

Exploring Dimensions of Empowerment from the Patients' Perspective in One Specialist Epilepsy Service in Ireland

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Abstract

Empowerment is integral to patient-centered practice, particularly as this relates to people with chronic conditions, though operationally it is poorly understood in this context. Empowerment, therefore, as experienced by patients with a chronic condition needs exploration. This article reports the experience of empowerment by patients in one specialist epilepsy service in Ireland as an exemplar of broader issues affecting empowerment of patients with chronic conditions. A Frameworks Approach was used to analyze in-depth interviews with patients ($n = 10$) in one Irish epilepsy service. Analysis was further informed by nonparticipatory observation of service delivery. Results indicate that patients' negative experiences of empowerment appear to be derived from traditional social norms relating to clinician patient power dimensions and social stigma internalized by clinicians at an unconscious level. With this in mind, educational approaches based upon critical social theory may provide a framework and guide to enable services to engage with these issues and embrace empowerment of patients with chronic conditions within therapeutic engagement.

Keywords

clinician–patient relationship, communication, culture/diversity, education, healthcare planning or policy, organizational culture, patient/relationship centered skills, patient perspectives/narratives

Introduction

Empowerment is a sine qua non of a patient-centered health care service, particularly for people with stigmatizing chronic conditions such as epilepsy (1–4). Research in Ireland indicates that patients with epilepsy play a passive role in their care (5). The literature identifies 9 dimensions of patient empowerment: “control”; (6) “participation”; (7) “shared decision-making”—which is increasingly emphasized within health services; (6) “support”; (8) “collaboration with service providers”; (9) “knowledge and understanding”; (10); “psychological coping”; (11) “power”; (7) and “system”—that is, “time, organization, and the service offered” (7). Empowerment improves patient outcomes and sense of engagement with their care (6–9). Barriers to empowerment include service structures, attitudes, and poor communication (5). Research exploring operational issues that support or hinder empowerment is lacking (12–14). This qualitative paper reports the experience of empowerment by patients with epilepsy attending an epilepsy service in Ireland.

Context—The Irish Health Care System

The Irish health care system is based upon a regional model with specialized services located in centers of excellence, largely in the capital city—Dublin (15). It is primarily funded publicly, though with a significant private sector (15). People with epilepsy are usually cared for within the public system (16). The National Epilepsy Care Programme of the Irish Health Service Executive emphasizes patient-centered care as a core principal of delivery (17). The

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Table 1. Interview Topic Guide.

Ground mapping question (nonspecific and opening up the subject, minimal probing, 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?*(5)

Dimension mapping questions (used to focus more on particular issues).

a. *What are your experiences in the provision of epilepsy care in the past compared to the present?* (5)
(reference answers to the NECP in this question)

b. *What are the issues that have you regarding the provision of your epilepsy care?* (5)

c. *What is your understanding of the term “empowerment” in relation to your care?* (5)

Perspective widening questions (more in-depth uncovering of issues). *Guided by the following list explore the patient’s views with regard to empowerment and current provision.*

a. **Engagement and empowerment:** active participation; decision-making; accessing appropriate care; resources; appointments (attendance and preparation) (5–8)

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 organizations; information provision; education (10)

c. **Collaborative:** involvement in decision-making (shared decision-making); participatory role; communication; active listening; trust; respect (6,7,9)

d. **Committed:** adherence; motivation; setting goals; changing behaviors (8,11)

e. **Tolerance of uncertainty:** management of uncertainty; emotional needs, stigma; depression and anxiety; and hope and positivity (1–6, 8,11).

Closing questions

a. *Reflecting on what we have talked about what for you are the key issues?* (5)

b. *As a service user what would you like to see changed?* (4,5)

c. *Before we finish the interview is there anything further you would like to say or add in relation to what we have discussed?*

Abbreviation: NECP, National Epilepsy Care Programme.

strategy policy only mentions “empower” once as it relates to “care partnerships” and gives no operational guidance on patient empowerment. Arguably, a move toward developing an empowering care partnership requires explicit operational guidelines supported by service design principles, clinician training, and patient education (18). In this context, using one specialist Irish epilepsy service as a case exemplar, this study explores the “felt” experience of empowerment from the patients’ perspective.

Methods

Study Setting

This study took place in an Irish Outpatient Department of a multidisciplinary epilepsy service. Patient referral is from all over the country through a general practitioner (GP) or specialists from other hospitals.

