents of empowerment for both service users and service providers (Hawks 1992, Rissel 1994, Rodwell 1996, Dowling *et al.* 2011). Time has also been linked to the process of empowerment (Patterson 2001).

The significance of equal partnership and respect is highlighted (Rappaport 1995, Rodwell 1996, Paterson 2001, Aujoulat *et al*. 2008). This encompasses open communication and effective information provision in which knowledge, values and power are shared (Hokanson Hawks 1992, Aujoulat *et al.* 2007). Historically, service user's views and concerns with regards to their health care have frequently been overlooked (Waitzken and Britt 1989). With this in mind, the establishment and maintenance of '*good communication'* for effective management of a chronic illness are identified (Todd and Ladon 1998 p.1). Service users need information in order to apply critical judgement with regards decision making (Irvine 1996). Thus, the role of service providers is to provide information and support, and to transfer leadership and decision-making to service users (Funnell *et al.* 1991, Rodwell 1996, Holmstrom and Roing 2010).

2.7.4 Consequences from a service user's perspective

The consequences of empowerment identified from the service user perspective include: (1) a positive self-concept; (2) a negative self-concept; (3) ability to set and reach goals; and (4) a development of competencies.

Empowerment is described as a positive self-concept such as: a personal transformation, personal power, personal satisfaction, self-efficacy, self-determination, self-esteem, sense of mastery, sense of hope and social justice (Gibson 1991, Ellis Stoll and Popkess-Vawter 1998, Ryles 1999, Hage and Lorenson 2005, Aujoulat *et al.* 2007, Dowling *et al.* 2011, Holmstrom and Roing 2010). Furthermore, improved psychosocial adaption (Aujoulat *et al.* 2007*),* and overall improvement in quality of life for service users (Gibson 1991, Aujoulat *et al.* 2007, Holmstrom and Roing 2010) are identified.

As a counterpoint, empowerment may confront people with '*social, cultural or historical realities'* (Gore 1993, p.6), resulting in a negative self-concept, for example raising such feelings as inadequacy, frustration, distress and diminished well-being (Finfgeld 2004). Arguably, therefore, empowerment may result in a painful experience for people with epilepsy who are shy, and aware of the stigma attached to an epilepsy diagnosis. Moreover, Freire (1998 p.144) suggests that people can adopt the oppressor's view of reality resulting in '*adhesion to the oppressor where people may not necessarily realise their oppression or recognise their relationship of antagonism to their oppressor'.*

Further consequences of empowerment include an increased ability to set and reach goals for the individual and social ends (Hawks 1992); development of competencies in order to gain mastery over one's own life (Ryles 1999); and improving self-management activities (Aujoulat *et al.* 2007, Scambler *et al*. 2012). This is significant for people with epilepsy insofar as social isolation and dependency on others are identified especially when it prevents people from driving and working (Beran 1999).

Overall, therefore it is suggested that whilst the consequences of empowerment can result in a positive experience, it can also result in a negative experience for service users. Other consequences of empowerment identified include the ability to set and reach goals; and the development of competencies.

2.7.5 Consequences from a service provider’s perspective

The consequences identified from a service provider’s perspective include: professional satisfaction; improved understanding of service user’s illness; and access to resources. Enhanced status and influence is gained through participation in the empowerment process (Simoni *et al.* 2004). This allows greater personal power and decreased stress for service providers (McCarthy and Holbrook 2008). Moreover, empowerment creates a trusting, respectful service user-service provider relationship (Rodwell 1996, Ellis-Stoll and Popkess-Vawter 1998, Finfgeld 2004, Dowling *et al.* 2011). Accountability, responsibility, willingness to see beyond the bedside and equal partnership has also been illustrated (Hess 1984). With this in mind, service providers can recognise the suffering of people with epilepsy and prevent further marginalization due to power inequities (Minkler 1989). Finally access to resources (Kanter 1979) which includes increased levels of knowledge, autonomy and control of practices (McCarthy and Holbrook 2008) is identified.

Unlike the negative consequences of service users empowerment, positive consequences of service provider empowerment was acknowledged and include professional satisfaction, improved understanding of service user’s illness and access to resources.

2.8 Operational definition of empowerment within epilepsy services

Stage 3 of Norris’s concept analysis informed the development of an operational definition of empowerment within epilepsy services, which was used in tandem with the model of empowerement outlined in section 2.9 below. The operational definition was:

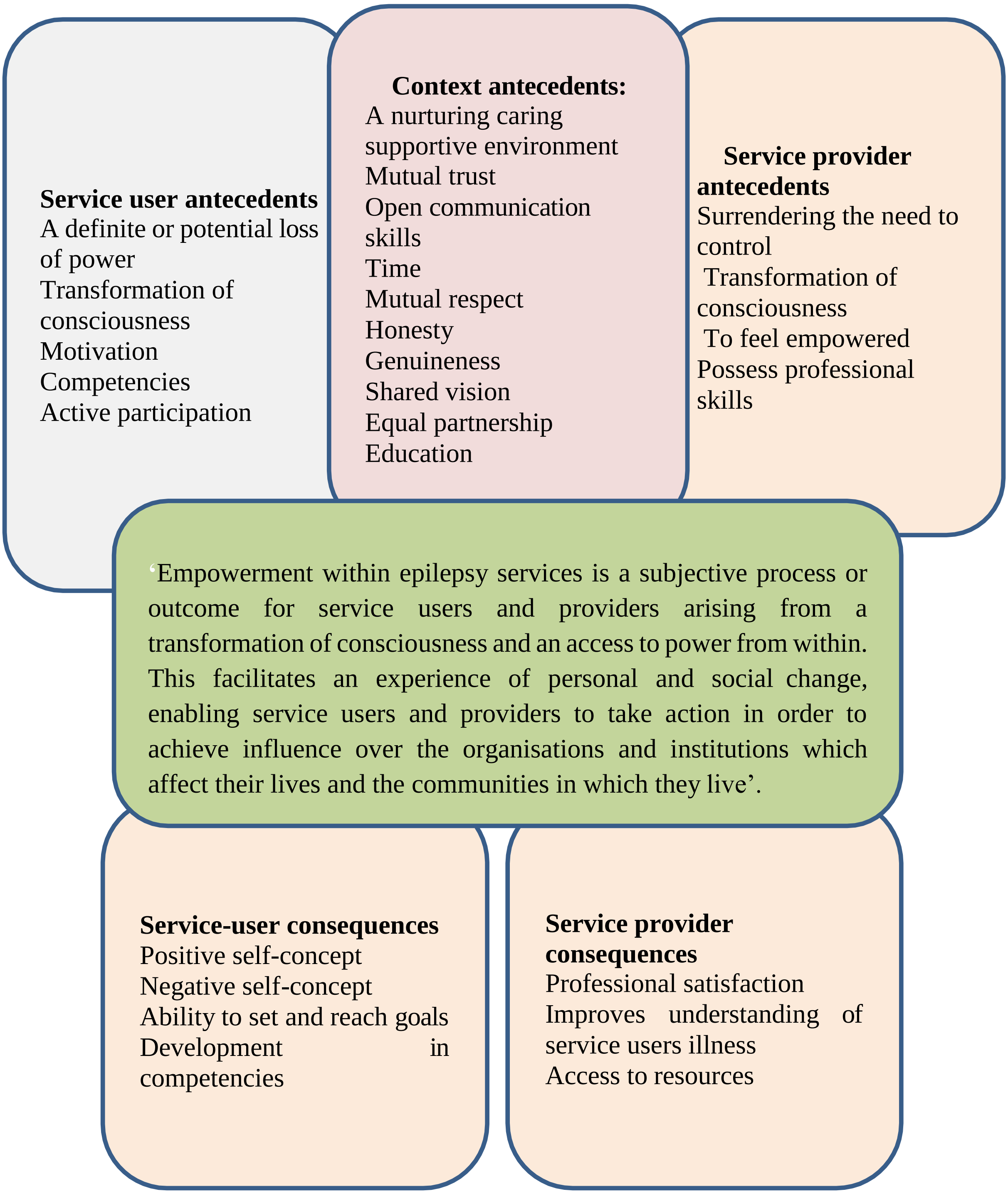
> ‘*Empowerment within epilepsy services is a subjective process or outcome for service users and providers arising from a transformation of consciousness and an access to power from within. This facilitates an experience of personal and social change, enabling service users and providers to take action in order to achieve influence over the organisations and institutions which affect their lives and the communities in which they live’*.

This operational definition guided the approach to this study in terms of focusing thinking for stage 1 of the Soft Systems analysis – that is gaining a general understanding of a situation considered problematic (see Section 10.2) by contrasting the situation against the operational definition and informing the development of a ‘root definition’. The operational definition provided an ‘ideal’ type against which to consider issues and findings. This was particularly useful in terms of helping to guide both the interview topic guide and also assisting in the interpretation of data.

2.9 Model of empowerment within epilepsy services

Complementing the development of an operational model outlined in Section 2.8, is Stage 4 of Norris's concept clarification. This involves the development of a conceptual model that illustrates the concept of empowerment within epilepsy services (See Figure 2.1). The model incorporates the operational definition of empowerment within Irish epilepsy services and the antecedents and consequences from a service user and provider perspective, as derived from the literature and concept analysis. Within the context of this study it helped to focus thinking in relation to the Soft Systems Analysis, particularly in terms of root definition and the construction of the conceptual model (See figure 10.3). Morse *et al.* (1996) argue that a mature concept reflects '*consensus and consistency with its use among theoreticians, researchers and practitioners'* (p.387). This concept clarification does not reflect this view and empowerment within epilepsy services, is revealed as an evolving concept, with some immaturity still evident as competing definitions, antecedents and consequences are evident in the concept analysis.

Figure 2.1: Model of empowerment within epilepsy services



Service user antecedents
A definite or potential loss of power
Transformation of consciousness
Motivation
Competencies
Active participation

Context antecedents:
A nurturing caring supportive environment
Mutual trust
Open communication skills
Time
Mutual respect
Honesty
Genuineness
Shared vision
Equal partnership
Education

Service provider antecedents
Surrendering the need to control
Transformation of consciousness
To feel empowered
Possess professional skills

'Empowerment within epilepsy services is a subjective process or outcome for service users and providers arising from a transformation of consciousness and an access to power from within. This facilitates an experience of personal and social change, enabling service users and providers to take action in order to achieve influence over the organisations and institutions which affect their lives and the communities in which they live'.

Service-user consequences
Positive self-concept
Negative self-concept
Ability to set and reach goals
Development in competencies

Service provider consequences
Professional satisfaction
Improves understanding of service users illness
Access to resources

2.10 Formulation of hypothesis

Stage 5 of Norris's concept clarification involves the formulation of a hypothesis. Therefore this concept analysis has identified the following questions:

1. What do people with epilepsy and service providers understand by empowerment?
2. What are the organisational issues and human factors within the service that support or hinder empowerment of people with epilepsy?
3. What are the organisation and human factors within the service that support or hinder empowerment of clinicians within the service?

Based on the above questions and the results of the concept analysis a critical reflection of the 'micro' and 'macro' levels of power that exists for service users and providers within epilepsy services is required and is explored in this study.

2.11 Empowerment of service users and providers in relation to epilepsy services

There are many reasons why a critical reflection on the '*micro*' and '*macro*' levels of power that exist for service users and providers within epilepsy services is warranted. For instance, service providers have difficulties in acknowledging the service user as 'experienced'. Moreover, deep-rooted communication habits can complicate collaborative efforts between service providers and service users (Tveiten and Meyer 2009)[6]. With this in mind, service users must be willing to assume responsibility, participate in goal-setting and decision making and accept behaviours that encourage empowerment (Hawks 1992). However the implementation of empowerment from theory to practice is not always straightforward. For example, although service providers may support empowerment as a goal of patient participation, their socialization to the practitioner as expert model of health care may be so deeply rooted that they proffer patient participation largely as an extension of their powerbase, rather than as a collaborative venture (Cahill 1998). Thus, if service providers remain uncritical of the rhetoric of empowerment and are not prepared to identify practices that deny participatory decision making in a person's care, then people with epilepsy may experience unmet expectations and frustrations in their interaction with service providers (Paterson 2001).

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[6] See Chapter 5, Section 5.3.2 and Habermas's Theory of Communicative action, in particular in relation to communicative competence and ideal speech.

It is argued that service providers require support when translating empowerment into practice and into a healthcare system that has not itself been designed to empower service users (Adolfsson *et al*. 2004, Corbally *et al.* 2007). Bearing this in mind, findings from this concept analysis demonstrate that a necessary antecedent for empowerment for both service users and providers is a transformation of consciousness. By engaging in critical self-reflection people with epilepsy and service providers can begin to understand how empowerment is facilitated or prevented, insofar, as it has the potential to enable change by facilitating the deconstruction and subsequent reconstruction of social realities (Kendall 1992).

Taking into consideration the '*micro'* and *'macro'* levels of power that exist within healthcare, the question is how can people with epilepsy and service providers engage in critical reflection? Arguably an educational intervention based on empowering principles and critical self-reflection such as CST is warranted. It illustrates how dialogue and problem-posing processes have the potential to construct realistic support for people with epilepsy that is personally and contextually specific.

Although a guide or map can be provided to assist in critical reflection and a transformation of consciousness, this can only provide a guide to the terrain, it cannot replace the experience of negotiating the terrain itself. For instance, the consequences of empowerment for each individual are likely to have differences from the general expectations. As previously stated, empowerment is a subjective process and although the consequences of empowerment may result in a positive self-concept for some it is reported as initiating a negative self-concept for others (Finfgeld 2004). Thus focusing upon and discussing how to solve problems does not necessarily shut out the social, cultural, or historical realities for people with epilepsy and service providers (Gore 1993). Therefore an awareness that a healthcare empowerment approach may result in a painful and demeaning experience for people with epilepsy who are shy, aware of the stigma attached to an epilepsy diagnosis, and unused to intellectual discourse is necessary. Indeed as Freire (1970) acknowledges a transformation of consciousness may result in a painful process. Moreover, healthcare empowerment approaches are viewed as intimidating to those in existing power structures (Miner and Ward 1992) and may be met with resistance. As a result, challenges exist when service user's choices differ to that of service providers (Tveiten and Meyer 2009). Bearing this in mind, service providers may need encouragement and support to accept the goals and priorities that people with epilepsy may hold.

2.12 Chapter summary

This Chapter carried out a concept analysis of empowerment within epilepsy services. An understanding of empowerment is necessary in order to adopt and evaluate epilepsy services in ways that can facilitate empowerment. In this context, concept analysis not only clarifies existing knowledge, it also identifies directions for further development if appropriate.

Whilst this Chapter provides an operational definition[7] and model of empowerment[8] of service users and providers and explores its relationship with epilepsy services, empowerment remains a complex and evolving concept. Arguably, education guided by 'CST' principles has the potential to '*hold the key*' for future advances of empowerment for people with epilepsy and service providers. For instance CST provides an opportunity to engage with the *'micro'* and '*macro'* levels of power, and therefore has the potential to empower service providers and people with epilepsy to gain access to personal power and autonomy over one's own life and engagement with clinical services. Moreover, findings presented have the potential to assist clinicians and policymakers understand the necessary antecedents with regards to empowerment for service users and providers within epilepsy services. Finally, the operational definition and conceptual model presented in this Chapter will guide this study in terms of data analysis and interpretation of findings.

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[7] See section 2.8 and an operational definition of empowerment within epilepsy services.
[8] See section 2.9 and a model of empowerment within epilepsy services.

CHAPTER THREE

A Literature Review: Empowerment and Epilepsy Health Care

3.1 Introduction

The previous Chapter outlines a concept analysis of empowerment within epilepsy health care and whilst it provides an operational definition and conceptual model of empowerment, it highlights the requirement for a critical reflection of the 'micro' and 'macro' levels of power that exists for service users and providers within epilepsy services. This Chapter, provides a critical synthesis of current literature pertaining to empowerment and epilepsy health care from the perspectives of services users and providers. Through this analysis, a summary of current knowledge on this topic will be provided, thereby placing this study in context, while also informing its design.

The characteristics of epilepsy and its impact on the person with epilepsy, their carer's and family have been highlighted in Chapter 1. The complexity of epilepsy highlights that to reach an optimal treatment outcome, it is crucial to consider people with epilepsy holistically (Buck *et al.* 1997, Bishop 2002). There is a growing recognition of the need to embrace Patient/Person-Centred Care (PCC) for all people with epilepsy with an emphasis on the coordination of epilepsy-specific services with care for comorbidities and with links to community services (England 2012). However, problematic to PCC as a viable framework for practice is the long-standing tradition of medical power and authority in relation to the patient as a passive consumer (England 2012). This has shaped health care practice and delivery structures Therefore, to integrate PCC into practice, there is a need to examine critically the context of power in health care organisations (Fredericks *et al.* 2012). This is the focus of this Chapter.

Firstly an outline of the search strategy is provided in section 3.2 and highlights the characteristics of included studies. In section 3.3, service user's perspectives of empowerment in relation to chronic illness/disease is described, while section 3.4 examines service user's level of empowerment. The effectiveness of empowerment strategies for service users is discussed in section 3.5. In section 3.6, service provider's perspectives of empowerment from an organisational, psychological, CST, and mixed theoretical approach is explored. Section 3.7 critically discusses the key findings arising from the literature reviewed and highlights the necessity for this current study. Finally section 3.8 provides an overall conclusion of this literature review.

3.2 Search strategy

The review of the literature was designed drawing on the principles of systematic reviewing as advocated by the Cochrane Collaboration. It was based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher *et al.* 2009, Higgins and Green 2011).

Despite a vast amount of literature on the topic of empowerment, a paucity of literature exists in relation to empowerment and epilepsy health care. Therefore a literature search was broadened to include chronic illness/disease, thus placing this study in context. The following search terms were used: empowerment; power; powerlessness; epilepsy; epilepsy services; people with epilepsy; service providers; health care professionals; clinicians; nurses; doctors; chronic illness; and chronic disease. The search was undertaken by searching the major databases including CINAHL, Medline, PubMed, Cochrane databases and Wiley Online library, as well as review of pertinent textbooks. Limiters were used, and the Boolean operators AND and OR were utilised.

The search strategy identified 1613 published research papers from the databases searched. Abstracts or full texts were screened to ensure they met the inclusion criteria. To be included in this review studies had to (1) be empirically researched from 1990-2019; (2) be peer reviewed; (3) be in English; (4) focus on empowerment; (5) focus on service users and providers perspectives; (5) involve people over 16 years old. Studies not meeting these criteria were excluded. While it is recommended by the Cochrane guidelines that research papers be graded according to level of evidence, this was not incorporated into this review. Instead, this review focused on assessing the nature of the study, methodologies, methods used and findings, all of which formed part of the critical appraisal of this systematic review.

3.2.1 Characteristics of included studies

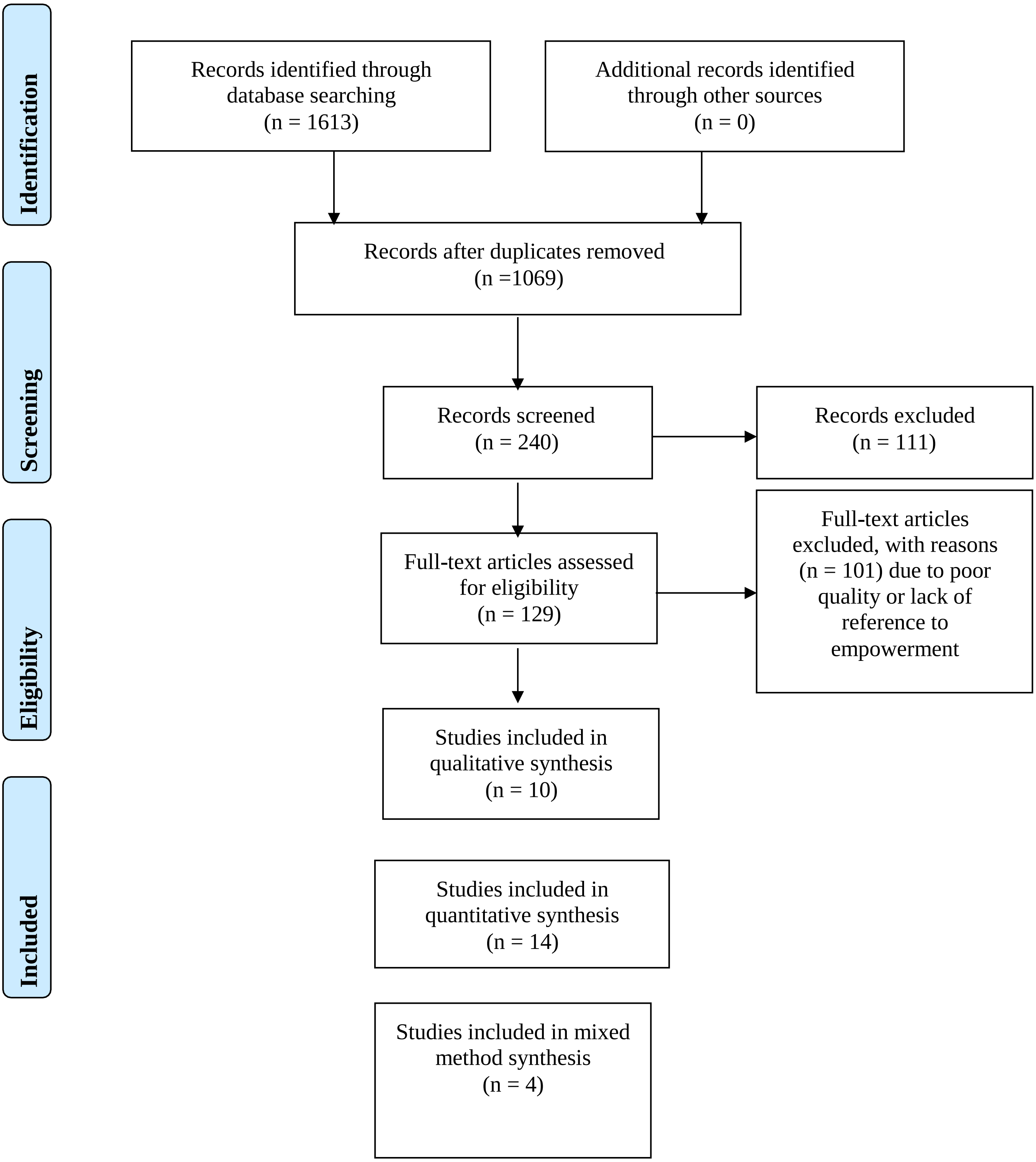
Studies selected for inclusion were based on the four phase PRISMA flowchart (see figure 3.1). A total of 28 articles are included in this review for critical analysis and presented in tables 3.1 to 3.5, representing the main categories that emerged from a range of national and international studies. The themes that emerged include: (1)

Empowerment and chronic illness/disease from the service user perspective; (2) Service user’s level of empowerment in chronic illness/disease; (3) Effectiveness of empowerment strategies for service users: and (4) Empowerment from the service provider’s perspective.

From the perspective of the service user all of the 13 studies were from outside Ireland: 3 were carried out in Sweden; 2 in the UK and Italy; 1 in Australia; 1 in Canada; 1 in Norway; 1 in Belgium, 1 in Hong Kong; 1 in China and 1 in the USA. All studies specifically included patients with a chronic illness and the largest number of participants that took part in one study was (n=456) patients (Brouse *et al.* 2010), and the smallest was (n=7) patients (Bulsara *et al*. 2004). Eight studies were undertaken using qualitative methods, whilst 4 were conducted using a quantitative approach and 1 using mixed methods. No Irish study exploring empowerment and the perspective of the service user is included in this study, thus indicating a lack of relevant Irish literature.

Fifteen studies from the perspective of the service provider were conducted in Ireland and internationally. The majority of the studies, however, were conducted internationally: 5 in the USA, 3 in Canada, 2 in Finland, and 1 in Iran and Italy. Nationally, 3 studies were conducted. The largest number of participants that took part in one study was (n=1874) nurses (Scott *et al*. 2003), and the smallest was (n=16) nurses (Fulton 1997). Ten studies were undertaken using quantitative methods, whilst 2 were conducted using a qualitative approach and 3 using mixed methods. No Irish study exploring empowerment and the perspective of the service provider within Irish epilepsy services is included in this study, thus indicating a lack of relevant Irish literature.

Figure 3.1 PRISMA flow chart



3.3 Empowerment and chronic illness/disease from the service user perspective

This section describes the service user perspective in relation to empowerment and chronic illness/disease (see table 3.1). The type of chronic illness identified in these studies included cancer; diabetes; mental health; and chronic kidney disease. No studies acknowledged epilepsy as a type of chronic illness.

A UK study conducted by Small *et al.* (2013) explored the views of 16 patients living with a long term condition. Using interviews and a modified grounded theory approach, empowerment was described as an internal process and an external process. The internal process was described by patients as changes in perceptions of the self, following diagnosis, whilst the external process was a relational process in which support and understanding from friends and practitioners played a central role in empowerment. Participants revealed many factors that support their empowerment such as: having a perception of personal control; developing one's own personal strategies; the ability to participate in the decision making process; enabling others in coping with their condition; and feeling in control through a good level of knowledge and understanding. Whilst findings highlight empowerment experiences as changes in perception of self-following a diagnosis, some participants acknowledged purposely limiting their knowledge and understanding of their illness as a strategy to stay in control. Small *et al*. (2013) defined empowerment as a mechanism to help patients with long term conditions better manage their health and achieve better outcomes which enhances patients feelings of control, self-efficacy and coping abilities. However, limitations of this study were acknowledged such as the assessment of validity was based on cross-sectional data, and sources were known to the author which may have biased the sample.

Similar findings were highlighted in a study conducted by Bulsara *et al.* (2004) who examined the common factors which patients and spouses believed could enable them to achieve a measure of control in managing their illness. Using a phenomenological approach, a purposive sample was used to re-interview 7 out of 12 patients who had previously participated in a pilot Haematology Shared Care project and who had developed a high level of ability in coping with their illness. At the service user's discretion, spouses were invited to participate and to contribute to the interview (three spouses participated). Data analysis was undertaken using QSR NVivo 5.0. Participants recognised the following vital to their sense of empowerment: determination to remain in control of their illness and treatment side effects; having the support of family and significant others; illness acceptance; maintaining hope; support and positive attitude from service providers; and ability to help others. Indeed, Bulsara *et al.* (2004) suggests that the person initiates an active and participatory role in controlling certain aspects of their lives. Although findings of this study highlight that service providers contribute to empowerment for both the service users with cancer and their families, it also suggests the importance of service providers developing an advanced awareness and knowledge of the strategies used by service users with cancer in coping with their illness. Whilst this study provides an understanding of a patient's lived experience, the generalizations about the findings of this study should be used with caution. Reasons for this include, a small sample size and service users were specifically selected through their demonstrated ability to use successful coping strategies.

In a qualitative study conducted in Norway, Tveiten *et al*. (2011) explored patient's views and experiences of empowerment in a psychiatric context. This study was undertaken in two psychiatric inpatient services and a purposive sample of 14 patients that were users of either or both service agree to participate. Data was gathered by the use of two focus groups and analysed using qualitative content analysis (LoBiondo-Wood and Haber 2002). Participants in both focus groups had prior acquaintance with each other and this may have influenced their contributions during the focus group. Despite this, however, findings acknowledged the importance of understanding when and how to participate in ones' own personal care, and learning about ones problems and diagnosis represented the possibilities of participation and presuppositions.

Participants discussed their experiences on being viewed as experts and underlined '*the importance of real acknowledgement, not acknowledgement as a formal claim* (Tveiten *et al*. 2011 p. 21). Findings revealed that available time, organisation and the service offered influenced participation. In addition, participants revealed that connecting with others experiencing illness both reduced perceived stigma and social isolation. The findings also highlight that collaboration between service users and providers had contrasting aspects. For example, whilst some participants experienced cooperation with service providers as well as acknowledgement and possibilities to influence their own treatment plan, others revealed that the cooperation was largely dominated by rules and regulations. Participants described not feeling a sense of true freedom in decision making and powerless because of the physician’s ability to force medication. As a counterpoint, others acknowledged experiences of being respected and equal members of the team. This study defined empowerment in healthcare as based on a philosopy of being seen as an equal, autonomous member of the healthcare team (Tveiten *et al*. 2011). Arguably, further focus groups or a larger sample may have enabled a greater depth of data.

On the other hand, Wahlen *et al.* (2006) purposively interviewed 11 patients with a different chronic illness diagnoses to examine their empowerment experiences in an intensive care environment. Using a phenomenological approach, findings recognised that patient empowerment in intensive care units consists of strengthening and stimulating the patient’s own inherent joy of life and will to fight. With this is mind, empowerment was described as a ‘power from within’. Other factors acknowledged that support empowerment include: a positive environment that encouraged feelings of value and motivation; feeling safe; receiving additional care; and participation (Wahlen *et al.* 2006). However, it is possible that data saturation was not reached given the small sample size. Moreover, patients interviewed reported a diverse range of acute and chronic conditions, therefore findings may not be transferable.

A study conducted in Hong Kong, explored the process of how cancer patients are being enabled and strengthened to overcome powerlessness (Mok *et al.* 2004). Twelve service users with cancer were interviewed and data was analysed using constant comparison. Findings suggest that the process of empowering cancer patients consists of more than just giving patients control, choice, or resources, such as knowledge and skills. In this context, optimal empowerment depends not so much on decisional control being made available, but rather on allowing the patient to control to what degree he or she will be able to participate in the decision-making process. Participants acknowledged that the basic social process of empowerment included finding meaning in life, seeking mastery over illness, and acceptance of illness. Mok *et al*. (2004) defined empowerment ‘*as making someone stronger and more confident especially in controlling their life and claiming their rights’* (p. 60). The authors suggest that nurses have an important role in facilitating patients to find meaning in life, as well as in the transformation of thoughts and attitudes.

In a similar exploratory study conducted in Belgium and Italy, Aujoulat *et al.* (2007) explored the process of empowerment as it may occur in patients with a chronic illness whose experience of illness has at some point induced a feeling of powerlessness. Using a phenomenological approach, 40 patients were interviewed either in Hospital, within a GP practice or at home. Findings highlight that powerlessness for service users extends well beyond medical and treatment issues, as participants expressed or demonstrated to have at some point or another a feeling of insecurity and a threat to their social and personal identity. Support from family and friends was described as important and patients described a sense of powerlessness without their partners. In addition, participation in meaningful activities was described as empowering because it allowed patients to feel a sense of purpose and to maintain roles in relationships and in the community. While this study defined empowerment as an experience that can evolve from situations or feelings of powerlessness, findings of this study are limited to a description of commonalities in situations that might lead to a feeling of powerlessness. Specific aspects such as the duration, intensity and interaction of powerlessness were not examined.

A Canadian, qualitative study examined decision making processes of patients with long standing Type 1 Diabetes (Paterson 2001). Using an adopted grounded theory approach 22 patients were recruited for this study and nominated as expert self-care managers. Participant’s consultations were audiotaped, followed by focus group interviews to clarify participant’s decision-making and factors that affected their decisions. Findings suggest that collaborative partnerships with healthcare professionals were essential for patients to actively participate in decision making about their diabetes management. However, the majority of patients with diabetes (n=13) revealed that they had met few practitioners whose practices were empowering. Practitioners were described as competent, however more like a professional as opposed to a partner. Disempowerment was described as occurring when practitioners discounted their experiential knowledge, and failed to provide the resources necessary to make it possible to participate in shared decision-making. The resources highlighted as necessary include: information; time; and resources. For example, the inadequate delivery of information provision can affect the willingness and ability for people with chronic illness to engage with service providers. Poor continuity of care, inadequate time with service providers, and long waiting times during hospital visits impacts negatively in relation to decision making. Moreover participants acknowledged that costs associated with long waiting times during appointments often resulted in a reluctance to engage with service providers in the time that is required to enact participatory decision making.

While this study was guided by the theory of symbolic interactionism, a limitation is that 11 patients were nominated by practitioners and judged to be expert self-managers and the remaining patients nominated themselves in response to an advert. Therefore, findings may not be transferable to a similar context in relation to people with diabetes who are less experienced in living with diabetes and who are not actively involved in the management of their condition.

Table 3.1 Characteristics of included studies: Empowerment and chronic illness/disease from the service user perspective

Author/ year	Country	Aim	Method/sample	Analytical technique	Findings	Theoretical approach
Small *et al.* (2013)	UK	To explore empowerment from the perspective of patients living with a long term condition	A qualitative study of 16 older adults with chronic conditions	Grounded theory	Empowerment was described by patients in terms of five dimensions: identity; knowledge and understanding; personal control; personal decision making; and enabling other patients.	No
Bulsara *et al.* (2004)	Australia	To identify the common factors which patients and spouses believed could enable them to achieve a measure of control in managing their illness	A qualitative study of 7 adults with cancer	Phenomenology	Control; support of family and significant others; illness acceptance; hope; support from family and others; positive attitude from service providers; ability to help others	No
Tveiten *et al.* (2011)	Norway	To gain knowledge of the patient's views and experiences of empowerment in a psychiatric context	A qualitative study of 14 adults in a psychiatric inpatient centre	Qualitative content analysis	Possibilities and presuppositions of participation; influence of the system on the empowerment process; and collaboration along a continuum of power; service provider interaction	No
Wahlen *et al.* (2006)	Sweden	To explore empowerment experiences of patients in an intensive care environment	A qualitative study of 11 Intensive care patients	Phenomenology	Power from within; Will to fight; positive environment; feeling safe; receiving additional care; and participation.	No
Mok *et al.* (2004)	Hong Kong	To explore the process of how cancer patients are being enabled and strengthened to overcome powerlessness	A qualitative study of 12 patients with cancer were interviewed.	Constant comparison.	Meaning in life, seeking mastery over illness, and acceptance of illness; knowledge and skills; On the other hand being objectified was more commonly a source of disempowerment	No
Aujoulat *et al.* (2007)	Belgium and Italy	To understand the process of empowerment and feelings of powerlessness	A qualitative study of 40 Adults with chronic conditions	Grounded theory & Phenomenology	Participants expressed a feeling of insecurity and a threat to their social and personal identity. Support from family and friends was described as important. Participation in meaningful activities was described as empowering	No
Paterson (2001)	Canada	To examine decision making processes of patients with long standing Type 1 Diabetes	A qualitative study of 22 adults with longstanding Type 1 Diabetes	Grounded theory	Practitioners discounted patients experiential knowledge, and failed to provide the resources necessary to make it possible to participate in shared decision-making	Symbolic interactionism

Table 3.2 Factors that support and hinder empowerment: A service user perspective

Study	Control	Participation	Shared decision making	Support	Colloboration/ Relationship with service providers	Knowledge and understanding	Psychological coping	Power	System
Small *et al*. (2013)	√		√	√		√			
Bulsara *et al*. (2004)	√			√	√		√		
Tveiten *et al*. (2011)		√	√	√	√			√	√
Wahlen (2006)	√	√					√	√	√
Mok *et al*. (2004)	√				√	√	√		
Aujoulat *et al*. (2007)	√	√		√			√	√	
Paterson (2001)	√		√		√				√

3.3.1 Emerging themes in relation to service users perspectives of empowerment

Synthesis of the findings of the above literature in relation to service users views in relation to empowerment resulted in the identification of nine dimensions of empowerment and include: (1) control; (2) participation; (3) shared decision making; (4) support; (5) collaboration with service providers; (6) knowledge and understanding; (7) psychological coping; (8) power; and finally (9) system (see table 3.2).

The concept of control was acknowledged in most studies as a factor that can support or hinder empowerment for service users with a chronic illness (Paterson 2001, Mok *et al.* 2004, Bulsara *et al.* 2004, Wahlen 2006, Aujoulat *et al.* 2007, Tveiten *et al.* 2011, Small *et al.* 2013). Participants revealed feelings of empowerment when they took control over their own illness (Bulsara *et al.* 2004; Mok *et al.* 2004). Among cancer patients in Hong Kong a sense of empowerment was reported when service users seeked both mastery over illness, and acceptance of illness (Mok *et al.* 2004). Lack of options were typically seen as disempowering for service users and findings acknowledged that developing one's own personal strategies; and control over their daily decisions as empowering. In addition, participation in meaningful activities in order to maintain social integration was highlighted as an important factor that supports service users empowerment

The ability to share in the decision making process with service providers was also recognised as empowering (Paterson 2001, Tveiten *et al.* 2011, Small *et al.* 2013). However, participants revealed not feeling a sense of true freedom in decision making and involvement in decision making on a superficial level as disempowering (Paterson 2001, Tveiten *et al.* 2011). With this in mind, Paterson (2001) suggests that empowerment is more than simply offering a role in decision making. Service providers must reflect on their behaviours and practices that have the potential to hinder decision making and empowerment for people with a chronic disease.

Support from service providers, family and peers was an essential dimension of service user empowerment (Bulsara *et al.* 2004, Aujoulat *et al* 2007, Tveiten 2011). Service providers were considered supportive when they listened and treated patients equally with respect. On the other hand, disempowerment was experienced when service providers did not listen and did not treat patients as equal partners in the healthcare encounter. It is suggested that service providers have difficulties in acknowledging the service user as ‘expert’ and deep-rooted communication habits can complicate collaborative efforts between service providers and service users, calling for the necessity for more self-awareness of both (Tveiten and Meyer 2009). Therefore, the findings suggest that service providers surrender control (Kane 2009) and communicate in an honest and genuine manner (Hawks 1992). In addition, support from family and friends was described as instrumental to service users empowerment as participants in Aujoulat *et al’s.* (2007) study described feelings of powerlessness without their partners. Peer support was reported in very positive terms and supporting other patients was recognised as empowering (Bulsara *et al.* 2004), consequently reducing perceived stigma and social isolation for service users (Tveiten *et al.* 2011, Small *et al.* 2013).

Whilst some participants reported good collaboration with service providers, others felt powerless in the service user-provider relationship as a result of limited decision making ability and feeling coerced in relation to medication compliance (Tveiten *et al.* 2011). Indeed in Canada, patients with Diabetes met few service providers whose practices were empowering (Paterson 2001). Participants highlighted the importance of respect, being listened to and being viewed as experts by service providers (Paterson 2001, Tveiten *et al.* 2011).

Findings recognised that knowledge and understanding of one’s illness enhanced not only a feeling of empowerment but also of control for service users and enhancing patient participation (Bulsara *et al.* 2004, Tveiten *et al.* 2011). However, some older adults with chronic conditions acknowledged purposely limiting their knowledge and understanding of their illness as a strategy to stay in control (Small *et al.* 2013), suggesting that empowerment may not be desired by all service users.

Forms of psychological coping were identified by service users as vital to the empowering process and included the concepts of surrendering, illness acceptance, maintaining hope, and feeling safe (Bulsara *et al.* 2004; Mok *et al*. 2004; Wahlen *et al.* 2006; Aujoulat *et al.* 2007). These concepts often occurred in tandem with the concept of power and need for control. Wahlen *et al.* (2006) describes empowerment as a ‘power form within’ and highlights that patient empowerment involves stimulating the patient's own inherent joy of life and will to fight. However, the feelings of insecurity, and threats to social identity was reported in service users in Belgium and Italy with chronic conditions (Aujoulat *et al.* 2007).

Finally this review highlights that organisational and system issues such as poor continuity of care, and insufficient time during consultations can impede participatory decision making for service users (Paterson 2001). Moreover, Wahlen *et al*. (2006) suggests the need for a positive environment to encourage feelings of value and motivation. With this in mind, these system issues require further examination in particular given the bio-psycho-social needs of people with epilepsy.

3.4 Service user's level of empowerment in chronic illness

This section examines service user's level of empowerment in chronic illness (see table 3.3). A recent quantitative study conducted by Turner *et al.* (2018) investigated the level of empowerment by women with epilepsy of child birth age, their decisional styles, and the perceived relationship with the clinician. This study also examined the relationship of empowerment level and decision-making style with clinical variables such as epilepsy type, seizure frequency, therapy, pregnancy status; and women who take valproic acid (VPA). Sixty women with epilepsy were enrolled (of which six were excluded) by three physicians over a period of 12 months at the Epilepsy Centre-Child Neuropsychiatry Unit, San Paolo Hospital, University of Milan. Participants completed three questionnaires widely used in medical decision-making literature: Psychological Empowerment Instrument (Spreitzer 1995); the General Decision Making Style (GDMS) scale (Scott & Bruce 1995; Gambette *et al.* 2008), and the Observing Patient Involvement (OPTION) scale (Elwyn *et al.* 2005). Statistical analyses were performed using SPSS version 22.

Overall, findings did not show signs of low empowerment nor of abnormal decision-making patterns for women with epilepsy. Moreover, the type of epilepsy, the frequency of seizures, and the treatment type (VPA versus no VPA) do not impact on empowerment, on decision styles, nor on the relationship with the clinician, with the only exception of a specific decision style, the avoidant style, that is more frequent in women treated with VPA with respect to those taking other therapies. In relation to VPA dosage, this study found that women taking equal or more than 700 mg/day of VPA have lower scores on empowerment in all dimensions compared with women with a VPA dosage lower than 700 mg/day. Findings recognise that the empowerment level of women with epilepsy is comparable with the general population and patients with chronic diseases (Riva 2014). Whilst this is the first study to investigate the influence of empowerment and decisional skills in women with epilepsy, it was conducted at a single centre study reflecting the practice style of one Epilepsy Centre, and therefore its findings cannot be generalised.

A similar quantitative study conducted in Sweden investigated the level of empowerment and self-efficacy in patients with coronary heart disease (Kohler *et al.* 2018). In this cross sectional study 446 patients were recruited from a Swedish hospital, and 157 consented to participate (response rate 35%). Patient empowerment was assessed using the SWE-CES-10 questionnaire; self-efficacy was assessed by the General Self-Efficacy Scale; well-being was assessed by the Cantril Lander, a single item indicator of well-being; and finally self-rated health was measured by the Visual Analog Scale. Descriptive statistics, chi squared tests, and simple and linear regression models were used to analyse the data. Similar to Turner *et al.'s* (2018) study, findings acknowledge high levels of patient empowerment and self-efficacy comparable to the general population and patients with chronic illness, Moreover, clinical and demographic variables were not associated with levels of empowerment or low self-efficacy. However, whilst all questionnaires were used in previous studies and have high reliability and validity, this study used cross sectional data that was collected during an intervention study and may have limited findings.

A UK mixed method study conducted a scoping literature review and 16 qualitative interviews with key stakeholders (patients (n=4), patient representatives (n=4), primary care clinicians (n=4), health managers (n=4) and health service researchers (n=4)) to develop a conceptual map of patient empowerment, including components of patient empowerment and relationships with other constructs such as health literacy, self-management and shared decision-making (Bravo *et al.* 2015). The scoping literature review followed the five-stage framework proposed by Arksey and O'Malley (2005) and interview transcripts were analysed using Ritchie & Spencer's five step approach (1994).

Five key components of patient empowerment were identified and include: underpinning ethos, interventions, moderators, indicators and outcomes of patient empowerment. The authors suggest that empowered patients report higher levels of self-efficacy, sense of meaning, coherence about their condition, health literacy, perceived control and feeling respected by their healthcare providers. However, in contrast to Kohler's (2018) study findings also suggest that service users scoring high for patient empowerment will have better self-reported outcomes. For example, be better adapted to their condition; have improved quality of life; report higher levels of well-being and satisfaction with life; and achieve some independence relating to their healthcare. The authors acknowledged limitations in relation to limited article inclusion and small sample size and suggested that findings may not be generalizable.

Table 3.3 Characteristics of included studies: Examining levels of empowerment for people with a chronic illness

Author/ year	Country	Aim	Method/sample	Analytical technique	Findings
Turner *et al.* (2019)	Italy	To investigate level of empowerment, decision making style and relationship with the clinician with women of epilepsy of child-birth age	A quantitative study of 54 women with epilepsy of child birth age	SPSS version 22. Data presented as means and standard deviation. Data compared with Mann-Whitney U test and t tests	No signs of low empowerment nor of abnormal decision-making patterns for women with epilepsy. Moreover, the type of epilepsy, the frequency of seizures, and the treatment type (VPA versus no VPA) do not impact on empowerment, on decision styles, nor on the relationship with the clinician, with the only exception of a specific decision style, the avoidant style, that is more frequent in women treated with VPA with respect to those taking other therapies.
Kohler *et al.* (2018)	Sweden	To assess the level of empowerment and self-efficacy in patients six to 12 months after a cardiac event	A quantitative cross sectional study of 157 patients with coronary heart disease.	Descriptive statistics and chi squared tests	High levels of empowerment and self-efficacy. Clinical and demographic variables were not associated with levels of empowerment or self-efficacy
Bravo *et al.*(2015)	UK	To develop a conceptual map of patient empowerment, including components of patient empowerment and relationships with other constructs such as health literacy, self-management and shared decision-making.	Mixed methods study: (1) Scoping literature review; (2) 19 qualitative interviews with key stakeholders (patients (n=4), primary care clinicians (n=4) patient representatives (n=4), health managers (n=4) and health service researchers (n-4)) to further develop the conceptual map	Scoping literature review followed Arksey and O'Malley (2005) framework: Interview transcripts were analysed using Ritchie & Spencer's five step approach	Five key components of patient empowerment identified include: underpinning ethos, interventions, moderators, indicators and outcomes of patient empowerment.

3.5 Effectiveness of empowerment strategies for service users

This section examines the effectiveness of empowerment strategies in service users with a chronic illness (see table 3.4). For example, Brouse *et al.* (2010) employed an empowering educational framework to promote colorectal cancer screening in an urban minority population. Participants in this study developed a sense of self-efficacy and an awareness of their own power as health care consumers.

In a similar qualitative study conducted in Taiwan, Chang *et al.* (2004) utilised empowerment principles through Freire's dialogical interviewing to educate people with cancer. Fifteen service users participated in interviews over a period of three months. Open-ended questions and participatory observation with reflective notes written by participants were used for data collecting. Five themes were identified as integral to the empowering process in which the researcher and patients participated interactively: (1) building rapport; (2) assessing disempowerment issues; (3) facilitating critical thinking; (4) joint creation; and (5) resource connection and positive feedback (Chang *et al.* 2004). The empowered outcomes at a personal level included redefining health, being confident, active involvement, revitalizing the sense of self, the desire to live for themselves, negotiating the goals of one's care plan and having the strength to help others. Whilst this study provides service providers with a process to build partnerships with patients and help them to overcome the suffering caused by cancer, the authors recognised that the recording process did not involve tape-recording, which may limit its reliability. Thus, subsequent researchers may wish to take more time to design a dialogical interview to build rapport before gaining the consent to record the entire empowerment process.

In Sweden, Nygărdh *et al.* (2012) aimed to evaluate improvement in the quality of care as a consequence of empowering interactions between service providers and patients. A comparative pre (n=25) and post (n=21) evaluation of an intervention involving improvement in quality of care directed at increasing empowerment of patients with chronic kidney disease pre-dialysis was conducted**.** Data was analysed using descriptive and inferential statistics. Findings acknowledged that the intervention to improve quality of care had a significant impact on empowerment for patients with chronic kidney disease regarding support of individuality, personal life situation and decisional control. However, whilst this study identified the benefits of empowerment strategies, the small sample size may have contributed to false conclusions.

Although currently there is no empirical literature on the effectiveness of an empowering approach for people with epilepsy, the above studies suggest it may be effective since the patient populations reported upon share some of the characteristics of people with epilepsy. Thus, for example, people with cancer and chronic kidney disease often become passive consumers of health and struggle with bio-psycho-social and structural difficulties and exclusions.

Table 3.4 Characteristics of included studies: Effectiveness of empowerment strategies

Author/ year	Country	Aim	Method/sample	Analytical technique	Findings
Chang *et al.* (2004)	China	To illustrate the empowering process for cancer patients through Freire ' s dialogical interviewing	A qualitative study through a three-month period of interviewing based on Freire’s dialogical method of 15 adults with cancer.	Content analysis & constant comparisons	Five themes were identified as integral to the empowering process in which the researcher and patients participated interactively: (1) building rapport; (2) control; (3) facilitating critical thinking; (4) joint creation; (5) resource connection and positive feedback.
Brouse *et al.* (2010)	US	To assess an empowering educational framework to promote colorectal cancer screening	A RCT of 456 patients. Control group received print communication and the experimental group received tailored telephone education (TTE).	Descriptive statistics	A sense of self-efficacy and an awareness of their own power as health care consumers
Nygărdh *et al.* (2012)	Sweden	To evaluate improvement in the quality of care as a consequence of empowering interactions between service providers and patients	A comparative pre (n=25) and post (n=21) evaluation of an intervention involving improvement in quality of care directed at increasing empowerment of patients with chronic kidney disease pre-dialysis	SPSS version 19.0. Data was analysed using descriptive and inferential statistics	The intervention to improve quality of care had a significant impact on empowerment for patients with chronic kidney disease regarding support of individuality, personal life situation and decisional control.

3.6 Empowerment from the service provider perspective

The studies found in relation to empowerment from the service providers' perspective discussed theoretical approaches to empowerment and its significance to nursing only and include: organisational/structural theory; psychological theory; CST and mixed theoretical approaches (see table 3.5). These are now discussed.

3.6.1 Organisational/structural theories

Organisational perspectives on empowerment suggest that the structure and organisation of the work environment which one works solely determines the individual's capacity to be empowered. Thus, access to information, support, and resources creates an empowering work force and environment (Kanter 1993). Many studies utilized Kanter's (1977; 1979) model[9] to explore and measure empowerment (Chandler 1992, Manojlovich and Laschinger 2002, Laschinger and Finegan 2005, Lautizi *et al.,* 2009, Naisirpour and Siadati 2011; Smith *et al.* 2012).

For example, Lautizi *et al.* (2009) adopted Kanter's theory to investigate the relationship between staff nurses' structural empowerment, work stress and job satisfaction in two healthcare settings in Italy. A convenience sample of 77 nursing staff employed in the Department of Mental Health was used in this study. Findings recognised a strong relationship between high levels of structural empowerment and job satisfaction. The authors suggest that organisational administration should make every effort to create organisational structures and systems that empower nurses to practice according to professional standards and optimise the use of their knowledge and expertise.

A similar study conducted by Manojlovich and Laschinger (2002) in Canada and the US, tested a work-life model based on Kanter's model on a random sample of 332 nurses to explore the benefits of the empowerment model. Access to opportunities and positive informal alliances was identified as the most empowering aspect of work whilst the least empowering aspect related to formal power. Whilst findings illustrated that participants felt that their environments are only somewhat empowering, this study

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[9] See Chapter 1, Section 1.6.1 and Kanter's Structural/Organizational Theory

only tested one configuration of the work-life model and therefore results cannot be generalised.

Naisirpou and Siaditi (2011) conducted a quantitative study in Iran to assess a model for nurses empowerment through characteristics of workplace and leadership strategies with a sample of 292 nurses. Findings recognised that management and leadership strategies employed in hospitals impact nurses sense of empowerment. Indeed workload, respect, access to information and having a voice in hospital related decisions all had impact on nurse's sense of empowerment. Likewise, a quantitative study conducted in Canada by Laschinger and Finegan (2005) examined a theoretical model which specified the relationships among structural empowerment, six areas of work-life that promote employee engagement, and staff nurses' physical and mental health. This study surveyed a random sample of 273 medical, surgical and critical care nurses using a Conditions of Work Effectiveness Questionnaire. Results found that structural empowerment had a direct effect on organisational trust, respect, job satisfaction and commitment.

However, Chandler (1992) investigated the process of staff nurse empowerment from two community hospitals and three medical centres in America. Using a qualitative structured interview a convenience sample of 56 nurses were asked to describe a situation where they felt empowered and a situation where they felt powerless. Findings recognise that whilst empowerment is contingent on information, resources, knowledge and support structures a critical component is to be found in interpersonal interactions. For example, participants felt empowered by the patient-practitioner relationship and the interactions with families/carers. In addition, the nurse-physician interaction was highlighted as empowering particularly when nurses were asked for their professional opinion. However, a convenience sample and the use of two questions during the interview has limitations in terms of findings and transferability. Whilst this study evaluated the working environment of staff nurses from two community hospitals and three medical centres, arguably it did not investigate the process of staff nurse empowerment.

A quantitative study conducted by Smith *et al.* (2012) examined the relationship between structural empowerment and anticipated turnover among 97 behavioural health nurses in the United States. Participants were asked to complete a questionnaire in relation to nurse's perceptions of empowerment. Factors that enhance nurse's perceptions of empowerment, particularly related to issues of retention and anticipated turnover. Whilst the majority of participants in this study perceived themselves as moderately empowered similar to findings in previous research (Laschinger 1996; 2000, Laschinger and Finegan 2005), there was a significant negative correlation between empowerment and anticipated turnover (Smith *et al.* 2012).

3.6.2 Psychological theory studies

Conger and Kanungo (1988) argue that empowerment as a purely organisational concept is limited without considering the individual. As outlined in Chapter 1, psychological empowerment[10] supports the influence of the individuals' response to their environment in relation to meaning, competence, self-determination, and impact, and is a personal attribute or quality and a measurement scale entitled the psychological empowerment questionnaire was developed to measure these dimensions (Spreitzer 1995).

An American study conducted by Sparks (2012) compared two generations of 451 nurses using Spreitzers (1995)[11] psychological empowerment questionnaire. Findings of this highlighted that older nurses were more empowered than younger nurses. The author suggests that psychological empowerment can be improved for younger nurses through targeting ways of finding meaning in their work. However, findings of this study may be limited as data such as work life balance, home life, children and distance from work were not included.

Kuokkanen and Leino-Kilpi (2001) explored the qualities of an empowered nurse, and factors that may support or hinder their empowerment. Their conceptual framework employed the concepts of meaning, impact, competence and self-determination. This study involved interviews with the first 30 nurses who presented themselves from a sample of 125 nurses who had participated in a career advancement project at a university hospital in Finland. The data were analysed by qualitative content analysis. Participants were asked as part of the research to evaluate their own state of empowerment and with just one exception all considered themselves empowered

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[10] See Chapter 1, Section 1.6.2 and Kanter's Structural/Organizational Theory

[11] See Chapter 1, Section 1.6.2 and Spreitzers's psychological theory

nurses. The following themes were identified and represent the performance and the qualities of an empowered nurse, as well as the promoting and preventing factors: moral principles (based on respect, honesty and equity); personal integrity (involving courage, flexibility, ability to act under pressure); expertise (competence, autonomy, having personal power, responsibility); innovation and creativity; and sociability. Indeed, based on the above findings, Kuokkanen and Leino-Kilpi (2002) developed an instrument to measure the qualities and the performance of an empowered nurse. Each scale consisted of 19 items using a five point Likert scale and were administered to 416 nurses. Participants recognised moral principles as their best quality, while future-orientation was their least reported quality. Whilst this study focused on the qualities of an empowered nurse, the author acknowledged that some of the questions were slightly ambiguous.

3.6.3 A CST perspective

Those who consider empowerment from a CST perspective suggest that the presence or absence of empowerment can only be understood in relation to the history and structures within which one finds themselves (Fulton 1997). A qualitative study conducted in the UK to explore 16 nurse’s views of empowerment employed CST to the research enquiry (Fulton 1997). This small-scale study employed two focus groups, and was composed of participants in an Empowerment for Practice course which was led by Fulton at Southampton University School of Nursing and Midwifery. Empowerment was described as a process and an outcome and having the freedom to make decisions and have choices. Moreover, having personal power along with feeling right about oneself, confident, and having self-esteem was highlighted. However, nurses highlight not feeling empowered and lack autonomy related to unequal relationships with the medical profession. The authors suggests that nurses in this study showed signs of oppression and therefore recommends the teaching of CST as an empowering paradigm within nursing education, equating empowerment with liberation. This small scale used only 2 focus groups from a self-selected sample and therefore findings cannot be generalised.

A qualitative study conducted by Falk-Rapael (2001) explored empowerment in public health and factors that may aid empowerment in practice. The first phase involved nine focus groups with 17 public health nurses from three rural and two urban regions in

Ontario. The second phase involved interviews with 6 patients whom the public health nurses had nominated as been empowered by their own health care practices. Whilst the public health nurses defined empowerment in this study as ‘a *process of evolving consciousness in which increased awareness, knowledge, and skills interacted with the clients active participation to move toward actualising potential’* (Falk-Rapael 2001.p4), the authors suggested that the extent to which the nurses themselves felt empowered other than reciprocal effects of the nurse-patient relationship remains unclear and requires further exploration. Whilst findings of this study suggested that patients support the nurse’s model of empowered caring, arguably a potential for bias exists in this study since patients were nominated by the public health nurse who participated in the focus groups.

Despite the limitations of Fulton’s (1997) and Falk-Rapeal (2001) studies, many of the findings correlate with the findings of a national study exploring empowerment amongst Irish nurses and midwives (Scott *et al.* 2003). The first phase of this study involved ten focus groups. Phase 2 of the study involved a national survey, set out to test the focus group findings with 1781 nurses and midwives. With a response rate of 46%, findings highlight that empowerment requires the presence of individual personal factors and environmental factors. This was evident in both focus group and survey data.

The findings from the focus groups articulated nurses’ and midwives’ experiences of empowerment in terms of six key and three interweaving themes. The key themes acknowledged include: individual factors, interpersonal factors, professional issues, organisational issues, management, and historical legacy whilst the interweaving themes were: education; professional respect; and control. Participants acknowledged factors that support and/or hinder their empowerment. For example, whilst nurse education; knowledge; and self-confidence was found to support empowerment, poor management; lack of education; lack of support; and lack of recognition hinders empowerment. This study however runs the risk of bias as participants were nominated by Directors of Nursing and other relevant managers

Similar results were found in a large mixed method Irish study analysing Public Health Nurses (PHN’s) perceptions of empowerment and advocacy within a child health surveillance program This study was undertaken in two phases (Cawley and

McNamara 2011). Phase 1 included a purposive sample of 9 PHN’s who agreed to participate in 2 focus groups. Phase 2, a purposive sample of 43 clients attending the child health screening program were surveyed. Thematic content analysis revealed that PHN’s did not perceive themselves as empowered and factors that hinder their empowerment include: workload; restricted access to power and opportunity; lack of professional advocacy; poor management style; and lack of support. The authors suggest that PHN’s need to be empowered in order to facilitate empowerment for their clients and suggested a more critical engagement with empowerment and self-efficacy in their work.

3.6.4 Mixed theoretical approach

A mixed theoretical approach was also found in studies examining nurse’s empowerment. For example, a study conducted in Connecticut by Stewart *et al.* (2010) assessed the relationship of psychological empowerment and structural empowerment in Nurse Practitioner practice. Structural empowerment was measured using the conditions of work effectiveness questionnaire-II (CWEQ-II), and psychological empowerment was measured using Spreitzer's psychological empowerment scale with a sample of 74 Nurse Practitioners. There were significant correlations between psychological and structural empowerment for total scores, and within 10 of these tools' subscales. Findings revealed high scores on perceptions of structural empowerment and psychological empowerment and Nurse Practitioners value their work and find meaning in what they do. The authors in this study highlight the importance for the organisation or practice setting to facilitate both psychological and structural empowerment to ensure successful practice.

An Irish study conducted by Casey *et al.* (2010) utilised a CST framework to assess if structural empowerment and CST were positively related to psychological empowerment. Surveys were administered to a convenient sample of 306 nurses attending a three day leadership course. The authors revealed that access to orgnaisations empowerment, CST and psychological empowerment had a positive impact on job satisfaction. The majority of participants perceived they were doing competent work and acknowledge that competence and meaning are core values of work. However, (44%) revealed they had little impact within their Department. Whilst potential bias exist in this study, arguably this mixed theoretical study broadens an understanding of empowerment.

3.6.5 Concluding comments

Studies that examined empowerment from an organisational theoretical perspective demonstrate how access to information, support and resources support the empowerment of nurses (Chandler 1992; Manojlovich and Laschinger 2002; Laschinger and Finnegan 2005; Lautizi *et al.* 2009; Naisirpour and Siadati 2011; Smith *et al.* 2012). On the other hand, studies that examined nurse’s empowerment from a psychological theoretical approach illustrate how nurses can bring his/her competencies to the workplace (Kuokkanen and Leino-Kilpi 2001; Kuokkanen and Leino-Kilpi 2002; Sparks 2012). Whilst these studies highlight that psychological empowerment is applicable to an international audience and is not culturally bound, arguably it only provides the researcher with a measure of empowerment rather than revealing the actual process (Kennedy *et al.* 2015).

Studies that utilised CST examined factors that support or hinder empowerment using a critical lens (Fulton 1997; Falk Rapael 2001; Scott *et al*. 2003; Cawley and McNamara 2011). Historically oppression in nursing has been acknowledged and therefore, exploring the system in which service providers practice and collaborate is required to address how to facilitate a culture of empowerment. Mixed theorectical approaches provides a broader lens of how to view empowerment and arguably has the potential to better understand this complex concept. The relationships between psychological empowerment and structural empowerment have been linked to work effectiveness, quality patient care, cost-effectiveness, and retention (Casey *et al*. 2010; Stewart *et al.* 2010)

Table 3.5 Characteristics of included studies: Empowerment from the service provider's perspective

Author/ year	Country	Aim	Method /sample	Organisational	Psychological	CST	Mixed	Findings
Lautizi *et al*. (2009)	Italy	To investigate the relationship between staff nurse's structural empowerment, work stress and job satisfaction	Quantitative (n=77)	√				A strong relationship between high levels of structural empowerment and job satisfaction.
Manojlovich and Laschinger (2002)	Canada & US	To explore the benefits of Kanter's empowerment model.	Quantitative (n=332)	√				Access to opportunities and positive informal alliances was identified as the most empowering aspect of work whilst the least empowering aspect related to formal power
Naisirpour and Siadati (2011)	Iran	To assess a model for nurses empowerment through characteristics of workplace and leadership strategies	Quantitative (n=292)	√				Management and leadership strategies employed in hospitals impact nurses sense of empowerment
Laschinger and Finnegan (2005)	Canada	To test a theoretical model which specified the relationships among structural empowerment, 6 areas of work-life and staff nurses' physical and mental health.	Quantitative (n=273)	√				Positive work environment; structural empowerment had a direct effect on organisational trust and respect, job satisfaction and commitment

Table 3.5 Characteristics of included studies: Empowerment from the service provider's perspective

Author/ year	Country	Aim	Method /sample	Organisational	Psychological	CST	Mixed	Findings
Chandler (1992)	US	To explore the process of staff nurse empowerment	Qualitative (n=56)	√				Information, resources, knowledge and support structures, interpersonal interactions. Work environment
Smith *et al.* (2012)	US	Examined the relationship between structural empowerment and anticipated turnover among behavioural health nurses	Quantitative (n=97)	√				Factors that enhance nurse's perceptions of empowerment, particularly related to issues of retention and anticipated turnover The majority of participants in this study perceived themselves as moderately empowered, and there was a significant negative correlation between empowerment and anticipated turnover
Sparks (2012)	US	To compare two generations of nurses using Spreitzers (1995) psychological empowerment questionnaire.	Quantitative (n=451)		√			Older nurses were more empowered than younger nurses.
Kuokkanen and Leino-Kilpi (2001)	Finland	To explore the qualities of an empowered nurse, and factors that may support or hinder their empowerment	Qualitative (N=30)		√			Five themes represented the performance and the qualities of an empowered nurse, as well as the promoting and preventing factors and include: moral principles; personal integrity; expertise; future orientation; and sociability.

Table 3.5 Characteristics of included studies: Empowerment from the service provider's perspective

Author/ year	Country	Aim	Method /sample	Organisational	Psychological	CST	Mixed	Findings
Kuokkanen and Leino-Kilpi (2002)	Finland	To measure the qualities of empowered nurse scale and the performance of an empowered nurse scale measured 19 items using a five point Likert scale.	Quantitative (n=416)		√			Nurses recognised moral principles as their best quality, while future-orientation was their least reported quality.
Fulton (1997)	UK	To explore nurses views of empowerment	Focus groups x2 (n=16)			√		Freedom to make decisions. Personal power, confidence and self esteem Empowerment is a process and outcome
Falk-Rapeal (2001)	Canada	To explore empowerment in public health and factors that aid empowerment	Mixed Focus group (n=17) Interview (n=6)			√		Process of evolving consciousness Reciprocal effects of the nurse-client relationship
Scott *et al.* 2003	Ireland	To explore empowerment amongst Irish nurses and midwives	Mixed methods (n=1874) Focus groups (n=93) Survey (1,781)			√		Factors that support empowerment include: nurse education; knowledge; and self-confidence poor management; lack of education; lack of support; and lack of recognition hinders empowerment.
Cawley and McNamara (2011).	Ireland	Public Health Nurses (PHN's) perceptions of empowerment and advocacy within a child health surveillance program	Mixed methods Phase 1 (n=9) Phase 2 (n=43)			√		PHN's did not perceive themselves as empowered and contributing factors included: workload; restricted access to power and opportunity; lack of professional advocacy; poor management style; and lack of support.

Table 3.5 Characteristics of included studies: Empowerment from the service provider's perspective

Author/ year	Country	Aim	Method /sample	Organisational	Psychological	CST	Mixed	Findings
Stewart *et al.* (2010)	US	Assessed the relationship of psychological empowerment and structural empowerment	Quantitative (n=74)Nurse Practitioners				√	High scores on perceptions of structural empowerment and psychological empowerment and Nurse Practitioners value their work and find meaning in what they do
Casey *et al*. (2010)	Ireland	To assess if structural empowerment and CST were positively related to psychological empowerment	Quantitative (n=306) nurses				√	97% revealed that competence and meaning are core values of work.44% have little impact within their Department.

3.7 Discussion

The initial aim of this literature review was to provide a critical synthesis of existing studies in relation to empowerment and epilepsy health care. However, due to a paucity of literature found the search was broadened to include chronic illness/disease. This review illustrates how many studies have been done in this area globally and in Ireland from perspectives of service users and providers. The focus of the review is to identify a gap in the literature in relation to empowerment and epilepsy health care and provide justification for this study.

Service users and providers described empowerment as a process and/or outcome and an access to power from within, similar to the definition of empowerment and epilepsy healthcare provided in Chapter 2[12]. Findings of this review also highlight that empowerment and power are inextricably linked and that power imbalances exist between service users and providers. The literature suggests however that the process of empowerment is incomplete without a shift in the balance of power (Rodwell 1996, Ryles 1999). Therefore, the reciprocal link between them needs to be further explored in order to further understand empowerment.

Examining service users and providers perspectives of empowerment in tandem enables an understanding of the reality of current issues in healthcare. Findings reveal that not all issues are common to service users and providers, often revealing different perspectives and priorities in relation to empowerment. Firstly, service users perspectives in relation to empowerment was examined and factors that support or hinder their empowerment include: control; participation; shared decision making; support; collaboration with service providers; knowledge and understanding; psychological coping; power; and finally the system. On the other hand, service providers perspectives of empowerment highlighted factors such as: access to information; support; resources; moral principles (based on respect, honesty and equity); personal integrity (involving courage, flexibility, ability to act under pressure); expertise (competence, autonomy, having personal power, responsibility); innovation and creativity; and sociability. These findings are similar to the findings of the concept analysis of empowerment and epilepsy health care presented in Chapter 2.

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[12] See Chapter 2, Section 2.8: Operational definition of empowerment within epilepsy services

Despite significant variation in diagnoses, culture and demographic details, this review found that service users with a chronic illness revealed similar factors that support or hinder their empowerment. For example, control over one's life and personal responsibility for health was a dimension identified most frequently and this included participation and shared decision making in the health care encounter (Paterson 2001, Mok *et al.* 2004, Bulsara *et al.* 2004, Wahlen 2006, Aujoulat *et al.* 2007, Tveiten *et al.* 2011, Small *et al.* 2013). Indeed, perceived personal control is a construct developed in health psychology, encompassing cognitive, decisional and behavioural dimensions and an important role in helping service users cope with one's illness (McAllister *et al.* 2008). Whilst some service users reported that been acknowledged as experts contributed to participation and increased self-confidence, others experienced the contrary. The literature highlights that to feel powerless and be ignored in the decision making process has been related to a reduction in functional abilities (Faulkner 2001, Rimmer and Rowland 2008). However, despite these issues studies revealed high levels of empowerment for service users (Kohler *et al.* 2018, Turner *et al.* 2019).

Exploring possible factors that may support or hinder empowerment for service users from an organisational/structural perspective was rarely mentioned. An exception to this was Tveiten *et al.*'s (2011) study who recognised that limited time available for participation, services offered and poor collaboration between service providers and users hinders empowerment. Furthermore rules and regulations were revealed as inhibiting participation and feelings of powerlessness. However, much of the research on service provider's perspectives of empowerment were limited to a nursing perspective only. A possible reason for this is that perhaps doctors have been socialised into believing that they are the key decision makers for service users (Nugus *et al.* 2010). Findings of this review highlight that nurses feel powerless. Roberts *et al.* (2009) suggests that the lack of power for nurses in the clinical environment is endorsed by the hierarchial structures and medical dominance over nursing for generations. Arguably, therefore it is time to explore nurses and doctors perspectives of empowerment to gain a deeper understanding of these issues.

Studies examing nurses perspectives of empowerment were based on Kanter's structural empowerment, Spreitzer's psychological empowerment and critical social empowerment. However, a lack of available qualitative research on a MDT perspectives and experiences of empowerment limits the richness of details. Moreover, whilst many studies described the effect of empowerment on nursing satisfaction, burnout, stress, and decision making, findings did not report on the direct impact of empowerment or lack of on patient health outcomes. Moreover, authors failed to describe how institutional culture and their own personal experience affected the framing of these studies and interpretation of the data.

3.7.1 Methodological issues

It is difficult to compare and contrast studies and draw definitive conclusions from this literature review due to differences in methodologies employed, variances in sample sizes, and theoretical approaches utilised. This is apparent in studies relating to service provider's views of empowerment, with a wide range of assessment tools used which include Kanter's model of structural empowerment; Spreitzer's (1995) psychological empowerment questionnaire; Kuokkanen and Leino-Kilpi (2002) measurement scale; and CWEQ-II scale, although it be must be noted that all tools have proven validity and reliability.

Whilst many studies exploring service provider's perspectives of empowerment employed a theoretical approach, the majority of studies exploring service user's perspectives did not. Moreover, finding significant relationships from the data, may have been limited due to small sample sizes in some studies reported. Finally, the majority of the research was undertaken in nursing and medical schools. It is suggested that researchers affiliated with nursing and medical schools may be influenced by a medical discourse and culture which can exclude a critical appraisal of the social context (Agner *et al.* 2018).

3.7.2 Gaps in the literature

Findings of this review identified a number of gaps within the literature that require further exploration. Firstly, while health policy advocates an empowering approach for service users and providers, no studies have explored empowerment within epilepsy services and healthcare. Although this literature reviewed examined service user's views with a chronic illness in relation to empowerment, there is no study undertaken to specifically explore people with epilepsy's views. It is clear therefore that further research is warranted exploring empowerment within epilepsy services.

While there is extensive research on nurses perspectives in relation to structural empowerment, research exploring service users views in relation to structural/organisational issues are lacking. Arguably this limits findings in relation to organisational issues, access to services and care provision, resources, culture and environment. Therefore, further research is required to identify the micro-meso and macro levels of power from the service user's and providers perspective. Thus, exploring organisational and system issues that either support or hinder empowerment for people with epilepsy is required. Systems thinking identifies the elements of a system and consists of looking at the whole system, instead of the parts (Ackoff 1999). Arguably attempting to solve complex issues without a systems thinking approach can lead to unintended consequences (Trbovich 2014).

This study will address these gaps and explore the micro-meso-macro levels of power within epilepsy services using a systems approach. In addition, this study will employ CST as a philosophical framework for this study exploring empowerment and epilepsy health care and reflections on the study will be undertaken.

3.8 Conclusion

This literature review has enabled the identification of a paucity of literature that specifically explores empowerment and epilepsy healthcare. Indeed, the limited amount of research examining empowerment from the perspective of the person with a chronic illness may not be applicable to people with epilepsy. Research has yet to address adequately the structural and organisational factors that may influence empowerment for service users such as access to services and care provision; discrimination; resources; and institutional culture. This is significant given the complexities of epilepsy as a chronic condition and recent strategies and programs that have been implemented to improve the quality of epilepsy health care (HSE 2010). Moreover, service provider's perspective of empowerment is limited only to nurses understanding. It is evident that many of the studies identified are based on the premise that organisational structures, and individual competencies are the source of empowerment, without exploring the experience or perspectives of empowerment by the service provider. Due to the methodological issues that have been highlighted, it is difficult to draw definitive conclusions from the literature reviewed. Therefore, further research is warranted in relation to empowerment and epilepsy healthcare. The present study aims to address this gap in the literature by exploring empowerment in one specialist epilepsy service in Ireland using a systems approach and CST.

CHAPTER FOUR

Towards an Empowered Perspective for Epilepsy Policy and Care Provision

4.1 Introduction

This Chapter explores the relationship between empowerment, health policy and care provision. Section 4.2 explores some key theoretical perspectives and their significance for epilepsy policy. In section 4.3 the importance of empowerment for policy development and care provision is recognised, and the need to reformulate debate within an empowered perspective explored.

In section 4.4 national and international epilepsy guidelines and models of care is detailed with possible explanations for the absence of an empowered perspective presented. In section 4.5, a movement towards the development of a health policy in relation to empowerment is explored. Arguably, this requires a stronger awareness of and connections between content, context, processes and actors for policy development (Walt and Gilson 1994).

4.2 Theoretical perspectives on health policy

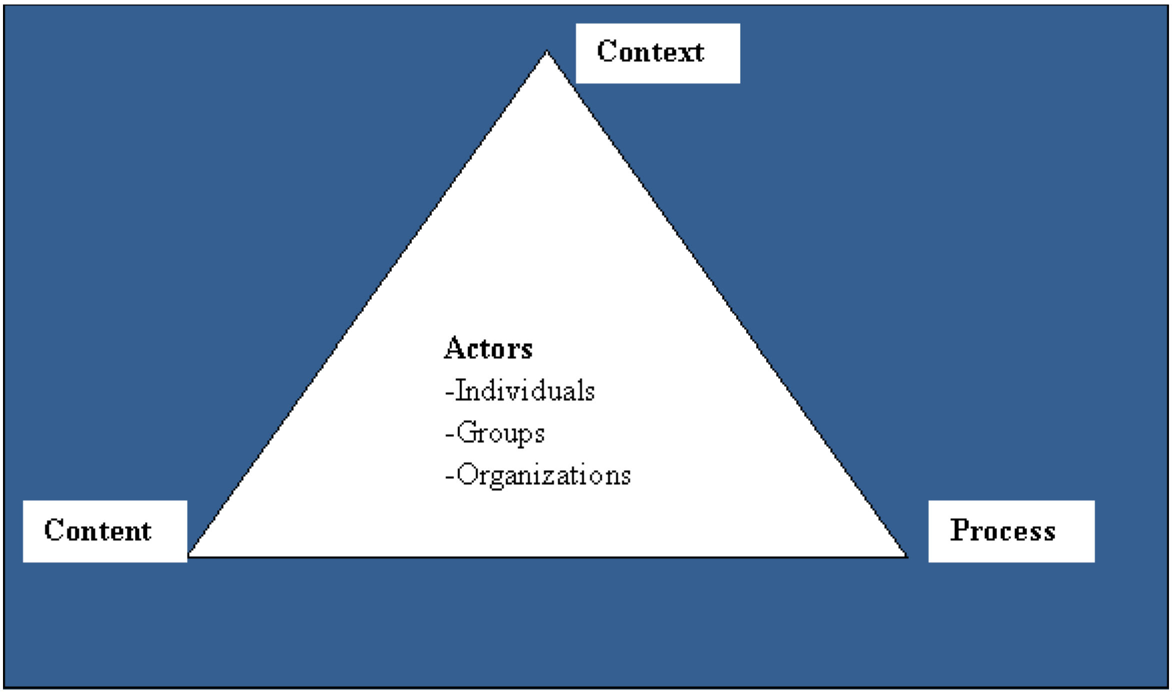
Exploring health policy encourages an in-depth understanding of today's constantly changing healthcare environment resulting in a greater ability to influence services (Fatchett 1994; 1998; 2012). Arguably, without critical thinking and understanding of government health policy, the desired learning improvements may not be achieved as a consequence of personal and or professional prejudice (Goodman 2011). In the rhetoric of modern health care systems, the patient role has evolved from passive recipient of medical care to active, empowered and informed co-producer of health. Policy analysis can contribute to realising health objectives, and to unravelling the complex mechanisms of power and process that underpin change (Buse *et al*. 2005).

Many theoretical frameworks can be used to understand health policy development and implementation (see Brewer and deLeon 1983, Kingdon 1984, Rogers and Pilgrim 2001, Duncan and Reutter 2006, Walt *et al*. 2008, Tantivess and Walt 2008, Crichton 2008). Rogers and Pilgrim (2001) outline a three-tier analytical framework for considering policy at macro (historical and current issues and how society reacts), meso (legislation, national policy frameworks, organisational) and micro (professional/service users) levels.

This three-tier level of analysis can demonstrate the patterns of continuity over time and across various societies as opposed to being '*temporary and provi sional'* (p. 225). This analytical framework, with a particular emphasis on the micro level situates well in relation to how empowerment is currently understood to operate at multiple levels within the social world – individual and relational (micro), organisational and institutional (meso) and societal (macro) levels (Rappaport 1981, Tveiten and Severinsson 2005).

Walt and Gilson (1994) outline a 'policy analysis triangle' framework which focuses on content, context, processes and actors and the interaction between all of them (Figure 4.1). In the centre are the actors and their actions that affect the policy. The corners of the triangle consist of the context, wherein policy is developed; the content of policy; and the process of policy, which is contingent on developing and implementing change (Walt and Gilson 1994).

Figure 4.1: Policy Analysis Triangle (Buse *et al.* 2005)



While there are similarities between Rogers and Pilgrim (2001) and Walt and Gilson (1994) frameworks, especially at the macro and meso levels, the latter places a stronger emphasis on the importance of actors for policy development. Arguably, a greater emphasis on the actors within epilepsy services from service providers, people with epilepsy, family/carers, politicians, policymakers to voluntary organisations for policy development will avoid the traditional content approach whereby those with power and knowledge in society were dominant in how policy evolved (Wren 2003). With this in mind, power and the policy process is now explored.

4.2.1 Power and the policy process

Power is a complex and multi-dimensional concept, and a central theme in the study of policy and policy process (Walt 1994). In policy contexts, the concept of power is typically conceived of in a relational sense, i.e. particular policy actors are understood to exercise their '*power over'* others (Buse *et al.* 2005 p. 21). For example, actors may exercise political power by bringing authority (which may be legally or traditionally determined) to bear, or by resisting the authority of others (Buse *et al*. 2005, Erasmus and Gilson 2008). Institutional power can range from coercion to inducement, depending on the choices and political resources available to authorities. Policy actors may also demonstrate power by influencing key policy decisions and/or by limiting the scope of other actors' activities (Parsons 1995). Apart from the direct exercise of power by one (group of) actor(s) over another, policy theorists have also highlighted the role of more diffused forms of power, such as that of elite groups to shape thoughts and ideas on a large scale, and the hegemonic potential of ideas themselves (Lukes 1974). More recently, post-positivist theorists such as Yanow (2000) and Fischer (2003) have drawn on the writings of political philosophers such as Jürgen Habermas to emphasise positive and productive aspects of 'communicative' power, of organizing action through discourse.

Habermas informed by CST identifies power relations inherent in policy processes (Morrow and Brown 1994, Mill *et al*. 2001). For instance, CST as a methodological approach to policy analysis is inclusive of different forms of knowledge. Fischer (1995 p.6) describes the essence of a CST approach as one of '*integrating the normative evaluation of a policy's goals with the kind of empirical work already characteristic of policy evaluation'*.

Furthermore, whilst traditional policy analyses entail the deductive evaluation of the relative merit of various policy proposals, critical analyses focus on how the interplay of the processes and contexts influence the definition of policy problems (content), agenda setting, and choice of policy instruments. A critical policy analysis exposes the ideologies and values underlying policy issues and their proposed solutions, and the inclusiveness or exclusiveness of the policy debate (Forester 1993, Fischer 1995).

Moreover, a critical analysis exposes the reality of organisational processes, particularly as they relate to how policies are experienced by people in their daily environments. Arguably, this has the potential to create a more balance policy and a clearer understanding of how people with epilepsy, carers and service providers experience the reality of policy problems and solutions.

The health policy triangle situates well in relation to how empowerment can be understood in relation to political, historical and cultural contexts (Brugha *et al.* 2014). The triangle is also flexible, because it can complement different theories of policymaking to help illuminate, which issues are chosen to get on the policy agenda and also how and why these are formulated and applied (Brugha *et al.* 2014). The importance of empowerment for policy development and understanding is now considered.

4.3 The importance of empowerment for policy development and understanding

There is growing recognition for the inclusion of empowerment within policy development, care provision and research (WHO 2006, Fitzsimons *et al.* 2012). However, despite empowerment being a key issue in many recent Department of Health (DOH) initiatives such as The *NHS* (National Health Service) *Plan* and *The Expert Patient* (DoH 2001), a paucity of literature with regards to empowerment of epilepsy care provision exist.

In the United Kingdom (UK), the Coalition Government has reiterated NHS commitment to patient empowerment with the publication in 2010 of the NHS White Paper: '*Equity and excellence: Liberating the NHS'* (NHS 2010). The 2010 White Paper takes forward strategies to: (1) give patients more choice and control over their healthcare; and (2) make hospital funding contingent upon performance against a range of quality measures including Patient-Reported Outcome Measures (PROMs) (DoH 2009). Together it is claimed that these initiatives will empower service users.

Indeed, the European Life Science Circle (ELSC) speakers call on the European Union (EU) to: (1) establish patient empowerment and self-management of chronic diseases as a priority of the new Commission's work program and to position these topics at the centre of all relevant EU health policy initiatives; (2) introduce EU-wide care models for chronic diseases that include behavioural and educational programmes which enable patients to take responsibility and manage their condition; and (3) ensure that core models and recommendations for health technology assessments currently developed at EU level follow predictable, common criteria and methodologies which take into account the actual patient-self management activity in the investigated treatment procedure. Therefore, developing a health strategy that is empowerment focused must be based on an explicit analysis of empowerment and health disparities (WHO 2006). With this in mind, international and national evidence based models of care with reference to empowerment is now explored.

4.4 Evidence Based Models of care for people with epilepsy

One of the challenges facing modern health care systems is to develop and implement new models of service that deliver increased capacity while providing a higher-quality, more cost-effective service within resource constraints (Westbrook *et al.* 2009). Consequently, there is an international and national move to transform the management of chronic diseases. In response to these challenges the WHO has recommended the Chronic Care Model (CCM) to guide healthcare system reform worldwide (IOM 2001). Moreover, in Ireland the HSE established a new strategy for the delivery of health care services to the public (HSE 2010). The proposed National Clinical Programmes, of which there are 26 acute medicine programmes, challenge traditional models of service delivery and cost structures with a move towards models of care that require service reconfiguration, reform and greater productivity (HSE 2011). The NECP is one such program and the implementation and changes occur within the context of a planned overall reform of the HSE outlined within the Programme for Government (Government of Ireland 2011). These models are now discussed further.

4.4.1 The Chronic Care Model

The CCM is an internationally recognised evidence-based theoretical model which identifies the essential elements of a healthcare system that encourages high-quality care for chronic illness (Wagner *et al.* 1996; 2001). The emergence of the CCM represents a response to growing numbers of chronically ill patients, the inability of current healthcare systems to meet the medical needs of chronically ill patients, the era of cost constraints alongside increased performance expectations from an informed public and the acknowledgement of the need for a shift from reactive to proactive healthcare systems (IOM 2001, Oprea *et al.* 2010). The CCM model aims to guide quality improvement by changing reactive acute-orientated care, to care that is planned, proactive, population-based and patient-centred (Wagner *et al.* 1996; 1998).

The CCM is designed on evidence-based research and practice interventions to assist this transition from a reactive to a proactive healthcare system. It includes a combination of patient, provider and system level interventions delivered in tandem through six key elements: (1) Healthcare system organisation (i.e. policies, goals and structures of healthcare systems); (2) Self-management supports (i.e. information and supports to facilitate patients to manage their care); (3) Delivery system design (i.e. coordinating care processes proactively to determine and address individual health needs); (4) Decision supports (i.e.healthcare provider access to evidence-based processes and clinical expertise and experience); (5) Clinical information systems (i.e. timely access to data about patients and populations); and (6) Community resources and policy (i.e. sustaining care through utilising community resources and public policy to facilitate care outside of the clinical setting) (Wagner *et al.* 2001) (see figure 4.2).

Figure 4.2: Chronic Disease Management Model (Wagner 1998)

Source: Effective Clinical Practice, 1: 2–4, Wagner: Chronic disease management: What will it take to improve care for chronic illness, © 1998, with permission from the American College of Physicians.

4.4.1.1 Health care system organisation

As illustrated in Figure 4.2, community resources and policies, health systems and healthcare organisations use self-management supports, delivery system designs, decision supports and clinical information systems to achieve productive and evolving interactions between informed enfranchised patients and prepared proactive practice teams, resulting in improved outcomes. Key focal points of the CCM are the development of interactions between the healthcare system and the community, and also between patients and healthcare providers (Wagner *et al.* 2001). Optimal chronic care is achieved when a prepared, proactive healthcare team interacts with an informed, enfranchised patient, and when the healthcare system interacts productively with the community.

The WHO has recommended the CCM for healthcare systems worldwide (IOM (IOM 2001, Oprea *et al.* 2010). The sum of the components of the CCM creates more effective healthcare delivery systems (Stellefson *et al.* 2013). With this in mind, the application of these recommendations and evidence of their effectiveness in epilepsy care are discussed.

4.4.1.2 Self-management support

Supporting people with epilepsy to develop the attributes and skills required to function as equal partners with clinical and social services, be empowered to make informed decisions, and competently self-manage with regard to their healthcare is warranted if they are to manage effectively the day-to-day challenges they face in their lives (Fitzsimons *et al.* 2012). Although studies of self-management programs for people with epilepsy have been outlined, the study of education for people with epilepsy is often neglected and is a poorly understood component of holistic practice within epilepsy healthcare.

4.4.1.3 Delivery system design

Improved integration of care has been identified as key to improving the quality, safety, and efficiency of health services for patients with chronic illness (Fitzsimons *et al.* 2012). Such integration aims to improve coordination of multidisciplinary care both within and across organisational boundaries. It promotes continuity through shared-care partnerships involving the patient, specialist epilepsy services; primary care, and epilepsy specialist services (Fitzsimons *et al.* 2012).

Currently epilepsy care in Ireland is shared between primary (General Practitioner (GP), secondary (hospital) and tertiary (specialist epilepsy services within a hospital) services. The GP is the first point of contact for people with epilepsy and responsible for their ongoing management of care (Varley *et al.* 2009). Two of the main epilepsy specialist centres for people with epilepsy in Ireland are located at St. James's Hospital (SJH) and Beaumont Hospitals in Dublin. These centres are staffed by consultant neurologists, neurology registrars', and Epilepsy Specialist Nurse's (ESN's). People with epilepsy are either reviewed by an ESN, a medical doctor or by both. However, complex cases are initially reviewed by a consultant neurologist.

International literature exploring people with epilepsy's experiences of healthcare identify a number of problems including: delays in access to specialist services; poor follow-up; inappropriate prescribing; poor information provision and educational delivery; lack of psycho-social supports; poor communication within the Multi-Disciplinary Team (MDT); lack of confidence in GP's ability; time constraints; and lack of resources (Ridsdale 1995, Thapar 1996, Ridsdale *et al.* 1996, Ridsdale *et al.* 2000, Mills *et al.* 2002, Noble *et al.* 2013). Studies identify that the majority of people with epilepsy are urgently admitted to secondary and tertiary care institutions (mostly through the Emergency Department (ED) at some point in the history of their illness and a significant proportion require multiple visits (Pugliatti 2007). However, despite the heavy burden of seizures in the ED, international studies suggest that the majority of patients are referred unnecessarily for admission to hospital and that the acute treatment of seizures is often ineffective and highly variable (Marson 2013).

Using a phenomenological approach, Varley *et al.* (2011) conducted one-to-one interviews with twenty (n=20) people with epilepsy in Ireland to explore their healthcare journey from onset of symptoms through to their first interaction with specialist epilepsy services. Similar inadequacies of service providers were identified including: delayed access to specialist review; disorganisation of existing services; uncertainty regarding the competency and role of primary care services; unmet information needs: and significant unmet needs for females with epilepsy.

A study of the interface between primary care and specialist services in Ireland demonstrated the challenges perceived by service providers to delivering a consistent high standard of epilepsy care (Varley *et al.* 2010). For example, geographic variation in availability of and access to epilepsy services leads to considerable inequalities for people with epilepsy. Furthermore, a lack of knowledge and confidence to manage epilepsy among GP's together with poor communication between primary and specialist services was considered a significant barrier to enhancing continuity of care. Whilst a model of shared epilepsy care between the primary and specialist sectors was considered the way forward, it was advised that this would require clearly defined roles, formalised clinical pathways, enhanced and continuing medical education, and support of information and communication technology.

Varley *et al.* (2009) conducted a survey to identify GP's perception of their role in the management of epilepsy in Ireland. A questionnaire was sent to a sample of 700 Irish GP's. Of 247 respondents 96% supported the concept of shared care for epilepsy. However, they were very dissatisfied with existing neurology services, including pathways of referral and access to specialist neurology advice and investigations. Moreover, a deficit in epilepsy care expertise among GPs was acknowledged. Indeed, this survey acknowledged significant opportunities for improved epilepsy management within the primary care sector in Ireland.

