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...
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, 48%). 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

<table>
<thead>
<tr>
<th>Number of respondents</th>
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<tbody>
<tr>
<td>&lt; 18 years (^a)</td>
</tr>
<tr>
<td>----------------------</td>
</tr>
<tr>
<td>Person with epilepsy</td>
</tr>
<tr>
<td>Family member (^a)</td>
</tr>
<tr>
<td>Not indicated</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

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

\(^b\) 17 respondents did not indicate age.
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