Study Aim

To explore the experience of patients with epilepsy in relation to dimensions of empowerment within one epilepsy service in Ireland.

Ethical Approval

The relevant ethics committee gave ethical approval for the study. A condition of ethical approval is that the clinical service would remain anonymous.

Study Design

This qualitative study comprised one to one interviews and a nonparticipatory observation of service. All 3 members of the research team are nurses, with 96 years’ experience between them. One is a registered general nurse and the other 2 are registered mental health nurses. Qualitative research by its nature often involves a small sample of interviewees, usually between 1 and 20 informants. The sample size is often dictated by the nature of the study, the availability of participants to be interviewed and the level of *data saturation*—that is when the same issues are reappearing among the interviewees sampled as the study progresses. One stops interviewing when data saturation is reached. For this study, one to one in depth interviews with patients with epilepsy (n = 10) were conducted by the same member of the team (the general nurse) over a 5-month period. The aim of these interviews was to capture the experience of empowerment—something a standard questionnaire would be unlikely to provide (19). An interview guide based on the extant literature on empowerment; what was already known in relation to people’s engagement with epilepsy services and results of a questionnaire administered a year previously to all patients attending the service under exploration was developed (5,19). The guide focused on asking patients about their understanding of empowerment; service experience and reflection on what should change. Questions referenced 3 subheadings—“Ground mapping”; “Dimension mapping”; and “Closing” questions (Table 1).

To supplement the interviews a nonparticipatory observation of service engagement between clinicians with patients,

Table 2. Demographic Details of Patients With Epilepsy.

Patients with epilepsy	Gender	Employment status	Age
PWE 1	Male	Unemployed	18-29
PWE 2	Male	Attending college	18-29
PWE 3	Male	Unemployed	18-29
PWE 4	Female	Employed	30-49
PWE 5	Male	Unemployed	18-29
PWE 6	Female	Unemployed	30-49
PWE 7	Male	Employed	30-49
PWE 8	Female	Employed	30-49
PWE 9	Female	Employed	30-49
PWE 10	Male	Employed	50-71

their families and carers took place. This provided insight into the social milieu of the service as referenced to principles of empowerment. The observations involved one member of the research team (the general nurse) shadowing clinicians and patients who agreed for up to 2 hours over a 20-day period. Field notes, including reflexive comments, were written up following observations (Table 4).

Inclusion and Exclusion Criteria

Inclusion criteria were

- aged 18 years and over;
- a diagnosis of epilepsy for 1 year or more; and
- ability to read and understand English language.

Exclusion criteria were

- under 18 years old;
- a diagnosis of epilepsy for less than 1 year;
- unable to read and understand the English language; and
- people with intellectual disabilities.

Pilot Study

The interview guide was piloted with a volunteer patient with epilepsy to test its administration and make adjustments if necessary (this person did not take part in the subsequent data collection exercise).

Participant Recruitment

Participant recruitment commenced once ethical approval was granted. In order to initiate recruitment, a number of meetings with the multidisciplinary team (MDT) took place to discuss the study. In this context, the MDT members were gatekeepers for the recruitment of patients. It is standard practice to recruit potentially vulnerable patients to a study through discussion with their clinician rather than directly approaching such patients (20).

Clinicians informed potential participants via an information leaflet outlining the study; what participation involved and how the results would be used. Reassurances that the data would be anonymized were given.

While there is a potential for bias through recruiting via a gatekeeper, there were indicators that this did not significantly bias the sample. Firstly, interviews were conducted with a wide range of patients attending the service. Therefore, the sample reflected range and typicality of service attendees (19). The only notable exceptions to this was people with intellectual disabilities and patients who were unable to read and understand the English language. People with intellectual disabilities were not selected for interview as they were likely to have multiple agency involvement and therefore a unique perspective that would warrant a separate study.

Secondly, during the interviews, both positive and negative views about the services and issues of empowerment were expressed. Finally, the results obtained were compared with the broader literature on empowerment within health services and appeared congruent with a number of themes identified (4,6–9).

Data Collection

A dedicated interview room in the clinical area was used to conduct the one-to-one interviews. A date and time for each interview was agreed. The timeframe of the interviews was over a 5-month period. The interviews took 5 months to arrange due to logistical issues including: identifying patients willing to be interviewed and coordinating times that were convenient for both the patient interviewee and the researcher carrying out the interviews. Participants were informed again of the interview's purpose and offered the opportunity to ask questions before or during the process. Participants were also informed that they could withdraw from the interview at any stage and decline to answer any question (s) without query and have the digital recorder turned off if they so wished. One member of the research transcribed the audio recordings. Two members of the research team reviewed a sample of the transcriptions for accuracy against the audio recordings.

