



Choice and control: How involved are people with epilepsy and their families in the management of their epilepsy? Results from an Australian survey in the disability sector

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ABSTRACT

This study explored the extent to which people with epilepsy and their families have choice and control over the management of their epilepsy and the support provided in the Australian disability sector. It measured the level of direct involvement in planning and recording of their epilepsy health-care needs and support required through the use of epilepsy management plans. An Australian online survey was completed by 118 adults with epilepsy and 171 family members of children and adults with epilepsy, providing demographic and diagnostic data and details of their epilepsy management plan, whether they were involved in writing the plan and the extent to which it included their views on how they want to be supported. Results indicate that just over half of all respondents had an epilepsy management plan, with 83% revised within the past 12 months. Although the majority of respondents were directly involved in writing their plan (87%), only two-thirds (66%) felt that their plan included their views on how they wanted to be supported. Open-ended comments from 111 respondents indicated their desire to be actively involved in this process, as either collaborative team members or ‘in charge’ of the process. In spite of a move towards person-centered approaches and greater choice and control, further emphasis must be placed on actively involving the person with epilepsy and their family in writing and incorporating their views on support within their epilepsy management plans. This research was undertaken by the Epilepsy Foundation to inform the development of epilepsy support resources for the newly introduced Australian National Disability Insurance Scheme.

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1. Introduction

Across the world, best practice models in health management and disability support are placing increasing emphasis on the individual's active involvement in the development of their own health management and support plan. A paradigm shift towards individualized supports and person-centered approaches has come to the fore, often explicitly mandated by government policy [1,2]. Evidence indicates that people with chronic disorders (including epilepsy, heart disease, diabetes, arthritis, and asthma) can effectively collaborate in managing their health [3,4], with good health outcomes associated with the patient's active participation in managing their condition [5].

Many people with epilepsy also experience additional comorbid disabilities [6,7]. These compounding factors often result in complex challenges to ensuring appropriate epilepsy education, management, and lifestyle changes. As people with a disability are more likely to experience poorer health and more complex needs than the general population, it is important that planning is in place to ensure that health needs

are met. In particular, people with intellectual disability are often left behind in the developments that are made to the health of other members of the community [8]. Many barriers to accessing health care exist, including few opportunities for empowerment to improve and protect their own health and limited numbers of appropriately trained health professionals, leading to significant health inequity [9–11]. Good communication between members of support teams, service providers, and health-care professionals is required on behalf of the person with a disability and their family to combat these issues [12].

In order to achieve active involvement in decision-making, disability research has long focused on the shift towards person-centered approaches. Person-centered planning (PCP) adopts an individualized approach, reflecting the unique circumstances of the person with a disability when assessing and organizing what is to be done [13]. This approach incorporates the views and aspirations of the persons themselves, their family, and wider network, ensuring that decisions about them are not made without them [14].

Epilepsy management plans, also termed ‘care plans’ or ‘support plans’, involve collating information on the individual's health-care needs and documenting how family and support staff should respond and support the individual to achieve their personal goals such as social

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inclusion and management of their epilepsy within a single document. The process is based on evidence and risk assessment and lists epilepsy support and interventions to be undertaken in the event of seizures, how the person's epilepsy outcomes are to be achieved, and the review of the support that will occur at regular times. These plans aim at helping people involved with the person living with epilepsy to recognize when seizures are occurring and at giving clear directions about the appropriate support and first aid to be provided to the person.

The UK National Institute for Health and Clinical Excellence (NICE) has produced guidelines for the diagnosis and management of epilepsy in adults and children [15]. The National Institute for Health and Clinical Excellence (2012) guidelines for epilepsy advise 'All individuals with epilepsy should have a comprehensive care plan that is agreed between the individuals, their family and/or carers as appropriate, and primary and secondary care providers.' [16]. It is emphasized that treatment and care should reflect the individual's needs and preferences, with people with epilepsy given the opportunity to make informed decisions about their care and treatment in collaboration with their health-care professionals. Good communication between health-care professionals and people with epilepsy (and their family and carers) is essential and should be supported by individually tailored, evidence-based written information. In addition, the treatment, care, and information given need to be culturally appropriate and accessible to people with physical, sensory, or learning disabilities and to people who do not speak or read English.