Findings of this study reveal important insights into the challenges experienced by both people with epilepsy and service providers in Ireland. It has been reported that the current structure and process of health care in Ireland results in a negative experience for people with epilepsy (Varley *et al.* 2011). Arguably what is required is an epilepsy service provision that is guided by empowered policy and practice. As current policy highlights, more meaningful engagement of service users, providers, and carers is required (Government of Ireland 2006).

ESN's have become an integral part of the epilepsy care team. They identify and document seizure activity, perform appropriate interventions, recognise signs of Anti-Epileptic Drug (AED) toxicity and share the responsibility of caring for people with epilepsy (Hosking *et al.* 2002, Long and McCauley 1996). Furthermore a key facet of their role is the provision of information and support to people with epilepsy, their families and caregivers (Greenhill *et al*. 2002, Higgins 2008).

Many studies have reported on people with epilepsy's perspectives with regards to the ESN's role and results illustrated a multitude of perceived benefits and values for the person with epilepsy (Sarkissian and Wennberg 1999, Ridsdale *et al.* 1999, Ridsdale *et al*. 2002). Moreover, studies undertaken to evaluate the effectiveness of ESN's in primary care highlight that Epilepsy Nurse interventions are highly beneficial and that people with epilepsy cared for by a ESN are well informed and have a high degree of satisfaction with care provision (Scambler *et al.* 1996, Sarkissian *et al.* 1999, Greenhill *et al.* 2002).

It is argued that ESN's employed in hospital epilepsy clinics can play a key role in supporting doctors and helping people with epilepsy self-manage (Stokes and Shaw 2004). A RCT to evaluate the effectiveness of nurse run Epilepsy Clinics in primary care has shown that such clinics for people with Epilepsy are feasible, well attended and significantly improve the level of advice and drug management (Ridsdale 1997). Many participants acknowledged that ESN's helped them to cope better by providing information, advice and support.

4.4.1.4 Decision support

Internationally, evidence-based clinical guidelines exist to inform clinical practice in the context of the diagnosis and management of epilepsy (SIGN 2003, NICE 2004, Stern 2006, NICE 2012, Baulac *et al.* 2015). The National Institute of Clinical Evidence (NICE) guideline outlines best practice in relation to the diagnosis, treatment and management of epilepsy in children, young people, adults and older adults (NICE 2004; 2012) and includes timelines for referrals from primary to specialist care for all individuals with suspected epilepsy. This document recommends that people with epilepsy should be empowered to manage their condition and have the opportunity to make informed decisions in partnership with service providers. It states that

> *'children, young people and adults with epilepsy and their families and/or carers should be empowered to manage their condition as well as possible'* (2012 p.13).

Also, it suggests that

> *people with epilepsy should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals'* (2012 p10).

The IOM (2012) has also outlined the broad general principles of epilepsy care. Throughout this report, the committee has emphasised a number of important elements of epilepsy care including: (1) patient centeredness and recognizing that people with epilepsy are more than their medical condition; (2) MDT involvement across disciplines and sectors (e.g., housing, education, employment; (3) community orientation, with the engagement of as many community resources as needed; and (4) education-focused, in order to improve the self-management skills of people with epilepsy and the skills of their family members, clinicians' knowledge and skills, and societal understanding (England *et al.* 2012).

Several studies have examined the adoption of epilepsy guidelines for practice (Frost *et al.* 2003, Davis *et al*. 2004, Williams *et al.* 2007). For example, in the UK, Frost *et al*. (2003) conducted a postal survey of 750 randomly selected service providers working in primary and secondary care to establish the degree to which good practice guidelines for epilepsy have been implemented and to identify positive and negative factors that affect their implementation. Whilst many participants acknowledged having an effective primary/secondary care liaison system, a lead physician with special interest in epilepsy, access to an ESN and support from the voluntary sector, overall results demonstrated large gaps in the implementation of good practice initiative. For example, many services did not provide a first time/fast track clinic for new diagnoses or investigations; use patient-held records; use protocols for review if seizures continue or for appropriate withdrawal of AED’s. Moreover, clinics dedicated to particular groups (people with Intellectual Disabilities (ID), children, women with epilepsy and older adults) had not been established. Participants also identified factors that prevented successful implementation of guidelines and these include: lack of time; staffing levels; workload; and competing priorities. As a counter point, participants acknowledged factors that have promoted and encouraged the successful adoption and application of good practice and these include: inputs from ESN’s; appropriate, timely and accessible professional development opportunities; and the support and enthusiasm of colleagues (Frost *et al.* 2003).

In Scotland, Davis *et al*. (2004) conducted a RCT to identify strategies used to implement a National epilepsy guideline in primary care. Sixty eight (n=68) GP’s and 1133 (n=1113) people with epilepsy participated in the TIGER trial. Results identified no change in outcome or process of care for people with epilepsy in any of the intervention groups.

Williams *et al.* (2007) carried out a qualitative study involving 47 primary care personnel from 13 general practices to explore reasons why epilepsy guidelines were not implemented in primary care. Participants revealed many factors and include: a lack of perceived need and motivation to change practice; reluctance to manage the disease; poor access to secondary services reduced the relevance of some of the guidelines; and finally insufficient time to become familiarised with the guidelines.

Whilst guidelines exist, there is no guarantee that they will be recognised, supported, or implemented in practice (Frost *et al.* 2003). Indeed it is argued that guidelines are blueprints for transforming care to achieve improved quality and efficiency, however such transformation requires individual behavioural and organisational change which is not achievable through simple passive dissemination of guidelines (Fitzsimons *et al.* 2012).

4.4.1.5 Clinical information systems

Timely sharing and exchange of standardised clinical information both within and across organisational boundaries is essential to the realisation of effective chronic disease management (Fitzsimons *et al.* 2012). However, this is limited by a lack of shareable patient medical records. Whilst Electronic Patient Records (EPRs) exist, their adoption into clinical practice has been slow (DesRoches *et al.* 2008, Jha *et al.* 2009).

According to Fitzsimons *et al.* (2012) EPRs have the potential to: (1) improve standardisation of medical vocabulary and record keeping; (2) allow services to be delivered in the most appropriate setting for the patient; (3) advance health services monitoring and planning; (4) enhance health service co-ordination and continuity of care and (5) facilitate clinical research data mining requirements. Unlike paper-based records, multiple users from a variety of locations can have simultaneous access to a centrally stored record via the internet thus improving availability of important clinical information at the point of patient care (Grimson 2001).

Appreciation of the potential of EPRs to support improvements in quality and efficiency of health service delivery is growing (Blumenthal 2010, Fitzsimons *et al.* 2013). This enabling technology can support the delivery of shared care networks that ensure people with epilepsy receive appropriate care when and where needed.

Recognizing that some aspects of the CCM are not easily translatable internationally, and in particular to low-resource settings, the WHO, in collaboration with Wagner, applied a global perspective to the CCM to create the Innovative Care for Chronic Conditions framework (WHO 2003, Epping-Jordan *et al.* 2004). In brief, the framework is based on a set of guiding principles acting at three levels. The 'micro level' emphasises the partnership between patients/families, healthcare teams and community partners. The 'meso level' refers to the healthcare organisation and community, with a particular emphasis on the need for continuity and coordination as well as for 'organised and well equipped' healthcare teams. Finally, the 'macro level', considers the policy and financing contexts, which are seen as key factors in any successful system response to chronic conditions (Epping-Jordan *et al.* 2004). In this context, and acknowledging an unmet demand for specialist epilepsy services in Ireland, a new evidence-based model (Bradley and Lindsay 2008, Irish Epilepsy Association 2010) for managing epilepsy care is currently being implemented by the Irish HSE. With this in mind, the NECP is now explored.

4.4.2 The National Epilepsy Care Programme (NECP)

The National Clinical programmes under the governance of the Division of Clinical Strategy and Programmes at the HSE in Ireland were developed in 2010 to explore the various complex patient journeys and to develop innovative approaches for key points of these journeys**.** The programmes seek to systematise complex healthcare needs in order to address the safety and quality deficits in Irish healthcare. The NECP is one of a number of clinical care programmes whose goal is to use international evidence and expert consensus to create a programme of improvement in the quality of, access to and value of, epilepsy care in Ireland[13].

The NECP has been charged with addressing the historic deficiencies in epilepsy care through a comprehensive change programme that delivers care from '*cradle to grave'* (HSE 2010). This programme has a 10-year vision for the trans-formation of epilepsy care in Ireland. The NECP aims to '*to provide the best value care for all people with epilepsy in the right place, at the right time, sharing the best available information'* (ibid p. 5). The three key objectives (figure 4.3) of the transformation plan are to: (1) improve quality of care across the healthcare spectrum; (2) improve access to expert

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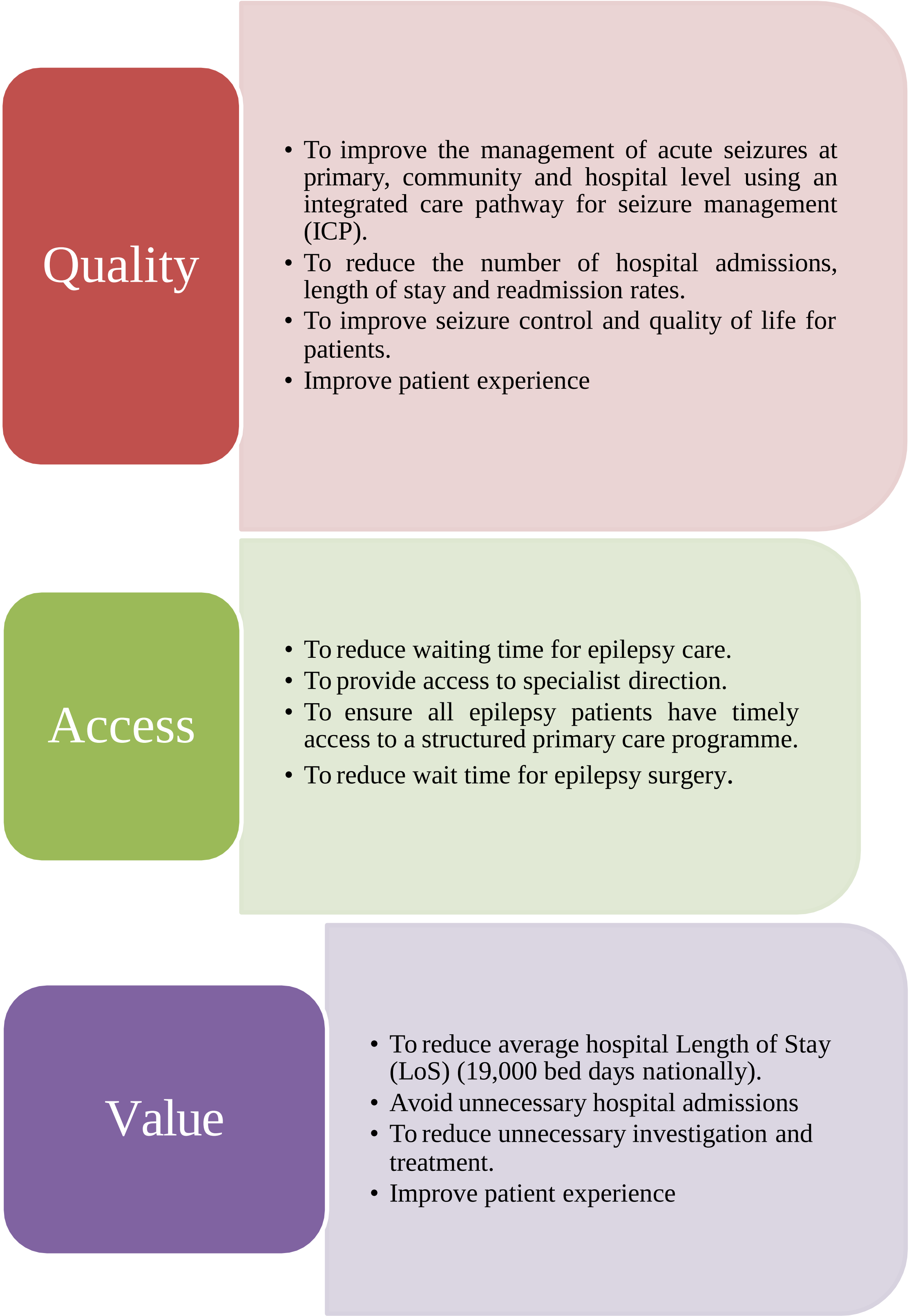
[13] *http://www.hse.ie/eng/about/Who/clinical/natclinprog/epilepsyprogramme/*

care and information; and (3) improve value conscious care by shifting care where possible from expensive hospital care to the community (HSE 2014).

Figure 4.3: Objectives of the NECP (HSE 2014 p.7)



Quality

- To improve the management of acute seizures at primary, community and hospital level using an integrated care pathway for seizure management (ICP).
- To reduce the number of hospital admissions, length of stay and readmission rates.
- To improve seizure control and quality of life for patients.
- Improve patient experience

Access

- To reduce waiting time for epilepsy care.
- To provide access to specialist direction.
- To ensure all epilepsy patients have timely access to a structured primary care programme.
- To reduce wait time for epilepsy surgery.

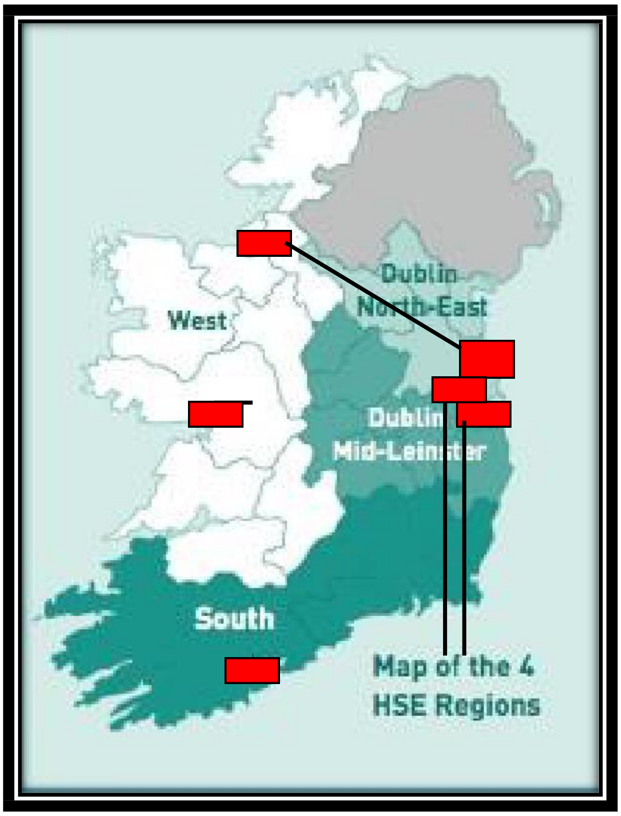
Value

- To reduce average hospital Length of Stay (LoS) (19,000 bed days nationally).
- Avoid unnecessary hospital admissions
- To reduce unnecessary investigation and treatment.
- Improve patient experience

It is a model of care delivery that is national, population based, multidisciplinary and collaborative and predominantly nurse led. Key components of the model are: structured primary care; regional epilepsy centers (four adult and two paediatric) (figure 4.4); the regional deployment of ESN's who will lead the delivery of integrated care; and a national center for complex epilepsy based at Beaumont Hospital, Dublin.

It is recognised since the 1960s that high quality health care services, particularly for patients with complex needs such as epilepsy, cannot be provided by one healthcare discipline alone or by a single sector (House of Commons Select Committee on Health 2012). The NECP aims to bring together clinical disciplines and enable them to share innovative solutions to deliver greater benefits to every person with epilepsy (HSE 2011)[14].

Figure 4.4: HSE Administrative Map: Regional Epilepsy Care Centre



Regional Epilepsy Care Centres

1. **North East**
   a. National adult and Surgical Centre
   b. National Paediatric Centre
2. **Dublin Mid Leinster**
   a. Adult
3. **HSE South**
   a. Adult
   b. Paediatric
4. **HSE West**
   a. ½ Adult (Galway)
   b. ½ Adult (Sligo)

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[14] Description of the current Irish epilepsy service: https://youtu.be/s6Bd8f7CKe8?list=FLoNNhGGAYkdavsSXp1iVzCg

4.4.2.1 Managed primary, secondary and tertiary care

Managed primary care will be delivered by GP's working with practice nurses and other community health workers with the support of a cohort of Registered Advanced Nurse Practitioner's (RANP) across the country, who will assist manage people with epilepsy with stable disease in the community, and will guide others less well-controlled through the health system providing them with the resources for self-management, point of contact and referral information for expert care in the epilepsy centre. It also highlights the vital role of not for profit organisations, in particular Epilepsy Ireland, as part of the overall infrastructure of epilepsy care. The programme has engaged with Epilepsy Ireland and their members with respect to educational requirements with a view to developing information and educational supports. Both the NECP and Epilepsy Ireland advocates for a patient centred service built on principles of respect, choice, patient involvement, access and information (HSE 2016).

The GP is considered the clinical leader for epilepsy care delivery in the community. A standard checklist for good epilepsy care will be developed which can be used in general practice with any red flags triggering rapid referral back to the regional epilepsy centre. Standard Operating Procedures (SOPs) have been developed to support the management of patients with epilepsy in the primary care setting (HSE 2016). However, a lack of knowledge and confidence to manage epilepsy among GP's at the primary care level together with poor communication between primary and specialist services is considered a significant barrier to enhancing continuity of care (Varley *et al*. 2011). With this in mind, the NECP aims to begin to address this perceived barrier through the development of telephone access to guiding information.

Front-line physicians delivering care at the emergency department in secondary and tertiary interface will be provided with an integrated seizure care pathway that will reduce admissions and length of stay, whilst improving patient safety by eliminating treatment variability. Experience of the nurse phone advice line in Beaumont hospital on the north side of Dublin has shown that telephone support has had a significant impact on presentations to the ED (Flynn *et al.* 2009).

The NECP envisages the recruitment on adequate numbers of registered ANP's to allow for the achievement of the recommended ratio of 1:140,000 populations. This equates to 32 posts across the country. Currently there are 17.25 whole time equivalent

ANPcs/RANPs and Clinical Nurse Specialist's (CNS) in post in adult epilepsy services. It is envisioned that every person with epilepsy will have access to an ANP service attached to one of the epilepsy centres. Nursing services have seen a significant expansion across all service delivery sites. The ANP roles and responsibilities in primary and acute care are identified in Box 4.1 and 4.2.

Box 4.1: Roles and responsibilities of ANP's in primary care

- Rapid access clinics in acute hospitals providing acute neurological care.
- Outreach clinics -ID services and non-acute hospitals.
- GP and community practice nurse support.
- Liaison with physicians in hospitals without neurology services, and with paediatricians.
- Telephone/e-mail/web support for patients.
- Links to Epilepsy Ireland (EI) and the Irish Branch of the ILAE.
- Ensure complete, accurate and up-to-date documentation of clinical encounters using an EPR.
- Implementation of SOPs and Management Operating Procedures (MOPs)
- Use of an EPR, SOP's and MOP's.
- Registration and measurement of Key Performance Indicator's (KPI), quality outcomes and clinical audit.
- Health Services Research, population health and clinical and translational research (HSE 2016 p.23-24).

Box 4.2: Roles and responsibilities of ANP's in secondary and tertiary care

- Provide routine follow up care to people with epilepsy attending the epilepsy outpatient services along with medical colleagues.
- Act in a consultancy capacity in reviewing patients with an established diagnosis of epilepsy who attend the ED or are admitted.
- Provide ongoing support to inpatients, families and parents of children admitted with seizures.
- Provide rapid access clinics in acute hospitals providing acute neurological care for ED discharges and first seizures.
- Supporting patients and families on the epilepsy surgery programme.
- Develop outreach clinics-ID services and non-acute hospitals.
- Provide GP and community practice nurse support.
- Liaise with regional physicians in hospitals without neurology services, and with paediatricians.
- Provide telephone/e-mail/web support for patients and families.
- Establish links to EI and The Irish Branch of the ILAE (HSE 2016 p. 23-24).

4.4.2.2 Epilepsy care provision: Access, quality and value

The NECP is committed to access, quality and value to include: (1) considerations for special groups; (2) patient with complex epilepsy; (3) national guidelines for epilepsy care; (4) development and implementation of a national EPR; (5) research; and (6) governance.

Firstly, the NECP has developed a SOP to guide transition from paediatric to adult epilepsy services. Further commitment to special groups includes: women who are pregnant; women with epilepsy; people with ID; people with co-morbid physical and psychological health difficulties and challenges.

Patients with complex epilepsy, requiring pre-surgical work-up and evaluation for possible device implantation will be referred to Beaumont and Cork University Hospital (CUH). There is a 4-bedded video telemetry unit in Beaumont Hospital, and a 2-bedded video telemetry unit in CUH. The national centre will be housed in Beaumont hospital and will provide a hub for the national EPR and tele-support rollout.

The consultant epileptologist /paediatric neurologist and programme clinical lead will provide oversight and governance and will have a role in epilepsy fellow and RANP training.

The NECP has reviewed and assessed all internationally recognised guidelines of care. In line with HSE policy the NECP will seek to marry evidence based clinical decision making with process improvements that will reduce variability across the health system in epilepsy care. It is envisaged that guidelines specific to the Irish health system will be developed and subsequently sent for sign-off by the clinical effectiveness committee. However, the NECP has created a number of SOPs and MOPs. Whilst forty two SOPs have been created, currently there are 13 SOPS in wide usage throughout the services.

Furthermore, the Programme for Government (2011) highlights the need to incorporate Integrated Communication Technology (ICT) into integrated health care systems. Arguably, success of the NECP care depends on clinicians having access to relevant clinical information when and where needed (Fitzsimons *et al*. 2013). Currently the NECP is utilising a EPR system and modules include: clinic administration, demographics, social history, epilepsy history, AEDs, allergies, clinical investigations, Vagus Nerve Stimulation (VNS) clinic, nurse telephone advice line, care-plan, and multidisciplinary meeting template. The EPR has been in daily use at Beaumont Hospital since 2008 and in SJH, Galway University Hospital (GUH) and Limerick University Hospital (LUH) since 2012. In 2014 it was rolled out to Sligo Regional Hospital, the Mater University Hospital Dublin, and Cavan Monaghan Hospital Group.

The EPR is also supporting outreach clinics in the ID sector (e.g. Daughters of Charity Clonsilla, St Mary's Drumcar, Cheeverstown, and in maternity care (e.g. National Maternity Hospital Holles Street, Rotunda Hospital, Our Lady's Hospital Drogheda. To date more than 6, 500 individual epilepsy patients have a validated electronic record. There are almost 60 users of the EPR including consultant epileptologists, non-consultant hospital doctors, clinical nurse specialists, community epilepsy nurses, researchers and clinical management personnel. The success of this EPR was acknowledged when it was awarded a Taoiseach's Excellence in Public Service Award in 2012.

An observational study undertaken by McQuaid *et al.* (2010) evaluated the introduction of an AED management module of an EPR in an epilepsy out-patient clinic. Participants acknowledged satisfaction with its usability and performance. Furthermore, the AED module of the epilepsy EPR prompted the user to ask clinically relevant questions that he or she might not otherwise have asked. A study undertaken by Fitzsimons *et al.* (2013) demonstrated that the Irish epilepsy-specific EPR functions in a meaningful way. In addition to supporting clinical care, it is a good tool for objectively and efficiently monitoring service quality. However, despite its effectiveness, interrogation of the EPR showed that aspects of epilepsy care were either not performed or not documented.

In addition, The NECP encourages participation in research of various forms including phenomenological and qualitative research, health service delivery research using both formative and summative research methodologies, population based research, translational research and basic mechanisms of epilepsy and is aligned with wider health research strategies (e.g. Science Foundation Ireland, Health Research Board, European Union). Joint programmes for clinical trials with industry are also encouraged to develop and test new treatments. Moreover, the programme has developed an SOP for research enrolment that is offered to all new and existing patients.

Finally, similar to the other programs, the epilepsy program has a defined governance structure with a national clinical lead and program manager, a clinical advisory group, and a national working group with the joint involvement of healthcare providers in primary, secondary and tertiary care. This national working group meets weekly to plan, implement and continuously evaluate the programme.

4.4.2.3 Concluding comments

The HSE Service Plan (2012) highlights the challenge facing the health care services in Ireland to maximise services through innovative and improved new ways of working. The NECP describes an integrated service which achieves positive outcomes for patients by enabling clinicians to work together across boundaries and different sectors to deliver safe, effective and person centred care. However, the realisation of many of the aims of the NECP is reliant on additional resources. Therefore, this study is both timely and relevant in relation to both the NECP and the broader issues of health policy, service design, transition and delivery in relation to empowerment within Irish epilepsy services.

4.5 Developing a health policy and care provision in relation to empowerment

Health policy nationally and internationally is prioritising patient empowerment and patient evaluations of healthcare (Ader 2007, NHS 2010, DoH 2012). However, despite this empowerment remains neglected and a poorly understood concept by service users and providers alike within epilepsy services (England *et al.* 2012, Fitzsimons *et al.* 2012).

Irish policy in relation to chronic disease is currently based on a strategy document entitled '*Tackling Chronic Disease; A Policy Framework for the Management of Chronic Diseases'* (DoHc 2008) and '*Healthy Ireland'* (2013) which emphasise the need for chronic illness prevention and management. This chronic disease policy framework addresses the challenges of chronic disease so as to reduce the burden for individuals, their carer's and the health system. The aims of this policy is to: (1) promote and to improve the health of the population and reduce the risk factors that contribute to the development of chronic diseases; and (2) promote structured and integrated care in the appropriate setting that improves outcomes and quality of life for patients with chronic conditions (DoHC 2008). '*Healthy Ireland'* is a National policy framework to improve the future health and wellbeing of the Irish people. It aims to increase the proportion of people who are healthy at all stages of life, and to reduce health inequalities (2013). The Programme for Government (2011) prioritises the need to address the inadequate and fragmented services for chronic illnesses. This policy recognises the need to implement a model for the prevention and management of chronic illnesses, and to achieve high quality care through comprehensive and integrated programmes in the community.

This framework for action underlines the importance of inter-sectoral activities for prevention of the emergence of adverse lifestyle factors that contribute to chronic disease. It addresses the management of chronic disease at different levels through a reorientation towards primary care and the provision of integrated health services that are focused on prevention and returning individuals to health and a better quality of life. It describes the active participation of service users in the management of their condition (DoHC 2008). However, an empowered perspective for policy and care provision is not considered, despite empowerment being a critical determinant of Irish health policy (DoH 2012). Recent major reports in the management of chronic disease in Ireland indicate that the majority of GP’s report that significant changes are needed in our health system to make Chronic Disease Management (CDM) work better and eliciting patients’ perspectives on CDM was highlighted as an important next step (Darker *et al.* 2011, 2012). With this in mind, patients reported being happy with the care they received for their chronic illness. However, despite this, patients are not asked about their ideas or goals when making a treatment plan. The CCM is a systematic approach to coordinating healthcare across different levels (individual, organisational, local and national). Evidence suggests that this model of ‘person centred care,’ with coordination across care settings and providers is more effective than single disease models or uncoordinated interventions (WHO 2011). As previously noted, developing a health policy in relation to empowerment requires a stronger awareness and connections between content, context, processes and actors (Walt and Gilson 1994). Each of these factors is now explored.

Walt and Gilson (1994) noted that health policy research focused largely on the content of policy, neglecting actors, context and processes. Their policy triangle framework is grounded in a political economy perspective, and considers how all four of these elements interact to shape policy-making. Walt and Gilson’s (1994) framework has influenced health policy research in a diverse array of countries, and has been used to analyze a large number of health issues, including mental health, health sector reform, tuberculosis, reproductive health and antenatal syphilis control (Gilson and Raphaely 2008).

Actors are influenced by the context in which they live and work. Actors are about the people or organisations involved in health policy change and the roles of policy actors, including implementers and beneficiaries, how actors use their power in taking forward, blocking or challenging policy implementation, and the influence of laws, norms and customs (institutions) over the behaviour of various stakeholders (Buse *et al*. 2005).

The context is heavily influenced by political and juridical system, history, cultural and social values, and the economic and demographic situation. Context includes situational factors (the specific conditions of a moment in history that impact on the policy change intended), structural factors (the relatively unchanged circumstances of the society and the polity such as the structure of the economy and the political system), cultural factors (the values and commitments of society and groups) and exogenous factors (the events and values outside of any one country or system). Context directs the analyst to consider political, economic, social and historical influences (Buse *et al*. 2005).

The policy making process is influenced by actors with their powers, values and expectations and is concerned with the way in which laws/policies are identified, formulated and implemented, their timing, the strategies used as well as the specific mechanisms or bodies established to take these strategies forward. The content of the policy is a result of all these dimensions. Content relates to the specific nature and design of legislation or policies, the interaction between these policies and other institutional changes, and existence of implementation guidelines (Buse *et al*. 2005). However, according to Ostrom (1999) debate often focuses on the content of policy rather than on actors, processes and contexts. Some possible explanations for the absence of an empowered perspective for Irish health policy are now explored. Arguably to achieve a greater understanding of the problems that exist in achieving policy and health systems that are empowered requires a stronger awareness of context, process and actors. In other words, what is required is a framework that goes beyond the content of a policy when studying the policy process and emphasises the importance of actors, the processes, and the context.

4.5.1 Possible explanations for the absence of an empowerment perspective

The year 2008 marked the start of the most profound economic crisis in the history of the Irish state. In 2010, the Irish Government sought emergency loans of €85 billion, popularly characterised as the ‘bailout’, from the International Monetary Fund (IMF) and the European Union’s Financial Stability Fund (EUFSF). The conditions, characterised as ‘austerity’, imposed by the lenders have significantly impacted on Irish society and public services, particularly the health services.

In February 2011, a Fine Gael-Labour Party coalition Government took power in Ireland from the discredited Fianna Fail-Green Party coalition. In terms of the immediate health care agenda, the new Government had to reduce spending (the largest of the public sector budgets) to ensure it was able to meet its austerity commitments (Wells and White 2014). Though severe reductions in expenditure on health had already been implemented in 2009 and 2010, they gathered pace with the election of the new government which, in its first finance bill of 2011, cut spending on health by €750 million. In 2009 the Government introduced an absolute ban on recruitment, including no replacement of staff (other than through re-deployment of existing staff), and a promotion freeze. This freeze was further supported by other measures such as the introduction of early retirement schemes in 2010 and 2012 and the promotion of incentivised career breaks in 2011 and 2013.

The challenges associated with the clinical environment within the Irish healthcare system were further compounded during this time by the introduction of the EU European Union Working Time Directive (EUWTD). This directive limits the working hours of doctors in hospitals to 48 hours per week (McGowan *et al.* 2013). This labour shortfall generated by the reduction in doctors' hours has been met with the development of advanced roles for nurses, such as advanced nurse practice. In addition to a shortage of doctors, further pressure on existing nursing staff has been created through an employment moratorium, salary cuts, increased working hours, incentivised retirement schemes and a restructuring of the hospital services (Wells and White 2014).

During the age of Florence Nightingale, nurses were viewed as having a supplementary role, existing primarily to provide assistance to the doctor (Porter 1991). The quest for a professional title, with equal educational opportunities similar to other allied professions, is evident in the appetite within nursing for further education and through the growth and development of a variety of nursing programmes over recent years. The failure of the nursing profession to attain all of the prerequisites of a 'professional' status, with a distinct body of knowledge and full autonomy, is well documented in the nursing literature (Porter 1991, Rutty 1998, Scholes 2008). According to Davies (1995) nurses frequently perceive their contribution in healthcare as being 'voiceless'. With this in mind, Scott *et al.* (2013) stressed the importance of inclusion of nurses in strategic committees to give nurses a voice and to empower nurses within their organisations. Moreover, specialist and advanced practice nursing roles have been developed in many specialist areas of nursing both nationally and internationally. However, the process of introducing new roles such as ESN's within established healthcare systems is both complex and challenging, as development and integration often challenges traditional disciplinary boundaries, requiring inter- professional teamwork and collaboration (Kilpatrick *et al.* 2013).

The power of the Catholic Church in Ireland and its close alliance with medicine and politics was widely reflected in health policy during the last century (Wren 2003). The power and authority of the Catholic Church was to remain strong up to the 1990s and its influence was particularly forceful and successful in its efforts to resist social reform in the domain where it saw itself as holding the moral monopoly, namely, on issues such as contraception, divorce and abortion (Moran 2009).

Service users are now viewed as active representatives and experts in the healthcare process. They are no longer viewed as passive but active and engaged with others both as service users of health care provision and as active negotiators and collaborators of care to be given (Olesen 2002). Indeed, a shift towards patient-centred language and principles of equity and fairness; a people-centred service is argued (Bergin *et al*. 2013). However, historically health care systems respond to the needs of patients with acute conditions better than those with chronic conditions who need on-going care (Bodenheimer *et al.* 2002, Marchibroda 2008). The CCM has modernised healthcare to respond proactively to patients with chronic illness. However, future evaluations need to look at outcomes important to all stakeholders, most importantly, patients and measure patient centred outcomes such as treatment burden, quality of life, and functional status (Boehmer *et al.* 2018).

Research exploring people with epilepsy views with regards to healthcare delivery further reinforces the necessity for direct patient participation as a priority for service planning and delivery (Varley *et al.* 2011). As current policy suggests, more meaningful engagement of service users, providers and carers is required (Government of Ireland 2006).

Whilst empowerment approaches are becoming increasingly central to guiding health care practice and policy development (McCormack *et al*. 2010) a competing difficulty in adopting the patient empowerment perspective, is the potential impact that patient empowerment can have on clinician-patient relationships. Patient empowerment may require clinicians to relinquish some control (both informational and decision-making), and become less compliance focused (Aujoulat *et al.* 2007). This would undoubtedly have some status implications, shifting the balance of power away from clinicians and towards patients, and this might be very uncomfortable for some clinicians and patients alike (Aujoulat *et al.* 2007).

A further counter-argument is that not all people want to be, or can be empowered at all times. For patients in acute care, there may be many who would prefer their doctor to make treatment decisions for them, at least in the short term (McAllister *et al.* 2012).

However, for patients with chronic conditions, relying on clinicians to be responsible for maintaining their health will become less tenable. Furthermore, if clinicians try to coerce people into making lifestyle changes to improve their (future) health, lifestyle changes that threaten fulfilment of their life goals, then this may lead to tensions in, and potentially, breakdown of the healthcare relationship (McAllister *et al.* 2012).

Paterson (2001) discusses the ‘myth of empowerment’. She argues that if service providers adopt the discourse of empowerment, without critical review, this may lead us into a false sense of security that all people with a chronic disease are able to participate fully in empowerment, if the practitioner only extends an invitation. The power relationships between individuals and service providers are challenged when individuals develop knowledge, which together with experiential learning compromises their usual passive roles. It is argued that there is a need for a culture change that can develop individual and professional expertise and allow individuals to be more actively involved in their care (Kinmonth *et al.* 1998, Rayman and Ellison 1998).

Service providers are trained and socialised in an approach to care based on the treatment of acute illness. However, using the acute care approach within epilepsy services can be limited. During their professional education, service providers are socialised to a set of responsibilities and expectations that define their professional identity. These responsibilities and expectations become so embedded in their professional identity they do not consciously think about them; rather they see their practices through them. According to Anderson and Funnell (2010) the power of this socialization process is such that one can believe in the empowerment approach intellectually and yet behave in ways that completely contradict it, without being aware of the contradiction. Dubois *et al.* (2008) highlights that the transformation of CDM requires the reconfiguration of roles, responsibilities and professional activities and such transformation requires the education and professional development of service providers to meet the requirements of evolving health services. Arguably service providers caring for patients with a chronic illness such as epilepsy, require more training on non-acute care and long term management of patients.

The 2001 Health Strategy, *Quality and Fairness*, also put a great emphasis on the importance of patient rights, setting out a vision of a health system that encourages you to have your say, listens to you, and ensures that your views are taken into account (DoHC 2001). A number of mechanisms to incorporate public views into consultative mechanisms and forums are being implemented. However, it would appear that inadequate attention is paid to analysing, understanding and factoring into attempts to reshape or change policy, the complex historical, social, cultural, economic, political, organisational and institutional context; actor interests, experiences, positions and agendas; and policy development processes that influence policy and programme choices.

4.6 Chapter summary

Whilst current policy addresses the principal of partnership and social inclusiveness as a way forward for health service provision, it still does not explicitly deal with the concept of empowerment and facilitating empowerment within healthcare. As mentioned previously people with epilepsy lack a sense of empowerment, and play a passive role within healthcare (Varley *et al.* 2011). Arguably, therefore what is required is an epilepsy service provision that is guided by empowered policy and practice. As current policy highlights, more meaningful engagement of service users, service providers, and carers is required (Government of Ireland 2006). Arguably this requires stronger connections to be forged between actors, processes, context and content factors for health policy and epilepsy service provision to enable empowerment to be facilitated.

SECTION 2

The Research Journey

CHAPTER FIVE

Methodology

5.1 Introduction

Research is based on an underlying philosophical assumption about what constitutes valid research and which method(s) are appropriate for the development of knowledge. Chapter 5 presents the philosophical and theoretical positions used in this study. Firstly, CST as a metatheory for the study of empowerment within epilepsy healthcare is explored. Secondly, a case for systems theory as a social ontology and SSM (Checkland 1981) as a methodological approach for the study of empowerment and epilepsy healthcare is presented. Finally, this Chapter describes the process of investigation which was used in this study.

In section 5.2 the underpinning assumptions of CST is presented. Section 5.3 describes and contrasts Habermas's features of CST with the positions of positivism and constructivism. In Section 5.4 the potential of Habermas's distinctive features of CST as an alternative framework for the study of empowerment within epilepsy healthcare is explored and its limitations recognised. In conclusion, it is argued that CST offers an alternative philosophical framework for the study of service user-service provider empowerment within epilepsy healthcare.

Section 5.5 briefly outlines the philosophical underpinnings of research paradigms and how systems theory relates to CST. In section 5.6, systems theory and their critical social underpinnings are introduced. Section 5.7 details a critical debate of SSM and its suitability for the study of empowerment and epilepsy healthcare. The merits of this methodological approach are argued for and its limitations recognised. This section concludes with a summary of the general characteristics of SSM and highlights its potential for the study of empowerment and epilepsy healthcare.

Section 5.8 describes the research setting, the reasons for selecting this research setting and how access was negotiated. In section 5.9 the research methodology of this study is outlined. Section 5.10 outlines the ethical considerations in relation to informed consent, anonymity and confidentiality. In section 5.11 sampling, developing the theoretical sample and recruitment issues are discussed. Section 5.12 outlines the data collection utilised for this study and includes: a literature review; reviewing policy literature; an observation of service operation, a survey, in-depth interviews and a focus group. In section 5.13 issues of quality as related to this study is explored. Finally from a CST perspective, section 5.14 presents a consideration of reflexivity within this study whereby the researcher's personal and professional thoughts and feelings are presented.

5.2 Critical Social Theory

For the purpose of this study, it was considered necessary to engage with a metatheory within which to develop the study. With this in mind, CST suggests a shared ontology and epistemology for social and nursing science and claims that CST resolves the debate between the extremes of subjectivism and objectivism (Morrow and Brown 1994).

The philosophical basis of CST has been largely linked with the German philosopher Jürgen Habermas, and others including Marx, Horkheimer, Adorno, Marcuse, Erich, Formm, Friere and Foucault. Habermas's ontology includes a dualism between '*subject-object relations'* (i.e. instrumental actions) and '*subject-subject relations'* (i.e. communicative actions) (Habermas 1984 p.11). The basic assumptions of CST, described by Browne (2000) are outlined in Box 5.1.

The decision to focus on Habermas's meta-theory is that arguably empowerment and epilepsy healthcare is grounded in a dialogical relationship between service users, service providers, policymakers and family/carers. Therefore, the features of such a dialogical relationship can be revealed only in a theory of communicative inter-subjectivity. Furthermore, Habermas (1984; 1987) promotes a two-level social theory that includes an analysis of communicative rationality, the rational potential built into everyday speech (micro-theory) and a theory of modern society and modernization (macro-theory) (White 1989).

Box 5.1: Underpinning assumptions of CST (Browne 2000)

- There is no ahistorical, value neutral or foundational knowledge that can be known outside of human consciousness.
- All knowledge is fundamentally mediated by socially and historically mediated power relations.
- Every form of social order entails domination and power.
- Language is central to the creation of knowledge and formation of meaning.
- Mainstream research generally maintains and reproduces systems of race, class and gender oppression.
- Facts (or truth claims) cannot be separated from the domains of values or ideologies.
- By explaining and critiquing CST serves as a catalyst for enlightenment, empowerment and emancipation and social transformation.
- Critically orientated knowledge should offer social and cultural critiques with a view to transforming normative foundations.

5.3 Habermas’s (1984; 1987) distinctive features of CST

Included among the distinctive features of Habermas’s (1984; 1987) account of CST are (1) Theory of knowledge constitutive interests; (2) Theory of communicative action, and (3) Theory of social world and life world. These three features are now explored and compared with the positions of positivism and constructivism.

5.3.1 Theory of knowledge-constitutive interests

The theory of knowledge-constitutive interest is designed to make one wary of the claim that knowledge is identified by a single interest (Morrow and Brown 1994). Habermas (1971) claimed that knowledge is bound by three cognitive interests: the technical interest, the practical interest and the emancipatory interest. The three types of knowledge based on these interests are (1) analytical-empirical knowledge; (2) historic-hermeneutic knowledge and (3) critical-dialectical knowledge.

5.3.1.1 Analytical-empirical knowledge

Analytical-empirical knowledge (technical interest) draws on propositional knowledge, laws and hypothesis. Positivism is consistent with Habermas’s technical interest. It holds a central belief that

> ‘*there exists a single reality that is independent of any observers interest in it and which operates according to immutable natural laws, many of which have a cause-effect form’*
> (Guba and Lincoln 1989 p. 84).

However, positivism has limitations insofar as people need to be viewed as human beings, who have emotions and feelings and who are capable of making their own decisions. For example, empirical research has highlighted low levels of involvement in decision making among service users in healthcare (Vahdat *et al*. 2014, Souliotis *et al*. 2018) and a lack of compromise with service providers with regards to treatment options (Stevenson *et al.* 2000). Therefore, positivism is inconsistent with holistic practices in its denial of unobservable values, including spiritual aspects and relationships within complex socio-political, ecological environments (Weaver and Olson 2006).

5.3.1.2 Historic-hermeneutic knowledge

Historic-hermeneutic knowledge (practical interest) is where meaning governs the construction of facts to yield interpretations and is structured into processes of understanding. Constructivism is consistent with Habermas’s practical interest. It is based on the assertion that '*reality is not self-evident, stable and waiting to be discovered but… a product of human activity'* (Rogers and Pilgrim 2005 p.15). This reality is socially constructed and what exists is dependent upon a person's interpretation and understanding of that reality (or multiple realities) and it's socially produced knowledge (Guba and Lincoln 1994). It seems to provide an appropriate philosophical basis for the analysis of the social world because it reflects the purpose of human speech and communication as the means of deriving rational, moral consensus (Grundy 1987). However, constructivism does not recognise that communicative interaction is a medium of domination of social power (Habermas 1988). It is argued that many decisions in healthcare care are the result of communication based on power. For example, a qualitative study by Skelton (1994) explored the hidden curriculum of patient education, and found that service providers do not stray from their own professional agenda, and use collaboration as a technique to conceal their dominance. While the significance of the constructivist paradigm is acknowledged, in particular, its exclusive concern with the self-understanding of social agents, it is argued that it has limited the sociological study of health care, for example stigma and discrimination in relation to a diagnosis of epilepsy (Weatherby-Fell 2011).

5.3.1.3 Critical-dialectical knowledge

A key difference that differentiates CST from other meta-theoretical positions is the critical dialectical knowledge or emancipatory interest. This interest is concerned with elimination of distortion from interaction and communication. CST is consistent with Habermas's emancipatory interest. It provides a context in which it becomes possible to go beyond description, explanation, prediction and understanding. It allows one to ask how social, political, economic, gender, and cultural factors interact to influence health or illness experiences (Ford-Gilboe *et al.* 1995). This is a key difference that distinguishes CST from other meta-theoretical positions. This approach offers a framework for understanding the distinction between empowering people to perform better in an imposed or fixed structure and empowering people to perform better by challenging the rationale of a given structure and changing it if necessary (Inglis 1997). Although analytical-empirical and historic-hermeneutic knowledge are fundamental to and necessary for social existence, these interests are not sufficient to fully comprehend social phenomena (Allen 1985, Kim and Holter 1995). For example, chronic illness has significant consequences for psycho-social and occupational ambitions (Fisher *et al.* 2000)[15]. Therefore, in order to address these issues a critical emancipatory knowledge that seeks to transform an unequal society is necessary (Trede and Higgs 2003).

It is argued that a healthcare system, including service providers can reproduce and reinforce externally based oppression (Waitzkin and Britt 1989). Research into health has often failed to understand inequalities within a multifaceted social world (Popay *et al.* 1998). For example, despite the positive outcomes of empowerment, anecdotally not all service providers are willing to allow service users to be involved in decision making. There is an epistemological limitation apparent here insofar as the question of power is ignored in interpretative approaches due to the exclusion of the analysis of external socioeconomic structures and causality (Morrow and Brown 1994) and positivist's denial of unobservable values. This impedes an understanding of the multifaceted relations of the social sciences and its potential impact on health care. Arguably, CST has the potential to facilitate changes for improvement within healthcare (Henderson 1994, Anderson 1996). For instance, arguably it has the potential to allow service providers and service users to explore and develop a more equal partnership.

5.3.2 Theory of communicative action

Habermas's theory of communicative action is the communication of at least two subjects capable of speech and action, who establish interpersonal relations by verbal or extra-verbal means (Habermas 1984). The two concepts involved in communicative action are communicative competence and ideal speech.

5.3.2.1 Communicative competence and ideal speech

Firstly, communicative competence involves competence in speech and symbolic interaction as well as linguistic competence (Kim and Holter 1995). Secondly, ideal speech refers to un-coerced, undistorted and non-authoritarian communication (Ray 1992). Outhwaite (1994) claims the four conditions required to enable an ideal speech are comprehensibility, truth, rightfulness and sincerity.

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[15] See Chapter 1, Section 1.2: Epilepsy: Overview of incidence and prevalence.

A number of empirical studies have found instances of service provider's communicative interactions with service users orientated to success concerning technical interests rather than critical emancipatory interests (Mishler 1984, Waitzkin and Britt 1989, Varley *et al.* 2011). Furthermore Morrow and Brown (1994) suggest that power relations engender forms of distorted communication. For example, it has been suggested that service providers communicate with professional dominance causing tension and distorted communication (Hyde and Roche-Reid 2004). For instance, a study by Varley *et al.* (2011) exploring the health care journeys experienced by people with epilepsy in Ireland describes interactions between people with epilepsy and service providers as intimidating. For example, one participant describes feeling '*silly'* and '*embarrassed'* when discussing medical history with service providers. Moreover, a major barrier to communicative action in healthcare is the lack of interactional opportunities, attributable partly to the 'system' due to time constraints, mismatch of agenda, lack of trust and power imbalances (Greenhalgh *et al.* 2006). This can result in a failure to nurture sincere communicative action. Therefore, to address such concerns, communicative action theory has been recommended as a means to address the service provider-user power imbalance (Burbank and Martins 2009). The significance of active listening, equal partnership and respect has been highlighted on many occasions (Rappaport 1995, Rodwell 1996, Paterson 2001, Aujoulat *et al.* 2008). With this in mind, a CST perspective identifies what establishes a communicative interaction and in what ways distorted communication can be explored (Holter and Schwartz-Barcott 1993).

5.3.2.2 Principles of undistorted communication

Habermas's (1990) principles of undistorted communication include: (1) Every participant must have an equal chance to initiate and to participate in communication; (2) Everyone must be allowed to challenge justifications and to defend validity claims; (3) No one should be prevented by internal or external coercion from engaging in communication and (4) Everyone must be allowed to express their attitudes, feelings and desires. Therefore, the outcomes of communication should be understanding and agreement arriving at a coherent consensus (Meadwell 1994).

According to Habermas emancipation and change needs to occur at the level of day-to-day communication (Spratt and Houston 1999). By asserting the principles of undistorted communication new perspectives can be examined in an organised, open way (Spratt and Houston 1999). Therefore, within a CST framework, any distortion with regards to interpersonal communication is a sign of social malfunction, and consequently, can be used to discover and describe potential inequalities or oppressions (Habermas 1988). It has the potential to uncover the constraints that prevent un-coerced communication (Wilson-Thomas 1995). For instance, service providers may experience and have an understanding of communication, however CST allows an opportunity to explore the micro and macro barriers that prevent un-coerced communication within healthcare and discover possibilities for change.

5.3.3 Theory of system and life-world

Within the theory of communicative action, Habermas explores the theory of the system and life-world and conceptualises society as having two equal perspectives: (1) the system in which people live and (2) the life-world of people as an essential part of that system (Froggatt *et al.* 2011). He identified the life-world as of equal importance to the system. It is a symbolic space where personality and culture are experienced and reproduced. This theory provides a way of understanding service user's healthcare from two perspectives, the individual's life-world characterised by inter-subjectivity and rational communication and the system which includes the organisational structures of healthcare and the wider society (Froggatt *et al.* 2011).

Habermas claims that control by the system may colonise or invade concerns of the life-world. Within healthcare the life-world of service users has been colonised by medical ideology (Mishler 1984) insofar as it maintains and replicates class structure and social dominance (Waitzkin and Britt 1989). For example, medical ideology is evident and affects both micro and macro levels of healthcare such as service user-service provider communication and as part of the social context of medical encounters (Waitzkin and Britt 1989). This is evident insofar as service users still have restrictions with regards to their economic, social and cultural rights (de Boer 2010).

The daily experiences and challenges that service users face in their 'life-world' influences how they understand and manage their condition and how they solve or fail to solve these challenges. A descriptive qualitative study by Varley *et al.* (2010) using appreciative enquiry highlight significant challenges for service users such as stigma, unequal access to services, inadequate human resources, lack of communication and knowledge. The literature suggests that service providers view service users as ‘objects’ or ‘bodies’ that need surveillance and monitoring (Manias and Street 2000). For instance, once a service user has received a diagnosis, they are referred to the bio-medical model of healthcare. However, within the bio-medical model the psychosocial needs of service users are not recognised (Weatherby-Fell 2011) and this is often viewed as an attempt for service providers to control service user’s behaviour (Dickinson 1999).

In order for service users to become equal partners in healthcare, they must be given the right to refuse treatment or to change it without reproach (Coates and Boore 1995). Although service provider-service user partnerships have intuitive appeal, the literature is unclear regarding the elements and processes of such partnerships (Gallant *et al.* 2002). To address these issues, Mohammad (2006) recommends CST as a framework to enable the formulation of partnerships with service users. For example, Mishler (1984) argues that if service providers contribute to more effective communication and negotiate a sharing of power, in turn would likely become more effective practitioners.

Healthcare systems, service providers and encounters can imitate and strengthen externally based oppression (Waitzkin 1991). However, there is no reason why the life-world information of service users should not be regularly sought. Kemmis (2001 p.100) recommends a ‘*communicative space’* to negotiate together how change can happen, in order to create a mutual understanding and address any conflicts of the life-world and system world. This communicative space has the potential to become a means to address inequities of power through a process of mutual understanding (Fraser and Honneth 2003). Listening to concerns, feelings, experiences, hopes and goals is the basis for broadening people’s awareness of their oppression.

Constructivism has made considerable contributions in explaining inequalities in healthcare (Wainwright and Forbes 2000). Positivism on the other hand uses scientific methods to describe and predict patterns in the physical world (Suppe and Jacox 1985). However, limitations from these philosophical frameworks have been outlined with the potential of a CST framework presented. The potential of CST as an alternative meta-theory framework for the study of empowerment within epilepsy healthcare is now explored.

5.4 The potential of CST as an alternative meta-theory framework for the study of empowerment within epilepsy healthcare

According to Wilson-Thomas (1995 p. 572) CST endeavours to: '*liberate individuals from conscious and unconscious constraints that interfere with balanced participation in social interaction'.* While the significance of the constructivist paradigm is acknowledged, in particular, its exclusive concern with the self-understanding of social agents, it is argued that it has also restricted the sociological study within healthcare. Arguably, therefore there is a need to shift away from the traditional epistemological and ontological assumptions associated with empowerment and healthcare. With this in mind, a growing number within the field of nursing science (Browne 2000); emancipatory approaches in nursing enquiry (Allen 1985, Heiden 1986); nursing education (Wilson-Thomas 1995, Ekstrom 2002); patient education (Wallerstein and Bernstein 1988, Hage and Lorensen 2005, Brouse *et al.* 2010); diabetes care (Dickinson 1999); sociology (Scott 1978); justice (Rozas 2007); research (Fulton 1997), medical adherence (Williams *et al.* 2005); community health education (Wallerstein and Berntein 1988, Van Wyk 1999); and empowerment education (Rindner 2004) view CST as an alternative meta-theory framework.

Since empowerment has a strong political dimension and requires self-reflection, dialogue, action and commitment to change (Carey 2000), arguably CST has particular applicability to the study of service user-provider empowerment within epilepsy healthcare, such as critical self-reflection, critique of ideologies, improvements in knowledge, communication and practice. It allows knowledge to be developed that is based on a critical reflection of the power relationships which are embedded in the structures and functions of society (Stevens 1989). Claims that the human capacity to engage in critically reflective thought makes change possible by facilitating the deconstruction and subsequent reconstruction of social realities has been made (Kendall 1992). Arguably, by engaging in critical self-reflection inherent problems can be realised which in turn will encourage service users, service providers and policymakers to challenge and question issues within healthcare. For example, a qualitative study by Thesen (2005) demonstrates an improved awareness of power inequities among service providers by engaging in self-reflection. With this in mind, CST offers a means of social change or emancipation through the possibility of acting as a catalyst for change. According to Fay (1975 p.109) if '*we as actors are able to recognise, through discourse, the constraints imposed on us then we may be able to act to remove these constraints'.* Social structures and ideologies need to be challenged in order to discover possible constraints in relation to empowerment of service providers and people with epilepsy. However, according to Keat (2013 p.2) limitations exist with regards to scientific knowledge insofar as it:

> '*Contributes to the maintenance of a form of society in which science is one of the resources employed for the domination of one class by another, and in which the radical transformation towards a more rational society are blocked and concealed'.*

While the significance of constructivism is acknowledged, it is argued that it is unable to identify the existence of self-misunderstanding of ideological consciousness (Keat 2013). Moreover, it is unable to recognise the significance of structural features of society that operate as unconscious determinants of social phenomena (Keat 2013). However, Holter (1988) argues that analytical empirical, historic-hermeneutic and critical dialectical knowledge allows understanding of the biological, psychological and sociological aspects of human nature.

CST has the potential to enable mutual growth and change between service providers and people with epilepsy. It facilitates an objective view of social phenomena in the context of historical and social practices (McCarthy 1990). It has also been suggested that CST liberates individuals from the restraints of coercion (Wilson-Thomas 1995). In this context, both people with epilepsy and service providers can develop a sense of empowerment and challenge the 'system' with regards to empowerment delivery and practice.

It is suggested that a lack of empowerment exists for service users and service providers within epilepsy healthcare (Varley *et al.* 2011). Arguably, CST provides a mechanism to analyse any oppressive conditions within healthcare (Manias and Street 2000). Furthermore, Stevens (1989) claims that the dominance of social, political and economic environments can be addressed by using a CST framework. Moreover, communicative action theory has been suggested as an instrument to address service provider-service user power imbalance (Burbank and Martins 2009). It can reveal circumstances that inhibit un-coerced or effective communication (Sokoly and Dokecki 1992). For example, a qualitative study exploring service provider's views of an empowering educational program for service users, highlight that although service providers embrace the concept of empowerment as a theory, need support with translating it into practice (Adolfsson *et al.* 2004). For empowerment to be facilitated in practice, it is claimed that research is required in order to understand how power operates in practice (Gilbert 1995).

5.4.1 Limitations of Habermas's CST

Although the potential of CST as a metatheoretical framework for the study of empowerment and epilepsy healthcare have been argued, limitations of Habermas's features of CST exist. For example, Carr and Kemmis (1986) claim that Habermas does not provide a 'recipe' on how to put his theory into practice and does not relate to 'real life' or the 'real world' which results in frustration, disillusionment and potential oppression. Moreover, it is argued that obstacles to Habermas's Theory of communicative action such as time constraints, mismatch of agenda, mistrust and power imbalances can result in a failure to nurture sincere communicative action (Greenhalgh *et al.* 2006).

Misgeld (1977) suggests that the distinction between 'system' and 'life-world' is misleading because it detracts from the practical point of the theory and blocks reflection upon actual social situations in the relevant societies of our time. Similarly, Outhwaite (1996) adds that the double-sided use of 'life-world' by Habermas has caused some misunderstanding of his work. As a counter point, Kemmis (2001) argues that the theoretical discourse of the life-world and system offers a way of understanding participant's perspectives as structured by the contrasting and sometimes competing imperatives of social systems and the life-worlds participants might inhabit.

Moreover, healthcare empowerment approaches are viewed as intimidating to those in existing power structures (Miner and Ward 1992) and may be met with resistance. As a result, challenges exist when service user's choices differ to that of service providers (Tveiten and Meyer 2009). Bearing this in mind, service providers may need encouragement and support to accept the goals and priorities that people with epilepsy may hold.

Whilst recognizing that such limitations exist, arguably Habermas's features of CST merit exploration with regards to empowering service users and providers within epilepsy healthcare. Wells (1995) argues that CST allows understanding of the social organisation of everyday practice. Therefore, service providers need to challenge social structures, organisations and ideologies to enable the discovery of possible constraints.

5.4.2 Concluding comments

This section explored the value of CST as an alternative approach for the study of empowerment and epilepsy healthcare. Most debate surrounding empowerment and epilepsy healthcare have been guided either implicitly or explicitly within a positivist or constructivist philosophy. The merits and limitations of these frameworks along with CST have been outlined. The central argument is a consideration of CST as an alternative meta-theoretical framework. The philosophical principles of CST merit exploration of service user-service provider empowerment within epilepsy healthcare. For example, CST offers a framework that can explore empowerment within epilepsy healthcare, through critical self-reflection that examines and challenges the liberal ideological basis of inquiry, knowledge, theory development and practice. It can enable service users and service providers to challenge the traditional norms, in order to uncover the hidden meanings and constraining socio-political barriers to optimal empowerment (Stevens 1989). In the absence of such critiques we run the risk of maintaining the status quo, inadvertently reinforcing patterns of power and forms of oppression enacted individually and institutionally. Arguably, greater depth and explanations of empowerment within epilepsy healthcare can be explored from a CST perspective.

5.5 Identifying and selecting a social ontology and research methodological approach: The case for Systems Theory and Soft Systems Methodology

While the previous section highlights the potential of CST as a meta-theory approach for the study of empowerment and epilepsy healthcare, it has been suggested that CST does not relate to the 'real world' (Carr and Kemmis 1986). However, according to Jordon (1988 p.7) systems theory explores holistic and integrative exploration of phenomena and events and consequently *'provides a platform for the integrated study of complexity in the human experience'*.

5.5.1 Philosophical underpinnings of research paradigms

A process of formal inquiry is said to be guided by a research paradigm, a set of basic beliefs requiring the researcher's 'worldview' (Guba and Lincoln 1994). Indeed, undertaking social research often raises a number of meta-theoretical questions that relate to ontology and epistemology (Robson 2003).

Ontology is the philosophy of the world view of reality (Heron and Reason 1997). Within social research, key ontological questions include: (1) does social reality exist independently of human conceptions and interpretations; (2) is there a common, shared, social reality or just multiple context-specific realities; and (3) is social behaviour governed by 'laws' that can be seen as immutable or generalizable (Snape and Spencer 2003).

Broadly speaking, three distinct ontological positions exist and include: (1) realism; (2) materialism and (3) idealism. Realism claims that there is an external reality which exists independently of people's beliefs or understanding. Likewise to realism, materialism also claims that there is a real world but that only physical or material features of that world hold reality. On the other hand, idealism emphasises that reality is only knowable through the human mind and through socially constructed meaning (Snape and Spencer 2003).

Epistemology is concerned with ways of knowing and learning about the social world (Snape and Spencer 2003). It is described as the theory of knowledge *'embedded in the theoretical perspective and thereby in the methodology'* (Crotty 1988 p.3). Within the social sciences epistemology is usually viewed as an epistemological dualism which divides research along objective-subjective lines (Bryman 2004). Positivist approaches account for the objective stance whilst interpretivist research accounts for subjective viewpoints. The purpose here is to briefly outline the position systems theory and SSM holds ontologically and epistemologically in relation to CST.

The ontology of CST assumes a mediating position between the extremes of subjectivism and objectivism and acknowledges the reflexive and subjective aspects of science (Morrow and Brown 1994). The outcome is a position that argues for critical realism at the level of ontology, with a diverse pragmatism in epistemology and methodology (Morrow and Brown 1994). It moves beyond the subjectivistobjectivist debate to a dialectical relationship between two philosophical traditions in an effort to address and alter relations of power that shape social reality (Browne 2000). This is a key difference that distinguishes CST from other meta-theoretical positions.

Incorporating systems theory and CST ensures an emancipatory and critical approach by the researcher to the system being examined. It is claimed that '*systems thinking without critique is blind with respect to its underpinning boundary judgements and their normative implication'* (Ulrich 2003 p.327). Moreover, it is suggested that when researching a complex system, CST without systems theory is limited with regards to understanding a system, its components, boundaries and relations to one another (Watson and Watson 2011). Bearing this in mind, CST and systems theory views are complimentary and necessary in order to understand complex systems where issues of power or oppression exist, such as within epilepsy healthcare (Varley *et al.* 2011).

5.5.2 Factors affecting the choice of the research approach

Research is a strategy of enquiry, moving from underlying assumptions to research design and data collection (Meyer 2009) and therefore selecting a research methodology is a task that confronts the researcher. The most common classification of research methods is a quantitative or qualitative approach and therefore, the choice of using a quantitative or qualitative approach or a combination of the two has to be addressed. While there is much historical debate regarding the merits of both methodologies it is argued that mixed methods use the strengths of both quantitative and qualitative methods for the purpose of breadth and depth of understanding (Greene 2008).

In selecting a methodology for research, arguably it is necessary to select a paradigm *'whose assumptions are best met by phenomenon being investigated'* (Guba 1981 p.76). With this in mind, the aim of this study is to explore empowerment of service users and providers within Irish epilepsy services using one specialist service as an exemplar. Therefore, the approach needed to lend itself to an exploration of the micro, meso and macro levels of power if a guide to a future action was to be formulated. Therefore, this study necessitated a mixed method approach. According to Creswell (2003 p. 212) mixed methods research is defined as:

> *'The collection or analysis of both quantitative and qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research'*

Although the potential of CST has been outlined previously it is not beyond limitations[16]. Therefore, to address the objectives of this study a methodological approach that recognises 'real life' or the 'real world' was required. Subsequently, this led me to the work of systems theory and the principles of SSM (Checklands and Scholes 1990). Arguably, SSM is recommended in situations where the issues for examination are unclear and variable (Wells 1995). It is entitled 'soft' *as* it primarily relies on the views of those on the inside of a situation, through exploring with them systems structures as they perceive them; how their activity is reflected in these structures; and how they would like things to change. It focuses on what is termed a 'Human Activity System' (HAS) (Checkland and Scholes 1990). Checkland (1999 p.134) defines a HAS as:

> *'A notional purpose system which expresses some purposeful human activity; activity which could in principle be found in the real world. Such systems are notional in the sense that they are not descriptions of actual real world activity (which is an exceptionally complex phenomenon) but are intellectual constructs; they are ideals types for use in debate about possible changes which might be introduced into a real-world problem situation'.*

Whilst CST aims to provide a critique of society for the emancipatory benefit of its members, SSM aims to problem solve within society without having 'a priori' value of political change (Mingers 1980). It should be noted, however that both CST and SSM deny the claim that rationality remain divorced from the domain of values and aims to unite theory and praxis, in order to develop a rational approach to the realm of communicative competence and achieve change. With this in mind, systems theory, SSM and its appropriateness to the study of empowerment and epilepsy healthcare is now explored.

5.6 Systems Theory

To link the various aspects of this study of empowerment within epilepsy services with the relevant underlying theories and research design, system theory will be defined and explored briefly in terms of specific application.

Systems theory is an interdisciplinary theory about every system in nature, in society and

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[16] See Section 5.4.1 and the discussion of Habermas's limitations of CST

in many scientific domains as well as a framework with which we can investigate phenomena from a holistic perspective (Capra 1997). Systems theory attempts to take a holistic view of the interrelations of component parts-the wider picture (Rose and Haynes 1999). It is the study of the general features of systems and how they interrelate and explores order and disorder, patterns, complexity, and change over time. According to Jordan (1988 p.7) a system is:

> *'A complex of interacting components together with the relationship among them that permits the identification of a boundary-maintaining entity or process'*

Systems theory has the potential to offer the construction of a holistic methodology for perceptual inquiry. For instance, it can model complex intrapersonal, interpersonal, intergroup, and human/nature interactions without reducing perceptual phenomena to the level of individual stimuli. Moreover, it relates to both epistemological and ontological situations. For example, Checkland (1981 p.102) illustrates that an observer engaged in systems research will give an account of:

> *'the world, or part of it, in systems terms; his purpose in so doing; his definition of his system or systems; the principle which makes them coherent entities; the means and mechanisms by which they tend to maintain their integrity; their boundaries, inputs, outputs, and components; and their structure'[sic].*

It is argued that management science is dominated by goal seeking and Checkland (1981) suggests that this is inadequate when real issues are concerned with relationship maintenance. With this in mind, systems theory in practice is a process for understanding complexity in organisations due to human activity. Thus, systems theory addresses the equity of value of all participants within a system and can appear based on ability and hierarchically assigned power (Swango-Wilson 2010). Arguably, one such process is SSM (Checkland 1981, Checkland and Holwell 1998, Checkland and Scholes 1999, Checkland 2000). The foundation of systems theory is now explored.

5.6.1 Basis of Systems theory

The basis of systems theory rests on two paired concepts: (1) emergence and hierarchy; and (2) control and communication (Checkland 1981).

Emergence is a key characteristic of a HAS. Emergence occurs when there is sufficient complexity in a system for additional properties or behaviours to emerge from the system (Checkland 1981). For instance, the safety and quality characteristics of complex systems are an emergent property of the system as a whole, as opposed to a property of individual system components. In relation to this study, a MDT can successfully provide care for people with epilepsy, but the individual components of a team cannot. They must be organised in a way to function as the MDT, hence the MDT is emergent. Thus, the system emerges from its components and the whole is greater than the sum of its parts (Hitchins 1992).

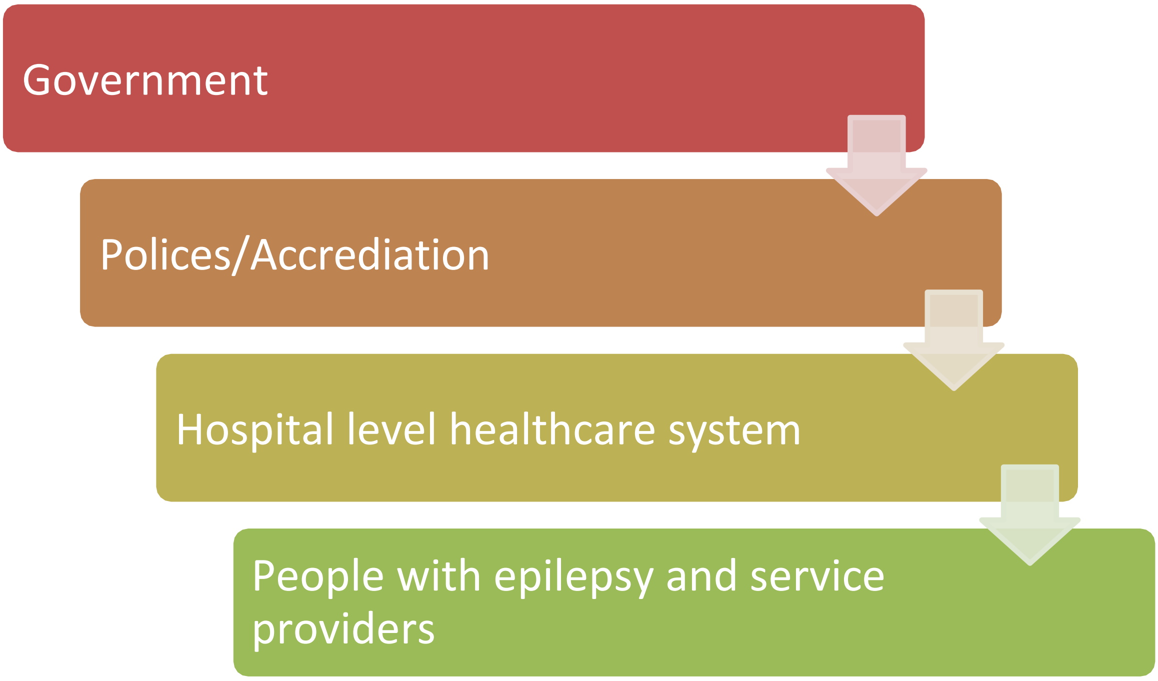
According to Checkland (1981 p.78), a HAS describes complexity as a hierarchy of levels, *'each more complex than the one below'*. In other words, complex systems can be expressed in terms of a hierarchy of levels within an organisation (Bailey 2006). However, although there is a requirement for hierarchies within a system to maintain order, misuse of power can exist within systems, resulting in biases which prevent the acknowledgement of personal value for many individuals (Anderson *et al.* 1999). Indeed, concerns have been made in relation to stereotyping and its effect on the ability of individuals within a system to achieve appropriate levels of power (Reynolds and Scott 2000). Hence, emergence and hierarchy refer to a general model of organised complexity.

The second pair of concepts within systems theory is control and communication. An open and dynamic complex system such as a healthcare system is viewed as a suite of interrelated subsystems that are kept in a state of dynamic equilibrium by feedback loops of information and control (Ackoff 1971). According to Rasmussen (1997) their relevant emergent properties are controlled by safety and quality constraints related to the behaviour of the system components or subsystems. Indeed, Rasmussen and Svedung (2000) suggest that since control implies the need for communication, reverse communication within the system hierarchy from controlled to controller is required to stimulate *'systems'* behaviour towards the accepted standard of safety and quality. According to Checkland (1981 p.83) this maintenance or survival of the hierarchy entails a: '*set of processes in which there is communication of information for purposes of regulation or control'*.

However, major barriers to communication within healthcare exists. With this in mind, systems theory is applied to this study exploring empowerment within epilepsy healthcare to construct a healthcare system hierarchy which consists of interacted systems linked with control and communication in different layers. This 4-layer model includes: (1) government; (2) policy/accreditation; (3) hospital-level healthcare system and finally (4) service users and providers (identified in figure 5.1). Inter-layer relationships are characterised by vertical control and communication, but the full regulatory structure also includes significant horizontal interrelations as well as self-regulation. According to Braithwaite and Westbrook (2005) the proper functioning of all these relationships is important for the achievement of quality healthcare. Arguably, a holistic healthcare systems relationship model can be developed by combining the concept of healthcare systems hierarchy and an analysis of control and communication relationships.

According to Ackoff (1981) the environment of every social system contains three levels of purpose: (1) the system; (2) it's parts and (3) the system of which it is a part (the supra-system). Systems theory models complex entities, created by multiple interactions of components by abstracting certain details of structure and component, and concentrating on the dynamics that define the characteristic functions, properties, and relationships that are internal or external to the system (Jordan 1998). With this in mind, a four step approach of analysis in systems theory is now described.

Figure 5.1: Healthcare systems Hierarchy



5.6.2 An approach to analysis in Systems theory

Jordan (1988) describes a four step approach of analysis in systems theory and includes: (1) consideration of the embedding context that includes, and is to some extent defined by, the phenomenon under consideration; (2) description of what may be defined as sub-wholes within the embedding; (3) attention to the specialised parts within the identifiable wholes, with emphasis on understanding the structures, their compositions and modes of operation; and finally (4) integrating the perspective obtained from the previous steps to gain an understanding of the overall phenomenon.

Systems theory and its foundations have been outlined. Checkland also acknowledges the significance of '*hard*' and '*soft*' systems thinking in relation to systems theory. This is now explored.

5.6.3 'Hard' and 'Soft' Systems thinking

Systems theory can be described as both 'hard' systems thinking and 'soft' systems thinking. Hard systems thinking is described as the 'optimization paradigm' and has a starting point in 'structured' problems (Checkland 1981). On the other hand, soft systems thinking is referred to the 'learning paradigm' and has a starting point in 'unstructured' problems in which there exists an ill-defined problem situation (Checkland 1981). However, in the business and organisational sciences, it was noted that hard systems thinking was often not sufficient to address all issues that management identified as core issues. Consequently, this led Peter Checkland to develop SSM as a response to the 'hard' systems theory. Indeed, SSM has the potential to deal specifically with the 'soft' or 'wicked' organisational and/or social problems. Wicked problems are complex, challenging issues that limit our ability to define, describe and implement solutions (Churchman 1967).

5.6.4 Concluding comments

Arguably, to improve performance of quality in healthcare systems, it is essential that the researcher adopt system thinking in research design and a holistic view of systems effectiveness (Chuang and Inder 2009). Indeed, the systems approach can be viewed as synergistic, focusing on the relationship between entities (Wilson 1984). With this in mind, a systems theory approach provides the necessary holistic insight to understand the study of empowerment within epilepsy services. SSM is one such approach and is now explored.

5.7 Soft Systems Methodology

SSM was developed in the 1970's at the University of Lancaster by Professor Peter Checkland, Professor Gwilym Jenkins, Dr. Brian Wilson and Dr. David Rippin. It's history and methodology is documented in four books: (1) Systems Thinking, Systems Practice (Checkland 1981b); (2) SSM in Action (Checkland and Scholes 1990); (3) Information, Systems and Information Systems (Checkland and Holwell 1998) and finally (4) SSM: a Thirty Year Retrospective (Checkland 2000). Further non-Checkland core texts include: Information in Action (Davies and Ledington 1991), Systems: Concepts, Methodologies and Applications (Wilson 1984;1990) and SSM: Conceptual Model Building and its Contribution (Wilson 2001). SSM employs systems theory in the creation of intellectual devices to learn about the world, or gather a worldview. It originated as a result of the demand to apply and study systems theory in practice. According to Patel (1995 p.13) SSM is unique because:

> *'It enables the analyst to embark on a process of learning about the real world situation being investigated, while simultaneously seeking to improve it by analysing the situation….and suggesting recommendations for further action to improve the problem situation'.*

Bearing this in mind, the philosophical foundations of SSM is now explored.

5.7.1 Philosophical underpinnings of SSM

Checkland (1981) suggests that SSM is aligned to the hermeneutic circle of enquiry. However, Mingers (1980) first viewed a possible connection between SSM and CST. Consequently, Checkland (1981) referred to Minger's paper and found a significant compatibility between CST and SSM. Indeed, Habermas (1978) also recognised the limitations of traditional 'hard systems analysis' and argued for an alternative approach to rational planning that accepts the world of meanings and values. Thus, both Habermas and SSM try to clarify a similar classification on human action, a '*purposeful activity or purposive rational action'* (Mingers 1980 p.46). Indeed, both deny the claim that *'rationality must remain divorced from the domain of values'* (Mingers 1980 p.46).

The aim of both SSM and CST is to unite theory and praxis and develop a rational approach to communicative interaction in order to bring about change. Moreover, Mingers (1980) argues that the validity of CST rests with the actors themselves. Similarly, SSM attempts to increase the awareness of actors in a problem situation ‘*both by spelling out the consequences of a particular Weltanschauung and by contrasting and demonstrating the validity of other, competing Weltanschauungen’* (Mingers 1980 p.47).

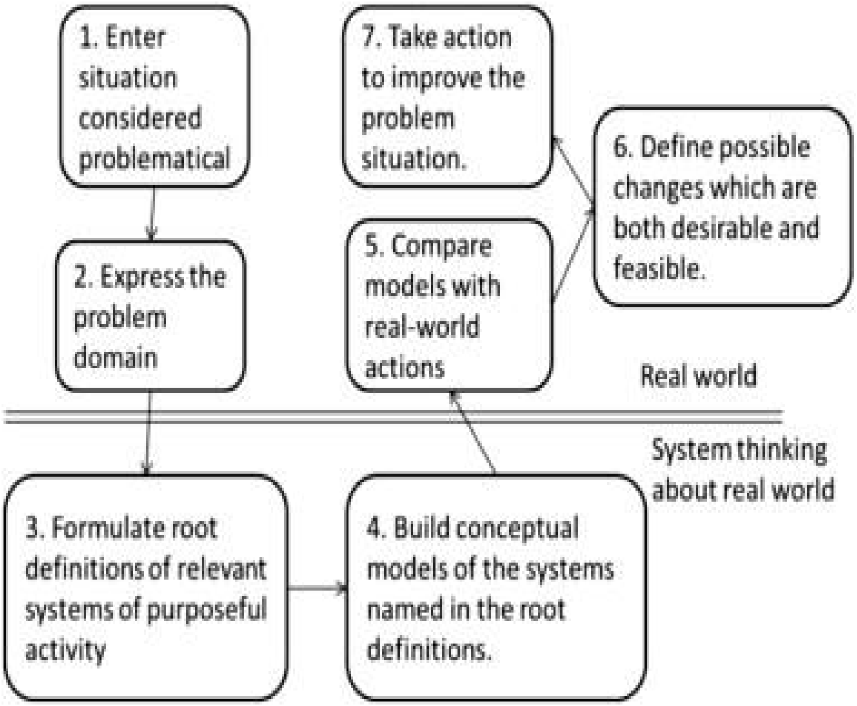
Although Checkland (1976) argues that (natural) science has been incredibly successful and can control variability through the use of laboratory experiments, he claims that problems in real-world organisations require a systemic, holistic approach that recognises their emergent properties and a ‘soft’ approach to deal with their lack of structure (Checkland 1976). With this in mind, the framework of SSM is now explored.

5.7.2 SSM framework

SSM has moved beyond prescriptive roots in systems theory to a more fluid, flexible approach that better reflects how SSM has been used in practice. Platt and Warwick (1995) suggest that the most popular version of SSM is Checkland’s (2000) methodology, offering seven identified stages, from expressing a problem situation through to an action stage as identified in figure 5.2. It should be noted, however, that not all of these stages need to be followed. SSM is a flexible methodology rather than a fixed method, and the seven steps are not usually followed rigidly (Checkland 2000) making it possible to repeat and reiterate stages as necessary. For example, if several changes are rendered impractical, the analyst can go back and search the rich picture for different solutions, and repeat stages 3-5.

In the SSM model, there is a line separating the ‘real world’ from the ‘systems world’. The ‘real world’ is the world where the problem is occurring and the human activity takes place. The ‘systems world’ is the analyses context in which the information from the real world is scrutinised and dissected in the problem solving process.

Figure 5.2: Seven stage model of SSM (Checkland 2000)

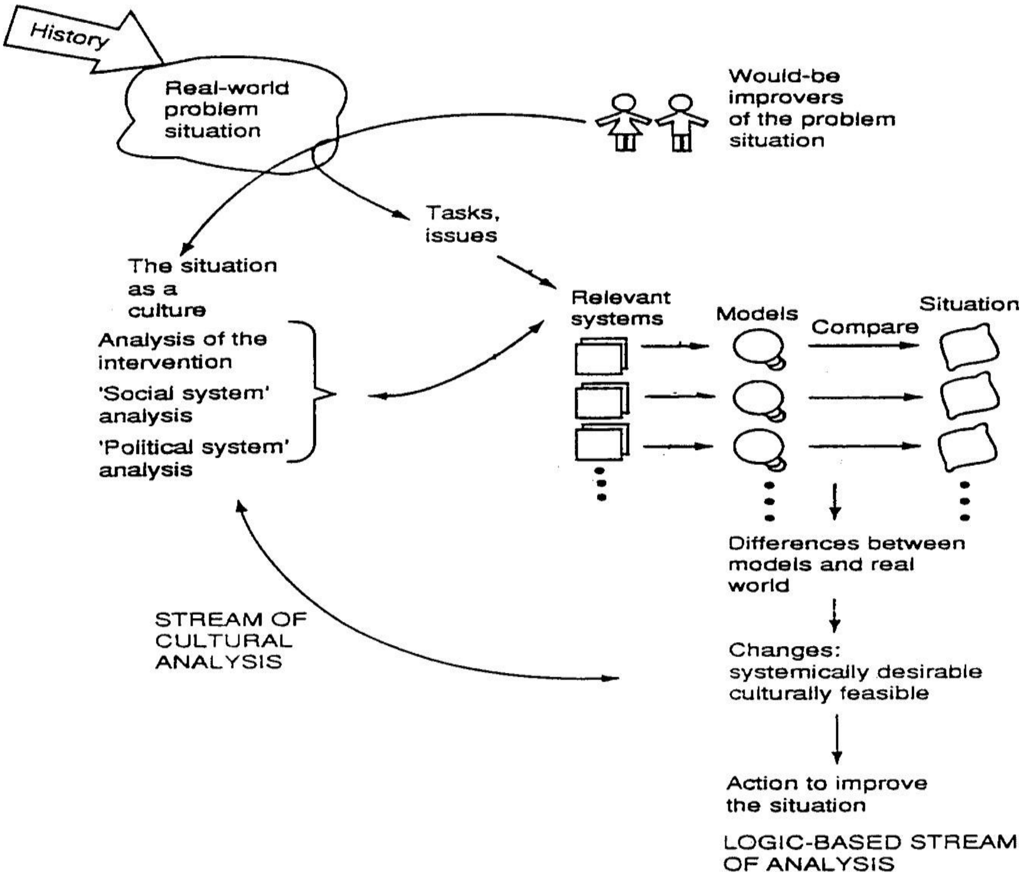


SSM can be used in a variety of ways to explore problematic situations including a more flexible use of the methodology (Checkland and Scholes 1990, Checkland 2000). This is expressed by the distinction between Mode 1 and Mode 2 use of the methodology. While Mode 1 is the traditional use of SSM by the seven-step process normally undertaken by an external researcher, Mode 2 is a more flexible use of the methodology where the concepts are used but not in a standard way, for instance, by an internal person.

In addition, SSM was redefined in the 1980's to a more generalised and flexible representation of the process (Checkland 1988b, Checkland and Scholes 1990). It was recognised as two frames of enquiry: (1) a stream of cultural analysis of the organisational context and (2) a stream of logic-based enquiry using traditional SSM models as identified in Figure 5.3. These two streams necessarily interact, and through a process of comparison and reflection, desirable and feasible changes can emerge (Checkland and Scholes 1990).

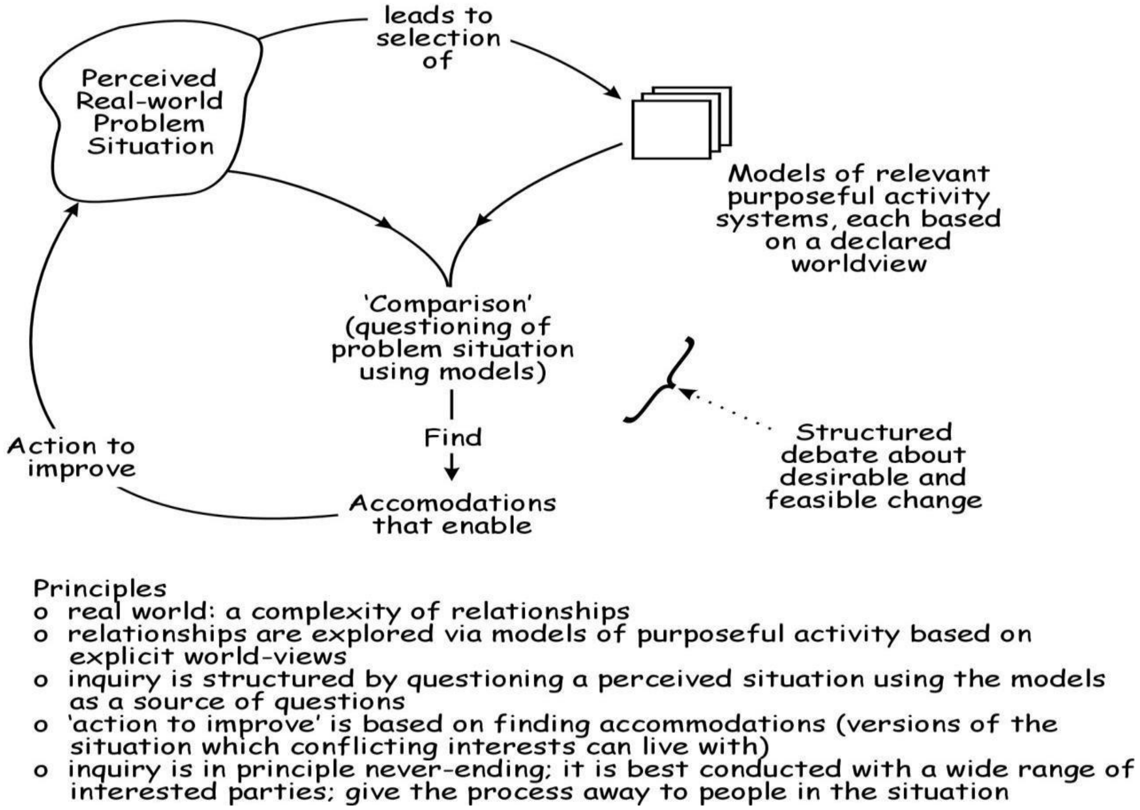
SSM provides techniques and general guidelines for expression of situations that are considered to be problematic. Out of this expression, key themes can be identified and modelled as systems of purposeful human activity that are relevant to debate about the situation.

Figure 5.3: The two-stream approach (Checkland and Scholes 1990)



Comparison of these conceptual models to the expression of the real-world situation is intended to stimulate debate about systemically desirable and culturally feasible change. Action in the real-world, informed by such debate, changes the situation, which in turn requires new expression. The process is intended to be iterative and ongoing as identified in Figure 5.4. Thus, SSM formally operates a learning cycle, employing learning from the experience of applying the methodology to further inform action in real-world situations (Checkland and Scholes 1990, Checkland 1999). Figure 5.4 presents several important principles of SSM. In particular the identification and conceptualization of relevant systems are undertaken from explicitly stated perspectives (world views or '*Weltanschauungen*'). Models of the same situation, based on different world views, may be quite different from each other. At the core of conceptual models is purposeful human activity. Human activity systems are imbued with values, intentions, and norms that are rooted in the *Weltanschauungen* that make each system meaningful in the context of the problem situation.

Figure 5.4: The inquiring/learning cycle of SSM. Figure A1 of Checkland (1999)



Principles
- o real world: a complexity of relationships
- o relationships are explored via models of purposeful activity based on explicit world-views
- o inquiry is structured by questioning a perceived situation using the models as a source of questions
- o 'action to improve' is based on finding accommodations (versions of the situation which conflicting interests can live with)
- o inquiry is in principle never-ending; it is best conducted with a wide range of interested parties; give the process away to people in the situation

SSM offers a methodological approach to deal with human activity in complex problematic situations. Indeed, it is human activity that so often makes environmental problem situations complex and intractable. With this in mind, arguably the declaration of world views and accompanying bundles of values, intentions, and norms that drive the expression and evolution of such situations is a promising route to deal with complexity within epilepsy services. Box 5.2 outlines five constitutive rules that represent SSM, allowing it to exist as a methodology, but with the benefit of flexibility (Checkland and Scholes 1990).

Box 5.2: Five constitutive rules of SSM (Checkland and Scholes 1990 p. 286-287)

1. SSM is a structured way of thinking about problem situations with the aim of improving the situation that can be part of day-to-day managerial work or as part of a specific study.
2. SSM's structure is derived from a systems approach. Any account that claims to be based in SSM must be expressible using the SSM epistemology.
3. Any account that claims to have used SSM should follow these guidelines: An explicit assumption is made to describe part of the real world as a system to be engineered; The SSM user is explicit in the transitions between real world and the reflective, systemic thinking about the real world; Models are created that typically capture purposeful activities and contain: emergent properties, layered structure, and mechanisms for communication and for control; and Models are used to trigger discussion and debate to define feasible improvements.
4. Each application of SSM should be consciously adapted to its particular situation.
5. Reflection on the methodology in practice can reveal new lessons to refine and extend SSM.

Checkland (2000) suggests that novice SSM practitioners follow the seven-stage model as shown in Fig 5.2. With this in mind, Checkland's (2000) seven stage framework as described below will guide this study in terms of data collection and analysis.

Stage 1: Situation considered problematic: The purpose of stage 1 is to gain a general understanding and wider view of the problem (Bowen and Shehata 2001). The term *problem situation* is used to describe the specific problem and its environment. Therefore, in this study a variety of methods were used to collect the relevant data and understand the situation. This was accomplished in 2 phases. Data collection was conducted over a 2 year period involving regular weekly visits to the OPD within one specialist epilepsy service in Ireland. This was accomplished in this study firstly by conducting a survey of people with epilepsy on their views of their service needs in relation to design and delivery[17]. Moreover, in depth interviews with people with epilepsy and service providers with reference to service user and clinician empowerment was

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[17] See Chapter 7: Epilepsy services in Ireland: A survey of people with epilepsy in relation to satisfaction, preferences and information provision.

undertaken. This analysis was further informed by a non-participatory observation of services within one epilepsy service in Ireland[18].