Data Analysis

A Frameworks Approach was used for the analysis (21), involving 5 stages: (a) familiarization with the data; (b) identifying a thematic framework; (c) indexing the themes; (d) charting those themes into a hierarchical framework, and finally, (e) mapping and interpretation of those themes. Data management was facilitated using NVivo 10. One member of the research team coded the data and 2 members of the team verified the coding. There were 4 emergent themes: (a) an understanding of empowerment; (b) power and powerlessness; (c) connecting empowerment to the system: epilepsy services and care interactions; and (d) "life world"

issues for patients with epilepsy (the space in which there is an interaction between the personal and cultural experience).

Results

For reporting purposes, interviewees are identified as patient with epilepsy male (PWEm) and patient with epilepsy female (PWEf) followed by a number according to the sequencing of each individual interview. Table 2 outlines the demographic details of the patients with epilepsy. Table 3 outlines the 4 emergent themes and presents some illustrative quotes from each theme.

An Understanding of Empowerment

“An understanding of empowerment” was defined as one’s ability to think critically and act autonomously (22). Overall, many patients appeared to have some understanding of empowerment in these terms. Some patients recognized an enhanced self-efficacy by being empowered (see Table 3).

Many related terms for empowerment were described 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). These terms would be congruent with the literature (18).

A small minority (n = 2) felt the concept lacked either meaning or a clear understanding (see Table 3). Neither of these patients shared any common characteristics that might account for this lack of understanding. One patient indicated empowerment seemed to be a cliché that was poorly understood within the epilepsy service (see Table 3).

Power and Powerlessness

“Power and Powerlessness” was referenced to 4 domains (23,24): the ability of some people to thwart or dismiss the efforts or decisions of other people (power over); the agency of a person to determine their options, act upon these without interference, and not to the detriment of others (power to); group action in relation to achieving an objective (power with); and a person’s sense of self-respect inter related to self-awareness in order to obtain a goal while respecting others’ rights in the process (power from within).

“Power over” related to fear of the medical professional in relation to the position of the patient and how clinicians discouraged participating in care related decision-making (see Table 3). “Power to” was related, to feeling disabled by their epilepsy condition to participate in decision-making. For others, an unequal partnership was highlighted. However, as a counter point, some patients identified their ability to participate and make decisions in their care (see Table 3). “Power with” was identified by some as the potential of support from others to help patients come to terms with their

diagnosis, “With the right doctor and right people around you one can deal with a diagnosis of epilepsy” (PWEm2). “Power from within” was associated with decision-making power in relation to medications and feeling in control of one’s life (see Table 3).

Connecting Empowerment to the System: Epilepsy Services and Care Interactions.

This theme consisted of operational indicators of empowerment within the service. Some patients reported their complete satisfaction with their experience of epilepsy services (n = 3). However, the majority reported a range of dissatisfactions. These included poor access to epilepsy services broadly; delays in relation to initiation of investigation procedures; poor continuity of care; lengthy delays between hospital appointments; and poor information provision in relation to how they should manage their epilepsy (see Table 3).

Improved psychosocial supports were identified to help patients in terms of anxiety, attention, and concentration issues. In relation to primary care, many patients reported lack of faith in the competency of their GP with respect to their care and expressed the view that GPs lack the expertise to manage their condition and/or remain passive with respect to patient needs (PWEm1; PWEm3; PWEf4; PWEm10).

Habermas argues that decisions involving human beings require a *lifeworld perspective* (that is a holistic view of the patient that extends beyond the engagement with a service to one that sees how that engagement improves or hinders their day-to-day life experience). It is an approach that foregrounds human experience within its relational, cultural, and historical context. Habermas calls this, “communicative competence” (25). Findings from this study suggest that patient–clinician interactions impact on patients’ level of empowerment—being “acknowledged,” “listened to,” “respected,” “taken seriously,” “supported,” and “treated as an equal” by clinicians impacted on patient empowerment experiences. As a counter point, poor patient–clinician interactions result in low levels of empowerment and feeling frustrated (see Table 3).

“Life World” Issues for Patients With Epilepsy

“Life world” is a space where personal and cultural impacts are experienced/interact (25). Four “life world” themes that impact on level of empowerment emerged: (a) the felt negative impact of a diagnosis; (b) the brunt of stigma; (c) social exclusion; and (d) poor societal understanding.