Unfortunately, reports on a fragmented health-care system in the UK indicate that the implementation of the NICE epilepsy management guidelines is problematic. Inconsistent and uncoordinated services continue, demonstrating the urgent need for improved continuity of care [5,17]. Although the NICE guidelines include 'outline care algorithms' for adults and children, different service providers adopt different approaches to care planning [18]. Within Australia, it is recognized that there is an urgent need for the NICE guidelines to be more widely adopted [19] in order to ensure that all epilepsy management plans are developed within a person-centered framework and incorporate the individual's needs, preferences, and informed decision-making on their care and treatment.

The aim of the current study was to explore the extent to which people with epilepsy and their family members within Australia are actively involved in the development of their epilepsy management plan and the support they receive from staff within the disability sector. Recommendations on ways to achieve greater choice and control in order to enhance person-centered epilepsy management in the disability sector are also discussed.

2. Methods

An online survey was developed using SurveyMonkey to explore the experiences and needs of adults with epilepsy and their family around the development of epilepsy management plans. The survey included 24 questions requesting sociodemographic and diagnostic information, an adapted epilepsy knowledge scale, and details of their epilepsy management plan.

This article reports on responses related to whether participants (or their family member) have an epilepsy management plan, when it was last updated, whether they were involved in writing the plan, the extent to which it includes their views on how they want to be supported, and how they would like to be involved in developing their plan (see online supplement). Responses to other questions including confidence in managing their epilepsy, as well as factors influencing their confidence levels, will be reported elsewhere.

Thirty disability and epilepsy organizations across each state and territory in Australia were contacted directly by the research team and asked to place an advertisement for the survey on their websites and newsletters to members. In addition, advertisements including the survey link were published in local and national newspapers and magazines (including 'The Big Issue'). Criteria for participation specified

that respondents were over 18 years of age, either with epilepsy themselves or were family members to a child or adult with epilepsy.

All survey responses were imported and analyzed using SPSS 20. Responses to open-ended questions were imported into NVivo10 where each response was read, discussed, and coded collaboratively by two researchers.

3. Results

The survey was completed by 291 respondents, consisting of 118 adults with epilepsy and 171 family members (see Table 1). Family members reported on 99 children under 18 years of age, with parents as the most frequent respondents ($n = 144$, 84%). The mean age of family members was 43 years, ranging from 20 to 76 years. Sixty-two percent of the respondents were from Victoria, with other participants from New South Wales (15%), Queensland (9%), Western Australia (7%), South Australia (4%), Tasmania (2%), Australian Capital Territory (0.3%), and Northern Territory (0.3%). The age range of the 291 people with epilepsy represented in this sample was from infant to 79 years (mean: 26.7, 17 missing), with 167 (58%) females with epilepsy.

Table 2 illustrates that just over half of all respondents ($n = 142$, 51%) indicated that the person with epilepsy (either themselves or their family member) had a substantially reduced capacity in communication, social interaction, learning, mobility, self-care, or self-management (12 missing). This population could be described as having a severe or profound core activity limitation, defined as sometimes or always requiring personal help or supervision with core activities of self-care, mobility, and communication [20]. This question was included to provide an indication of whether the respondent might be eligible for the newly introduced Australian National Disability Insurance Scheme and inform the development of resources targeted for this population. It also provides a point of comparison between respondents with and those without high levels of self-reported disability.

Respondents were asked to identify the person with epilepsy's main disability type from a presented list. 'Neurological disability' was the most common across all groups. Those who indicated a 'severe core activity limitation' reported higher rates of intellectual disability, physical disability, and autism spectrum as their primary disability compared with those who did not.

There is a small but statistically significant difference between the mean ages of the persons with epilepsy within the two groups. Those with a severe core activity limitation were, on average, 24 years of age, whereas those without a severe core activity limitation were, on average, 30 years of age. Over half of the respondents from each group indicated that epilepsy had been diagnosed for longer than 11 years, indicating long-term experiences in managing and living with the effects of epilepsy in both cohorts.

Just over half of all respondents indicated that they (or their family member with epilepsy) had an epilepsy management plan (57%). This figure was slightly higher for those with a severe core activity limitation (65%) and dropped to only 50% for those without when separated into the two groups. Children were more likely to have an epilepsy management plan than adults, particularly when there was no severe core activity limitation. Reassuringly, of those who indicated that they had

Table 1
Survey participants by respondent category.

	Number of respondents		
	<18 years ^a	>18 years	Total ^b
Person with epilepsy	–	107	118 (41%)
Family member ^a	99	67	171 (59%)
Not indicated	–	1	2
Total	99 (36%)	175 (64%)	291

^a Family member reporting on child under 18 years of age.

^b 17 respondents did not indicate age.

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