The intention of data collection in SSM is to provide material for an analysis of the situation, from which one can then develop a 'rich picture', 'root definition' and 'conceptual model'. The identification and evaluation of the obstructions to effective outcomes is generated by contrasting this conceptual model with reality (Wells 1995). However, the difficulty lies in deciding when one has enough data. Within the context of this study, the parameters were set by the need to obtain the views of both service providers and people with epilepsy until data saturation had been reached.

Stage 2: Problem situation expressed*:* Once this information was gathered the problem situation was expressed as a 'rich picture', enabling the main issues to be identified[19]. The purpose of the picture is to symbolically depict the relationships and 'feel' of a situation (Checkland and Scholes 1990). However, it is not used to devise a plan of action. By means of the picture-building process key features of empowerment issues within epilepsy healthcare were identified (eg. the people, processes, places, relationships and viewpoints involved), perceived issues (eg. barriers to empowerment) and the characteristics of possible improvements from a 'systems thinking' perspective.

Stage 3: Root definitions of relevant systems*:* Having identified relevant systems that need investigation, stage 3 requires a root definition of each system to be constructed. Root definitions describe what the system is and what it aims to achieve. Checkland (1981p.167) defines a root definition as a:

> *'hypotheses concerning the eventual improvement of the problem situation by means of implemented changes which see to both the systems analyst and problem owners to be likely to be both feasible and desirable'.*

Root definitions are formulated using the mnemonic CATWOE: (1) Customer (beneficiaries of the system); (2) Actor (system participants); (3) Transformation; (4) Weltanschauung (Worldview); (5) Ownership and (6) Environment (Checkland and Scholes 1990). Utilising these elements[20] (see table 10.1) a root definition was

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[18] See Chapter 8, Issues of Empowerment within epilepsy services in Ireland using one specialist service as an exemplar: Service users and providers perspective

[19] See Chapter 10, Section 10.3, figure 10.1: Presenting the rich picture of empowerment within Irish epilepsy services.

[20] See Chapter 10, Section 10.4.1: Table 10.1-CATWOE Analysis and Irish epilepsy services.

constructed in order to express the core purpose and activity of the Irish epilepsy service[21].

Stage 4: Conceptual models of systems derived: Once the root definition for the system was established stage 4 requires the construction of a conceptual model which describes the activities that must take place in order to achieve the transformation. According to Platt and Warwick (1995) the conceptual model is built by identifying the key activities within the root definition and expressing each activity in a phrase containing a verb which can then be associated to form the conceptual model. A conceptual model was built by looking at what activities needed to be undertaken for the system to be as depicted in the root definition. The implied key activities were 'unpacked' in terms of verbs and a conceptual model of the epilepsy service was built[22] (see figure 10.3).

Stage 5: Comparison of models and the real world: At this stage a level of debate is introduced to compare the conceptual model with the models with the real world situation and to highlight possible changes. The purpose of this stage is to analyse the similarities and differences between the model and the real world in a thorough and structured manner (Bowen and Shehata 2001). The discussion should focus on whether or not the various perceptions are being met and if there are any discrepancies. The comparison can be carried out in a number of ways such as by interviews or benchmarking or as Checkland suggests, by formal questions and the employment of a matrix for comparing conceptual models with real world situations (Checkland and Scholes 1990). He also added the further criteria by which a transformation would be judged, which he describes as the five E's. These are: (1) Efficacy (will it work); (2) Efficiency (will it work with minimum resources); (3) Effectiveness (does it contribute to the goal of the organisation); (4) Ethics (is it morally sound) and finally; (5) Elegance (is it aesthetically pleasing).

Although the original approach developed by Checkland (2000) was prescriptive, recent developments indicate that if root definitions and rich pictures contain sufficient detail to enable practicalities and implementation issues to be evaluated, the process is made easier. This is achieved mainly by ensuring that all the verbs used in the conceptual model

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[21] See Chapter 10, Section 10.4.2: Root definition

[22] See Chapter 10, Section 10.5: Figure 10.3-A conceptual models of systems derived.

stem directly from the root definition (Checkland and Tsouvalis 1997). This stage should then reveal areas where improvement may be possible. For this current study the problem owners participated and approved the conceptual models that I created and this was accomplished in this study by undertaking a focus group. Chapter 9 reports the findings of a focus group (n=8) with people with epilepsy (n=4) and service providers (n=4) to compare the conceptual of the service with its service operation[23]. A comparison of the conceptual analysis with the service operation is identified in table 10.1.

Stage 6: To identify changes: At this stage the researcher and problem owner(s) deliberate and discuss what changes are feasible and practical taking into consideration the cultural and political environment. The participants then need to come to an agreement or consensus as to which changes are systemically desirable. This may require some iteration of the process and revisiting earlier stages. Checkland (2000) suggests a return to the CATWOE elements to ensure there are no areas of contradiction or physical and financial constraints. A review of assumptions can also be revealing in creating a larger range of possibilities.

Checkland (2000) identifies three principal areas of change and these include: (1) structural change; (2) procedural change; and (3) attitudinal change. He acknowledges that the first two types of change are relatively straight forward and can be implemented by authority. However, attitudinal change is far more difficult to implement and requires considerable monitoring to ensure it is being achieved. He describes attitudinal change as inclusive of influence, expectations, behaviour and some of the intangible characteristics of both individual and collective consciousness of people in groups (Checkland 2000). He further suggests that the changes considered should meet two main criteria: they must be systemically or logically desirable and they must be culturally feasible.

Stage 7: Action: This final stage is about 'taking action' where findings are applied and evaluated as part of an ongoing process and is concerned with the implementation of changes. It is envisaged that the changes will be translated into planned service objectives. This stage is not part of the current study and therefore conclusions about their possible success remains speculative. Future research is required to implement these changes and to ensure a continuous process of refinement. The potential of

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[23] See Chapter 9: Results of focus group.

Checkland's SSM for the study of empowerment within epilepsy healthcare is now explored.

5.7.3 The potential of Checkland's SSM for the study of empowerment within epilepsy healthcare

SSM is described as an interpretative approach, providing a structure for action research to solve organisational problems (Checkland 1975). It is recommended in situations where the issues for examination are unclear and variable (Wells 1995) and provides a process for understanding how to structure purposeful action that leads to a particular and meaningful objective (Checkland 1981, Checkland and Scholes 1999). SSM also provides a window through which the complexity of such human interaction can be investigated, described and understood. Furthermore, it allows the identification of change that is both systemically desirable (in that it will alleviate some of the problems and issues) and culturally feasible (in that actors within the system will be inclined to engage with the changes proposed and the change process itself). With this in mind, SSM encourages learning and understanding and arguably has the potential to lead to agreed change between all stakeholders and facilitate empowerment within epilepsy healthcare.

The significance of SSM has been described in healthcare research in recent years. For example, it has been used to explore several aspects of the NHS in Britain and include: (1) to support and understand the information systems needs from a business and clinical perspective (Checkland and Holwell 1993); (2) to evaluate the British NHS during its centralization process (Checkland and Scholes 1990, Hindle *et al.* 1995); and (3) to evaluate organisational change efforts in the NHS (Rose and Haynes 1999). This approach ensures that Information Technology (IT) efforts were not evaluated solely as IT projects, insofar as their evaluation also included social and political contexts. It also encouraged formative evaluation, reflection and improvement to support change.

SSM has also been used in combination with simulation. Holm and Dahl (2011) identified SSM as a useful precursor for an emergency department simulation model. Moreover, Lehaney and Paul (1994; 1996) identified how SSM could support reasoning with simulation development in an OPD at Watford General Hospital. Activities within the OPD such as external X-ray, Electro-Cardio-Gram (ECG), and laboratory testing services were monitored and SSM proved a valuable methodology to support reasoning with the simulations on what improvements could be considered. In addition, the potential of SSM to improve the use of simulation models for resource planning in the healthcare sector have been argued (Lehaney and Hlupic 1995). Also, the benefit of combining simulation and SSM through a mixed mode modelling approach has been suggested (Lehaney and Clarke 1997).

Moreover, SSM has been used to explore health care system improvements. Wells (1995) used SSM to analyse nurse management and activity in a psychiatric in-patient facility. Wider inferences were drawn concerning the competence of Registered Mental Nurses (RMNs) practicing within in-patient facilities, and the role of Colleges of Nursing in operating effectively in the new care and market paradigms. Furthermore, Wells (2005) utilised a SSM approach to examine the role of Hospital-based industrial units and their role and significance to service users and providers. Brenton (2007) used SSM to improve communication between an acute inpatient unit and a rehabilitation service. He suggested that it was particularly useful in *'drawing out what were seen to be quite simple issues that were relatively straightforward to address'* (Brenton 2007 p.16) and enables the researcher to take account of the whole picture and refocus thinking.

Rose (1997) identifies SSM as a useful approach to support research and evaluation in several different ways, including the development of research questions, conducting research and defining and supporting the process of research. Underpinning SSM is a belief that in a problem situation there is often a sense of discontent without focus (Checkland 1981). It is in such situations of 'discontent without focus' that SSM thrives and assists the researcher/clinician in making sense of the 'messy' situation.

Exploring empowerment within epilepsy healthcare represents a complex social reality. For instance, it is identified that people with epilepsy have little or no insight into the concept of integrated or shared care and play a passive role with regards to their healthcare (Varley *et al.* 2011). Arguably, exploring empowerment using traditional frameworks may only explain a concept in very general and vague terms. Bearing this in mind, it is claimed that a systems approach is necessary to understand the management of chronic illness and a necessary aspect to successfully design clinical decision support tools and telemedicine care for chronic disease programs

(Carson *et al.* 1998). Therefore, SSM is an approach which is systematic and has the potential to establish and structure a debate concerning actions for improving the problem situation.

Embracing SSM enables members of an organisation to adapt a mode of thinking that challenges the traditional methodologies. According to Jacob (2004) SSM has the potential to empower organisational members by providing them with improved understanding and control of change related issues and problems. This is achieved by: (1) approaching issues holistically; (2) viewing organisational change coherently; (3) recognising and exploring problem situations; (4) surfacing discourses and meanings; (5) regarding strategy as multidimensional; (6) modelling purposeful activity systems with a view to improvement; and (7) aiding strategic thinking.

5.7.4 Concluding comments

This section emphasises the philosophical, methodological and practical aspects of systems theory and SSM. SSM is a problem solving methodology in a systems context approach. It analyses human activities as systems and subscribes a solution that will address the whole situation and not just the specific problem. SSM has proven itself as a flexible evaluation and improvement tool for 'wicked' problems. It has been used in several aspects of healthcare, from addressing problematic situations at an organisational level to determining the early requirements for clinical information systems. Therefore, SSM can be described as a holistic and systemic approach.

Indeed, epilepsy healthcare represents a complex social reality in part due to the 'micro', 'meso' and 'macro' levels of power that exist. Arguably, in relation to this study of empowerment and epilepsy healthcare, systems theory and SSM has the potential to provide an opportunity to engage with the 'micro', 'meso' and 'macro' levels of power, and empower both people with epilepsy and service providers.

5.8 Process of Investigation: Research Setting to Isssues of Sampling, Data Collection and Quality

This section describes the process of investigation which was used in this study. This study was conducted in one Irish urban hospital. This hospital operates an epilepsy service within the HSE and serves an urban and rural population. It also provides an OPD service once a week for people with epilepsy nationwide. This centre is staffed by consultant neurologists, neurology registrars, ESN’s and service user representatives from Epilepsy Ireland of the Irish Epilepsy Association, which is the main epilepsy support group for people with epilepsy in Ireland.

5.8.1 Selecting and negotiating access to the research site

Selecting research settings and populations encompasses identifying those which, by virtue of their relationship with the research questions, are able to provide the most relevant, comprehensive and rich information (Lewis 2003). Moreover, negotiating access to the research site requires patience and sensitivity and can be critical to the success of a study (Ritchie and Lewis 2003). Indeed a single point of contact within the research site who can serve as a ‘champion’ for a study can avoid many communication difficulties. Factors influencing the selected research site in this study were: (1) the population of interest; (2) service providers who were willing to participate and (3) a gatekeeper who was willing to champion the study in terms of access to the research site to successful progression and completion.

Negotiating access was first achieved by attending several meetings with members of the NECP. These meetings led to informal discussions with service providers within the research site who would, potentially, be involved in this study both individually and at a group level. There were three levels of access to negotiate within the research site-executive management (Director of Nursing (DoN), The Patient Advisory Committee (PAC) and the Clinical Director), clinical management (ESN’s and other members of the MDT) and service user representatives (Epilepsy Ireland) within the epilepsy service. The early contact with first gatekeepers (DoN, PAC and Clinical Director) was made and permission for access was granted, contingent upon ethical approval.

I discussed my sampling intentions, for example the intention to carry out a survey, and interview people with epilepsy and service providers within the specialist service with these key gate keeper groups. It was at this point the gatekeepers highlighted the MDT weekly meetings that took place within the service and suggested that I attend these to inform clinicians within the service of my research, which I duly did. At the first of these meetings I presented a research proposal (see Appendix B) to the team members and discussed it with them, answering any questions they had. The right of all participants to refuse to partake in the research was stated and the participants were told that reporting of observations of service would be done thematically, and not by individual.

Clinicians, whilst in a position to refuse to be involved with the research, may have been placed in a position where it would be difficult to say in such a public forum. However, this issue was addressed through informal discussions and one to one meetings to provide clear information regarding the aim and objectives of the study, the process involved and provide an opportunity to be questioned. All members of the MDT showed great interest in the study. Five members of the team decided they would prefer not to take part in terms of interview and this was respected.

During these meetings eight service providers agreed to participate in one-to-one interviews and four agreed to participate in the focus group. Letters of invitation and information leaflets were given to all service providers that agreed to participate and it was agreed that service providers would email the researcher a date and a time that suited them best to be interviewed.

5.8.2 Research Aim, Objectives and Methodology

5.8.2.1 Aim

To explore and analyse the epilepsy service as a system with reference to dimensions of empowerment using CST. It encompasses the following objectives:

5.8.2.2 Objectives

(1) To utilise CST to analyse and define the concept of empowerment in the Irish health service.

(2) To develop a situational analysis and conceptual model of the service utilising ‘soft systems’ methods with reference to the NECP.

(3) To explore and critically analyse organisational issues and human factors in service provision that support or hinder empowerment.

(4) To compare the conceptual model of the service with its service operation.

(5) To draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland as this relates to empowerment.

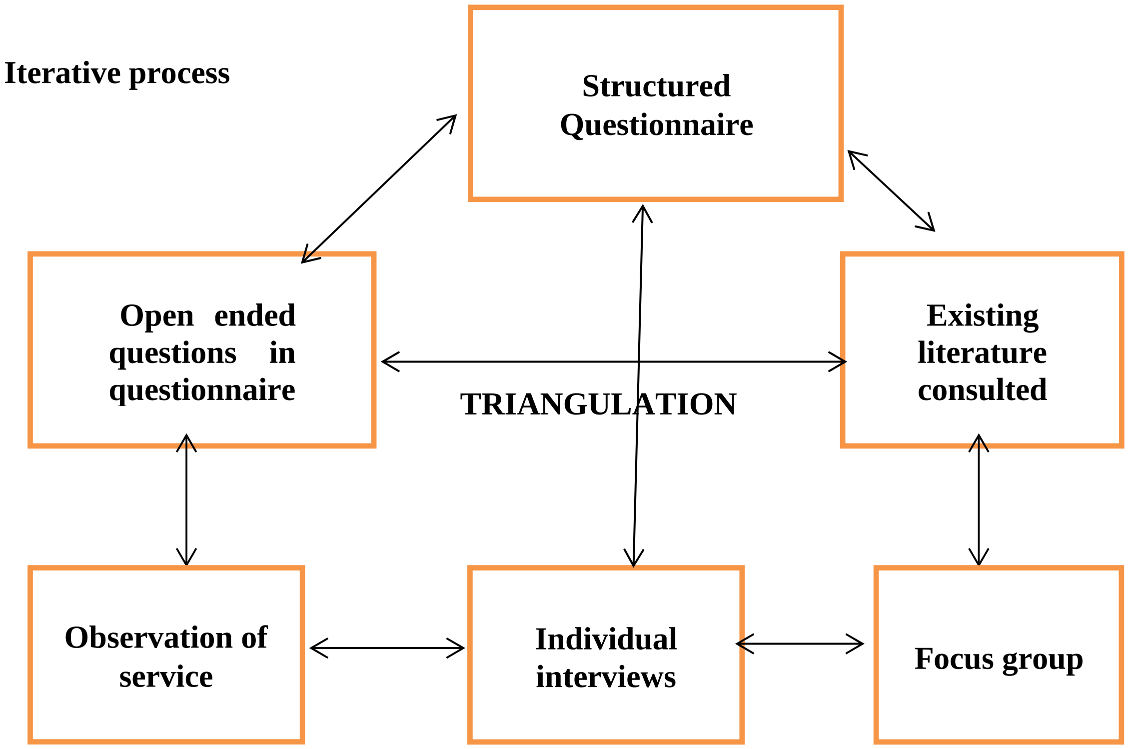
5.9 Methodology and approach

A mixed method methodology using systems theory and Checkland's SSM was used. Mixed methods research is viewed as the third methodological movement and has much to offer health and social science research. It emerged in response to the limitations of the sole use of quantitative or qualitative methods and is now considered by many as a legitimate alternative to these two traditions (Doyle *et al.* 2009). Indeed, it provides a more complete and comprehensive picture of the study phenomenon (Bryman 2006).

Mixed methods can be used to expand the scope of a study as researchers seek to capture method-linked dimensions of a target phenomenon (Greene *et al.* 1989). Furthermore, mixed methods investigations may also be used to gain better understanding of research problems by converging numeric trends from quantitative data and specific details from qualitative data (Punch 1998, Mertens 2003, Tashakkori and Teddlie 2010).

It was decided to conduct in depth interviews and an observation of service after the quantitative survey in order to explore deeper findings and provide greater depth and understanding of data. Thus, a variety of different approaches were used in this study as illustrated in figure 5.5. The advantage of using mixed methods is that it promotes triangulation by looking at the issues under investigation from various perspectives. The mixed method approach was iterative in nature and comparative analysis of data was conducted throughout the process of analysis. Thus the study adopted a mixed method approach which promoted triangulation through the eclectic use of qualitative and quantitative methods

Figure 5.5: Mixed method approach



This mixed methods methodological approach is underpinned by CST[24]. It has the potential to offer service providers and people with epilepsy a way forward to accomplish change that is congruent with critical thinking. This approach allowed the researcher and participants to critically reflect together, sharing knowledge and understanding, with the intention of developing practical and feasible changes.

5.10 Ethical considerations

This section outlines the ethical considerations arising from this study and the precautions taken to protect all participants. Human rights must be safeguarded in research, and ethical codes and principles provide these guidelines. However, every researcher must evaluate these for him/herself (Punch 1994), achieved by using reflective ethical inquiry and constant self-questioning throughout the research process (Kylma *et al.* 1999).

Central to the conduct of rigorous research is close adherence to ethical considerations such as voluntary consent, informed consent, confidentiality, and non-maleficence

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[24] See Section 5.4 and the potential of CST as a metatheory for the study of empowerment and epilepsy healthcare

(McAuley 2003). However, this can be particularly challenging when working with vulnerable groups and sensitive issues (Davies 2005). The following section describes the ethical issues that occurred throughout this study and how they were resolved.

5.10.1 Obtaining ethical approval

Ethical approval was sought and granted from WIT Ethics Committee (Appendix C), the Regional Ethics Committee, HSE (Appendix D), and Nursing Ethics Committee HSE (Appendix E). Permission was also granted by the PAC (Appendix F) at the research site. This required the submission of an application form and research proposal to each committee. An attendance for interview was requested at the WIT Ethics Committee. This interview was primarily concerned with ethical issues concerning people with epilepsy and service providers. In particular the members of the ethics committee focused on techniques of dealing with issues revealed during the research process that led participants to reveal unethical or malpractice behaviours or if the researcher observed any unethical or malpractice behaviours during the research process. In case of such events, and on the advice of the WIT ethics committee, a consultant neurologist and an ESN were identified within the epilepsy service to deal with such issues if they arose.

5.10.2 Informed consent

Eliciting consent to participate in the study, and ensuring that the participants' consent is informed, is a fundamental part of ethical approval for any study (Robson 2011). From a research perspective, the potential for harm for participants is to a large extent socially or psychological based (Byrne 2001). The researcher was aware that participants in this study may feel in a vulnerable position and, therefore, it was essential to negate any feelings of coercion (Cohen *et al.* 2007, LoBinodo-Wood and Haber 2010). Bearing this in mind, all participants were invited to participate on a voluntary basis and provided with detailed information, in verbal and written format, in relation to the study.

Informed consent entails using skills of listening, clarifying, making explicit the implicit and fostering a consent dialogue throughout the research process (Roberts 2002). Munhall (1991) suggests that consent should not be seen as a once-off event but as ongoing. She talks of process consent to signify the process of acquiring or reaffirming consent over the period of a study. This enables participants to make decisions as to whether they still want to party to the study. Bearing this in mind, process consent was viewed more appropriate for this study. This allowed participants the opportunity to consent to participate on an ongoing basis-from initial briefing meetings and introductions, to pre and post survey, interview and focus group stages, to writing up and dissemination of findings.

5.10.3 Survey, observation of service, one-to-one interviews, and focus group.

This section outlines the ethical considerations whilst undertaking data collection.

5.10.3.1 Survey

Firstly, all people with epilepsy attending an specialist epilepsy centre on their day of clinical review that met the inclusion criteria were invited to participate in the survey by the MDT gatekeepers (an ESN and a consultant neurologist). Letters of invitation and information leaflets (Appendix G) were distributed in the waiting room of an OPD clinic to 153 prospective service users, of whom 102 took part. Of those participants that were willing to complete the survey each participant was offered the opportunity to ask questions prior to completion of the survey. Each participant was informed that they had the right to withdraw at any stage and the right not to answer any questions.

Participants either completed the paper survey/questionnaire in the waiting room of the OPD or in a room allocated to the researcher either before or after the patient's appointment. The survey took no longer than 20 minutes to complete. However, using service providers to identify service users that were suitable to participate, could have biased the sample. All participants were informed that this study would form part of a doctorate submission with the potential for findings to be published. Participants were asked were they still willing for the contents of their survey to be used. Two participants requested that their survey be withdrawn and these requests were adhered to.

5.10.3.2 Observation of services

Secondly, I carried out periods of observation in the OPD, and observed, with the participants' permission, processes or events in relation to both their experiences of the health service and empowerment experiences within the Irish epilepsy services. Since the current study was conducted in the OPD, it was considered more appropriate and feasible for me to take on the role of an observer in order to further understand people's actions, interactions and exchanges. Gold (1958) identifies four roles the researcher may adopt to engage in direct observation – the *complete observer*, *observer as participant*, *participant as observer* and *complete participant*. The merits of each of these have been rehearsed in the literature over a number of years (Robson 1997, Wagner *et al.* 2012). For this study, '*observer as participant'* was chosen. An '*observer as participant'* involves the researcher's role being recognized by the participants under observation and their knowledge of the goals of the observer's research. In this regard there is some interaction between the researcher and the participants. The researcher's aim is to play a neutral role within the environment under observation, but everyone is aware of their presence. However, over time, participants get used to that presence and thereby comfortable with the observation role. It is the recognised approach in SSM. Therefore, the researcher played a neutral role during observation, and service users did not seem too act differently during observations. All participants were informed that this study would form part of a doctorate submission with the potential for findings to be published.

Some participants were willing to talk to me during the observation of service and often took the initiative to share some of their experiences in relation to empowerment within the epilepsy services. Participants were asked were they still willing for the contents of this observation to be used. All participants agreed.

5.10.3.3 One-to-one interviews

Thirdly, all individual interviews were held in the OPD department in a private room allocated to the researcher. Members of the MDT identified service users best positioned to participate. Sixteen people with epilepsy were approached by the MDT gatekeepers (an ESN and a consultant neurologist) and ten agreed to participate. The researcher recruited the service providers (see section 5.8.1). Letters of invitation and information leaflets were given to all people with epilepsy who agreed to participate. I met with these participants prior interview and any issues with regards to their involvement were addressed. Prior to each interview, dates and times of interviews were agreed and all participants were informed again of the purpose of the interview and offered the opportunity to ask questions before or during the interview process. They were also informed that they could withdraw from the interview at any stage and decline to answer any question (s) and have the digital recorder turned off without compulsion. The consent form for individual interviews (Appendix H) was explained and all participants signed. This indicated that participants were willing to be interviewed and that the interview could be recorded. All participants were informed that the interviews would form part of a doctorate submission with the potential for findings to be published. Participants were asked were they still willing for the contents of their interview to be used. All participants agreed.

5.10.3.4 Focus group

Finally, six people with epilepsy were approached to participate in the focus group by the MDT gatekeepers (an ESN and a consultant neurologist) and four agreed to participate. The researcher recruited the service providers (see section 5.8.1). Prior to the focus group, a date and time of the focus group was agreed with all participants by the gatekeeper. Prior to the focus group, all participants were informed again of the purpose of the study and offered the opportunity to ask questions before or during the focus group. They were also informed that they could withdraw from the focus group at any stage and decline to answer any question(s) and have the digital recorder turned off without compulsion. The consent form for focus groups (Appendix I) was explained and all participants signed the consent form. This indicated that participants were willing to be interviewed and that the focus group could be recorded. The focus group was held in an allocated room within the research site made available to the researcher.

All participants were informed that the focus group would form part of a doctorate submission with the potential for findings to be published. Participants were asked were they still willing for their participation in the focus group to be used. All participants agreed.

5.10.4 Confidentiality and anonymity

Confidentiality and anonymity are important ethical dimensions in social research. According to Denzin and Lincoln (2005) the most likely source of harm in social science inquiry concerns disclosure of participants' personal information. Confidentiality implies that any personal data that could lead to the identification of the participant will not be reported (Kvale 1996). Bearing this in mind, confidentiality and anonymity were maintained by adhering to the following:

- All questionnaires were anonymous and secured in a locked filing cabinet in a locked room in the School of Nursing and Healthcare at WIT.
- All data was entered into the Statistical Package for the Social Sciences (SPSS) on a desktop PC and password protected.
- All interviews took place individually and in a private room allocated to the researcher by the NECP, with the exception of interviews with policymakers which were nominated in a building and room of their choice.
- The focus group took place in a private room allocated to the researcher by a gatekeeper.
- The tape recording and transcripts of the individual interviews and focus group were stored in a locked filing cabinet in a locked room in the School of Nursing and Healthcare at WIT.
- Any information transferred to a computer was password protected.
- Audio interviews were categorised by a number for the purpose of identification rather than by name. The only person who had access to the tape recordings was the researcher. Supervisors have access to transcript analysis via a CAQDAS programme, NVivo 10.
- At no stage did the participants name appear on the interview tape or the transcripts.
- Each tape recording and printed transcript was given a number for identification purposes only.
- The researcher was the only person who knew these numbers- assurances was given not to disclose this information to anyone.
- Information that might identify a participant was not used in any publications or presentations resulting from the study.
- All data was protected following the Data Protection Acts (2003) and Freedom of Information Acts (1997; 2003).
- Data will be retained only for as long as necessary and in accordance with the WIT Records Retention Policy.

The issues of confidentiality could be problematic if issues revealed during interviews disclosed unethical or malpractice behaviours. However, participants were free to talk to people about their participation in the study, if they so wished.

5.10.5 Concluding comments on ethical considerations

This study explored issues in relation to empowerment and epilepsy service provision and possible issues revealed during interviews such as unethical or malpractice behaviours were anticipated for. In trying to deal with such issues, it was important that informed consent was a continuous process and was (re)negotiated throughout the study. Furthermore, on the advice of the WIT ethics committee, a consultant neurologist and an ESN within the research site were identified to manage unethical concerns or unsafe practices.

5.11 Sampling and recruitment

Sampling is an important step in the research process because it helps to inform the quality of inferences made by the researcher that stem from the underlying findings. The researcher's choices relating to sampling techniques when using a mixed methods research approach involves selecting a sampling design for both quantitative and qualitative elements of the study. According to Kemper *et al.* (2003 p.292) the understanding of a wide range of sampling techniques in one's methodological repertoire greatly '*increases the likelihood of one's generating findings that are both rich in context and inclusive in scope'*. This study used a multilevel sampling strategy that involves the use of two or more sets of samples which were extracted from different populations (Onwuegbuzie and Collins 2007).

Quantitative research ideally involves probability sampling to permit statistical inferences to be made. On the other hand, qualitative research typically involves purposeful sampling to enhance understanding of the information-rich case (Patton 2002). Probability sampling is oriented toward the development of nomothetic knowledge, from generalizations from samples to populations, whilst purposeful sampling is oriented toward the development of idiographic knowledge (Sandelowski 2000). Purposive sampling is a form of non-probability sampling, where people from a pre-specified group are purposely sought out and sampled (Procter and Allan 2006). Indeed, purposive sampling is justified to select individuals, groups and settings that are considered to be 'information rich' and fit the purpose of the study (Robson 2011). However, Sandelowski (2000) argue that purposeful and probability sampling techniques can be beneficial when combined.

Mixed method researchers have 24 sampling schemes from which to choose, 5 probability sampling schemes and 19 purposive sampling schemes (Onvuegbuzie and Collins 2007). There are a range of different approaches to probability sampling such as: simple; stratified; cluster; systematic; and multi-stage random. The approaches to purposive sampling include: maximum variation; homogenous and heterogeneous; theoretical; critical case; confirming-disconfirming; snowball/chain; extreme case; typical case; intensity; politically important case; random purposeful; stratified purposeful; criterion; opportunistic; mixed purposeful; convenience; quota; multi-stage purposeful; and random. All approaches produce different types of sample arrangements depending on the aims of particular studies. Many mixed method studies utilise some form of purposeful sampling (Onvuegbuzie and Collins 2007). This study required two separate decisions: (1) the sampling technique to identify participants and (2) determining the sample size necessary to answer the research objectives (Collins 2010).

5.11.1 Recruitment of sample and issues of bias

The recruitment of the sample (hereon referred to as participants) commenced once ethical approval was granted and permission for access to the research site was given. All attendees of the service were viewed as potential participants, as were the clinical staff of the service. In order to initiate recruitment, I firstly held a number of meetings with the MDT at the research site to discuss both the study aims and objectives, data collection approaches and recruitment of participants. In this context, the MDT members were viewed as a prospective sample and also as gatekeepers to the recruitment of service user participants. In the context of the latter, recruitment of patients who are potentially vulnerable is often done through reliance on the clinical judgement of clinicians rather than a researcher approaching such patients.

Lincoln and Guba (1985) characterise the attributes of the researcher as instrument as responsiveness; adaptability; having a holistic emphasis; focused on knowledge base expansion; and possessing a ‘process’ immediacy, that facilitates adaptation to context and awareness of the resultant biases. Certainly bias can flow from the subjective but the way to deal with this is for the researcher to attempt to be self-aware, self-critical, acknowledge the potential for bias where this might exist and to explain fully the rationale for research decisions and conclusions, honestly detailing the research process that led to such conclusions. Within qualitative research ‘reflexivity’ and auditability are the means through which one attempts to indicate this and thereby demonstrate objectivity. These issues are acknowledged in Chapter 6.

Whilst there is a potential for bias through recruiting via a gate keeper, there were a number of factors in this study that indicated to me, as the researcher as instrument, that this did not significantly bias the results obtained in terms of controlling for bias in the sample. Firstly, the interviews I conducted were with a wide range of service users (from the perspective of qualitative range and typicality of participants) reflected the types of people with epilepsy attending the service (with the notable exception of people with intellectual disabilities – however, this group are likely to have multiple agency involvement and probably have unique issues that would warrant a separate study). Secondly, during the interviews with service user participants there was a wide range of both positive and negative views expressed about the services received and issues of empowerment. Finally, the results obtained within this studywere compared to the broad literature on empowerment within health services and appeared to congruent with a number of themes that can be identified on empowerment.

Purposeful sampling is synonymous with qualitative research and allows the researcher to choose the participants that are likely to generate the most useful data (Patton 1990). In other words, the sampling strategy should be determined by the purpose of the research. The approach taken needs to be one that learns from the experiences of people who are ‘information-rich’ (Patton 1990, p. 169) and who can best help us to understand the research phenomenon being explored (Coyne 1997). For this study participants selected included: people with epilepsy; clinicians; ESN’s; and service user representatives within one specialist epilepsy service. However, it is acknowledged that there are many other stakeholders that hold views in relation to this study’s research questions, aims and objectives such as psychologists, psychiatrists, family members and carers and whilst not interviewed is acknowledged as a limitation of this study.

5.11.2 The participant sample

The first phase of data collection in this study consisted of a survey. The second and third phases of data collection consisted of individual interviews, observation of an epilepsy service and a focus group and the sample was selected using a theoretical purposive sample of service users and providers. Theoretical sampling allows for flexibility during the research process (Glaser 1978, Strauss and Corbin 1990) and is the process of data collection whereby the researcher simultaneously collects, codes and analyses the data in order to decide what data to collect next.

The key criteria for service user participation was that they be currently engaged with the epilepsy service, with a diagnosis of epilepsy, aged 18 year or over. The key criteria for service provider participation was that they were employed by the selected research site as a service provider or a patient advocate employed by Epilepsy Ireland.

The overall participant sample consisted of service users, service providers/policy maker and a patient advocate from Epilepsy Ireland. Firstly, one hundred and two (n=102) people with epilepsy who were attending the service were surveyed. Whilst (n=102) participants completed and returned the questionnaire, eight participants failed to respond to questions in relation to demographics. Sixty-six percent (n=62) of the sample were female and 34% (n=32) were male with eight participants not answering. Participants ranged from 18 to 75 years old (mean age =37; SD 12.9), with 54.5% (n=48) aged 30 to 49, 33% (n=30) aged 18 to 29, and 12.5% (n=13) aged 50 to 75 with eleven participants not answering. With regards to education, 36.4% (n=32) have completed a secondary qualification; 31.8% (n=28), a college degree; 18.2% (n=16) an alternative qualification; 13.6% (n=12) no formal qualification with fourteen participants not answering.

Seven (n=7) service providers, one patient advocate (n=1) and ten (n=10) people with epilepsy were interviewed (see table 5.1). Four (n=4) service users, three (n=3) service providers and one (n=1) policymaker/service provider participated in the focus group (see table 5.2). All samples were selected from one epilepsy service in Ireland and theoretical sampling was the approach used to select and develop the sample.

My initial data collection began with a survey of people with epilepsy’s views with regards to health service delivery in Ireland. Using a sample size calculator, ascertained by a statistician employed as a researcher/ lecturer within the Department of Nursing and Health Care at WIT with no relationship with this research study that in order to report the findings at a confidence level of ninety five percent (95%) and a confidence interval of ten percent (10%), ninety (n=90) completed questionnaires would be required. This was achieved as one hundred and two (n=102) questionnaires were completed and returned by participants, achieving a response rate of sixty six percent (66%).

Developing the theoretical sample and data collection began with service users. The purpose for starting here was to get an initial sense of people with epilepsy's views with regards to epilepsy service delivery. This was reflective of the priorities within the initial research question and the need to develop a 'rich picture' of the situation as required under SSM. Prior to and during data collection, both national and international literature with regards to empowerment, healthcare policy and epilepsy service provision was consulted. This literature, the study's operational definition and conceptual analysis as it related to empowerment along with the findings of the initial survey later informed the development of the individual interview and focus group topic guides[25].

Qualitative samples are usually small in size for a number of reasons and include: (1) if the data is properly analysed, very little new evidence is obtained from additional data; (2) there is no requirement to ensure that the sample is of sufficient size to provide estimates or to determine statistical difference; (3) qualitative data yields rich information, therefore in order to do justice to these, sample sizes need to be kept reasonably small and (4) in terms of resources the management of large sample sizes would be difficult to conduct and analyse (Ritchie and Lewis 2003). The overall sample consisted of current registered service users and service providers. Ten service users and eight service providers were interviewed (see table 5.1). The researcher also recognised that by the final interview data saturation had been reached.

The sample size of focus groups is an important consideration. Whilst some authors suggest that 6-10 is optimum (Morgan 1998, Bloor *et al.* 2001), others suggest a sample size as few as three and a maximum of 12 is sufficient (Tracy 2013). However, Parahoo (1997) argues that, while sample size is an important issue in focus groups, it should not be the starting point. Rather, the purpose for which the participants are recruited should determine the number of potential participants. Therefore, due to a small numbers of service users (n=4) and service providers (n=4) available to participate, one focus group was conducted (see table 5.2). The service users (n=4)

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[25] See Appendix L: Interview topic guide and Appendix M: Focus group topic guide.

whom participated in the focus group did not participate in the one-to-one interviews. However, the service providers (n=4) whom participated in the focus group also participated in the one-to-one interviews.

Table 5.1: Demographic details of participants interviewed

PWE=Person with epilepsy; SP=Service provider

Code	Participant type	Gender	Employment status	Age
PWE 1	Service user	Male	Unemployed	18-29
PWE 2	Service user	Male	Employed	18-29
PWE 3	Service user	Male	Unemployed	18-29
PWE 4	Service user	Female	Employed	30-49
PWE 5	Service user	Male	Unemployed	18-29
PWE 6	Service user	Female	Unemployed	30-49
PWE 7	Service user	Male	Employed	30-49
PWE 8	Service user	Female	Employed	30-49
PWE 9	Service user	Female	Employed	30-49
PWE 10	Service user	Male	Employed	50-71
SP 1	Service provider	Female	Neurology registrar	30-49
SP 2	Service provider	Female	ESN	30-49
SP 3	Service provider	Female	ESN	30-49
SP 4	Service provider	Female	Neurology registrar	30-49
SP 5	Service provider	Female	ESN	30-49
SP 6	Service provider	Female	Patient advocate	30-49
SP 7	Service provider	Female	Consultant neurologist	30-49
SP 8	Service provider	Male	Consultant neurologist	30-49

Table 5.2: Demographic details of participants within focus group

PWE=Person with epilepsy; SP=Service provider

Code	Participant type	Gender	Employment status	Age
PWE 1	Service user	Female	Employed	18-29
PWE 2	Service user	Female	Employed	30-49
PWE 3	Service user	Male	Unemployed	18-29
PWE 4	Service user	Male	Employed	30-49
SP 1	Service provider	Female	ESN	30-49
SP 2	Service provider	Female	ESN	30-49
SP 3	Service provider	Female	Neurology registrar	30-49
SP 4	Service provider	Male	Consultant neurologist	30-49

5.12 Data collection strategy

This study used a mixed method sequential explanatory research design. Sequential mixed method designs involve multiple phases of data collection in which the research purpose, and particular set of research questions, determine the particular sequence

(Creswell and Plano-Clark 2007). The strengths and weaknesses of mixed methods designs have been widely discussed in the literature (Creswell 2003, Creswell 2009). The main strengths of mixed methods include that it is straightforward in nature and is feasible for a single researcher to implement. Limitations include the lengthy time to complete, which has been previously demonstrated by mixed methods researchers (Creswell 2009). Data collection techniques employed in this study included: (1) a literature review; (2) reviewing policy literature; (3) an observation of service operation; (4) a survey of service users; (5) in depth interviews with service users and providers; and (6) a focus group with service users, providers and policymakers. Having considered the methodological issues of priority, implementation, and integration of the quantitative and qualitative approaches, a research plan was devised to conduct the methods and sequence of data collection phases required to answer the research objectives of the study as outlined in table 5.3.

Table 5.3: Data collection methods required to answer research objectives

Objectives:	1. To utilise critical social theory to analyse and define the concept of empowerment in the Irish health service	2. To develop a situational analysis and conceptual model of the service utilising 'Soft Systems' methods with reference to the National Epilepsy Care Programme..	3. To explore and critically analyse organisational issues and human factors on service provision that support or hinder empowerment.	4. To compare the conceptual model of the service with its service operation.	5. To draw wider inferences for the development and operationalization of epilepsypolicy and practice in Ireland.
Methodology					
Literature review.	🟩				
Reviewing policy literature		🟩			
Observation of service operation.	🟩	🟩	🟩		
Survey of people with epilepsy		🟩	🟩		
Interviews with service users and providers.	🟩	🟩	🟩		
CATWOE Analysis.				🟩	
Comparative analysis of situation.				🟩	
Focus group with service users, providers and policymakers				🟩	
Overall analysis.					🟩
Dissertation.					🟩

5.12.1 Literature review

A literature review is a routine component of any research study and an important methodical component. The search strategy focused on identifying national, international literature and published literature with regards to empowerment and epilepsy healthcare**[26]**. A review of the reference sections from recently published journal articles, review articles, and textbook chapters were also conducted in order to identify other pertinent publications. The search revealed that considerable attention has been given to the concept of empowerment in recent years. Accessing this literature identified knowledge in relation to the origins of empowerment; an understanding of empowerment; concepts related to empowerment; and antecedents and consequences of empowerment from service users and providers perspective. However, a paucity of literature in relation to empowerment and epilepsy healthcare was identified (see Chapters 2 and 3).

5.12.2 Policy literature review

For this study national and international health policy with regards to empowerment and chronic illness was undertaken[27]. It is argued that studying health policy encourages an in-depth understanding of today's constantly changing healthcare environment (Fatchett 1994; 1998; 2012). However, in the absence of critical thinking, the desired learning improvements may not be achieved (Goodman 2011). Habermas identifies that power relations are inherent in policy processes (Morrow and Brown 1994, Mill *et al.* 2001). With this in mind, CST as a methodological approach to policy analysis is inclusive of different forms of knowledge. According to Fischer (1995 p.6) the essence of a critical theory approach is one of '*integrating the normative evaluation of a policy's goals with the kind of empirical work already characteristic of policy evaluation'*. Indeed, a critical policy analysis exposes the ideologies and values underlying policy issues and their proposed solutions, and the inclusiveness or exclusiveness of the policy debate (Forester 1993, Fischer 1995). Moreover, it exposes the reality of organisational processes, particularly as they relate to how policies are experienced by people in their daily environments.

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[26] See Chapters 2, 3 and 4: Theoretical and empirical literature in relation to empowerment and epilepsy healthcare.

[27] See Chapter 4: Towards an empowered perspective for epilepsy policy and care provision.

5.12.3 Observation of service operation

Observation allows the researcher to capture the actions, behaviours and use of language in a given situation and expose the reality of a given situation (Borbasi *et al*. 2005). According to Robson (2003 p.310) observation '*is an appropriate technique for getting at real life in the real world'*. Indeed, a major advantage of observation as a data collection technique is its directness. It can be dichotomised as formal or informal observation. Informal approaches are less structured and allow the observer considerable freedom in what information is gathered and how it is recorded.

The observation of services involved general observations of behaviour and talk watching and documenting what any participant did and said, present over a 20 day period (May and Pope 1995). None of the service users interviewed were observed. Participants were shadowed for periods of 30 minutes to 2 hours over the 20 day period during the survey administration and field notes were taken. In total, 48 hours of observation were conducted. The purpose of the observations of service included: (1) to enhance an understanding of empowerment within epilepsy services using one specialist epilepsy service in Ireland as an exemplar; (2) to complement interview data by exploring in greater detail the range of factors that support or hinder empowerment for people with epilepsy and service providers; (3) to explore the similarities and differences between the interview data and observation data; (4) to use observation to inform subsequent interviews; and (5) discover the context in which care is given.

Whilst a positivist approach suggests that a researcher should maintain a sense of detachment from the research subject in order to preserve objectivity during fieldwork (de Laine 2000), the naturalistic paradigm argue for researcher interaction and involvement in observation, asserting that the influence of 'self' within the fieldwork is integral to the process (Mulhall 2003). However, the role of 'self' within the research has generated a considerable amount of literature (Coffey 1999, Borbasi *et al.* 2005, Roberts 2007), suggesting that it is of considerable consequence. For instance, Cheek (1996) contended that the 'reality' contextualised by a researcher in the field is a constructed reality, composed of a number of alternate viewpoints. The written testament of the researcher represents a reality framed by the researcher, the research participants and the reader of the textual account. Thus, the researcher can only present their personal interpretation of the situation and that this must not be assumed to be authentic.

There is an understanding that qualitative studies are shaped not only by the researcher's participation in the field but also by their use of reflection on the data, by their cultural background, experiences and beliefs (Van Maanen 1995). In this context, the use of reflexivity allowed me the opportunity to recognise and accept and account for the influence of 'self' on the research. I recognised that my personal interpretation and representation of realities might not symbolise those of the participants. Therefore, validation of personal perceptions was sought from the participants. Additionally, memos were recorded during periods of observation to document personal reflexive comments.

Accurate portrayal of the views of participants was something which I had to grapple with, remaining objective so that personal interpretations did not obscure the participant's reality. Undertaking observation can account for difficulties such as maintaining objectivity (Gerrish *et al.* 2003). Therefore the observer must find equilibrium between involvement and indifference, familiarity and strangeness, and familiarity with remoteness. According to Robson (2011) the observer must possess great sensitivity and personal skill to obtain meaningful data.

The researcher must be aware that too much time spent writing notes can negatively impact the ability to become immersed in the experience (Emerson *et al.* 2007). Therefore, the initial plan was to make simple notes of the observations in real time and to add detail as soon as possible afterwards. In order to maintain simplicity, there were no predetermined set of codes devised and field notes were recorded using a pen and pad. Key observational data included: facial expression; gestures; movements of various actors involved (including people with epilepsy, service providers, members of the MDT, and family/carers (Silverman 2008); physical environment (layout of settings and décor); space and resources (room allocation) (Mulhall 2003). These types of observations were recorded and used to interpret situations as they arose. Each field note was maintained separately from the others, and would have a set layout with the day and date, and the pseudonym of the participant. In this way, the use of observation provided a holistic view of the service users, providers, members of the MDT, family and carers within the epilepsy service. Arguably these observations were valuable and played a role in the overall context of analysis. However, limitations of observation include the substantial time and commitment required in order to gather sufficient data of robust quality for analysis by the researcher (Robson 2011).

5.12.4 Survey

A survey design is highly popular among researchers and can involve conducting and analysing first quantitative and then qualitative data (Creswell 2009). According to Robson (2003) survey questions should be designed to help achieve the goals of the research and in particular, to answer the research questions.

In this study, a cross-sectional descriptive survey design involving both quantitative and qualitative items exploring the views of people with epilepsy in Ireland with regards to health service delivery was used. An extensive review of validated tools was undertaken as to source a validated tool which would obtain the correct data to answer the research questions. In this regard, permission was sought and granted to use and adapt Poole et al.'s (2000) questionnaire (Appendix J) entitled 'Patient's perspectives of services for epilepsy: a survey of patient satisfaction, preferences and information provision in 2394 people with epilepsy'. Poole *et al.'s* (2000) questionnaire was divided into nine sections and consisted of 70 questions with regards to (1) epileptic seizures; (2) medications; (3) satisfaction with epilepsy care; (4) visits to the hospital, GP and other healthcare providers; (5) preferred and actual source of care; (6) information provision; (7) services for the newly diagnosed; (8) services for people with epilepsy under 19 years old (9) and socio demographic details.

The PAC advised that Poole *et al's* (2000) questionnaire consisting of 70 questions was too long and suggested the use of a shorter questionnaire for patients to complete. An adapted questionnaire (Appendix K) for use within an Irish context was divided into seven sections and consisted of 50 questions with regards to: (1) medications; (2) satisfaction with epilepsy care; (3) visits to the hospital (for the purpose of this study hospital care/visits to the hospital refers to the epilepsy specialist service outpatient department), GP and other healthcare providers; (4) preferred and actual source of care; (5) information provision; (6) services for the newly diagnosed; and (7) socio-demographic details.

Only twenty-seven participants (n=27, 26%) completed all questions within the questionnaire. In SPSS, missing values were coded by using numbers 999 and valid percent was reported throughout the study. Whilst the survey tool did not explicitly look at measuring empowerment, the participants views of service delivery was considered important to examine before engaging in interviews relating to empowerment. The data from the survey provided a basis for an evaluation of current practice and helped inform the development and focus of the instruments (observation and interview guides).

5.12.5 Individual interviews

Interviews are described as a fundamental process through which knowledge about the social world is constructed in normal human interaction (Rorty 1980). In depth interviews were used because they are more consistent with a CST approach. A critical 'dialogue' can provide the means of collectively generating theory by providing conditions which help participants critically reflect on empowerment within the socio-historical context[28]. According to Lather (1986 p.266) this allows the researcher to consciously use the research process: '*to help participants understand and change their situation…. for the purpose of empowering the researched'*.

Researching sensitive areas can be challenging and good rapport needs to be developed before quality expression and in-depth discussion of the substantive areas can be achieved (Wengraf 2001). Therefore, each interview began with a general discussion to establish rapport. Time was spent answering questions regarding the study and the consent process. Each participant was given assurance regarding confidentiality at the beginning of every interview. Each interview started when the participant indicated that they were ready to begin. In this study, an unstructured in-depth interview was used where I used ground mapping questions to allow participants to express issues.

5.12.5.1 The interview topic guide

An interview topic guide is strongly recommended and should be given careful consideration when been designed (Arthur and Nazroo 2003). It provides documentation of subjects to investigate that serves as an interview agenda, guise, or *aide-memoire* (Burgess 1984). It ensures that relevant issues are covered

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[28] See Section 5.4: The potential of CST as a metatheory framework for the study of empowerment and epilepsy healthcare

systematically and with some uniformity, whilst equally allows the participant flexibility to pursue salient details that are of interest to them (Arthur and Nazroo 2003).

An interview topic guide (Appendix L) was designed based on a concept analysis and review of empirical literature[29] which was carried out prior to data collection and questions and statements were formulated as outlined by Legard *et al.* (2003). The interview topic guide was piloted with a colleague in order to experience its administration. As a result of this exercise, no adjustments were deemed necessary. In addition, drawing from the concepts of theoretical sampling, each interview was subjected to a preliminary 'listening' analysis to identify issues that might need follow up with another participant in a subsequent interview. The professional/organisational position of the service providers also suggested that certain issues needed to be followed up with some more than others. For example, the questions posed to the ESN's focused more on 'professional' issues and internal relations with management whilst neurology doctors focused more on issues of 'political' relations with management and other services. However, the essential components of the guide remained unchanged.

In all, ten (n=10) individual interviews of service users were conducted followed by seven (n=7) service providers and one (n=1) patient advocate. The interviews took place in various interview rooms attached to a clinical area in one hospital setting. The duration of interviews varied between 30 and 60 minutes. The interview schedule consisted of open ended questions that gathered data on the perceptions and satisfaction of the services provided; an understanding of empowerment; barriers and facilitators to empowerment; and changes that participants felt were necessary in order to facilitate empowerment within the Irish epilepsy service. Permission to tape record interviews was given by all participants. All interviews were transcribed by myself and imported into NVivo 10. As a result of the interview process, themes emerged and subsequent questioning was informed as a result which formed further discussion for remaining individual interviews and focus group.

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[29] See Chapter 2: The social space of empowerment within epilepsy services: The map is not the terrain.

5.12.6 Focus group

A focus group can be defined as a small group of people who interact with each other and explore a pre-defined topic (Bowling 2009). The strengths of focus groups include: (1) a highly efficient and effective way of gathering the opinions of a number of participants (Robson 2011) (2) a means of listening to the perspectives of key stakeholders and consumers alike, learning from their experiences of phenomenon (Halcomb *et al.* 2007); (3) compared to one-to-one interviews participants within focus groups are serendipitously empowered by the process (Parahoo 1997) and (4) it is easier for participants to disclose attitudes and practices in an environment that is open and secure with peers (Kitzinger 1996, Gomm 2008). Thus, focus groups offer the possibility that one unexpected comment from one individual will lead to deeper insights from others as they explore and clarify their views (Kitzinger 1995). The purpose of the focus group was to share findings of the data collected from the survey, one-to-one interviews and observation of service and explore with the participants potential service improvements and desirable and feasible changes that are needed to facilitate empowerment within the Irish epilepsy service.

Tracy (2013) advocates that the *in vivo* characteristics of the focus group can be transformative for participants, in that they raise an awareness and understanding of important topics, as well as obtaining from them data for research purposes. All of the service users and providers in this study were part of the same epilepsy service. Their views and experiences of empowerment and disempowerment were discussed through the use of focus groups, which included group dynamics and a discussion forum. However, according to Redmond (2000) a weakness of the focus group can arise where a dominant participant overshadows the contribution of other participants. It is necessary, therefore, to be aware of this risk, and to manage the focus group so that all individuals are facilitated to contribute equally. In addition, some participants may require encouragement and sensitivity in order for their views to be elicited and facilitation of the focus group requires expertise (Kitzenger 1996, Robson 2011). As lead facilitator, I found that my prior experience in undertaking research along with my experience as a nurse and lecturer was beneficial in the coordination and management of the focus group. I was familiar with managing group discussions and included both service users and providers into a group dynamic.

5.12.6.1 Focus group process

Initially it was important that I consult with other more experienced researchers, from whom I gained much insight into the organisation and facilitation of the focus group. The help and support of my research supervisors was invaluable and encouraged reflexivity and deeper analysis throughout the process.

The administration and planning of focus groups is an important part of the research process. Roberts (1997) comments that the ultimate success or failure of data collection hinges on careful planning and facilitation. According to Polit and Hungler (1997) qualitative researchers should strive to collect data in naturalistic and realistic settings. With this in mind, one of the gatekeepers, an ESN within the service facilitated the logistics of the focus group. This gatekeeper identified and recruited service users that met the inclusion criteria. An information leaflet outlining the purpose of the focus group was supplied to all that was willing to participate and the gatekeeper organised a date, time and venue within the research setting that suited all participants. The gatekeeper also participated in the focus group.

Before the focus group began all participants were informed of the purpose of the focus group, and reminded about the ethical principles, including the right to withdraw from the study at any stage. Any questions from participants were answered and written consent was obtained to proceed with an audio-taped focus group interview. Each participant was also given assurance regarding confidentiality. The focus group began when all participants indicated that they were ready to begin.

5.12.6.2 Focus group topic guide

As previously discussed the use of a topic guide in qualitative research is strongly recommended. The focus group topic guide (Appendix M) was designed based on the literature and the findings of the survey and individual interviews[30]. Robson (2011) suggests that typically fewer than 10 questions can be asked in an hour. The sequencing of the questions is important, and those questions requiring more thought and introspection should be left until the participants become more vocal and relaxed.

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[30] See Chapter 2: The social space of empowerment within epilepsy services: The map is not the terrain. See Chapter 7: Epilepsy services in Ireland A survey of people with epilepsy in relation to satisfaction, preferences and information provision. See Chapter 8: Issues of empowerment within Irish epilepsy services using one specialist service as an exemplar: Service users and providers perspectives.

Initial questions were open allowing flexibility for participants to pursue salient ideas and issues that were of interest to them. The topic guide was used as a reminder of issues that needed to be explored with regards to empowerment within epilepsy healthcare. The focus group guide providing structure at the start of the interviews, but once the participants started talking and thinking about empowerment it became less valuable. At the end of the focus group all participants were thanked and provided with information regarding the completion timeframe.

5.13 Issues of quality: Validity, reliability and trustworthiness

The issue of quality in qualitative and quantitative research is a concern and source of intense debate within nursing literature (Lincoln and Guba 1985, Creswell 1998, Polit and Hungler 1999, Seale 1999, Boyton and Greenhalgh 2004, Polit and Beck 2008). Issues of quality in this study are now explored.

5.13.1 Issues of quality in quantitative research: validity and reliability

In quantitative research, validity and reliability of a survey instrument is essential for reducing errors that may occur as a result of measurement problems in the research study. While validity refers to whether a measurement instrument accurately measures what it is supposed to measure (Polit and Hungler 1999), reliability denotes the measurement is consistent and accurate (Polit and Beck 2008).

An extensive review of validated tools was undertaken to answer the survey research questions. In addition permission was sought and granted to use and adapt Poole *et al.'s* (2000) questionnaire. Whilst no reports of validity and reliability from other studies in relation to Poole *et al's* (2000) questionnaire appear to exist, content validity pertaining to the adapted questionnaire items was sought from a panel of experts with previous research experience. This panel of experts included three ESN's, one consultant neurologist; a statistician; and two academic research personnel involved in previous research. The experts reviewed the questionnaire in order to assess whether the questions were relevant to people with epilepsy. Subsequently some questions were omitted from the survey tool as they were not deemed relevant within an Irish context. For example, Poole *et al's* (2000) questionnaire was divided into nine sections and consisted of 70 questions. The PAC committee and the panel of experts acknowledged that the time frame necessary to complete all the questions in Poole *et al's*. (2000) questionnaire was not feasible in particular within the OPD. As a result the adapted questionnaire was divided into five sections and consisted of 50 questions. Sections omitted included questions in relation to epileptic seizures; medications; services for the newly diagnosed; and services for the people with epilepsy under 19 years old.

A pilot study was undertaken to test the suitability of the instrument and identify potential and actual problems with data collection and to examine analytical strategies (Polit and Beck 2006). With this in mind, the adapted questionnaire was piloted with a group of service users (n=10) to ensure adequacy and relevance of questions. Most of the suggested changes from the pilot study referred to minor editing changes with word changes and revision of the overall layout which were amended prior to the main study. The layout of the questionnaire was changed to enable the questionnaire to be better understood and easier to complete for participants. It is argued that the layout and general appearance of the questionnaire plays an important role as to whether a potential participant will fill out the questionnaire (Boyton and Greenhalgh 2004). The results of the pilot survey helped to establish stability and internal consistency, reliability, face and content validity. Also, the PAC converted the questionnaire into the hospital format and the questionnaire was completed in 30 minutes or less.

The most widely accepted statistical measurement of internal consistency reliability is Cronbach's (1951) Alpha co-efficient. Cronbach's Alpha measured the internal consistency of the items in the questionnaire and demonstrated good internal consistency, with a reported Cronbach's alpha coefficient of 0.7, which validated that the use of the questionnaire for people with epilepsy (n=102) yielded consistent results.

5.13.2 Issues of quality in qualitative research: Trustworthiness

The issue of quality in qualitative inquiry is a concern and has been a cause for ongoing debate within nursing literature. Terms such as rigour, trustworthiness, credibility, validity, reliability, among others are used to refer to the issue of quality within qualitative research. Lincoln and Guba (1985) substituted the terms validity and reliability with the concept trustworthiness. A trustworthy study is truthful and consistent and trustworthiness depends on how the research process has been carried out and how closely the findings represent the experiences of the participants (Clayton and Thorne, 2000). Indeed, trustworthiness of qualitative research can be established by using four strategies: (1) credibility; (2) transferability; (3) dependability; and (4) conformability (Lincoln and Guba 1985, Creswell 1998).

5.13.2.1 Credibility

Credibility is defined as the extent to which data and data analysis are believable and trustworthy. According to Lincoln and Guba (1985), gaining feedback on the data, from the participants themselves, is one method of increasing credibility. With this in mind, constant feedback was advocated during the interview process. In addition, the focus group enabled the researcher explore feedback on the findings of the previous data, and gain interpretations and conclusions from the participants themselves. Thus, this enabled meeting criteria that Fay (1977 p.218) identifies as essential for the development of emancipatory knowledge through the processes of '*reciprocal reflexivity and critique'*. Indeed such mutual negotiation of meaning and power in research design, allows the researcher to consciously utilise the research process '*to help participants understand and change their situation, for the purpose of empowering the researched'* (Lather 1986 p.266).

5.13.2.2 Transferability

Transferability is considered a major challenge in qualitative research however a researcher can enhance transferability by detailing the research methods, contexts, and assumptions underlying the study. According to Seale (1999 p.45) transferability is achieved by *'providing a detailed rich description of the settings studied to provide the reader with sufficient information to be able to judge the applicability of the findings to other settings that they know'.*

This study has adopted a SSM approach[31] and therefore the researcher has provided a rich picture of the problem situation[32], so that data and description speak for themselves in order to enable the reader to appraise the significance of the meanings attached to the findings and make their own judgement regarding the transferability of the research outcomes.

5.13.2.3 Dependability

Dependability is the consistency of observing the same finding under similar circumstances. According to Seale (1999), dependability can be achieved through

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[31] See Section 5.7 and a critical debate of SSM and its suitability for the study of empowerment and epilepsy healthcare.

[32] See Chapter10, Section 10.3, figure 10.1, presenting the rich picture of empowerment within Irish epilepsy services.

auditing which consists of the researcher's documentation of data, methods and decisions made. Auditing for dependability requires that the data and descriptions of the research should be elaborate and rich. It may also be enhanced by altering the research design as new findings emerge during data collection. This was achieved by the use of questions that were clear and consistent with the study's objectives. In addition, appropriate settings, and appropriate participants were used for data collection. Moreover, supervision occurred regularly throughout the research process.

5.13.2.4 Confirmability

Confirmability is the degree to which the research findings can be confirmed by others. Seale (1999) argues that auditing could be used to establish confirmability in which the researcher makes the provision of a methodological self-critical account of how the research was done. Truthfulness is established when the participant's perspectives have been clearly and accurately presented, and confirmed when the situation is recognised by others. To accomplish this, the researcher firstly acknowledged her own influence on the data, made her own presuppositions explicit by continuous self-critique and self-appraisal. In addition, NVivo 10 allowed the researcher to audit the coding process and as a result more robust interpretations of data were achieved[33] (Koch and Harrington 1998).

5.14 A consideration of reflexivity

Maintaining a close relationship within the research process and immersion in the environment provides contextual richness as a basis for checking, questioning and theorizing, therefore establishing credibility (Smyth 2006). Indeed, personal reflexivity involves acknowledging and reflecting upon ways in which the researchers own beliefs, experiences, values, culture, gender and political influences have shaped the research process (Wolfe 2003).

Hammersley and Atkinson (1995) argue that the researcher needs to recognise the reflexive nature of the social research endeavour. According to Johnson *et al.* (2001) the reflexive critique needs to consider research techniques and procedures as an essential precondition in qualitative research to establish rigour. Thus a critical reflection on one's self and one's relationship to the research process acts as an essential element in

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[33] See Chapter 6, Section 6.4.3 and querying the data.

maintaining its integrity and protecting the validity of the findings. Reflexivity in this context has two components-the interaction of the researcher with their choice of research subject and the interaction of the researcher with those who are the subject of that research (Kleinman and Copp 1993). The interpersonal responses that result from this interaction, what is termed *reactivity* may be a significant influence on the research process and its outcome (Patton 1990).

Patton (1990) does not appear to consider reactivity in terms of the practical difficulties of dealing with reactivity. For instance, one may be *pulled* by one's professional background, should that be the same as those who are under observation, towards bias. This may be indiscernible since personal and professional values can be enmeshed and operate at an unconscious level. Thus, it can be more difficult to be aware of and take account of such influences in order to deal with any bias that may result. Alternatively, such professional bias could also be termed 'insight' and alert one to issues that researchers without a sympathetic professional background might miss. In this context, professional bias works as a positive in terms of understanding what one hears and observes.

During data collection, occasionally, I felt saddened; provoked by the level of disempowerment experienced by people with epilepsy and service providers. Participants were familiar with the experience and 'struggle' of disempowerment and if they were not feeling disempowered at the time of the interviews and focus group, they had previous experiences so they could relate to it.

People with epilepsy detailed their incidences of disempowerment unaware of the impact they were having on me. Indeed, their experiences were very disappointing for me from the perspective of being a nurse, in particular when their experience was a consequence of barriers within the epilepsy services. At times I felt embarrassed, as I found it difficult to separate from my own nurse identity. I was also shocked by how little I knew of the plight of people with epilepsy in relation to their lack of autonomy, control, and empowerment. I would have considered myself patient-centred, with many years of experience. However, I became more consciously aware of the struggles that people with epilepsy endure. Indeed service providers may never acknowledge these struggles whilst providing care for a person with epilepsy. I became cognisant that fellow colleagues like my-self perhaps do not consider the challenges that people with epilepsy very often face.

Service providers also demonstrated their sense of frustration with regards to empowerment within epilepsy healthcare and how restricted they feel in terms of their own identity within the service, the care that they are unable to provide to people with epilepsy and their sheer lack of power in relation to making changes that are needed within the service. Service provider's level of frustration echoed loudly as it highlighted my own previous feelings of frustrations with regards to healthcare delivery throughout my own career as a nurse.

Disentangling 'insight' from bias can be a difficult task. For example, during data collection within the epilepsy service I identified with the service providers as a nurse. This gave an insight into their frustrations, because of similar experienced frustrations. However, it might have led to a bias in a selective/focused observation of those issues that I found frustrating. This was dealt with in a number of ways. One was through discussion with colleagues. Philips (1990) argues that the qualitative researcher needs to subject their views to the critical scrutiny of informed others, what he refers to as acceptance of the 'critical spirit'. Therefore, a regular dialogue with colleagues about the project was conducted. This proved helpful in terms of clarifying what research approach to take in the early stages of the project and, combined with written reflection understanding the dynamics involved. The second was self-reflection and consciousness of separating observation from interpretation within note taking in the field. Finally, considering personal influences, if any, that may account for the phenomenon.

Miles and Huberman (1994) suggest that one should keep a journal of one's research experiences and thoughts. Consequently one needs to consider a reflexive account in the reporting of a study. Schön (1991) suggests a number of areas that one may reflect upon of relevance to the research endeavour, including strategies and theories held about behaviour and feelings about a situation that led them to act in a particular way or the way they have constructed a problem, or the role which they have constructed for themselves in a particular situation. Schön's (1991) ideas, with which I was already familiar prior to this research, served to provide a focus around which I could formulate a strategy to deal with the issues of bias and insight consequent of reactivity.

I decided to keep a journal in which I would record my thoughts on the study as it progressed. For example, when taking observational notes writing down memos in a margin of my note book as thoughts occurred to me and taking five to ten minutes after an interview to write up a reflection and became a reflective diary of thinking (Rolfe 2006) in my ongoing analysis of the data. This approach fits with current discussions on CST and reflexivity[34]. Indeed, one observation recorded was that neither service provider's nor people with epilepsy were consciously aware of each other's level of disempowerment or frustration. Freire maintained that oppression locks both the oppressed and the oppressor into a relationship with each other (Roberts 2007) and draws a link between this mutual relationship and dialogue, '*a dialogical relationship'…'open to discovery and to knowing more'* (Freire 1998 p.99). The emphasis on this relationship with each other is not merely significant in terms of the social aspect of individual identity but it is also a feature of how we come to know the world:

> '*Awareness of the world, which makes awareness of myself viable makes unviable the immutability of the world. Awareness of the world and awareness of myself make me not only a being in the world, but one with the world and with others. It makes me a being capable of intervening in the world and not only of adapting to it. That is why not only do we have a history but we make our history, which equally makes us and thus makes us historic' (Freire 2004b p.15).*

Confirmability is the ability of the research process to accurately expose the perceptions of stakeholders and not to rely on a researcher's own construction to the detriment of the others (Miles and Huberman 1994). This requires a researcher to remain self-aware that personal beliefs might influence the research and its credibility. The onus is on a researcher to ascertain whether interpretations are correct, adjust any deficiencies, add new material if it is relevant to do so, remedy misinterpretations and clarify any inconsistencies (Miles and Huberman 1994). This was tracked effectively using NVivo memos[35].

Dependability is tightly bound to confirmability, and both aspects of the inquiry process should be auditable by reviewers of the study. Thus, the planning and process of the research include justification of a researcher's decisions and actions. The researcher needs to ensure that the research activity is enhanced by raising the quality of researcher-respondent interaction, ensuring that the language used in each question is clear and unambiguous of meaning. Therefore, aspects of Habermas's communicative action

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[34] See Section 5.2: CST as a metatheory framework for the study of empowerment within epilepsy healthcare.

[35] See Chapter 6, Section 6.3.1.1. and familiarization and memo writing.

theory were engaged and these facilitated attempts to ensure that language was free from coercion, unambiguity and authority throughout the research process[36].

5.15 Chapter summary

The methodological approach used for this study of empowerment in epilepsy services using one specialist service as an exemplar have been outlined. Firstly, the value of CST as an alternative approach for the study of empowerment and epilepsy healthcare is explored. Most debate surrounding empowerment and epilepsy healthcare have been guided either implicitly or explicitly within a positivist or constructivist philosophy. The merits and limitations of these frameworks along with CST have been outlined. The philosophical principles of CST merit exploration of service user-service provider empowerment within epilepsy healthcare. For example, CST offers a framework that can explore empowerment within epilepsy healthcare, through critical self-reflection that examines and challenges the liberal ideological basis of inquiry, knowledge, theory development and practice. It can enable service users and service providers to challenge the traditional norms, in order to uncover the hidden meanings and constraining socio-political barriers to optimal empowerment (Stevens 1989). In the absence of such critiques we run the risk of maintaining the status quo, inadvertently reinforcing patterns of power and forms of oppression enacted individually and institutionally. Arguably, greater depth and explanations of empowerment within epilepsy healthcare can be explored from a CST perspective.

This Chapter also emphasises the philosophical, methodological and practical aspects of systems theory and SSM. SSM is a problem solving methodology in a systems context approach. It analyses human activities as systems and subscribes a solution that will address the whole situation and not just the specific problem. SSM has proven itself as a flexible evaluation and improvement tool for 'wicked' problems. It has been used in several aspects of healthcare, from addressing problematic situations at an organizational level to determining the early requirements for clinical information systems. Therefore, SSM can be described as a holistic and systemic approach. Indeed, epilepsy healthcare represents a complex social reality in part due to the 'micro', 'meso' and 'macro' levels of power that exist. Arguably, in relation to this study of empowerment and epilepsy

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[36] See Section 5.3.2 and Habermas's Theory of Communicative Action.

healthcare, systems theory and SSM has the potential to provide an opportunity to engage with the ‘micro’, ‘meso’ and ‘macro’ levels of power, and empower both people with epilepsy and service providers.

Finally, an emphasis on the ethical considerations, data collection, reliability and validity are explored. Central to this study was the objective of maintaining the highest standards of scientific rigor, thus ensuring an ethical sound and robust endeavour. In this context, this Chapter provides a reflective section that provides insight into my thoughts and feelings during this stage of the process. Data analysis and issues of consistency in coding are presented in the next Chapter.

CHAPTER SIX

Process of Investigation: Data analysis

6.1 Introduction

Data analysis in a mixed method study can be complex because the researcher has to be adept at analysing both quantitative and qualitative data as well as integrating the results in *'a coherent and meaningful way that yields strong meta-inferences'* (Onwuegbuzie and Combs 2010, p.398). This study yielded quantitative and qualitative data through the use of a survey, interviews, observation of service, and a focus group. With this in mind, this Chapter describes the process of data analysis which occurred sequentially in two phases (in which the quantitative analysis phase preceded the qualitative analysis phase) (Onwuegbuzie and Teddlie 2003).

Section 6.2 describes the analysis of quantitative data. In section 6.3 qualitative data analysis and issues of procedure are discussed. The five stages of Ritchie and Spencer's (1994) Framework Analysis/Approach are detailed. Section 6.4 reflects on the experience of using a CAQDAS programme, NVivo 10, when used in conjunction with the Frameworks approach. This Chapter concludes in section 6.5 by outlining some benefits for using a CAQDAS programme.

6.2 Quantitative data analysis

Quantitative data analysis is described as the systematic organisation and synthesis of research data aimed to address the research question (Polit and Beck 2006). The findings of a survey identifying the views of people with epilepsy with regards to health service delivery in Ireland[37] was analysed using SPSS Version 21.0 with responses to open-ended questions analysed using a thematic content analysis (Elo and Kyngas 2008).

A statistician was consulted during the design and analysis of the questionnaire and statistical analyses included a standard reliability analysis of the questionnaire items, in order to confirm suitability of the questionnaire within an Irish setting. For the analysis of satisfaction with primary and hospital care, only participants who had attended their GP or a doctor at an epilepsy specialist centre in one of the specialist centres in Dublin, in the last 12 months were included. Responses were measured by calculating the

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[37] See Chapter 7: Epilepsy services in Ireland: A survey of people with epilepsy in relation to satisfaction, preferences and information provision.

proportion of responses that indicated satisfaction such as '*very satisfied', 'fairly satisfied'* and lack of satisfaction such as *'not very satisfied'* and '*not at all satisfied'*. Only twenty-seven participants (n=27, 26%) completed all questions within the questionnaire. Valid percent was reported throughout this study.

Careful examination of the inputted information for values that appeared to lie outside the normal range was undertaken (Polit and Hungler 1999). Descriptive analysis of the data was expressed as means (±standard deviation) and percentages. Participants were grouped by age and gender and chi-squared tests were used to compare findings. The level of significance was taken as $P < 0.05$. This value is increasingly considered the maximum acceptable rate for Type I error (Bordens and Abbott 2007). In addition, internal consistency reliability was also undertaken[38].

6.3 Qualitative data analysis and issues of procedure

According to Marshall and Rossman (1995) qualitative data analysis is a process of bringing order, structure and meaning to the mass of collected data. The researcher is required to be alert, flexible and positively interact with data collected (Corbin and Strauss 2008). There is often no clearly agreed approach to qualitative data analysis (Robson 2003) and often based on epistemological assumptions about the nature of qualitative enquiry and the aims and focus of the analytical process (Spencer *et al.* 2003).

Many different approaches to analysis exist including: grounded theory; content analysis; thematic analysis; ethnography; adaptive theory; and frameworks analysis/approach. Whilst many approaches to analysis are diverse, Miles and Huberman (1994, p. 9) identify recurring features in the steps of analysis between the various approaches including: (1) affixing codes to the initial observations and interviews; (2) making comments, reflections and memos; (3) sorting through the materials trying to identify similar phrases, relationships between the variables, patterns, themes, distinct differences between sub-groups and common sequences; (4) isolating these patterns and processes, commonalities and differences so that they can be taken out to the field to help focus the next wave of data collection; (5) gradually elaborating a small set of generalizations that cover the consistencies discerned in the database and (6) linking these generalizations to a formalised body of knowledge in the form of constructs or theories.

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[38] See Chapter 5, Section 5.13.1 and issues of quality in quantitative research: validity and reliability.

A qualitative methodology based on Ritchie and Spencer's (1994) Framework Analysis/Approach was used (sometimes known as Frameworks). '*Frameworks*' involves five stages: (1) familiarisation with the data; (2) identifying a thematic framework; (3) indexing the themes; (4) charting those themes into a hierarchical framework and finally (5) mapping and interpretation of those themes. Data management and analysis for this study was facilitated using a CAQDAS programme- NVivo 10.

The Frameworks Approach is particularly suited to the analysis of cross-sectional descriptive data, enabling different aspects of the phenomena under investigation to be captured (Ritchie and Lewis 2003). Its emphasis on 'charting' and 'mapping' means that researchers' interpretations of participants' experiences are transparent (Ritchie and Lewis 2003). The interconnected stages within the Frameworks Approach explicitly describe the processes that guide the systematic analysis of data from the development of descriptive to explanatory accounts. Overall, the significant advantage of the Frameworks Approach is that it is specifically developed to provide a robust interpretation of qualitative data that can be used to inform policy; one of the key aims of this research in terms of facilitating empowerment within service development.

6.3.1 Qualitative data management and analysis-The frameworks approach

The interconnected stages within the framework approach explicitly describe the processes that guide the systematic analysis of data from the development of descriptive to explanatory accounts. These are now explored.

6.3.1.1 Familiarisation

Familiarization refers to the process whereby the researcher becomes familiarised with the data collected often described as a process of '*immersion*' (Ritchie and Spencer 1994 p.179). This process began once each interview was conducted by listening to each audio recording and reading all notes that were made during the observation of service and reflections documented during the interviews. Analysis began with the creation of a new project entitled 'Empowerment within Irish epilepsy services'. From here two source folders were created - for interview and focus group transcripts (see Appendix L and M) and audio files. At different stages during data collection, audio recordings, transcripts of audio recordings, notes of observation of service, reflection notes recorded after each interview were imported into NVivo 10. Each entire transcript was read over several times comparing them to the audio recordings. This facilitated familiarity with the data. Listening to the interviews and focus group gave a sense of what was of concern to participants, as well as highlighting the emotional ambience within specific interviews such as their frustration, vulnerability, fears, or hope.

Once all data was imported it was at this point that a number of analytical options within NVivo were available to be used. NVivo 10 allowed for classification of information in relation to an individual case (that is each interview). The classification function was used to record descriptive information pertaining to each interview (e.g. participant type, age, gender, employment status, and healthcare professional type). This facilitated future analytical procedures such as asking questions of the data and making constant comparisons to advance theoretical development[39]. Comparative analysis was undertaken by adopting 'selective coding', derived from Grounded Theory. Selective coding is described by Strauss and Corbin (1990, p.116) as a '*process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development'*. Whilst Maggs-Rapport (2001), argue that researchers should firmly ground themselves within one approach if their research is to have validity, Johnson *et al*. (2001) state that absolute conformity to a given research procedure does not necessarily guarantee rigour, but rather a sense of procedural security and rigidity in the research process. They argue that the reality of the research endeavour in the field, dealing as it does with the realities of everyday life, often means that the researcher has to take a pragmatic as opposed to a 'pure' view in terms of methodological approach. The essential condition for rigour, they believe, is not methodological purity, but rather the reasoned rationale for combining methods as it appeals to '*acceptable understandings of validity, honesty, avoidance of deception and the provision of relevant evidence'* (Johnson *et al*. 2001, p.248). Figure 6.1 displays an extract from a NVivo case profile in relation to the one-to one interviews and observation of service.

It was during the familiarization stage that a research diary within NVivo 10 was created supplemented by a number of what are termed *'memos'* for different purposes

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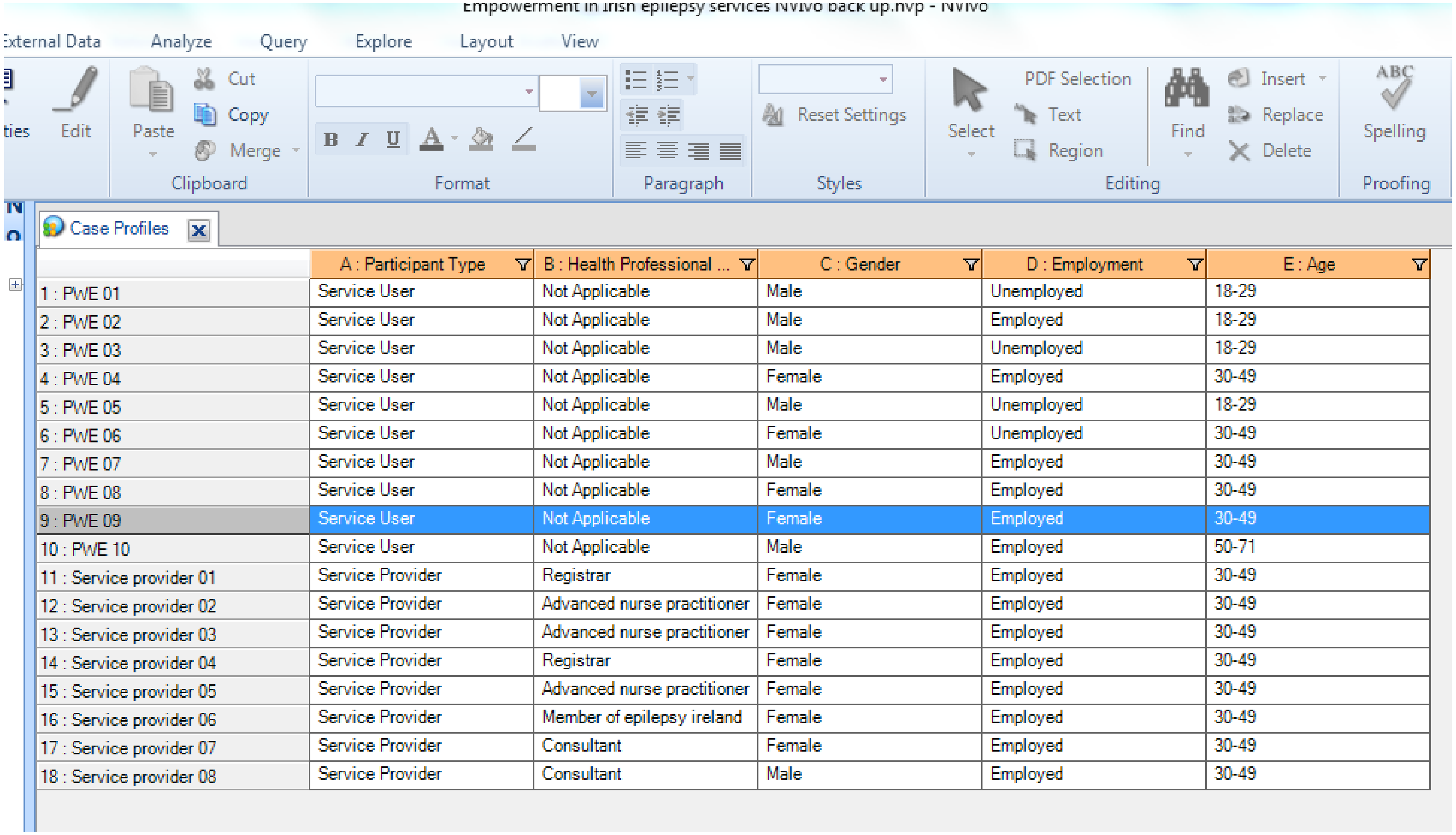
[39] See section 6.4.3 and querying the data.

and these are linked back to the central research diary. According to Ryan and Russell Bernard (2000) memo writing tries to generate discussion and self-dialogue that shapes a union between theoretical reflection and the practical issues around data collection and analysis. Memos were recorded for each participant and issues that were considered important for them documented. These memos were initially hand written following each interview, during the observation of service and following the focus group.

These were imported into NVivo 10. Additionally, notes were generated after listening to and reading the data, observing and discussing anything that seemed of potential interest and significance, as well as any impressions, thoughts, and ideas I had in light of the research aim. This facilitates researchers to *'live with'* the data and is a process that raises awareness of key ideas and recurrent themes which can be immediately noted and linked to data.

Figure 6.1: Extract from NVivo - Case profile



	A : Participant Type	B : Health Professional ...	C : Gender	D : Employment	E : Age
1 : PWE 01	Service User	Not Applicable	Male	Unemployed	18-29
2 : PWE 02	Service User	Not Applicable	Male	Employed	18-29
3 : PWE 03	Service User	Not Applicable	Male	Unemployed	18-29
4 : PWE 04	Service User	Not Applicable	Female	Employed	30-49
5 : PWE 05	Service User	Not Applicable	Male	Unemployed	18-29
6 : PWE 06	Service User	Not Applicable	Female	Unemployed	30-49
7 : PWE 07	Service User	Not Applicable	Male	Employed	30-49
8 : PWE 08	Service User	Not Applicable	Female	Employed	30-49
9 : PWE 09	Service User	Not Applicable	Female	Employed	30-49
10 : PWE 10	Service User	Not Applicable	Male	Employed	50-71
11 : Service provider 01	Service Provider	Registrar	Female	Employed	30-49
12 : Service provider 02	Service Provider	Advanced nurse practitioner	Female	Employed	30-49
13 : Service provider 03	Service Provider	Advanced nurse practitioner	Female	Employed	30-49
14 : Service provider 04	Service Provider	Registrar	Female	Employed	30-49
15 : Service provider 05	Service Provider	Advanced nurse practitioner	Female	Employed	30-49
16 : Service provider 06	Service Provider	Member of epilepsy ireland	Female	Employed	30-49
17 : Service provider 07	Service Provider	Consultant	Female	Employed	30-49
18 : Service provider 08	Service Provider	Consultant	Male	Employed	30-49

6.3.1.2 Identifying a thematic framework

Identifying a thematic framework occurs when the researcher recognises emerging themes or issues in the data set. It aims to organise data in a meaningful and manageable way for subsequent retrieval, exploration, and examination during the final mapping and interpretation stage. Ritchie and Spencer (1994) argue that the process of developing framework categories is informed both by *a priori* concern as well as emergent issues arising from an earlier familiarization with the data.

In keeping cognisant of the methodological approach, the thematic framework was not established based on *a priori* issues which formed the basis of the research objectives and interview schedule. I began to pilot the initial framework on a number of interviews. This gave me the opportunity to identify chunks of data that did not fit into the initial framework. For some initial subthemes created, I later extracted and combined with a different subtheme. The initial decision to extract and combine subthemes was time consuming. However, once the decision was made it took little time to perform this with NVivo 10. It is worth noting that the thematic framework is only tentative and there are further chances of refining it at subsequent stages of analysis (Ritchie and Spencer 1994). I began coding the data (which involves the indexing and charting stage). Figure 6.2 displays an extract from NVivo 10 illustrating a final thematic framework.

Figure 6.2: Extract from NVivo 10- Final thematic framework

Name	Sources	References
1.0 Understanding of empowerment	19	100
1.1 Participants levels of empowerment	19	45
1.2 Participants understanding of empowerment	8	9
1.3 An understanding of 'power from within'	9	15
1.4 An understanding of 'power over'	4	8
1.5 An understanding of 'power to'	12	20
1.6 An understanding of 'power with’	3	3
2.0 Organisational and management factors	19	120
2.1 Voluntary organisations	11	13
2.2 Communication	4	6
2.3 Epilepsy care provision	10	17
2.4 Epilepsy services	19	51
2.5 Management	4	5
2.6 Resources	11	20
2.7 The system	5	8
3.0 Interpersonal Factors	19	283
3.1 Communication	19	137
3.2 Respect	16	19
3.3 Psycho-social supports	18	46
3.4 Partnership	16	62
3.5 Family, carer and peer support	8	19
4.0 Individual Factors	19	174
4.1 Fear	11	24
4.2 Frustration	11	18
4.3 Hope	2	2
4.4 Negative self-concept	8	12
4.5 Vulnerability	9	16
4.6 Positive self-concept	2	3
4.7 Education	9	25
4.8 Information Provision	19	51
4.9 Competencies	11	23
5.0 Social and cultural factors	15	53
5.1 Stigma	8	12
5.2 Structural factors	8	13
5.3 Societal awareness and understanding	8	19
5.4 Professional relationships	4	9

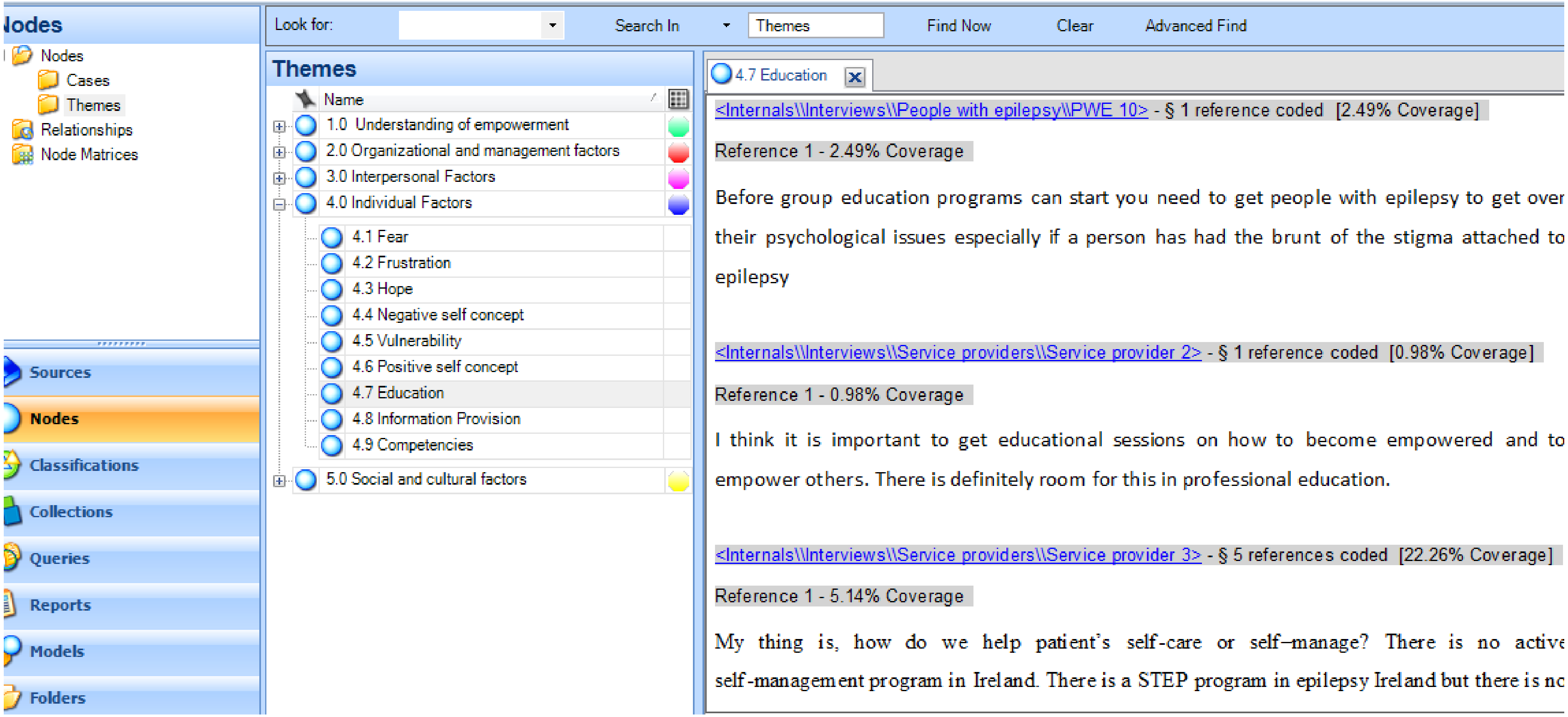
6.3.1.3 Indexing

Indexing identifies sections of the data that correspond to a particular theme. This process was applied to all data that had been gathered (i.e. transcripts of interviews and observations of data). This was accomplished by working through the transcript text, highlighting a portion of the text and deciding which category (or categories) from the framework to assign the text to. The highlighted text was 'dragged and dropped' into the relevant category in the list outlined in figure 6.3.

