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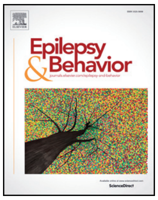

Review

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.

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.

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

3.1. 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