Many patients used words such as: “disempowered”; “self-destruct”; “suicidal”; “depression”; “frazzled”; “poor sleeping pattern”; “forgetfulness”; “lazy”; “tired”; “seizures”; “stress”; “memory problems”; “paranoia”; “guinea pig”; and “anxiety” to describe the impact of a diagnosis of epilepsy had on them.

Table 3. Themes and Examples of Illustrative Quotes.**An understanding of empowerment**

“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” (PWEm6).

“Being empowered means that I was able to make better decisions for my own epilepsy and my own treatment” (PWEm1).

“I don’t really know what empowerment is” (PWEm5).

“I suppose giving you the power to do something for yourself” (PWEm9).

“Empowerment is one of those words that does not mean anything . . . I have yet to figure a way in which empowerment can be understood in the context of epilepsy” (PWEm7).

Power and powerlessness

“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” (PWEm1).

“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. There is a knowledge deferential in those who are in control and those that are controlled” (PWEm10).

“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” (PWEm6).

“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” (PWEm4).

“I am supported by staff. I do feel assertive to make decisions about my medications and the doctor reviewed the prescriptions” (PWEm2).

“You are prompted here at this service and they inquire about different things and aspects of your epilepsy” (PWEm3).

“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” (PWEm2).

Connecting empowerment to the system: epilepsy services and care interactions

“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”? (PWEm7).

“The service I got from the hospital was an odd scan here and there and blood tests to check drug levels” (PWEm4).

“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” (PWEm6).

“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).

“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).

“A more positive service is needed so that people are not afraid of using the service making it more attractive to the patient” (PWEm4).

“I don’t really talk about my epilepsy to my GP because it’s not really their field and you need to be specialised” (PWEm3).

“The GP might check the tablets you are on and dosage and increase or reduce your dosage but offers no psychological or social support” (PWEm4).

“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).

“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).

“Life World” issues for patients with epilepsy

“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).

“There’s 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” (PWEm1).

“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” (PWEm7).

“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 say they were freaked out because I had epilepsy and I was annoyed” (PWEm2).

Abbreviations: GP, general practitioner; PWEm, patient with epilepsy male.

Patients described how their negative construction of their diagnosis became a lens through which they viewed their relationship to their surrounding norms and environment

(see Table 3). Many patients talked about the “brunt of stigma” as a result of negative reactions by society. For example, the difficulty in securing employment in relation to prejudice and

Table 4. Observation of Service: Paternalistic Practices by Family, Carers, and Clinicians.

“Power and Powerlessness” and “Connecting Empowerment to the “System: Epilepsy Services and Care Interactions”—ESN’s sometimes wait to discuss a patient with a registrar/consultant in relation to medication changes before they involve the patient. Little to no communication in relation to delays discussed with patients with epilepsy, leaving many frustrated and angry.

Power and Powerlessness’ and “Life World” Issues—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.

discrimination. Overall patients identified social exclusion as people’s reaction to their diagnosis (see Table 3).

An Observation of Service

Paternalistic practices by family members, carers, and some clinicians was evident during the observation of service diminishing patients’ empowerment space (see Table 4).

While clinicians listened to patients’ views, they appeared not willing to surrender control in relation to medication choice and decision-making. It was not clear whether clinicians within the service recognized this, which may indicate an unconscious bias among some toward patients’ empowerment. The observations of the service interfaced with the observations some patients made of their service experience in the one-to-one interviews. Particularly as these related to “Power and Powerlessness” and “Connecting Empowerment to the System: Epilepsy Services and Care Interactions.”

Discussion

This qualitative study used a Framework Approach to analyze in-depth interviews with 10 patients with epilepsy in one Irish epilepsy service. Analysis was further informed by nonparticipatory observation of service delivery. Four themes were identified with respect to empowerment and include (a) an understanding of empowerment; (b) power and powerlessness; (c) connecting empowerment to the system: epilepsy services and care interactions; and (d) “life world” issues for patients with epilepsy.