The aim of indexing is to create a more manageable data set. However, at times it was unclear about certain sections of data that did not *'fit'* with the initial framework. Subsequently a further code was created and identified as '*other'*. This enabled me to return to this node and decide if a further theme needed to be developed or indeed if the portions of the data fitted with the initial themes. Thus, the development of the framework is an ongoing process that may continue to be adapted, even when you have moved on to the later stages of framework analysis.

Once indexing is completed, NVivo enables you to extract all data coded to a category for a specific participant, group of participants, or all participants, facilitating many potential avenues for exploration in the later stages of data analysis. Moreover, it allows the removal of text from a relevant category by decoding. Figure 6.3 displays an extract from NVivo, illustrating the list of framework categories at the top, and the transcript text below.

Figure 6.3: Extract from NVivo-Framework categories



<Internals\\Interviews\\People with epilepsy\\PWE 10> - § 1 reference coded [2.49% Coverage]

Reference 1 - 2.49% Coverage

Before group education programs can start you need to get people with epilepsy to get over their psychological issues especially if a person has had the brunt of the stigma attached to epilepsy

<Internals\\Interviews\\Service providers\\Service provider 2> - § 1 reference coded [0.98% Coverage]

Reference 1 - 0.98% Coverage

I think it is important to get educational sessions on how to become empowered and to empower others. There is definitely room for this in professional education.

<Internals\\Interviews\\Service providers\\Service provider 3> - § 5 references coded [22.26% Coverage]

Reference 1 - 5.14% Coverage

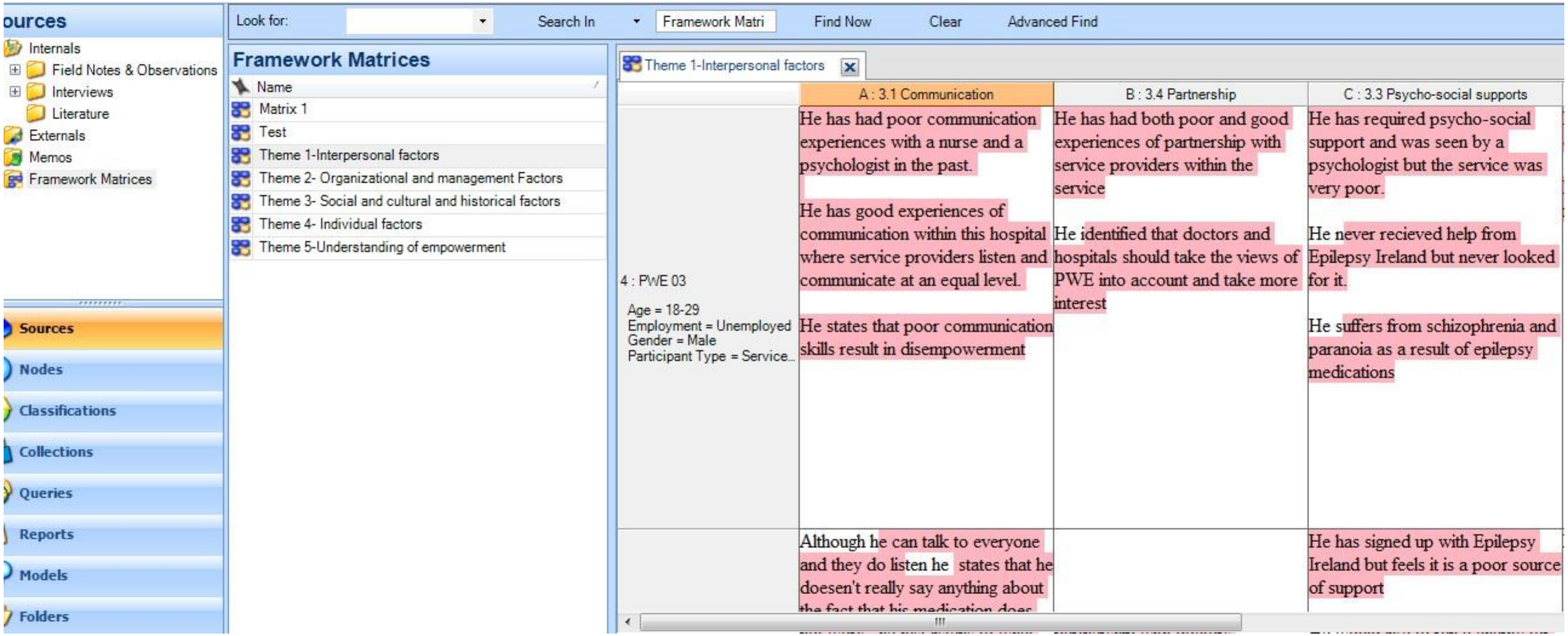
My thing is, how do we help patient's self-care or self–manage? There is no active self-management program in Ireland. There is a STEP program in epilepsy Ireland but there is n

6.3.1.4 Charting

Charting facilitates data analysis in the next stage of framework analysis by synthesising the data that was indexed in the previous stage into a more manageable format. A spreadsheet is used to generate a matrix and the data are ‘charted’ into the matrix. It involves summarising the indexed data for each category and organising the summaries in chart form. Cases were kept in the same order in each chart for clarity purposes (Ritchie and Spencer 1994).

In order to chart an interview, each thematic framework was read, summarizing all data and providing a summary for each category. NVivo 10 linked the summary to the relevant part of the transcript text. By clicking on the summary enabled the retrieval of transcript text linked to that part of the summary, making it easy to move between the summaries and the original transcript text. Figure 6.4 displays an extract from the framework in NVivo 10 illustrating the charting process that I used. The rows show the categories from the framework and participants are shown in the columns.

Figure 6.4: Extract from NVivo-Charting process



	A : 3.1 Communication	B : 3.4 Partnership	C : 3.3 Psycho-social supports
4 : PWE 03 Age = 18-29 Employment = Unemployed Gender = Male Participant Type = Service...	He has had poor communication experiences with a nurse and a psychologist in the past. He has good experiences of communication within this hospital where service providers listen and communicate at an equal level. He states that poor communication skills result in disempowerment	He has had both poor and good experiences of partnership with service providers within the service He identified that doctors and hospitals should take the views of PWE into account and take more interest	He has required psycho-social support and was seen by a psychologist but the service was very poor. He never recieved help from Epilepsy Ireland but never looked for it. He suffers from schizophrenia and paranoia as a result of epilepsy medications
	Although he can talk to everyone and they do listen he states that he doesn't really say anything about the fact that his medication does		He has signed up with Epilepsy Ireland but feels it is a poor source of support

6.3.1.5 Mapping and interpretation

The mapping and interpretation stage moves beyond data management toward understanding it. According to Ritchie and Spencer (1994) the researcher at this point is cognisant of the objectives of qualitative analysis, which are: defining concepts, mapping range and nature of phenomena, creating typologies, finding associations, providing explanations, and developing strategies. Thus, any strategy or recommendations made by the researcher echo the true attitudes, beliefs, and values of the participants.

The coding stripes function within NVivo was particularly useful for early conceptual development. Coding stripes are coloured bars that allow the researcher to view how content has been coded, and facilitates the task of comparing categories and concepts (Bringer *et al.* 2006). Coding stripes were used to provide a visual overview of how the nodes created might relate to one-another. For example, one of the most commonly referenced initial nodes was ‘*communication’.* To gain further insight all the data coded at this node was examined and coding stripes were used to identify any potential early relationships between other emergent concepts. This recognised that much of the data coded at communication was also coded at ‘epilepsy services’ and ‘participant’s level of empowerment’. The coding stripes also provided potential contextual information about communication by identifying some of its potential sources. The most prominent of these were interactions with service providers, families, carers and peers. Therefore the coding stripes provided a valuable exploratory tool that facilitated the iterative theory building process.

During the mapping and interpretation stage data was reviewed within the framework matrix once again to look for emergent patterns and participants views with regards to empowerment. For example, a number of statements that related to participants feelings of ‘*power’* and ‘*powerlessness’* were found. Firstly, it was recognised by the majority of people with epilepsy that being *‘acknowledged’* ‘*listened to’*, *‘respected’, ‘taken seriously’, ‘supported’, and ‘treated as an equal’ by service* providers positively impacted on empowerment experiences. However, poor communication and not been treated as an equal negatively impacted on empowerment experiences for people with epilepsy. Moreover, they identified the importance of being treated as a *‘subject’* with ‘*a life to lead’* as opposed to been viewed as an *‘object’*. These areas were further developed and analysed[40]. Working through the charted data, recognised that for many people with epilepsy, the fear of disclosure was significant in relation to stigma and prejudice. Furthermore, service providers described feelings of fear in particular when people with epilepsy and their families became angry and aggressive. By the time I had completed the mapping and interpretation of all my data, several themes emerged and included: (1) An understanding of empowerment; (2) Power; (3) System issues; (4) Lifeworld issues; (5) Communicative competence; and (6) antecedents to empowerment[41].

6.3.2 Analysis of observational data

Field notes and my recordings of observations and perceptions were developed, revisited and refined following each period of observation through an iterative process. Data from observations are generally not entered into the raw data that will be coded and categorised for analysis as is the case with the interview data (Rodwell 1998). Rather they will be used as 'background' to increase depth and scope in the process of generating findings and developing interpretations and understandings. This approach was adopted in the current study. My main intention within the analysis was to look for themes, patterns or relationships that were related to practices or factors that either support or inhibit empowerment within Irish epilepsy services using one specialist epilepsy service as an exemplar. According to Charmaz and Mitchell (2001) coding incident-by-incident is more appropriate for observational data than word-by-word or line-by-line coding partly because the field notes already comprise the researcher's own words and interpretations. Observations and field notes were analysed through incident-by-incident coding or coding the whole events or scenarios (see box 6.1). I wrote analytic memos during my observational field work (see box 6.2). I compared the memos from my analysis of observational data with those regarding interview analysis in order to gain an integrated rather than a partial understanding of the findings generated from the entire data set.

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[40] See Chapter 8: Findings of one-to-one interviews and an observation of service.

[41] See Chapter 8: Findings of one-to-one interviews and an observation of service.

Box 6.1: Observation of service: Coding incident by incident: Service providers lack 'power to' improve care provision as a result of lack of resources and space

A member from Epilepsy Ireland is available every Wednesday to provide psycho-social supports for people with epilepsy attending the OPD. On many occasions members of the MDT approach an advocate from Epilepsy Ireland to provide support and information to people with epilepsy. However, on many occasions no room or office is available and no support or information provision can be provided leaving everyone frustrated and annoyed.

Box 6.2: Example of a memo written during observation of service

During a consultation with a medical doctor a male person with epilepsy was asked to describe how he had been feeling for the past 6 months. The person with epilepsy was very happy to talk to the service provider, however was continuously interrupted by his wife. She completely rejected her husband's occurrence of events and began to answer most of the questions posed by the service provider. While the person with epilepsy tried to answer, his wife was determined to control the situation and eventually the person with epilepsy began to retreat within himself.

6.4 CAQDAS-NVivo 10 and Data analysis

CAQDAS are recognised globally for supporting the management of qualitative data. It is a specialist package that was developed by Professor Lyn Richard. This section presents a reflection on the use of CAQDAS and how it supports the researcher in their analysis of data using qualitative approaches.

There is much debate for and against the use of CAQDAS in qualitative research (Seale 2010). Advantages include the speed that CAQDAS methods offer the analyst for handling larger amounts of textual data and an ability to assist with conceptualization of data and theory building (Ritchie and Lewis 2003). Also, improvements in rigor or consistency of approach, the facilitation of team research and the relative ease of navigation and linking of data have been acknowledged (Weitzman 2000)[42]. Moreover it facilitates the researcher in mapping relationships on screen (Denzin and Lincoln 2011, Bergin 2011). Disadvantages include issues in relation to quality, and to what extent

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[42] See Chapter 5, Section 5.13.2 and issues of quality in qualitative research: Trustworthiness.

concepts of validity, reliability and generalizability are applicable to qualitative research (Friese 2010). Furthermore, it is argued that the very ease, speed, and power of the software have the potential to encourage the researcher to take '*shortcuts*' and allows researchers to undertake complicated analyses without fully understanding the principles of the techniques they are applying (Weitzman 2000 p. 807-8). Nevertheless, it is acknowledged that the qualitative researcher that does not use software beyond a word processor will be hindered compared with those who do (Miles & Huberman 1994). For instance, arguably CAQDAS allows greater speed at handling large volumes of data; improves the rigor of qualitative studies and facilitates consistent coding schemes for team researchers (Seale 1999).

6.4.1 NVivo 10

Although many different CAQDAS exist, NVivo 10 is the most widely known and probably used. It is designed for qualitative researchers who need deep levels of analysis for small or large volumes of data. It is not methodological-specific. Indeed it supports the analysis of qualitative data in five significant ways: (1) managing and organising the data; (2) manging ideas; (3) querying data; (4) modelling visually by creating graphs to demonstrate the relationships between the conceptual and theoretical data and finally (5) reporting from the data (Bazeley 2007).

6.4.2 A reflection on the use of CAQDAS- NVivo 10

Arguably, the use of NVivo 10 in conjunction with the Frameworks Approach supports rigorous and rich qualitative data analysis. However, researchers need to be aware of the demands placed on them in trying to balance the mechanics of working through a CAQDAS program such as NVivo 10 while simultaneously maintaining fidelity with a chosen analytical and epistemological approach. This can be particularly evident in a loss of focus during the 'coding' of data in this study[43]. This section identifies that to avoid this potential pitfall one needs to develop and abide by a clear plan of action that incorporates time to reflect on the inter-relationship with one's chosen approach and CAQDAS.

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[43] See Section 6.4.2.2 and reflections on coding the data.

A mistake that can be made by the novice researcher when using a CAQDAS is to *'dive'* straight into using it without thinking specifically about what and why one wants to use the CAQDAS. In addition, there is a temptation to imagine that one can learn the programme as one goes along with doing the study. These are potentially costly mistakes. Firstly, if one does not ask oneself for what reason one is using CAQDAS one is likely to misapply it. The most obvious question one needs to ask oneself in this context is about the nature of the data being collected (for example group or individual interviews, visual data-such as video or photographs-or documentary or observational data or an amalgam of two or more of these) and whether the CAQDAS lends itself to inputting and storing such data (this includes ease of input).

Secondly, one need's to ask oneself what is the goal of using CAQDAS within one's specific study. Thus, is it merely to facilitate storage or is it to assist in more complex data analysis and how compatible is it with one's chosen approaches to data collection and epistemology. This is also a particularly important question to answer in terms of its contribution to rigour. Indeed, one might argue in this regard that modern requirements in relation to opening up one's data and analysis to external scrutiny (for example academic journals which require submission of data) means that one has to place CAQDAS within one's study in order to meet such requirements.

Thirdly, one needs to think about obtaining training in the use of the chosen CAQDAS package preferably some initial training in the early stages of the study followed by more intensive training prior to utilising the CAQDAS specifically in the analytical process. Training avoids misapplication of the programme and consequent mistakes and wastage of precious research time. Questions that need to be asked in this regard relate to ease of access to training and affordability.

Thinking about and answering these questions will assist the researcher to choose not only the right CAQDAS package but also the right time to use a CAQDAS package. In addition, it forces the researcher to think about the relationship of the CAQDAS to the overall qualitative approach adopted in any study. In the context of this study these questions led to choosing to use NVivo 10 and seeking out training as the first step in its application. With this in mind, a reflection on the use of CAQDAS-NVivo10 training is now discussed.

6.4.2.1 Reflections on NVivo 10 training

I had no prior experience in the use of NVivo 10 apart from an introductory training day as part of a research course. Whilst this gave an appreciation of what it had to offer it did not make me proficient. Indeed, the 'proficiency' mistake is one that should be avoided – the 'I' have done a short course and therefore now know how to do it' type of thinking. Rather the introductory course should lead one to discuss with others, in this case my two supervisors, the suitability and nature of obtaining further NVivo training and what it would contribute to the pursuit of the study.

Initially such discussion started from the epistemological point CST and in particular the degree to which NVivo 10 would support or discourage reflexivity. Arguably, NVivo 10 facilitates reflexivity by supporting efficient data management and interrogation of a large body of evidence through a range of methods to explore the data and experiment with various interpretations, whilst simultaneously providing options to record notes/ memos and observations on one's thinking and insights and reasons for the interpretations drawn (Bergin 2011).

Within the context of this study, such a discussion led to a focus on the need to produce a demonstrable audit trail of analytical thinking processes co-joined with the results of the analysis as a means to reinforce the trustworthiness of study's findings. With this in mind, it was acknowledged that NVivo 10 had the potential to render all stages of the analytical process traceable and transparent. In addition, there were practical reasons for using NVivo 10. For instance, two of my supervisors had extensive knowledge and experience of the use of NVivo software and, in their role as supervisors of the research, would be able to provide ongoing advice on its application as well as provide an on-going check that it was being applied appropriately referenced to the Frameworks Approach used in the study. Moreover, the academic institution where the research was located had a licence for NVivo use and thus made it an affordable and easily accessed option. Finally, the supervisory team had strong connections and access to national expertise and support in relation to NVivo training which could be used as additional support in its use. I had access to this support remotely at any time using the internet and this was of great benefit throughout the process of data analysis.

6.4.2.2 Reflections on coding the data

Coding provides the analyst with a formal system to organise the data, uncover and document additional links within and between concepts that are described in the data. Coding data in NVivo 10 involves the creation of different types of nodes. A node is a collection of references about a specific theme, place, person, or other areas of interest (Bazeley 2007). The different types of nodes can be identified as free nodes, tree nodes, case nodes, relationship nodes and matrices. A free node is a 'stand-alone' node with no clear logical connection with other nodes. However, you can convert a free node to a tree node by moving it into a tree folder. Tree nodes are organised in a hierarchical structure starting at a parent node and moving to specific categories- child nodes. Case nodes are concerned with participant attributes such as demographic details. Relationship nodes define a relationship between two or more project items, for example person with epilepsy and service provider or between two tree nodes. Finally, matrices are the result of a matrix-coding query that is used to further explore relationships between nodes.

The development of the code structure is an iterative and lengthy process, which begins at the data collection phase. A well-crafted, clear, and comprehensive code structure promotes the quality of subsequent analysis (Miles and Huberman 1994). Having imported the interviews and observations of service, the process of creating nodes began. However, while recognizing codes within a project one may begin to lose focus when using CAQDAS such as NVivo10. One may become so obsessed with 'the technology' that one forgets the analytical approach that one is using. This was certainly the experience in this project. For example, a set of preliminary nodes from the one-to-one interviews consisting of 51 preliminary codes relating to participant's views of empowerment were identified and then coded through NVivo 10. Once this stage was completed it was realised that this had not been referenced to the analytical approach, rather the intellectual energy had focused on getting the technology right. Consequently, discussion with supervisors led to a decision to cease analysis through NVivo, until a clearer understanding of the analytical strategy had been achieved. Data analysis resumed once this had been done (including further familiarisation and 'practice' with NVivo10). The coding framework was then hierarchically organised under five dominant themes (see box 6.3) as identified from the combined interviews and observational data.

The charting process was time consuming and at times sections of interview text was repeated. It took time to trust the software as I felt I would lose key aspects of the data. However, by the time I had completed the mapping and interpretation of all my data, several themes emerged (see box 6.4). However, NVivo 10 has the ability to refer back to the original text during the interpretative analysis stage. With this in mind, summaries should be kept concise to meet the purpose of reducing the data set.

Box 6.3: Dominant themes identified following familiarisation

- An understanding of the concept ‘empowerment’
- Interpersonal factors
- Individual factors
- Organisational and management factors
- Social and cultural factors

Box 6.4: Dominant themes identified following mapping and interpretation

- An understanding of the concept ‘empowerment’
- Power
- System issue
- Lifeworld issues
- Communicative competence
- Antecedents to empowerment

Issue of quality in qualitative research has been highly debated (Tracy 2010, Sandelowski & Leeman 2012, Morse 2015, Cai & Zhu 2015, Polit and Beck 2017)[44]. Ensuring rigor and transparency in data analysis is imperative. With this in mind, the framework approach offers the matrix structure that is visually straightforward and can facilitate recognition of patterns in the data including drawing attention to contradictory data (Gale *et al.* 2013). Moreover, the summarised data is kept within the wider context of each case, thereby encouraging thick description that pays attention to complex layers of meaning and understanding (Popay *et al.* 1998). Indeed, it is easy to recognise relevant data extracts to illustrate themes and to check whether

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[44] See Chapter 5, Section 5.13.2 Issues of quality in qualitative research: Trustworthiness.

there is adequate evidence for a proposed theme. In this context, a clear audit trail from original raw data to final themes is evident.

6.4.3 Querying the data

Query tools in CAQDAS enables the probing of data and identifies overlap and discrepancies in content. Indeed, many query options can be created and saved within NVivo 10 and include: (1) advanced find; (2) text search query; (3) word frequency query; (4) coding query; (5) coding comparison; (6) compound query; (7) group query; (8) and matric coding query. These are now explored:

(1) Advanced find allows a search of all project items based on a combination of criteria such as all queries added to a project or all sources coded within a specific timeframe.

(2) Text search query lists all sources that contain a specified word, text or phrase and provides a way of coding your sources. Moreover, it provides a quick way of searching the literature for a specified text. This became particularly useful for the analyses of the literature that I imported.

(3) Word frequency query lists frequently occurring words or concepts and the numbers of times they occur in selected items. This enables the identification of themes and subthemes and allows a search for words that occur most frequently. It also enables the development of a word cloud, tree map and cluster analysis.

(4) Coding query discovers all content coded at selected nodes, a combination of nodes, or nodes with particular attribute value. For example, I was able to discover all content acknowledged by people with epilepsy in relation to '*fear'*.

(5) Coding comparison compares coding done by two users or groups of users.

(6) Compound query combines a text search query with a coding query to search for text in or near coded content. Two text search queries can be combined to search for content where one term precedes another.

(7) Group query finds items that are associated in a particular way with other items. The items could be associated by coding, attribute value or relationship.

(8) Matric coding query cross tabulates the coding intersections between two lists of items.

6.4.3.1 Matrix coding query

I used matrix coding queries to determine the number of cases and references coded by the attributes ‘participant type’ (people with epilepsy, service provider, patient advocate) and ‘gender’. In so doing, I could view the number of cases and references coded at the free nodes by selected attributes and then compare how I coded on to the theme and subtheme. This was a valuable tool for me as it both displayed my consistency in coding on. For example, table 6.1 outlines both themes ‘interpersonal factors’ and ‘organisational and management factors’. The first row shows initial coding to the theme and identified that I coded 10 people with epilepsy and 8 service providers. The first row shows initial coding to the subtheme communication and highlights that I coded communication 160 times. No significant differences to the number of nodes were identified to the attribute gender.

Table 6.1: Matrix query-To determine the number of cases and references coded by the attributes ‘participant type’ and ‘gender’

Interpersonal factors	People with epilepsy	Service providers	Male	Female
Sources	10	8	7	11
Communication	97	63	83	90
Family/carer and peer support	11	5	6	10
Partnership	33	29	25	37
Psycho-social supports	24	20	16	29
Respect	9	9	5	13
Organisational and management factors	People with epilepsy	Service providers	Male	Female
Communication	0	3	0	3
Epilepsy care provision	4	9	5	8
Epilepsy services	28	20	19	30
Management	0	5	0	5
Resources	2	17	3	16
The system	0	8	1	7

However, in a further matrix query undertaken with regards to gender (table 6.2), it was identified that the subthemes societal awareness and understanding, structural factors and vulnerability were coded more times to male participants compared to female participants. This led me to review the above subthemes in relation to people with epilepsy, gender and employment status. This highlighted that although a higher percentage of male people with epilepsy were unemployed compared to females, males identified more issues with regards to employment, societal understanding and consequently vulnerability.

Table 6.2: Matrix query: Factors identified in relation to gender

Social-cultural-historical factors	People with epilepsy	Service providers	Observation of service	Male	Female
Professional relationships	0	8	0	0	8
Societal awareness and understanding	16	4	0	15	5
Stigma	9	3	0	4	8
Structural factors	13	0	0	10	3
Individual factors	People with epilepsy	Service providers		Male	Female
Fear	19	5	0	12	12
Frustration	11	6	0	11	6
Hope	1	1	0	1	1
Negative self- concept	11	0	0	6	5
Vulnerability	14	0	0	10	4
Positive self- concept	3	0	0	2	1
Education	2	24	0	5	21
Information Provision	22	28	0	15	35

6.4.4 Concluding comments on the use of a CAQDAS-NVivo 10

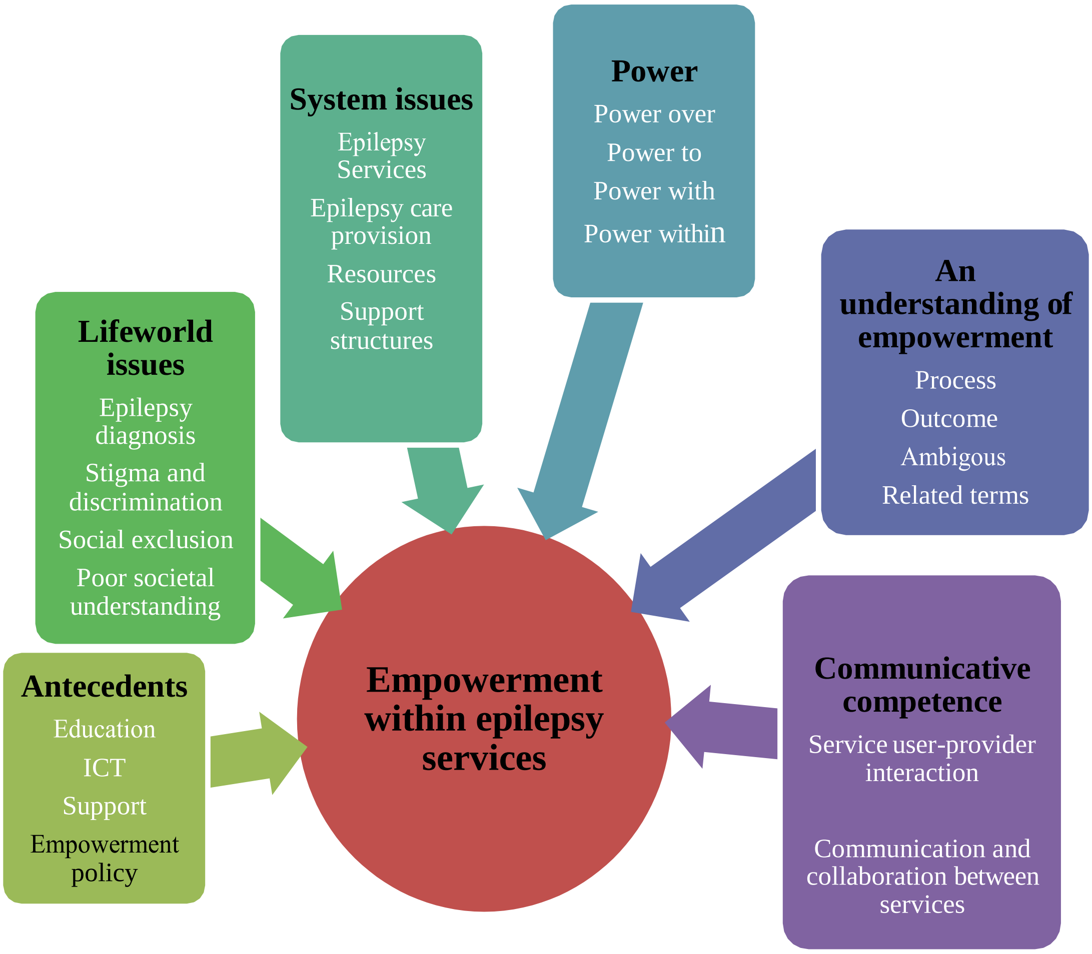
ArguablyNVivo 10 in conjunction with the framework approach was a valuable asset for my data analysis. The single location storage system with easy access to my data and my literature was very advantageous. The hierarchical structure along with the indexing and charting of the data and framework matrix made it easier and more convenient for me to view and get a sense of my findings and this compared more favourably to previous studies that I had undertaken where I used pen, paper and highlighter pens.

Arguably the use of CAQDAS-NVivo 10 enabled me to clearly see links in the data that would not have been possible using more traditional methods. Moreover, the efficiency of the NVivo 10 programme facilitates data entry and retrieval. As soon as the data has been transcribed and transported, coding can begin. Once a segment of data has been coded, it is possible to retrieve that segment and the surrounding text immediately, without trawling through the data. This ease of navigation of data is beneficial and labour-saving, especially when dealing with large volumes of qualitative data.

A further benefit of NVivo 10 is its ability to increase the capability for the data to inform the research. For example, I was able to create models that illustrate the associations between different elements of the data. Figure 6.5 illustrates the association between empowerment and epilepsy healthcare.

The options to query and audit the coding processes offered by NVivo 10 enabled more robust interpretations of data to be achieved. It assisted me to illustrate how my reflections and ideas (recorded in memos) relate to the larger world of the researched (recorded as documents in the data) and how these concepts align with or differ from other contexts, usually derived from the literature. Furthermore, NVivo 10 facilitates accurate and transparent data analysis processes (McLafferty and Farley 2006). For example, my supervisors could easily browse through this project and understand how the analysis of the data was done. Also the ability to have empirical data and literature together in one place makes connections when writing much easier to identify. Finally, NVivo 10 allowed me to import my literature and link both the literature, audio recordings and transcripts to the findings. In conclusion, the use of CAQDAS-NVivo 10 is challenging but a valuable means for advancing the robustness of qualitative data.

Figure 6.5: A model of empowerment and epilepsy healthcare



6.5 Chapter summary

Data analysis is a complex process and demands clear thinking on the part of the analyst. The use of four complementary methodologies of data-gathering enabled me to collect comprehensive information about empowerment within one specialist epilepsy service in Ireland. This Chapter has discussed the process of quantitative and qualitative data analysis for the study of empowerment and epilepsy health care. Ritchie and Spencer’s (1994) Framework Analysis/Approach were used for the analysis of qualitative data and NVivo 10 facilitated this process. A reflection on the use of CAQDAS-NVivo 10 was presented. Arguably, NVivo 10 in conjunction with a framework approach assists rich qualitative data analysis and is a valuable asset for advancing the rigor of qualitative research. The results of this process of analysis are presented using SSM.

SECTION 3

Data, Soft Systems Analysis and Discussion

CHAPTER SEVEN

Epilepsy Services in Ireland: A Survey of People with Epilepsy in Relation to Satisfaction, Preferences and Information Provision

7. 1 Introduction

Building on the previous three research design Chapters, Chapters 7 to 10 present and analyse the findings of this mixed method sequential exploratory study utilising a soft systems method, referenced to CST. To date research exploring service user's and provider's perspectives on empowerment in relation to epilepsy care is lacking despite health policy advocating a partnership approach. Therefore, the aim of this study is to explore and analyse the epilepsy service as a system with reference to dimensions of empowerment.

Chapter 7 describes and analyses a survey of people with epilepsy on their views of their service needs in relation to design and delivery. Results highlight that despite high levels of satisfaction with hospital and primary care, participants offer several suggestions to improve healthcare delivery, such as: less delay in accessing specialist care and hospital appointments; better communication; and easier access to investigatory services. Findings demonstrate that for people with epilepsy the burden of the disorder is substantial and complex encompassing social, psychological and structural difficulties. Poor information provision particularly among women is reported. Furthermore, a lack of empowerment in people with epilepsy is highlighted.

Chapter 8 describes and analyses the views of people with epilepsy and their service providers in relation to empowerment within Irish epilepsy services using one specialist epilepsy service as an exemplar. Six core themes emerged that influence empowerment within epilepsy services and these include: (1) an understanding of empowerment; (2) power and powerlessness; (3) connecting empowerment to 'system' issues, epilepsy services and care provision; (4) empowerment, care provision and 'communicative competence'; (5) connecting empowerment to 'life world' issues; and (6) antecedents to empowerment. Findings demonstrate that service providers cannot facilitate empowerment in part due to lack of training and service pressures. Furthermore, a lack of empowerment for people with epilepsy is highlighted. In this context, Chapters 7 and 8 address Research Objectives (RO) 1 and 2.

RO 1: *To utilise CST to analyse and define the concept of empowerment in the Irish health service.*

RO 2: *To explore and critically analyse organisational issues and human factors on service provision that support or hinder empowerment with reference to the NECP*.

Chapter 9 reports the findings of a focus group involving people with epilepsy and service providers. Five themes emerged and these include: (1) improvements in communication and collaboration within the Irish epilepsy service; (2) involvement of people with epilepsy in the design and delivery of the service; (3) an ambassador program to promote understanding, social inclusion and foster empowerment related to epilepsy; (4) provision of an empowering education and training for service providers; and (5) legalising medicinal cannabis for people with epilepsy.

Chapter 10 presents a soft systems analysis exploring empowerment within epilepsy services using one specialist epilepsy in Ireland as an exemplar and describes the application of stages 1-7 of Checkland's (2000) SSM. To do this it draws upon the data presented in Chapters 7 to 9. Firstly, a situational analysis of empowerment within Irish epilepsy services is presented via the illustration of a rich picture of the problem situation. Secondly, a root definition and conceptual model of empowerment within Irish epilepsy services is described. It compares the conceptual model of the service with its service operation and identifies desirable and feasible changes that have the potential to improve care provision and support empowerment within the Irish epilepsy. In this context Chapter 10 addresses Research Objective 3, 4 and 5.

RO 3: *To develop a situational analysis and conceptual model of the service utilising 'soft systems' methods.*

RO 4: *To compare the conceptual model of the service with its service operation*

RO 5: *To draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland.*

This Chapter describes and analyses the views of people with epilepsy in Ireland on their views of their service needs in relation to design and delivery. The aim and objectives of this survey is presented in section 7.2. In section 7.3 the response rate of the survey is outlined. Section 7.4 ascertains the satisfaction of people with epilepsy with regards to service delivery and explores the views of people with epilepsy in relation to how health care provision could be improved.

In section 7.5 actual and preferred sources of epilepsy care for people with epilepsy is outlined while section 7.6 evaluates the level of information provision for people with epilepsy. A discussion of the survey results is undertaken in 7.7. Finally, section 7.8 concludes with a summary of the findings.

7.2 Aim and objectives of survey

7.2.1 Aim

The aim of this survey is to identify the views of people with epilepsy within an Irish epilepsy service in relation to satisfaction, preferences and information provision.

7.2.2 Objectives

Specific objectives were set as follows:

- Ascertain satisfaction of people with epilepsy with regards to service delivery.
- Identify actual and preferred sources of epilepsy care.
- Assess levels of information provision for people with epilepsy.
- Explore the views of people with epilepsy in relation to how health care provision could be improved.

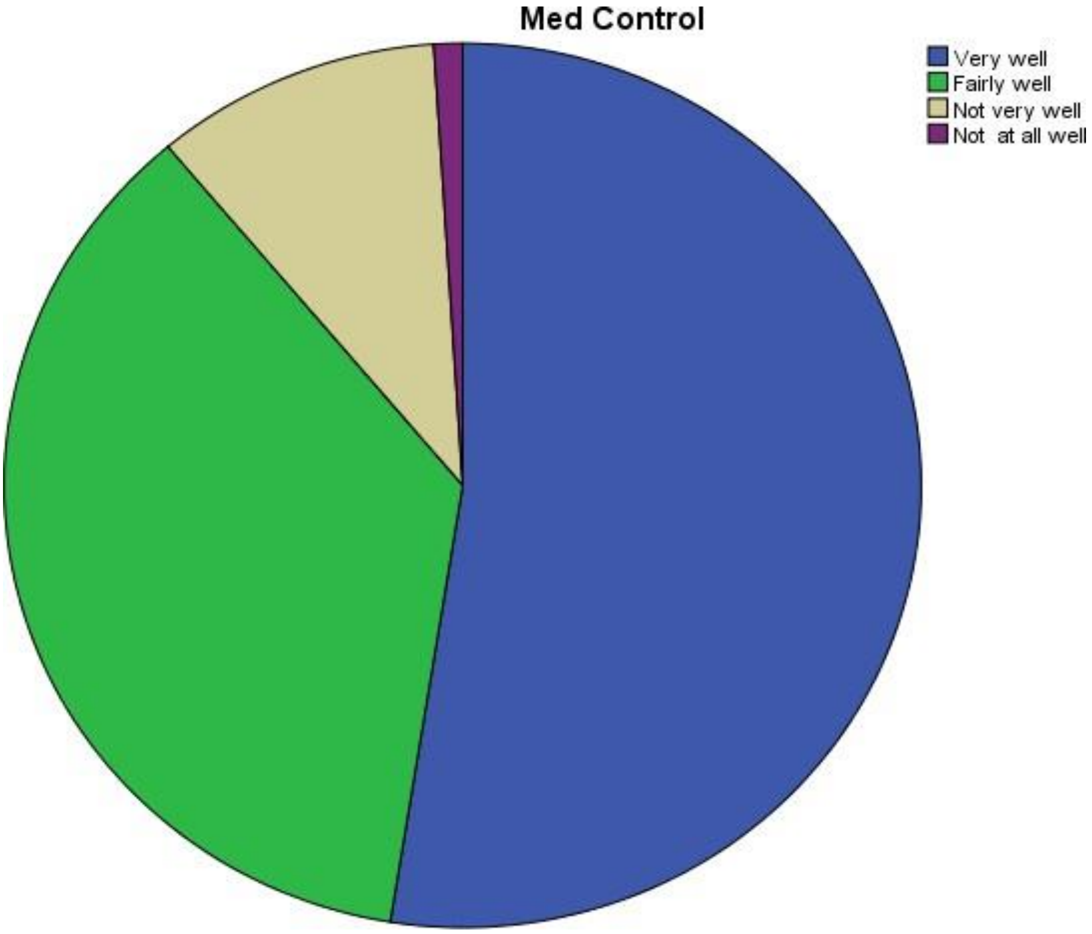
7.3 Response Rate

A cross-sectional descriptive survey design involving both quantitative and qualitative items was administered to a sample of one hundred and fifty-three (*n* = 153) people with epilepsy attending an epilepsy specialist centre. In total one hundred and two (*n* = 102) questionnaires were completed and returned, which represented a 66% response rate.

7.4. Medications

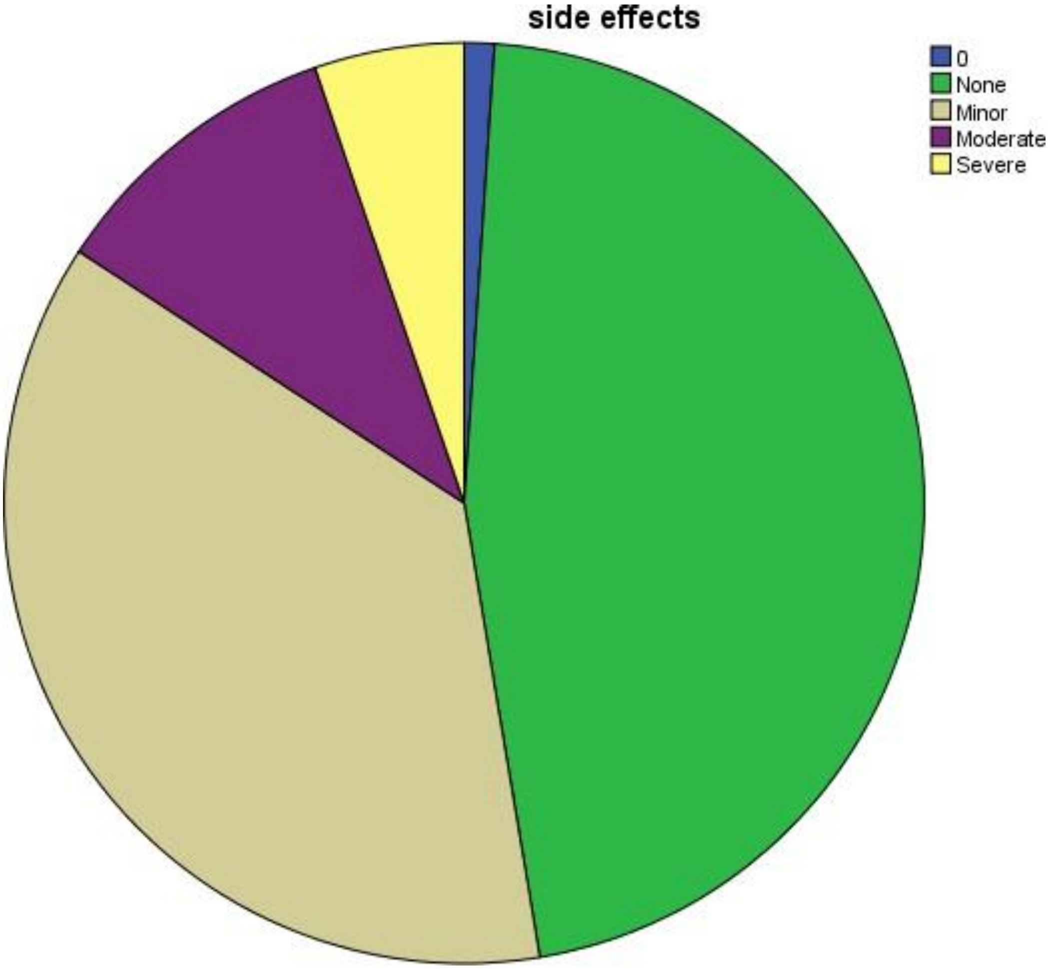
The age range when participants first experienced an epileptic seizure was between 1 and 71 years old with 59.8% having their first seizure at age 18 years or younger. The majority of participants (82.4%, n= 84) could name their epilepsy medications, whilst 17.6% (n=18) either did not know or failed to answer. Figure 7.1 identified that 52.5% (n=52) of participants reported that their medicines control their seizures very well, 36.4% (n=36) fairly well, 10.1% (n=10) not very well and 1.0% (n=1) not at all well.

Figure 7.1: Effects of medicine and seizure control



In relation to medication and its side effects figure 7.2 outlines that 46.3% (n=44) of participants report no side effects of medications, 36.8% (n=35) minor side effects, 10.5% (n=10) moderate side effects whilst 5.3% (n=5) report severe side effects.

Figure 7.2: Side effects of medications



7.5 Satisfaction with epilepsy services

Overall satisfaction with epilepsy services was high. Ninety four point eight percent (n=92) were overall satisfied with general hospital care in comparison to 90.8% (n=69) with primary care. There was slightly higher satisfaction for hospital care compared to primary care with regards to specific sub-measures of care (see Table 7.1) with no significant differences for age and gender in overall satisfaction levels for both primary or hospital care. Fifty five per cent (n=53) were satisfied in relation to continuity of care (seeing the same doctor on different visits, or the same doctor more often than not) for hospital care. Participants were asked to suggest ways to improve epilepsy healthcare provision. Suggestions included a reduction in delays in accessing specialist care and hospital appointments; improved communication skills by service providers; greater societal awareness of epilepsy; improved access to investigations; better continuity of care at and between clinic and hospital appointments; better information provision and access to free transport and disability allowances.

Table 7.1: Overall level of satisfaction for hospital and primary care and for specific sub-measures of care

	Hospital care	Primary care
Overall satisfaction with care	94.8% (n=92)	90.8% (n=69)
Find it easy to talk to doctor	92.8% (n=90)	90.9% (n=70)
Doctor takes views about epilepsy into account	87.6% (n=85)	74% (n=57)

Participants were asked to highlight three areas of their life most affected by epilepsy. Seventy eight (n=78, 76%) participants responded and the majority highlighted lifestyle (n=38, 24.0%), driving (n=31, 19.6%) and work (n= 27, 17.0%) as the areas most affected by their epilepsy. Other areas identified as being affected by their epilepsy were: self-confidence and self-esteem; academic life; family life; memory and concentration; mental health; energy levels; sports; independence; poor coordination and mobility; embarrassment due to stigma and sleep. However, only 25.3% (n=21) of participants stated that they required assistance. Some of the areas identified included: more help and support from experts in the field of epilepsy care; (18.7%, n=3); improvements in medication (18.7%, n=3); better information provision (18.7%, n=3); help with building self-confidence (12.5%, n=2); memory and concentration (12.5%, n=2); academic life (6.2%, n=1); and improved quality of their mental health (6.2%, n=1). Participants were asked to comment on the open-ended question: ‘Is there anything else you would like to tell us about your epilepsy’. Open-ended questions were analysed using a thematic content analysis. Responses from female (f) and male (m) participants (p) were both negative and positive with regards to epilepsy and epilepsy healthcare provision. For instance, one participant stated:

> ’*When I raise issues, I feel I am forced into things, and now feel I shouldn’t say anything at all*’ *(PWEm38).*

Some participants expressed frustration regarding the psychological, social and structural difficulties that they encounter. For example,

> ‘*I have had epilepsy for 16 years and yet still find it hard and difficult to accept. It has an effect on my life especially work and social life which is why sometimes I get angry and find it difficult to accept’ (PWEf22).*

> ‘*After 18 years of having epilepsy I’ve just got my first 12 month seizure free but feel the constant increase and switching of medication made little difference accept bring on side effects. Paranoia is one of the main ones I am having issues with. I’d have preferred if I’d adjusted my life many years ago such as refraining from drink, keeping fit, and getting plenty of sleep. That way I wouldn’t be on all the unnecessary medications I am taking at the moment’ (PWEm23).*

Some participants expressed confusion and concern with regards to epilepsy healthcare provision. For example, one participant commented:

> *‘Why can’t you find out what is wrong’? When will this be over? (PWEm79).*

As a counter point, participants reported a positive experience with regards epilepsy services and one person suggested that:

> *’Standards of care have vastly improved’ (PWEm18).*

One participant commented that:

> *’My access to epilepsy services and the services I receive are excellent. I can see my consultant when it is needed and my GP is both understanding and informed. My consultant is excellent. My epilepsy is difficult to control and all efforts I feel are being made to get the best quality of life for me’ (PWEf63).*

7.5.1 Visits to the hospital, GP and other healthcare providers

Table 7.2 illustrates that the majority (82.5%, n=80) of participants have regular appointments with their hospital doctor, whilst 58.8% (n=60) have seen an ESN. However, although 94.8% (n=73) (with twenty five participants not answering) find it easy to get an appointment to see a GP and 94.5% (n=69) (with twenty nine participants not answering) find it easy to see a GP as an emergency about their epilepsy, only (11.5%, n=9) have regular appointment to see a GP. Furthermore, only 2.1% (n=2) of participants have seen a social worker, 5.2% (n=5) a psychologist/psychiatrist, and 9.1% (n=9) a counsellor in the last 12 months.

Table 7.2: Visits to a hospital doctor, epilepsy specialist nurse, GP, counsellor, psychologist, and social worker in the last 12 months

Visits with healthcare providers	% n
Hospital doctor	82.5% (n=80)
Epilepsy specialist nurse	58.8% (n=60)
GP	11.5% (n=9)
Counsellor	9.1% (n=9)
Psychologist/Psychiatrist	5.2% (n=5)
Social worker	2.1% (n=2)

7.6 Preferences for care

Participants were asked to indicate their actual and preferred source for epilepsy care. Table 7.3 illustrates that the majority of participants identified hospital doctor as the actual (78.4%, n=80) and preferred (76.5%, n= 78) source of epilepsy care. Reasons for doctor preference included: (1) doctor knows more about epilepsy (32.4%, n=69); (2) doctor knows about me and my history (23.4%, n=50) and (3) you get more time to discuss things fully (10.8%, n=23). There was no statistically significant difference in doctor preference with regards to gender or age categories. Seventy five percent and 89.7% preferred hospital doctor in the 18-29 and 30-49 age category respectively, 63.6% in the 50-71 age categories' with 36.4% of participants preferring hospital doctor and GP equally.

Table 7.3: Actual and preferred source of epilepsy care

	Actual source	Preferred source
Hospital	78.4 % (n=80)	76.5% (n=78)
Primary	5.9% (n=6)	6.9% (n=7)
Hospital & Primary equally	10.8% (n=11)	11.8% (n=12)
Not sure	4.9% (n=5)	0.9% (n=1)
Don't mind		3.9% (n=4)

7.7 Information provision

People with epilepsy were asked whether they had received information on issues relating to their diagnosis, risk factors, safety precautions, lifestyle restrictions and support from voluntary organisations. Between ninety three and ninety six of participants responded to all issues and table 7.4 illustrates results.

Table 7.4: Information provision for men and women (n=102) in relation to epilepsy

General questions	Yes	No	Don’t know	N/A
What caused your epilepsy	62.1% (n=59)	24.2%(n=23)	9.5% (n=9)	4.2% (n= 4)
What type of epilepsy you have	74.0% (n=71)	15.6% (n=15)	10.4% (n=10)	
Becoming free of epilepsy attacks	54.3% (n=51)	27.7% (n=26)	17.0% (n=16)	1.0% (n= 1)
Driving restrictions	84.4% (n=81)	10.4% (n=10)	3.1% (n=3)	2.1.% (n=2)
Potential risks	74.5% (n=70)	18.1% (n=17)	7.4% (n= 7)	
Hazardous activities	71.0% (n=66)	20.4% (n=19)	8.6% (n= 8)	
Side effects of medication	68.4% (n=65)	26.3% (n=25)	3.2% (n=3)	2.1% (n=2)
Free prescriptions	75.3% (n=70)	18.3 (n= 17)	5.4 (n= 5)	1.0% (n=1)
Job restrictions	55.8% (n= 53)	30.5% (n=29)	6.3% (n= 6)	7.4% (n=7)
Alcohol use	90.5% (n= 86)	6.3% (n= 6)	1.1% (n= 1)	2.1% (n= 2)
Adequate sleep	83.0% (n= 78)	10.6% (n=10)	6.4% (n= 6)	
TV/Video/ Flashing lights	75.8% (n= 72)	16.8% (n=16)	2.1% (n= 2)	5.3% (n= 5)
Voluntary groups	48.4% (n= 46)	37. 9%(n=36)	9.5% (n= 9)	3.2% (n= 3)
Help from social services/ allowances	29.5% (n= 28)	52.6% (n=50)	14.7% (n=14)	3.2% (n= 3)

All results were pooled together and overall information provision was 67.6% in relation to issues of epilepsy. Only 29.5% (n=28) received information regarding help from social services and 48.4% (n=46) from voluntary organisations. The proportion of informed participants was 80% or above with regards driving restrictions (84.4%, n=81), alcohol use (90.5%, n=86), and adequate sleep (83.0%, n=78). There was no statistically significant difference in the overall level of information provision between males and females (58.5% versus 63.5%) and age categories (18-29 = 65.1%; 30-49 = 66.3%; 50-71 = 61.8%).

Women with epilepsy were asked whether they received information on issues relating to contraception and pregnancy. Between fifty eight and sixty two of participants responded to all topics and table 7.5 illustrates results. A deficit in information provision for women was highlighted. Overall 44.1% of women with epilepsy were provided information in relation to issues of contraception and pregnancy. Only 8.6% (n=5) received information regarding Vitamin K whilst 15.5% (n=9) received information regarding breast feeding.

Table 7.5: Information provision for women (n=62) in relation to contraception and pregnancy

	Yes	No	Don't know	N/A
Problems with contraception	47.6% (n=29)	39.3% (n=24)	3.3% (n= 2)	9.8% (n= 6)
Pre-pregnancy planning	67.7% (n= 42)	21.0% (n=13)	▨	11.3% (n= 7)
Folic acid	75.8% (n= 47)	14.5% (n= 9)	▨	9.7% (n= 6)
Risk to baby	67.7% (n= 42)	16.1% (n=10)	6.5 % (n= 4)	9.7 % (n= 6)
Vitamin K	8.6% (n= 5)	67.2% (n=39)	10.3% (n= 6)	13.8% (n= 8)
Safety considerations	20.7% (n= 12)	56.9% (n=33)	6.9% n= (4)	15.5% (n= 9)
Breast- feeding	15.5% (n= 9)	62.1% (n=36)	6.9% (n= 4)	15.5% (n= 9)

Whilst 65.7% (n=67) of participants could name their type of epilepsy, 32.4% (n=33) either did not know or failed to answer. Although 56.5% (n= 52) of participants indicated they would like more information provision, only 39.2% (n=38) of participants would like to talk more to a health worker about their epilepsy. A majority (37.7%, n=23) of participants stated that they would prefer to talk more with an ESN.

Participants were asked to indicate up to three sources of information provision. The majority of participants (35.5%, n=77) indicated they received most of their information with regards to their epilepsy from hospital doctors. Others sources included: ESN's (16.6%, n=36); literature (11.5%, n=25); hospital nurses (10.1%, n=22); GP (9.7%, n=21); voluntary organisations (9.2%, n=20); media (5.1%, n=11); family/friends (1.4%, n=3); and community nurses (1.0%, n=2).

7.7 Discussion of survey results

Many of the findings in this study are consistent with previous research. Thus whilst, there are high levels of satisfaction with primary and secondary services, similar to previous research findings, participants felt that services needed to improve with respect to less delay in accessing specialist care and hospital appointments; better communication; easier access to investigatory services; better information provision (Poole *et al*. 2000, Al-Adawi *et al*. 2003, Rajpura and Sethi 2004, Hayes *et al.* 2007, Chinthapalli *et al.* 2008, Varley *et al.* 2009, Ross *et al.*2010,Varley *et al.* 2011).

Hospital doctors were highlighted as the actual and preferred source of epilepsy care. This is consistent with Poole *et al.'s* (2000) research. The majority of participants highlighted the reason for doctor preference was 'doctor knows more about epilepsy'. In terms of preference for regular medical contact with doctors (82.5% with hospital specialist doctors and 11.5% with GPs) it would appear that there may an overuse/ unnecessary contact with specialist service doctors, and underuse of primary care support. This may be the result of a lack of confidence in GPs' knowledge/ ability to assist people with epilepsy in the day to day medical management of their condition.

A study by Varley *et al*. (2009) highlighted a lack of knowledge and confidence to manage epilepsy among GPs at the primary care level together with poor communication between primary and specialist services. This is considered a significant barrier to enhancing continuity of care (Betts and Smith 1994, Moran *et al.* 2000) and thus may play a part in the over reliance on specialist service hospital doctors. Indeed, in this regard, only 10.8% of participants indicated that their care was shared between hospital doctor and GP. Although a model of shared epilepsy care between the primary and specialist clinical services are part of the new model of care in Ireland, these results would suggest that considerable improvement is required. In light of the above results, one interesting finding from this study is the confidence shown by participants in ESN's. It is claimed that epilepsy specialist nurse's increase and improve communication between service providers and people with epilepsy (Mills *et al*. 1999). Certainly, the results in this survey would indicate that they are popular with service users. The NECP programme is addressing care provision for epilepsy in the primary care setting using GPs working with ANPs who are specialists in epilepsy nursing care.

This studydemonstrates the complex social, psychological and structural difficulties that people with epilepsy confront. For instance, lifestyle, driving, work, self-confidence/self-esteem, academic life, family life are but a few areas highlighted and consistent with previous research (Fisher *et al.* 2000, Varley *et al*. 2011). These can lead to social isolation and dependency on others especially when it prevents people from driving and working (Beran 1999). Therefore it is surprising that only a small number of participants had seen a counsellor (9.1%), a social worker (2.1%), or psychologist/psychiatrist (5.2%) in the last 12 months. Moreover, few participants have received information regard psychosocial support. Such support requirements beg the question how best to deliver this care and what systems and structures should be put in place?

Findings indicate a deficit in information provision to participants in relation to their condition, social welfare entitlements and supports. For example the specific type of epilepsy they had (65.7% could only name their specific type). In relation to the information on the specific management of the condition, the results are particularly striking in relation to the information gap for women. For example, lack of information in relation to pregnancy and the importance of receiving vitamin K to maintain clotting factors in the blood for the baby (8.6%) and the transmission of anti-epileptic drugs to babies through breast feeding (15.5%). Thus results of this study highlight the need for improvements in educational based information especially for women of childbearing age.

A key feature with regards to education and people with epilepsy is the nature in which service providers control the selection, evaluation, organisation and transmission of information. Also, people with epilepsy are not provided with information in writing with regards to the type of epilepsy they have. However, effective information giving should enable people with epilepsy to develop the attributes and skills required to function as equal partners, make informed decisions and competently self-manage with regards to their healthcare. Therefore, it may be argued that new pedagogies are warranted (Johnston *et al.* 2005), recognizing service users' interpretation of their illness (Tabak *et al*. 2003). Findings of this study suggest a shift from the traditional epistemological and ontological assumptions associated with information giving and people with epilepsy.

Chronic disease management strategies recommend that patients be empowered to self-manage their health care, however, participants in this study appear largely to play a passive role. For example, one participant suggested *'feeling forced into things'*. This indicates a need for a more collaborative approach between people with epilepsy and service providers so that shared expectations can be established and decisions jointly made in striving to achieve realistic and desired outcomes. Although service providers may support empowerment as a goal of patient participation, their socialization to the' practitioner as expert' model of health care may be so deeply rooted that they proffer patient participation largely as an extension of their power base, rather than as a collaborative venture (Cahill 1998). Therefore, future research that explicates more effective partnerships between service providers and people with epilepsy is needed.

Improving epilepsy services in Ireland requires assessing the needs of all stakeholders and the development and implementation of a realistic action plan. Emerging technologies in healthcare has the capacity to provide people with online home access to their medical records via hospital based web portals and provides the potential to empower people to self-manage their chronic illness (Van der Vaart *et al*. 2014). In this regard, improving speed of access to information and support is important. Two-way integrated computerised technology is envisaged as part of the future service provided by the NECP. However, it has yet to be fully implemented, exploited and evaluated within the Irish epilepsy services.

7.8 Chapter summary

This Chapter described and analysed the views of people with epilepsy with regards to health service delivery in Ireland. Findings identified high levels of satisfaction with hospital and primary care. It has been reported that the current structure and process of health care in Ireland results in a negative experience for people with epilepsy (Varley *et al*. 2011). A study by Varley *et al.* (2011) reported that many participants expressed the view that although empathetic to their illness, GPs lack the expertise to manage their condition and/or continue to remain passive with respect to patient needs. Therefore, the results of this survey highlight improvement in epilepsy care insofar as the majority of participants indicated a high satisfaction with both primary and secondary care.

This Chapter has provided a basis for an evaluation of current practice and offer indicators to epilepsy services on how epilepsy care can be further improved. It highlights the need to fully understand the social, psychological, structural and educational difficulties of people with epilepsy and to ensure that these issues are taken into account in any plans for service transformation. Engaging people with epilepsy with greater psycho-social support is clearly needed to more fully address these issues**.** Moreover, an empowered framework for educational delivery is warranted. This can result in greater informed decision-making, positive behavioural changes, and a more active role in the management of epilepsy (Hovinga *et al.* 2008). This is not just a challenge for health service providers within epilepsy services but requires a greater collaborative approach from all stakeholders.

Findings presented in this chapter suggest a lack of empowerment for people with epilepsy. For example, people with epilepsy reported their frustration regarding the psycho-social and structural difficulties they encountered and feeling ‘forced into things’ when issues were raised. With this in mind, organisational issues and human factors on service provision that support or hinder empowerment within epilepsy services using one specialist epilepsy service in Ireland as an exemplar for people with epilepsy and service providers is the subject of Chapter 8.

CHAPTER EIGHT

Issues of Empowerment within Epilepsy Services using one Specialist Epilepsy Service in Ireland: A Service User's and Provider's Perspective

8.1 Introduction

This Chapter describes and analyses the perspectives of people with epilepsy and their service providers in relation to empowerment within epilepsy services using one specialist epilepsy service in Ireland. In depth interviews with people with epilepsy (n=10) and service providers (n=8) with reference to service user and clinician empowerment was undertaken. This analysis was further informed by data generated from a non-participatory observation of services within one epilepsy service in Ireland[45]. A qualitative methodology based on Ritchie and Spencer's (1994) Framework Analysis/Approach (sometimes known as Frameworks) was used to analyse this data[46]. Findings are presented under the following six headings: (1) an understanding of empowerment; (2) power and powerlessness; (3) connecting empowerment to system issues: epilepsy services and care provision; (4) empowerment, care provision and communicative competence; (5) connecting empowerment to life world issues; and (6) antecedents to empowerment.

Section 8.2 explores and analyses how people with epilepsy and service providers understood and gave meaning to the concept of empowerment. Section 8.3 examines the significance of power and powerlessness in relation to participants levels of empowerment. In section 8.4 factors that support and/or hinder empowerment for people with epilepsy and service providers in relation to epilepsy services and care provision are examined. For instance, access to epilepsy services and care provision for people with epilepsy; role and competency of the GP; human and financial resources; and organisational support are explored. Section 8.5 explores the concept of 'communicative competence', particularly in relation to service user-provider interactions; professional communication; and collaboration within epilepsy services.

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[45] See Chapter 6, Section 6.3.2: Analysis of observational data.

[46] See Chapter 6, Section 6.3.1: Qualitative data management and analysis-The frameworks approach.

In section 8.6 life world issues that impact on people with epilepsy's level of empowerment is described while section 8.7 describes the antecedents to empowerment. Section 8.8 outlines a discussion of key findings in relation to the empirical literature and illustrates the factors that support and/or hinder empowerment at the macro, meso and micro levels of epilepsy healthcare. Finally, section 8.9 concludes with a summary of findings. The following abbreviations are used: PWE: M (person with epilepsy male); PWE: F (person with epilepsy female); SP: F (service provider female); SP: M (service provider male).

8.2 An understanding of empowerment

While a significant number of people with epilepsy and service provider's value empowerment, a minority of people with epilepsy acknowledged no understanding of empowerment. Overall, participants described empowerment as a process and outcome and acknowledged other related terms. These are now briefly expanded upon.

8.2.1 Empowerment as a process and an outcome

According to Friere (1993) empowerment is a process of increasing one's ability to think critically and act autonomously. This study acknowledged empowerment as a process of gaining control over one's life, and independence for people with epilepsy. For example, one female person with epilepsy revealed the following:

> *'Empowerment is choosing to live the life that you want to live, so if you want to work you can work if you want to drive you can drive, look after your kids, so you can do everything independently' (PWEf6).*

A further male person with epilepsy suggested:

> *'Empowerment means having strength in yourself.... to be able to take control of oneself and basically not to be submissive' (PWEm1).*

Likewise, service providers acknowledged empowerment as a process of both gaining control over both personal life and work life. For instance, a strong, autonomous, assertive and competent practitioner, respected by both service users and colleagues was acknowledged:

> *'Having good control over personal health and social and economic life is having a good empowerment over your life.... autonomous in his/her work, a competent specialist, assertive, respected by the team and by the patients' (SPf1).*

Empowerment was also described as an outcome by many participants. According to Freire (1993) empowerment is an outcome when an enhanced sense of self-efficacy occurs as a result of the process (Friere 1993). With this in mind, people with epilepsy recognised an enhanced sense of self-efficacy as a result of been empowered as revealed in the following quote:

> *'Been empowered means that I was able to make better decisions for my own epilepsy and my own treatment' (PWEm1).*

One male person with epilepsy describes empowerment as:

> *'Standing up in what you believe in….to be self-assured enough to take the reaction regardless of what that is' (PWEm7).*

Whilst service providers acknowledged that been empowered results *'in a huge amount of job satisfaction' (SPf5)* the majority of service providers viewed the outcomes of empowerment in relation to improving care provision and facilitating empowerment for people with epilepsy as revealed in the following quotes:

> *Been empowered and been able to make decisions means to give a good quality of service. It means to empower your patient to look after their health, look after their medication' (SPf1).*

> *'Empowerment is been strong enough to take on somebody else's concerns' (SPf6).*

> *'You need to be empowered to empower other people' (SPf2).*

8.2.2 Related terms and empowerment

Many related terms for empowerment were described by people with epilepsy such as: *'self-management' (PWEf9); 'independence' (PWEf6); 'self-assurance' (PWEm7); 'self-esteem' (PWEm4); 'self-advocacy' (PWEf6); 'not to be submissive' (PWEm1); and 'having a voice' (PWEf6)*. Moreover, *'equality' (PWEm7); 'happiness' (PWEf8);* and *'getting the best out of one's life' (PWEf8)* were acknowledged.

However, others identified empowerment as having no inherent significance or *'intrinsic value'* and suggested uncertainty in terms of how empowerment can be understood in the context of epilepsy as suggested by one male person with epilepsy:

> *'Empowerment is one of those words that do not mean anything. It does not actually have any intrinsic value if you say the word…I've yet to figure a way in which empowerment can even be understood in the context of epilepsy' (PWEm7).*

On the other hand service providers understood empowerment in terms of an ability to do ones job and terms highlighted include as: '*autonomous' (SPf2; SPf4; SPf6); 'accountable' (SPf2); 'responsible' (SPf2); 'knowledgeable' (SPf2)* and an *'expert practitioner' (SPf2; SPf7).*

> '*Empowerment as a person is having the knowledge and expertise in your area so you are empowered because I feel competent, whereas if you don't have the experience and starting out you are extremely nervous, so you are not empowered'.*

In addition, mutual respect within the epilepsy service was viewed as important for service providers *(SPf5; SPf7).*

> *'I think empowerment is respect, not necessarily top down respect, but it comes from your colleagues that you work with and support, and the people that you are taking care of and that there is a respect for the efforts that you are making, so it's kind of a mutual thing'* (SPf5).

8.2.3 Concluding comments

Overall, therefore it could be said that empowerment is understood as a complex and multifaceted concept. Whilst some people with epilepsy lack an understanding of empowerment, the majority of participants acknowledged empowerment as a subjective process and an outcome. Several related terms to people with epilepsy's understanding of empowerment regarding their epilepsy and self-management was revealed, whilst service providers acknowledged empowerment in terms related to their ability to carry out one's job.

8.3 'Power and powerlessness'

Results acknowledged the significance of power and powerlessness for people with epilepsy and service providers' level of empowerment. Power was described in different ways such as: (1) power over; (2) power to; (4) power with; and (4) power from within. People with epilepsy and service providers expressed fear at individual, relational and resource setting levels. These are now explored.

8.3.1 Power over

'Power over' was acknowledged by people with epilepsy as controlling power and referred to the capacity of some individuals to control others. For example, relational fear was experienced by people with epilepsy when interviewed by the medical profession.

'I can't really talk to the consultant. The consultant has got too much of a presence and I am scared stiff of him and I imagine a lot of people feel the same' (PWEf6).

'I felt disempowered when one of the cardiac consultants here insisted on putting me on a beta blocker even when I told him I wasn't keen because I had a suspicion that the beta blocker was part of my problem. He was very arrogant so and so. I was already seeing a cardiologist elsewhere. His manner and behaviour made me feel disempowered. There was no decision for myself. It was like 'put him on it now' (PWEm10).

Others reported the inability to participate in their care:

'Do they expect people with epilepsy to be brain dead because they have epilepsy and not ask questions? That is not my problem. That is their problem. I would hate to think that other patients that are not as confident as me would be treated like that' (PWEf:4).

'*When I was first diagnosed the nurse tried to hide the information from me. I told her I was entitled to know. I feel hurt because of this. What can I do to challenge or change this? (PWE m:7)*.

Additionally, paternalistic practices by family members and carers was evident during the observation of service and consequently people with epilepsy lacked autonomy (see example Box 8.1).

Box 8.1: Observation of service: Paternalistic practices by family and carers

During a consultation with a medical doctor a male person with epilepsy was asked to describe how he had been feeling for the past 6 months. The person with epilepsy was very happy to talk to the service provider, however was continuously interrupted by his wife. She completely rejected her husband's occurrence of events and began to answer most of the questions posed by the service provider. While the person with epilepsy tried to answer, his wife was determined to control the situation and eventually the person with epilepsy began to retreat within himself.

Whilst service providers acknowledged taking people with epilepsy's views into account and '*allowing them to make their own decisions' (SPf1; SPf7; SPf4)* others described their '*unwillingness to surrender control' (SPf2; SPf4; SPf7)* and acknowledged failing to listen to people with epilepsy's concerns and viewpoints with regards to medication choice and decision making:

'I am not sure if I'm totally comfortable surrendering complete control about medications and med choices' (SPf4).

'*In other services with different neurologists patients are expected to do what their told and are not really expected to have an opinion' (SPf5).*

Indeed, service providers admitted that it can be difficult to be patient centred all of the time:

> *'I do recognise that it can be difficult to be patient centred all the time but we are trying to allow patients to be actively involved in their care and we do allow the patient to steer us in the way they would like their epilepsy managed' (SPf3).*

A conflict between the nursing profession and the medical profession as a result of medical dominance was suggested by some of the nurses interviewed; negatively impacting on nurses' sense of empowerment as reported by one ESN:

> '*Conflict with the medical profession can inhibit my empowerment especially when there is a disagreement with what I should or should not be doing and I suppose embracing the whole ANP role' (SPf5).*

Whilst this is clearly perceived as an issue by this informant, it is not clear that the medical professionals within the service recognise this since the interviews with doctors within the service did not indicate that they had any issue with the role of the ESN. This may indicate one of two things. Firstly, that there is unconscious attitude and behaviour amongst medical professionals towards ESN's empowerment (hence their lack of recognition of it as an issue) or, secondly, that it reflects an expectation of medical behaviour on the part of ESN's who may be socialised into believing that the medical profession resent their empowerment and thereby see medical behaviour, including disagreement, through this lens.

8.3.2 Power to

'Power to' is the ability of an individual to increase their choices and act on them without weakening the power of another (Rowlands 1997). However, people with epilepsy reported the '*inability to participate'* (PWEf:4) within the Irish epilepsy services, and '*rely solely on the experts*' (PWEf: 6).

'Overall I have left my epilepsy in the hands of neurologists and I have not seen outside counsellors or support from others…..People who suffer from any neurological or mental disability will often lack confidence because they will feel they won't be mentally capable or believable to lodge a complaint. They will leave decisions in the hands of others' (PWEm: 1).

For others an unequal partnership was highlighted:

'*I don't think people with epilepsy and service providers have an equal partnership. It's way imbalanced. Partly because the amount of knowledge needed to understand epilepsy is huge. If you have a deficit in the understanding base there will always be a deficit in empowerment. I don't necessarily* *feel in control of my life but I don't think that has anything to do with epilepsy. I think that is a whole separate issue in terms of are we in control of our lives anyway. There is knowledge deferential in those who are in control and those that are controlled' (PWEm:10).*

However, some people with epilepsy acknowledged the ability to participate and make decisions in their care:

'I am supported by staff. I do feel assertive to make decisions about my medications and the doctor reviewed the prescriptions' (PWEm:2).

'You are prompted here at this service and they inquire about different things and aspects of your epilepsy' (PWEm: 3).

A significant number of service providers acknowledged empowerment as having the power to make decisions, gain autonomy and facilitate empowerment for people with epilepsy:

> *'Power to do what you want or need to do to empower patients to help them to do something' (SPf6).*

However, one person with epilepsy acknowledged that service providers are in denial and have no power to facilitate empowerment for people with epilepsy:

> *'There is nothing a service provider can do to empower a person with epilepsy to change this. You can see in a service providers eyes they would want to do more and say more but they are totally disempowered because there is nothing they can do. They are totally in denial. It totally contradicts the word empowerment' (PWEm7).*

This was also reiterated by service providers in relation to having no power to make changes within the service in order to improve care provision:

> *'We are two years down the road and we have no plan in place with regards to psychological services and I am frustrated at times within the service. Will we be struggling in 5 years' time and going forward? Where are we going to be?' (SPf3).*
>
> *'No the system is not empowering me to give the care all the way from diagnosis to management' (SPm8).*

A lack of resources and space identified during the observation of service results in service providers with little power to enable psychosocial supports for people with epilepsy (See Chapter 6, Box 6.1).

8.3.3 Power with

'Power with' is acknowledged as a collective action by a group (Rowlands 1997). With this in mind, people with epilepsy identified the potential of support from others to help them come to terms with their diagnosis.

> *'With the right doctor and right people around you one can deal with a diagnosis of epilepsy' (PWEm2).*

Whilst the significance of peer support was reported, people with epilepsy did not communicate during their hospital appointments. Whilst many service providers also acknowledged the significance of peer support for people with epilepsy, service providers suggested that joint decision making between service providers and people with epilepsy has the potential to '*negate the institutional disempowerment to a certain extent' (SPf7).*

8.3.4 'Power from within'

'Power from within' refers to a psychological change which establishes itself from gaining control over one's own life and the ability to do things (Veneklasen and Miller 2002). Some people with epilepsy acknowledged having decision making power in relation to medications and feel in control of one's life:

> *'Ultimately I have the decision making power myself. I can just stop taking them'* [medication] *(PWEm10).*

> *'I haven't let epilepsy ruin my life. I feel in control of my life….I feel empowered and I set goals and I am saving to go abroad' (PWEm2).*

However, at an individual level some people with epilepsy described experiencing fear and vulnerability as a symptom of their illness, in particular as a result of the unpredictable and variable nature of seizure occurrence. Consequently, people with epilepsy suggest that '*you can't overcome a diagnosis of epilepsy' (PWEm7),* and *'you can't disclose your diagnosis (PWEm7; PWEm3; PWEf9).* Moreover, the fear of disclosure was significant in relation to stigma and prejudice:

> '*The vast majority of people with epilepsy don't talk about it- that's a typical example of not being empowered' (PWEm7).*

> '*A lot of people with epilepsy try to hide the fact that they have epilepsy' (PWEm3).*

At a resource level a lack of '*control'*; *'freedom'*; and '*personal privacy'* was acknowledged by people with epilepsy. Indeed one person with epilepsy acknowledged the need for enhanced social and leadership skills to *'be able to take control' (PWEm1).* Findings of this study suggest that many people with epilepsy lack power from within and play a passive role with regards to their participation in healthcare decisions. Whilst observing the service, people with epilepsy passivitywas evident in relation to their healthcare.

As a counter point, the majority of service providers described a sense of empowerment as the following quote reveals:

> *'I feel I have decision making power and allowed to make decisions. I don't feel that anyone from a clinical point of view thinks that I should or could not give my opinion or say my opinion is not as valid as somebody else's* '*(SPf7).*

8.3.5 Concluding comments

Overall, therefore it could be said that people with epilepsy experience different levels of power and powerlessness within Irish epilepsy services. Indeed, the imbalance of power is evident as service providers have difficulties with surrendering control and allowing people with epilepsy to make their own decisions. Moreover, paternalistic practices by service providers and families are evident. Consequently intimidations, humiliations, and dignity violations were acknowledged by people with epilepsy. Whilst the majority of service providers described a sense of 'power from within' others acknowledged frustration with having no power to make changes within the service.

8.4 Connecting empowerment to the 'system': Epilepsy services and care provision

System issues that impact on participant's level of empowerment include: (1) access to epilepsy services and care provision; and the (2) role and competency of the GP; human and financial resources; and organisational support. These are now explored.

8.4.1 Access to epilepsy services and care provision

Overall, people with epilepsy were happy with epilepsy services and care received. Responses to care received include '*excellent', 'really good', 'great', 'valued' 'welcomed' 'great aftercare', 'cant praise it enough' 'don't think anything could be improved with the service'* and *'the doctors, nurses and staff are really good'.*

Moreover, people with epilepsy identified services as empowering.

> *'In the current service there are many more examples of empowerment been promoted than disempowerment' (PWEm1).*

For people with epilepsy the benefits of nurse led services were articulated and the email service provided by the specialist epilepsy service was identified as helpful:

> *'The email service offered is great because you can ask questions that you forget to ask at the clinic, and they are very good for getting back to you'.*

However, people with epilepsy still encounter poor access to epilepsy services and investigation; poor continuity of care; and experience lengthy delays between hospital appointments.

> *'The service I got from the hospital was an odd scan here and there, blood tests to check drug levels' (PWEf4).*

> *'You see a consultant one day and a different doctor the next, and a different day the next. So you don't get to build up a relationship. Because you see different people all the time and the new person does not know anything about you, there just looking at your file and they certainly don't know anything about you as a person' (PWEf6).*

> *'A 6 month or one year wait is too long between visits. In this time patients could be having seizures, or medications may not be working out. I have seen my GP but he can't change the medications that I am on' (PWEm1).*

Moreover, during the observation of service it was identified that people with epilepsy experience lengthy delays during hospital appointments (see Box 8.2)

Box 8.2: Observation of service: Delays during hospital appointments

Delays during hospital appointments were observed regularly. While some patients can be seen very quickly others can have up to a 2-3 hour delay. This can be as a result of emergencies; some consultations take longer than others in particular if service users are unwell; and ESN's sometimes wait to discuss a patient with a registrar/consultant in relation to medication changes. However, poor communication in relation to delays were discussed with people with epilepsy, leaving many frustrated and angry.

A requirement for the provision of a positive service to better engage people with epilepsy was recognised.

> *'A more positive service is needed so that people are not afraid of using the service making it more attractive to the patient' (PWEf4).*

Whilst 'Epilepsy Ireland' a voluntary organisation to support people with epilepsy was recognised for providing good support, people with epilepsy recognised that '*there is little Epilepsy Ireland can do to help' (PWEm1).*

The need for alternative strategies and techniques such as '*mindfulness training'* to help people with epilepsy in terms of anxiety, attention and concentration issues were recognised. Additionally, poor information provision and educational delivery was acknowledged. While group educational programs have recently been implemented, service providers recognised that delivery was '*a bit ad-hoc'* and '*is not interactive at all' (SPf5).* It seems that for some people with epilepsy too much emphasis is placed on seizure management

> *'The emphasis seems to be always getting the seizures stopped which I can understand because its important part of it but I think it has become too focused on it' (PWEm1).*

Overall, service providers identified epilepsy services and care provision as '*progressive'*, '*innovative', 'supportive'* and '*open',* in particular since the introduction and implementation of the NECP:

> *'Since the development of the NECP, care provision has improved and now there is a Rapid Access Clinic (RAC) in certain areas and people are getting seen a lot quicker and if people run into problems they can to the Accident and Emergency (A&E) department with seizures they could then get to be seen in a RAC clinic in 3-4 weeks' (SPf2).*

However, it seems a geographic variation in availability, access and quality to Irish epilepsy services and care provision for people with epilepsy exists:

> '*The services are patchy and inadequate in some areas and exemplary in some locations and less good in others. It's not a reflection on the personnel who provide the service, I think it's where personnel with expertise in epilepsy are located and it's also geographic location' (SPf7).*

Service provider reported '*little access to the services outside the mainstream' (SPf3; SPf5)* in particular for people with epilepsy in prison:

> *'Patients that are in prison are not represented and are not getting a good service from us. They can't contact us and we don't know when there coming in' (SPf5).*

Indeed, one service provider identified unequal access as a determinant to the level of empowerment for people with epilepsy:

> *'If services were more uniform across the geographical location so that everyone is getting the same experience then there would be less differences in the level of empowerment between patients' (SPf7).*

Furthermore, a clear lack of psycho-social supports for people with epilepsy was identified by service providers:

> *'I don't think the psychosocial issues are being met. I don't know if we are massively equipped to deal with this or even that we are competent to deal with this and certainly don't have the time' (SPf5).*

Service providers acknowledged that health literacy was an issue for people with epilepsy and identified the need for tools or checklists to be implemented within the service to ensure a reasonable level of understanding with regards to information delivery. While group educational programs have recently been implemented, service providers recognised that delivery was '*a bit ad-hoc'* and '*is not interactive at all' (SPf5).*

8.4.2 Role and competency of the GP

People with epilepsy revealed insecurity regarding the role and competency of their GP with respect to their care. Many participants expressed the view that GP's lack the expertise to manage their condition and/or continue to remain passive with respect to patient needs (PWEm1; PWEm3; PWEf4; PWEm10) as the following quotes reveal:

> '*I don't really talk about my epilepsy because it's not really their field and you need to be specialised' (PWEm3).*

> '*I have seen my GP but he can't change the medications that I am on. Medication's need to be changed by a neurologist' (PWEm1).*

> *'He might check the tablets you are on and dosage and increase or reduce your dosage but offers no psychological or social support' (PWEf4).*

Service providers revealed little confidence in GP's competency in relation to epilepsy care. For one male service provider:

> '*GP's are a lot more comfortable to sit down with patients to talk about an issue with regards to asthma' (SPm8).*

He suggests that people with epilepsy need *'managed primary care' where patients get called every year to visit with their GP, an intelligent resource'(SPm8).* Moreover, whilst SOP's have been developed for primary care it is suggested that GP's don't utilise them: *'we can't get them [GP's] to use it [SOP's]' (SPm8).*

Finally, service providers recognised that the current healthcare system has to make concessions, in particular in relation to primary and specialist care collaboration and shared care in order to sustain specialist services:

> *'I don't think anyone ever is really going to have the power to tell GP's what to do. I think it will happen when the system realises that this is the only way to sustain a specialist service. It will come to the point where we won't be able to take on new work if we can't get patients out of the service. So the system will have to make some concessions. I think it is achievable and part of a package of measure' (SPm8).*

8.4.3 Human and financial resources

In terms of human and financial resources there was general agreement by service providers that '*time constraints'*, *'busy workloads' 'lack of funding'* and '*lack of space'* impinge negatively on service providers level of empowerment, autonomy and professional development.

> *'Empowerment for me is getting things done that the patient needs and it's not always happening' (SPm8).*

Service provider's revealed feeling '*overwhelmed'*:

> *'The amount of work that needs to be done is overwhelming and there is a total lack of time and lack of resources' (SPf6).*

> *'Space is also an area that disempowers me. Trying to organise space, one minute you have a space and you are organising everything, the next minute you are told oh sorry you can't have that space. It is very disempowering, and this is coming from management' (SPf2).*

From a structural power perspective, appropriate resources are an essential element in the capacity for empowerment (Kanter 1993). Service providers acknowledged that lack of resources result in poor psycho-social supports for people with epilepsy:

> '*I think there is a big gap with psychosocial issues for people with epilepsy at the moment. I don't think we have the funds. Ideally there should be a neuropsychologist/ neuro-psychiatrist in every epilepsy clinic or we should at least have access to them regularly and patients don't. Social needs are not met because there always seen in busy clinics' (SPf4).*

8.4.4 Organisational support

Service providers acknowledged poor organisational support and feel powerless in relation to improving or enhancing the service. For example, service providers are aware of the fact that their opinions on how to improve the service have negative connotations:

> *'The organisation does not enhance my empowerment. On a number of occasions I have for things that I felt would enhance our service and I have been told to keep my mouth shut, not*

> *in those words but basically don't rock the boat, don't complain about things, don't look for anything, you are not going to get it. This is very disempowering' (SPf 7).*

8.4.5 Concluding comments

Overall, whilst high levels of satisfaction with epilepsy services and care provision were acknowledged, people with epilepsy still encounter: poor access to epilepsy services and investigations; poor information and educational delivery; poor continuity of care and experience lengthy delays during and between hospital appointments. The need to fully understand the social, psychological, structural and educational difficulties of people with epilepsy and the provision of greater supports was identified**.** Although service providers highlight improvements in epilepsy services and care provision in particular since the introduction and implementation of the NECP, it seems that a geographic variation in availability, access and quality to epilepsy services and care provision is a determinant to the level of empowerment experienced by people with epilepsy. People with epilepsy identified that GP's lack the expertise to manage their condition and/or continue to remain passive with respect to patient needs. Moreover, service providers acknowledged their frustration with the role and competency of the GP in relation to epilepsy care. Arguably, better primary care provision, collaboration and understanding are required in order to sustain a specialist epilepsy service. Finally, service provider's level of empowerment is negatively affected by the lack of human and financial resources.

8.5 Empowerment, care provision and 'communicative competence'

Habermas (1984) argues that decisions involving human beings require a lifeworld perspective, an approach which foregrounds human experience within its relational, cultural and historical context (Habermas 1984) which he terms communicative comptence. This study suggests that service user-provider interactions impact on people with epilepsy's level of empowerment. This is now explored.

8.5.1 Service user-provider interaction

The majority of people with epilepsy revealed both positive and negative experiences of service provider interactions. For example, being '*acknowledged', 'listened to', 'respected', 'taken seriously', 'supported'*, and *'treated as an equal'* by service providers positively impacted on empowerment experiences for people with epilepsy:

> *'I felt empowered when I saw my consultant here and he went down through my whole case history. He talked to me on a one to one. It was like a sit down and a chat. He took an interest in my case and it made me really feel empowered. It made me feel that I was worth something and valued. I felt better walking out of the office'* (PWEm3).

> *'My own doctor asked me what plan I wanted and how I felt on the current medication that I was on and how did I think it would want to be changed. This surprised me because nobody ever asked me this and it made me feel very empowered. I felt confident and listed too' (PWEm1).*

As a counter point, poor service user-provider interactions and not being treated as an equal negatively impacts on empowerment experiences for many people with epilepsy. Experiences of frustration and vulnerability was acknowledged:

> *'When doctors and nurses don't listen it makes you feel disempowered. Like they think what their saying is 'gold' and their on a pedestal and your down there. They do not take your views or ideas into account' (PWEm3).*

> *'I felt very frustrated a couple of years before this from a previous doctor when I was just trying to tell him that the medication wasn't working for me and he did not listen and just continued me on this medication' (PWEm1).*

> *'If they don't listen or communicate with you on a one to one basis it is really disempowering. It doesn't give you much confidence in the system and that it-self is disempowering' (PWEm3).*

> *'I asked a lot of questions at one appointment. I was asked by one doctor what I did for a living. He asked me about my plans to have children and I said I wasn't planning. He said to me 'Why do you think it is all about you? I would like to ask him what did he mean by this? I felt his level of respect for women or patients was terrible. I felt disempowered. Do they expect people with epilepsy to be brain dead because they have epilepsy and not ask questions? That is not my problem. That is their problem. I would hate to think that other patients that are not as confident as me would be treated like that. It does not affect my level of respect for service providers. I just get on with it. However, even if I say this, this is not the point and it could still upset you'* (PWEf4).

Service providers acknowledged the need to improve their interactions with people with epilepsy:

> *'I think within the services we need to improve our interactions with the patients and encourage the patient with the email, phone and educational service' (SPf3)*

As a counterpoint, others expressed feelings of fear during some interactions with people with epilepsy and families. It was revealed that people with epilepsy can be '*angry*' and '*aggressive' (SPf4; SPf6*) as a result of their epilepsy, medications or a frustration with the service. One service provider acknowledged having to leave the door open during a consultation:

> *'They [people with epilepsy] can start off being nice and then get angry within a couple of minutes. It's like they just turn. It could be the epilepsy, medications, but I do keep the door open. First time it happened I did feel disempowered' (SPf6).*

Consequently, feelings of disempowerment were expressed by one female service provider:

> '*When patients get very angry and they take their frustrations or stresses out on you, which is something to do with what they are going through or the system, like waiting times, not getting scans done etc' (SPf4).*

8.5.2 Professional communication and collaboration

Service providers suggest that care provision can be compromised as a result of poor communication within the Irish epilepsy services. There was a fear of consequence in relation to getting things done or repeating work that had already been carried out:

> *'There is sometimes a break-down in communication to get things done or repeating things that have been done' (SPf5).*

Poor '*engagement', 'working relationships',* and '*collaboration'* within the specialist service and also with primary and voluntary care services were identified *(SPf6; SPm8; SPf3).*

> '*The other thing that we didn't get right is that the engagement with Epilepsy Ireland is not as stream line as I would like it.... It is a communication issue with regards to epilepsy Ireland, however I think it will get better. I think they need a presence here and we need to be able refer patients to them easier' (SPm8).*

> *'Looking at how our clinic works and complex cases are been seen every 6 months, we need to look at how the gap is filled in, whether that is the GP or somebody else' (SPf3).*

One service provider suggested that whilst care provision can be complex, an alignment of goals between the services is required.

> *'Provision of care can be complex. It needs constant engagement with the main players. It's not just the job of one person. It's the people who are in charge of the service on both sides that need to align their goals- that's the problem. Alignment of goals takes time and it takes a year of meetings before people realise that their talking about the same thing' (SPf5).*

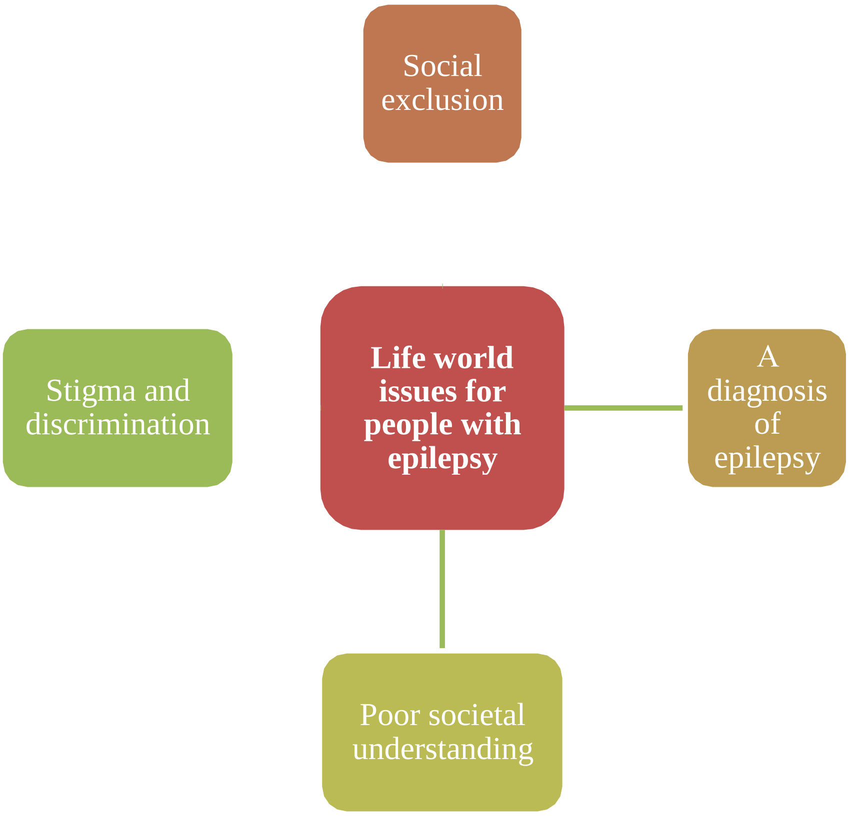
8.5.3 Concluding comments on empowerment, care provision and 'communicative competence'

Overall, therefore it could be said that poor service user-provider interactions can result in disempowerment for both people with epilepsy and service providers. As acknowledged previously one reason perhaps for this is that an imbalance of power exists within epilepsy services[47]. People with epilepsy acknowledged feelings of frustration and disempowerment as a result of not been listened to and not treated as an equal. Although service providers acknowledged possible reasons for people with epilepsy's anger and aggression, arguably a further reason is that people with epilepsy are an oppressed group and are now consciously aware of the stigma; discrimination and social isolation that is attached to them as a group. Service providers also acknowledged that major improvements are needed in relation to communication, collaboration and working relationships within the specialist service. An alignment of goals between the services such as primary care and the voluntary service 'Epilepsy Ireland' was identified as necessary.

8.6 Connecting empowerment to 'life world' issues for people with epilepsy

Life world issues that impact on people with epilepsy's level of empowerment were identified and include: (1) a diagnosis of epilepsy; (2) stigma and discrimination; (3) social exclusion; and (4) poor societal understanding (see Figure 8.1)

Figure 8.1: Life world issues that impact on people with epilepsy's level of empowerment



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[47] See section 8.3.5 Concluding comments on power and powerlessness.

8.6.1 A diagnosis of epilepsy

Findings demonstrate the complex psychological, social and structural difficulties that people with epilepsy confront. For instance, mental health, lifestyle, driving, work, academic life, family life, personal relationships, memory and concentration are some areas highlighted:

> *‘Epilepsy has held me back. I didn’t have a clear path in education and career choice. I slept a lot in school because of epilepsy and my medications. I repeated 5th and 6^{ty} year. I feel like I have woken up from a sleep or foggy dream. It has impacted on everything’ (PWEf6).*

The side effects of medications were acknowledged:

> *‘I have psychiatric issues arising from the medications. They have only found out that these issues are because of the medications. I have memory problems as well’ (PWEm10).*
> ‘*I forget lots of things because I am on medications and some people can prey on that’ (PWEm2).*

Some people with epilepsy suggested feeling ‘*like a burden’* to their families, partners or carers. They acknowledge feeling ‘*guilty*’ and *‘bad’* for having to be *‘looked out’* for by their loved ones. On the other hand, some people with epilepsy identified feeling *‘trapped’* by their epilepsy and the feeling of ‘*constantly been watched over’* by families, partners or carers. Consequently the majority of people with epilepsy feel disempowered as this quote illustrated:

> *‘Disempowered is the word I would use to articulate everything I felt so far since I have been diagnosed with epilepsy. You don’t feel comfortable talking about it, wanting to talk about it, wanting to break the social pattern of not talking about it because you are the minority’ (PWEm7).*

People with epilepsy described their symptoms as needing to be understood and explained from a biological-psychological-social level. Symptoms such as: ‘*self-destruct’; suicidal’; ‘depression’; ‘frazzled’; ‘poor sleeping pattern’; ‘forgetfulness’; ‘lazy’; ‘tired’; ‘seizures’; ‘stress’; ‘memory problems’; paranoia’; ‘guinea pig’; and ‘anxiety’* was expressed. Although there was a strong willingness by service providers to understand, listen to and deal with symptoms as best they could the management of symptoms shifts primarily towards the biological level and the control of seizures.

8.6.2 Stigma and discrimination

Many people with epilepsy recognised the ‘*brunt of stigma*’ is as a result of negative reactions by society.

> *'If you mention epilepsy people will immediately recoil as opposed to saying something like cancer there will be immediate sympathy. With epilepsy it's an immediate 'pull away' and you automatically feel isolated' (PWEm7).*

People with epilepsy also described the significance of being viewed as a '*subject*' with '*a life to lead'* as opposed to being viewed as an '*object'*. For example, it was suggested that the medical profession view people with epilepsy as medical instruments.

> *'You know by the medical profession that they have objectified everyone they view. They stop seeing patients as people they see them as medical instruments' (PWEm7).*

Moreover, the difficulty in securing employment in relation to prejudice and discrimination was acknowledged. For example, it was suggested that employers view epilepsy as a *'weakness' (PWEm1)* and '*a liability' (PWEm7).* People with epilepsy identified personal feelings of shame and embarrassment as a result of epilepsy and a fear of enacted stigma:

> *'There not supposed to be prejudice against you but they will employ someone else over you and they still view it as a liability. I have spoken to other people with epilepsy that have dealt with these issues' (PWEm 1).*
>
> *'Personally I think employers think people with epilepsy are a liability and I totally understand that. In a job interview I don't feel I can say that I have epilepsy. There is no legal requirement for me to say it. But it makes jobs and interviews a lot more difficult' (PWEm7).*

Indeed, in a matrix query with regards to gender, structural issues and vulnerability were coded more times to male participants compared to female participants[48]. No reasons for this were acknowledged.

8.6.3 Social exclusion

Many people with epilepsy identified social exclusion and this negatively affected their levels of empowerment. One person with epilepsy expressed their inability to overcome a diagnosis of epilepsy as a result of '*been shoved in the corner' (PWEm7)* and experience rejection of contact. Moreover, fear and distress of disclosing their diagnosis of epilepsy to a future partner was recognised:

> *'If you have epilepsy you can't open yourself up. There is a girl I am getting on well with at the moment so when do I tell her 'oh by the way I may have a seizure on our wedding day' (PWEm7).*

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[48] See Chapter 6. Section 6.4.3.1, table 6.1 and matrix coding query and factors relating to gender.

8.6.4 Societal awareness and understanding

The majority of people with epilepsy identified poor societal awareness regarding epilepsy and its management.

> *'People have misinformation about epilepsy and view it as a weakness especially in employment' (PWEm1).*

Furthermore, people with epilepsy suggested that society fear epilepsy and have preconceived notions of epilepsy:

> *'Socially people don't have a clue unless they know someone with epilepsy. For some people they have a fear of it, they have a preconceived notion of what epilepsy is and they don't know how to deal with it' (PWEm10).*
>
> '*One person did stay they were freaked out because I had epilepsy and I was annoyed. People deal with different things in different ways' (PWEm2).*

It was also recognised that poor understanding '*is the reason people don't have empathy for epilepsy' (PWEm10).* In a further matrix enquiry, male participant's coded societal awareness and understanding more than compared to female participants[49].

8.6.5 Concluding comments

Overall, therefore it could be said that a diagnosis of epilepsy affects people with epilepsy's life world in relation to psychological, social and structural difficulties. People with epilepsy feel disempowered and this level of disempowerment is enhanced further by stigma; discrimination; social exclusion and societal lack of understanding in relation to epilepsy. It was identified that the subthemes societal awareness and understanding; structural issues and vulnerability; were coded more times to male participants compared to female participants.

8.6 Antecedents to empowerment

Having identified factors that negatively influence levels of empowerment within epilepsy services, service providers identified antecedents to empowerment within Irish epilepsy services and these include: ICT; support structures; education; and empowerment policy (see Figure 8.2).

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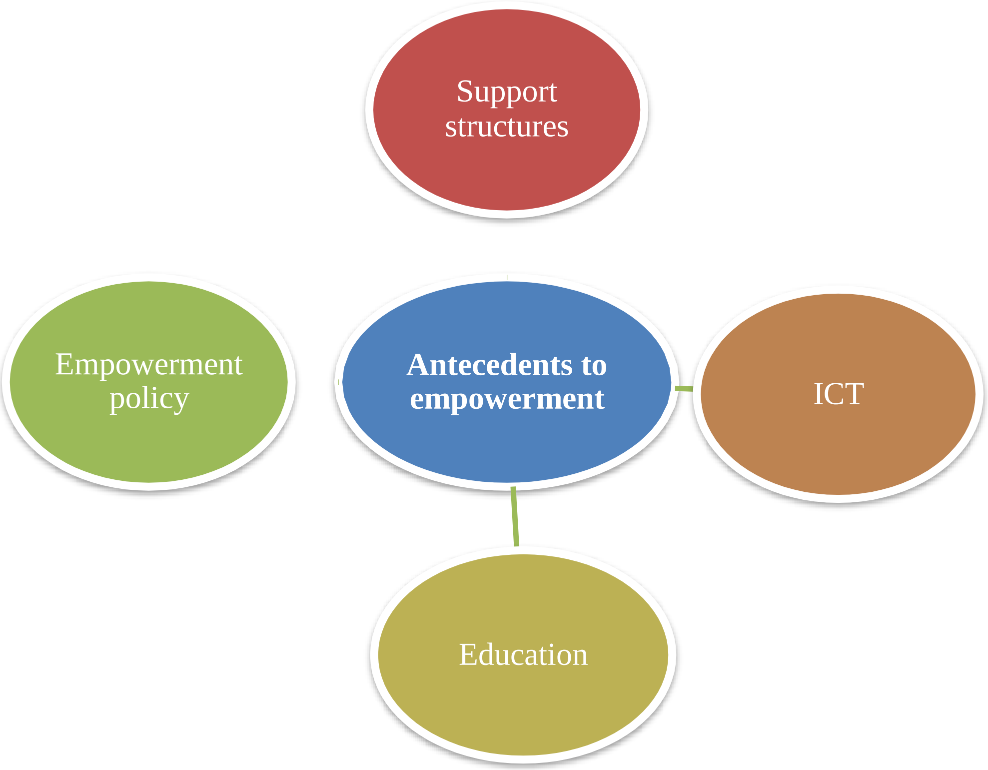
[49] See Chapter 6: Section 6.4.3.1 Matrix coding query.

Figure 8.2: Antecedents to empowerment



8.6.1 Information Communication Technology

Service providers considered ICT as an important ingredient in enhancing communication and sharing of information between healthcare sectors to improve shared care between services:

> '*If there was a chronic disease management program in general practice that we were part of that every patient with a chronic disease was recognised..... I think ICT would enable this'... (SPm8).*

8.6.2 Support structures

Service providers suggested that managerial and professional support was needed so that service providers '*feel backed up professionally' (SPf5)* and safe in a system that can be difficult at times:

> *'There is no real support for staff if someone is rude to you. They have patient services for complaints but as service providers we don't have the same. I don't feel at all that we have the same support network at all or grounds for defending ourselves. There has to be sort of protective mechanism for clinicians and doctors given how difficult the system can be sometimes' (SPf4).*

ESN's identified fear in relation to advanced decision making and autonomy with regards to their future role as an ANP and acknowledged the need for improved professional support in particular in relation to legal and professional responsibilities.

Service providers recognised that poor community support exists to deal with stigma and acknowledged the significance of assessing people with epilepsy's needs within the service:

> *'In the community there is a probably not a lot of support out there and it's very disjointed and it's difficult because patients don't really want to deal with it along with the stigma of epilepsy. So we need to assess what people want' (SPf5).*

8.6.3 Empowerment policy

Service providers acknowledged that change could only be effective if there was political will to do so. With this in mind, there was a call for the development and implementation of an empowering policy for chronic illness:

> '*Empowerment is such a big broad subject and no government policy is in place on empowerment and we know chronic disease is going to be such a problem in the next few years' (SPf3).*

8.6.4 Education and training

Service providers recognised that the provision of empowering education for people with epilepsy has the potential to reduce seizure frequency, improve the *'self-management'* and '*quality of life'* for people with epilepsy and enable service providers to share decision making with service users. There was also the view by many service providers that additional professional education and training for service providers to facilitate self-empowerment and the empowerment of others was needed:

> *'I think it is important to get educational sessions on how to become empowered and to empower others. There is definitely room for this in professional education' (SPf2).*

Moreover, ESN's suggested that more skills within their own education were necessary to help them overcome barriers to their future advanced role within the service:

> *'I think for the advanced practice with regards your role development and legal aspects, it would be great to get skills with regards to barriers to your advanced role within your own profession and other professions' (SPf5).*

Furthermore, service providers identified poor societal awareness regarding epilepsy and its management.

> *'I think the public has a very poor understanding of epilepsy. I think there is still a lot of stigma, difficulties in employment and school. I think people have fixed views of what epilepsy is and how to fix it (kind of voodoo)'… I think it's more of a social problem rather than a service problem with regards to the reason people with epilepsy are disempowered' (SPf7).*

With this in mind, one service provider suggests that '*providing education to the general population is required' (SPf7).*

8.6.5 Concluding comments

Overall, therefore it could be said that the development and implementation of ICT structures has the potential to improve communication within the service. Moreover, more support is a necessary antecedent to empowerment for people with epilepsy and is lacking within the service and community. Service providers also require managerial and professional supports in particular ESN's. Education was deemed a necessary requirement for service providers to facilitate and enable empowerment within the epilepsy service. Whilst service providers advocate that people with epilepsy live a normal life as possible, they tend to prioritise symptoms within an illness context and fail to focus on the person's life world. One reason for this is that arguably service providers view this as a community issue as opposed to a service issue. Given the complexity of the concept of empowerment and the many factors that impact on people with epilepsy and service provider's level of empowerment a healthcare policy in relation to empowerment for chronic illnesses is necessary.

8.7 Discussion: Empowerment within Irish Epilepsy services using a specialist epilepsy service as an exemplar

Consistent with the literature, the findings from this current study suggest that empowerment is a complex and multi-faceted concept (Gilbert 1995, Rodwell 1996, Ryles 1999). Arguably any discussion of empowerment would be superficial without an understanding of power (Gilbert 1995, Honey 1999, Morrall 1996, Ryles 1999). According to Kuokkanen *et al.* (2007) power and empowerment are interwoven, and that in order to understand empowerment one needs also to understand power. Similarly, Bradbury-Jones *et al.* (2007) suggested that the difficulty in understanding power and its relationship to empowerment is that they both take on different forms in different contexts. Power can be seen and understood in observing how people or institutions (or in this case within epilepsy services) are influenced, controlled and organised. Bearing this in mind, this study acknowledged the close link between power and empowerment with many people with epilepsy acknowledging the significance of a ‘power from within’ to their experience of empowerment.

Whilst some people with epilepsy lacked an understanding of empowerment the majority of service users and providers acknowledged empowerment as a subjective process and outcome and an access to ‘power from within’. This enables people with epilepsy to gain control over one’s life, make better decisions and self-manage. For service providers the ability to provide a good service and facilitate empowerment for people with epilepsy was also identified. Indeed, according to Chandler (1992 p.66) empowerment is a means to *‘enable individuals to feel effective so they can successfully execute their jobs’.* Therefore, at the very least, empowerment provides an impetus for action, or appears to propel action.

Findings from this study suggest an imbalance of power within the Irish epilepsy service. Service providers claim control over knowledge and make decisions for people with epilepsy and arguably not consciously aware of their disempowering practices. This was evident as one service provider acknowledged not feeling totally comfortable *surrendering complete control’* about medication choice to the person with epilepsy. Although some people with epilepsy recognised feeling in control of their life, others acknowledged a lack of power and do not feel in control of their life[50].

As indicated in the review of the literature, there are a number of different perspectives from which empowerment and power can be viewed (i.e. organisational/structural theory, psychological theory, poststructuralism; and CST[51]. Whilst it was possible to identify aspects of all theoretical perspectives on empowerment dispersed throughout the findings of this research, arguably CST is broad enough to illustrate completely, the broad spectrum of factors which have the potential to impact on empowering experiences within the Irish epilepsy service[52]. For example, through the lens of CST, one can see how the power and knowledge of service providers acknowledged in this study can potentially be oppressive to people with epilepsy through the imposition of choice and the discursive power of medical values. In this context, CST assumes that all social systems, including

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[50] See Section 8.3.1 and 8.3.2

[51] See Chapter 1: Section 1.7: Theoretically underpinnings of empowerment.

[52] See Chapter 5: Section 5.4 The potential of CST as an alternative meta-theory framework for the study of empowerment within epilepsy healthcare.

health care, are potentially oppressive (Dickinson 1999). Considering the service user-provider relationship, this becomes even more evident because of the influences of biomedical knowledge, power, status, and issues of access to diagnostics and treatment (Fredericks *et al.* 2012). CST is described by Mathews and Scott (2008) as an approach where oppressive social structures are maintained by the dominant.

Whilst there are high levels of satisfaction with epilepsy services and care provision, similar to previous research findings (Poole *et al.* 2000, Al-Adawi *et al*. 2003, Rajpura and Sethi 2004, Hayes *et al.* 2007, Chinthapalli *et al.* 2008, Varley *et al.* 2009, Ross *et al.* 2010, Varley *et al.* 2011), people with epilepsy felt that epilepsy services and care provision can negatively impact on their empowerment experiences. Improvements with regards to engagement of all stakeholders within the service, shared epilepsy care and continuity of care were highlighted. Strikingly, these findings suggest that empowerment within the service will be ineffective, in terms of implementation and service user experience, if it takes place in one part of that service experience and not in other aspects. Therefore, for empowerment to be truly effective there needs to be a holistic service engagement with both the concept and the operation. Thus, although a model of shared epilepsy care between the primary and specialist clinical services is part of the new model of care in Ireland, these results would suggest that considerable improvement is required. With this in mind, the NECP in collaboration with academic partners from the Royal College of Surgeons in Ireland (RCSI), Maynooth and Dublin City Universities is conducting a project entitled Epilepsy Partnership in Care (EPiC) to explore and advance the integration of care and services provided. The EPiC Project aims to realise the promise of Integrated Care for people with epilepsy in Ireland (Fitzsimons *et al.* 2017). It is collaboratively observing and cataloguing the diversity of needs, and experiences within the epilepsy care domain in Ireland from the day-to-day life of the person with epilepsy to the experiences of those who deliver services and care (Fitzsimons *et al.* 2017).

A significant theme identified suggests that poor communication is distorting the service experience. This was most evident during the service user-provider interaction. Moreover, service providers described poor collaboration amongst the specialist service, primary care and the voluntary organisation, Epilepsy Ireland was also recognised. This is in line with previous research findings in relation to the difficulties in inter-professional teamwork in accomplishing collective performance in healthcare (Kvarnström *et al.*

2011). According to Tylefors *et al.* (2005) teamwork involving various professional contributions should be considered in person-centred care. Likewise, service providers in the present study suggest a need for inter-professional and organisational collaboration and cooperation to facilitate empowerment within the Irish epilepsy service.

Writers such as Habermas state that distorted communication can result in disempowering life situations and certainly the results from this study echo this sediment. Thus, it would seem that professional communication is a significant weakness within the current service which, as research indicates, if not addressed will make it difficult to empower people with epilepsy (Varley *et al.* 2011). Thus the challenge for service providers is to find a balance between the notion of beneficence and respect for autonomy. Hess (1996) suggests that a communication based on mutual trust and responsibility, respect for each other's expertise and acknowledgement of equality between two human beings could be the means to ensure balance between these two positions. However, respect for autonomy requires service providers to actively support patients in making decisions about treatment, and then to accept such decisions (Olsen 2000).

CST, in particular Habermas's communicative action theory, is recommended as a means to address service provider/user communication imbalance (Burbank and Martins 2009). Habermas's (1990) principle of undistorted communication is whereby the force of argument or reason succeeds in discussion. This can be achieved when there is ability for all affected to be participants in communication, when participants are able to develop some common understandings, and when there is a readiness of participants to listen to ideas and arguments presented.

People are largely socialised by way of their childhood, integration within society and the occupations and professions they locate themselves in (Clouder 2003). Consequently, two socialization processes tend to occur- lay and professional. Contemporary literature states that professional socialization involves the subconscious internalization of customs, values, beliefs and professional responsibilities (Dinmohammadi *et al.* 2013). Traditionally service providers made decisions for the patient based on a belief that they know what is best for the patient (Emanuel & Emanuel 1992). In recent years, professional socialization have advocated that patients be viewed as partners in healthcare and experts on their own bodies, symptoms and situation (Vahdat *et al.* 2014, Pomey *et al.* 2015, Delaney 2018). However, an outcome of this study that impacted on empowerment experiences for people with epilepsy was the identification of potential or actual threatening situations particulary in relation to service user-provider interactions. Arguably, such situations were managed by service providers through social inferences that were primarily referenced to lay socialization norms and values for practice as opposed to a professional socialization context.

Findings from this study provide further support that stigma, discrimination and social exclusion continue to be associated with a diagnosis of epilepsy (Jones *et al*. 1984, Scambler and Hopkins 1986, Jacoby 1994, MacLeod and Austin 2003, Jacoby *et al.* 2005, Jacoby and Austin 2007, Bandstra *et al*. 2008, Hermann *et al*. 2016). Consequently people with epilepsy experience feelings of fear and vulnerability. Epilepsy has an ancient and well-documented association with stigma. Owsei Temkin's (1971) book entitled: *The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology* maintained that epilepsy has been interpreted as both a physiological process and an effect of spiritual influences. In 1997 the editorial of the British Medical Journal summarised the history of epilepsy as '*4000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma'* (Kale 1997 p.2). In 1996, the ILAE, International Bureau for Epilepsy (IBE) and WHO jointly launched the Global Campaign Against Epilepsy (GCAE), the aim of which is to reduce the treatment gap and bring people with epilepsy 'out of the shadows', and so prevent and eliminate the stigma. The IOM also highlighted epilepsy stigma as an important priority, stressing the continuing negative effects of stigma on people with epilepsy (IOM 2012).

Stigma is defined as '*an attribute which is deeply discrediting* (Goffman 1963 p.3), and the person who carries this discredit becomes generally undesirable, often resulting in social rejection (Jones *et al*. 1984). An evaluation of the literature highlight that people with epilepsy can struggle with enacted stigma (the negative attitudes expressed by others on grounds of perceived social unacceptability or inferiority) and/or felt stigma (personal feelings of shame and embarrassment over having epilepsy and a fear of enacted stigma (Scambler and Hopkins 1986, Jacoby 1994, MacLeod and Austin 2003), in addition to the seizures and restrictions caused by epilepsy. Stigma is linked with poor self-esteem, greater social isolation, and poor psychological health, QoL, and epilepsy. Bearing this in mind, this study reveals a high control (Jacoby 2002, Jacoby *et al.* 2004, Jacoby *et al.* 2005, Jacoby and Austin 2007, Bandstra *et al*. 2008, Hermann *et al*. 2016) prevalence of both enacted and felt stigma among people with epilepsy. Enacted stigma experienced by people with epilepsy has been explored in many studies (Suurmeijer *et al*. 2001, Harden *et al*. 2004, Malaughlin *et al.* 2007, Kumari *et al.* 2009). Findings from this study suggest that felt stigma was mostly explained with concealment behaviour, concerns related to social life, and concerns related to future occupation, similar to a previous study (Aydemir *et al.* 2016). According to Scambler and Hopkins (1990) concealment is an important strategy used by people with epilepsy to appear to be normal. However, it is argued that by concealing the condition causes negative effects which are as serious as disclosing it and encountering enacted stigma (Klink and Campbell 2009).

Whilst a body of literature acknowledges that gender has no relationship with people with epilepsy's QoL, social life, employment, education and self-esteem (Baker *et al.*1997, Christensen *et al.* 1997, Fernandez *et al*. 2017), findings from this study identified that male participants expressed structural issues and vulnerability more times compared to female participants. Indeed the QoL of people with epilepsy appears to be related to the level of social support they receive through the various societal structures, including emotional support, informational support, instrumental support, appraisal, social companionship and affectionate support (Amir *et al.* 1999). Social support mechanisms help people to overcome many of the difficulties they encounter. Individuals with good social support usually have an increased sense of control over their lives, enabling them to have better coping mechanisms for handling adversities (Amir *et al.* 1999, Mula and Sander 2016). Findings from this study therefore suggest that the burden of epilepsy, concerns not only the physical hazards of epilepsy but also the psychosocial consequences involved, such as the negative attitudes of people towards people with epilepsy, manifested as social stigma, social isolation and lack of support. Social barriers to optimal care and health outcomes for people with epilepsy result in huge disparities. Bearing these findings in mind, the Irish healthcare system needs to invest in awareness programmes to increase public knowledge and reduce stigma in order to minimise such disparities.

Findings from this study suggest that epilepsyservices are hierarchical and oppressive in nature. ESN's struggle to deal with medical dominance and this lack of power in the clinical environment for nurses is further endorsed by the hierarchical structures and the dominance of medicine over nursing (Roberts *et al.* 2009). Indeed findings from this study suggest that ESN's experience difficulties with trying to '*fit*' into their new advanced position because of the autonomy they are expected to exercise in relation to the resentment of others nurses not so empowered. Arguably, such situations were managed by service provider in this study through social inferences that were primarily referenced to a lay socialisation of expectations of the nurses' role in relation to medical authority, which runs counter to to a modern professional socialisation context of empowerment and autonomy.

Oppressed group behaviour, within this regard, is not a new phenomenon in nursing and was described by Freire as far back as the 1970's. According to Smith (2010) nurse-to-nurse discrimination and oppression demonstrates a lack of empowerment. Roberts *et al.* (2009) researched oppressed group behaviour in nursing found that nurse managers can change these behaviours and improve the culture within the workplace by encouraging a more open approach to both questioning and engagement within the working environment. However, alternatively an oppressive culture, facilitates a hierarchical relationship between the medical and nursing professions and may lead to situations where lack of respect becomes acceptable and accepted both within respective nursing groups within a service and between professions, which affect service delivery and the willingness to overtly empower patients. Whilst, such issues were not directly noted in the obervations of service they were raised in the individual interviews with nurses within this service. The capacity of ESN's to question such culturally derived approaches and attitudes is fundamental to driving change within a service. In this context, the findings in this study would suggest that there needs to be an emphasis with nurse education both at undergraduate and postgraduate levels on the experience of disempowerment and how this can be addressed by practitioners. Empowerment in this context, therefore may be viewed as liberating those who are oppressed and thereby improving both service delivery and the willingness to overtly empower and commit to the empowerment of people with epilepsy (Kuokkanen and Leino-Kilpi 2000).

Findings of this study suggest that ESN's require more skills with regards to their advanced role within the service. It has been suggested that epilepsy specialist nursing has developed in an *ad hoc* manner owing to the lack of consistency in the role, the caseloads and service provision (Goodwin *et al.* 2004). Higgins *et al.* (2006) argue that the development and evolution of the role has been heavily influenced by various factors and these include: (1) the healthcare organisation's needs; (2) consultants' views; (3) resources and (4) the individual nurses input. An assessment of the suitability of the clinical learning environment, and whether it is ready to accommodate and socilaise ESN's into this environment should be considered.

Much literature highlights the diverse role of the ESN and includes the bio-psycho-social and educational needs of people with epilepsy (Foley *et al.* 2000, Greenhill *et al.* 2002, Minshall 2004, Dupras 2005, Ford 2012). A key role of the ESN is patient assessment and management which involves a high degree of decision making and autonomy regarding approaches to care for people with epilepsy (Ford 2012). However, results of this study suggest that some of the medical profession have difficulties with embracing the role of the ESN and consequently this negatively impacts on nurses' level of empowerment within the epilepsy service. Therefore, this hierarchical power dynamic needs to be exposed and openly discussed within education and practice. ESN's need to be made aware of the risks of powerlessness and provided with strategies to empower them in their practice. Roberts *et al.* (2009) suggest that the lack of power in the clinical environment for nurses is endorsed by the hierarchical structures and the dominance of medicine over nursing for generations.

Both people with epilepsy and service providers acknowledge the requirement for greater psycho-social supports. Additionally, many service providers verbalised their vulnerabilities within the service and with regards to a paucity of managerial support. Therefore, in light of the global nursing and medical shortage it is important that efforts are made to retain staff and sustain a lifetime career in healthcare. Therefore, it is necessary to ensure that staff are empowered and supported within the healthcare system. A number of contemporary studies describe difficulties with retention of staff in the current environment (Duchscher and Myrick 2008, Aiken 2012). In addition, there is growing acknowledgement in the literature that the environment in which care is provided, impacts job satisfaction and staff retention (Hayes *et al.* 2015, Norman 2013) and consequently affects how care is delivered (Laker *et al.* 2012). Future research exploring the culture of empowerment and environment within epilepsy services is needed.

This study suggests that there is a lack of empowerment of people with epilepsy within Irish clinical services. However, findings also indicate that service providers cannot facilitate empowerment in part due to lack of training and service pressures. A lack of resources, busy workload, and time constraints were acknowledged and are known to be constraining factors in the operation of person centred care (Rogers and Pilgrim 2005). The UK's NICE guidelines recommend that adequate time should be set aside in the clinical consultation to provide information to the service user, which should be revisited on subsequent consultations. In this context, appropriate resources have been highlighted as an essential element in the capacity for empowerment (Kanter 1993). According to Walseth and Schei (2011 p.81) healthcare consultations should prioritise the lifeworld of patients:

> *'Decisions should spring from a respectful dialogue concerning patients' commitments, feelings and practical circumstances, sharing reflections concerning what is right, what is good and what is practically feasible for the patient; conversations where the world of everyday life is given language and reflected upon'*

This definition powerfully represents the findings of this study and confirms the need to include within the consultation discussions, the person with epilepsy's life world as well as issues related to AED's and the risks associated with different treatment options.

Service providers in the present study described disrespect for their contribution to improve patient care within the service. In addition, health care systems have failed to create an environment that promotes quality interactions and partnerships with patients (WHO 2002). Participation in care has been viewed as an active process of taking responsibility for decisions concerning one's own health (Cahill 1996; 1998). There is evidence that the involvement of the person with a disease in making decisions as to choice of treatment improves their feelings of control and partnership in health care (Colombo *et al.* 2012). With this in mind, a CDM program and ICT was considered important by participants in enhancing communication and collaboration amongst all stakeholders. Indeed, among the recommendations for CDM is the support of ICT. Arguably, involving people with epilepsy is necessary in order to develop, adapt and standardise guidelines, taking into account issues such as health literacy. Moreover, it is argued that there is a risk of disconnect from one's health care, which is particularly pronounced if one is limited in resources, and if one does not possess the skills or means to access and evaluate online health information (Johnson 2011). Indeed, two-way ICT is envisaged as part of the future service provided by the NECP. However, it has yet to be implemented, exploited and evaluated within the Irish epilepsy services.

Education, support structures, ICT and empowerment policy were identified in this study as antecedents to empowerment within Irish epilepsy services. While poor information provision and educational delivery for people with epilepsy were recognised, service providers acknowledged the potential of educational delivery based on empowering principles. Effective education is essential and directly correlated to improved outcomes for people with epilepsy (May and Pfafflin 2002, England *et al.* 2012). However, whilst there is a body of research which points to knowledge deficits, unmet information needs (Varley *et al.* 2011) and lack of empowerment (Varley *et al.* 2011) the study of education for people with epilepsy is neglected and a poorly understood component of holistic care within epilepsy service delivery.

Historically the only philosophical debate with regards to education and people with epilepsy has been guided either within a positivist (Helgeson *et al.* 1990, May and Pfafflin 2002) or constructivist (Reid *et al.* 2001) philosophy. However, limitations of these approaches have been recognised (Kim and Holter 1995, Pawson and Tilley 1997, Graham 1999, Barr and Threlkeld 2000, Jang and Yoo 2012). Therefore, new pedagogies are warranted (Johnston *et al.* 2005) recognizing the views of people with epilepsy regarding their illness (Tabak *et al.* 2003). As previously discussed CST is associated with the Brazilian philosopher Paulo Freire (1921-1997)[53]. Freire (1970, p.45) refers to traditional educational philosophical paradigms as a '*banking concept of education'*, whereby '*students*' accept ideologies and values of society without question. He describes it as an act of depositing information in which learners (people with epilepsy) are the 'containers' to be filled and the teachers (service providers) are the depositors. Freire argues, as an alternative, that no genuine learning can occur unless 'students' are actively involved in controlling their own education (Freire 1972). Effective education is the means whereby an oppressed group can become aware of their oppression and empower people to be engaged with the world and to foster change (Freire 1972).

This meta-theoretical framework has emerged as a valuable lens through which to view, critique, and address the issue of health and educational disparities. Included among the distinctive features of Freire's account of CST are: (1) dialogue; and (2) problem posing. Dialogue is a conversation between equal partners which aims to gain insight and understanding of the world around us (Freire 1970). It is the process of talking together

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[53] See Chapter 5, Section 5.2 and CST.

in a way that enables individuals to understand thoughts, feelings and values within themselves and between others, thereby facilitating a transformation of consciousness (Park 2000). Freire (1970) argues that the principle of dialogue is the ‘word’ in which no individual can say a true word alone, or say it for another (Freire 1970). Therefore, within a supportive CST educational framework within healthcare the aim of dialogue is to negotiate shared meaning or consensus (McLaughlin 2000) and contribute to a more equitable relationship between service provider and service user. The five requirements for dialogue to exist include: (1) love; (2) humility; (3) faith; (4) hope; and (5) critical thinking.

Freire (1970) argues that individuals who lack humility and love cannot become equal partners with others. Indeed without faith dialogue may result in a *‘farce which inevitably degenerates into paternalistic manipulation’* and cannot exist without hope and critical thinking (Freire 1970, p.72). One of the many responsibilities of educators is to uncover opportunities for hope, regardless of the obstacles (Freire 1970). Problem-posing is a practice that inspires people to critically recognise the way they exist in the world and see the world (Freeman and Vasconcelos 2010). It involves a culture circle, an active space of learning and exchange of knowledge (Freire 1972). To structure this process, service providers may use ‘codifications’ to pose problems and stimulate discussion (Freire 1972).

Freire’s distinctive features of CST have particular significance for people with epilepsy. Friere believed that there should be a strong emphasis on dialogue based upon respect and working cooperatively. As opposed to the ‘banking concept of education’, he argued that educators should employ problem-posing education, a concept whereby people develop their power to perceive critically the way they exist in the world through ‘dialogue’. However, whilst there is a clear willingness by service providers to further develop their knowledge and skills to provide educational delivery that is empowering, barriers such as a lack of resources mean that political commitment beyond rhetoric is needed if the conditions for empowerment are to be truly created. Moreover, as a result of poor collaboration and communication this study highlights the ‘untapped’ resource of the voluntary organisation ‘Epilepsy Ireland’. It is argued that community resources have the potential to fill the gap in services that are not provided within the health care organisations (WHO 2002).

This study highlights the need for a coherent legislative framework and empowerment policy. Comprehensive care for people with epilepsy extends beyond the medical model of care and requires a holistic approach. For instance, people with epilepsy identified the potential of peer support groups and mindfulness therapy. It is argued, without this level of coordination at the sector level, the quality and coherence of services diminishes (WHO 2002). To facilitate patient-centred, health care organisations have had to invest financially in the development and delivery of seminars to service providers to develop their interpersonal skills so that they are able to work in partnership with patients to establish a collaborative relationship. These seminars have reinforced various aspects of caring that enable service providers to work with patience and sensitivity, accept patients ideas and values, deal with variability, and consider why specific care is planned and the anticipated benefits that will result from decisions made (Price 2006).

8.8 Chapter summary

This Chapter described and analysed the views of people with epilepsy and their service providers in relation to empowerment within epilepsy services using one specialist epilepsy service in Ireland as an exemplar. Data analysis was guided by a qualitative methodology based on Richie & Spencer's (1994) Framework Analysis. Similar to people with epilepsy's understanding, service providers acknowledged empowerment as a subjective process and outcome. Whilst people with epilepsy viewed empowerment as the ability to gain control over one's life, service providers recognised empowerment as the ability to facilitate empowerment for people with epilepsy.

An imbalance of power was clearly evident within the Irish epilepsy services. Consequently people with epilepsy largely play a passive role within their healthcare, and lack a power from within, Findings also acknowledged paternalistic practices by service providers and families/carers and consequently people with epilepsy acknowledge not feeling in control over their own lives. Whilst both the medical and nursing profession recognised difficulties with surrendering control to people with epilepsy, it also seems that conflict exists between the medical and nursing profession in relation to the emerging role of the ESN.

This Chapter also suggests that considerable improvement in terms of service user-provider interactions are needed. The potential of Habermas's principles of CST in relation to communication improvements within epilepsy services is argued[54]. Findings also suggests that considerable improvement in terms of services and care provision is required in terms of access to services; investigations and information provision. It highlights the need to fully understand the social, psychological, structural and educational concerns of people with epilepsy and to ensure that these concerns are taken into account in any plans for service transformation in order to develop empowerment strategies within epilepsy services both nationally and internationally. Arguably, an empowered framework for educational delivery is warranted along with improved resources to enable an educational delivery that is based on the principles of CST[55]. This can result in greater informed decision-making, positive behavioural changes, and a more active role in the management of epilepsy (Hovinga *et al.* 2008). The need for communicative and pedagogical skills among service providers in a collaborative endeavour are confirmed by this study along with the need for a consciousness of structural power relations within the institutional context. The potential of Habermas's principles of CST in relation to communication improvements within epilepsy services is argued.[56]

Additional to the findings presented in this Chapter, a number of antecedents to empowerment within epilepsy services were identified as significant for service providers. These include the further development and implementation of ICT, better psycho-social-structural supports for people with epilepsy, managerial and professional support for service providers, and an empowering education for both people with epilepsy and service providers and finally, a healthcare policy that has real meaning in terms of operationalizing empowerment for people with epilepsy. Such antecedents and incorporating these antecedents to current epilepsy healthcare are the subject of Chapter 11.

The results of this study suggest that problems are evident within the macro, meso and micro level of health care. Arguably empowerment begins with a conscious and critical

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[54] See Chapter 5, Section 5.4 and the potential of CST for the study of empowerment within epilepsy healthcare.

[56] See Chapter 5, Section 5.4 and the potential of CST for the study of empowerment and epilepsy healthcare

examination and reflection by all stakeholders of factors that support or hinder empowerment within Irish epilepsy services.

CHAPTER NINE

Exploring Desirable and Feasible Changes Required to Facilitate Empowerment within the Irish Epilepsy Service

9.1 Introduction

Chapter 7 examines people with epilepsy's views of their service needs in relation to design and delivery. Chapter 8 highlights the perspectives of people with epilepsy and their service providers in relation to empowerment within epilepsy services using one specialist epilepsy service in Ireland as an exemplar. This Chapter presents the findings of phase 3 of this study, a focus group (n=8) with people with epilepsy (n=4) and service providers (n=4). The aim of the focus group was to share findings of the data collected from the previous two research phases and explore with the participants potential service improvements and desirable and feasible changes that are needed to facilitate empowerment within the Irish epilepsy service. The following abbreviations are used: PWEm (Person with Epilepsy male), PWEf (Person with Epilepsy female), SPf (Service Provider female), SPm (Service Provider male).

Within the focus group five core themes were identified. Section 9.2 examines participants views in relation to improvements in communication and collaboration within epilepsy services. In section 9.3 the significance of involving people with epilepsy in the design and delivery of the service is explored. Section 9.4 explores the potential of an ambassador program to promote understanding, social inclusion, and foster empowerment related to epilepsy. In section 9.5 the provision of an empowering education and training for service providers is described while section 9.6 explore the role of legalising medicinal cannabis for people with epilepsy. Section 9.7 provides a discussion of key findings in relation to the empirical literature. Finally, section 9.8 concludes with a summary of the findings.

9.2 Improvements in communication and collaboration within epilepsy services

Findings of phase 1 and 2 of this research study highlight that improvements in communication and collaboration are needed within the Irish epilepsy service. People with epilepsy report poor communication and interaction with the GP, whilst service providers acknowledged poor collaboration between the specialist service and primary care. With this in mind, participants in the focus group discussed these issues further and acknowledged desirable and feasible changes. These are now explored.

Whilst people with epilepsy acknowledged good interactions with service providers at the specialist centre, the majority of people with epilepsy acknowledged poor communication and interaction with GP's. Indeed GP's lack the expertise to manage their condition and/or continue to remain passive with respect to patient needs. For one male person with epilepsy:

> '*The problem with the GP is that they do not sit the patient down and say how is this medication working for you, how do you feel on this medication. I think that is half the battle' …so that the GP can understand the needs from the user's point of view (PWEm3).*

Others acknowledged having little interaction with their GP and are not confident with regards to any change:

> *'It has not happened to me in about 40 years of having epilepsy and I don't think it's going to change' (PWEm4).*

One male person with epilepsy acknowledged his frustration with the GP who changed medications on his prescription without any consultation with him or the specialist service:

> *'The limictal is working but all of a sudden my GP turns around and says you have to go from 200mg to 300mgs. That means I will be taking 600mgs a day...It's when I go to collect my prescription it's a different prescription. I've gone on 4 different medications because of them. At one stage I just thought they were testing me out on different medications to see what my reaction was' (PWEm3).*

Service providers acknowledged that GP's and pharmacists in general do not get involved in the management of care for people with epilepsy, in particular in relation to medical prescriptions written by the specialist service:

> '*The usual problem is say that the community care services including the pharmacist and your GP is that they don't want to do anything they don't want to change anything even when they should. Like sometimes when someone has difficult contacting us, it might be that we wrote the prescription wrong or the dose is too high or something. Obviously we want people to use common sense and for the GP to say actually they have written that wrong and make a judgement and change the prescription but usually they don't. However, when they see a script from us and because it's a complex area they don't change it' (SPm4).*

Although a majority of participants in the study identified that GP's current role in Ireland is confined to refilling prescriptions for AEDs, it was recognised by people with epilepsy that GP's should have a more active role in relation to communication and follow up:

> *'That is the GP's job to sit you down and see how you think this is performing for you. I mean they put me on Keppra which meant 3 weeks in bed. The doctor never made a phone call to see if it had agreed, do you like it, or does it have a drowsy effect. I think they should follow up and see what effects the medication has if they do change your medications' (PWEm3)*

Service providers recognised that the telephone advice line provided by the specialist epilepsy services could be very useful for GP's and that they should be encouraged to engage with this service for any queries or problems. Also, service providers suggested that a once off prescription written by a service provider within a specialist service does not need to be transcribed again by a GP. This has the potential to reduce prescription confusion and error as outlined below:

> '*I think for me as a practitioner if I was trying to change something, time and time again we come up with errors on prescriptions. Something has happened from what has been prescribed in the clinic from what the person ends up taking. One of the explanations might be that our hospital prescriptions have to be prescribed on to the medical card prescription…. So for me as a practitioner I would just love to be able to write the general prescription for a person with epilepsy, but that it doesn't need to be transcribed – to try and take that out but I don't know how we would do that but if was just the script that we wrote in the clinic and that was the one that you [person with epilepsy] brought to the pharmacy…our letter always goes to the GP to tell them what you are on but this transcribing seems to be causing problems'* (SPf1).

Service providers acknowledged poor communication and collaboration between specialist services and primary care. One service provider reported that GP's rarely seek advice from the specialist service:

> *'I suppose looking back over the few years its striking how few GP's ask us for advice on the phone' (SPm4).*

One ESN acknowledged that that little collaboration exists between services:

> '*We are not all running off the same hymn sheet and that's a big task to take on trying to do something the same way and then when a GP needs an answer he knows where to go and who to go to'* (SPf2).

ESN's also recognised that nurses are the link between primary care and people with epilepsy. However, in terms of human resources, the current lack of adequate numbers of ESN's to link with GP's in primary care are leading to deficits in epilepsy care in Ireland as revealed in the following quote:

> 'We foresee that we would work more with the GP's and be the link with the GP's and people with epilepsy but at the moment we are tied to more clinical stuff and day to day running of the service here' (SPf2).

Indeed, people with epilepsy reiterated the need for the specialist service to collaborate more effectively with GP's:

> 'Ya but if you guys [service providers within the specialist service] could explain a bit better [to the GP's] and how epilepsy has different effects on different people' (PWEm3).

A lack of continuity between service providers at the specialist centres caused anxiety for some people with epilepsy. Additionally, information provision by service providers was acknowledged as sporadic and lacked continuity of care:

> *'I came up here on the 18th June 2014 and everything I was told in that session was completely different than the following year when I saw you. I mean everything such as driving and that was in the epilepsy clinic. I saw two different people and they gave me two completely different. It was very confusing and caused me a lot of anxiety. It nearly pulled me back a bit more because I wasn't expecting it' (PWEf2).*

With this in mind, service providers acknowledged the difficulty with facilitating continuity of care:

> '*We try and allocate the person to the same clinician but it does not always work because of holidays and people are away. We did talk about people having their own patient list but I guess there is a lot of organising around this' (SPm4).*

Bearing these issues in mind, one service provider suggested that all people with epilepsy attending the clinic should be provided with a letter outlining details of their diagnosis and current list of medications. This has the potential to reduce confusion for people with epilepsy and GP's in primary care:

> *'I am wondering would it help if you had a copy of the letter for you {the person with epilepsy} and the GP would get the same letter? (SPm4).*
> *'I do think that we should start giving letters to the patients, and it's very clear that you [people with epilepsy] should have a letter and that you can follow your progress' (SPm4).*

One female person with epilepsy acknowledged that this would be very useful in terms of remembering what was said during the consultation.

> '*I do think as I know I go out very confused and you come out forgetting half the stuff the doctor said' (PWE f2).*

Additionally, non-computerised medical practices were seen as contributing to the gap in communication and transfer of information between services. The potential of electronic communication for exchanging information and advice between service providers and people with epilepsy was recognised.

> *'In the near future we will be creating a portal on the computer so you will be able to get a summary of your condition from here plus you will be able to add to the portal for example if you have had a seizure and we can look at what date that was'(SPm4).*

9.3 Involving people with epilepsy in the design and delivery of the service

People with epilepsy expressed confusion and disempowerment as a result of feeling powerless in decision making within the service. For example, one person with epilepsy commented:

> *'I am trying to explain to him that I'm healthy..... I am not the one that has put it on the prescription [different AED's]... this hasn't come from me like .....That's where I'm confused and I feel disempowered because if I go and argue this issue to one or the other(service provider), the other will take each other's side so I can't really argue and I won't get any medication at all and I will get worse then' (PWEm3).*

During the focus group discussion service providers inquired to what people with epilepsy would like to receive from an educational program. People with epilepsy suggested that they would like other people with epilepsy to deliver the educational programs to share their 'life' experiences of how to come to terms with epilepsy and cope with life issues. For instance,

> *'I would want to hear about other people with their experiences, how they coped and how they came to terms with it [epilepsy]. How they coped with situations for themselves like looking for a job and things like that and techniques if you are feeling down, things like that'(PWEf2).*

A majority of participants agreed that people with epilepsy should deliver educational programs for people with epilepsy. For instance, service providers stated:

> *'You learn much better from each other and your experiences and how to overcome things' (SPf1).*

Involving patients in the design and delivery of the service and the significance of exploring people with epilepsy's views with regards to future design and delivery was acknowledged by all participants in the focus group. With this in mind, the introduction of a patient group to provide educational delivery and support for people with epilepsy was suggested as a desirable and feasible change within epilepsy services:

> *'A patient group to try and help each other because everyone has their own experiences and it might actually help other people' (PWEf2).*

9.4 An ambassador program to promote understanding, social inclusion, and foster empowerment related to epilepsy.

People with epilepsy described experiences of discrimination and stigma with regards to employment opportunities. For example:

> *'I am a hairdresser and I asked an employer if you were to interview two people with a job with the same qualification and experience and one person had epilepsy who would you employ? And she said I know it's against the law but I would employ the person that didn't have epilepsy' (PWEf1).*

> *'I went to an open interview and the person giving out the application forms said this is the criteria for filling out the application form and if anyone has epilepsy put it on the form' (PWEf2).*

Others identified social exclusion as a result of societal negative attitudes and beliefs. For example, one male person with epilepsy stated:

> *'It's like in any gym in the country if you have epilepsy you are not allowed in' (PWEm3).*

For others education was an issue due to teacher's lack of understanding. For example, one female person with epilepsy commented:

> *'I think teachers should be made more aware [of epilepsy]. I got suspended more times over partial seizures' (PWEf1).*

Service providers acknowledged that discrimination and social exclusion exist for people with epilepsy. Whilst people with epilepsy reported seeking support from Epilepsy Ireland, they did not find them useful in this matter and were told to seek legal advice. Although one person with epilepsy sought legal advice she was informed she was only entitled to standard redundancy. One service provider encouraged people with epilepsy not to disclose they have epilepsy as there is no legal requirement to do so. In this context, the majority of participants acknowledged the need for peer support for people with epilepsy:

> *'We here this all the time…You learn much better from each other and your experiences and how to overcome things' (SFf2).*

It was acknowledged that people with epilepsy require more support, however service providers acknowledged that they are unable to provide this support:

> *'You need lots of help and explanation and we can't give it all. Were just not able to but not only that we don't know half the things you need, however you do…' (SPm4).*

With this in mind, people with epilepsy were asked would they be prepared to talk to others about their personal experience:

> *'Would you be prepared to come in and talk to people* [with epilepsy] *and give that experience, because if you are not we can't do it. Not only can we not do it we don't know it. We don't have the personal experience of it' (SPm4).*

Suggestions were made by participants for feasible and desirable changes that have the potential to eradicate discrimination and stigma. Whilst, the benefits of public campaigns were acknowledged, it was recognised that they are expensive and not beneficial in the long term. However, the potential of an ambassador program was recognised. This would involve people with epilepsy acting as ambassadors for communities. These ambassadors would make contact with the local school to talk to children about epilepsy, and provide talks in health care centres to improve societal understanding and awareness in relation to epilepsy and act as a peer support. In addition, linking with Epilepsy Ireland in relation to support and back up was identified.

> *'Epilepsy Ireland has a school pack and one of their community resource officers could give you some back up with that. You could say to Epilepsy Ireland I want to go into a school to talk to the kids about epilepsy and they will support you and that's the kind of thing that you need to do and unfortunately there is no resource behind it, there should be and that something that should be discussed' (SPm4).*

9.5 Providing an empowering education and training for service providers

People with epilepsy also acknowledged limitations with regards to current information provision and educational delivery. For example, one female person with epilepsy highlighted that most of educational content is structured towards the medical aspects of epilepsy only:

> *'Well I have attended a couple [educational programs] with Epilepsy Ireland and I actually didn't find them great. Information was generalised such as there is so many different types of epilepsy, this is children's epilepsy, medications, etc..it wasn't helpful' (PWEf2).*

Whilst one service provider acknowledged the need to empower GP's 'to take on more effective care within the community' (SPf2), others recognised the limitations of medical education as GP's 'are generally only trained in paeds, obs, gynae (SPf3).

ESN's described the process of training as an ANP 'difficult'. Indeed, there seems to be confusion with regards to the ANP role within the epilepsy service. More support with clear roles was recognised. For example:

> *'I think if we are prepared to empower the service with our level of training* [ANP] *we need more support and that the roles that we don't do any more are covered'* (SPf2).

In relation to how to facilitate empowerment for people with epilepsy, one service provider acknowledged the potential for people with epilepsy to deliver educational programs to medical and nursing students:

> '*I think that you can artificially bring in someone with power points presentations and this is how you empower patients, however, everyone would be asleep half way through it. But if you had patients giving the lectures and you said to the students look this is a patients experience, you need to listen now. This is a powerful tool (SPm4).*

9.6 Legalising medicinal cannabis for epilepsy

At the beginning of the focus group, participants were asked about their views in relation to the issues identified in terms of their empowerment. It was at this point that the subject of legalising cannabis was acknowledged by people with epilepsy. Many people with epilepsy acknowledged the negative effects of AED's and reported cognitive, emotional, and behavioural side effects. As a counter point, the positive effects of medicinal cannabis to manage treatment-resistant epilepsy and to obtain a more favourable side-effect profile compared to standard AED's was identified. In this context, many acknowledged feelings of frustration and lack of empowerment as a result of the current illegal status of medicinal cannabis in Ireland:

> *'I can't understand how the medical marijuana has not* been brought in or *introduced' (PWEf1).*

The majority of people with epilepsy reported that they would use medicinal cannabis if legalised in Ireland. Indeed, one male person with epilepsy reported currently using cannabis products in an attempt to find an alternative treatment due to experiencing intolerable side effects of conventional AED's. He identified success in reducing seizure frequency after commencing cannabis products.

> *'I totally agree it should be brought in {medicinal cannabis}. It's called CBD and I have been medicating myself with that for the past couple of months and my seizures have severely dropped' (PWEm3).*

Service providers recognised the relative safety of medicinal cannabis and one male service provider is actively supporting its legalisation:

> *'You know it's certainly a safe drug for adults …… 'I know that this is frustrating slow but I am actually going to the Oireachtas tomorrow to present a paper around it, a framework*

> *around it for allowing this drug to be prescribed, but it's probably going to take a year' (SPm4).*

One service provider acknowledged people with epilepsy's lack of empowerment in relation to the unavailability of medicinal cannabis and whilst legalising cannabis in Ireland will take time he is confident that progress will be made:

> *'It's a very interesting point about that you feel you have a lack of empowerment in that you know that this has the potential to be useful to you and you are asking it to be prescribed and yet it's not been prescribed. I think that this is a disempowering thing but all I can say is that there will be progress made, however, the natural flow of things…legal things are slow' (SPm4).*

However, it was identified that challenges with regards to the prescribing of medicinal cannabis exist. Service providers lack knowledge in relation to medicinal cannabis and consequently feel fear in relation to prescribing.

> *'A lot of the doctors are not aware of the research around it and they are afraid of being asked to prescribe it which has been called illegal to be prescribed to children' (SPm4).*

However, one male service provider suggests that education can 'bring the whole medical profession on board' (SPm4).

9.7 Discussion of focus group results

Findings from this focus group suggest that poor communication and collaboration within epilepsy services is distorting the service experience. Poor communication and interactions with the GP was acknowledged by the majority of people with epilepsy. In fact an inbalance of power in the GP-patient interaction seems to result in frustration and disempowerment for people with epilepsy. Furthermore, a lack of knowledge and confidence to manage epilepsy among GP's was identified.

The need for access to shared medical records and more timely exchange of information between epilepsy services were repeatedly mentioned by participants. In addition, and similar to previous research the role of ICT and EPR's is acknowledged as a possible solution in alleviating these concerns (Ruland *et al.* 2008, Fitzsimons *et al.* 2013). Whilst the potential of providing a letter to people with epilepsy for exchanging information and advice between healthcare providers was acknowledged arguably a move towards Personally Controlled Health Records (PCHR) will enable patients to manage their own health data (Steinbrook 2008). The success of such initiatives will negate the need for paper records, and enable service users to share their data with multiple service providers

(Steinbrook 2008). Indeed, control over one's health data has the potential to place patients more in command in health care delivery with consequences for the way healthcare is structured and in how information and communications technologies are utilised (Grimson and Grimson 2002).

People with epilepsy emphasised that GP's should have a more active involvement in care provision and follow up. With this in mind, service providers in this study suggested that the telephone advice line provided by specialist epilepsy services has the potential to be very useful for GPs in terms of care provision and follow up. As previously mentioned a key innovation of the NECP is the creation of a cohort of ANP's in epilepsy to augment existing medical services and to reconfigure care away from hospital based services to more appropriate, cost-effective primary care/community based services by providing GP and community practice nurse support. In this context, it is envisioned that every person with epilepsy in Ireland will have access to the epilepsy ANP service attached to one of the adult or paediatric services health care professionals (HSE 2014). An ESN as a member of the MDT, has specialist education and expertise in epilepsy and plays a key role in the management and support of people with epilepsy across primary, secondary and tertiary care. The ESN's profile can include being registered as an: RANP; ANPc; and CNS. The Specialist Epilepsy Nurse(s) Evaluation (SENSE) report, a national study into the role, impact and cost effectiveness of the ESN outlined that ESN's in Ireland are now involved in the education of a wide range of service providers. Although ESN's were primarily hospital-based, their educational reach extended beyond their own organisation to primary care services and the wider community including GPs, ID services and nursing homes (Higgins *et al*. 2017).

The clinical aspect of the ESN role is underpinned by the principles of holistic person centred care; continuous assessment; responsive action; empowerment and collaboration with people with epilepsy, their family members and the MDT (Higgins *et al.* 2017). The SENSE report (Higgins *et al*. 2017), found that ESNs' impact positively on the lives of people with epilepsy because of their enhanced knowledge of epilepsy and epilepsy related issues. Consequently, they can promote service users' confidence to self-manage; improve their sense of involvement in care; enhance service users' preparedness for tests and investigations and be sensitive to improving services users' psychological well-being. In addition, they co-ordinate care more effectively and provide prompt identification of problems as they arise. Their overall impact, as a consequence, is that there is improved service user satisfaction with care overall (Higgins *et al.* 2017).

Service users are increasingly invited to take an active role in their own care as well as the design and delivery of the service. Indeed service user's experimental knowledge is now considered to be complimentary to professional's knowledge (Caron-Flinterman *et al.* 2005). This is certainly highlighted in this study as service providers acknowledged the potential of patient participation in particular with regards to delivery of educational programs. According to Castro *et al.* (2016) individual patient participation resolves around a patient rights and opportunities to influence and engage about his or her care through dialogue whilst collective patient participation is the contribution of patients in shaping health and social care services by means of active involvement in a range of activities at the individual, organisational and policy level that combine experimental and professional knowledge.

Several initiatives that have implemented patient participation highlight improvements and include: (1) access to services (Nilsen *et al.* 2006, Fudge *et al.* 2008) (2) patient safety (Longtin *et al.* 2010); and (3) patient satisfaction (Fudge *et al.* 2008, Sahlsten *et al.* 2008). The Irish project EPIC aims to realise the promise of PCC in the management of epilepsy by creating the conditions that allows people with epilepsy to work together with health service providers to design care processes that suit patient needs and respect their individual preferences (Fitzsimons *et al.* 2017)[57].

Findings of this focus group highlight the challenges faced by people with epilepsy in relation to discrimination and social exclusion. Indeed, societal lack of understanding can intensify the challenges faced by people with epilepsy, in particular with regards to lifestyle, driving, work, stigma, self-confidence and self-esteem, academic life, family life, memory and concentration, medication management, mental health, energy levels, independence, poor coordination and mobility, and emotional stress as highlighted in previous studies (Wagner *et al.* 2001a).

Misunderstanding and misperceptions about epilepsy has resulted in stigma-negative attitudes and beliefs related to those living with the disorder that can result in social

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[57] http://www.hse.e/eng/services/news features/masterclass

exclusion, and discrimination. This has appeared in the workplace, in schools, and in the community because of the public's inexperience with appropriate seizure response, persistent myths about epilepsy, and their lack of understanding about the abilities of people with epilepsy (IOM 2012, England *et al.* 2012). Consequently, people with epilepsy experience 'felt' stigma, and been ashamed of their condition because of the fear of prejudice and discrimination (Jacoby and Austin 2007). Therefore, the potential of an ambassador program led by people with epilepsy to improve societal understanding and awareness in relation to epilepsy and act as a peer support was recognised. Hopkins (1984) states that people with epilepsy have the ability to positively affect prejudice and associated stigma on a broader social level, insofar as they to decide what and how much to say and what to conceal. Participants in this study acknowledged public campaigns as expensive and not beneficial in the long term.

There was a general consensus that change could only be effected by the provision of an empowering education and training for service providers. The hierarchical power dynamic needs to be exposed and openly discussed in academia and practice. Nursing and medical students during their educational programmes need to be made aware of the risks of powerlessness and be provided with strategies to empower them in their practice. Additionally, this study highlights the 'power' of educational delivery for service providers by people with epilepsy.

Findings highlight that people with epilepsy in Ireland are willing to seek the legalisation of medicinal cannabis. Moreover, for those who have used cannabis extracts forepilepsy report a high level of perceived efficacy with cannabis products. The use of plant-derived cannabinoids for seizure reduction has been described for centuries (Pertwee 2014). Indeed a small number of yet-to-be published placebo-controlled clinical trials have reported positive outcomes with cannabidiol (CBD), a major non-intoxicating cannabinoid found in some strains of the cannabis plant, in various forms of severe paediatric epilepsy (Hess *et al.* 2016, Devinsky *et al*. 2014). However, CBD is not yet available as a registered medicine to all people with epilepsy, and the use of untested cannabis-based products raises some concerns such as the uncontrolled nature in which some of these products are manufactured, the short and long-term safety profile of cannabinoid use in humans, particularly in children and in combination with AEDs. Therefore, a stronger scientific evaluation is needed (Friedman and Devinsky 2015).

Findings of this focus group provides insight into the use of cannabis products for epilepsy, in particular some of the likely factors influencing use, as well as novel insights into the experiences of and attitudes of people with epilepsy and service providers in the Irish community towards medicinal cannabis. Despite the issues associated with the use of untested cannabis products, what is clear is that service providers cannot ignore that people with epilepsy are using cannabis-based products in Ireland, and reporting considerable benefit to their condition. This highlights the growing need to listen to patients and educate service providers and people with epilepsy on cannabis-based products. Further research is necessary to increase our knowledge of the efficacy, interaction effects, and safety of CBD, and to explore the potential role of other cannabinoids, either alone or in combination, in the treatment of epilepsy. Further research seeking opinions on and experiences with the use of cannabis-based products for the treatment of epilepsy is required.

9.8 Conclusion

This Chapter described and analysed the views of people with epilepsy and service providers with regards to desirable and feasible changes that are needed to facilitate empowerment within Irish epilepsy services. Findings identified desirable and feasible changes to improve communication and collaboration within epilepsy services and involve people with epilepsy in the design and delivery of the service. In addition, the potential of an ambassador program to improve understanding, promote social inclusion, and foster empowerment related to epilepsy was described.

Findings recognised the need for an empowered framework for educational delivery for service providers, in which they can challenge, identify and examine their own beliefs with regards to educational requirements and delivery for people with epilepsy, rather than from the meaning assigned by their institution or policy maker. It is reported that the utilisation of knowledge and experience of service users could greatly benefit quality of care and ultimately quality of life (DOHc 2001). Finally, people with epilepsy in Ireland are willing to seek the legalisation of medicinal cannabis. Whilst, many issues are associated with the use of untested cannabis products, improving partnerships between service providers and people with epilepsy is necessary in order to ensure that decisions respect the needs and preferences of people with epilepsy (Institute of Medicine (IOM 2001).

CHAPTER TEN

A 'Soft Systems' Analysis

10.1 Introduction

This Chapter draws upon the data presented in the preceding chapters and describes the application of stages 1-7 of Checkland's (2000) SSM for this study exploring empowerment within epilepsy services using one specialist epilepsy service in Ireland as an exemplar. It presents a situational analysis and conceptual model of the service and compares the conceptual model of the service with its service operation.

SSM is a cyclic iterative approach of enquiry for formulating and structuring thinking about problems in a situation where people have diverse views of the world. SSM is not about analysing systems found in the real world, but rather about applying systems thinking to problems in complex situations to provide a series of intellectual constructs that generate learning and understanding of the often hidden variables in the complex situation. In this context, this chapter addresses RO 3.

RO 3: *To develop a situational analysis and conceptual model of the service utilising a 'soft systems' method.*

Section 10.2 describes stage 1 of Checkland's (2000) SMM and presents the problem situation unstructured. In section 10.3, stage 2 of SSM is defined and the problem situation is presented and illustrated as a 'rich picture'. In section 10.4, stage 3 of SSM is described and the formation of a root definition using the mnemonic 'CATWOE' is outlined. Stage 4 of SSM is discussed in section 10.5 and the construction of a conceptual model describing the activities that must take place in order to achieve the transformation of empowerment within Irish epilepsy services is outlined. Section 10.6 describes stage 5 of SSM and compares the conceptual model of the service to its service operation. In section 10.7, stage 6 of SSM is presented, outlining desirable and feasible changes required to facilitate empowerment within Irish epilepsy services. Section 10.8 describes stage 7 of SSM and draws wider inferences for the development and operationalization of epilepsy policy and practice in Ireland. Finally, section 10.9 concludes with a summary of findings.

10.2 Stage 1 of SSM: Enter situation considered problematical

Stage 1 of SSM explores a problem situation by inquiring about key stakeholders, important issues, interconnected problems, behavioural patterns, cultural characteristics, and power relations in the situation. This exploration results in an understanding of the problem situation (Checkland and Scholes 1999) and is described as the 'finding out stage'. Information is gathered about the problem from various sources and may include: written information; surveys; informal interviews; observations; and formal samples or information from any available source comprising both primary and secondary data. Both formal and informal organisational structures are examined and any prevailing issues or assumptions are identified. In this context, organisational politics and taboos can be identified and individual concerns or mistrusts can also be included.

This was accomplished in this study in 2 phases. Phase 1 consisted of a survey of people with epilepsy on their views of their service needs in relation to design and delivery[58]. Phase 2 entailed in depth interviews with people with epilepsy and service providers with reference to service user and clinician empowerment. This analysis was further informed by a non-participatory observation of services within one epilepsy service in Ireland[59].

10.3 Stage 2 of SSM: Express the problem domain

Having gathered information from people with epilepsy and service providers, stage 2 of SSM involves expressing the problem situation within Irish epilepsy by means of a '*rich picture'*. The *'rich picture'* of the situation, representing its main elements, was formulated by looking for commonly stated problems, purposes and activities. By means of the picture-building process the main issues in relation to empowerment within epilepsy services are identified. Rich Pictures are pictorial representation of a messy problem situation. They include a range of elements such as opinions, concerns, conflicts, constraints as well as structural arrangements. Checkland (1998) suggests they should include structure, processes, issues and concerns. In this way the rich picture provides an analysis of the situation.

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[58] See Chapter 7: Epilepsy services in Ireland: A survey of people with epilepsy in relation to satisfaction, preferences and information provision.

[59] See Chapter 8: Issues of empowerment within Irish epilepsy services using one specialist service as an exemplar: Service users and providers perspectives.

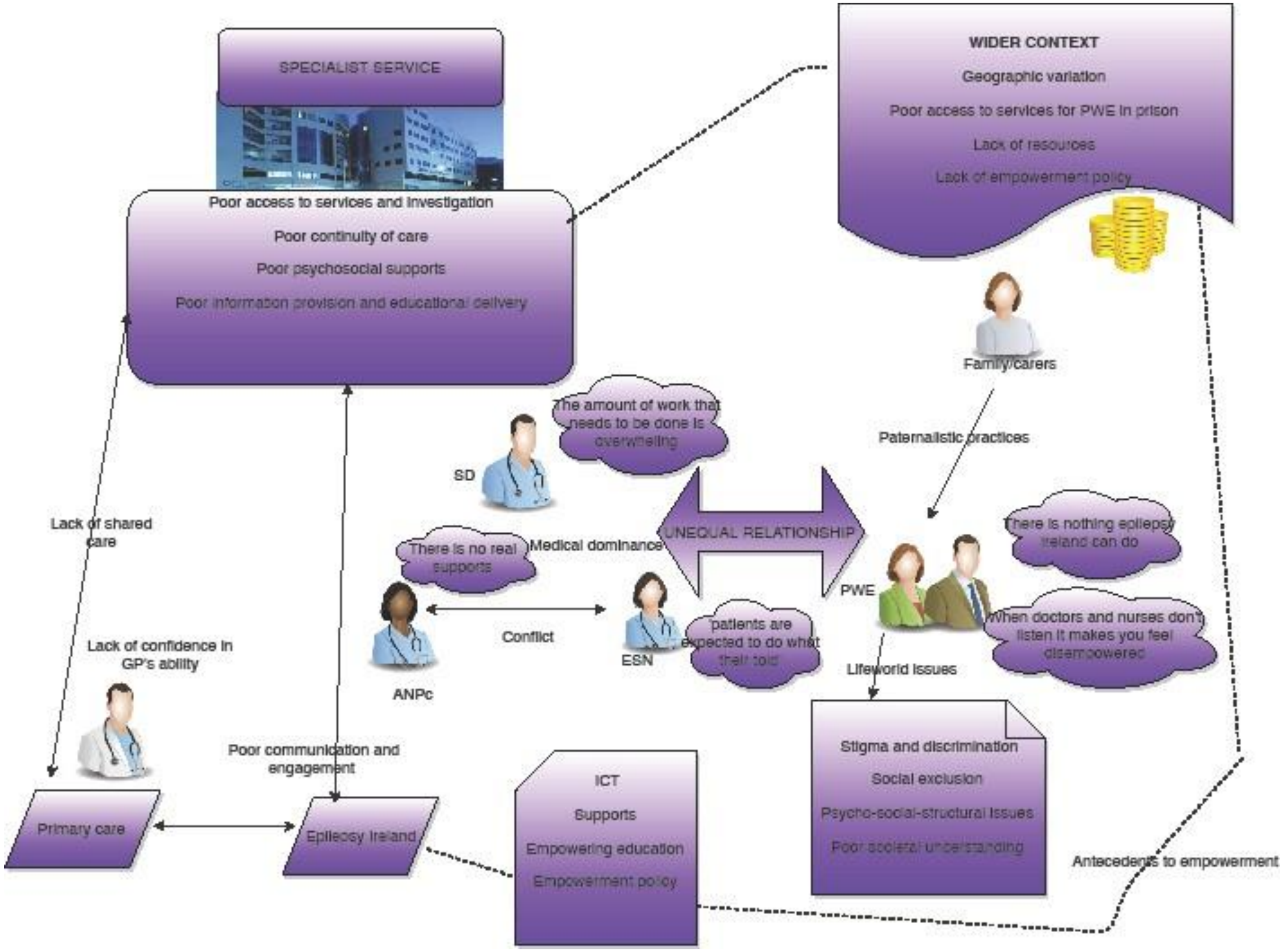
Figure 10.1 illustrates a rich picture of people with epilepsy's and service provider's views in relation to empowerment within epilepsy services using one Irish specialist epilepsy service as an exemplar. From this rich picture issues and factors that inhibit empowerment for people with epilepsy and service providers emerged. The following abbreviations are used: PWE: People With Epilepsy; SD: Specialist Doctor; GP: General Practitioner; ESN: Epilepsy Specialist Nurse.

In a wider context, geographic variation in availability, access and quality to Irish epilepsy services and care provision exists in particular for people with epilepsy in prison. Moreover, a lack of human and financial resources along with no empowerment policy is a barrier for empowerment within the Irish epilepsy service.

Key factors that inhibit empowerment for people with epilepsy include: delays in access to specialist care and investigations; poor continuity of care; a lack of confidence in GP's knowledge and ability; poor information provision and educational delivery; and poor psychological, social and structural support. Whilst Epilepsy Ireland was recognised for providing good support, people with epilepsy acknowledged that there is little Epilepsy Ireland can do to help. Poor communication, interactions and unequal relationships by service providers alongside paternalistic practices by family and carers result in disempowerment for people with epilepsy. In addition, lifeworld issues such as psycho-social-structural issues, stigma and discrimination, social isolation and poor societal awareness negatively impacts on people with epilepsy's level of empowerment.

Factors that inhibit empowerment for service providers include: poor communication and engagement within the specialist services, with GP's and Epilepsy Ireland. Indeed a lack of shared care between the specialist service and primary care was evident. A lack of managerial and professional support was acknowledged with service providers feeling overwhelmed in relation to their workload. Poor interactions with people with epilepsy and medical dominance negatively impacts on service providers level of empowerment. Taking these issues into account service providers acknowledged necessary antecedents to empowerment. ICT was highlighted as an important factor in enhancing communication and sharing of information between health care sectors. Further support structures were highlighted as essential in particular managerial and professional supports for service providers along with psycho-social supports for people with epilepsy. Whilst the provision of an empowering education for both service providers and people with epilepsy was acknowledged, service providers highlighted that the development and implementation of an empowerment policy was necessary in order for these changes to be effective.

Figure 10.1: Rich picture



10.4 Stage 3 of SSM: The formation of a root definition using the mnemonic 'CATWOE'

Having identified some key issues, developing relevant systems that would address these issues is required. With this in mind, stage 3 of SSM requires a ‘Root Definition’ of each system to be constructed. Checkland (1981 p.167) defines a Root Definition as a*:*

> ‘*hypotheses concerning the eventual improvement of the problem situation by means of implemented changes which seem to both the systems analyst and problem owners to be likely to be both feasible and desirable’.*

A root definition expresses the core intention of a purposeful activity system. Root definitions are simply used to think about what is likely to ‘*make sense’* (Pidd 2003 p.130) to address the problem situation and as a step to the development of a conceptual model that leads to questions about how to better *‘explore the real world situation’* (Checkland and Holwell 1998 p.160). However, in order to be valid, it must encompass a number of elements which Checkland characterised under the mnemonic 'CATWOE' (customers, actors, transformation process, 'world view', owners, and environmental constraints) (Checkland and Scholes 1990). These are now explored.

10.4.1 CATWOE

The mnemonic **CATWOE** is used to identify the six elements that should encompass the emergent properties of the system under consideration (Flood and Jackson 1991). Table 10.1 outlines the six elements of CATWOE pertinent to this study of empowerment within Irish epilepsy services.

10.4.1.1 The Customers: C

C: The government, service providers and people with epilepsy.

The customers of this transformation can be seen as a wide ranging group of interested parties. Firstly, the Irish government, representing the nation, will benefit from an efficient and empowered healthcare service. Secondly, service providers within the Irish epilepsy services will benefit from the potential positive outcomes of empowerment and include: power; autonomy; decision making ability; and work satisfaction. Finally, people with epilepsy will benefit from the potential outcomes of empowerment and include; a power from within; control; and self-management.

Table 10.1: Irish epilepsy service: CATWOE

CATWOE
Customers: The victims or beneficiaries of the transformation process: The government, service providers and people with epilepsy.
Actors: Those who do the activity: People with epilepsy, service providers, policymakers, members of Epilepsy Ireland and educators.
Transformation process: The conversion of an input process to an output: Transforming the epilepsy service so that Irish epilepsy service can facilitate empowerment for both people with epilepsy and service providers
Weltanschauung: The world view that make the transformation meaningful: A belief that an epilepsy service based on an empowering philosophy and delivery can improve the quality of life for people with epilepsy and their service providers.
Owners: Those who have the power to modify or stop the system: People with epilepsy, service providers, policymakers and educators.
Environmental constraints: Constraints within the environment of the system: Include the medical model; educational limitations; lack of resources and support structures; professional conflict and lack of an empowerment policy.

10.4.1.2 The Actors: A

A: The policy makers, service providers, people with epilepsy, members of Epilepsy Ireland and educators.

The actors are the people concerned with the transformation and for this study include the policy makers, service providers and people with epilepsy within the Irish epilepsy service. Other related parties are the representatives of the voluntary organisation Epilepsy Ireland and nursing and medical educators. Whilst service providers are not the drivers of change, they are the principal participants in whom the change process rests.

10.4.1.3 Transformation: T

T: Transforming the epilepsy service so that Irish epilepsy service can facilitate empowerment for both people with epilepsy and service providers.

The transformation required is transforming the epilepsy service so that people with epilepsy and service providers feel empowered. The major barriers to this transformation are factors outlined in the rich picture (figure 10.1). With this in mind, there is a requirement for further education based on an empowering philosophy along with additional support structures, resources and the use of ICT for people with epilepsy and service providers. Finally, an empowerment policy for chronic illnesses needs to be developed and implemented to guide all stakeholders within the epilepsy service.

10.4.1.4 Worldview or Weltenshauung: W

W: A belief that an epilepsy service based on an empowering philosophy and delivery can improve the quality of life for people with epilepsy and their service providers. There are several significant worldviews to consider in this study such as the views of: policymakers; government; people with epilepsy; service providers; members' of the voluntary organisation; and families/carers. However, the worldview of people with epilepsy and their service providers is considered to be the most relevant in achieving the transformation.

10.4.1.5 The Owners: O

O: The owners are the policymakers, service providers, people with epilepsy and educators.

The owners are those people to whom the system is answerable. The people driving change within the Irish epilepsy service are policymakers, service providers and people with epilepsy. However, as the educational system is a provider of professional education for both nurses and doctors they could also be recognised as having ownership interest.

10.4.1.6 Environment: E

E: Environmental constraints within the system include: Medical model of healthcare; lack of resources; poor support structures, professional conflict and lack of an empowerment policy. The environment is overall based on a medical model. As a result communication issues and power inequities exist within the service. A lack of resources and space is also acknowledged. Moreover, poor support structures and lack of empowerment policy is recognised.

10.4.2 Root definition

According to Checkland and Scholes (1990) it is often useful to begin with an image or metaphor to represent the problematic situation, as a preliminary to constructing the root definition. With this in mind, an image utilised at peer reviewed poster and oral presentations[60] to represent the problem situation was considered (see figure 10.2). This image represents empowerment within the Irish epilepsy service. The two stone objects represent service providers and people with epilepsy, whilst the light bulb characterises the lack of empowerment within the Irish epilepsy service. The bubbles that surround the stone objects signifies factors that support or hinder empowerment within the service. The egg represents the potential contribution of this study to theory and knowledge in relation to empowerment and epilepsy health care.

Figure 10.2: An image representing empowerment within Irish epilepsy services

Utilising this image and the elements as outlined in table 10.1, a root definition was constructed in order to express the core purpose and activity of the Irish epilepsy service:

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[60] See Chapter 1, Section 1.9: Author's notes of peer-reviewed publications arising from this study to date.

> *‘A system that enables stronger connections to be forged between all stakeholders (people with epilepsy, service providers, policy makers, GP’s, members of epilepsy Ireland, family/carers, and educators) to enble empowerment to be facilitated within the Irish epilepsy service. Maintained by the provision of good access to epilepsy services, care provision, and psychological, social and structural support’s for people with epilepsy. Resources are used in an optimal way, whilst at the same time ensuring appropriate staffing, physical infrastructure and support structures for service providers to ensure good physical and mental working conditions. Ensuring good collaboration, communication, equal partnership and respect between all stakeholders and safeguarding the continuing development and acquisition of empowered skills for both service user’s and providers by the provision of an educational framework based on a Critical Social Theory philosophy’.*

10.5 Stage 4 of SSM: Build conceptual models of the systems named in the root definitions

Conceptual models are used to illustrate the relationships between the elements defined in the root definitions. It is an account of the activities which the system must do in order to represent the system as it is defined in the root definition (Checkland 2000). Their construction follows an iterative cycle as part of the process of analysis and they are primarily concerned with expressing the objective rather than the method of achieving the transformation. Having generated a root definition, stage 4 required the construction of a conceptual model which will describe the activities that must be undertaken for the system to be depicted in the root definition. With this in mind, the conceptual model was built by identifying the key activities within the root definition and the activities were ‘unpacked’ in terms of verbs (Hindle and Braithwaite 2001). According to Platt and Warwick (1995), these can then be associated to form the conceptual model. Box 10.1 presents the implied activities identified within the root definition.

Box 10.1 The implied activities identified within the root definition

1. Reconfirm the needs of people with epilepsy and service providers within the Irish epilepsy service.
2. Provide available support facilities for the social, psychological and structural difficulties, people with epilepsy encounter.
3. Provide an available support system for service providers to deal with lack of resources and work stress.
4. Devise and implement a plan to improve people with epilepsy's 'lifeworld' that has been most affected by a diagnosis of epilepsy.
5. Devise and implement a strategy to improve healthcare delivery issues such as improving shared care and access to specialist care and investigations.
6. Provide an appointment system to improve delays during hospital appointments.
7. Identify service provider's communication and information provision practices.
8. Improve communication and collaboration between all stakeholders within the Irish epilepsy service.
9. Improve professional working relationships.
10. Improve information provision for people with epilepsy.
11. Devise and implement an empowerment curriculum in medical and nursing education basesd on a CST philosophy.
12. Devise and implement a strategy for the provision of a government's policy in relation to empowerment.
13. Devise and implement a strategy to improve societal awareness and understanding of epilepsy.
14. Devise and implement a community peer support group for people with epilepsy.
15. Communicate results of this study to service providers and people with epilepsy, the steering committee members of the NECP and relevant policymakers.
16. Implement and evaluate the above.

This list was broken down further, to assist in clarifying what the conceptual model should involve, by interpreting the key activities in the process of care (based on the aim of the NECP)[61]. From this system the conceptual model of how the Irish epilepsy service should be carrying out its activity to meet the requirements implied in the root definition was identified. The resulting model consisted of an overall system with a number of subsystems (service system; communication system; professional system; education system and intelligence system). The focus is the concept of empowerment and quality care within Irish epilepsy services. In this context, figure 10.3 outlines the conceptual model and is entitled 'Empowerment and quality care within the Irish epilepsy service'.

10.5.1 The validity of the conceptual model

The requirements for establishing the validity of any model depend on the type of model being constructed and the use that is to be made of it. Validity of a model is commonly described as the extent to which the model can be said to be an adequate representation of reality. However, in the case of SSM, the conceptual models built may be of systems that are not actually in existence at all. Therefore, conformance to reality is not an appropriate question to consider. Examining the validity of any model generated as part of a soft systems enquiry is difficult. Indeed, Checkland (1995) suggests that there are two aspects that can help differentiate a good model from a 'bad' one and these relate to whether the models developed are in any sense relevant and whether the models are competently built. The question of competence relates to ensuring that the root definitions and conceptual models have been derived systematically from the rich picture and the issues identified within it and also that the conceptual models are built only from the root definition. The relevance of the models is a matter for the participants to determine and is related to the extent to which the models generated improve the understanding of issues and the generation of subsequent actions.

The conceptual model outlined in figure 10.3 acknowledges a number of changes needed within the Irish epilepsy service particularly in relation to services and care provision. Additionally, major changes with regards to communication, education, and support structures for both people with epilepsy and service providers are identified. Arguably, a better understanding of the needs and expectations of people with epilepsy and service provider gives considerable validity to the model that has been developed.

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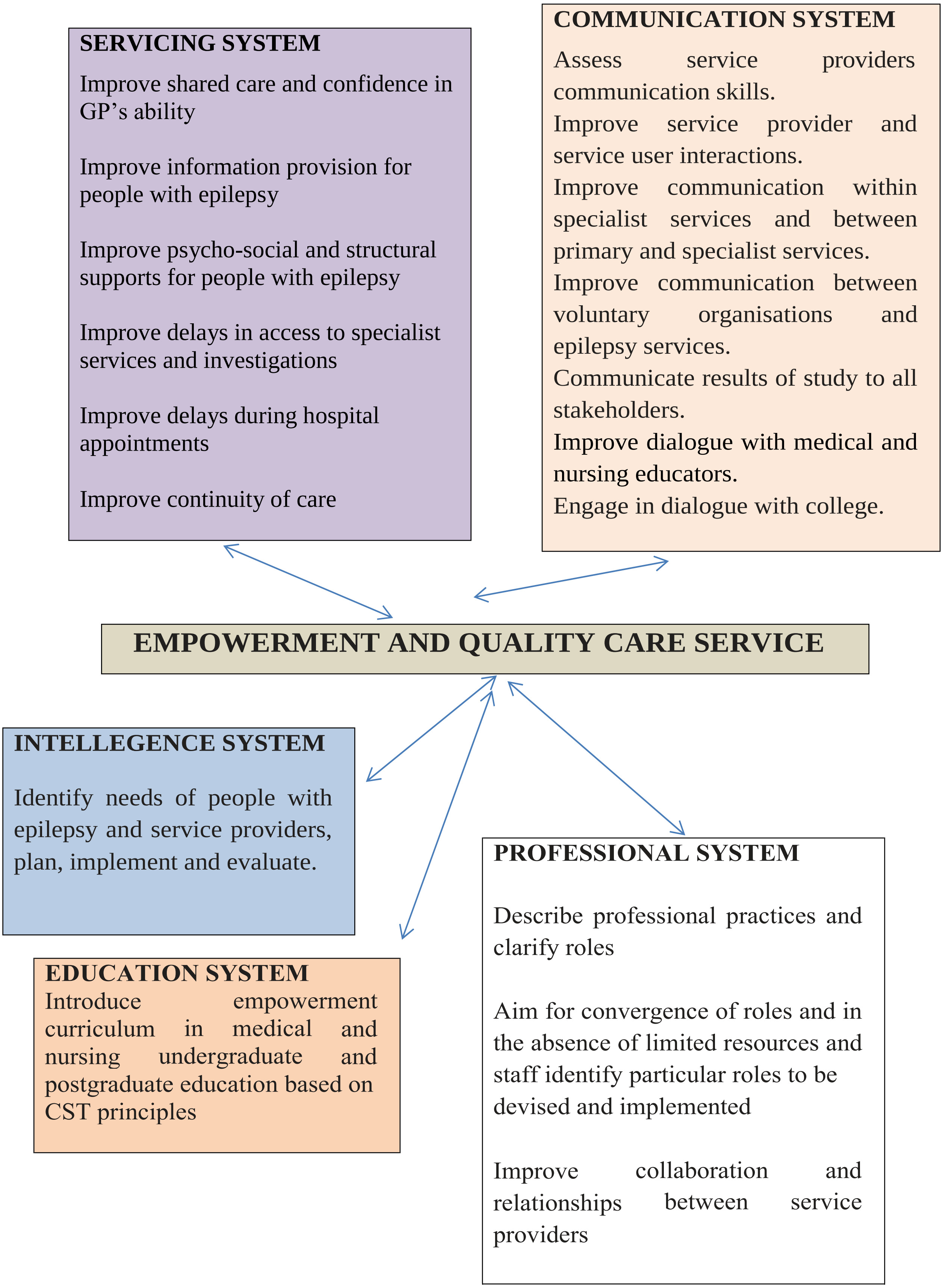
[61] See Chapter 4: Section 4.4.2 and the NECP

Figure 10.3: A conceptual model: ‘Empowerment and quality care within the Irish epilepsy service’.



SERVICING SYSTEM

Improve shared care and confidence in GP’s ability

Improve information provision for people with epilepsy

Improve psycho-social and structural supports for people with epilepsy

Improve delays in access to specialist services and investigations

Improve delays during hospital appointments

Improve continuity of care

COMMUNICATION SYSTEM

Assess service providers communication skills.
Improve service provider and service user interactions.
Improve communication within specialist services and between primary and specialist services.
Improve communication between voluntary organisations and epilepsy services.
Communicate results of study to all stakeholders.
Improve dialogue with medical and nursing educators.
Engage in dialogue with college.

EMPOWERMENT AND QUALITY CARE SERVICE

INTELLEGENCE SYSTEM

Identify needs of people with epilepsy and service providers, plan, implement and evaluate.

EDUCATION SYSTEM

Introduce empowerment curriculum in medical and nursing undergraduate and postgraduate education based on CST principles

PROFESSIONAL SYSTEM

Describe professional practices and clarify roles

Aim for convergence of roles and in the absence of limited resources and staff identify particular roles to be devised and implemented

Improve collaboration and relationships between service providers

10.6 Stage 5 of SSM: Compare conceptual models with real-world actions

Stage 5 of SSM involves a comparison of the conceptual model with the problem as expressed in stage 2. The purpose of this stage is to analyse the similarities and differences between the model and the real world in a thorough and structured manner (Bowen and Shehata 2001). Formal questions were posed along with the employment of a matrix (see table 10.2). After comparing the model with real-world actions within the Irish epilepsy service, the following questions were posed:

1. What were the common factors in relation to issues within the Irish epilepsy service?
2. How did these factors affect empowerment for people with epilepsy and service providers?
3. What role did educational, organisational and societal support play?
4. What strengths could be built upon?

Utilising these questions, a comparison of the conceptual model with reality indicated a lack of effective shared care between the specialist, tertiary and primary care service. Indeed, a lack of confidence in the GP’s management of epilepsy was evident. Consequently, people with epilepsy are becoming over reliant on the specialist service. As a result service provider’s workload within the specialist service is not sustainable leaving service providers feeling frustrated and overworked. Distinct lack of collaboration, poor communication and delegation between services hinder empowerment within the Irish epilepsy service. Whilst the voluntary organisation ‘Epilepsy Ireland’ play a vital role in supporting Irish people with epilepsy, it is evident from the findings of this study that major gaps exist in relation to psycho-social and structural supports. With this in mind, the potential of peer support and societal awareness and understanding to improve the lifeworld for people with epilepsy was acknowledged.

Findings of this study highlight that medical and nursing education inadequately provides service providers with the knowledge or skills to facilitate empowerment within the epilepsy service. A clear lack of empowering philosophy was evident within the service. People with epilepsy lack an understanding of empowerment and service providers are uncertain of how to facilitate empowerment for people with epilepsy. Currently, both one-to one and group educational programs are been implemented within the service, however lack a clear educational philosophy.

ESN’s are not supported within the service and little dialogue exists between them and the nursing college in particular in relation to their new roles and responsibilities. ESN’s do not have the skills and knowledge to deal with issues and barriers with regards to their new role within the epilepsy service. This has left both ESN’s and other members of the MDT with a confused view of what is expected of them and what to expect once their studies are completed. In addition, poor organisational and managerial support is evident.

The final question was: What were the strengths of the epilepsy service? After looking at the comparison of the conceptual model and the reality, it is evident that some service provider’s within the specialist epilepsy service are extremely committed to improving and evaluating the service. This became apparent with the support and participation throughout this research study by these service providers. In addition, service providers acknowledged their lack of empowering skills and knowledge and indicated that they wanted to professionally develop. Finally, with the development of the NECP, the epilepsy service appears to be making great advances in improving care for people with epilepsy within Ireland (HSE 2014). The NECP committee has developed KPI’s which are currently evaluating the NECP. Therefore, this commitment has the potential to enable the implementation of change along with professional development and empowering policy within the service.