Consistent with the literature, the findings from this study suggest that empowerment is a complex and multifaceted concept (26,27). This study indicates empowerment as a subjective process or outcome, arising from an access to “power from within” resulting in a sense of autonomy, self-confidence, and feeling respected (6–11). However, there are a range of issues that impact negatively on patients’ service experiences derived from wider societal prejudices toward stigmatizing illness that may be internalized at an unconscious level in terms of the nature and balance of power between clinician and patient. At the core of this, patient experience is communication which, as research indicates, if not addressed, will make it difficult to empower patients with epilepsy (14). Writers such as Habermas state

that distorted communication (that is failure to provide opportunities or preventing people from communicating their desires) can result in disempowering life situations. It would seem that communication, as illustrated by this study, can convey these power imbalances and attitudes. As research indicates, if not addressed, this makes it difficult to empower patients (8). Habermas’s principle of undistorted communication emphasizes mutual respect and rational discussion as a means through which a more empowering patient–clinician relationship can be achieved (25). Thus participants are able to develop some common understandings, when there is a readiness of participants (in this case clinicians) to listen to ideas and arguments presented by their patients. In this regard, one of the more interesting aspects of our findings relates to patients’ dissatisfaction with broader care system in terms of indicators of empowerment where they highlighted lengthy delays, poor continuity of care, and difficulty in accessing services that served to emphasize their disempowered status. This was further emphasized in terms of many patients’ views of their GPs lack of knowledge about their problems and the specialist service with which they were engaged. These issues are indicative of a service that operationally is disempowering in spite of a rhetoric of being patient centered.

Overall, our interviews and observations highlighted an iterative relationship between the patients’ felt experience of power and powerlessness. This included self-care as it related to their power to make decisions for themselves counterpointed to a balance of power between themselves, clinicians, and service operation. This was articulated through a struggle for power between patients, sometimes their carers/family, the service, and the patients in which their felt powerlessness because of their diagnosis (with its inherent social stigma) was often emphasized. What is striking is that the specialist services seemed blind to the need to support patients in relation to the disempowering nature of their diagnosis within both the service and the wider society.

Limitations

This study was conducted in one specialist service in Ireland and focused on patients’ experience of that service. In this context, it may be argued, perceptions were service-specific as opposed to an exploration of the entire Irish epilepsy

ecosystem. Also, the study did not focus on the experience of clinician's view of empowerment rather only the patients' perception of clinicians' willingness to engage with empowerment. These issues could be seen as limitations to the study. In mitigation, the service studied is attended by patients from all over Ireland. These patients did share their experiences of the ecosystem of epilepsy care in Ireland outside of the specific service. In this regard, the service under study may be considered a micro example of the broader services' rhetorical commitment to empowerment that may need to be examined at the patients' "felt" experience of empowerment.

The sample size in this study is a small self-selecting one. Also the sample only consisted of patients with the ability to read and understand the English Language. Conclusions about epilepsy services therefore, in general, may be criticized in this regard. Having said that, when data saturation was achieved there was a high degree of emergent consensus among those interviewed (28). This gives some confidence to the conclusions reached.

Strict co-rater analysis was not followed in this study because of logistical limitations and this could be seen as a study weakness. However, all initial textual and observational analysis (interview transcripts, an observation of service, and note taking) and analytical themes were discussed between the field researcher and the other 2 researchers involved in the project. These discussions included critical "testing" of the field researcher's analytical conclusions against the data presented and adjustments to emergent themes were made as a result. This certainly did challenge any over interpretation of the data. Secondly, a reflective engagement between the field researcher and the data during the analytical process led to a high degree of consciousness in not over interpreting the data in relation to personal bias.

Conclusion

Findings from this study would suggest that considerable improvement in terms of interpersonal training and delivery of support may be needed if services are to embrace and authentically operationalize patient empowerment—particularly in the context of chronic disease management. While services may adopt the rhetoric of person-centered approaches to care to implement them at a "felt" level requires a significant change in professional and organizational culture and structures as this relates to communication between clinician and patient. Arguably, educational approaches based upon critical social theory may provide a framework and guide to enable a positive therapeutic engagement experience with these issues (29). Critical social theory 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 utilized in practice (29).

Future studies are warranted to explore how communication interactions between clinician–patient, family, and carers impact on levels of empowerment for patients with epilepsy and to assess the effect of communicative competence on empowering outcomes. We propose more specific studies to examine issues at an organizational level to explore how access to epilepsy services and care provision; support structures; shared decision-making; societal attitudes; stigma; and discrimination impact on empowerment experiences.

Authors' Note

The Regional HSE Ethics Committee and the Waterford Institute of Technology (WIT) Research Ethics Committee gave ethical approval for the study. A condition of ethical approval was that the clinical service would remain anonymous.

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