Table 10.2: Comparing the conceptual analysis with the service operation

System	Activity	Exist	Mechanism	Performance
Servicing System	Shared care and confidence in GP's ability	Partial	Via MDT and ESN's.	Sporadic as a result of resources and staff shortages.
	Information provision for people with epilepsy	Partial	Through one-one and group educational programs	Ad hoc delivery and not informed by any model or philosophy. Tends to focus on medical aspects of epilepsy and medications
	Psycho-social and structural supports for people with epilepsy	Partial	Member of Epilepsy Ireland present at weekly OPD clinic	Sporadic. At times no allocated room available for member of Epilepsy Ireland. Uptake by people with epilepsy limited and irregular
	Access to specialist services and investigation	Partial	Via MDT	Sporadic, in particular in secondary and tertiary hospitals.
	Continuity of care	Partial	Patients allocated to a particular service provider during weekly meetings	Sporadic as a result of staff levels and annual leave, sick leave etc.

Table 10.2: Comparing the conceptual analysis with the service operation

System	Activity	Exist	Mechanism	Performance
Intelligence system	Identify needs of people with epilepsy	Partial	On admission and through MDT meetings and individual service provider care provision	Tends to focus on medical aspects of epilepsy and medication. Psycho-social and structural difficulties rarely addressed.
	Identify needs of service providers	No	No staff development or support program	No discussion or method for exploring service providers needs
	Plan implementation	Yes	Through MDT meetings and individual service provider care provision-care plan and task allocation	Ad hoc as not informed by any philosophy or model
	Evaluate progress	Partial	Through MDT meetings	Ad hoc as not informed by any philosophy or model

Table 10.2: Comparing the conceptual analysis with the service operation

System	Activity	Exist	Mechanism	Performance
Communication system	Dialogue with GP	Partial	MDT	Sporadic. Lack of understanding of services role.
	Dialogue with people with epilepsy	Yes	On-going within the service as an inpatient and outpatient	Sporadic-based on individual communication skills.
	Dialogue with MDT	Yes	Weekly business meetings	Effective for in-patient care. Does not involve all key workers.
	Dialogue with voluntary organisation 'Epilepsy Ireland'	Partial	Member of Epilepsy Ireland present weekly at OPD	Sporadic. Very little communication between service providers and members of Epilepsy Ireland. Service is ineffective as a result of lack of collaboration, communication and space allocation. Moreover, people with epilepsy do not request this support.
	Dialogue with college	Partial	Links with medical and nursing colleges as a result of postgraduate education	No discussion or methods to support student whilst undertaking new roles such as advanced nursing practice.

Table 10.2: Comparing the conceptual analysis with the service operation

System	Activity	Exist	Mechanism	Performance
Professional system	Professional practices and roles	Yes	Allocation to certain professional role	Sporadic. Lack of understanding of individual professional role
	Convergence of roles	Yes	Advanced role for nursing staff	Limited at times and individual.
	Service provider collaboration	Yes	MDT meetings	Sporadic
Educational system	Empowering curriculum in nursing and medical undergraduate and postgraduate education	Partial	Introduced in nursing undergraduate and postgraduate curriculum	Limited. Little discussion on facilitating and implementation of empowerment within a healthcare system.

10.7 Stage 6: Define possible changes which are both desirable and feasible

Changes can usually be classified into three inter-related types: (1) structure; (2) processes (3) and attitudes (Wilson 1984). Therefore by comparing the conceptual model with reality, it can be seen that change is required in all three areas. Land (1994) stressed the importance of addressing what is feasible and desirable so that any change is discussed and implemented with the agreement of participants and pays full regard to the culture, environment and politics of the system. Therefore, a focus group with service providers and people with epilepsy was undertaken to share findings of the data collected and explore potential service improvements and changes that are needed.

During the focus group, the participants' worldviews were contrasted with each other, so that accommodations could be made on what changes may be possible to improve the quality of epilepsy healthcare provision and facilate empowerment within the Irish epilepsy service. The focus group seeked accommodations among participants on the conceptual model and the included activities on whether or not they are 'relevant' to the situation. Then, it became possible to find changes through the process of 'comparison.' During this process, the criterion for defining changes is participants' agreement with suggested change statements. Four (n=4) people with epilepsy and four (n=4) service providers agreed to participate in a focus group. The findings of this focus group is now explored.

Table 10.3 summarises the key findings of the focus group and changes that are both desirable and feasible to facilitate empowerment within epilepsy services. However, it is worth noting that these changes may have limitations in terms of human and financial resources and also legal implications.

10.8 Stage 7 of SSM: Take action to improve problem situation

The final stage of SSM is concerned with the implementation of changes to address the problem of a lack of empowerment within epilepsy services. To ensure that these changes were implemented in a clear and measurable way, the planned changes were translated into planned service objectives within the epilepsy service with defined time boundaries. Table 10.4 identifies wider inferences for the development and operationalization of epilepsy policy and practice in Ireland.

While CDM strategies recommend that patients be empowered to self-manage their healthcare, the importance of empowerment for healthcare policy and service provision needs to be more explicitly recognised and the need to reformulate debate within an empowered perspective advanced. Arguably, a move towards developing an empowering health policy and service provision requires a stronger awareness of the macro, meso and micro levels for policy development.

The results of this analysis suggests that improving care provision for people with epilepsy requires reconfiguration of the primary–tertiary interface and establishing clearly defined roles and formalised clinical pathways. This study highlights the need to ensure appropriate access to the required psycho-social and structural supports for people with epilepsy. A greater emphasis on the implementation of person-centred approaches to care with more active involvement of people with epilepsy as experts, negotiators and collaborators of care is required. Moreover, results of this study suggest that a shift is needed from the traditional epistemological and ontological assumptions associated with communication and education within epilepsy services. With this in mind, further research on organisational culture and structures in order to investigate people with epilepsy's level of involvement in service design and delivery is required.

This study indicates that in order for people with epilepsy to be empowered within the Irish epilepsy service a climate of psych-social-structural support is needed. In addition, peer support is also acknowledged as necessary for people with epilepsy. Organisational management can impact service providers' sense of empowerment in clinical practice as acknowledged in this study. However, it is vitally important that service providers perceive themselves and those they provide care with as empowered clinicians. Therefore, improved organisational support is essential for service providers as this positive influence of empowerment will improve patient care, and provide many benefits to the clinical learning environment. For example, a study undertaken by Laschinger (2008) identified that professional practice environment characteristics mediated the relationship between structurally empowering work conditions and both job satisfaction and nurse-assessed patient care quality.

This study contributes to a growing body of knowledge testifying the challenges that exist within healthcare services and presenting the possibilities of improvement through the adoption of empowering approaches. This opportunity to use empowerment to improve the experience of both service users and providers needs to be grasped. It is imperative that service providers in practice and academia work together to bring about change to empower clinician’s which will improve the service for service providers and potentially for people with epilepsy. Therefore, disempowered service providers need to be supported within the healthcare system over the trajectory of their careers in order to sustain the perpetual demands on them.

Table 10.3: Participants views of changes that are both desirable and feasible to facilitate empowerment within epilepsy services

Improve communication and collaboration within epilepsy services	• GP's to improve communication and interaction with people with epilepsy. • GP's to engage with the telephone advice line within the specialist service • A once off prescription that does not need to be transcribed by the GP to reduce confusion and error. • Specialist service to collaborate with GP's and facilitate their empowerment • ANP's will link more with GP's to improve communication and collaboration within the service • Letter to be provided to each person with epilepsy and the GP with patients diagnosis and list of medications to reduce confusion • Ensure the role out of ICT to improve communication
Involving people with epilepsy in the design and delivery of the service	• Setting up of a patient group • Educational delivery for people with epilepsy by people with epilepsy
The potential of an ambassador program to improving understanding, promote social inclusion, and fostering empowerment related to epilepsy	• Development of an ambassador program • Link with epilepsy Ireland • Peer support
Provision of an empowering education and training for service providers	• People with epilepsy should deliver lecturers to medical and nursing students on how to facilitate empowerment within the epilepsy services
Legalising medicinal cannabis use for epilepsy	• Supporting and legalising medicinal cannabis. • Educate service providers to reduce confusion and fear in relation to the prescribing of medicinal cannabis

Adopting empowerment within epilepsy services as a policy goal implies a commitment to encouraging a process of more equitable distribution of power at the micro, meso and macro levels of healthcare. It implies increasing people with epilepsy's control over their lives both individually and collectively and their participation and influence in institutional decision making. Without a clear definition of empowerment, the Irish epilepsy services runs the danger of merely renaming old top-down approaches as part of an empowerment policy, without altering the content and character of their programmes or examining the need for changes in organisational culture and process required. With this in mind this study acknowledges a clear definition of empowerment for both people with epilepsy and their service providers. People with epilepsy defined empowerment as a subjective process or outcome and an access to 'power from within'. This enables people with epilepsy to gain control over one's life, make better decisions and self-manage. Likewise, service providers defined empowerment as a subjective process and outcome arising from an access to 'power from within'. In addition, the ability to provide a good service and facilitate empowerment for people with epilepsy was also identified.

Table 10.4: Wider inferences for the development and operationalisation of epilepsy policy and practice

OBJECTIVE	**DESIRED OUTCOME**	**LEAD**	**BY WHEN?**
Continuous dialogue between ESN’s	To support ESN’s, ensuring that they feel confident in their new emerging role	ANP/Nurse manager	Sept 2019
Educational support in relation to empowerment	To ensure that all service providers can facilitate and implement empowering approaches	MDT	Sept 2019
Leadership skills made available to service providers	To improve collaboration and communication between all service providers	MDT	Sept 2019
Continuous engagement with the legal system and provision of information and education of service providers and people with epilepsy in relation to medical cannabis	To reduce seizure frequency and side effects of AED’s and to legalise medicinal cannabis for people with epilepsy.	Policy makers and member of the MDT	Sept 2019
A letter to be provided to each person with epilepsy and their GP outlining patients diagnosis and current medications	To prevent confusion and error with regards to a person with epilepsy’s care plan and medications	MDT in the specialist centre	Sept 2019

Table 10.4: Wider inferences for the development and operationalisation of epilepsy policy and practice

OBJECTIVE	**DESIRED OUTCOME**	**LEAD**	**BY WHEN?**
Electronic communication for exchanging information made available	Improving interactions with people with epilepsy, specialist centre and primary care	Policy makers and member of the MDT	Sept 2019
Empower GP's to take a more active role with regards to care provision for people with epilepsy	Improve interaction and relationships between people with epilepsy and GP's	ANP's	Sept 2019
A once off prescription written by the service provider within a specialist service and one that does not need to be transcribed again by a GP	To reduce prescription confusion and error.	ANP's	Sept 2019
ANP's to link and collaborate more with primary care.	Improve collaboration and links with primary care	ANP's	Sept 2019
Telephone advice provided by specialist epilepsy services should be reiterated to the GP	To improve interaction with the specialist centre and to have a point of contact if any issues takes place within primary care	ANP's	Sept 2019

Table 10.4: Wider inferences for the development and operationalisation of Irish epilepsy policy and practice

OBJECTIVE	DESIRED OUTCOME	LEAD	BY WHEN?
Peer support groups to be implemented and ambassador programs to be developed and implemented	To improve understanding, promote social inclusion, and foster empowerment related to epilepsy	People with epilepsy and members of Epilepsy Ireland	Sept 2019
Continuous engagement between people with epilepsy, service providers and members of Epilepsy Ireland	Improve societal understanding and social exclusion	MDT, people with epilepsy and Epilepsy Ireland	Sept 2019
Mindfulness therapy to be implemented	Improve psycho-social and structural difficulties for people with epilepsy	MDT and link with epilepsy Ireland	Sept 2019
ESN’s to provide information in relation to the role of the ANP to the MDT	To improve understanding of the role of the ANP	ANP	Sept 2019

Table 10.4: Wider inferences for the development and operationalisation of Irish epilepsy policy and practice

OBJECTIVE	**DESIRED OUTCOME**	**LEAD**	**BY WHEN?**
People with epilepsy to provide lectures to medical and nursing students	To improve service providers understanding of epilepsy and how to facilate empowerment	People with epilepsy	Sept 2019
People with epilepsy to provide education and information provision to people with epilepsy (peer support)	To provide people with epilepsy with support and to discuss experiences of living with epilepsy	People with epilepsy	Sept 2019

10.9 Chapter summary

This chapter firstly describes a situational analysis of empowerment within epilepsy services using one specialist service as an exemplar and Checkland's (2000) SSM. A rich picture of the problem situation was presented and highlighted factors that inhibit empowerment for people with epilepsy and service providers within the Irish epilepsy service. Having identified key issues a root definition using the CATWOE mnemonic was described outlining the key activities that need to take place in order to facilitate empowerment within Irish epilepsy services. Bearing these activities in mind, a conceptual model of how the Irish epilepsy service should be carrying out its activity to meet the requirements implied in the root definition was presented. The conceptual model entitled 'Empowerment and quality care within Irish epilepsy services' highlighted a number of subsystems to consider and include: service system; communication system; professional system; education system and intelligence system. This chapter has compared the conceptual model of the systems named in the root definition with its service operation by presenting the results of a focus group of people with epilepsy and service providers. Identified desirable and feasible changes that are required to improve the quality of epilepsy care provision and facilitate empowerment within epilepsy service are presented. Whilst the implementation phase is not part of this study, wider inferences for the development of epilepsy policy and practice are outlined for future consideration.

CHAPTER ELEVEN

Concluding Discussion and Recommendations

11.1 Introduction

This study explored and analysed one specialist Irish epilepsy service using Checkland's Soft Systems Methodology (SSM) as an organising methodology. The study's aim was to explore and analyse the epilepsy service as a system with reference to dimensions of empowerment using Critical Social Theory (CST). This Chapter critically discusses the findings of this study with regard to CST, empowerment and epilepsy healthcare. It considers the limitations of this study, draws conclusions from the findings and presents recommendations for future practice, policy and research.

In Section 11.2 a critical discussion of the key findings of this study with respect to its aim and the five Research Objectives (RO) is presented. Section 11.3 critiques CST and Checkland's (2000) SSM as a methodological approach and its application to this study and considers any further limitations of this study. In section 11.4 recommendations for clinical practice are discussed whilst implications for policy are presented in section 11.5. In section 11.6 recommendations for future research arsing from this study are discussed. Section 11.7 presents this study's contribution to theory and knowledge. Finally section 11.8 presents an overall conclusion to the study.

11.2 A critical discussion of key findings

Section 11.2 examines the key findings of this study with respect to its aim and objectives. The focus of this section is to provide additional insight relating to empowerment and epilepsy health care and critically discuss the factors that support or hinder empowerment of service users and staff. The section will also reflect on the Chronic Care Model (CCM) (Wagner *et al.* 2001) and critically discuss it in relation to the conceptual framework developed in this study which proposes a number of antecedents to empowerment.

The aim of this study was to explore and analyse one epilepsy service as a system with reference to dimensions of empowerment using CST. To achieve this aim this study was guided by five research objectives:

(1) To utilise CST to analyse and define the concept of empowerment in the Irish health service.

(2) To develop a situational analysis and conceptual model of the service utilising 'soft systems' methods with reference to the NECP.

(3) To explore and critically analyse organisational issues and human factors in service provision that support or hinder empowerment.

(4) To compare the conceptual model of the service with its service operation.

(5) To draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland as this relates to empowerment.

This discussion is organised around the study's five Research Objectives (RO's).

11.2.1 RO 1: To utilise CST to analyse and define the concept of empowerment in the Irish health service

The potential of CST for the study of empowerment and epilepsy healthcare was explored in Chapter 5. Identifying an appropriate definition and conceptual model of empowerment within Irish epilepsy services was discussed and presented in Chapter 2 by undertaking a concept analysis of empowerment and an examination of the international literature as this related to people with epilepsy and service providers. Chapter 3 provided a critical synthesis of current international literature pertaining to empowerment and epilepsy health care from the perspectives of services users and providers. Finally, Chapter 7, Chapter 8 and Chapter 9 analysed and defined the operationalisation of empowerment in one Irish epilepsy service through a service user survey, observation of practice, one-to-one interviews and a focus group with people with epilepsy and clinicians about their views of empowerment within one epilepsy service in Ireland.

CST offers a way forward to explore and at least, theoretically, accomplish change. Multiple studies identify that patients who are involved with decisions about their care and the management of their conditions have better outcomes compared to those who are not (Stevenson *et al.* 2000, Wagner *et al.* 2001a, Karnielli-Miller *et al.* 2009, Elwyn *et al.* 2012). Therefore, the hierarchial power dynamic within health care needs to be explored in relation to empowerment in the 'real world'.

Within this study, most people with epilepsy understood empowerment as the ability to make better decisions and self-manage their condition; clinicians identified empowerment as the ability to provide a good service and facilitate empowerment for people with epilepsy, albeit with a permissive mind set. Many of the determinants (subthemes) that represent the theme ‘An understanding of empowerment’ (see Chapter 8, Section 8.2) also present themselves in the concept analysis described in Chapter 2. It is noteworthy that a majority of findings from the qualitative analysis, generally align with the findings of the concept analysis in Chapter 2.

This study identified empowerment as a subjective process and outcome arising from an access to ‘power from within’ for the individual as this relates to a sense autonomy, self-confidence and feeling respected as encompassed in the principles of Person Centred Care (PCC) (Stewart 2001). This definition is supported by the broad literature described in Chapters 2 and 3. However, it is interesting to note that whilst many of the clinical participants in this study engaged with the components of empowerment through PCC this was articulated in terms of permission (‘allowing’) the patient to participate – thus implicitly reinforcing the hierarchical relationship between clinician and service user. This suggests that whilst clinicians in this service mostly engaged with empowerment in principal, the way they articulated that engagement was through a permissive discourse of giving up control to the service user rather than seeing it as an embedded right of partnership (see Chapter 8, Section 8.3.1).

There is an assumption under CST, that people want to be empowered. Many service users in this study did speak positively about wanting to be or indeed feeling empowered (See Chapter 8, Section 8.3.4). However, it was also clear that there was a minority who were uncomfortable with the idea of being asked for their views or to contribute to their plan of care. The reasons for this appear to be derived from two sources – firstly, a sense of inadequacy/deference to clinical expertise and, secondly fears about being explicit around taking part derived from a sense of shame and not being used to talking openly about their condition in the wider society (See Chapter 8, Sections 8.3.2, 8.3.4 and 8.6.1).

Similar to previous research studies exploring service users and providers’ perspectives of empowerment (see Chapter 3), this study also highlights an imbalance of power within epilepsy services, derived from socialised perceptions of hierarchy and professional expertise, with many participants reporting feeling powerless. Whilst some people with epilepsy reported having decision making power in relation to medication and feeling in control of their life, others reported feelings of fear in relation to their interactions with service providers and an inability to participate in their care. This is supported in the literature. For example, a Canadian study (Gibson 1995) of children's neurological disability services reported that where the medical model predominated service providers are unwilling to listen to the concerns and viewpoints of service users. In this regard, Chandler (1992) argues that 'power over' is associated with control, influence and domination (see also Section 11.2.3.1 below). Fitzsimons *et al.'s* (2012) review of literature of evidence based models of care for people with epilepsy found that services often deliver care without taking account of the health and social aspirations of people with epilepsy (see also Toofany 2006).

11.2.2 RO 2: To explore and critically analyse organisational issues and human factors on service provision that support or hinder empowerment with reference to the NECP

A further objective of this study was to explore and critically analyse organisational issues and human factors on service provision that support or hinder empowerment for people with epilepsy and service providers within epilepsy services using one specialist epilepsy service in Ireland as an exemplar. These issues were addressed in the first and second phases of this study (reported in Chapters 7 to 10).

The National Epilepsy Care Program (NECP) has 3 main goals: 1) the delivery of improved quality of care; 2) improved access to specialist care for people with epilepsy; and (3) delivering on value (cost) to ensure the sustainability of the programme into the future (HSE 2014 p.7). While some service providers in this study identified improvements in the epilepsy services and care provision since the development and implementation of the NECP (see Chapter 8, section 8.4.1) it is evident from the findings of this study that further improvements are required as presented in the rich picture using a soft systems approach (see Chapter 10, figure 10.1).

Within the national context of empowerment of people with epilepsy overall, many service users and the clinicians within the specific service under study reported wide variation in terms of access to epilepsy services locally and poor support from primary care. These hindrances to empowerment were exacerbated by a lack of sufficient resources to fund local services and no national policy guidelines to drive the operationalisation of empowerment (see Chapter 8. Section 8.7).

Factors that appear to inhibit empowerment for service providers included: poor engagement; collaboration and communication within the specialist services, GPs and Epilepsy Ireland; lack of managerial and professional support; poor interactions with people with epilepsy; poor professional relationships and limitations in professional education with regards to empowerment.

Though there appeared to be high levels of satisfaction with epilepsy services and care provision (See Chapter 7), people with epilepsy offered several suggestions to improve empowerment experiences, such as: improved access to specialist services and investigations; better continuity of care; better information provision; improved psycho-social-structural supports; more confidence in GPs' knowledge and ability; improved engagement with Epilepsy Ireland and better communication and interactions between service providers. In addition, people with epilepsy stated that their lifeworld was negatively affected as a result of an epilepsy diagnosis (see Chapter 8, Section 8.7).

A significant finding from this study that impacted upon empowerment experiences with the specific service was intimadatory barriers to empowerment between the service user and the clinician resulting from perceived power imbalances between the two arising from professional situational power and resultant tensions and articulation frustration on the part of the service user towards the clinican in the consultation environment. Experiences of *'fear', 'frustration'* and '*vulnerability'* were central to these intimadatory situations (see Chapter 8, sections 8.3.1, 8.5.1, 8.5.2, 8.6.2, and 8.6.3). Arguably, such situations were framed through social inferences that were primarily referenced to lay socialization, norms and values as to the role of the 'patient' and the clinician coming up against expectations of services and having needs met. It would appear that service providers professional socialization through being with other clinicians, their training and their clinical practice experience also contributed to these situations (See Section 11.2.3.1 below).

A specific professional concern in terms of not feeling prepared to be empowered within the local service was voiced by a number of ESNs. They identified a fear in relation to advanced decision making and autonomy with regards to their future advanced role and talked about the need for improved professional and organisational support in particular in relation to their legal and professional responsibilities (see Chapter 8, section 8.6.2). This would indicate that changes to role or responsibilities should always be accompanied by a consideration and operationalisation on the part of health organisations and policy-makers to address what is needed to empower those whose roles and responsibilities expand before that expansion takes place.

11.2.3 RO 3: To develop a situational analysis and conceptual model of the service utilising 'soft systems' methods

Using a soft systems method the first purpose of this objective was to develop a situational analysis of the Irish epilepsy in relation to empowerment. A secondary ambition of this objective related to the development of a conceptual model of the service. This objective is initially identified in the concept analysis and policy findings (Chapters 2 and 4), and principally examined in phases 1 and 2 of this study (Chapters 7 and 8). A situational analysis (rich picture) of empowerment within Irish epilepsy services is identified in figure 10.1. The range of key issues extracted from the rich picture, enabled a root definition of empowerment within epilepsy services to be developed. From this root definition a conceptual model was developed and identified in figure 10.3.

Systems approaches are increasingly advocated in healthcare organisations to improve understanding of influential factors in healthcare environments and manage health systems' complexities (WHO 2000; 2007, de Savigny and Adam 2009). A consistent theme throughout this study is that empowerment is a complex and multifaceted concept within healthcare. As indicated in Chapter 5 (Section 5.6.1), Checkland (1981) presents a way of understanding complex systems by distinguishing two pairs of concepts: (1) emergence and hierarchy; and (2) control and communication.

System's thinking enables the holistic appreciation of factors that lead to poor organisational performance (Fortune and Peters 1995). Moreover, it enables all relevant stakeholders to participate in the process of improvement, taking account of their differing perspectives. This, in turn, has the effect of engaging them in the change process and moving towards a process of continual improvement.

Empowerment is an emergent phenomenon based on the interactive relationships of individuals and groups as they create and recreate their socio-political realities. With this in mind, systems' thinking requires a holistic approach to understand how things influence one another within a whole; in contrast to Descartes's scientific reductionism (Ackoff 2008). Since empowerment is located in emerging relationships, the methods of science with exclusive focus on 'objectivity' are constrained to study empowerment within Irish epilepsy services.

As outlined in Chapters 2 and 8, empowerment within Irish epilepsy services is a subjective process and outcome arising from an access to power from within. With this in mind, empowerment must be understood at the macro, meso and micro levels of epilepsy healthcare. The discussion that follows will identify how each paired system concepts relates to empowerment and care provision and requires analysis at its own level. As stated in Section 5.6.1 the basis of systems theory rests on two paired concepts: (1) emergence and hierarchy; and (2) control and communication in what is termed a Human Activity System – HAS (Checkland 1981). This section discusses the findings in relation to these two elements of the identified HAS in the epilepsy service under study.

11.2.3.1 Emergence, hierarchy, empowerment and care provision

Epistemologically, emergence and hierarchy are interdependent concepts. Neither a one-level epistemology nor a one-level ontology is possible to help us to understand the real world (Broad (1923) cited in Checkland 1981). The findings of this study suggest the existence of local hierarchical structures (both formal and informal) as this relates to a concept of 'power over' (See Chapter 2, Section 2.5.3 and 2.7.1; Chapter 4, Section 4.2.1 and Chapter 8, Section 8.3.1) and, within the service this was found to be illustrated by such issues as the 'power of presence' based on perceptions of formal status, eg. the medical profession, and informal status such as personal attributes, such as perceptions of knowledge (which were not necessarily based on formal hierarchy – see Chapter 8, Section 8.4.2).

This kind of characterisation of hierarchy relates to the emergence of professional language at a micro level indicator of authority particularly as this relates to the empowerment/disempowerment of the service user versus the professional and personal self-confidence in terms of status and inter-relationships.

The hierarchical structure within this service as it relates to more macro institutions shows a complexity of hierarchy and language in terms of what is and is not acceptable to communication to the wider organisation, for example as this relates to system change (see Chapter 8, Section 8.4.4). In this context, it may be argued, that the system as a whole will impose an influence on its lower level which is a kind of top-down causality, where local hierarchies understand inadequacy provision but feel both disempowered to voice it, told to ‘shut up’ and rather to manage within an existing unchanged system – ‘don’t rock the boat’. In general, hierarchy and emergence within this systems relates to local interpretations and abilities to navigate organised complexity in terms of interpersonal relations and relations between the micro world of practice and the macro world of organisational hierarchy. What is striking is that it would appear, despite the rhetoric, is that patient centredness and, by implication, patient empowerment, is highly dependent on interpersonal relationships rather than a systems level structure.

Chapter 2 highlights that an understanding of power is essential in order to recognise empowerment. An imbalance of power is evident within Irish epilepsy services as service providers primarily control the rhetorical space at local level and have difficulties with surrendering control in particular the medical profession. For example, service providers claim control over knowledge and make decisions for people with epilepsy. Moreover, a lack of power in the clinical environment for nurses is acknowledged and further endorsed by the hierarchical structures and the dominance of the medical profession (see Chapter 8, Section 8.4.2).

11.2.3.2 Control and Communication

The concept of control and communication provides an important support for explaining how the hierarchical structure is perpetuated and operates in the system as a whole and why it has an adaptive ability to survive in a dynamic environment. Checkland (1981) indicates that all control processes are dependent on communications, and that communication is the most powerful concept in system movement because it brings specific meanings to a HAS which will then influence possible action.

Findings of this study indicate that having control over one's personal and worklife (a sense of autonomy) is important for people's empowerment. In this context controlling practices within epilepsy services were identified. For example, people with epilepsy talked about their inability to make decisions, in particular when service providers failed to surrender control (See Chapter 8, Section 8.3.1). On the other hand, some service providers identified a lack of power and control in order to make changes within the service to improve care provision (See Chapter 8, Section 8.4.2).

Within the context of communicative competence, theoretically open dialogue is significant for equal partnership and respect (see Chapter 2, Section 2.7.3). Indeed, there was some evidence within this study that supported this. However, there was also evidence that dialogue could be controlled through professional power in terms of perception of expertise, presence of authority or overt closing down of challenge for both people with epilepsy and between professionals within the service and also between the service and wider organisation thereby proving a barrier to change and a reinforcement of the status quo (See Chapter 8, Sections 8.5.1 and 8.5.2 and also Chapter 10, Section 10.6, Figure 10.1 and Table 10.2).

This study suggests that poor communication is distorting service experiences. A number of people with epilepsy described not being listened to and not treated as an equal, whilst service providers identified feelings of fear as a result of people with epilepsy's anger and aggression and indeed sometimes also feeling that they, the professionals, were not being listened to. Major improvements in relation to communication and alignment of goals between the specialist service; primary care and the voluntary service 'Epilepsy Ireland' was identified as necessary. Morrow and Brown (1994) suggest that power relations engender forms of distorted communication. Therefore, to address such concerns, Habermas's communicative action theory is recommended as a means to address the service provider-service user power imbalance (Burbank and Martins 2009). The significance of active listening, equal partnership and respect is highlighted on many occasions (Rappaport 1995, Rodwell 1996, Paterson 2001, Aujoulat *et al.* 2008).

These findings merit further study from a CST perspective with a specific focus on communication within epilepsy services. By asserting the principles of undistorted communication new perspectives can be examined, and consequently, can be used to discover and describe inequalities or oppressions (Habermas 1988). It has the potential to uncover the constraints that prevent un-coerced communication (Wilson-Thomas 1995).

The conceptual model (see Chapter 10, figure 10.3) consisted of an overall system with a number of subsystems (service system; communication system; professional system; education system and intelligence system) in relation to how Irish epilepsy services should be carrying out its activities to meet the requirements implied in the root definition.

The conceptual model developed within this study offers new ways of understanding empowerment and epilepsy health care and provides a number of suggestions for practice. Firstly, understanding the needs of people with epilepsy and service providers within the Irish epilepsy service is highlighted (See Chapter 10, Section 10.5). The situational analysis identified numerous challenges within the system and highlights areas that require improvements. For example, the findings of this thesis suggest that shared care between primary and specialists services remain poor (See Chapter 8, Section 8.4.2). This finding is significant and should not be underestimated in any future strategy to reform epilepsy services and care provision. With this in mind the coordination of care can be improved by further establishing networks of shared care between all stakeholders and making available electronic communication for exchanging information to all stakeholders. Moreover, this conceptual model offer the genesis for new avenues of enquiry and evaluation in relation to empowerment and chronic illness (See Section 10.5).

Empowering educational approaches are discussed (see Chapter 5, Section 5.4 and Chapter 8, Section 8.7). A CST perspective offers educators/clinicians a way to challenge the traditional models of educational delivery for people with epilepsy by posing the following questions: What are the issues of power and control that are embedded in development and delivery of educational approaches for people with epilepsy? Who develops and decides what educational content should be delivered to people with epilepsy? What social structures and relations such as culture, economics, race, age, or gender contribute to making educational delivery an oppressive structure within epilepsy education and how can people with epilepsy be empowered to competently self-manage their condition?

It may be argued that CST has significance in supporting service providers and researchers to make sense of problems in service delivery and promote initiatives for change and improvement (Hart and Bond 1995). For example, CST offers a research perspective that may help uncover enabling and/or restrictive practices within healthcare (Wells 1995). Thus, engaging in critical self-reflection allows service providers and people with epilepsy to understand how empowerment is facilitated or prevented within epilepsy services.

The Chronic Care Model (CCM) emerged in the 1990's as an approach to respond proactively to people with chronic illness (see Chapter 4, section 4.4.1). It includes a combination of patient, provider and system level interventions delivered in tandem through six key elements:(1) Healthcare system organisation; (2) Self-management supports; (3) Delivery system design; (4) Decision supports; (5) Clinical information systems; and (6) Community resources and policy (Wagner *et al.* 2001). However, Boehmer *et al.* (2018) suggests that the chronic care landscape has evolved beyond the implied singular concepts of the original CCM. For example, patients now present with multiple chronic conditions and increasing psycho-social complexity. Whilst the implementation of the CCM has substantially improved medical outcomes, enhanced patients' quality of life and decompressed social burden, Yeoh *et al.* (2018) argues that limitations exist in relation to the CCM such as service providers working in isolation as this relates to multiple conditions; does not recognise the differentials between patients' desires to be empowered or not leading to difficulties in motivation; errors and omissions in clinical information systems and the collaborative input of non-statutory organisations and patient representative groups within the community. To address this, Yeoh *et al.* (2018) suggests that further optimisation and integrative applications of the six CCM components are required. With this in mind, SSM accounts for elements/activities of a HAS in which people are purposefully engaged, and the relationships between those activities/elements as a whole system (Platt and Warwick 1995). Thus it may be argued that SSM has a greater holistic focus than CCM since sub-sytems and human activities are not treated in isolation. SSM, unlike CCM, encourages a modus of thinking in which the ideal of a service is explored within the context of real world complexity through what people (actors do and believe) in order to identify what needs to change and how in order to achieve the stated ideal. As such, it provides a guide action which CCM may miss.

11.2.4 RO 4: To compare the conceptual model of the service with its service operation

Using a soft systems method the purpose of this objective was to compare the conceptual model of the Irish epilepsy service with its service operation. Having developed a conceptual model, a comparison was then made with the proposed 'real-world' epilepsy care provision in order to form a basis for debate at policy level about change (identified in table 10.2). By comparing the conceptual model with reality, it seems that performance was either poor or ad hoc and changes are required with regards to empowerment and Irish epilepsy health care in relation to (1) structure; (2) processes and (3) attitudes.

By utilising a SSM's approach and comparing the conceptual model of the service with its service operation, significant findings in relation to desirable and feasible changes with regard to empowerment within epilepsy services were identified and hence what actions are needed (see Chapter 10, section 10.7 and table 10.3). Quality improvement, intelligence, communication, professional and educational perspectives were examined (see Chapter 10, Section 10.5 and figure 10.3). For example, improving epilepsy services and care provision is required to ensure an effective quality improvement system, meeting the real-world needs of all the stakeholders in collaboration with the NECP. In a similar manner, desirable and feasible changes were identified for the other four perspectives.

11.2.5 RO 5: To draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland

Using a soft systems method the purpose of the final objective of this study was to draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland. This was achieved by undertaking a focus group (n=8) with people with epilepsy (n=4) and service providers (n=4) in order to share findings of the data collected and explore potential service improvements and changes that were needed in order to facilate empowerment that extended from the specific service under study to wider Irish epilepsy services. During the focus group, the participants' worldview were contrasted with each other, so that accommodations could be made on what changes may be possible to improve the quality of epilepsy healthcare provision. These include: (1) improvements in communication and collaboration within epilepsy services; (2) involving people with epilepsy in the design and delivery of the service; (3) an ambassador program to promote understanding, social inclusion, and foster empowerment related to epilepsy; (4) provision of an empowering education and training for service providers; and finally (5) legalising medicinal cannabis for people with epilepsy. The planned changes were translated into planned service objectives for the Irish epilepsy service with defined time boundaries (see table 10.4).

11.3 Potential limitations of this study

This section considers limitations to this study. The study involved a mixed methods approach to data collection, involving a qualitative component - one to one interviews, focus group interviews and personal observations of practice – and a quantitative element involving a survey of service users (See Chapter 5 and Chapters 8 and 9) with an overall analysis of the HAS in Chapter 10 utilising an SSM approach.

11.3.1 Critical Social Theory: A meta-theoretical critique

CST offers potential for the development of theory and research in a number of ways. Firstly, its realist ontology advocates for an improved approach to social existence, one that is free of domination, power inequities and oppression whilst epistemologically CST is transactional and subjective (Browne 2000). This challenges all theorists and researchers to reflect on their beliefs and issues of procedure for research (Habermas 1971).

CST researchers stimulates awareness of societal constraints and reveals the ideological hegemony embedded in the forms, meanings and rituals of a culture. In other words, they discover their own ontological and epistemological assumptions and preferences that inform their research within a study (Cecez-Kecmanovic 2001). Furthermore, they expose their political agendas by questioning, expressing, and reflecting upon their experiences, beliefs and values. As a counter point, traditional approaches reflect the perspective of the researcher and not the 'life-world' of participants (Guba and Lincoln 1989). This reflexive practice assists researchers recognise their own engagement with participants within a study, linking and comparing circumstances and experiences from the past in order to develop mutual understanding (Cecez-Kecmanovic 2001). For example, Kincheloe and McLaren (2005 p.292) argue that:

> ‘*Critical researchers enter into investigation with their assumptions on the table, so no one is confused concerning the epistemological and political baggage they bring with them to the research site’*

Secondly, it offers a historical framework and challenges the theoretical and/or ideological underpinnings of everyday practice (Lather 1986). It allows knowledge to be developed that is based on a critical reflection of the power relationships within society (Stevens 1989). Furthermore, CST is concerned with the elimination of distortion form communication and interactions. This is the key difference that distinguishes CST from other metatheoretical positions. Arguably CST allows research to reach areas that were not possible within traditional frameworks (Smyth 2006).

From a critical theory perspective Horkheimer (1972 p. 249) commenting on critical theory proclaims that ‘the theory is concerned with society as a whole’. Morrow (1994) argues that good critical research even if focusing on a particular level of enquiry should remain aware of other levels and their influence on the research area. Thus, an important methodological contribution of this research is the way it links societal, organisational and individual perspectives.

Given the philosophical constraints of positivism and constructivism CST supports a wide range of research methods (Morrow and Brown 1994). For example, it incorporates both nomothetic and ideographic explanation in its conception of methodology (Morrow and Brown 1994). Nomothetic explanation refers to a method of enquiry with the goal of identifying and explaining patterns found in a population, whereas ideographic explanation is inquiry directed towards understanding the uniqueness of an individual case (Morrow and Brown 1994). Furthermore, mixed methods encompassing both qualitative and quantitative approaches are consistent with Habermas’s philosophy (Grundy 1987). A strong congruent relationship exists between action research and CST insofar as both seek emancipation based on critical-dialectical knowledge between participants and researchers (Levin 1994). It is argued that ‘part of the task of an action research project, then, is to open communicative space and to do so in a way that will permit people to achieve mutual understanding and consensus about what to do’ (Kemmis 2001 p.100). Furthermore, participatory action research arose as a separate research methodology within the critical paradigm. By carrying out a participatory action research project the reflection phase creates a self-awareness which enables participants to give a voice to topics that are important to them (Koch *et al*. 2000). This inclusiveness has the potential to improve and change practice, and to enhance the sense of belonging, involvement and empowerment of those involved.

Empowerment needs an enabling environment to emerge and the role of service providers in nurturing empowerment is vital if it is to be successful. Results of this study indicate that service providers cannot facilitate empowerment as a result of professional limitations and service pressures. CST has the potential to enable people with epilepsy the flexibility to derive their own meanings (and discover themselves) and it forces service providers to be more creative, responsive to the needs and broaden their own understanding of a topic. It is as if the teacher and the student co-create the curriculum through their interaction. Paulo Freire gives an excellent summary of the qualities required for this sort of 'dialogic' relationship (love, humility, faith, hope and critical thinking) (1970; 1993).

Although the potential of CST to explore new ways to research and develop knowledge that would not be recognised by using traditional philosophical frameworks has been argued, it does have limitations (see Chapter 5, Section 5.4.1). Chapter 5 discusses that CST is not a unified theory but rather constitutes diverse writings of many theorists. A further criticism of Habermas's CST is that it doesn't relate to the real situation and is utopian in character (Carr and Kemmis 1986). Another is that Habermas's theory is orientated towards the individual (Fay 1987) and is therefore a weakness when wanting to initiate social change on a workplace scale.

According to Kincheloe and McLaren (2005), action or the potential for action at this political level is the desired outcome of CST, whilst Denzin and Lincoln (2005) suggest that no one person is completely emancipated from the socio-political situation. To address the specifics of any social research study requires a methodological approach that recognises realist ontology, but equally so, epistemological debates within the social sciences. To address the objectives of this study exploring empowerment within epilepsy services requires a methodological approach that recognises 'real' life or the 'real' world and this led to the work of systems theory and Checkland's SSM (2000).

Whilst it cannot be claimed that this study facilitated empowerment within the epilepsy service, it has however enabled people with epilepsy and service providers to engage in critical reflection and open dialogue around the issue and therefore has the potential to engage all stakeholders in an equal partnership within Irish epilepsy services. With this in mind, a methodological critique of SSM is now explored.

11.3.2 Soft Systems Methodology: A methodological critique

SSM is a methodology based on soft system thinking and was developed as an answer to the unsuccessful application of hard system methodologies in 'messy' complex real world problem situations' (Checkland 1981). The aim of SSM is to cope with those situations in which people in a problem situation perceive and interpret the world in their own ways and make judgements about it, using standards and values that may not be shared by others. Therefore, systems thinking in relation to policy issues can benefit from the adoption of SSM (Checkland and Scholes 1990). SSM is described as a process of investigation and learning (Checkland and Poulter 2006 p.1):

> *'SSM is an approach which, in use, enables those taking part to learn their way to agreed action which they perceive will 'improve' the problem situation, it is a consciously organised process of inquiring and learning.'*

Given the complexity of the concept of empowerment within Irish epilepsy services, the potential of SSM as a methodological approach for this study was appealing for a number of reasons. For example, it provides a way of understanding problem situations by taking account of often ignored contexts and interpretations thereby overcoming the limitations of traditional 'reductionist' thinking (Jacobs 2004). Moreover, it provides a coherent approach to group and individual thinking about context, complexity, and the ambiguities of policy (Checkland and Scholes 1990 p.228). Thus, detailed analysis of change enables those using SSM to identify underlying roles, norms, and values (Checkland and Scholes 1990 p.49) with particular reference to the subjective interpretations and standpoints of those involved in the problem situation.

Facilitating empowerment within Irish epilepsy services was identified as a rich, messy, complex and nuanced field with many challenges. In order to properly tackle this challenge, an appropriate methodology was required. While hard system approaches have been successfully used to solve well-defined problems involving objective reality, arguably they are too rigid to be used within human activity systems where human actors have predominant roles. A number of researchers highlight the difficulty in changing organisational culture (Wilkins and Ouchi 1983, Edwards and Kleiner 1988). This study exploring empowerment within epilepsy services referenced to a specialist epilepsy service in Ireland demonstrated that an SSM process has the potential to assist the first steps in achieving cultural change; namely changes in beliefs concerning the purpose(s) of an organisation and the development of strategies to support such change. However, it also highlights the complexity of the concept of organisational culture and cultural change and recognises that there are many aspects of culture which are wider than the roles, norms and values related to organisational purpose, and these may not change as a result of change in Weltanschauung.

Whilst the potential of SSM has been highlighted, it is not beyond limitations. Firstly, it is identified that its models are not normative, but ideal, being an expression of one 'world view' in one area (Schmidt and Carstensen 1990, Lane and Olivia 1994, Jackson 2003). Secondly, it is argued that Checkland's (2000) use of terminology in SSM such as the root definition of a relevant system is a 'notional system' as the 'real world' system does not yet exist (Schmidt and Carstensen 1990). In addition, a further limitation of SSM within this study was the role played by the researcher. Coming from the outside led to a number of problems which, on reflection, could have an influence on the final analysis. One of these is that the researcher has the potential to put a false construct on the overall picture of the situation, because one was not part of it and was concerned about the acceptability of the findings to the MDT.

11.3.3 Further potential limitations within this study

With regards to the qualitative component, a possible weakness of this study overall was the potential for subjectivity involved in having only one researcher to engage in textual and observational analysis (interview transcripts, an observation of service and note taking). However, it is in this context a number points can be made. Firstly, much of the approach to both data collection and analysis is qualitative which necessarily involves an act of interpretation by one or more researchers. The act of interpretation is of itself a subjective one. The issue in this regard is can the interpretation put forward be supported by the evidence collected and presented and appear to be a reasonable one. Secondly, in this regard, the SSM approach emphasises the importance of developing a 'whole system' analysis and therefore providing opportunities for confounding variables in the data to emerge and be explored, highlighting any contradictions that would need to be accounted for. In this regard reflexive awareness, discussion of interpretation with others and ultimately review by external people (such as PhD examiners) acts a control.

However, taking all the above in to account, it could nevertheless be argued that a better approach would have been to have subjected the material to an independent analysis separate from the data collector (ie. myself) or coterminous comparative analysis of descriptive codes in order to develop and apply the consensual interpretative framework with regards the data (a form of inter-rater reliability). However, in practice such an approach, I would argue, does not substantially remove criticisms around potential for bias and would have proved impractical in this particular study; in part due to lack of funding to employ some-one to do this; time frames available and that it was constrained by the requirements of submission of a doctoral thesis (for example that the work had to be predominantly one's own). Having said that, the analysis was subjected to independent interrogation through critical discussions of my interpretations of the data with my supervisors and this certainly challenged any over interpretation of the data that I might make.

Overall, in terms of transferability (the qualitative equivalent of generalisability), potential for bias and my role as researcher is reflected upon and discussed in Chapter 5. My interpretation of the literature and findings of phase 1 and phase 2 of this study moulded the interview and focus group topic guide. Even though a level of rigour was applied to every aspect of the research, my view of the world may have influenced both 'coding on' and analysis to some degree. The issue of subjectivity was dealt with in a number of ways. Firstly, as previously stated, by subjecting the analysis and conclusions to the scrutiny of my supervisors. Secondly, through self-reflection and being conscious of separating my observation from interpretation within note taking in the field.

With regards to the survey instrument, data collection and analysis (See Chapter 7) no reports of validity and reliability from other studies in relation to Poole *et al.'s* (2000) questionnaire appear to exist. Whilst content validity pertaining to the adapted questionnaire items was sought from a panel of experts with previous research experience (see Chapter 5, Section 5.13.1) no person with epilepsy was consciously approached to assess for content validity as at the time, patient commentary was invited through submission of the survey instrument to the Patient Advisory Committee (PAC) in addition to a panel of experts drawn from medicine and nursing. On reflection this could be seen as a weakness in relation to the content validity of the instrument, because there was no person with epilepsy specifically invited to comment. However, it should be noted that the instrument is widely used in epilepsy service evaluations which suggests a certain content validity does exist with regards to people with epilepsy. In addition, I was not aware whether any members of the PAC did or did not suffer from epilepsy themselves, therefore it is possible that a member of the committee was drawn from the targeted service user group. Having said that, I would recommend that any future use of the instrument involve a conscious consultation with people with epilepsy viz. seeking commentary on content validity.

Another potential limitation is that some people with epilepsy did not answer all questions. Missing data was coded by using numbers 999, on the advice of the School statistician, and valid percent was reported throughout the study. Nevertheless, this may have affected the validity of the findings, such as reducing statistical power and the representativeness of the sample with regards to the survey. However, it should be noted that survey findings were largely confirmed by one to one and focus group interviews.

This study was conducted in one specialist epilepsy service in Ireland. In this context it did not represent the Irish epilepsy ecosystem and conclusions about the epilepsy services in general arising from this study may be criticised in this regard. Having said that, the service studied is a national service with service users from all over Ireland attending and thereby sharing their experiences of the ecosystem of epilepsy care in Ireland. The service under study itself, may be considered a micro example of an element of interaction with the rest of the eco-system of care.

A further limitation, is that participants self-selected for inclusions in this study and therefore this may reflect a bias with regards to collating their views of empowerment alone and ignoring the views of those who do not participate. Having said that, this is often a problem in any study that invites volunteer participation.

A further limitation, it could be argued, is that this study did not obtain the participation of the full range of actors involved in the epilepsy ecosystem. For example, no GP’s or other MDT members such as psychologists, psychiatric services managers, community workers and administration staff were asked to participate in this study. In addition no family members and carer’s were included. SSM is focused on the immediate actors within a service and the study focused upon those in terms of the participation of clinicians. Also both budget available and time constraints impinged upon who it was practicable to approach within the allocated time frame for data collection. To address this a post-doctoral study could present the results of this study to these other actors to evaluate the degree they had or did not have to similar issues.

Whilst service users with an ID were not excluded from this study, none participated in this study as they were not asked to by the gatekeepers to participate. Gatekeepers clinical judgement on the service users’ ability/ vulnerability in relation to participation is most likely the reason for this. However, there is increased emphasis on the importance of including people with ID in service evaluation type research because they often have specific needs and issues that other users of the same service do not have. Indeed, this would warrant a separate study in its own right (Gregory *et al.* 2001, Iacono *et al*. 2014).

The influence of clinicians as gatekeepers may have influenced the selection of individuals selected for this study. However, results obtained within this study were compared to the broad literature on empowerment within health services and appeared to be congruent with a number of themes that can be identified on empowerment as discussed in this Chapter.

Finally, although the intent to implement actions to facilitate empowerment within the epilepsy service was agreed during the focus group discussion, evaluating the actual implementation was outside the scope of this study. However, there is further opportunity to return to the organisation to implement the outcomes as part of further research.

11.4 Recommendations for improving empowerment – practice

This study highlights that there may be geographic variation in availability, access and quality of Irish epilepsy services and care provision (see Chapter 8, section 8.4.1). In addition, a lack of shared care between the specialist, tertiary and primary care exists. This inequality and lack of shared care requires urgent reform and reconfiguration. Whilst a model of shared epilepsy care has been introduced amd implemented (see Chapter 4, section 4.4.2), findings of this study suggests that considerable improvement is required. This is significant for all stakeholders as empowerment within the service will be ineffective, in terms of service user-provider experience, if it takes place in one part of that service experience and not in other aspects. This study suggests that confusion exists in relation to professional roles and responsibilities within the epilepsy service and therefore professional roles and responsibilities should be more clearly formalised.

Significant impediments to optimum empowerment have been demonstrated in this study of people with epilepsy and their service providers. Therefore, greater emphasis on the implementation of empowerment approaches to care with more active involvement of people with epilepsy as experts, negotiators and collaborators of care is required. In this context a number of recommendations are made for clinical practice based on the findings of this thesis:

- Epilepsy services need to provide structured and integrated care for all people with epilepsy (see Chapter 10, table 10.4).
- Clarification of roles and responsibilities for all stakeholders must be formalised and a clear definition of ‘shared care’ should be collaboratively agreed and understood by all stakeholders (see Chapter 10, table 10.4).
- Establishing networks of shared care and making available electronic communication for exchanging information should be considered to improve the coordination of care (see Chapter 10, table 10.4).
- The EPR should be further implemented to improve the continuity and standardisation of care (see Chapter 10, table 10.4).
- Service providers need to acknowledge people with epilepsy’s personal treatment goals and outcomes and adopt an inclusive holistic approach to people with epilepsy, demonstrating an awareness of the challenges they face (see Chapter 10, table 10.3 and 10.4).

- A less hierarchial approach to power within epilepsy services should be adopted by ensuring all stakeholders have an equal partnership (see Chapter 8, section 8.3.1).
- Support structures and leadership skills should be made available to all service providers within epilepsy services to improve collaboration and communication between all service providers (see Chapter 10, table 10.4).
- People with epilepsy should actively participate in the management of their epilepsy, provide peer support and in the provision of education to other people with epilepsy, nursing and medical students (see Chapter 10, table 10.3 and 10.4).
- CST principles should be introduced and integrated into the curriculum for health care undergraduate education and at postgraduate specialist level a greater depth of understanding of its principles and how these should be utilised in practice. This will enable service providers to critically examine and reflect on the traditional approaches that have been used and that limit the actuality of empowering people with epilepsy (see Chapter 10, table 10.4).

11.5 Recommendations for policy arising from this study

To ensure effective policy the engagement of all stakeholders is required. Policy development needs to recognise and engage with the concerns of both people with epilepsy and service providers. A review of UK policy frameworks for supporting evidence-based health care specifically argues for greater attention to be paid to fostering new boundary spanning mechanisms in order to encourage knowledge flow across professional boundaries (Lindsay and Dutton 2012). In this regard policy implementation analysis of professional and role boundaries and collaboration needs to pay attention to the means by which different professions share and debate their ‘knowledge’ and embed it into local practice (Ferlie *et al.* 2009).

Constructing boundaries around areas of professional expertise is seen as a common theme in the practice and value systems of health professionals. However, these behaviors are problematic if they prevent necessary collaboration across disciplines and organisations (Mallinson *et al.* 2006, House of Commons Select Committee on Health 2012). The NECP, with its new structures and ways of cross disciplinary working in epilepsy care will require the development of boundary spanning roles and practices for the benefit of patient care. These will determine success or failure in relation to effective program implementation. Further research that considers the operationalization and impact of boundary spanning in relation to program delivery and outcome is needed.

Whilst current policy addresses the principal of partnership and social inclusiveness as a way forward for health service provision, it still does not explicitly deal with the concept of empowerment and facilitating empowerment within healthcare. As mentioned previously people with epilepsy lack a sense of empowerment, and play a passive role within healthcare (Varley *et al.* 2011). Arguably, therefore what is required is an epilepsy service provision that is underpinned by the principles of empowerment.

This study describes the potential of an analytical framework derived from Walt and Gilson (1994) that interrogates the context, process, content, and actors of policy development and implementation[62]. Context refers to the broader situational and structural factors influencing the reform. The process analysis investigates the way in which policies are identified, formulated, and implemented; the timing of events; and the strategies used at each stage. The analysis of content focuses on the nature and details of the policy proposals. The study of actors is concerned with the key stakeholders involved in developing and implementing the reforms, as well as their differing roles, values, interests, and influence (Walt and Gilson 1994).

Service providers in this study acknowledged the need for an empowering policy for chronic illness. The context of exploring empowerment within the Irish epilepsy service was examined mainly from four dimensions: organisational; communication; cultural and social. Whilst the content of an empowerment policy for the Irish epilepsy service should include the changes identified by the participants in the focus group, all the key actors (people with epilepsy, service providers, policymakers, GP’s, members of epilepsy Ireland, and family and carers) involved in relation to empowerment policy within Irish epilepsy services should be recognised. With this in mind, the relationships between the actors outside the epilepsy service need further exploration to understand their influence on policymaking and to frame the options beyond those generated by the epilepsy service. Further research is required in relation to leadership, institutional capacity, and policy processes required to implement an empowerment policy nationally and internationally.

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[62] See Chapter 4, Section 4.5: Developing a health policy and care provision in relation to empowerment.

Findings from this current study highlight that people with epilepy lack empowerment. Moreover, service providers are unable to faciliate empowerment within epilepsy services in part due to lack of training and service pressures. This study suggests that the current structure of epilepsy care in Ireland does not facilitate empowerment and requires policies, structures and financial incentives to be made available to support people with epilepsy and service providers in working together. In this context a number of recommendations are made for policy based on the findings of this thesis:

- Respect and dignity policies should be adopted in order to create an empowering and inclusive environment within epilepsy services.
- Clinical guidelines and policies must be developed, integrated and implemented within epilepsy services specific to empowerment for service users and providers within the Irish healthcare system.
- Stronger connections to be forged between actors, processes, context and content factors for health policy and epilepsy service provision to enable empowerment to be facilitated.

11.6 Recommendations for Future Research Arising from this Study

This study's findings suggest that there are significant policy and practice challenges within epilepsy services in Ireland in terms of PCC and empowerment. The extent of deficit and challenge within existing epilepsy services as they relate to empowerment points to a number opportunities for future research.

Firstly, the wider inferences for the development and operationalisation of epilepsy policy and practice need evaluation (see table 10.4). It is my intention to return to the organisation to evaluate an implementation of the recommendations arising out of the SSM analysis within the specific epilepsy service as part of further research.

Secondly, whilst this study provides a practical working definition and a conceptual model of empowerment within epilepsy health care this merits some additional empirical work to further test suitability and usability. Further insights with regards to empowerment within the Irish epilepsy service could be achieved through longitudinal studies that look at each of the developments described in this thesis at different (future) points in time. This would allow continuous learning and updating of the conceptual framework of empowerment within Irish epilepsy services.

Thirdly, this study highlights that poor communication can distort service experiences. Future studies are warranted to explore how communication interactions impact on levels of empowerment for all stakeholders within epilepsy services, for example:

- To examine the role of communication interactions within epilepsy services and its impact on empowerment experiences for service users and providers.
- To explore the impact of communication skills training programs and interventions to foster communicative competence.
- To assess the effect of communicative competence on empowering outcomes.

Fourthly, while findings from this study report knowledge deficits and unmet information needs of people with epilepsy, the study of care literacy of people with epilepsy is neglected and is a poorly understood component of empowerment within epilepsy service delivery. This study describes the potential of an educational framework for people with epilepsy based on CST principles and therefore suggests a quasi-experimental study to compare Freire's CST educational approach versus traditional approaches to education of people with epilepsy not only about their condition but, more radically, about how they can advocate for their needs both health and social.

Lastly, I would propose more specific studies to examine issues at an organisational level. This study was conducted in one specialist epilepsy service in Ireland which is not necessarily representative of the Irish epilepsy ecosystem. Therefore, future studies to explore how access to epilepsy services and care provision; support structures; shared decision making; stigma and discrimination impact on empowerment experiences are needed, for example:

- To compare a primary and tertiary sample of people with epilepsy with regards to their views of epilepsy services, care provision and empowerment.
- To explore the views of all members of the Irish epilepsy ecosystem in relation to empowerment.
- To examine the origins and implications of stigma for people with epilepsy.
- To explore how prejudicial beliefs are generated and perpetuated and how and when they translate into discriminatory behaviors.
- To examine service user-provider partnerships within epilepsy service.
- To explore people with epilepsy's level of involvement in service design and delivery.

- To examine the efficacy, interaction effects, and safety of CBD, and to explore the potential role of other cannabinoids, either alone or in combination, in the treatment of epilepsy.
- To explore opinions on and experiences with the use of cannabis-based products for the treatment of epilepsy.
- To evaluate the current configuration and operationalisation of telehealth delivery within the NECP and explore, with the programme team, how telehealth can be further developed to enhance care and delivery is needed.

11.7 Contribution to theory, knowledge and the literature

This section presents this study's contribution to theory, knowledge and the published literature. It is the first study to utilise CST to explore issues of empowerment for people with epilepsy and, within an Irish context, to utilise SSM in a health care setting (See Chapters 2, 5, 7, 8, 9 and `10). Thus in this regard it has contributed to theory as this relates to a gap in the literature in epilepsy care and service delivery. Phase 1 of this study (a survey of people attending the specialist service of their views on their service needs in relation to design and delivery) adds to the body of knowledge that explores the views of people with epilepsy with regards to service design and delivery and in particular with their satisfaction with the care that they receive (See Chapter 7). In this context, this study provides a useful knowledge into these issues within Ireland that is of relevance to future service development.

Phase 2 and 3 of this study involved a non-participatory observation of service provision accompanied by one-to-one interviews with service users and service providers and a focus group about empowerment within one epilepsy service (Chapters 8, 9 and 10) providing a new potentially important contribution to knowledge as this relates to power differential dynamics and their impact on people with epilepsy and service providers experiences of empowerment; lack of professional training with regards to empowerment and an over reliance on socialisation processes within the service to compensate for this.

Finally, this study has contributed to knowledge and state of the art through publication of three papers in significant high impact peer review journals in the field of epilepsy reporting on the survey data of satisfaction, service preferences and information provision amongst people with epilepsy attending the epilepsy service (Bennett *et al.* 2015); the potential of CST as an educational approach for people with epilepsy (Bennett *et al.*

2016a) and on a concept analysis of empowerment relating to people with epilepsy and service providers (Bennett *et al.* 2016b).

11.8 Chapter conclusions

Six core themes were identified that highlight factors that support or hinder empowerment at the micro, meso and macro levels of healthcare delivery in epilepsy. They include: (1) an understanding of empowerment; (2) power and powerlessness; (3) connecting empowerment to '*system'* issues, epilepsy services and care provision; (4) empowerment, care provision and '*communicative competence'*; (5) connecting empowerment to '*life world'* issues; and (6) antecedents to empowerment.

An outcome of this study was the identification of desirable and feasible changes to facilitate empowerment within Irish epilepsy services. These include: (1) improvements in communication and collaboration within epilepsy services; (2) involving people with epilepsy in the design and delivery of the service; (3) an ambassador program to promote understanding, social inclusion, and foster empowerment related to epilepsy; (4) provision of an empowering education and training for service providers; and (5) legalising medicinal cannabis for people with epilepsy.

The findings from this study have significant policy implications for practice, education and research relating to empowerment within Irish epilepsy services. The need to develop an empowered perspective for Irish epilepsy healthcare and practice are argued for, and the findings from this study support this initiative. However, policy development must be accompanied by the implementation of meaningful advancement of care provision. This study highlights an absence in the professional socialisation of service providers as this relates to service user empowerment. Therefore, there is a need to link empowerment for health and care provision to the training and education of service providers both at undergraduate and post graduate levels.

This study suggests a number of strategic considerations in adopting an empowerment approach within Irish epilepsy services. Empowerment is a complex concept and arguably over-used term and therefore, it is necessary to use it with clarity and focus. Within epilepsy healthcare, empowerment is a useful concept because it emphasises the idea of people with epilepsy and service providers as active partnering actors in, rather than passive recipients of, healthcare and development strategies. It also draws attention to the fact that the lives of people with epilepsy and the communities in which they live are shaped by political processes involving local power, inequality and oppression – both overt and subtle.

It is important that the micro, meso and macro levels of empowerment should not be addressed in isolation. Links between the different levels of empowerment need to be considered in programme planning and implementation. The findings of this study suggest the need for people with epilepsy to be involved in the design and delivery of the service on an ongoing basis. The participation of people with epilepsy in planning at all stages is essential if development programmes are to be empowering in nature.

Peer support was widely recognised by all participants as a positive influence to empower people with epilepsy. Attention should also be given to including societal consciousness-raising.

Since the specific context is crucial to understanding processes of empowerment, key performance indicators of empowerment need to be devised specific to epilepsy healthcare. This will be most useful if indicators are generated through a participatory process underpinned by a CST philosophy.

Promoting empowerment also involves examining organisational culture, structures and processes and identifying where these may conflict with empowerment goals, for example, in terms of participation and compliance. Efforts should be made to address these organisational issues, through a change management process. For example: retraining in participatory approaches; communication and an empowering philosophy. Service providers within the epilepsy service who are thus engaged will, these findings suggest, be motivated and take pride in their work and have the capacity to treat people with epilepsy holistically.

While CCM strategies recommend that patients be empowered to self-manage their healthcare, the importance of empowerment for healthcare policy and service provision needs to be more explicitly recognised and the need to reformulate debate within an empowered perspective advanced. An active learning process and a two way communication between service providers and people with epilepsy, as opposed to an expert-led, top-down approach, are needed to facilitate an equal partnership between service users and providers.

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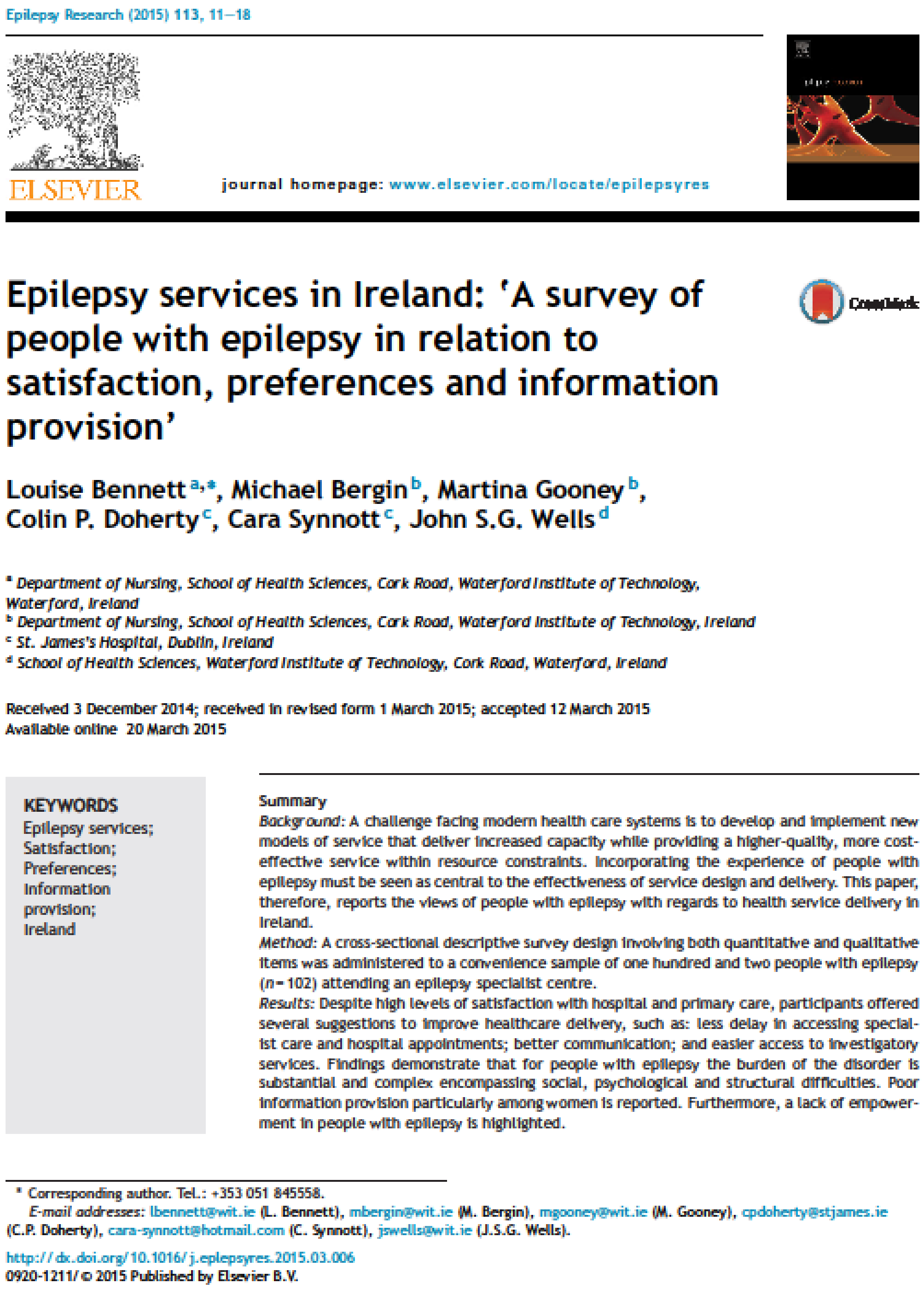
Appendix A: Peer-reviewed publications from this study to date



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Epilepsy services in Ireland: 'A survey of people with epilepsy in relation to satisfaction, preferences and information provision'

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Summary

Background: A challenge facing modern health care systems is to develop and implement new models of service that deliver increased capacity while providing a higher-quality, more cost-effective service within resource constraints. Incorporating the experience of people with epilepsy must be seen as central to the effectiveness of service design and delivery. This paper, therefore, reports the views of people with epilepsy with regards to health service delivery in Ireland.

Method: A cross-sectional descriptive survey design involving both quantitative and qualitative items was administered to a convenience sample of one hundred and two people with epilepsy (n = 102) attending an epilepsy specialist centre.

Results: Despite high levels of satisfaction with hospital and primary care, participants offered several suggestions to improve healthcare delivery, such as: less delay in accessing specialist care and hospital appointments; better communication; and easier access to investigatory services. Findings demonstrate that for people with epilepsy the burden of the disorder is substantial and complex encompassing social, psychological and structural difficulties. Poor information provision particularly among women is reported. Furthermore, a lack of empowerment in people with epilepsy is highlighted.

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Conclusion: This study has implications for the reform and development of epilepsy services in relation to practice, education and research. It provides a basis for an evaluation of current practice and identifies opportunities for future service reorganization to improve the quality and efficiency of healthcare provision.

Introduction

Irish healthcare policy emphasizes the need for more collaborative approaches in the management and delivery of care (DOHC, 2008). Indeed, people's experiences are now central to assessing performance of healthcare services as they relate to quality of care, patient engagement and enhanced accountability of clinical services to local communities (Luxford, 2012). The person with a chronic condition such as epilepsy is likely to have a life-long engagement with clinical services (Tinetti et al., 2012; Ralston et al., 2004) and therefore identifying and incorporating their experiences must be seen as central to effective service design and delivery.

This paper reports on the views of people in Ireland with epilepsy on their views of their service needs in relation to design and delivery. To date there is a lack of research internationally that explores the views of people with epilepsy with regards to these issues and in particular people with epilepsy's satisfaction with care they receive. In this context, this study provides a useful insight into these issues that may be of relevance to service development outside of Ireland.

Background

Epilepsy is a chronic neurological disorder characterized by recurrent unprovoked seizures. It is the most com- mon serious neurological condition after stroke (Hadjikoutis and Smith, 2005). For people with epilepsy the burden of the disorder is substantial and complex with physiological, psychological and social difficulties that limit lifestyle, education, driving and employment even where good control of epilepsy is reported (Fisher et al., 2000). Consequently, health-related quality of life is significantly poorer accompanied by higher rates of comorbidity in people with epilepsy when compared to the general population (Elliott et al., 2009). The Irish Epilepsy Association (2010) suggests that approximately half of all deaths related to epilepsy could be prevented if there was better care, education and services in place. However, a Cochrane review reports that an optimum system of care for people with epilepsy has not yet been empirically determined (Bradley and Lindsay, 2008).

In this context, a challenge facing modern health care systems is to develop and implement new models of service that delivers a high-quality, more cost-effective service that significantly improves the lives of people with epilepsy (Westbrook et al., 2009). This is reflected in recent Irish health care policy, which challenges traditional models of service delivery and cost structures with a move towards models of care that require service reconfiguration, reform and greater productivity (HSE, 2011).

With this in mind, a National Epilepsy Care Programme (NECP), under the direction of the office of Clinical Strategy and Programmes of the Irish Health Service Executive (HSE), has been charged with addressing the historic deficiencies in epilepsy care through a comprehensive change programme that delivers care from 'cradle to grave' (HSE, 2010). This programme has a 10-year vision for the transformation of epilepsy care in Ireland. It aims 'to provide the best value care for all people with epilepsy in the right place, at the right time, sharing the best available information' (ibid p. 5). This will be achieved primarily through care provision within the primary care setting involving General Practitioners (GPs) and Advanced Nurse Practitioners (ANPs) who have a specialist interest in epilepsy. These primary care professionals will collaborate with six regional epilepsy centres throughout Ireland that will be staffed by a new cohort of epilepsy nurses and supported by epilepsy medical fellowships. These services will be delivered through specified care pathways and will cover epilepsy presentations in emergency departments and medical assessment units. The NECP will also address the care of highly complex epilepsy cases.

Current configuration of services in Ireland

Currently epilepsy care in Ireland is shared between primary (General Practitioner — GP), secondary (hospital) and tertiary (specialist epilepsy services within a hospital) services. The GP is the first point of contact for people with epilepsy and responsible for their ongoing management of care (Varley et al., 2009).

Two of the main epilepsy specialist centres for people with epilepsy in Ireland are located at St. James's (SJH) and Beaumont Hospitals in Dublin. These centres are staffed by consultant neurologists, neurology registrars', Epilepsy Specialist Nurse's (ESN) and are either reviewed by an ESN in lieu of a medical doctor or by both. However, complex cases are initially reviewed by a consultant neurologist. Information regarding the person's epilepsy and care provision is provided by all healthcare professionals within the service.

Method

Aim of this study

Bearing in mind the current policy emphasis and service configuration this study aims to identify the views of people with epilepsy with regards to health service delivery in Ireland. Specific objectives were set as follows:

- Ascertain satisfaction of people with epilepsy with regards to service delivery.
- Identify actual and preferred sources of epilepsy care.
- Assess levels of information provision for people with epilepsy.
- Explore the views of people with epilepsy in relation to how health care provision could be improved.

Design

A cross-sectional descriptive survey design involving both quantitative and qualitative items exploring the views of people with epilepsy in Ireland with regards to health service delivery was used. In this regard, permission was sought and granted to use and adapt Poole et al.'s (2000) questionnaire entitled 'Patient's perspectives of services for epilepsy: a survey of patient satisfaction, preferences and information provision in 2394 people with epilepsy'. Poole et al.'s (2000) questionnaire was divided into nine sections and consisted of 70 questions with regards to (1) epileptic seizures; (2) medications; (3) satisfaction with epilepsy care; (4) visits to the hospital, GP and other healthcare providers; (5) preferred and actual source of care; (6) information provision; (7) services for the newly diagnosed; (8) services for PWE under 19 years old (9) and socio demographic details. An adapted questionnaire for use within an Irish context was divided into five sections and consisted of 50 questions with regards to: (1) socio-demographic details; (2) satisfaction with epilepsy care; (3) visits to the hospital (for the purpose of this study hospital care/visits to the hospital refers to the epilepsy specialist service outpatient department), GP and other healthcare providers; (4) preferred and actual source of care and (5) information provision.

Inclusion and exclusion criteria

Inclusion criteria

Aged 18 years and over with a diagnosis of epilepsy for one year or more.

Ability to read and understand the English language.

Exclusion criteria

Under 18 years old and unable to read and understand the English language.

Diagnosis of epilepsy for less than one year.

Ethics

Ethical approval was granted by Waterford Institute of Technology Research Ethics Committee and the research ethics committee at the hospital. A condition of ethical approval was that the hospital would remain anonymous. Furthermore approval was granted by the patient advisory committee (PAC) at the hospital. All participants agreed voluntarily to participate in the study after receiving detailed information and explanation of the research/evaluation aims and reassurances that the data would be anonymized and only used for research/evaluation purposes.

Pilot

The questionnaire was reviewed by a panel of experts to determine its validity for use within an Irish context. It was then piloted with a group of service users ($n = 10$) to ensure adequacy and relevance. The questionnaire was completed in 30 min or less.

Administration

All people with epilepsy attending an epilepsy specialist centre in one of the specialist centres in Dublin, from July 2013 to December 2013 that met the inclusion criteria were invited to participate in the survey. A cover letter outlining the study and what participation involved was given to potential participants. Participants completed the paper survey/questionnaire in the waiting room in the clinical area of the specialist centre. One hundred and fifty-three questionnaires ($n = 153$) were handed out with a response of one hundred and two ($n = 102$) questionnaires completed and returned (66% response rate).

Data analysis

Quantitative data was analyzed using Statistical Package for the Social Sciences (SPSS) Version 21.0 with responses to open-ended questions analyzed using a thematic content analysis. Descriptive analysis of the data was expressed as means (±standard deviation) and percentages. Participants were grouped by age and gender and chi-squared tests were used to compare findings. The level of significance was taken as $P < 0.05$. Statistical analyses included a standard reliability analysis of the questionnaire items, in order to confirm suitability of the questionnaire within an Irish setting. For the analysis of satisfaction with primary and hospital care, only participants who had attended their GP or a doctor at an epilepsy specialist centre in one of the specialist centres in Dublin, in the last 12 months were included. Responses were measured by calculating the proportion of responses that indicated satisfaction such as 'very satisfied', 'fairly satisfied' and lack of satisfaction such as 'not very satisfied' and 'not at all satisfied'. Only twenty-seven participants ($n = 27$, 26%) completed all questions within the questionnaire. Valid percent will be reported throughout this study.

Results

Demographic details

Sixty-six percent ($n = 62$) of the sample were female and 34% ($n = 32$) were male with eight participants not answering. Participants ranged from 18 to 75 years old (mean age = 37; SD 12.9), with 54.5% ($n = 48$) aged 30 to 49, 33% ($n = 30$) aged 18 to 29 and 12.5% ($n = 13$) aged 50 to 71 with eleven participants not answering. The age range when participants first experienced an epileptic seizure was between 1 and 71 years with 59.8% having their first seizure at age 18 or younger. With regards to education, 36.4% ($n = 32$) have completed a secondary level qualification; 31.8% ($n = 28$) a college degree; 18.2% ($n = 16$) an alternative qualification;

Table 1 Overall level of satisfaction for hospital and primary care and for specific sub-measures of care.

	Hospital care		Primary care	
	%	*n*	%	*n*
Overall satisfaction with care	94.8	92	90.8	69
Find it easy to talk to doctor	92.8	90	90.9	70
Doctor takes views about epilepsy into account	87.6	85	74.0	57

13.6% (*n* = 12) no formal qualification with fourteen participants not answering. A majority of participants (82.4%, *n* = 84) could name their epilepsy medications, whilst 17.6% (*n* = 18) did not know or declined to answer.

Satisfaction with epilepsy services

Overall satisfaction with epilepsy services was high. Ninety-four point eight percent (*n* = 92) were overall satisfied with general hospital care in comparison to 90.8% (*n* = 69) with primary care. There was slightly higher satisfaction for hospital care compared to primary care with regards to specific sub-measures of care (see Table 1) with no significant differences for age and gender in overall satisfaction levels for both primary or hospital care. Fifty-five per cent (*n* = 53) were satisfierd in relation to continuity of care (seeing the same doctor on different visits, or the same doctor more often than not) for hospital care.

Participants were asked to suggest ways to improve epilepsy healthcare provision. Suggestions included a reduction in delays in accessing specialist care and hospital appointments; improved communication skills by service providers; greater societal awareness of epilepsy; improved access to investigations; better continuity of care at and between clinic and hospital appointments; better information provision and access to free transport and disability allowances.

Participants were asked to highlight three areas of their life most affected by epilepsy. Seventy-eight (*n* = 78, 76%) participants responded and the majority highlighted lifestyle (*n* = 38, 24.0%), driving (*n* = 31, 19.6%) and work (*n* = 27, 17.0%) as the areas most affected by their epilepsy. Other areas identified as being affected by their epilepsy were: self-confidence and self-esteem; academic life; family life; memory and concentration; mental health; energy levels; sports; independence; poor coordination and mobility; embarrassment due to stigma and sleep. However, only 25.3% (*n* = 21) of participants stated that they required assistance. Some of the areas identified included: more help and support from experts in the field of epilepsy care; (18.7%, *n* = 3); improvements in medication (18.7%, *n* = 3); better information provision (18.7%, *n* = 3); help with building self-confidence (12.5%, *n* = 2); memory and concentration (12.5%, *n* = 2); academic life (6.2%, *n* = 1); and improved quality of their mental health (6.2%, *n* = 1).

Participants were asked to comment on the open-ended question: 'Is there anything else you would like to tell us about your epilepsy'. Responses from female (F) and male (M) participants (P) were both negative and positive with regards to epilepsy and epilepsy healthcare provision. For instance, one participant stated

> 'When I raise issues, I feel I am forced into things, and now feel I shouldn't say anything at all' (P38: M, 35).

Other participants expressed frustration regarding the psychological, social and structural difficulties that they encounter. For example,

> 'I have had epilepsy for 16 years and yet still find it hard and difficult to accept. It has an effect on my life especially work and social life which is why sometimes I get angry and find it difficult to accept' (P22: F, 28).

> 'After 18 years of having epilepsy I've just got my first 12 month seizure free but feel the constant increase and switching of medication made little difference accept bring on side effects. Paranoia is one of the main ones I am having issues with. I'd have preferred if I'd adjusted my life many years ago such as refraining from drink, keeping fit, and getting plenty of sleep. That way I wouldn't be on all the unnecessary medications I am taking at the moment' (P23: M, 35).

Other participants expressed confusion and concern with regards to epilepsy healthcare provision. For example, one participant commented:

> 'Why can't you find out what is wrong'? When will this be over? (P79: M, 33).

However, other participants reported a positive experience with regards epilepsy services and one person suggested that:

> 'Standards of care have vastly improved' (P18: M, 75).

Another participant commented that:

> 'My access to epilepsy services and the services I receive are excellent. I can see my consultant when it is needed and my GP is both understanding and informed. My consultant is excellent. My epilepsy is difficult to control and all efforts I feel are being made to get the best quality of life for me' (P 63: F, 39).

Visits to the hospital, GP and other healthcare providers

Table 2 illustrates that the majority (82.5%, *n* = 80) of participants have regular appointments with their hospital doctor, whilst 58.8% (*n* = 60) have seen an epilepsy specialist nurse. However, although 94.8% (*n* = 73) (with twenty-five participants not answering) find it easy to get an appointment to

Table 2 Visits to a hospital doctor, epilepsy specialist nurse, GP, counsellor, psychologist, and social worker in the last 12 months.

Visits with healthcare providers	%	*n*
Hospital doctor	82.5	80
Epilepsy specialist nurse	58.8	60
GP	11.5	9
Counsellor	9.1	9
Psychologist/psychiatrist	5.2	5
Social worker	2.1	2

see a GP and 94.5% (*n* = 69) (with twenty-nine participants not answering) find it easy to see a GP as an emergency about their epilepsy, only (11.5%, *n* = 9) have regular appointment to see a GP.

Furthermore, only 2.1% (*n* = 2) of participants have seen a social worker, 5.2% (*n* = 5) a psychologist/psychiatrist, and 9.1% (*n* = 9) a counsellor in the last 12 months.

Preferences for care

Participants were asked to indicate their actual and preferred source for epilepsy care. Table 3 illustrates that the majority of participants identified hospital doctor as the actual (78.4%, *n* = 80) and preferred (76.5%, *n* = 78) source of epilepsy care. Reasons for doctor preference included: (1) doctor knows more about epilepsy (32.4%, *n* = 69); (2) doctor knows about me and my history (23.4%, *n* = 50) and (3) you get more time to discuss things fully (10.8%, *n* = 23). There was no statistically significant difference in doctor preference with regards to gender or age categories. Seventy-five percent and 89.7% preferred hospital doctor in the 18—29 and 30—49 age category respectively, 63.6% in the 50—71 age category, with 36.4% of participants preferring hospital doctor and GP equally.

Information provision

People with epilepsy were asked whether they had received information on issues relating to their diagnosis, risk factors, safety precautions, lifestyle restrictions and support from voluntary organizations. Between ninety three and ninety six of participants responded to all issues and Table 4 illustrates results. All results were pooled together and overall information provision was 67.6% in relation to issues of epilepsy. Only 29.5% (*n* = 28) received information regarding help from social services and 48.4% (*n* = 46) from voluntary organizations. The proportion of informed participants was 80% or above with regards driving restrictions (84.4%, *n* = 81), alcohol use (90.5%, *n* = 86), and adequate sleep (83.0%, *n* = 78). There was no statistically significant difference in the overall level of information provision between males and females (58.5% versus 63.5%) and age categories (18—29 = 65.1%; 30—49 = 66.3%; 50—71 = 61.8%).

Table 3 Actual and preferred source of epilepsy care.

	Actual source		Preferred source	
	%	*n*	%	*n*
Hospital	78.4	80	76.5	78
Primary	5.9	6	6.9	7
Hospital and primary equally	10.8	11	11.8	12
Not sure	4.9	5	0.9	1
Do not mind	3.9	4		

Table 4 Information provision for men and women (*n* = 102) in relation to epilepsy.

General questions	Yes % (*n*)	No % (*n*)	Do not know% (*n*)	N/A% (*n*)
What caused your epilepsy	62.1 (59)	24.2 (23)	9.5 (9)	4.2 (4)
What type of epilepsy you have	74.0 (71)	15.6 (15)	10.4 (10)	—
Becoming free of epilepsy attacks	54.3 (51)	27.7 (26)	17.0 (16)	1.0 (1)
Driving restrictions	84.4 (81)	10.4 (10)	3.1 (3)	2.1 (2)
Potential risks	74.5 (70)	18.1 (17)	7.4 (7)	—
Hazardous activities	71.0 (66)	20.4 (19)	8.6 (8)	—
Side effects of medication	68.4 (65)	26.3 (25)	3.2 (3)	2.1 (2)
Free prescriptions	75.3 (70)	18.3 (17)	5.4 (5)	1.0 (1)
Job restrictions	55.8 (53)	30.5 (29)	6.3 (6)	7.4 (7)
Alcohol use	90.5 (86)	6.3 (6)	1.1 (1)	2.1 (2)
Adequate sleep	83.0 (78)	10.6 (10)	6.4 (6)	—
TV/video/flashing lights	75.8 (72)	16.8 (16)	2.1 (2)	5.3 (5)
Voluntary groups	48.4 (46)	37.9 (36)	9.5 (9)	4.2 (3)
Help from social services/allowances	29.5 (28)	52.6 (50)	14.7 (14)	3.2 (3)

Table 5 Information provision for women ($n = 62$) in relation to contraception and pregnancy.

	Yes % (*n*)	No % (*n*)	Do not know % (*n*)	N/A % (*n*)
Problems with contraception	47.6 (29)	39.3 (24)	3.3 (2)	9.8 (6)
Pre-pregnancy planning	67.7 (42)	21.0 (13)	—	11.3 (7)
Folic acid	75.8 (47)	14.5 (9)	—	9.7 (6)
Risk to baby	67.7 (42)	16.1 (10)	6.5 (4)	9.7 (6)
Vitamin K	8.6 (5)	67.2 (39)	10.3 (6)	13.8 (8)
Safety considerations	20.7 (12)	56.9 (33)	6.9 (4)	15.5 (9)
Breast-feeding	15.5 (9)	62.1 (36)	6.9 (4)	15.5 (9)

Women with epilepsy were asked whether they received information on issues relating to contraception and pregnancy. Between fifty-eight and sixty-two of participants responded to all topics and Table 5 illustrates results. A deficit in information provision for women was highlighted. Overall 44.1% of women with epilepsy were provided information in relation to issues of contraception and pregnancy. Only 8.6% ($n = 5$) received information regarding Vitamin K whilst 15.5% ($n = 9$) received information regarding breast-feeding.

Whilst 65.7% ($n = 67$) of participants could name their type of epilepsy, 32.4% ($n = 33$) either did not know or failed to answer. Although 56.5% ($n = 52$) of participants indicated they would like more information provision, only 39.2% ($n = 38$) of participants would like to talk more to a health worker about their epilepsy. A majority (37.7%, $n = 23$) of participants stated that they would prefer to talk more with an epilepsy specialist nurse. Participants were asked to indicate up to three sources of information provision. The majority of participants (35.5%, $n = 77$) indicated they received most of their information with regards to their epilepsy from hospital doctors. Others sources included: epilepsy specialist nurses (16.6%, $n = 36$); literature (11.5%, $n = 25$); hospital nurses (10.1%, $n = 22$); GP (9.7%, $n = 21$); voluntary organizations (9.2%, $n = 20$); media (5.1%, $n = 11$); family/friends (1.4%, $n = 3$); and community nurses (1.0%, $n = 2$).

Discussion

Many of the findings in this study are consistent with previous research. Thus whilst, there are high levels of satisfaction with primary and secondary services, similar to previous research findings, participants felt that services needed to improve with respect to less delay in accessing specialist care and hospital appointments; better communication; easier access to investigatory services; better information provision (Varley et al., 2009, 2011; Ross et al., 2010; Chinthapalli et al., 2008; Hayes et al., 2007; Poole et al., 2000; Rajpura and Sethi, 2004; Al-Adawi et al., 2003).

Hospital doctors were highlighted as the actual and preferred source of epilepsy care. This is consistent with Poole et al.'s (2000) research. The majority of participants highlighted the reason for doctor preference was 'doctor knows more about epilepsy'. In terms of preference for regular medical contact with doctors (82.5% with hospital specialist doctors and 11.5% with GPs) it would appear that there may an overuse/unnecessary contact with specialist service doctors, and underuse of primary care support. This may be the result of a lack of confidence in GPs' knowledge/ability to assist people with epilepsy in the day to day medical management of their condition.

A study by Varley et al. (2009) highlighted a lack of knowledge and confidence to manage epilepsy among GPs at the primary care level together with poor communication between primary and specialist services. This is considered a significant barrier to enhancing continuity of care (Moran et al., 2000; Betts and Smith, 1994) and thus may play a part in the over reliance on specialist service hospital doctors. Indeed, in this regard, only 10.8% of participants indicated that their care was shared between hospital doctor and GP. Although a model of shared epilepsy care between the primary and specialist clinical services are part of the new model of care in Ireland, these results would suggest that considerable improvement is required.

In light of the above results, one interesting finding from this study is the confidence shown by participants in the epilepsy specialist nurses. It is claimed that epilepsy specialist nurse's increase and improve communication between service providers and people with epilepsy (Mills et al., 1999). Certainly, the results in this study would indicate that they are popular with service users. The NECP programme is addressing care provision for epilepsy in the primary care setting using General Practitioners (GPs) working with Advanced Nurse Practitioners (ANPs) who are specialists in epilepsy nursing care.

This study demonstrates the complex social, psychological and structural difficulties that PWE confront. For instance, lifestyle, driving, work, self-confidence/self-esteem, academic life, family life are but a few areas highlighted and consistent with previous research (Varley et al., 2011; Fisher et al., 2000). These can lead to social isolation and dependency on others especially when it prevents people from driving and working (Beran, 1999). Therefore we found it surprising that only a small number of participants had seen a counsellor (9.1%), a social worker (2.1%), or psychologist/psychiatrist (5.2%) in the last 12 months. Moreover, few participants have received information regarding social services and voluntary organizations. Fisher et al. (2000) suggest that even for people with well controlled epilepsy, there is a need for ongoing medical and psychosocial support. Such support requirements beg the question how best to deliver this care and what systems and structures should be put in place?

Findings indicate a deficit in information provision to participants in relation to their condition, social welfare entitlements and supports. For example the specific type of epilepsy they had (65.7% could only name their specific type). In relation to the information on the specific management of the condition, the results are particularly striking in relation to the information gap for women. For example, lack of information in relation to pregnancy and the importance of receiving vitamin K to maintain clotting factors in the blood for the baby (8.6%) and the transmission of anti-epileptic drugs to babies through breast-feeding (15.5%). Thus results of this study highlight the need for improvements in educational based information especially for women of childbearing age.

A key feature with regards to education and people with epilepsy is the nature in which service providers control the selection, evaluation, organization and transmission of information. Also, people with epilepsy are not provided with information in writing with regards to the type of epilepsy they have. However, effective information giving should enable people with epilepsy to develop the attributes and skills required to function as equal partners, make informed decisions and competently self-manage with regards to their healthcare. Therefore, it may be argued that new pedagogies are warranted (Johnston et al., 2005), recognizing service users' interpretation of their illness (Tabak et al., 2003). We suggest a shift from the traditional epistemological and ontological assumptions associated with information giving and people with epilepsy.

Chronic disease management strategies recommend that patients be empowered to self-manage their health care, however, participants in this study appear largely to play a passive role. For example, one participant suggested 'feeling forced into things'. This indicates a need for a more collaborative approach between people with epilepsy and service providers so that shared expectations can be established and decisions jointly made in striving to achieve realistic and desired outcomes. Although service providers may support empowerment as a goal of patient participation, their socialization to the' practitioner as expert' model of health care may be so deeply rooted that they proffer patient participation largely as an extension of their power base, rather than as a collaborative venture (Cahill, 1998). Therefore, future research that explicates more effective partnerships between service providers and people with epilepsy is needed.

Improving epilepsy services in Ireland requires assessing the needs of all stakeholders and the development and implementation of a realistic action plan. Emerging technologies in healthcare has the capacity to provide people with online home access to their medical records via hospital based web portals and provides the potential to empower people to self-manage their chronic illness (Van der Vaart et al., 2014). In this regard, improving speed of access to information and support is important. Two-way integrated computerized technology is envisaged as part of the future service provided by the NECP. However, it has yet to be implemented, exploited and evaluated within the Irish epilepsy services.

Limitations

Limitations of the study include a relatively small sample size which makes the detection of significance less likely. Participants in this study attended a tertiary epilepsy clinic therefore this may reflect a bias result in satisfaction levels and care preferences. Further research is necessary to compare a primary and tertiary sample of people with epilepsy.

Conclusion

It has been reported that the current structure and process of health care in Ireland results in a negative experience for people with epilepsy (Varley et al., 2011). A study by Varley et al. (2011) reported that many participants expressed the view that although empathetic to their illness, GPs lack the expertise to manage their condition and/or continue to remain passive with respect to patient needs. This study highlights improvement in epilepsy care insofar as the majority of participants indicated a high satisfaction with both primary and secondary care.

This study has provided a basis for an evaluation of current practice and offer indicators to epilepsy services on how epilepsy care can be further improved. It highlights the need to fully understand the social, psychological, structural and educational difficulties of people with epilepsy and to ensure that these issues are taken into account in any plans for service transformation. Engaging people with epilepsy with greater psycho-social support is clearly needed to more fully address these issues.

An empowered framework for educational delivery is warranted. This can result in greater informed decision-making, positive behavioural changes, and a more active role in the management of epilepsy (Hovinga et al., 2008). This is not just a challenge for health service providers within epilepsy services but requires a greater collaborative approach from all stakeholders.

Conflict of interest

The authors have no conflict of interest to declare.

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Review

The social space of empowerment within epilepsy services: The map is not the terrain

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abstract

Empowerment is now seen as an integral component of holistic practice and service design in healthcare, particularly as it relates to the improvement of quality of life for people with epilepsy. However, the literature suggests that empowerment is a neglected and poorly understood concept by service users and providers alike within epilepsy services. Conceptual ambiguity is a further impediment to its understanding and implementation. Bearing this in mind, a clear definition of empowerment is needed in order to realistically recognize, encourage, and prioritize empowerment as a service design philosophy. Therefore, this paper undertakes a concept analysis of empowerment with reference to epilepsy services. Results indicate that empowerment demands a transformation of consciousness and a readiness to act on this transformation in order to allow people to gain personal power and autonomy over their own life, including the self-management of their condition. With this in mind, a critical reflection on the 'micro' and 'macro' levels of power that exist within epilepsy services is warranted with reference to theoretical principles. In this context although the map is not the terrain, we argue that an educational intervention guided by critical social theory principles has the potential to encourage an understanding of empowerment and 'holds the key' to future advances for its implementation within epilepsy services.

1. Introduction

Empowerment is an integral component of holistic practice and service design in healthcare, particularly as it relates to the improvement of quality of life for people with epilepsy [1–5]. The Living Well with Epilepsy II conference [4] recommends that systems and models of care foster empowerment and independence for people with epilepsy and support their efforts towards improved seizure control and a positive quality of life. Furthermore, chronic care models emphasize patient-centeredness and the need for both community and health-care systems to work together to achieve desired outcomes [6]. However, the literature suggests that empowerment is a neglected and poorly understood concept by service users and providers within epilepsy services [7,8].

In Ireland, recent health-care policy challenges traditional models of service delivery and cost structures with a move towards models of care that require service reconfiguration, reform and greater productivity [9]. Consequently a National Epilepsy Care Programme (NECP), under the direction of the office of Clinical Strategy and Programmes of the Irish Health Service Executive (HSE), has been charged with addressing the historic deficiencies in epilepsy care through a comprehensive change program that delivers care from 'cradle to grave' [10]. This program has a 5-year vision for the transformation of epilepsy care in Ireland and aims to: (1) improve access to expert care and information; (2) improve the quality of care across the health-care spectrum from prevention, through managed primary care, to complex surgical care for difficult epilepsy; and (3) improve value conscious care by shifting care where possible from expensive hospital-based care to the community ([10], p. 5). All aspects of epilepsy care will be addressed with a specified care pathway, delivered by specified experts, including newly appointed advanced nurse practitioners. However, the provision of epilepsy services that are empowering is one of the challenges facing the new model of care within Ireland.

While there is a body of research which points to a lack of empowerment for people with epilepsy [11,12], research exploring organizational structures within which service providers function and how they are supported in practice to facilitate empowerment for people is lacking. Perhaps as a result of this, it may be argued that conceptual ambiguity further compounds any attempt for the provision of services that are empowering [13]. Arguably, research undertaken for the purpose of knowledge development should begin with exploring existing knowledge in order to develop a conceptual and theoretical understanding of the concept to be researched [14]. Indeed, without a clear conceptual foundation, the quality of research and theory construction is weakened and its maturity compromised [15]. Bearing this in mind, a clear definition of empowerment is needed in order to adopt and evaluate epilepsy services in ways that realistically recognize, encourage, and prioritize empowerment. An empowerment definition within research depends both on the specific people and context involved [16]. For the purpose

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of this paper, an examination of people with epilepsy and service providers within Irish epilepsy services will be undertaken. In this regard, empowerment will be referenced to critical social theory.

1.1. Defining epilepsy as a chronic condition

Epilepsy is a chronic neurological disorder characterized by recurrent unprovoked seizures and is the most common serious neurological condition after stroke [17]. For people with epilepsy, the burden of the disorder is substantial and complex, compromising biological, psychological, and social challenges. For example, lifestyle, driving, work, self-confidence/self-esteem, academic life, and family life are areas highlighted [11,12,18]. Compared with the general population, people with epilepsy are up to 50% more likely to suffer from depression and have an 8-fold increased risk of developing a mental health issue [19,20]. In addition, stigma, myth, fear, and discrimination still exist in relation to a diagnosis of epilepsy and lead to poor self-esteem and social exclusion, restrictions, overprotection, and social isolation [21]. Consequently, health-related quality of life is significantly poorer [22], and higher rates of comorbidity have been reported in people with epilepsy compared with the general population [23].

2. Methods

Concept analysis is a method or approach by which concepts that are of interest to a discipline are examined in order to explicate their characteristics or attributes. It entails synthesizing existing views of a concept and distinguishing it from other concepts with the aim of resolving gaps or variations in the knowledge base of the discipline [24]. It includes a number of approaches that, on the surface, appear similar but possess significant philosophical differences [25]. The concept analysis methods developed in recent years include Walker and Avant's [26] and Norris's [27] methods of concept analysis, an evolutionary concept analysis [28], simultaneous concept analysis [29], utility method [30], principle-based method of concept analysis [31], and hybrid model of concept development [32].

An eclectic methodological framework based on aspects of Norris's [27] and Rodgers' [25] views of concept analysis was undertaken. Norris's [27] framework was chosen because it is systematic, with a focus on clear-cut phases during the analysis process, and contributes to clarifying, describing, and explaining concepts [33]. The five steps outlined in Norris's [27] method include: (1) identification of the concept of interest from within the discipline as well as from the viewpoint of other disciplines; (2) observation of the concept and repeated descriptions of the concept to provide a systematized description of the concept (look for patterns and sequences); (3) deciding on an operational definition of the concept; (4) development of a model, which illustrates the concept; and (5) formulation of hypothesis. All five stages will be included in this concept analysis.

The seven stages outlined in Rodgers' [25] method include: (1) identify and name the concept of interest; (2) identify surrogate terms and relevant uses of the concept; (3) identify and select an appropriate realm (sample) for data collection; (4) identify the attributes of the concept; (5) identify the references, antecedents, and consequences of the concept, if possible; (6) identify concepts that are related to the concept of interest; and (7) identify a model case of the concept. It is argued that the antecedents and consequences of a concept are often overlooked in a concept analysis [34]. Therefore, we decided that Rodgers' [25] stage of antecedents and consequences would be included in this analysis. Table 1 highlights a synthesis of Norris's [27] and Rodgers' [25] method of concept analysis that has been utilized.

Table 1
A synthesis of Norris's [27] and Rodgers' [25] method of concept analysis.

- Identify and select an appropriate realm (sample) for data collection (methods)
- Identification of the concept of interest from within the discipline as well as from the viewpoint of other disciplines
- Observation of the concept and repeated descriptions of the concept to provide a systematized description of the concept
- Identify concepts that are related to the concept of interest
- Antecedent and consequential occurrences
- Deciding on an operational definition of the concept
- Development of a model, which illustrates the concept
- Formulation of hypothesis

3. Concept analysis

Using a hybrid concept analysis methodology, this section aims to clarify the ambiguities of empowerment in order to promote its adoption by service users and providers as an integral part of epilepsy service in Ireland.

3.1. Identify and select an appropriate realm (sample) for data collection (methods)

The databases CINAHL and PUBMED were searched using the keywords 'empowerment', 'healthcare', 'epilepsy', and 'epilepsy services' both separately and together. Literature published in English from January 1990–July 2015 was included. The authors examined all abstracts and full texts of the articles deemed eligible for the review. Reference lists from identified articles were manually screened. The criterion for inclusion of a paper in the review was the presence of empowerment (with or without people with epilepsy). The list of references of eligible articles was examined in search of additional books and reports. A total of 391 articles were identified as potentially eligible after abstract review. Two hundred and thirty-two (n = 232) articles were excluded because they did not address the concept for review. The final yield was one hundred and fifty-nine (n = 159) papers and books. Ten concept analyses were identified to help clarify the core dimensions of empowerment which focus on empowerment from the perspective of (1) service users, (2) service providers, and (3) service user–service provider relationships [13,35–43].

3.2. Identification of the concept of interest from within the discipline as well as from the viewpoint of other disciplines

The first task of this concept analysis was to identify empowerment from within the discipline and from other disciplines. The results of this stage of analysis identified: (1) the origins of empowerment, (2) the historical debate with regard to health-care empowerment, and finally, (3) an examination of empowerment from within the discipline and other disciplines. These are now explored.

3.2.1. The origins of empowerment

The origins of empowerment can be traced to: (1) Paulo Freire, a Brazilian educator in the 1950s who dedicated his life and teaching to the struggle of aiding oppressed and marginalized communities to achieve liberation; (2) Beatrice Wright and her work on discrimination and stereotypical attitudes towards people with disabilities; (3) Wolf Wolfensberger (1934–2011), a German-American academic who influenced disability policy and practice through his development of North American Normalization; (4) John Kosciulek, who introduced the consumer-directed theory of empowerment to the field of rehabilitation; (5) Michael Wehmeyer and his contributions of the functional theory of self-determination; and finally, (6) Michael Rosenbaum's contribution on learned resourcefulness among people with epilepsy.

Freire [44] described oppression as 'dehumanization' (p.44) and defined it as "a concrete historical fact not a given destiny but the result of unjust order". Oppression or unequal power decreases a person's self-esteem and autonomy [45]. It is maintained by social institutions in order to control people, their resources, and finances [46]. Freire [47] advocated sharing power with the oppressed, rather than doing things for them. At a later date, social movements promoted the rights of ethnic and sexual minorities, and women further developed the concept of empowerment.

Wright's [48,49] most enduring contributions to an understanding of the disability experience was her attention to values and their transformation during the disability adjustment process. According to Wright [49], mechanisms employed by self-accepting persons with disability include: (1) the enlargement of their scope of values, accomplished by developing interest in attainable goals; (2) the subordination of the values of body appearance and performance, to qualities of human worth that are still within grasp, such as personality attributes; (3) the 'containment' of disability effects to prevent the perceived 'spread' of limitation to the entire self; and finally, (4) the transformation of comparative-status values and the assessment of one's qualities in comparison to the qualities of others or cultural norms.

Additionally, much of Wolfensberger's work has been concerned with ideologies, structures, and planning patterns of human service systems, concerning people with intellectual disabilities who are often rejected and socially excluded from mainstream society. According to Wolfensberger [50], normalization implies the use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people. During his research in the US, Wolfensberger succeeded his work on normalization through his concept of social role valorization [51]. He suggested that poor attitudes towards people with learning disabilities could be countered through inclusion and creating opportunities to take on valued social roles. Indeed, both stigma reduction/prevention and societal attitude changing can be achieved by: (1) the enhancement of the social image of a person or group; (2) the enhancement of the competence of the person or group, including bodily, sensory, intellectual, and social performances; and (3) the practice of valued skills and habits [52].

Within the disability movement, empowerment has been used to reflect a changed understanding of the self and one's place in society. Kosciulek [53 p.197] defined empowerment as: "*the process by which people who have been rendered powerless or marginalized develop the skills to take control of their lives and their environment*". He argues that consumers of rehabilitation services should gain power over the services they receive and, in the process, gain or regain control over their lives [53]. With this in mind, self-determination has become part of the demands by people with disabilities in the self-advocacy movement, and these ideas have been incorporated into the disability rights and empowerment movement. Thus, Wehmeyer et al. [54] proposes a functional theory of self-determination and identifies four essential characteristics of self-determined actions: (1) the person acts autonomously; (2) the behavior is self-regulated; (3) the person initiates and responds to the event(s) in a psychologically empowered manner; and (4) the person acts in a self-realizing manner.

Rosenbaum [55] has recently suggested that individuals may differ in the extent to which they are able and willing to self-regulate internal responses (such as emotions, pain, and cognitions). This general repertoire of self-control skills is identified as learned resourcefulness [56] and is a basic behavioral repertoire [57] that is learned from the moment of birth and serves as a basis for coping with stressful situations. Bearing this in mind, Rosenbaum & Palmon [58] illustrated that a participant's psychological adjustment to epilepsy is a joint function of their perceived repertoire of self-control skills (i.e., their learned resourcefulness) and of the extent to which he was exposed to uncontrollable seizures.

3.2.2. The historical debate with regard to health-care empowerment

The historical debate with regard to health-care empowerment first appeared as a foundation for health promotion in the World Health Organization (WHO) Ottawa Charter of 1986 [59], with social justice and equity recorded among fundamental conditions for health. During the 1980s and 1990s, empowerment was adopted politically as part of the 'new right' ideology of consumerism within health and social care [60].

3.2.3. An examination of empowerment from within the discipline and other disciplines

Empowerment is explored in a wide range of contexts within healthcare such as professional empowerment [61–64], mental health [13,39,65], older people [66,67], chronic illness [43,68], nursing education [36,69], nursing management [70], froma service user–service provider perspective [35,37,38,40–42], and finally family empowerment [71–74]. From other disciplines, empowerment is explored in psychology, sociology, and economics [40,75]. Once the concept of empowerment has been identified, Norris's [27] 2nd stage of concept analysis includes observation and description of the concept and is now explored.

3.3. Observation and description of empowerment

An observation and description of empowerment is required in order to provide a systematized discovery of patterns and sequences. The results of this stage of analysis observes and describes empowerment (1) as a process and outcome, (2) an understanding of power, (3) different levels of empowerment, (4) theoretical underpinnings of empowerment, and (5) related terms with regard to empowerment. These are now expanded upon.

3.3.1. A process and an outcome

The literature identifies empowerment as a process, and this includes: (1) a social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives [35]; (2) an enabling process or a product arising from a mutual sharing of resources and opportunities which improves decision-making to achieve change [37]; (3) a helping process [37,42]; (4) a dynamic process associated with growth and development where competency is enhanced [46]; (5) an interactive process through which people experience personal and social change, enabling them to take action to achieve influence over the organizations and institutions which affect their lives and the communities in which they live [76]; and finally, (6) a transactional process where there is a sharing of power between people to achieve mutually beneficial interactions [35]. This process involves microfactors (intrapersonal, self-esteem, and efficacy), mediating structures (group membership and involvement), and macrofactors (social and political activities) [77]. On the other hand, empowerment is described as an outcome such as: (1) an active involvement in health-care issues, (2) the negotiation of health-care goals [78], and (3) an enhanced sense of self-efficacy as a result of empowerment [13,75,79–81].

Chronic disease management strategies recommend that patients be empowered to self-manage their healthcare. However, in a study by Bennett et al. [11], people with epilepsy appear largely to play a passive role. For example, one participant suggested 'feeling forced into things'. This indicates a need for a more collaborative approach between people with epilepsy and service providers so that shared expectations can be established and decisions jointly made in striving to achieve realistic and desired outcomes.

3.3.2. An understanding of power

The literature argues that an understanding of power is essential in order to recognize empowerment [82]. Power is described in different ways such as power over, power to, power with, and power from within. Firstly, *power over* is controlling power, which refers to "the capacity of some actors to override the agency of others" [83 p.14]. *Power to* refers to the ability of an individual to increase own choices and act on them without weakening the power of another. *Power with* refers to a collective action by a group [82]; and finally, *power from within* refers to a person's sense of self-worth and self-knowledge. It includes an ability to recognize individual differences while respecting others.

Power from within is the capacity to imagine and have hope and affirms the common human search for dignity and fulfillment [84].

Historically, power relations exist between service providers and people with epilepsy. For example, mothers of children with neurological disabilities reported difficulty in experiencing a sense of power in settings where the hierarchical medical model predominated [35]. They also described situations where service providers were unwilling to share their power and failed to listen to the mothers' concerns and viewpoints. To achieve empowerment, arguably, access to and control of power is required [82,83]. Empowerment involves a sharing or transferring of power [13,41,46]. This requires structural change and 'top-down' transference of power within services [60]. Indeed, Hawks [36] claims that one can empower others if one empowers themselves. However, it is argued that it is impossible for one person to empower another [85,86]. Bearing this in mind, as power relations exist between service providers and service users, we argue that power from within is warranted with regard to empowerment of all stakeholders within epilepsy services.

3.3.3. *Different levels of empowerment*

Depending on the context of its use, empowerment encompasses different levels which include individual, organizational, and community levels [87,88]. Firstly, an individual level, often termed the 'micro level' of empowerment, is linked to personal power and is concerned with ideologies of self-care, self-responsibility, self-determination, and personal control [89]. At this level, individuals can accept ownership and responsibility for their own health and social situation, rather than be dependent on service providers [35]. Secondly, a group level, often termed the 'macro level' of empowerment, is linked to the individual level but manifests itself through collective action, such as voluntary groups and social networks. Finally, a community level, also termed the 'macro level' of empowerment, is linked with political action [90]. Bearing this in mind, we argue for the need to concentrate on the interface between the 'macro' and 'micro levels' of empowerment. For instance, changes are necessary not only in personal behavior, but also in social situations and organizations that influence individual lives [91].

3.3.4. *Theoretical underpinnings of empowerment*

Theoretically, empowerment is viewed from many vantage points such as critical social theory (CST) [46,92], organizational theory, management theory, social psychological theories [46], and poststructuralism [93]. However, we argue that CST is more relevant to this concept clarification insofar as it provides a mechanism to analyze oppressive conditions within healthcare [94] and uncover the constraints and conditions that prevent uncoerced or rational communication [95]. Moreover, it offers a framework that can explore empowerment within epilepsy services, through a critical self-reflection, one that examines the microlevels and macrolevels of power.

In summary, empowerment can be viewed as a process and/or outcome arising from a power from within. By considering an interface between the macrolevels and microlevels of empowerment of all stakeholders within epilepsy services, there is a potential to define how individual empowerment can contribute to group empowerment and how the increase of a group's power can enhance the functioning of its individual members [96]. With this in mind, concepts that are related to empowerment are now explored.

3.4. *Identify concepts that are related to the concept of interest*

Empowerment lacks clarity and several related terms identified in the literature add to this lack of clarity. Among these related terms of empowerment include self-management [97–102], self-determination of health and treatment-related goals through participation and negotiation [68,103,104], self-efficacy regarding disease and treatment-related behaviors [80,81,105], enablement [106,107], and a change of consciousness [108].

According to de Boer [109], self-management refers to the adaptive health behaviors and activities that a person with epilepsy can perform to promote seizure control and enhance well-being. Although a number of recent self-management techniques and programs for people with epilepsy are described in the literature [97–102], a Cochrane review reported that only two met the definition of epilepsy self-management. It is argued that participant drop out and attrition in self-management studies is due to a lack of patient-centered planning [110]. Comparing service providers and people with epilepsy's self-management needs, findings of a study by Johnson et al. [110] illustrated consistent dissonance in the views of service providers and people with epilepsy. This indicates the need to consider the person with epilepsy's input in self-management programs. Thus, the need for the development, evaluation, and expansion of epilepsy self-management has been suggested [111]. With this in mind, Bennett et al. [92] argues for the potential of CST as a philosophical approach for the education of people with epilepsy.

The literature reports that the quality of life of people with epilepsy can be severely compromised by statutory conditions on driving and employment [4,112,113]. In this regard, self-determination is the product of both the person and the environment insofar as the person utilizes the skills, knowledge, and beliefs at his/her disposal to act on the environment with the goal of obtaining valued and desired outcomes [114]. Empowerment is also associated with the term enablement throughout the literature. The attributes of enablement in healthcare include: (1) contribution to the therapeutic relationship, (2) consideration of the person as a whole, (3) the facilitation of learning, (4) valorization of the person's strengths, and (5) supporting decision-making [107]. Indeed, service user empowerment is described as a process whereby nurses enable individuals to be effective [106].

Moreover, empowered individuals often exhibit various self-regulatory qualities such as high self-efficacy perceptions and a sense of agency or personal control [115]. Self-efficacy is a central and ongoing individual mechanism (which operates by means of cognitive, motivational, and affective processes) which is comprised of a person's perceived belief in her capability to exercise control over events [116]. Self-efficacy is positively associated with self-management [80,117]. However, the high levels of perceived stigma for people with epilepsy results in lower levels of self-efficacy to manage epilepsy [118].

It is suggested that it useful to conceptualize empowerment as change in consciousness that results from the influence of internal and external factors [108]. For example, internal factors considered to be significant in advocating health-relevant behaviors include: (1) knowledge about risk factors and risk reduction; (2) attitudes, beliefs, and core values; (3) social and life adaptation skills; (4) psychological disposition such as self-efficacy, and (5) physiology. On the other hand, external factors include: (1) social support; (2) media, e.g., public service announcements; (3) sociocultural, economic, and political factors; (4) biologic; (5) health-care system; (6) environmental stressors; and (7) societal laws and regulations [119].

Other related terms of empowerment include: mutual decision-making [37,42], participation [36,38,39,43], individualized knowledge acquisition [38,41,42], goal setting [36,120], autonomy [37,39,41,42], negotiation [39], active listening [38,42], open communication [36,43], support [39,120], greater access to financial or intangible resources [41], respect [121], acceptance [120], coping strategies [120], and trust [121]. Therefore, supporting people with epilepsy to develop the attributes and skills required to function as equal partners with clinical and social services, be empowered to make informed decisions, and competently self-manage with regard to their healthcare is warranted if they are to manage effectively the day to day challenges they face in their lives [8]. The antecedents and consequences of empowerment are now explored.

3.5. Antecedents and consequences

Antecedents are those events that must occur prior to the existence of a concept. Consequences are those events that occur as a result of a concept [24].

3.5.1. Antecedents from a service user's perspective

The antecedents identified from the perspective of service users include: a loss of power and control, a transformation of consciousness, motivation, active participation, and competencies. Arguably, a loss of power and control is required for empowerment to occur [13,35]. This loss of power and control can relate to both a hierarchical, power-based relation of a health-care service, and a diagnosis of epilepsy and seizure disorders. At the service organization and delivery level, people with epilepsy are poorly informed and often poorly consulted. Indeed, one of the significant findings from a study by Bennett et al. [11] is that people with epilepsy feel less empowered when dealing with services, in part due to a lack of information structures to assist them in both managing the consequences of their condition and providing them with a basis for informed decision-making.

Indeed, epilepsy is a disorder characterized by loss of control [122]. For instance, seizures may occur at any time with little or no warning. Bearing this in mind, studies have reported that people with epilepsy have a more external locus of control compared with people with other medical conditions [123–125]. Moreover, stigma continues to contribute significantly to the loss of power and control in people with epilepsy. Internalized stigma ('felt stigma') refers to beliefs and fears within a person with epilepsy whereas interpersonal stigma refers to discrimination from others. On the other hand, institutional stigma refers to society's position on epilepsy [126]. Indeed, it has been identified that people with epilepsy often internalize societal perceptions and consequently feel disempowered [127]. Conversely, personal empowerment has long been considered the opposite of 'felt stigma' [128].

An awareness that one's life chances are being undermined by politics, economics, and disenfranchisement is required [13], insofar as people with epilepsy still experience serious limitations in economic, social, and cultural rights. For example, many people with epilepsy have unmet needs in areas such as civil rights, education, employment, residential and community services, and access to appropriate healthcare [109]. This can lead to social isolation and dependency on others especially when it prevents people from driving or working. In Ireland, people with epilepsy expressed frustration regarding the psychological, social, and structural difficulties that they encounter [11]. For example, one participant stated "I have had epilepsy for 16 years and yet still find it hard and difficult to accept. It has an effect on my life especially work and social life which is why sometimes I get angry and find it difficult to accept" [11].

Certainly, service users need significant power over their own future to feel empowered [129]. With this in mind, service users must be willing to take responsibility, and participate in goal setting [13,36]. Service users' desire to change is central to the empowerment process [38]. However, according to Dilorio et al. [80], people with epilepsy are less committed to the process of improving the management of their disease because of uncontrolled seizures, a lack of knowledge and educational resources, and insufficient social support. Consequently, people with epilepsy become discouraged and unmotivated to change their behaviors. However, motivation is vital in the empowerment process [35,37,38,42] and even more so in the reality of powerlessness and oppression [126]. Bearing this in mind, service users need to be active participants [35,36] and be willing to work alongside service providers. This requires service users to be actively involved in the decision-making process [127,128] and be equipped with the knowledge, skills, attitudes, and self-belief to modify aspects of their lives [116].

3.5.2. Antecedents from a service provider's perspective

The antecedents identified from the perspective of service providers include: surrendering the need to control, to feel empowered, possession of professional skills, and a transformation of consciousness. For empowerment to transpire, service providers need to surrender control [35,41–43]. However, the literature suggests that service providers view service users as objects or bodies that need surveillance and monitoring [129]. Indeed, empowerment has been claimed as a 'double edged sword' disguising and justifying paternalistic practices [130]. Furthermore, research demonstrates that service providers discount the expertise knowledge of service users and do not provide the resources necessary to make informed decisions despite intentions to foster participatory decision-making [68,131]. With this in mind, service providers need to embrace service user's decision-making [132].

As previously stated, service providers must themselves be empowered in order to empower service users [43]. However,a dilemma facing service providers with regard to empowerment is that they are expected to engage in processes that are empowering for service users often without consideration as to whether they themselves are empowered practitioners [133]. According to Chavasse [134], no one can value others unless they value themselves. As a counter point, Skelton [85] argues that the idea of nurses empowering themselves in order to empower others is a little naïve.

Furthermore, a personal capacity for growth and a desire for autonomy and self-determination is an essential antecedent for empowerment [41]. Gibson [35] argues that nurses can help service users empower themselves by using resources that will foster a sense of control and self-efficacy. However, if service providers adopt the discourse of empowerment, without critical review, a false sense of security that all people with a chronic disease are able to participate fully may evolve. This has been described as the 'myth of empowerment' [68]. Therefore, empowerment involves a process of helping people develop a critical awareness of the causes of their problems and a readiness to act on this awareness [46].

Indeed, empowering people with epilepsy and the promotion of self-care requires service providers to understand and appropriately deliver their role in the health-care process [12]. Arguably, embracing empowerment requires a paradigm shift from the traditional approach to healthcare [135]. It is suggested that an alternative paradigm has the potential to increase awareness of power issues among service providers and create an urge for empowering practices [92].

3.5.3. Context antecedent from both a service users and service provider's perspective

The person with a chronic condition such as epilepsy is likely to have a lifelong engagement with clinical services [136,137]. With this in mind, the literature identifies that a nurturing, caring, and supportive environment [36,43], one that is based on mutual trust, honesty, genuineness, shared vision, and respect, are necessary antecedents of empowerment for both service users and service providers [36,37,43]. Adequate face-to-face contact time has also been linked to the process of empowerment [68].

The significance of equal partnership and respect has been highlighted on many occasions [37,40,68]. This encompasses open communication and effective information provision in which knowledge, values, and power are shared [36,40]. Historically, service user's views and concerns with regard to their healthcare have frequently been overlooked [138]. With this in mind, the establishment and maintenance of 'good communication' for effective management of a chronic illness have been identified [92]. Service users need information in order to apply critical judgment with regard to decision-making [139]. Thus, the roles of service providers are to provide information and support and to transfer leadership and decision-making to service users [37,42].

3.5.4. Consequences from a service user's perspective

The consequences identified from the service user perspective include: (1) a positive self-concept, (2) a negative self-concept, (3) ability to set and reach goals, and (4) a development of competencies.

Empowerment is described as a positive self-concept such as: a personal transformation, personal power, personal satisfaction, self-efficacy, self-determination, self-esteem, sense of mastery, sense of hope, and social justice [13,35,38,40,42,43]. Furthermore, improved psychosocial adaptation [40] and overall improvement in quality of life for service users [35,40,42] have been identified.

As a counter point, empowerment can result in a negative self-concept such as feelings of inadequacy, frustration, distress, and diminished well-being [39]. As Freire [140 p.144] described, people can adopt the oppressor's view of reality resulting in "adhesion to the oppressor where people may not necessarily realize their oppression or recognize their relationship of antagonism to their oppressor", resulting in low self-esteem and self-hatred. Further, consequences of empowerment include an increased ability to set and reach goals for the individual and social ends [36], development of competencies in order to gain mastery over one's own life [13], and improving self-management activities [40,141]. This is significant for people with epilepsy insofar as social isolation and dependency on others have been identified especially when it prevents people from driving and working.

3.5.5. *Consequences from a service provider's perspective*

The consequences identified from a service provider's perspective include: professional satisfaction, improved understanding of the service user's illness, and access to resources. Enhanced status and influence is gained through participation in the empowerment process [142]. This allows greater personal power [143] and decreased stress for service providers [143]. Moreover, empowerment creates a trusting, respectful service user–service provider relationship [37–39,43]. Accountability, responsibility, willingness to see beyond the bedside, and equal partnership have also been illustrated [144]. With this in mind, service providers can recognize the suffering of people with epilepsy and prevent further marginalization due to power inequities [145]. Finally, access to resources [146] which includes increased levels of knowledge, autonomy, and control of practices [143] has been identified.

3.6. *Operational definition of empowerment within epilepsy services*

Stage 3 of Norris's concept clarification encompasses deciding on an operational definition. Therefore, results of this concept analysis identifies empowerment within epilepsy services as a subjective process or outcome for service users and providers arising from a transformation of consciousness and an access to power from within. This facilitates an experience of personal and social change, enabling service users and providers to take action in order to achieve influence over the organizations and institutions which affect their lives and the communities in which they live.

3.7. *Model of empowerment*

Stage 4 of Norris's concept clarification involves the development of a model, which illustrates the concept of empowerment within epilepsy services as outlined in Fig. 1.

3.8. *Formulation of hypothesis*

Stage 5 of Norris's concept clarification involves the formulation of a hypothesis. Therefore, this concept analysis has identified the following questions:

- What are service users and providers' views of empowerment within epilepsy services?
- What are the organizational issues and human factors on service provision that support or hinder empowerment?
- Are service providers able and willing to surrender control?
- What are the effects of an educational program for service users and providers based on empowering principles?
- How would empowerment affect the key stakeholders of the epilepsy service?
- How much does health-care empowerment depend on information technology?

Based on the above questions and the results of the concept analysis, a critical reflection of the 'micro' and 'macro' levels of power that exists for service users and providers within epilepsy services is required.

4. Empowerment of service users and providers and its relationship to epilepsy services

There are many reasons why a critical reflection on the 'micro' and 'macro' levels of power that exist for service users and providers within epilepsy services is warranted. For instance, service providers have difficulties in acknowledging the service user as 'experienced'. Moreover, deep-rooted communication habits can complicate collaborative efforts between service providers and service users [147]. Additionally, a major barrier to communication within healthcare is the lack of interactional opportunities, attributable partly to the 'system' due to time constraints, mismatch of agenda, lack of trust, and power imbalances [148].

With this in mind, service users must be willing to assume responsibility, participate in goal-setting and decision-making and accept behaviors that encourage empowerment [36]. However the implementation of empowerment from theory to practice is not always straightforward. For example, although service providers may support empowerment as a goal of patient participation, their socialization to the 'practitioner as expert' model of healthcare may be so deeply rooted that they proffer patient participation largely as an extension of their powerbase, rather than as a collaborative venture [149]. Thus, if service providers remain uncritical of the rhetoric of empowerment and are not prepared to identify practices that deny participatory decision-making in a person's care, then people with epilepsy may experience unmet expectations and frustrations in their interaction with service providers [68].

However, it is argued that service providers require support when translating empowerment into practice and into a health-care system that has not itself been designed to empower service users [150,151]. Bearing this in mind, findings of this concept analysis demonstrate that a necessary antecedent for empowerment for both service users and providers is a transformation of consciousness. By engaging in critical self-reflection, people with epilepsy and service providers can begin to understand how empowerment is facilitated or prevented, insofar as it has the potential to enable change by facilitating the deconstruction and subsequent reconstruction of social realities [152].

Taking into consideration the 'micro' and 'macro levels' of power that exist within healthcare, the question is how can people with epilepsy and service providers engage in critical reflection? We propose that an educational intervention based on empowering principles and critical self-reflection such as CST is warranted. A paper by Bennett et al. [92] explores the potential of Freire's CST as an educational framework for people with epilepsy. It illustrates how dialogue and problem-posing processes have the potential to construct realistic support for people with epilepsy that is personally and contextually specific.

Arguably, CST can generate knowledge that is based on a critical reflection of the power relationships which are embedded in the structures and functions of society [153]. It has the potential to offer service providers and people with epilepsy a way forward to accomplish change that is congruent with critical thinking. For instance, within a supportive CST educational framework, the aim is to negotiate shared meaning or consensus [154] and contribute to a more equitable relationship between people with epilepsy and service providers. Moreover, CST has the potential to enable mutual growth and change between service providers and people with epilepsy. It facilitates an objective view of social phenomena in the context of historical and social

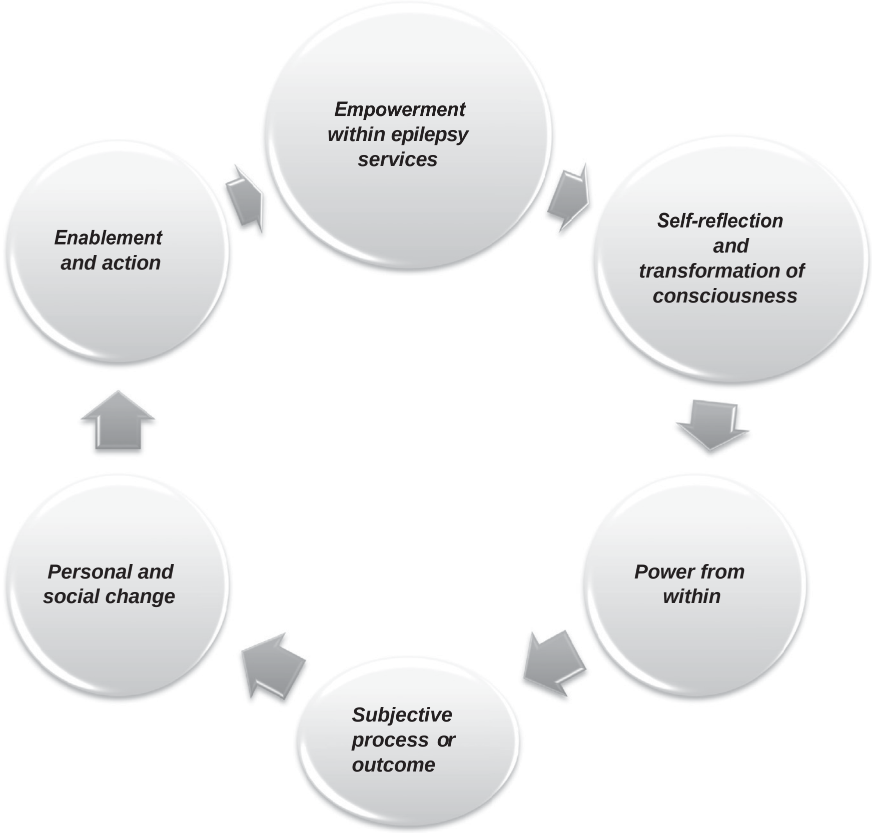

Fig. 1. Model of empowerment within epilepsy services.

practices [155]. It has also been suggested that CST liberates individuals from the restraints of coercion [156]. In this context, both people with epilepsy and service providers can develop a sense of empowerment and challenge the 'system' with regard to empowerment delivery and practice.

Critical social theory has the potential to empower people with epilepsy to gain skills and confidence to manage their illness on a daily basis and to impact upon biopsychosocial difficulties. Moreover, Bennett et al. [92] suggest that CST principles should be introduced and integrated into the curriculum for health-care undergraduate education, and that at the postgraduate specialist level, a greater depth of understanding of its principles and how these should be utilized in practice should also be introduced. This will enable service providers to critically examine and reflect on the traditional approaches that have been used and that limit the actuality of empowering people with epilepsy. However, for change to be effective within practice, there must be a change in the organizational culture. Therefore, Bennett et al. [92] recommend that this movement be championed by a group of change agents such as epilepsy specialist nurses (ESNs) and ANPs.

In addition to CST empowering principles, health-care systems should incorporate the elements of normalization within educational and support programs. It is crucial, therefore, that true social integration be accomplished, which can only be done by helping devalued individuals become more valued members of society. Normalization strategies must take into account the particular individual concerned, the limits of our current know-how, and the individual's own choice of his or her personal goals and means. Incorporation of the normalization principle into training programs for service providers and into health-care systems offers a viable means of accomplishing this goal.

Although a guide or map can be provided to assist in critical reflection and a transformation of consciousness, providing a map can only provide a guide to the terrain; it cannot replace the experience of negotiating the terrain itself. For instance, the consequences of empowerment for each individual are likely to have differences from the general expectations. As previously stated, empowerment is a subjective process, and although the consequences of empowerment may result in a positive self-concept for some, it has been reported as initiating a negative self-concept for others. Thus, focusing upon and discussing how to solve problems does not necessarily shut out the 'social, cultural, or historical realities' for people with epilepsy and service providers [157].

Therefore, an awareness that a health-care empowerment approach may result in a painful and demeaning experience for people with epilepsy who are shy, aware of the stigma attached to an epilepsy diagnosis, and unused to intellectual discourse is necessary. Indeed, as Freire [158] acknowledges, a transformation of consciousness may result in a painful process. Moreover, health-care empowerment approaches are viewed as intimidating to those in existing power structures [159] and may be met with resistance. As a result, challenges exist when service users' choices differ from those of service providers [147]. Bearing this in mind, service providers may need encouragement and support to accept the goals and priorities that people with epilepsy may hold.

5. Conclusion

Concept analysis not only clarifies existing knowledge, it also identifies directions for further development if appropriate. While this paper provides a definition and model of empowerment of service users and providers and explores its relationship with epilepsy services, empowerment remains a complex and evolving concept. Arguably, education guided by CST principles has the potential to 'hold the key' to future advances of empowerment for people with epilepsy and service providers. For instance, CST provides an opportunity to engage with the 'micro' and 'macro' levels of power and, therefore, has the potential to empower service providers and people with epilepsy to gain access to personal power and autonomy over one's own life and engagement with clinical services.

Empowerment appeals to a multidisciplinary research audience, and many of the issues discussed in this paper can become the basis for further research enquiry. Moreover, the conceptual model findings presented in this paper have the potential to assist clinicians and policymakers to understand the necessary antecedents with regard to empowerment for service users and providers within epilepsy services. This paper is both timely and relevant in relation to people with epilepsy and the broader issues of health policy, service design, transition, and delivery in relation to the development of epilepsy healthcare. In order to improve the quality of care for people with epilepsy, it is necessary to understand the concept of empowerment within epilepsy healthcare.

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Conflict of interest statement

The authors have no conflict of interest to declare.

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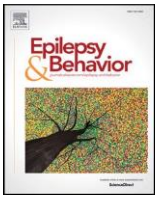

Review

The potential of critical social theory as an educational framework for people with epilepsy

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Effective education can support people with epilepsy to develop the attributes and skills required to function as equal partners with clinical service providers, make informed decisions, and competently self-manage their healthcare. However, despite knowledge deficits, unmet information needs, and a poor sense of empowerment, the study of education for people with epilepsy is often neglected and is a poorly understood component of holistic practice within epilepsy healthcare. Historically, the only debate with regard to education and people with epilepsy has been guided either within a positivist or within a constructivist philosophy. We argue that new pedagogies are warranted, recognizing the views of people with epilepsy regarding their illness. Therefore, this paper explores the potential of an educational framework for people with epilepsy based upon critical social theory (CST). By utilizing a CST approach for education, people with epilepsy are engaged with as active 'participants'. This is a key difference that distinguishes CST from other metatheoretical frameworks. It has the potential to support people with epilepsy to acquire the skills and confidence to manage the biopsychosocial challenges associated with their condition.

1. Introduction

Epilepsy is a chronic neurological disorder characterized by recurrent unprovoked seizures and is the most common serious neurological condition after stroke [1]. For people with epilepsy, the burden of the disorder is substantial and complex, with biological, psychological, and social (biopsychosocial) challenges that limit lifestyle, education, driving, and employment, even where good seizure control is reported [2,3]. In addition, stigma associated with epilepsy can result in social discrimination and the experience of prejudice-based behavior on the part of the general public [4]. Consequently, quality of life is significantly poorer for people with epilepsy, accompanied by higher rates of comorbidity, when compared to the general population [5].

This review builds on a study of one hundred and two ($n = 102$) people with epilepsy within Ireland with regard to their views of their service needs in relation to design and delivery [3]. One of the significant findings from this study and previous research is that people with epilepsy feel less empowered when dealing with services, partly because of a lack of information structures to assist them in both managing the consequences of their condition and providing them with a basis for informed decision-making [3,6–11]. This review, therefore, explores the significance of and relationship of educational frameworks with regard to empowering people with epilepsy. Arguably, as the wider study seems to suggest [3], traditional educational approaches are inadequate in meeting those needs. As an alternative, this review explores the potential of Freire's critical social theory (CST) as an educational framework for countries that have healthcare systems in place for people with epilepsy. Indeed, it provides an empowering and more effective framework than traditional approaches upon which to base new models and approaches for the education and support of people with epilepsy.

Effective education is essential and directly correlated to improved outcomes for people with epilepsy [12,13]. Supporting people with epilepsy to develop the attributes and skills required to function as equal partners with clinical and social services, be empowered to make informed decisions, and competently self-manage with regard to their healthcare is warranted if they are to manage effectively the day-to-day challenges they face in their lives [14]. Holistic care for people with epilepsy, therefore, should not only include seizure control but also psychological support and social integration [15]. While there is a body of research which points to knowledge deficits, unmet information needs [3,6], and lack of empowerment [3,6], the study of education for people with epilepsy is neglected and a poorly understood component of holistic care within epilepsy service delivery.

Historically, the only philosophical debate with regard to education and people with epilepsy has been guided either within a positivist [13,16] or within a constructivist [17] philosophy. However, limitations of these approaches have been recognized [18–22]. Therefore, we argue

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that new pedagogies are warranted [23], recognizing the views of people with epilepsy regarding their illness [24]. People with epilepsy have identified many concerns and issues about living with epilepsy that are rarely addressed by service providers and struggle with the demands of this chronic illness and the uncertainty it adds to their lives [3]. Bearing this in mind, service providers must ensure that these concerns and issues are overcome by identifying an educational framework that is guided by more empowering principles, for example, CST. Therefore, current educational provision, debate with regard to educational approaches, and their significance for people with epilepsy are now explored.

2. Studies of current educational programs for people with epilepsy

Although a number of self-management programs for people with epilepsy are described in the literature, a Cochrane review [25] reported that only two met the definition of epilepsy self-management. The first, Modular Service Package Epilepsy (MOSES), is an interactive program for people with epilepsy who are 16 years of age and older and was developed by a multidisciplinary group (neurologists, nonmedical professional helpers, and representatives of national epilepsy associations) [17]. Modular Service Package Epilepsy is designed for group education and includes the following nine modules: living with epilepsy, epidemiology, basic knowledge, diagnostics therapy, self-control, prognosis, psychosocial aspects, and network epilepsy. Its aim is to support people with epilepsy to achieve a better understanding of epilepsy, achieve more self-confidence, and become experts in self-management.

Modular Service Package Epilepsy was assessed across three German-speaking countries through a randomized control trial (RCT) [13]. The results illustrated that, compared to the control group ($n = 129$), participants in the intervention group ($n = 113$) showed improvements in relation to knowledge of epilepsy, seizure frequency, and coping with epilepsy. However, there were no significant differences on measures of activities of daily living, mobility and leisure behaviors, self-esteem, mood, and other psychosocial adjustment behaviors [13].

The second self-management program is a two-day psychoeducational intervention for people with epilepsy entitled Seizure and Epilepsy Education (SEE) program. This program involves 16 sessions over 2 days and covers medical, social, and emotional aspects of epilepsy. Using a prospective randomized trial, Helgeson et al. [16] assessed the SEE program and assigned participants to either an intervention SEE group ($n = 20$) or a control group ($n = 18$). Compared to the control group, the intervention group demonstrated a substantial improvement in overall understanding of epilepsy and improved psychosocial functioning (a person's ability to perform the activities of daily living and to engage in relationships with others in order to meet the demands of the community in which the individual lives) [26]. Furthermore, the intervention group demonstrated a significant decrease in their fear of death, brain damage, and hazardous self-management practices. However, no significant changes were noted on measures of mood and psychosocial adjustment (a process in which a person moves from a state of disablement to a state of enablement) [27].

Drawing upon behavior theory, DiIorio et al. [28] developed an interactive website intervention tool called WebEase (Epilepsy Awareness Support and Education). WebEase is designed to encourage people with epilepsy to take medications and adopt strategies to reduce seizure triggers such as stress and inadequate sleep. WebEase is based on a transtheoretical model, SCT, and motivational interviewing. An evaluation of WebEase using a preexperimental design was conducted and participants identified the program as relevant, acceptable, and easy to use [28]. Significant improvements were seen in epilepsy self-management, sleep quality, self-efficacy, and social support. Although the results illustrated higher engagement in the 'chat'feature of the program, this study reported low engagement in the intervention (only 42.9% of participants completed all modules). A further evaluation study on the practicality of delivery of EASE (Epilepsy Awareness Support and Education) by nurses over the telephone was conducted by DiIorio et al. [29]. Twenty-two ($n = 22$) participants were randomly assigned to either an intervention ($n = 11$) or a control group ($n = 11$). The intervention included a face-to-face session with a nurse followed by four telephone sessions over 12 weeks. However, the results demonstrated little statistical significance between the intervention and control groups.

3. Traditional philosophical positions with regard to education for people with epilepsy

An understanding of the interrelationship of educational philosophy with program design is important for service providers because choice of paradigm not only influences program design but also influences professional behaviors, attitudes, program satisfaction, and effectiveness [30]. Historically, much of the philosophical debate with regard to education for people with epilepsy has been guided either within a positivist or within a constructivist philosophy [13,16,17,28,29]. However, limitations of these approaches have been recognized. For instance, although positivism (that is, a belief that there 'exists' a single reality and a view of the world based around cause and effect) and constructivism (that is, a belief that newly acquired knowledge is built upon and within the context of previous learning) are seen as central to and necessary for social existence [31], it is argued that they are not adequate enough to fully understand social phenomena [18].

It is claimed that although positivism has produced scientific advances, it has also contributed to an ethos that is negatively critical of ideas, information, and knowledge from alternative philosophies [20]. Thus, it has been suggested that within healthcare, it has encouraged instructive delivery of treatment and privileges of service providers' authority and is not suitable to facilitate patient-centered models of care [21]. Furthermore, the significance of constructivism is acknowledged, in particular its awareness of factors associated with contextual and meaningful learning [32]. However, it is argued that it is unable to consider the social world as greater than people's interpretations of it, to a social world that also includes structural and institutional aspects, that are in some ways independent of an individual's thinking [19].

Social cognitive theory (SCT) refers to a psychological model of behavior that emerged primarily from the work of Albert Bandura [33,34]. It adopts a position of ontological reductionism and epistemological nonreductionism [35]. Initially developed with an emphasis on the acquisition of social behaviors, SCT continues to emphasize that learning occurs in a social context and that much of what is learned is gained through observation. Self-efficacy is a major concept of SCT. It is an important psychological construct denoting confidence in one's personal ability to perform a task or specific behavior or successfully change a specific cognitive state, regardless of circumstances or contexts [33]. It enables individuals to select a course of action in an informed manner, understand consequences of decisions, gain knowledge, be self-reflective, and exercise self-control [34]. While the significance of SCT is recognized as a useful behavioral theory to improve the self-management behaviors of people with chronic conditions such as epilepsy [29], a lack of consistency regarding the content and clinical efficacy of SCT self-management programs is found among the reviewed studies on enhancing self-efficacy in people with chronic illness [22].

Arguably, service providers need to acknowledge the personal treatment goals and outcomes of people with epilepsy [36]. However, within the traditional debate, it would appear that service providers are not prepared to share their knowledge and decision-making power with service users [37,38], feel compelled to teach all topic content and allow little, if any, time for discussion or active learning [39], and view service users as 'victims' [40]. This approach to education is not empowering and does not require service users to become active participants [41]. Yet despite these findings, which have a long-standing provenance, little or no programs or studies appear to exist with regard to an empowering educational approach for people with epilepsy. Consequently, service providers are planning and delivering treatment support without clearly understanding and taking account of the health and social goals and aspirations of people with epilepsy [3,14].

With this in mind, it may be argued that the 'traditional' framework with regard to education is limited in its ability to support people with epilepsy to effectively self-manage their biopsychosocial difficulties. For instance, although it is illustrated that traditional educational programs impact positively on patients' knowledge, coping with their epilepsy, and possibly seizure frequency, no significant improvements have been reported in measures of acceptance of disability, depression, anxiety, self-efficacy, or overall psychosocial or social problems [13,16,28,29,42]. These limitations may be attributed, in part, to a lack of attention to enhancing an individual's psychosocial process variables, such as resilience, decision-making skills, coping skills, and empowerment. Some indication of this may be discerned in a recent survey of people with epilepsy in relation to satisfaction, preferences, and information provision conducted by Bennett et al. [3]. Overall, this survey found a high satisfaction with hospital and primary care; however, there were several results which should give pause for thought. These included underuse of primary care support, greater need for psychosocial support, a need for improvements in communication, greater societal awareness of epilepsy, better information provision, more help and support from experts in the field of epilepsy care, and help with building self-confidence. These results suggest that an empowering framework for educational delivery is missing and is therefore warranted [3].

Empowerment emphasizes equality in the relationship between a service provider and service user [43] and is an integral part of self-management with regard to a chronic disease [44]. However, the traditional frameworks with regard to education and people with epilepsy often ignore the psychosocial and structural difficulties of living with a chronic disease such as epilepsy. Therefore, arguably, there is a need to shift away from traditional epistemological and ontological assumptions associated with education and people with epilepsy [23]. A growing number of experts within the field of nursing education [45–48], patient education [49,50], medical adherence [51], community health education [52,53], and empowerment education [54] view critical social theory (CST) as an alternative metatheory upon which to base empowering educational programs for people with chronic conditions. An educational framework based on empowerment has the potential to facilitate the individual to acquire social, communication, and decision-making skills; to lower anxiety levels; improve self-efficacy; and increase a sense of control with regard to healthcare [55–58]. With this in mind, Freire's perspective on CST, as an educational framework for people with epilepsy, is now outlined.

4. Critical social theory

Critical social theory is a metatheoretical framework [59]. Its realist ontology advocates an improved approach to social existence [59]: one that is free of domination, power inequities, and oppression [31]. It offers a historical framework which proposes that what is seen as real has been shaped by social, political, cultural, economic, gender, and ethnic values [60].

Epistemologically, CST is transactional and subjective where 'the investigator and the investigated object are assumed to be interactively linked, with the values of the investigator inevitably influencing the enquiry' [61, p. 110]. In other words, the epistemology in this metatheory is based on interactions of the researcher and the researched and subjectivity.

Critical social theory is concerned with issues of politics, power, and justice and the ways that society, education, religion, gender, race, sexuality, social discourses, organizations, and cultural situations interact to create a social system [62]. Bearing this in mind, it aims not only to study and understand society but also to critique and change society, raising consciousness and affecting the balance of power in favor of those less powerful or oppressed [63]. The basic assumptions of CST, described by Browne [31], are outlined in Table 1.

Table 1
Underpinning assumptions of CST [31].

- There is no ahistorical, value-neutral, or foundational knowledge that can be known outside of human consciousness.
- All knowledge is fundamentally mediated by socially and historically mediated power relations.
- Every form of social order entails domination and power.
- Language is central to the creation of knowledge and formation of meaning.
- Mainstream research generally maintains and reproduces systems of race, class, and gender oppression.
- Facts (or truth claims) cannot be separated from the domains of values or ideologies.
- By explaining and critiquing, CST serves as a catalyst for enlightenment, empowerment, and emancipation and social transformation.
- Critically orientated knowledge should offer social and cultural critiques with a view to transforming normative foundations.

Critical social theory influences personal as well as group choices, recognizing that many of life's options are influenced by social attitudes [64]. Thus, social attitudes or norms may control many options for people with epilepsy such as lifestyle, school, and employment. With this in mind, the aim of CST is to expose oppressions that may place constraints on individual or social freedom [31].

Critical social theory has been associated largely with the Brazilian philosopher Paulo Freire (1921–1997). Freire [65, p. 45] refers to traditional educational philosophical paradigms as a 'banking concept of education', whereby 'students' accept ideologies and values of society without question. He describes it as an act of depositing information in which learners (people with epilepsy) are the 'containers' to be filled and the teachers (service providers) are the depositors. Freire argues, as an alternative, that no genuine learning can occur unless 'students' are actively involved in controlling their own education [66].

Effective education is the means whereby an oppressed group can become aware of their oppression and empower people to be engaged with the world and to foster change [66]. This metatheoretical framework has emerged as a valuable lens through which to view, critique, and address the issue of health and educational disparities. Included among the distinctive features of Freire's account of CST are (1) dialog and (2) problem posing. These features are now explored in relation to education for people with epilepsy.

5. Freire's distinctive features of CST

Freire's distinctive features of CST have particular significance for people with epilepsy. Freire believed that there should be a strong emphasis on dialog based upon respect and working cooperatively. As opposed to the 'banking concept of education', he argued that educators should employ problem-posing education, a concept whereby people develop their power to perceive critically the way they exist in the world through 'dialog'.

5.1. Dialog

Dialog is a conversation between equal partners which aims to gain insight and understanding of the world around us [65]. It is the process of talking together in a way that enables individuals to understand thoughts, feelings, and values within themselves and between others, thereby facilitating a transformation of consciousness [67]. Freire [65] argues that the principle of dialog is the 'word' in which no individual can say a true word alone or say it for another [65]. Therefore, within a supportive CST educational framework within healthcare, the aim of dialog is to negotiate shared meaning or consensus [68] and contribute to a more equitable relationship between service provider and service user.

The five requirements for dialog to exist include the following: (1) love, (2) humility, (3) faith, (4) hope, and (5) critical thinking. Freire [65] argues that individuals who lack humility and love cannot become equal partners with others. Indeed without faith, dialog may result in a 'farce which inevitably degenerates into paternalistic manipulation' and cannot exist without hope and critical thinking [65, p. 72]. One of the many responsibilities of educators is to uncover opportunities for hope, regardless of the obstacles [65].

As previously stated, limitations exist with regard to the traditional educational frameworks for people with epilepsy. Issues with regard to dialog have been identified in the literature [69]. For instance, service providers have difficulties in acknowledging the service user as 'expert' and deep-rooted communication habits can complicate collaborative efforts between service providers and service users, calling for the necessity for more self-awareness of both [70]. Therefore, it is suggested that service providers surrender control [71] and communicate in an honest and genuine manner [72]. Furthermore, people with epilepsy in Ireland have identified a requirement for improved communication [3]. Therefore, a significant difference that distinguishes CST from other frameworks is the emphasis upon the collective knowledge that emerges from the dialog, insofar as the insight that emerges from the dialog could not have developed without a person's active participation. This knowledge is new for both the learner and the educator/clinician.

Chronic disease management strategies recommend that service users be empowered to self-manage their healthcare [73]. However, the literature suggests that people with epilepsy largely play a passive role regarding the management of their condition [3,6]. This indicates a need for an improved collaborative approach between people with epilepsy and service providers, insofar as shared expectations can be established and decisions jointly made in striving to achieve realistic and desired outcomes.

A study carried out by Bennett et al. [3] demonstrates the complex social, psychological, and structural difficulties that people with epilepsy confront. For instance, lifestyle, driving, work, self-confidence/self-esteem, academic life, and family life are but a few areas highlighted and consistent with previous research [2,6]. These can lead to social isolation and dependency on others especially when it prevents people from driving and working [74]. Bearing this in mind, Freire [65] suggests that an awareness raised from dialog has the potential to motivate people to identify ways in which to deal with their daily challenges. In other words, an understanding of how their social reality affects learning can help people with epilepsy recognize the need to defy existing oppressive conditions, consider alternatives, and then set learning goals related to personal learning and informational need outcomes. However, as a counter point, dialog can result in a painful process, insofar as individuals can become cognisant of the fact that their understanding or consciousness is false. An awareness of how both the oppressor and the oppressed have lost their humanity emerges [75], leading to perhaps a breakdown in trust and collaborative relationships.

As highlighted in Dilirio et al.'s [29] study, participants indicated a high engagement in the 'chat' feature of the program. These aspects of an educational program seem to appeal to people with epilepsy. Arguably, dialog has the potential for devising solutions to dilemmas, insofar as people with epilepsy can develop an understanding of obstacles and challenges with regard to psychosocial management and 'act upon this reality in order to transform it' [65, p. 149]. Such dialog has the potential to become a prelude to much-needed change with regard to education and people with epilepsy. It becomes the basis upon which a critical and problem-posing dialog can be developed, acquired, and practiced. However, for dialog to be truly effective, it needs to be linked with Freire's [76] second distinctive feature of CST — problem posing.

5.2. Problem posing

Problem posing is a practice that inspires people to critically recognize the way they exist in the world and see the world [77]. It involves a culture circle, an active space of learning, and exchange of knowledge [78]. To structure this process, service providers may use 'codifications' to pose problems and stimulate discussion [78].

A code is described as an actual physical depiction of an identified community issue in any form, for example, role play, stories, slides, photographs, and song [53]. By utilizing problem posing, people with epilepsy can reflect on the meaning the 'code' has in their lives from a sociocultural, political, historical, and economic perspective, thereby supporting them to share their emotional reaction [54].

The culture circle links the following three dialectical and interdisciplinary phases: (1) thematic investigation, (2) encoding/decoding, and (3) critical probing [79]. The thematic investigation phase seeks to detect the generative topics with regard to interactions between people and society, within a given culture context. Generative themes are the topics or issues that are raised through the process of dialog. The presence of a code allows the representation to be converted into signals (encoded) that can be transformed into representations (decoded) [80].

Within this encoding/decoding phase, issues are encoded and decoded via the dialog created, effectively raising the consciousness of the culture circle participants regarding the world in which they live. Within the critical probing phase, the culture circle participants learn to recognize issues and distinguish the limits of possibility. During this phase, there is a process of action–evaluation–action that enables participants to understand the need for cultural, political, and social actions and to resolve contradictions. Hence, discussion of codes deepens both learners' and educators' understanding of issues and encourages analysis of the theme that it represents. In this context, discussion and exploration of generative themes has the potential to lead to new insights and facilitate change. For instance, stigma related to epilepsy is a major concern across the world which service providers often fail to address [81]. Utilizing Freire's distinctive features of CST in a group educational program enables the theme of stigma to be understood. For example, people with epilepsy may begin by taking a photo or drawing a picture regarding their experience of stigma. Once the photographs or pictures are developed, people with epilepsy can choose a subset of pictures or photos to share and engage in dialog about their photo or picture. Group interactions can address the relation of each photo or picture to the designated theme, the issues depicted in the photo or picture, and their relevance to the lives of people with epilepsy. A photo or picture has the potential to help people use visual evidence to recognize and voice their problems and potential solutions to significant others in their lives, for example, policy makers [82].

Stigma, myth, fear, and discrimination still exist in relation to a diagnosis of epilepsy and lead to poor self-esteem and exclusions, restrictions, overprotection, and social isolation [83]. According to Freire [65], problem-posing education involves an uncovering of reality, striving for the emergence of consciousness. This consciousness allows 'people' to take the necessary actions to improve their life conditions [65]. Based on CST, service providers can facilitate the person with epilepsy to perceive the stigma attached to a diagnosis of epilepsy, to find its source, and to identify the negative effects it has on the person with epilepsy; in other words, to become consciously aware of their oppression. Furthermore, service providers can advocate and empower people with epilepsy to organize themselves as a group, protest, and bring about change.

While robust data is lacking to support problem-posing education for people with epilepsy, there is anecdotal evidence to suggest that many people with epilepsy seek mutual respect, decision-making capabilities, and an equitable relationship with service providers. For instance, a recent study conducted by Bennett et al. [3] found that participants identified feeling angry and frustrated regarding the psychosocial and structural difficulties that they encounter in engagement with services. Therefore, improving partnerships between service providers and people with epilepsy is necessary in order to ensure that decisions respect the needs and preferences of people with epilepsy [84]. Passivity and general compliance among people with epilepsy often lead to poor expectation of treatment outcomes and reluctance to raise important issues with service providers [6]. While the literature highlights that concordance should replace the concept of compliance and adherence [85], compliance remains an important aspect of information provision for people with epilepsy. By utilizing problem posing, people with epilepsy can reflect on biopsychosocial difficulties and how these difficulties affect their lives. It can enable service providers and people with epilepsy to engage in a two-way learning process rather than a power relationship in which the service provider 'forces' compliance [86]. This provides a more inclusive understanding with regard to their education that goes beyond positivism and constructivism.

6. The potential of an educational framework for people with epilepsy based on CST

Several papers discuss how different components of Freire's philosophy of education have been effective in healthcare. For example, Wallerstein and Bernstein [53] present a case study of an alcohol and substance abuse prevention (ASAP) program for adolescents in schools and community settings. The results of this three-stage empowering educational program identified a heightened awareness of the consequences of drinking while driving and an increased confidence in talking about drug and alcohol abuse with friends and in groups.

Brouse et al. [87] employed Freire's CST as an educational framework to promote colorectal cancer screening in an urban minority population. Participants in this study developed a sense of self-efficacy and an awareness of their own power as healthcare consumers. Furthermore, Freire's distinctive feature of dialog was utilized for educating people with cancer [88]. Improvements in outcomes at a personal level were identified such as the following: confidence, active involvement, revitalizing the sense of self, the desire to live, negotiating the goals of one's care plan, and having the strength to help others. Although currently there is no empirical literature on the effectiveness of the CST approach for people with epilepsy, the above studies suggest it may be effective since the patient populations reported upon share some of the characteristics of people with epilepsy. Thus, for example, people with cancer and adolescents with an alcohol/substance abuse problem often become passive consumers of health and struggle with biopsychosocial and structural difficulties and exclusions.

There is a growing recognition of the need to embrace patient/person-centered care (PCC) for all people with epilepsy with an emphasis on the coordination of epilepsy-specific services with care for comorbidities and with links to community services [12]. Person-centered care views the person with a chronic illness as an expert and an active participant in the educational process [89]. However, a problem with PCC as a viable framework for practice is the long-standing tradition of medical power and authority in relation to the patient as a passive consumer that has shaped healthcare practice and delivery structures. Therefore, to integrate PCC into practice, there is a need to critically examine the context of power in healthcare organizations [90].

Arguably, a metatheoretical framework that facilitates collaborative relationships and fosters PCC, such as CST, is the key to closing the gap between the promise and the reality of effective education for people with epilepsy. It may be argued that through the lens of CST, one can see how the power and knowledge of service providers can potentially be oppressive to patients through the imposition of decisions and the discursive power of medical values to limit information giving and thereby to shape those decisions of service users/patients without consideration of their views [91]. Indeed, Freire's CST, as an educational framework for people with epilepsy, has the potential to enable all people with epilepsy to engage in a dialogical, as opposed to a monological, encounter with healthcare professionals and services.

Within traditional philosophical approaches, service providers are deemed as experts. They control the selection, evaluation, and transmission of knowledge, and as a result, people with epilepsy become passive participants in the educational process. As a counter point, within a CST approach to learning, service providers are colearners engaging in dialog, and they facilitate shared knowledge. Problem posing is utilized to enable people with epilepsy to discover and apply solutions to problems and issues. People with epilepsy determine their learning needs, and service providers facilitate change in health behavior at individual, group, and community levels [53].

Critical social theory incorporates interactive teaching strategies designed to involve people with epilepsy in meeting their educational requirements. By incorporating the experiences of a person with epilepsy, a curriculum ensures that the content provided is relevant. Dialog and problem posing enables people to engage in self-reflection and focus on their experiences [92]. The use of discussion can reinforce a behavior change intervention [93]. With this in mind, CST has the potential to enable mutual growth and change between service providers and people with epilepsy. It facilitates an objective view of social phenomena in the context of historical and social practices [94].

Critical social theory is a process which combines the elements of enlightenment, empowerment, and emancipation [95]. It can free individuals from the constraints of domination and distorted communication by creating knowledge which furthers autonomy and responsibility [96]. From this perspective, education is not viewed as a series of interventions where people with epilepsy are treated as an 'object', rather, they are engaged with as an active 'participant'. This distinguishes CST from a positivist and constructivist philosophy.

Arguably, CST has the potential to enable people with epilepsy and service providers to develop an awareness of factors that inhibit or facilitate educational requirements. For instance, it has been suggested that CST liberates students from the restraints of coercion [45]. In this context, both people with epilepsy and service providers develop a sense of empowerment and can challenge educational content and delivery in order to deal with entrenched biopsychosocial difficulties such as uncontrolled seizures, comorbid conditions, and stigma associated with epilepsy.

Critical social theory is concerned with oppressive and unjust relationships and advocates for the freedom from power inequities and oppression [31]. Historically, power relations exist between service providers and people with epilepsy. For example, mothers of children with neurological disabilities reported difficulty in experiencing a sense of power in settings where the hierarchical medical model predominated [97]. They also described situations where service providers were unwilling to share their power and failed to listen to the mothers' concerns and viewpoints. Critical social theory can generate knowledge that is based on a critical reflection of the power relationships which are embedded in the structures and functions of society [98]. It offers a way forward to accomplish change that is congruent with critical thinking. Multiple studies have identified that patients who are involved with decisions about their care and the management of their conditions have better outcomes compared to those who are not [99,100].

Therefore, service providers need to challenge, identify, and examine their own beliefs with regard to educational requirements and delivery for people with epilepsy rather than from the meaning assigned by their institution or policy maker. Mohammed [101] recommends CST as a framework that can enable the formation of partnerships with service users. It is reported that the utilization of knowledge and experience of service users could greatly benefit quality of care and, ultimately, quality of life [73]. Empowering people with epilepsy and the promotion of self-care require service providers to understand and appropriately deliver their role in the healthcare process [6]. It is argued that emancipatory knowledge can be produced when service providers and service users are together prepared to question the assumptions underlying the conduct of clinical practice [102].

The growing insight into the complexity of epilepsy has led to an understanding that, to reach an optimal treatment outcome, it is crucial to consider people with epilepsy holistically [103,104]. Empirical literature highlights that for many persons with epilepsy, the medical features of epilepsy are the least disabling aspect of life, compared to psychosocial and structural difficulties that people with epilepsy confront [2,3,6]. Effective education not only requires improvements in medical knowledge but also improvements in psychosocial self-management [15]. Thus, an educational framework based on CST allows understanding of the biopsychosocial aspects of human nature [96]. Moreover, it offers the educator an opportunity to move beyond the levels of description and explanation in order to develop a critical reflective analysis of the political nature of education.

A CST perspective offers educators/clinicians a way to challenge the traditional models of educational delivery for people with epilepsy by posing the following questions: What are the issues of power and control that are embedded in development and delivery of educational approaches for people with epilepsy? Who develops and decides what educational content should be delivered to people with epilepsy? What social structures and relations such as culture, economics, race, age, or gender contribute to making educational delivery an oppressive structure within epilepsy education, and how can people with epilepsy be empowered to competently self-manage their condition?

It may be argued that CST has significance in supporting service providers and researchers to make sense of problems in service delivery and promote initiatives for change and improvement [105]. For example, CST offers a research perspective that may help uncover enabling and/or restrictive practices within healthcare [106]. It allows knowledge to be developed based on a critical reflection of the power relationships which are embedded in the structures and functions of society [98]. Thus, engaging in critical self-reflection allows service providers and people with epilepsy to understand how empowerment is facilitated or prevented within epilepsy services.

7. Limitations of critical social theory

Although the potential of CST has been highlighted above, it is not beyond its limitations. For instance, Gore [107] points out that for 'students' who are confident, loquacious, and used to academic culture, problem posing holds relatively few fears. It is argued that allowing 'students' to focus and discuss problems does not necessarily shut out the 'social, cultural, or historical realities for students' [107, p. 6]. Therefore, an awareness that an educational framework based on CST may result in a painful and demeaning experience for people with epilepsy who are shy, aware of the stigma attached to an epilepsy diagnosis, and unused to intellectual discourse is necessary.

Mooney and Nolan [48] claim that adopting a CST educational approach into a healthcare system is a challenge and remains a difficult task. There are several reasons why the application of a CST educational framework is not more widely adopted within healthcare. Firstly, service providers may lack the appropriate knowledge with regard to CST and be unable to engage in empowering principles. Secondly, a number of service providers may prefer to engage in traditional educational approaches and, thus, provide care that is not reflective of empowering principles. Finally, curriculum content remains influenced by organizations and institutions. The implication of this is that the service provider/educator is unable to decide upon the structure and process of an empowering educational delivery.

Moreover, healthcare empowerment approaches are viewed as intimidating to those in existing power structures [108] and may be met with resistance. As a result, challenges exist when service users' choices differ to that of service providers [70]. Bearing this in mind, service providers may need encouragement and support to accept the goals and priorities that people with epilepsy may hold.

While recognizing that such limitations exist, arguably, Freire's features of CST merit exploration with regard to an educational framework for people with epilepsy, insofar as people with epilepsy are likely to have a lifelong engagement with clinical services [109,110] and incorporating their experiences must be seen as central to the effectiveness of service design and delivery. Therefore, knowledge and understanding of the wider context within which people with epilepsy exist, from a CST perspective, need to be incorporated within epilepsy services design and delivery to ensure that the person with epilepsy, when engaged with services, is dealt with in terms of their individual needs and holistically. This will have the benefit of identifying, for example, potential social and psychological difficulties that may impede the person with epilepsy in the effective self-management of their condition.

8. Implementing Freire's CST as an educational framework for people with epilepsy

Healthcare is discursively influenced by traditional power and authority; therefore, adopting a new strategy into a healthcare system is always complex. Bearing this in mind, significant planning and accommodation are required to implement Freire's educational framework within epilepsy services. Firstly, we suggest that CST principles be introduced and integrated into the curriculum for healthcare undergraduate education followed by, at a postgraduate specialist level, a greater depth of understanding of its principles and how these should be utilized in practice. This will enable service providers to critically examine and reflect on the traditional approaches that have been used and that limit the actuality of empowering people with epilepsy.

Secondly, for change to be effective within practice, there must be a change in the organizational culture. Indeed, the following three factors must be addressed: (1) the evidence for change, (2) the context in which change is being introduced, and (3) how this change will be facilitated [111]. Therefore, implementing Freire's CST as an educational framework, for both people with epilepsy and the healthcare professionals with whom they engage, has to be a movement that is championed by a group of change agents. For example, a study by Bennett et al. [3] identified that people with epilepsy would rather talk about their epilepsy to an epilepsy specialist nurse (ESN) [3]. It is claimed that ESNs increase and improve communication between service providers and people with epilepsy [112]. With this in mind, we recommend that ESNs and advanced nurse practitioners be identified as change agents.

No longer can tradition, outdated organizational structures, or poor communication impede effective and efficient education for people with epilepsy. As previously stated, for change to be effective within practice, evidence for the extent and impact of change is required. McCarthy et al. [58] compared outcomes for parents who participated in both empowering and traditional educational approaches to asthma education. Significant differences were found with regard to a sense of control, ability to make decisions, and ability to provide care by the parents who participated in the empowering educational approach.

As previously stated, studies that have compared the effects of traditional educational approaches for people with epilepsy have measured outcomes such as living with epilepsy, epidemiology, basic knowledge, seizure frequency, self-control, prognosis, psychosocial aspects, network epilepsy [13], self-management, sleep quality, self-efficacy, and social support [29]. However, the literature suggests that the consequences of empowerment also include a personal transformation, personal power, personal satisfaction, self-determination, self-esteem, sense of mastery, sense of hope and social justice [43,50,113–117], an increased ability to set and reach goals for individual and social ends [72], and development of competencies in order to gain mastery over one's own life [115]. These outcomes are significant for people with epilepsy as health-related quality of life is significantly poorer, and higher rates of comorbidity have been reported in people with epilepsy compared to the general population [5]. Therefore, in order to test Freire's educational approach in the realm of epilepsy, we suggest that a quasi-experimental study be carried out by the 'change agents' to compare these novel outcomes for people with epilepsy who participate in both Freire's CST educational approach and the traditional approaches to education.

9. Conclusion

Most debate surrounding education and people with epilepsy has been guided, either implicitly or explicitly, within a positivist or within a constructivist philosophy. The merits and limitations of these established frameworks have been outlined. While an educational framework based on CST is not beyond limitations, this review illustrates how dialog and problem-posing processes have the potential to construct realistic support for people with epilepsy that is personally and contextually specific. It has the potential to empower people with epilepsy to gain skills and confidence to manage their illness on a daily basis and to impact upon biopsychosocial difficulties. In this regard, it may be argued that while the traditional approaches to education for people with epilepsy demonstrate some improvements in relation to knowledge of epilepsy and biopsychosocial self-management, a one-time educational program is rarely effective to sustain the types of change needed to effectively self-manage epilepsy. Furthermore, these programs are not tailored to fit the priorities, goals, resources, culture, and lifestyle of people with epilepsy. To effectively self-manage their condition, people with epilepsy must be able to set goals and make frequent daily decisions that are both effective and fit their values and lifestyles while taking into account their biopsychosocial difficulties. Educational approaches based upon CST, however, provide an opportunity to engage these issues and thereby have a great potential to empower people with epilepsy in their day-to-day lives and in their engagement with clinical and social services.

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Conflict of interest statement

The authors have no conflict of interest to declare.

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Appendix B: Research proposal

Research Proposal: Empowerment in Irish epilepsy services: A ‘Soft Systems’ study referenced to Critical Social Theory.

Abstract

Empowerment is an integral, but often neglected and poorly understood component of holistic practice in epilepsy care. People with epilepsy in Ireland suggest they do not have a sense of empowerment or insight into the concept of ‘integrated shared care’. As the connection between empowerment and quality of life is highlighted more in the literature, a compelling need exists to address empowerment in epilepsy care. Information Communication Technology (ICT) is envisaged as part of the future services provided by the National Epilepsy Care Program (NECP) in Ireland. However, lack of empowerment of service users’ and service providers’ is a barrier facing the implementation and integration of ICT.

This proposal aims to explore and analyse the epilepsy service as a system with reference to dimensions of empowerment using Critical Social Theory (CST). A ‘soft systems’ method approach will be used involving three phases. Phase 1 will entail a literature review of epilepsy care, epilepsy policy and observation of service operation. Informal interviews of service users and service providers regarding the operation of the Irish epilepsy service will be carried out with reference to service user and clinician empowerment. Finally, with regards to patients’ perspectives on services for epilepsy, a survey of patient satisfaction, preferences and information provision in people with epilepsy will be undertaken. Phase 2 will involve conducting one-to-one, semi-structured interviews with service users and service providers. These interviews will focus on perceptions of the concept of empowerment as it is experienced in the epilepsy service and to explore and analyse organisational issues that support or hinder empowerment in epilepsy health care. Phase 3 will involve conducting focus groups with people with epilepsy and service providers to identify changes that may be required in the service to improve service user and clinician empowerment.

Allowing service users and service providers the occasion to articulate their views on service provision will provide an opportunity for them to be empowered within the

context of Irish health care, whilst providing valuable data to draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland.

1.0 Introduction and Background

The World Health Organisation (WHO 2006) projects a rise in the number of epilepsy cases from approximately 40 million in 2005 to more than 50 million by 2030. Such a rise has economic implications as more than 15 billion euro is spent annually on the treatment of epilepsy in Europe. A recent Cochrane review on systems of care for epilepsy reports that an optimum system of care has not yet been empirically determined (Bradley and Lindsay 2008). Therefore, improving quality of life in epilepsy is the main goal of international and national policy (DOH 2008, HSE 2011).

Empowerment is an integral, but often neglected and poorly understood, component of holistic practice in epilepsy care. Indeed, there is a requirement for increased personal empowerment to better deal with the various aspects and challenges people with epilepsy face (May *et al.* 2002). With this in mind, the Irish health strategy clearly purports to encourage the empowerment of patients (Department of Health and Children 2001). However, people with epilepsy in Ireland have suggested they do not have a sense of empowerment or insight into the concept of integrated shared care (Varley *et al*. 2011). As the connection between empowerment and Quality of Life (QOL) is highlighted in the literature, a compelling need exists to address empowerment in epilepsy care. In order to facilitate empowerment of people with epilepsy, service providers need to understand the perceptions of empowerment from the patient's perspective. The patient's perspective then needs to be integrated with the empowerment perceptions of service providers and policy makers. Furthermore, the relationship between empowerment and organisational structure requires clarification.

Empowerment is defined as '*a process, a mechanism by which people, organisations, and communities gain mastery over their affairs'* (Rappaport 1987 p. 122). Definitions of empowerment encompass the levels of individual, group and community. At an individual level, empowerment is suggested to be psychological in nature, and linked to concepts such as self-esteem and personal control (Rissel *et al*. 1996). At a group level, empowerment is linked to the individual level but manifests itself through collective action, such as voluntary groups and social networks (Schulz *et al*. 1995). At a community level, empowerment is associated with political action (Segal *et al*. 1995).

The literature suggests that outcomes of empowerment include self-management; self-determination; self-efficacy; knowledge and understanding; enhanced quality of life; enhanced capacity to cope; ability to set and reach goals; personal transformation of self; personal satisfaction; sense of control (Gibson 1991, Aujoulat *et al.* 2007), sense of learning; sense of connectedness and sense of justice (Gibson 1991). Despite the outcomes of empowerment there is evidence that not all service providers are willing to allow patients to become involved in making decisions about their care (May 1992). Furthermore several research studies have highlighted that service providers are not prepared to share their knowledge and decision making powers with patients (May 1992, Johnson 1997, Payne 1998, Henderson 2003). Labonte (1994) noted that many service providers are relatively powerless in their organisations and need to claim legitimacy or power for themselves in order to be effective in their work with less powerful groups external to their organisation.

1.1 The Irish Context

To improve the management of epilepsy in Ireland, the Health Service Executive (HSE) established a new strategy for the delivery of health care services for people with epilepsy (HSE 2010). The NECP, under the direction of the office of Clinical Strategy and Programmes, has been charged with addressing the historic deficiencies in epilepsy care through a comprehensive change programme that delivers care from '*cradle to grave*' in epilepsy (HSE 2010). This will be achieved by addressing three core objectives:

1. Improving access to expert care and information
2. Improving the quality of care across the healthcare spectrum from prevention, through managed primary care to complex surgical care for difficult epilepsy.
3. To improve value conscious care by shifting care where possible from expensive hospital based care to the community.

The Epilepsy Research Department at Beaumont Hospital, Dublin has developed and integrated into clinical practice an electronic information exchange system (www.epilepsy programme.ie). This Electronic Patient Record (EPR) consolidates electronically the medical information of patients with epilepsy attending the hospital. The EPR is Web-based so that patient information can be securely accessed via the internet by authorised users. It facilitates the timely sharing and exchange of patient information both within and across organisational boundaries, thereby promoting a continuum of health services. Integrated, comprehensive two-way ICT is envisaged as part of the future services provided by the NECP for people with epilepsy. It is widely argued that access to health information via the internet empowers patients (Henwood *et al.* 2003). However, a lack of empowerment of service users and providers is a barrier facing the implementation and integration of ICT support. It is an opportune time to re-evaluate epilepsy care services, particularly as the focus in health service planning has shifted to embrace the user's perspective, and also because of the major future advances in ICT. Therefore this proposal is both timely and relevant in relation to people with epilepsy and the broader issues of health policy, service design, transition and delivery in relation to the development of Irish epilepsy health care. If the HSE is to improve the quality of care for people with epilepsy, then it is necessary to understand the concept of patient empowerment.

1.2 Justification for this study

Empowerment remains inadequately understood as a concept in epilepsy health care (Varley *et al*. 2011). There is a lack of research related to service user and service provider perspectives on empowerment in relation to epilepsy care. Also, there is a paucity of research into the organisational structures within which service providers function and how they are supported in practice to facilitate empowerment for people with epilepsy. Furthermore, insights from the organisational–sociological literature regarding collaboration of all stakeholders including service users is lacking as this relates to epilepsy care. In particular, there is a need to examine epilepsy services with reference to the needs and views of the service users and providers. The aim of this study is therefore to address this deficit in the literature by exploring the dimensions of empowerment using CST with reference to the operation of the Irish epilepsy service as a system. A systems approach will be utilised drawing upon principles of 'soft systems' methodology (Checkland and Scholes 1990).

1.3 Conclusion

The literature indicates that a definition of empowerment is not straightforward. Health services often fail to address the empowerment needs of service users and service providers. This may be due to a combination of poor management style, lack of education, lack of support, lack of recognition from management and other professionals (DOHC 2003). Allowing service users, providers and policymakers the occasion to articulate their views on service provision will provide an opportunity for them to be empowered within the context of Irish health care, whilst providing valuable data to draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland.

2.0 Research Methodology

2.1 Aim

The aim of this proposal is to explore and analyse the epilepsy service as a system with reference to dimensions of empowerment using CST. This aim encompasses the following objectives:

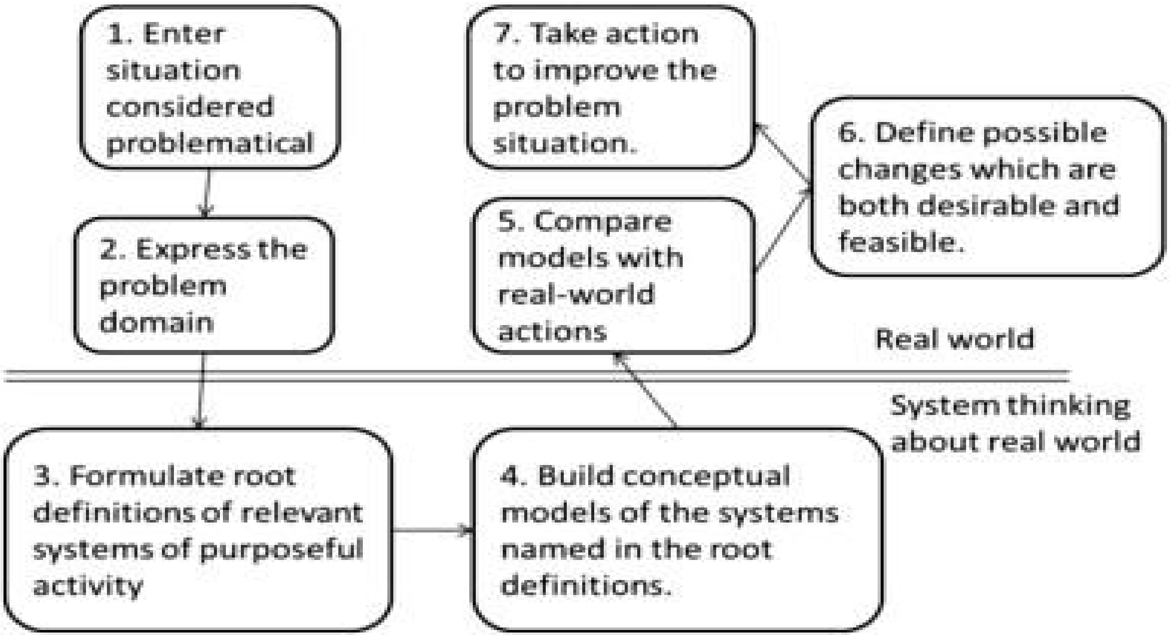
2.1.1 Objectives

1. To utilise CST to analyse and define the concept of empowerment in the Irish health service with reference to the NECP.
2. To develop a situational analysis and conceptual model of the service utilising 'soft systems' methods.
3. To explore and critically analyse organisational issues and human factors on service provision that support or hinder empowerment.
4. To compare the conceptual model of the service with its service operation.
5. To draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland.

2.2 Research Design

A 'Soft Systems' Methodologt (SSM) using a mixed method approach will be employed to analyse and define the concept of empowerment in the Irish health service and to explore and analyse organisational issues that impact service provision that support or hinder empowerment in people with epilepsy. A SSM as developed by Checkland (1981) adopts a research approach to focus on creating change rather than simply describing the problem. This is achieved by developing models of relevance to the 'real world' or practice situation. These models are compared against perceptions of the 'real world'. These comparisons initiate an iterative process, a debate that leads to a decision about purposeful action. The SSM framework (Figure 1) encourages discussion within a systemic context offering seven identified stages, from expressing a problem situation through to an action stage.

Figure 1: Seven stage model of SSM (Checkland 1981).



This seven stage framework as described below will guide this study in terms of data collection and analysis.

Stage 1: Situation considered problematic:

The purpose of stage 1 is to gain a general understanding and wider view of the problem (Bowen and Shehata 2001). This will be accomplished by conducting a literature review of epilepsy care, epilepsy policy, and observation of service operation. Formal and informal interviews of service users and service providers regarding the operation of the Irish epilepsy service will be carried out with reference to service user and clinician empowerment. Finally, with regards to patients' perspectives on services for epilepsy, a survey of patient satisfaction, preferences and information provision in people with epilepsy will be undertaken.

Stage 2: Problem situation expressed:

Once this information is gathered the problem situation is expressed as a 'rich picture', enabling the main issues to be identified. Wells (1995) argues that the difficulty lies in deciding when one has enough material but suggest that parameters are usually set by time.

Stage 3: Root definitions of relevant systems:

Having identified relevant systems that need investigation, stage 3 requires a root definition of each system to be constructed. Checkland (1981 p. 167) defines root definitions as '*hypotheses concerning the eventual improvement of the problem situation by means of implemented changes which seem to both the systems analyst and problem owners to be likely to be both feasible and desirable*'. Checkland and Scholes (1990) formulate root definitions using the CATWOE mnemonic as outlined in table 1.

Table 1: Irish epilepsy service: CATWOE

CATWOE
Customers: Beneficiaries of the transformation process which include service users and service providers of the Irish epilepsy service.
Actors: Those who carry out the transformation process which are service users, service providers and policymakers of the Irish epilepsy service.
Transformation process: The conversion of an input into an output, which is transforming the epilepsy service so that service users and service providers are empowered.
Weltanschauung: The meaningful context in which 'T' is carried out which is the belief that empowerment can improve quality of life for both service user and service provider.
Owners: Those who can stop/prevent 'T' being carried out including policymakers.
Environmental constraints: Elements outside the system that nevertheless affect it, including curriculum regarding empowerment in medical and nursing education.

Stage 4: Conceptual models of systems derived:

Once the root definition for the system is established then stage 4 will require the construction of a conceptual model which will describe the activities that must take place in order to achieve the transformation. The conceptual model is built by identifying the key activities within the root definition and expressing each activity in a phrase containing a verb which can then be associated to form the conceptual model (Platt and Warwick 1995).

Stage 5: Comparison of models and the real world**:**

This stage deals with the comparison of the conceptual model with the problem as expressed in stage 2. The purpose of this stage is to analyse the similarities and differences between the model and the real world in a thorough and structured manner (Bowen and Shehata 2001).

Stage 6: To identify changes:

This will be achieved by conducting focus groups with service users and providers to generate discussion and debate any differences and similarities. This stage of the process will identify any desirable and feasible changes.

Stage 7: Action:

This final stage is concerned with the implementation of changes. It is envisaged that the changes will be translated into planned service objectives, ensuring the faciliatation of empowerment within epilepsy services in Ireland. Table 2 outlines data collections methods required to answer research objectives.

Table 2: Data collection methods required to answer research objectives.

Objectives:	1. To utilise CST to analyse and define the concept of empowerment in the Irish health service with reference to the NECP	2. To develop a situational analysis and conceptual model of the service utilising 'SSM,.	3. To explore and critically analyse organisational issues and human factors on service provision that support or hinder empowerment.	4. To compare the conceptual model of the service with its service operation.	5. To draw wider inferences for the development and operationalization of epilepsy policy and practice in Ireland.
Methodology					
Literature review.	🟩				
Reviewing policy literature		🟩			
Observation of service operation.	🟩	🟩	🟩		
Survey of people with epilepsy		🟩	🟩		
Interviews with service users and providers.	🟩	🟩	🟩		
CATWOE Analysis.				🟩	
Comparative analysis of situation.				🟩	
Focus group with service users, providers and policymakers				🟩	
Overall analysis.					🟩
Dissertation.					🟩

2.3 Population and sample

The population of interest includes service users currently attending the Irish epilepsy service at St. James's Hospital (SJH), service providers (nurses and doctors) working at SJH and policymakers within the HSE working with the NECP.

2.3.1 Interviews and focus groups

A purposive sample, a non-probability approach to sampling was chosen, as it allows the researcher to select participants that will best contribute to the information needs of the study (Polit and Beck 2006). Purposive sampling is the conscious selection of participants from a clearly defined group and is deemed appropriate on the basis that those who are selected can provide the necessary data to answer the research aims and objectives (LoBiondo-Wood & Haber 1998). The sample population will include service users, service providers and policy makers involved with the Irish epilepsy service.

2.3.2 Survey

A random sample of a population of 2000 service users attending the OPD clinic at SJH will be utilised. With a confidence level of 95%, a sample size of 324 (n=324) service users will allow the study to determine patients satisfaction of epilepsy services with a confidence interval of +/- 5%. Table 3 outlines the sample size required for surveys, interviews and focus groups.

Table 3: Sample size for survey, interviews and focus groups.

Survey	*Interviews*	*Focus groups*
Service user: A random sample of service users attending an OPD clinic for 6 months n= (324)	Service user n= (20-30) Service provider n= (20-30)	Service user, provider and policymakers n= (8)

2.4 Inclusionand exclusion criteria

2.4.1 Inclusion criteria

<u>Service users:</u>

1. Adults (age 18 or over) with a diagnosis of epilepsy greater than one year.
2. Currently engaged in treatment and care within the Irish epilepsy services.
3. Considered well enough by the multidisciplinary team to participate.

<u>Service providers and policymakers:</u>

1 Service providers and policy makers currently involved with the epilepsy service in Ireland.

2.4.2 Exclusion criteria

Service users:

Not considered well enough by the multidisciplinary team to participate in interview and be unable to complete a survey.

2.5 Negotiation of access

A meeting with key members of the Irish epilepsy service was conducted. This meeting provided clear information about the aims and objectives of the study and the process involved and also emphasised the voluntary nature of participation. Service providers and policymakers can agree to participate verbally following the meetings or subsequently via telephone or email. Dr Colin Doherty, Clinical Lead for the NECP is aware that this research is due to take place and fully supports this study.

2.5.1 Recruitment process

The recruitment process for service users will be discussed at initial meetings. I propose that the service providers are best situated to identify service users that are suitable to participate. A participant information leaflet will be provided to explain what the study entails, emphasise the voluntary nature of participation and to maximise the possible benefits this study hopes to achieve for future services. This information leaflet will ensure that the participant's well-being will be secure with no risks involved. Participants will be informed that they will have the right to review and withdraw the analysis of their interview at any-time. A contact number for the researcher will also be made available to each of the participants.

2.6 Data collection Strategy

Data will be collected in three phases

Phase 1 will involve:

- A literature review of epilepsy care and epilepsy policy. This will be undertaken by searching the major bibliographic databases using the search terms 'empowerment', 'epilepsy, 'epilepsy service', 'service users', service providers', 'satisfaction of epilepsy services' and 'epilepsy policy'. The titles and abstracts of articles will be reviewed and articles will be included only if they meet the following three criteria: (1) describe the results of empirical research; (2) explicitly address empowerment of service users and service providers in the epilepsy service; (3) refined to the English language only. The data abstraction and synthesis process will consist of re-reading, isolating, comparing, categorizing and relating the data to each other.
- Observation of service operation. This will involve observation of the epilepsy service provided at the OPD at St James's |Hospital, and involve weekly visits for a period of 4 months lasting on average 4 hours. Observation can provide a rich picture and

deemed an appropriate technique for getting at real life in the real world (Robson 2003). The researcher will adapt the participant-as-observer framework (Robson 2003). Observational material will be recorded in the form of field notes, typed up in full by the researcher and imported into NVivo 10. Field notes will include key quotations and phrases, observation of verbal and non-verbal behaviours, time of events and activities, and the researcher's views and feelings at the time of observation (Gray 2004).

- Informal interviews of service users and service providers regarding the operation of the Irish epilepsy service will be carried out with reference to service user and clinician empowerment.
- A survey of patient satisfaction, preferences and information provision for people with epilepsy will be undertaken.

  Permission has been granted to use and adapt the questionnaire developed by Poole *et al.* (2000). The decision to use this survey is based on the appropriateness of the instrument to the objectives of the study and the degree to which they could be adapted to meet the specific needs of the study. Results of phase 1 will inform formal interviews for phase 2. It is projected that data collection for phase 1 will run over four calendar months from June 2013-September 2013.

Phase 2 will involve conducting one-to-one, semi-structured interviews with service users and service providers to analyse and define the concept of empowerment in the Irish epilepsy service and to explore and analyse organisational issues that support or hinder empowerment in epilepsy care. It is anticipated that 20-30 service users and a similar number of service providers will be interviewed. One-to-one interviews will give the participants more time to disclose their experiences with fewer interruptions. It is projected that data collection period for phase 2 will run concurrently with phase 1 from Sept 2013-February 2014.

Phase 3 will entail conducting focus groups with service users and service providers to identify changes that may be required in the service to improve service user and clinician empowerment. It is projected that data collection for phase 2 will run for 3 months from November 2014-January 2015.

2.7 Data Analysis

This study yielded quantitative and qualitative data through the use of a survey, interviews, observation of service, and a focus group. Data analysis occurred sequentially in two phases (in which the quantitative analysis phase preceded the qualitative analysis phase) (Onwuegbuzie and Teddlie 2003).

2.7.1 Survey

Descriptive and inferential statistics will be carried out for this survey. Satisfaction of primary care and secondary care will be quantified by calculating the proportion of responses that indicate satisfaction (e.g.'Very satisfied', 'fairly satisfied'). Information provision will be quantified by calculating the proportion of patients that recall receiving information. All the topics will be combined in order to obtain an overview of information provision. The proportion of positive responses will be calculated to obtain an overall level of information provision. Patients will be grouped by age and seizure severity and chi-squared tests will be used to compare the findings in both categories. For the purpose of this study I will consult with Michelle Foley a statistician located in the School of Nursing,WIT.

2.7.2 Interviews and focus groups

Individual and focus group interviews will be analysed using the framework approach by Ritchie and Spencer (1994). This framework will involve the following five key stages: (1) familiarisation; (2) identifying a thematic framework; (3) indexing; (4) charting; and (5) mapping and interpretation.

2.8 Ethical Considerations

Researchers have an ethical responsibility to recognise and protect the rights of their subjects (Burns and Grove 2007) and the following ethical considerations will be adhered to

- Ethical approval for this study has been granted by the ethics committee of WIT. Ethical approval is currently been sought from SJH ethics committee.
- A participant information leaflet will be provided and will aim to maximise the possible benefits this study hopes to achieve for future services, and to ensure that the participant's well-being will be secure with no risks involved. Participants will be informed that will have the right to review and withdraw the analysis of their interview

at any-time. A contact number for the researcher was also made available to each of the participants.

- Written consent will be sought from service users, service providers and policymakers regarding interviews and focus groups.
- All participants will be informed that they had the right to withdraw at any stage, decline to answer any question(s) and have the digital recorder turned off without obligation. They will be offered the opportunity to ask questions before or during the interview process.
- All questionnaires will be anonymous. All data will be secured in a locked filing cabinet in a locked room in the school of nursing at WIT. This data will be entered into SPSS on a desktop PC and will be password protected.
- All interviews will take place individually and in a private room allocated to the researcher at SJH, with the exception of interviews with policymakers which will be nominated in a building and room of their choice. All interviews will be digitally audio-recorded. Data will be transferred to NVivo 10 on desktop PC and password protected. All audio interviews will be categorised by a number for the purpose of identification rather than by name. Only Ms Louise Bennett will have access to audio data. Supervisors will have access to transcript analysis via NVivo.
- All data will be protected following the Data Protection Acts (2003) and Freedom of information Acts (1997, 2003).
- Data will be retained only for as long as necessary and in accordance with the WIT Records Retention Policy.

2.9 Conclusion

A SSM using a mixed method approach will be employed to analyse and define the concept of empowerment in the Irish health service and to explore and analyse organisational issues that impact service provision that support or hinder empowerment in epilepsy health care. CST and Checkland’s (1981) seven stage model will guide the theoretical framework. This study will provide an understanding of the current operation of the Irish epilepsy services as a system and particularly the degree to which it facilitates service users and clinicians empowerment. It is anticipated that the data collected in this study will provide a basis for an evaluation of current practice and provide indicators to the Irish epilepsy service and the wider Irish Health service on how service users and clinicians empowerment can be further improved. Future recommendations for practice and policies in relation to collaborative empowerment for service users and service providers will be made.

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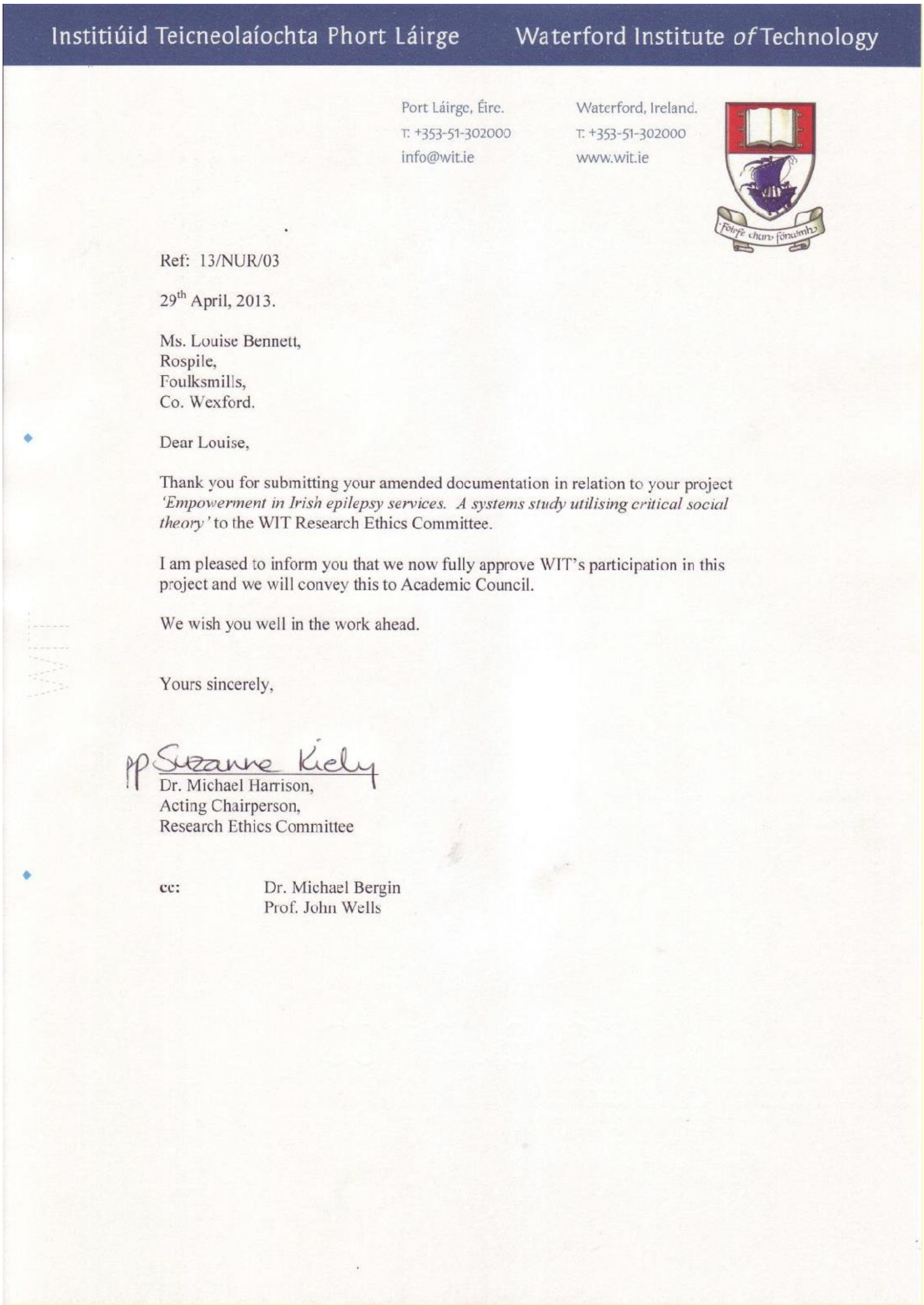
Appendix C: Ethics Approval-Waterford Institute of Technology



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Ref: 13/NUR/03

29th April, 2013.

Ms. Louise Bennett,
Rospile,
Foulksmills,
Co. Wexford.

Dear Louise,

Thank you for submitting your amended documentation in relation to your project *'Empowerment in Irish epilepsy services. A systems study utilising critical social theory'* to the WIT Research Ethics Committee.

I am pleased to inform you that we now fully approve WIT's participation in this project and we will convey this to Academic Council.

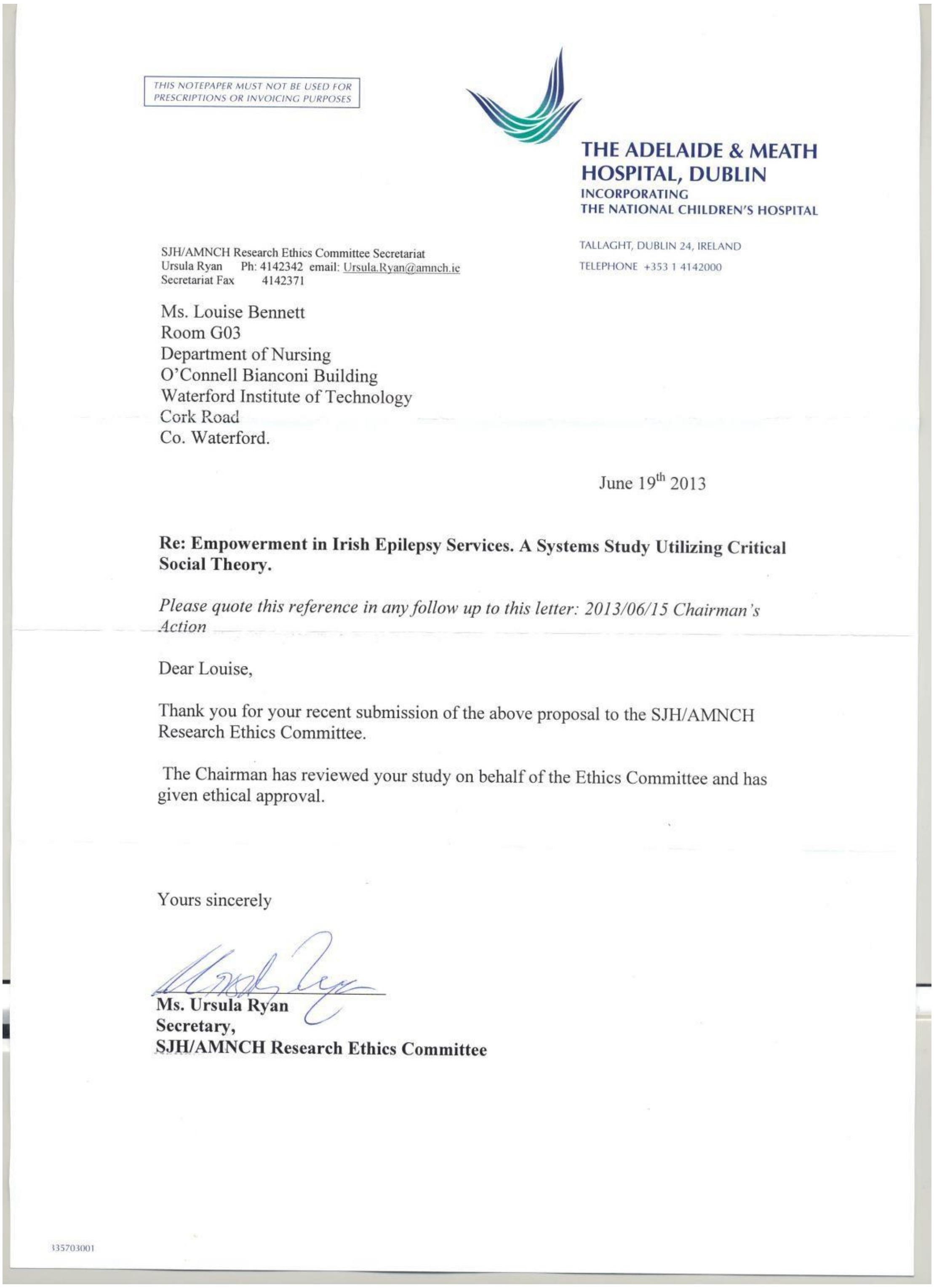
We wish you well in the work ahead.

Yours sincerely,

pp Suzanne Kiely
Dr. Michael Harrison,
Acting Chairperson,
Research Ethics Committee

cc: Dr. Michael Bergin
Prof. John Wells

Appendix D: Ethics Approval: Health Services Executive - Regional



THIS NOTEPAPER MUST NOT BE USED FOR
PRESCRIPTIONS OR INVOICING PURPOSES

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SJH/AMNCH Research Ethics Committee Secretariat
Ursula Ryan Ph: 4142342 email: Ursula.Ryan@amnch.ie
Secretariat Fax 4142371

Ms. Louise Bennett
Room G03
Department of Nursing
O'Connell Bianconi Building
Waterford Institute of Technology
Cork Road
Co. Waterford.

June 19th 2013

Re: Empowerment in Irish Epilepsy Services. A Systems Study Utilizing Critical Social Theory.

Please quote this reference in any follow up to this letter: 2013/06/15 Chairman's Action

Dear Louise,

Thank you for your recent submission of the above proposal to the SJH/AMNCH Research Ethics Committee.

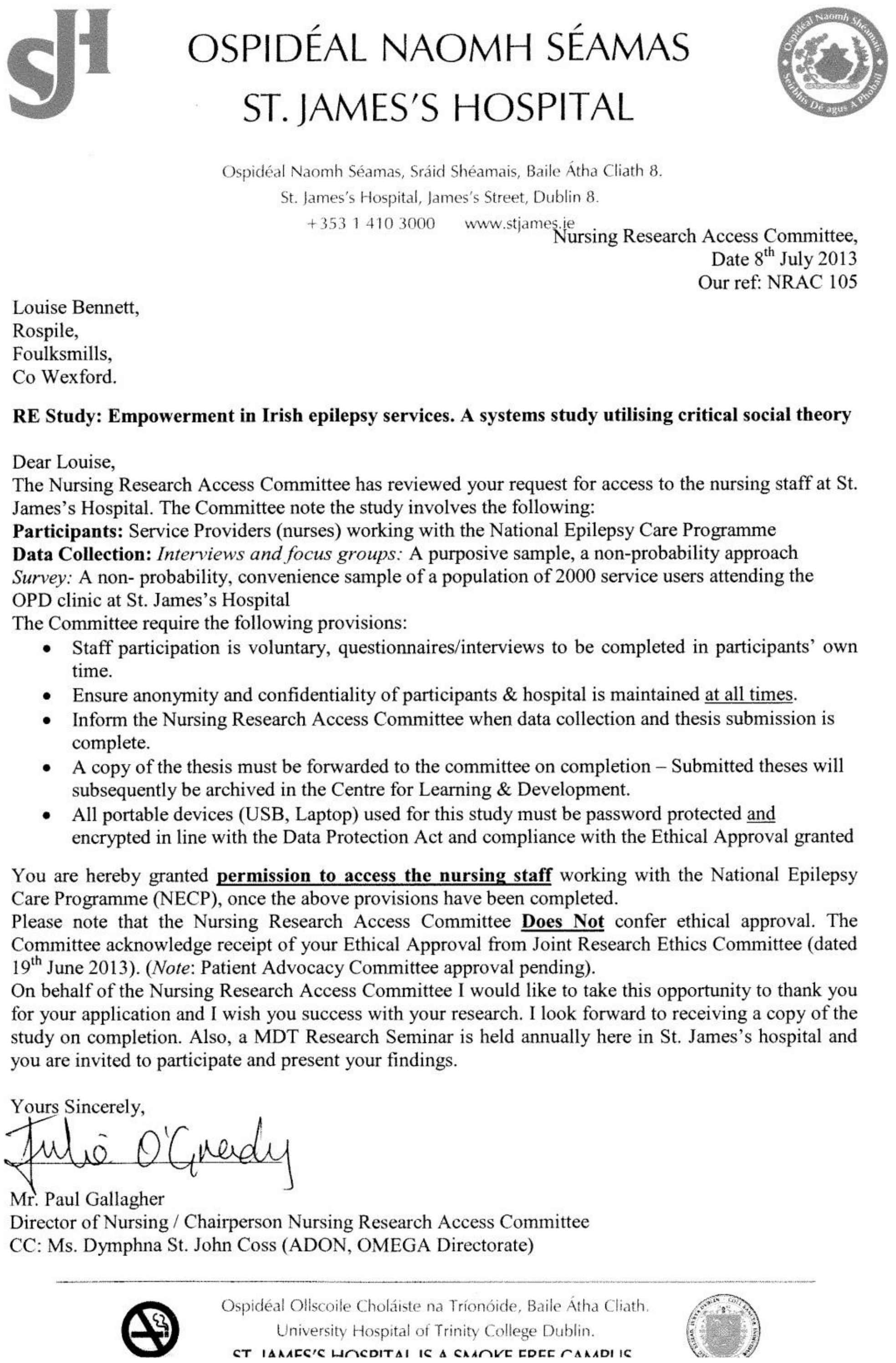
The Chairman has reviewed your study on behalf of the Ethics Committee and has given ethical approval.

Yours sincerely

Ms. Ursula Ryan
Secretary,
SJH/AMNCH Research Ethics Committee

135703001

Appendix E: Ethical Approval- Nursing Committee



OSPIDÉAL NAOMH SÉAMAS
ST. JAMES'S HOSPITAL

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Nursing Research Access Committee,
Date 8th July 2013
Our ref: NRAC 105

Louise Bennett,
Rospile,
Foulksmills,
Co Wexford.

RE Study: Empowerment in Irish epilepsy services. A systems study utilising critical social theory

Dear Louise,
The Nursing Research Access Committee has reviewed your request for access to the nursing staff at St. James's Hospital. The Committee note the study involves the following:
Participants: Service Providers (nurses) working with the National Epilepsy Care Programme
Data Collection: *Interviews and focus groups:* A purposive sample, a non-probability approach
Survey: A non- probability, convenience sample of a population of 2000 service users attending the OPD clinic at St. James's Hospital
The Committee require the following provisions:

- Staff participation is voluntary, questionnaires/interviews to be completed in participants' own time.
- Ensure anonymity and confidentiality of participants & hospital is maintained at all times.
- Inform the Nursing Research Access Committee when data collection and thesis submission is complete.
- A copy of the thesis must be forwarded to the committee on completion – Submitted theses will subsequently be archived in the Centre for Learning & Development.
- All portable devices (USB, Laptop) used for this study must be password protected and encrypted in line with the Data Protection Act and compliance with the Ethical Approval granted

You are hereby granted **permission to access the nursing staff** working with the National Epilepsy Care Programme (NECP), once the above provisions have been completed.
Please note that the Nursing Research Access Committee **Does Not** confer ethical approval. The Committee acknowledge receipt of your Ethical Approval from Joint Research Ethics Committee (dated 19th June 2013). (*Note*: Patient Advocacy Committee approval pending).
On behalf of the Nursing Research Access Committee I would like to take this opportunity to thank you for your application and I wish you success with your research. I look forward to receiving a copy of the study on completion. Also, a MDT Research Seminar is held annually here in St. James's hospital and you are invited to participate and present your findings.

Yours Sincerely,

pp Julie O'Grady

Mr. Paul Gallagher
Director of Nursing / Chairperson Nursing Research Access Committee
CC: Ms. Dymphna St. John Coss (ADON, OMEGA Directorate)

Ospidéal Ollscoile Choláiste na Tríonóide, Baile Átha Cliath.
University Hospital of Trinity College Dublin.
ST. JAMES'S HOSPITAL IS A SMOKE FREE CAMPUS

Appendix F: Patient Advocacy Committee Approval

Dear Louise,

The attached study has been approved by the PAC Committee.

Regards,

Hazel Kirwan (CEO Office) (on behalf of Carol Hickey)

Appendix G: Letters of invitation and information leaflets

Participation Information Leaflets-Interview

Participation Information Leaflet s for people with epilepsy

Louise Bennett,
Department of Nursing,
School of Health Science,
Waterford Institute of Technology

Title of study: Empowerment in Irish epilepsy services: A systems study utilising critical social theory.

My name is Louise Bennett. I am a Registered General Nurse undertaking a PhD study at the Department of Nursing, Waterford Institute of Technology. The aim of this research is to explore empowerment in epilepsy services. Empowerment is about 'having or taking more control over all aspects of your life'. The study has the potential to deliver an improved quality of care for patients with epilepsy who use epilepsy health services in Ireland and elsewhere.

To participate in this research study you must be 18 years or over with a diagnosis of epilepsy 1 year or more. Participating in this research is completely voluntary. Participation will involve completing a survey regarding patient satisfaction, preferences and information provision of epilepsy services in Ireland. All questionnaires will be anonymous. In addition you will be asked to participate in a one to one interview in the OPD clinic, at St. James's Hospital. All interviews will be digitally audio-recorded. The interview may last up to 45 minutes. The recording and transcripts of the interview will be stored in a locked cupboard in my office at Waterford Institute of Technology. All information transferred to a computer will be password protected. At no stage will your name appear on the interview tape or the transcript. Each recording and printed transcript will be given a number for identification purposes only. I will be the only person who knows these numbers and who you are. I will not disclose this information to anyone. When the research is completed all material will be destroyed. I will not inform anyone of your participation in the study.

Answering questions or talking can be difficult. You may choose not to answer any interview question and you can stop your participation in the research at any time. You may choose to take a break during the interview, withdraw during the interview or divide the interview in 2 parts.

In the event of any issues revealed during observation, or the interviews disclose unethical or malpractice behaviours, I have an ethical obligation to report such events. In anticipation of such events a consultant neurologist and senior advanced nurse practitioner will be identified within the research site to report such issues.
If you decide to participate now, you may change your mind and stop at any time. You will be given a copy of this document for your records and one copy will be kept with the study records. Be sure that questions you have about the study have been answered and that you understand what you are being asked to do.

If you have questions about this research you can contact Louise Bennett at lbennett@wit.ie or phone 0851252081/ 051 845593.

Participation Information Leaflet for service providers-Interview

Louise Bennett,
Department of Nursing,
School of Health Science,
Waterford Institute of Technology

Title of study: Empowerment in Irish epilepsy services: A systems study utilising critical social theory.

My name is Louise Bennett. I am a Registered General Nurse undertaking a PhD study at the Department of Nursing, Waterford Institute of Technology. The aim of this research is to explore empowerment in epilepsy services. Empowerment is about 'having or taking more control over all aspects of your life'. The study has the potential to deliver an improved quality of care for patients with epilepsy who use epilepsy health services in Ireland and elsewhere.

To participate in this research you must work within the epilepsy services of the HSE. Participating in this research is completely voluntary. If you agree to be part of the research study, you will be asked to participate in a one to one interview in the OPD clinic, at St. James's Hospital on two occasions. All interviews will be digitally audio- recorded. The interview may last between 30 and 60 minutes. The recording and transcripts of the interview will be stored in a locked cupboard in my office at Waterford Institute of Technology. All information transferred to a computer will be password protected. At no stage will your name appear on the interview tape or the transcript. Each recording and printed transcript will be given a number for identification purposes only. I will be the only person who knows these numbers and who you are. I will not disclose this information to anyone. When the research is completed all material will be destroyed. I will not inform anyone of your participation in the study.

Answering questions or talking can be difficult. You may choose not to answer any interview question and you can stop your participation in the research at any time. You can choose to take a break during the interview, withdraw during the interview or divide the interview in 2 parts.

In the event of any issues revealed during observation, or the interviews disclose unethical or malpractice behaviours, I have an ethical obligation to report such events. In anticipation of such events a consultant neurologist and senior advanced nurse practitioner will be identified within the research site to report such issues.

Even if you decide to participate now, you may change your mind and stop at any time. You will be given a copy of this document for your records and one copy will be kept with the study records. Be sure that questions you have about this study have been answered and that you understand what you are being asked to do.

If you have questions about this research you can contact Louise Bennett at lbennett@wit.ie or phone 0851252081/ 051 845593.

Participation Information Leaflet for service providers and people with epilepsy-Focus group

Louise Bennett,
Department of Nursing,
School of Health Science,
Waterford Institute of Technology

Title of study: Empowerment in Irish epilepsy services: A systems study utilising critical social theory.

My name is Louise Bennett and I am a lecturer and researcher currently undertaking a research study entitled 'Exploring empowerment in Irish epilepsy services' at Waterford Institute of Technology (WIT). Empowerment is about 'having or taking more control over all aspects of your life'. This study has the potential to deliver an improved quality of care for people with epilepsy who use epilepsy health services in Ireland and elsewhere.

The final phase of this research study involves conducting mixed focus groups of people with epilepsy and clinicians to identify changes and opportunities for improvements that may be required in the service to improve both people with epilepsy and clinician empowerment. A focus group interview is a method of gathering data in research and is made up of 6-8 participants. Within this focus group the results of both a survey of one hundred and two people with epilepsy in relation to epilepsy services in Ireland and interviews exploring people with epilepsy and clinicians views of empowerment will be presented and used as the starting point for the discussion.

Participation will take up approximately 60 minutes of your time. All participants in the group will have opportunities to contribute and this information will be treated as confidential by all involved. Your participation is completely voluntary and if you choose to participate you are free to withdraw your consent at any time without obligation to anyone.

Your identity will be strictly anonymous. Names or contact details will not appear in any report or publication. The recordings will be transcribed and stored in a laptop with the researcher's user name and password.

If you require any further information on this research study, please feel free to contact Louise Bennett at lbennett@wit.ie or by telephone at 051-845558.

Appendix H: Consent for interviews

Consent to participate in an interview for a research study

Title of study: Empowerment in Irish epilepsy services: systems study utilising critical social theory.

Principal researcher: Louise Bennett RGN, RNP, RNT, MSc, PG/Dip (Ed):

I give my consent to be included in the above study.

I understand that my participation in the study is voluntary and that I may withdraw at any stage. I give permission to be interviewed and for the interview to be tape recorded. The contents of the tapes will also be transcribed.

I understand that I may decline to answer any questions during the interview, and also, can request to have sections of the interview erased or that the total interview be not used for the purposes of the study. I understand that my identity will not be made known to anyone and that the principal researcher will be the only person with knowledge of my identity.

I understand that this research study has the hospital research ethics committee approval. I understand that in the event of any issues revealed during observation, or the interviews disclose unethical or malpractice behaviours, such events will be reported. I understand that a consultant neurologist and senior advanced nurse practitioner have been identified within the research site to report such issues.

I have received the information leaflet and any concerns or questions regarding the study have been addressed.

Signature of participant: ______________________________________

Signature of researcher: _______________________________________

Date: ____

Appendix I: Consent for focus group

Consent to participate in a focus group for a research study

Title of study: Empowerment in Irish epilepsy services: A systems study utilising critical social theory.

Principal researcher: Louise Bennett RGN, RNP, RNT, MSc, PG/Dip (Ed):

Title of study: Empowerment in Irish epilepsy services. A systems study utilising critical Social Theory.

My name is Louise Bennett. I am a Registered General Nurse undertaking a PhD study at the Department of Nursing, Waterford Institute of Technology. The aim of this research is to explore empowerment in epilepsy services. Empowerment is about 'having or taking more control over all aspects of your life'.

Participating in this research is completely voluntary. If you agree to be part of the research study, you will be asked to participate in a focus group at St. James's Hospital. The focus group will be digitally audio-recorded. Your participation is entirely up to you and you may withdraw from the research at any stage. The focus group may last between 30 and 60 minutes. All data collected will be secured in a locked filing cabinet in a locked room in the school of nursing at WIT. Data will be transferred on desktop PC and password protected. Only Ms Louise Bennett will have access to audio data.

Answering questions or talking can be difficult. You may choose not to answer any interview question and you can stop your participation in the research at any time. You can choose to take a break during the focus group, or withdraw during the focus group at any time. By signing this document, you are agreeing to be part of the study. Even if you decide to participate now, you may change your mind and stop at any time. You will be given a copy of this document for your records and one copy will be kept with the study records. Be sure that questions you have about this study have been answered and that you understand what you are being asked to do. If you have questions about this research you can contact Louise Bennett at lbennett@wit.ie or 0851252081/ 051 845593.

I have received the information leaflet and any concerns or questions regarding the study have been addressed

I agree to participate in the study.

Signature of participant Date

Signature of researcher Date

Appendix J: Seeking permission to use and adapt questionnaire by Poole *et al.* (2000)

Seeking permission to use and adapt questionnaire by Poole *et al.* (2000)

Louise Bennett,
School of Nursing,
Waterford Institute of Technology.
Email address: lbennett@wit.ie
Phone: 051 845593

Dear Dr Moran

I am presently undertaking a PhD at the School of Nursing in Waterford Institute of Technology. The aim of my study is to explore and analyse the epilepsy service as a system with reference to dimensions of empowerment using critical social theory.
I enjoyed reading your research study titled 'Patients perspectives on services for epilepsy: a survey of patient satisfaction, preferences and information provision in 2394 people with epilepsy'. This questionnaire would be very appropriate in meeting the objectives of my study.

I am writing to ask permission to use your questionnaire. I may need to amend it to the Irish setting where deemed appropriate if ok by you?

I would be very grateful,

Thanking you,

Yours sincerely

Louise Bennett.

Permission granted to use and adapt questionnaire by Poole *et al*. (2000)

Dear Louise,

Yes of course, no problem.

All authors have given their consent including Dr Poole, Dr Gail Bell, Prof Simon Shorvon, and Dr Juliet Solomon.

I do not have the questionnaire on record, however Gail Bell has a copy and it can be forwarded to your address.

Best wishes,

Nick Moran.

Appendix K: Adapted questionnaire

ST. JAMES'S HOSPIT
James's Street, Dublin 8

Epilepsy Service Questionnaire

Completing the Questionnaire

For each question tick clearly inside one box using a black or blue pen.

Please do not write your name or address anywhere on the questionnaire.

Your answers will be treated in confidence.

The first three questions are about the medicine you take for your epilepsy.

1. How well do you think the medicines you take control your attacks?

☐Very Well

☐Fairly Well

☐Not very well

☐Not at all well

2. Do you have any side- effects from your current medication?

☐None

☐Minor

☐Moderate

☐Severe

3. How many different medicines do you take for your epilepsy?

Number:_______________

Please list them:

____

____

____

____

Section 2: The following few questions are about services for epilepsy. First, some questions about visits to your family doctor's surgery (General Practitioner (GP) Health centre).

4. In the last **<u>12 months</u>**, how many times have you seen a doctor at the surgery **about your epilepsy?**

☐None ***(Please go to Section 3)***

☐Please write the number of times __________

5. Do you have regular appointments to see your GP about your epilepsy, or do you only go along when you have a particular problem because of it?

☐ I have regular appointments

☐ I only go when I have a problem

6. How easy do you find it to get an appointment when you need to see a GP about your epilepsy?

☐ Very easy

☐ Fairly easy

☐ Not very easy

☐ Not at all easy

7. How easy is it for you to see a GP as an emergency about your epilepsy?

☐ Very easy

☐ Fairly easy

☐ Not very easy

☐ Not at all easy

8. How easy do you find it to talk to your GP about your epilepsy?

☐ Very easy

☐ Fairly easy

☐ Not very easy

☐ Not at all easy

9. Do you feel your GP takes your views about your epilepsy into account?

☐ Most of the time

☐ Not enough

☐ Don't know

10. Overall, how satisfied are you with the care you have had from your GP for your epilepsy?

☐ Very satisfied
☐ Fairly satisfied
☐ Not very satisfied
☐ Not at all satisfied

Section 3: Next some questions about visits to the hospital.

11. **In the last 12 months**, how many times have you been to an outpatient clinic (Not accident and emergency/casualty) **because of your epilepsy?**

☐ None – please go to Question 17
☐ Please write the number of times

12. Thinking about the outpatient clinic you have been to most **in the last 12 months**, did you see the same doctor every time you went to the clinic? (Please tick only one answer)

☐ saw same doctor every time I went
☐ saw same doctor more often than not
☐ saw a number of different doctors
☐ only went to the clinic once

13. Do you have regular appointments to see a hospital doctor about your epilepsy?

☐ Yes
☐ No

14. How easy do you find it talk to the hospital doctors about your epilepsy?

☐ Very easy
☐ Fairly easy
☐ Not very easy
☐ Not at all easy

15. Do you feel the hospital doctors take your views about your epilepsy into account?

☐ Most of the time
☐ Not enough
☐ Don't know

16. Overall, how satisfied are you with the care you had from the hospital **for your epilepsy**?

☐ Very satisfied
☐ Fairly satisfied
☐ Not very satisfied
☐ Not at all satisfied

17. **In the last 12 months**, how many times have you been to a Casualty or Accident and Emergency Department **because of your epilepsy?**

☐ None
☐ Please state number of times _______

18. **In the last 12 months**, how many times have you been admitted to hospital overnight as an emergency **because of your epilepsy**?

☐ None

☐ Please state number of times _______

19. If you have stayed in hospital overnight, how many nights did you stay in last time **because of your epilepsy?**

Please write the number of nights ________

20. **In the last 12 months**, have you seen any of these people **about your epilepsy?**

	Yes	**No**	**Don't know**
Counsellor	☐	☐	☐
Psychologist / Psychiatrist	☐	☐	☐
Social Worker	☐	☐	☐

21. Have you **ever** had an EEG (a brain wave recording)?

☐ Yes

☐ No

☐ Don't know

22. Have you **ever** had an ambulatory EEG (an EEG recorder carried on your waist, allowing you to walk around during the recording)?

☐ Yes

☐ No

☐ Don't know

23. Have you **ever** had an EEG when you were videoed (video telemetry)?

☐ Yes

☐ No

☐ Don't know

24. Have you **ever** had a brain scan?

☐ Yes

☐ No

☐ Don't know

If yes, have you had a:

☐ CT scan (sometimes called a CAT scan)

☐ MRI scan (magnetic scan)

☐ Other (**please specify)**________

☐ Don't know

25. **In the last 12 months**, have you had a blood (or saliva) test to check your anti-epileptic drug levels?

☐ Yes

☐ No

☐ Don't know

26. Have you **ever** had brain surgery to help your epilepsy?

☐ Yes

☐ No

Section 4: Now some more general questions about epilepsy services

27. Which doctor(s) do you feel **mainly** looks after your epilepsy?

☐ GP
☐ Hospital doctor
☐ Both GP and hospital doctor equally
☐ Not sure
☐ Other doctor, please specify

28. Which doctor would you prefer to get all or most of your epilepsy care from?

☐ GP
☐ Hospital doctor
☐ Both GP and hospital doctor equally
☐ Not sure
☐ Other doctor, please specify
☐ Don't mind

29. If you prefer just one doctor, why would you prefer this one?

☐ the care is more personal
☐ the doctor knows more about epilepsy
☐ the doctor knows more about me / my history
☐ the doctor is more understanding
☐ it is easier for me to get there
☐ You get more time to discuss things fully
☐ You usually see the same doctor each time
☐ The doctor is easier to contact
☐ There are facilities for special tests
☐ Other – please specify

____

☐ Don't mind

30. Have you seen a specialist epilepsy nurse in **the last 12 months?**

☐ Yes
☐ No
☐ Don't know

If yes, do they help you cope with your epilepsy?

☐ Yes
☐ No
☐ Don't know

31. If you had to suggest ways in which your health care for epilepsy could be improved what would they be?

____
____
____
____

32. What **three** areas of your life have been most affected by your epilepsy?

____
____
____

33. Do you need more help in any of these areas?

☐ Yes
☐ No
☐ Don't know

If yes, please say what help you need

____
____
____

Section 5: Next some questions about what you have been told about epilepsy.

34. Have you been given any information about the following?

	Yes	No	Don’t know	Not applicable
a. What caused your epilepsy				
b. What type of epilepsy you have				
c. The chances of becoming free of epilepsy attacks				
d. Driving restrictions				
e. Potential risks of having epilepsy				
f. Potentially hazardous activities				
g. Job restrictions				
h. Side- effects of medication				
i. Free prescriptions				
j. Alcohol use				
k. Need for adequate sleep				
l. TV/ video games/flashing lights				
m. Voluntary groups				
n. Help from social services/allowances				

35. If you are a woman (men please go to question 36) were you told about:

	Yes	No	Don’t know	Not applicable
o. Problems with contraception				
p. Need for pre-pregnancy planning				
q. Folic acid before and during early pregnancy				
r. Risk to your unborn baby caused by medicines taken during pregnancy.				
s. Vitamin K in the last few weeks of pregnancy				
t. Safety considerations in looking after your baby				
u. Breast feeding				

36. Would you like more information about any of these areas listed in question 34 and 35?

☐ Yes

☐ No

☐ Don’t know

37. Where did you get most of your information about epilepsy and available services?
(**Please tick your three highest choices**)

☐ GP

☐ Hospital Doctor

☐ Community nurse / health visitor

☐ Hospital nurse

☐ Specialist epilepsy nurse

☐ Voluntary organizations (eg epilepsy charities)

☐ Literature (eg books, magazines, leaflets)

☐ Media (e.g. TV / Radio)

☐ Friends or Family

38. Do you feel you know enough about your condition?

☐ Yes

☐ No

☐ Don’t know

39. Do your close family / friends know what to do if you had an attack?

☐ Yes

☐ No

☐ Don’t know

40. Would you like to talk more to a health worker about your epilepsy?

☐ Yes

☐ No

If yes, who would you like to talk to? (**please tick up to three boxes**)

☐ GP

☐ Hospital doctor

☐ Community nurse / health visitor

☐ Hospital nurse

☐ Specialist epilepsy nurse

☐ Other

☐ Don’t know

Section 6: Only answer this next section if you were told you have epilepsy for the first time in the last 12 months. If you were not, please go to section 7

41. When you had your first attack, where did you first go for help?

☐ Your GP

☐ A& E/ Casualty

☐ Other (please specify)

42. Were you later referred to a hospital doctor for a full check-up of your epilepsy?

☐ Yes

☐ No

If no please go to section 7

If you answered yes, how many weeks did you have to wait for your appointment to see the hospital doctor?

____

43. Do you think the wait was reasonable?

☐ Yes

☐ No

☐ Don’t know

44. What type of specialist did you see? (**Please tick one box only**)

☐ Neurologist

☐ General Physician

☐ Psychiatrist

☐ Neurosurgeon

☐ Other (please specify)

☐ Don’t know

Section 7: Next a few general questions about you:

45. What type of epilepsy have you been told you have?

____

46. Are you?

☐ Male

☐ Female

47. In what year were you born?

19_____

48. How old were you when you had your first epileptic attack?

____

49. What is the highest level of qualification you have obtained?

☐ No formal qualifications

☐ Leaving Certificate

☐ College Degree

☐ Other

ANY OTHER COMMENTS

If there is anything else you would like to tell us about your epilepsy please do so here

THIS WILL HELP US TO HELP YOU

THANK YOU

Please check that you answered all the questions that apply to you.

Appendix L: Interview topic guide

Interview topic guide

Ground Mapping Questions (*non-specific and opening up the subject, minimal probing, service providers and service users can raise issues that are of most interest to them).*

a. What are your views in the provision of epilepsy care in the Irish health service?

Dimension Mapping Questions (used to focus more on particular issues).

a. As a service provider/service user what are your views/experiences in the provision of epilepsy care in the Irish health service with reference to the NECP?
b. As a service provider/service user what are the issues for you regarding the provision of epilepsy care?
c. As a service provider/service user what is your understanding of empowerment
d. Based upon responses to (a) and (b) focus is established.

Perspective-Widening Questions (more in-depth uncovering of issues*). Guided by the following list explore their views and issues with regard to empowerment and epilepsy service provision*

a. **Engagement and empowerment:** active participation; decision making; accessing appropriate care; resources; appointments (attendance and preparation); accessing care.
b. **Informed:** Knowledge and understanding of epilepsy (Diagnosis, symptoms, risks, side effects of medications); awareness of treatment options (risks and benefits); Awareness of available resources; voluntary organisations; information provision; education.
c. **Collaborative:** involvement in decision making (shared decision making); participatory role; communication; active listening; trust; respect.
d. **Committed:** adherence; motivation; setting goals; changing behaviors.
e. **Tolerance of uncertainty:** management of uncertainty; emotional needs-stigma; depression, anxiety; hope, positivity.

Finally

Tell me your thoughts/ views about the care you provide/receive?

As a service user/service provider what are the key issues for you?

As a service user/service provider what would you like to see changed?

Before finishing the interview is there anything you would like to say or add to what has been discussed

Appendix M: Focus group topic guide

Focus group topic guide

Introduction: Brief outline study; what is involved; anonymity; confidentiality and potential benefits of the study and present circumstances. Findings from Phase 1 and 2 to be relayed to group in order to obtain their views and perceptions.

Ground Mapping Questions: *(non-specific and opening up the subject, minimal probing, service providers and service users can raise issues that are of most interest to them).*
What are your views with regards to the results presented of phase 1 and 2 of this research study?

Dimension Mapping Questions *(used to focus more on particular issues).*
As a service provider/PWE what are your view with regards to the following issues identified from the results of phase 1 and 2 of this research study

- Organisational structure and epilepsy care provision
- Empowerment- Power and powerlessness
- Information provision and educational delivery
- Supports
- Communication

Based upon responses a focus is established.
Perspective-Widening Questions *(more in-depth uncovering of issues).*

Guided by the following list explore their views and issues with regard to

a. *Empowerment- Organisational structure and epilepsy care provision*

- Poor access to specialist care and investigations
- Unequal access to care for people with epilepsy in rural areas and prison
- Poor continuity of care
- Lengthy delays during and between hospital appointments.
- Lack of knowledge and confidence to manage epilepsy among General Practitioners (GP's)
- Poor collaboration with other services.
- Lack of resources; space; funding.
- Time constraints; busy workloads.
- Too much focus of epilepsy care provision is with regards to seizure management.
- Lack of an empowerment policy.

b. *Empowerment- Power and powerlessness*

- Not been treated as an equal by service providers.
- Equal partnership can vary between service providers
- Feelings of fear by people with epilepsy and service providers as a result of

poor interactions

- Paternalistic practices within the epilepsy service by both service providers and families/carers.
- Societal lack of understanding and empathy-social exclusion and fear of disclosure.
- ANPc's report conflict with the medical profession and nursing colleagues with regards to their advanced role within the service.

c. Empowerment and issues related to information provision and educational delivery

- Poor information provision and educational delivery-ad hoc delivery, not interactive, limitations of group education
- Bombarded by too much information at diagnosis
- Booklets alone are too generic, and information links on hospital website are limited
- Improvements are required in relation to sexual health for women with epilepsy
- Service providers acknowledged lack of resources and time constraints
- Health literacy is an issue for some people with epilepsy-Information that can be understood
- Chat group needed between people with epilepsy and mindfulness and stress management programs
- Improved interactions between service providers and people with epilepsy are acknowledged
- Many service providers acknowledged limitations in terms of their own education in how to educate people with a chronic illness and how to facilitate empowerment

d. Empowerment and issues related to support structures

- Lack of psychological, social and structural supports for people with epilepsy.
- Support provided by epilepsy Ireland is not utilised to its full potential-Lack of space and office within the service.
- Poor access and awareness to alternative strategies such as mindfulness programs, to help with anxiety, attention and concentration issues.
- People with epilepsy identified the need for peer support groups they would like to discuss epilepsy with so to discuss common problems or shared concerns.
- Due to stigma, prejudice, and societal lack of understanding-participants acknowledged that societal education is needed in order for people with epilepsy to live and work a normal life.
- Many contributions were made in relation to the negative effect managers have on service provider's experience of empowerment.
- ESN's struggle at times with the emerging role of the ANP within the service due to lack of support, poor interactions and lack of professional backup.
- Service providers identified that managerial and organisational support is required.

e. *Empowerment and issues of communication*

- Communication issues and barriers between all stakeholders within the service- not been listened too and acknowledged
- Improvements during interactions with people with epilepsy was acknowledged and the need for additional professional training
- Poor communication with other services such as Epilepsy Ireland, primary care, and GP's.
- Service providers identify that there are issues with communication within the service and with the voluntary service Epilepsy Ireland.
- Literacy issues.
- A Chronic Disease Management (CDM) program and Information Communication Technology (ICT) was considered important in enhancing communication and collaboration.

Are there ways that could improve on the issues?
And how do you envisage that this should be carried out?

Finally

Tell me your thoughts/ views about the results identified
As a service user/service provider what are the key issues for you?
As a service user/service provider what would you like to see changed?
Before finishing the interview is there anything you would like to say or add to what has been discussed

Appendix N: Example of Transcripts from one-to one interviews

Person with Epilepsy (PWEm1)

Researcher: ***What are your views in the provision of epilepsy care in the Irish health service?***

I think waiting times are too long. A 6 month or 1 year wait is too long between visits. It can't be helped here really as there are very few consultant neurologists.

Researcher: ***As a service user what are your views/experiences in the provision of epilepsy care in the Irish health service with reference to the NECP? As a service user what are the issues for you regarding the provision of epilepsy care?***

Care could be improved with basic questions between patients and ESN's. Patients don't always have to see a doctor. A 6 month or one year wait is too long between visits. In this time patients could be having seizures or medications may not be working out. I have seen my GP but he can't change the medications that I am on. Medications need to be changed by a neurologist.

Researcher: ***As a service user what is your understanding of empowerment?***

Empowerment means having strength in yourself. I don't think I'm empowered. I don't feel very strong. I'm not a big person, although I have gained a lot in the last few months.

Researcher: ***How do you manage uncertainty and how does it affect your level of empowerment?***

There were a few issues when people found out that I had epilepsy. I got a bit of hassle and I try and not tell anyone. I try and keep it a secret. This is one of the main issues for me. There is still very much a 'stigma' attached to epilepsy. People have misinformation about epilepsy and view it as a weakness especially in employment. There not supposed to be prejudice against you but they will employ someone else over you and they still view it as a liability. I have spoken to other people with epilepsy that have dealt with these issues.

Researcher: ***In terms of your own engagement are you actively involved in your own care?***

I have had epilepsy since I was eleven years old. My epilepsy has changed over time. Overall I have left my epilepsy in the hands of neurologists and I have not seen outside counsellors or support from others. The first specialist I seen put me on a medication and it made me suicidal and it went on for years. Although I told him this it wasn't really sorted out. There are improvements needed in terms of listening to patients.

There is definitely room for improvements such as outside supports and care support. For example, anybody that has children with epilepsy, disability resources have been cut. Special needs assistants have been cut by one third so this needs to be improved and in patient liaison with families and hospitals. It's all down to budget. Epilepsy Ireland is brilliant and I have worked with them.

Researcher: ***Do you feel involved in your care and listened too?***

It surprises me how much the doctors and nurses respect me. I respect them but it varies. The older doctors are nice enough. The student doctors have a ‘god’ complex, but it will work its way out of them. I mostly trust my doctors and I feel if there is something wrong I will tell them. Their response to this has improved. There is small links provided by St James's Hospital website but there not generally very good. I feel generally ok at the moment and where I am going. I feel under control at the moment but in relation to other people I'm unsure.

Researcher: ***Do you feel you are fully informed and have adequate knowledge and understanding of epilepsy?***

Information provision-I know enough to get me by, but not as much as I would like. When I come to appointments it’s mostly about medications but I haven’t received much information regarding side effects and what these medications are going to do to my body and my future. I find information about epilepsy from the internet. The older generation would be at a loss here.

Researcher: ***Do you feel motivated in terms of setting goals?***

My epilepsy is under control and I have plans for the future. However I’d like to have more social skills and leadership skills and be able to take control.

Researcher: ***Tell me your thoughts/ views about the care you receive? As a service user what are the key issues for you?***

My own doctor asked me what plan I wanted and how I felt on the current medication that I was on and how did I think it would want to be changed. This surprised me because nobody ever asked me this and it made me feel very empowered. I felt confident and listed too.

However, I felt very frustrated a couple of years before this from a previous doctor when I was just trying to tell him that the medication wasn’t working for me and he did not listen and just continued me on this medication. I have a very good relationship with doctors and nurses when I do see them. I don’t feel I would make a complaint however I don’t feel anything would be done if I made a complaint.

Researcher: ***As a service userwhat are the key issues with regards to empowerment and what would you like to see changed?***

In the current service there are many more examples of empowerment been promoted than dis-empowerment. However, several times I just feel there is a checklist and you are just pushed out the door and you don’t get time to get the information that you require. I can understand this but you don’t get a chance or time to say things that you need to say. Empowerment means to be able to take control of oneself and lead others and basically not to be submissive. Being empowered means that I was able to make better decisions for my own epilepsy and my own treatment and that turned out well until several changes happened. If I had been able to see a doctor sooner this could have changed this. I am starting college again this month and epilepsy does not affect college. People who suffer from any neurological or mental disability will often lack confidence because they will feel they won’t be mentally capable or believable to lodge a complaint. They will leave decisions in the hands of others.

Researcher: ***Before finishing this interview is there anything you would like to say or add to what has been discussed?***

No

Service provider transcript of one-to-one interview(SPf1)

Researcher: ***What are your views in the provision of epilepsy care in the Irish health service?***

The service I work in I think is a very good service with very fair quick and easy access and very thoughtful and caring team with regards epilepsy patients. We are trying to improve the service all the time. We aim for 70% of referrals to be seen within 4-6 weeks and we are achieving this and now we are trying to aim for 100%.

Researcher: ***As a service provider what are your views/experiences in the provision of epilepsy care in the Irish health service with reference to the NECP? What are the issues for you regarding the provision of epilepsy care?***

We do provide individual educational sessions but now we come to the conclusion that group educational sessions would be also very welcome and we have a very good example. We did have one group session with men and we are now setting up women group sessions.

I think that certainly in this service PWE can make decisions and it is accepted. If we think that the patient's decision is inappropriate, we try and explain and probably give more information, and give the pro's and con's. At the end of the day we do tell them that they have the right to decide themselves and chose and we do certainly empower them to choose for themselves.

Tackling psychosocial issues is a problem. We don't have enough social workers to attend the clinic and maybe try to help patients with social issues, and certainly we don't have any psychological support in the clinic. We don't have a reliable referring system to this service. Could be a lack of interest of the psychology speciality to attend this particular clinic or maybe this hasn't been looked into.

We are very constrained in the clinic in terms of time so there is only a certain amount of time that you can spend with patients in the clinic and you try to go through all the issues, and the most important issues would be seizure activity, number of seizures, and how the patient is responding to treatment, side effects of treatment and then you have less time to address women health issues but we try and do the basic stuff like folic acid, and women that are in childbearing range and am addressing the contraception, interaction with medications, and maybe touch on breast feeding, but we do not have enough time to address all issues within the clinic.

Some of these patients that who are not in the service yet, may not be aware that there is a specialist service dedicated for epilepsy and they may not be aware that a dedicated service can provide more care and more focused and targeted care for these patients.

I think probably for these patients a lack of information that these services exist and that these services provide good care, and that services can look after their medications, and if their epilepsy is not been controlled for many years they may not be aware that new medications can provide good control over these seizures. I think these are the main issues and concerns

I know certainly that the staffing issue are arising now and because the services are bigger and we have a greater number of patients, new patients, new referrals. I understand from the team and I certainly know that there are concerns about the nursing staff, so yes staffing is an issue.

Researcher: ***As a service provider/service user what is your understanding of empowerment?***

Having good control over personal health and social and economic life is having a good empowerment over your life. An empowered person would be autonomous in his/her work, a competent specialist, assertive, respected by the team and by the patients.

Being empowered and been able to make decisions mean to give a good quality of service. It means to empower your patient to look after their health, look after their medication and I certainly encourage our patients not to be shy and not wait for their next appointment but I do give them contact details. I always tell them their health is in their hands so therefore they have to look after themselves as well as us. They have to know what medications they are taking, the dose that they are taking, side effects of their medication, to be aware they exist and if they do have any side effects to call us immediately and not wait for their next appointment. I always tell them not to be shy and pick up the phone and insist on talking to one of us'.

I think an empowered person is Autonomous in his/her work, a competent specialist, assertive. I think an empowered person is respected by the team and by the patients. I feel autonomous and respected. There is mutual respect. I feel empowered and have personal power.'

There are gaps in communication certainly as they are everywhere else. It's a human factor. Isn't it? Too have gaps in communication? It is something that we are looking at the moment in the clinic, in the service and finding out where there is communication break-down. The way our staff nurses have their schedule sometimes there is overlap and they are able to hand over certain issues that have to be discussed with us but sometimes there is a lot of overlap and they change. It's hard to explain you have to be aware.

Researcher: ***Do you feel that you participate within the service and how does this affect your level of empowerment***

The epilepsy care service has a business meeting every Wednesday and every week we discuss issues and any breakdown in communication, or any issues. We try to improve the service and try to find out where the mistakes and how to avoid it.

I am always provided with the opportunities to do research here and audits and the staff is very supportive of it and I certainly do think that there are loads of opportunities and learning possibilities here. My opinion is always listened to and people are always looking for my opinion.

Since I started this service I am running 2 rapid access clinics and there was always a problem that the clinic was running late and I had to do other jobs. So I was given the opportunity /option of changing the time of the clinic so I chose to start a bit earlier so I was listened to, nobody had any objection and the appointments were made earlier to meet my needs. Another example is that we mapped the process of getting the referrals into our service and to what is happening to the referral up until the first visit in the rapid access clinic of the patient. I don't actually participate within that process. My first encounter in the rapid access clinic was when I was invited to that meeting and my opinion was asked on how to avoid some of the blocks in this process and I was listened too.

Researcher: ***Is there any example that you can give me that has inhibited your experience of empowerment?***

I would say bleeps, been interrupted during the clinics or during my job and been distracted has been disempowering. This is my main issue. I have been trying very hard, emailing and calling and there was no change. I felt very frustrated. I kept been distracted. I did discuss with HR and switch board and they kept referring me one to another. It is more like an organisational issue. It has nothing to do with care providers. Every time I brought my issue to management everyone seemed to be nice and helpful but the problem wasn't solved anyway.

Researcher: ***Tell me your thoughts/ views about the care you provide? As a service provider what are the key issues for you in relation to empowerment and what would you like to see changed?***

My level of empowerment effects how I empower people with epilepsy because there is probably nothing better for a patient with epilepsy to have a confident staff that is discussing all issues, and encouraging the patient to look after themselves and not let it slip out of their hands and to keep looking for help if it is needed.

Low levels of empowerment for PWE are from the stigma of epilepsy and probably social issues outside the hospital.

Within the epilepsy service we always advocate that this is a chronic illness and like other illnesses they have to live their lives as normal as possible and a diagnosis of epilepsy does not mean they have to stop working or living a normal life so I think it is a huge community issue rather than a service issue.

I never had information on empowering epilepsy patients but I have witnessed it. When I go with the consultant and see the patients. So it's not a one to one day or a dedicated study day, or dedicated course but watching your consultant (empower) doing that is probably more valuable. I think we could do with say a 3 hour course on how to empower our patients and how to encourage them to take ownership of their disease and condition would be certainly welcomed.

Researcher: ***Before finishing this interview is there anything you would like to say or add to what has been discussed?***

No

Appendix O: Focus group transcript

Researcher: *What are your views with regards to the results presented of phase 1 and 2 of this research study? Tell me your thoughts/ views about the results identified***?** *As a service user/service provider what are the key issues for you? As a service user/service provider what would you like to see changed?*

PWE 1F: I don't agree with the drugs, the epilepsy drugs and I can't understand how the medical marijuana has not been brought in or introduced. Although it gives a judgemental impairment and co-ordination issues, I'm on Epilim chromo and there are 2 lists of side effects that are possible and I can't understand how families can be broke up such as that girl in Cork, that 4 year old child that had to move to Oklahoma and I can't understand why the medical Marjuana isn't brought in.

PWE 3M: I couldn't agree with you more to be quite honest. I have been on 4 different types of medications for epilepsy and I seem to be the one that gets all the side effects.

PWE 1F: I'm the same ya.

PWE 3M: I totally agree it should be brought in. It's called CBD and I have been medicating myself with that for the past couple of months and my seizures have severely dropped. Especially when you are getting used to a medication, they go and change the medication and up the medication and the hospital is telling you it's going to take so long to kick into your system and that you have to give it a chance and when you go through all the hard part and give it a chance, bed ridden for a couple of days because of the medications, then they tell you ok we're going to change your dosage or were going to change that around just when you start to feel normal and you know that the medication is starting to work for you, they go and change it and that causes serious amounts of frustration for me personally.

Researcher: *So is that disempowering for you?*

PWE 3M: Yes and each time I have an appointment to come to the epilepsy clinic, its cancelled, not due to you guys ('*looks at the service providers'*) but due to work going on in the hospital or something like that and therefore I'm left for another 6 months with all these questions building up. In the meantime I end up in the A&E with a busted lip, head or face so I don't know why this (CBD) isn't legalised. It's legalised in one shop in town but it should be legalised right across, especially with people that have this problem because we don't know when it's going to happen.

PWE 1F: For MS patients and Parkinson's patients as well, it should be legalised. MS patients have tremors as well. I have researched into this massively and I can't understand how it's not (apart from the money situation) I can't understand how it's not legalised.

Researcher: *Are there ways that could improve this issue? And how do you envisage that this should be carried out?*

SP 4 M: At one level it's very simple, you know it's certainly a safe drug for adults, for children however there are other issues. A lot of the doctors are not aware of the research around it and they are afraid of being asked to prescribe it which has been called illegal to be prescribed to children. My feeling is that and I know that this is frustrating slow but I am actually going to the Oireachtas tomorrow to present a paper around it, a framework around it for allowing this drug to be prescribed, but it's probably going to take a year.

PWE 1F: That would be brilliant.

SP 4 M: There is no other country in the world that has legalised this drug for medical use. You know there are countries where cannabis is legal like Colorado that everyone can take for just like recreational use but there is no country in the world other than Australia that actually have a framework for prescribing this drug to Children so we will be the really only the second country in the world to do it.

PWE 3M: It's called Charlotte's web.

SP 4 M: So ya its very complicated and there is going to be I mean, I'm part of a wider group that's looking at getting it in but the key challenge is that not that people like me know a lot about this are convinced by it, the problem is to bring the whole medical profession on board, which can be frightening and rightly so, you are asking the medical profession to prescribe. Are you prescribing yourself and supplementing your treatment?[looks at PWE 3M?].

PWE 3M: I have been prescribing myself over 6 months.

SP4M: To a certain extent that's fine with me, that is your decision but asking a doctor to do out a prescription is a complicated thing.

PWE 1F/ PWE 3M: Oh ya: I totally understand.

SP 4 M: Anyway getting back to the point and you know it's a very interesting point about that you feel you have a lack of empowerment in that you know that this has the potential to be useful to you and you are asking it to be prescribed and yet it's not been prescribed. I think that this is a disempowering thing but all I can say is that there will be progress made and that the natural flow of things –legal things are slow. Actually Charlotte's web is illegal.

PWE 3M: I have been in contact with him and he served over 18 months in America for a girl that was taking over 60 seizures a day. She went from having so many seizures a day to learn how to get an education. I understand that it is totally illegal and I do get that, 100% but I'm on Limictal at the moment and they have me on Buccal diazepam injections and I was waking up and my girlfriend has to administer an injection, so it feels degrading to me personally. The limictal is working but all of a sudden my GP turns around and says you have to go from 200-300mgs. That means I will be taking 600mgs a day. Before I was diagnosed with epilepsy I was a very active person, now I Just….

SP4M: Is the GP making that decision based on what? Is he consulting with us?

PWE 3M: He has been consulting with my pharmacist.

SP4M: Right

PWE 4M: Sounds like a chink in the chain? [looks at SP4M and PWE 3 M].

PWE 3M:I'm left every 2 weeks when I go to get my prescription, going hang on a minute I was on this 2 weeks ago and now they want me on this.

SP4M: And you haven't been speaking to us about all these changes?

PWE 3M:I have told my GP and the pharmacist that I'd be here today and I wasn't willing to up any medication or go any further until I spoke to yourselves. That's what makes me feel that they have the decision over me like.

Researcher: *These issues have been identified in the study, a lack of confidence in the GP's ability. Are there ways that this could be improved?And how do you envisage that this should be carried out?*

SP4M: Usually what happens is that the GP goes 'I'm not making any changes [all service providers agree] and that's a more common problem that we have.

PWE 3M: Can I ask a question? If I'm given a prescription from SJH and its put on a prescription that it is SJH can my GP change that?

SP4M: Well he has to

PWE 4M: It leaves me kind of confused.

SP4M: Have you a medical card?

PWE 3M: Ya

SP4 M: He has to put it on the medical card that's the law.

PWE 3 M: But has he the power for argument sake to remove or change medication.

SP4M: Yes he does have the power, but whether he should or not is an interesting question. I mean why is he doing it?

PWE 3 M: I'm totally against it, I can go three weeks, perfect, healthy and then I walk up the stairs and…….

SP1F: Have you asked him why he takes it off? Is it an error? Does he think that you don't need it?

PWE 3 M: He reckons I'm taking it on a regular basis whether it's one a month, or whether its 2 weeks between the month, so he's like why do you need it when you don't need it then?

SP4M: So he doesn't understand why we prescribe it?

SP4M/SP1F: That is very frustrating

PWE 3 M: Ya and I am trying to explain to him that I'm very healthy. I'm grand other than but when I need it, I need it. I am not the one that has put it on the prescription this hasn't come from me like.

SP4M: He does understand

PWE 3 M: I think it's very embarrassing to be perfectly honest because my girlfriend has to administer it and she has to see me in the way I am, that's why I don't understand what is going on between the GP and the doctor.

SP4M: Ya

PWE 3 M: That's where I'm confused and I feel disempowered because if I go and argue that this issue to one or the other, the other will take each other's side so I can't really argue and I won't get any medication at all and I will get worse then.

SP1F: And in any part of that conversation did the GP say let's talk to SJH?

PWE 3 M: Ya they said they would get on to epilepsy clinic and they will sort all that and do the paperwork. I'm up with my GP once a week looking for all of this looking for proof all the time.

SP1F: Ok

PWE 3 M: My girlfriend has given up work to look after me full time. I'm grand one minute, not grand the next and its more frustrating than anything else.

SP3F: Is it better to get weekly prescriptions?

PWE 3 M: I don't understand it myself.

SP2F: You don't get a monthly script?

PWE 3 M: No I know my plan is I should go up every 2 weeks. This has all been explained to me by yourselves but then you go home, hand in a prescription that I know is from the hospital, for the month, for whatever medications and then when I go and collect that 2 weeks later there a few things removed on it.

Researcher*: Are there ways that could improve on the issues? And how do you envisage that this should be carried out?*

SP4M: The usual problem is say that the community care services including the pharmacist and your GP is that they don't want to do anything they don't want to change anything even when they should like sometimes when someone has difficult contacting us, it might be we wrote the prescription the wrong way or the dose is too high or something, obviously we want people to use common sense and for the GP to say actually they have written that wrong and make a judgement and change the prescription but usually they don't. When they see a script from us and because it's a complex area they don't change it.

PWE M3: And that's what I always thought, they don't want to do that and mess with the neurology part.

SP4M: These guys are doing active stuff with your prescription?

PWE M3: It's when I go to collect my prescription it's a different prescription. I've gone on 4 different medications because of them. At one stage I just thought they were testing me out on different medications to see what my reaction was.

SP1F: And do you have your medication list with you.

PWE M3: I think my partner has them. I know that I am on buccal diazepam which I don't agree with. Limictal 200mgs a day and some other small tablet, that I don't agree with either (it makes me drowsy) and all that type of stuff.

SP4M: My immediate thoughts are when you have a poor interaction with your primary care services either pharmacy or GP, that's why we have a phone line here, it's not open 24/7, there is specific times that it is open.

PWE 3M: I understand that.

SP4M: But we will always get back to you and we will talk to your GP in the meantime and we will try and come up with a solution.

PWE 3M: I am happy I on the Limictal. I know that my seizures have dropped dramatically since I went on the Limictal and I started on the 50mg and I said to myself I am not going over 50mg because of liver complications but know that I know it's working there [GP] trying to change it and trying to supplement it with some other tablet.

SP4M: Can I ask, [looking at PWE 3M]. I will talk to you later specifically about that and how to resolve it but can I ask everybody a wider question-Does everyone have Discilium?

PWE 1F: I find epilium chromo makes me very slow.

PWE 3M: Your reaction?

PWE 1F: My reactions, speech, everything even when I talk to people I get my words mixed up. I feel they don't. I don't feel 100%. I am not myself and I just don't like them at all.

SP4M: And have you explored during your visits trying something else?

PWE 1F: I have tried 2 other tablets and they didn't agree with me but Epilium Chromo controls my seizures but I know I am them too long, although they are controlling my seizures.

SP4M: So if CBD oil was available you would?

PWE 1F: By far and I am anti-drug but by far I would agree with it. If it was available I would definitely take it.

Researcher: *Are there ways that could improve on the issues? And how do you envisage that this should be carried out?*

PWE 3M: I think the problem with the GP is that they do not sit the patient down and say how is this medication working for you, how do you feel on this medication. I think that is half the battle. That is the GP's job to sit you down and see how you think this is performing for you. I mean they put me on Keppra which meant 3 weeks in bed. The doctor never made a phone call to see if it had agreed, do you like it, or does it have a drowsy effect. I think they should follow up and see what effects the medication has if they do change your medications.

PWE 4M: Do you think the GP would do that thou? I have never had any contact with the GP. It's just being [SP4M] and the gang here.

PWE 3 M: I don't think there is much contact with me and the GP but I do think that at least when you do go down to get your prescription or check-up that at least ask how you are and how the medication is working for you or how do you feel on it?

PWE 4M: It has not happened to me in about 40 years of having epilepsy and I don't think it's going to change.

SP2F: I think for me as a practitioner if I was trying to change something, time and time again we come up with errors on prescriptions something has happened from what has been prescribed in the clinic from what the person ends up taking- something happens. And one of the explanations might be that our hospital prescriptions has to be prescribed on to the medical card prescription and I know myself I had to get prescriptions done, repeat prescriptions and I certainly don't see the GP and don't expect to see the GP but I am not sure that my most up to date prescription is the one that is rewritten every time unless I change or check to make sure. So for me as a practitioner I would just love to be able to write the general prescription for PWE but that it doesn't need to be transcribed – to try and take that out but I don't know how we would do that but if was just the script that we wrote in the clinic that was the one that you brought to the pharmacy as opposed to being the middle piece because our letter always goes to the GP to tell them what you are on but this transcribing seems to be causing problems.

SP 3 F: And we always spend a lot of time writing doses, schedules and is very specific.

SP2F: And they are quite difficult to understand.

Researcher: *How can we find a resolution to this?*

SP2F: Once the patients are stable and for repeat prescriptions there is no change, then ideally they would go back to their GP and have that conversation with their GP.

Researcher: *And if this doesn't work*?

SP1F: And we have talked about this as a group in particular GP' s that we work very closely with to empower them maybe to take on more effective care within the community.

SP 3 F: There is a whole education around that because there are generally trained in paeds, obs, gynae…

Researcher: *Are there ways that could improve on the issues? And how do you envisage that this should be carried out? Is more training required?*

SP4M: I am not optimistic about that

Researcher: *What role are ANP's going to play in the future of epilepsy health care?*

SP1F: We forsee that we would work more with the GP's and be the link with the GP's and PWE but at the moment we are tied to more clinical stuff with SJH day to day running of the service, resources but it's not just that its every part of the community work differently. We are not all running off the same hymn sheet and that's a big task to take on trying to do something the same way and then when a GP needs an answer he now where to go and who to go to.

SP4M: I suppose looking back over the few years its striking how few GP's ask us for advice on the phone.

All service providers: Agree

SP4M: You [PWE 3M] can contact us in the future if you have issues and we are happy to deal with them, we get a lot of phone calls and emails. I think you use emails a lot but it's remarkable how few GP's will call us. We do send them [GP's] letters and our contact details are on the letters.

SP3M My confusing part is surely the GP can pick up the phone?

SP4M: Ya Ya

SP3M: That will sort my prescription and I don't have to be bothering you and other people with worse conditions that can be helped.

Researcher: *And you are asking him to do that?*

SP3M: Pretty much. Like this injection I feel terrible when I do come too and my girlfriend has administered the injection. I feel terrible because I know I couldn't pull through on my own, I never needed them until I was prescribed them. I feel I could still do without them. I would just like all medications sorted.

SP4M: Can I ask a question? I think that this is very interesting. When you are in your clinic visit say you are in seeing me or one of the girls have you said this before?

PWE3M: Yes

SP4M And what kind of reaction did you get?

PWE3M :I have always got like oh we will take care of that and we will send a letter to your GP and I get just pissed off with my last GP that I changed my GP.

SP4M: So sorry, yes were saying sorry we understand you.

PWE3M: Ya, it's no problem. And the last time I was here you changed the Limictal and I met a very nice doctor and he explained everything to me and sat me down.

SP4M: I am delighted that you had this conversation.

PWE3M: Yes I did, the best conversation I have had since I was diagnosed and to be honest I don't think I would have tried that medication if that guy hadn't explained it so well.

SP4M: We would love to give that service to everyone. We probably have 2500 patients… we probably could give one good conversation with everyone but it would mean that all other interactions would necessarily be short if we are going to see everyone. It's very frustrating because there is so much need out there.

SF 3 F: And that's before we look at emergencies.

SP4M: How can we fix it? How can we have a good conversation with everyone? Does everyone feel they have had a good conversation?

PWE 1F: I have asked to see you after today. I find I got in this hospital even though it is a good hospital I feel I did get mixed reviews. I was completely confused. I came up here on the 18th June 2014 and everything I was told in that session was completely different than the following year when I saw you. I mean everything such as driving and that was in the epilepsy clinic. I saw two different people and they gave me two completely different…. it was very confusing and caused me a lot of anxiety. It nearly pulled me back a bit more because I wasn't expecting it.

SP4M: I am wondering would it help if you had a copy of the letter for you-yourself and the GP would get the same letter?

All PWE –All nodded and agreed

SP4M: There is a lot of technical language that the GP's would be used to getting.

PWE 4 M: In this day of age technical language is easy overcome.

SP4M: At the very least you will have an exact of what has been decided.

SP2F: You know what was said.

SP4M: Do you think that would be helpful?

PWE 1F: I do think as I know I go out very confused and you come out forgetting half the stuff the doctor said.

Researcher: *Results of this study acknowledged that PWE would like to see the same service provider at each visit. Are there ways that you could improve on this? And how do you envisage that this should be carried out?*

SP4M: We try and do that and we plan when the clinic is coming up and have a certain amount of clinicians and we try and allocate the person to the same clinician but it does not always work because of holidays, people are away. We did talk about people having their own patient list but I guess there is a lot of organising around this because if you are not coming back till next year. SP1F needs to know that she is not taking holidays that week and that you are not taking holidays that week and that is your one yearly visit and you wanted to see that doctor and now I am going to see somebody else and I am going to get a different story from them.

PWE 1F: Do you have to say to an employer that you have epilepsy because on your CV they want to know if you have any medical background? I am a hairdresser and I asked an employer if you were interviewed two people with a job with the same qualification and experience and one person had epilepsy who would you employ. And she said I know it's against the law but I would employ the person that didn't have epilepsy. Do you have to say that?

SP1F: And do you agree with her?

PWE 1F: I do agree with her

SP4M: You need to tell an employer if you are going to do a job that will put other people at risk, but hairdressing wouldn't and I wouldn't say it.

PWE 2 F: I went to an open interview and the person giving out the forms said this is the criteria for filling out the application form and if anyone has epilepsy put it on the form.

SP4M: I can tell you why they said that, it is an insurance thing that if you had a seizure they would be liable. The point is if you don't tell them then they are not liable.

PWE 3M: It's like in any gym in the country if you have epilepsy you are not allowed in.

SP4M: Well don't tell them!!!

PWE 3M: Well if something happens when you are in the gym?

SP4M: Ya so what. There is no legal recourse. They can't sue you it just means that you can't sue them. If you have a seizure and bang your head it's all on you.

PWE 2 F: Well in my case I was in a job for 14 years and they found out I had epilepsy and they conveniently made redundant when I was due to go back to work.

SP4M: They should be sued for that.

PWE 2 F: Well I sought advice about the matter, the way they had it worded, they said they didn't need me when I came back that they split my workload amongst the other staff.

Researcher: *Are there ways that could improve on this issue? And how do you envisage that this should be carried out?*

SP1F: I would say go to Epilepsy Ireland with this type of complaint.

PWE 2F: I did go and they just said that you need to seek legal advice.
SP1F: And did you seek legal advice?

PWE 2F: Yes and they said I was entitled to standard redundancy and this is what it should be.

SP4M: And unfortunately that is one of the bias and there is nothing you can do.

Researcher: *And is there anything as a group that we can suggest that we can do about this?*

PWE 2 F: I am facing obstacles like declaring that I have epilepsy at job interviews.

SP4M: I wouldn't say it!!

PWE 2 F: Then would anything happen?

Researcher: *What about societal awareness. Is there any change needed here within society?*

PWE 3M: I would have no problem explaining to children.

PWE 1F: I think teachers should be made more aware. I got suspended more times over partial seizures.

PWE 2 M: It's extremely embarrassing. I have been to several places and took seizures and I have never gone back like in friends' houses.

PWE 2 F: I am the same. My first big seizure was in my place of work. I was friendly with this woman in work and she seen me and seemingly I went bizark after the seizure. I was giving out to the ambulance driver but of course I wasn't diagnosed. I didn't know what happened but when I was diagnosed I was so embarrassed when I saw the same lady she doesn't look at me and I feel awkward as well.

Researcher: *Results of this study also highlighted the lack of psychosocial supports within the service for PWE. Are there ways that could improve this issue? And how do you envisage that this should be carried out?*

PWE 2 F: I did look at mindfulness, I would like to try it and I have read up about it. I just feel I am coming to terms with everything but I'm so angry. Why did that happen? There is a lot of anger and confusion and the medication and the side effects and I get terrible headaches and when I said to the doctor I get headaches she said that's not too bad there is worse side effects but when I get these headaches there literally blinding. I just want to curl up in a ball in a dark room.

PWE 3 M: Nodding.

PWE 2 F: Where do you get help? Do you just get on with it? Tough… because the GP says is not a major side effect.

Researcher: *Poor access and awareness to alternative strategies such as mindfulness programs, to help with anxiety, attention and concentration issues for PWE was acknowledged in this study. In addition, lack of resources, space, and funding was also highlighted. Are there ways that could improve on the issues? And how do you envisage that this should be carried out*?

PWE 2 F: Well I have attended a couple with Epilepsy Ireland and I actually didn't find them great. Information was very generalised such as there is so many different types of epilepsy, this is children's epilepsy, medications, it wasn't helpful.

SP1F: What would you want to hear?

PWE 2 F: I would want to hear about other people with their experiences, how they coped and how they came to terms with it. How they coped with situations for themselves like looking for a job and things like that and techniques if you are feeling down, things like that.

SP4M: It would make more sense coming from other people.

PWE 2 F: I think so rather than, it was a bit of a washout, not that some of the information was useful but I was geared to the one thing and there said there was going to be a question and answer session but their wasn't.

Researcher: *People with epilepsy identified the need for peer support groups they would like to discuss epilepsy with so to discuss common problems or shared concerns. What about a patient group?*

PWE 2 F: Yes to try and help each other because everyone has their own experiences and it might actually help other people. There is a missing link because the one that I went too there was a young girl up there and she had horrific experiences and she was getting her life back on track and she actually lost the power of her body and that was very interesting because it was her experience and the rest was just facts and figures. Maybe the steps program is different and I was asked to go on the steps program but it is difficult to go if you are not driving and your off the road so maybe if there was something for the steps program if your off the road if there was list of patients with their numbers that if you were off the road you could get a lift off a person and it's all well and good saying come and do the Steps program.

SP2F: And we here this all the time. You learn much better from each other and your experiences and how to overcome things.

PWE 2 F: And how to overcome the work situation as well.

SP4M: How would you change things? How could you help us redesign how we deliver the epilepsy services? What would you change?

PWE 2 F: As of from here, I don't know, you have the helplines.

PWE 4 M: I can't fault the service from here.

PWE 3M: The connection with the GP's so that the GP can understand the needs from the user's point of view. The GP doesn't know everything.

PWE 4 M: But the GP's are a separate body and these guys have minimum influence over the GP.

PWE 3M: Ya but if you guys could explain a bit better and how epilepsy has different effects on different people.

SP4M: One of the things that is striking listening to you all that are talking is that how much more you need and I know that you are not asking us for it and you need lots of help and explanation and we can't give it all, were just not able to but not only that we don't know half the things you need but you do right, so there is a big discussion in the health services about involving patients in the design and delivery of health services, so I have asked you about the design question and there is a couple of things that have come out and I do think that we should start giving letters to the patients, and it's very clear that you should have a letter and that you can follow your progress.

PWE 2 F: Ya. I have asked the GP for a letter from yourself and its great.

SP4M: In the near future we will be creating a portal on the computer so you will be able to get a summary of your condition from here plus you will be able to add to the portal for example if you have had a seizure and we can look at what date that was.

Researcher: *Would this facilitate empowerment?*

All participants - Everyone agree

SP4M: We would be delighted to hear more about your views of the design of the service. How about delivery of the service? What would you be prepared to do? Would you come in and talk in a group. If we had a group meeting with patients would you be prepared to come in? We would all be there and we would get a discussion going. It's like what we done here today but it would be great if we had a prepared talk. So say now it has taken 45 minutes to talk about this anger that you have. It's really important. Would you be prepared to come in and talk to people and give that experience because if you are not we can't do it, not only can we not do it we don't know it. We don't have the personal experience of it, like Thomas's experience with his GP-that will resonance with a lot of people. Your own experience with the drug that it's the only one that is working, but you feel awful on it. Like this is what people with epilepsy want to hear. Not only can't we do it. Like we can't put it up on a slide because that will be too general. Like it has to be a story, someone is giving a story

SP2F: Also there is something for you to gain in that. There could be a story from someone else that are on Epilium and they could say well I did this or I did that and there are potential gains to learn from others.

All PWE: All PWE nod and agree.

PWE 3M: Of course there is ya.

PWE 3M: Like I don't know anybody that has epilepsy besides myself. If you do talk to people that have experience I am sure you will get something from them.

PWE 2 F: My husband has epilepsy since childhood but his thankfully is well dealt with and he hasn't had seizures for 15 or 16 years but like that he doesn't understand because he was a small child when he was diagnosed. And I am trying to explain to him and it's just not the same. I thought I would have something in common but yet we haven't.
All Service providers: [All agree ya]

SP3M: Can you grow out of epilepsy? Will you always be on medication?

SP4M: The definition of being cured from epilepsy is recently defined and you would have had no seizures for at least 10 years and 5 of those you can't have any medications and you are considered cured and it does happen to people but the problem is of course some people it doesen't.

PWE 4 M. Epilepsy hit me bad when my wife died. Whether it's like a post stress thing or whatever I don't know I don't know.

SP4M: This is a high possibility yes**.**

PWE 3M: Do you find when you have seizures when you are calm down you develop a seizure?

PWE 4 M: My wife had motor neuron disease for five years and if I was ever going to be stressed it would have been those 5 years but I didn't have one. So I am just wondering is there a correlation between adrenaline working through your system and epilepsy?

SP4M: Ya keeping protecting you almost.

PWE 4 M: Ya

PWE 3M: I find the more worked up I get and then when I calm down it's going to be a bad seizure.

SP4M: That actually is very common.

PWE 3M: That's a big question answered.

Researcher: *For the clinicians and your empowerment. Some service provider feel disempowered because of lack of support from the organisation. ESN's report some conflict with the medical profession with regards to their advanced role within the* *service. Are there ways that could improve this issue? And how do you envisage that this should be carried out?*

SP1F: It is a very difficult process. It's a commitment from nurses as we need to be trained and educated at this level even if the hospital supports them and the team supports them. But it is a new development in nursing and it is difficult to define our role. So what is the difference between some nurses that work 20 years in an epilepsy service to that of an ANP? So what we are trying to show is that we are working at a different level to these nurses, so things like nurse prescribing and things like that. The patient only meets the ANP at the clinic and they make a judgement about their care and she decides knowing that they are doctors and a medical team around and a consultant but she makes that decision about what I am going to do for this patient today because I am going to base that decision based on my own clinical experience and level of training and that's what we are working towards and it's not just in epilepsy but it's across the board. I think any chronic disease will have ANP's. It's the resources that come after it. I think if we are prepared to empower the service with our level of training we have we need the support and the roles that we don't do any more are covered and we find that difficult to understand. Where will we be in 5 year's time and if patients find the value in our role but we haven't heard yet how valuable the patients find the nurse's as of yet.

Researcher: *Where do we find that support in the meantime?*

SP1F: We talk to our ADON.

SP2F: And I think the colleagues that we work with are our support and then you know it's about gaining momentum and people are very wary about it. You know they say you do what now, but you are only a nurse. And this is nursing colleagues and I think it's a lack of knowledge so probably the lack of support is to come from ourselves and other nurses that are pushing these boundaries that we continue to inform and tell people. It's always going to be harder for the person that goes first and that is probably the cross to bear but certainly support top down, but our team our supportive.

Researcher: *What are the support measures within the team?*

SP4M: We have to have all the nurse working professionally. I understand that some patients may need to see me in certain complex cases as I am the person with the most experiences to get a handle on something complex. At another level all the doctors and nurses work at the same level. Now I don't know if that's the perception you have? [looks at PWE].

PWE F 2 and PWE 3M: No I never mind who I see.

SP4M: Great because that's exactly what we want because it wouldn't work.

Researcher: *Results of this study also highlighted poor information provision and educational delivery for PWE. Are there ways that could improve on this issue? And how do you envisage that this should be carried out?*

SP2F: Sometimes it's a struggle because sometimes you will have somebody that is very motivated in their care. They want to make decisions and it's a two way street and then you will have some patients that will say you just decide I don't care so it's probably an individual patient by patient thing by how much a patients wants to run with or the driving force in their care but the culture. It also depends on what team you work on. If the person on the top of the team and making decisions that there model or how they perceive the patient will filter down to the rest of the staff and if that person has a more traditional view of hierarchy this is what I say, this goes, you take this tablet, you do this when I say it. If they have an overview that no we make decision together I think that filters down to the team. But coming from the bottom up as well would be really good.

SP4M: I think that you can artificially do like bring in someone with power points presentations and this is how you empower patients, everyone would be asleep half way through it. But if you had patients giving the lectures and you said to the students look this is a patients experience, you need to listen now. This is a powerful tool so again it's the design and delivery stage of every part of the health service.

SP4M: This is what I am saying too (Looks at PWE F2) you need to commit to this and you won't get paid for it. Patients have to understand this. We need you to do this. And unfortunately this is our job and we can paid for it and you all have jobs and we have to ask you to do this.

SP4M And like (looks at PWE 3M) and I know you said that you would have no problem going to schools. Epilepsy Ireland have a school pack and one of their community resource officers could give you some back up with that. You could say to Epilepsy Ireland I want to go into a school to talk to the kids about epilepsy and they will support you and that's the kind of thing that you need to do and unfortunately there is no resource behind it, there should be and that something that should be discussed. Maybe a grant that available that something that wants to do it for a year.

PWE 3M I would definitely love to do because I know that I have frightened my nieces and nephews when I got a seizure. I was so ashamed of myself because they look at me as the big strong one and I couldn't look at the kids straight in the face for about 6 weeks because I felt so low but if I could go and explain that to children where they wouldn't freak if they see someone compulsing on the ground because that is what most people do.

Researcher: *And how do you envisage that this should be carried out?*

SP2F: I think if there was some like public campaign you know like for stroke victims FAST. If we could get a public campaign.

SP4M: You know the thing about those is that they do these occasionally but they cost a lot of money. They have an impact while they are happening and they then seem to fall off. While there are good if there was an idea like everyone with epilepsy like somewhere down the line they would be some kind of ambassador for epilepsy in their locality. Contact the local school, the local health centre and willing to talk about their condition and if they had it embedded in it like an ambassador program.

SP1F: Even the patients that on the phone all the time we do invite the patients to meet the nurses one on one but even if we had a group of patients that were willing to talk to somebody because these things we are quite stuck on where to go. We don't have five people to send you guys to talk to like difficulties in employment etc…

PWE 2 F: Even like epilepsy Ireland, the lady in the midlands had such a huge area to cover so somebody with epilepsy in the area went in and talked to a certain amount of areas. There are only a couple of centres with epilepsy Ireland and it’s such a huge are to cover.

SP2F: I think we need support groups and there are out there for other things and it’s not led by any expert it’s led by … but there has to be one person who says I am going to find a community centre .. I’m going to put up posters, everyone can go to discuss difficulties, they have something in common, but it has to be one person who is driving and possibility have to sit there on their own for several weeks but it takes one person.

Researcher: *Before finishing the interview is there anything you would like to say or add to what has been discussed*