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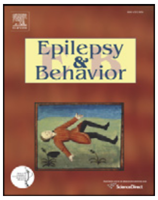

A qualitative study of carers' and professionals' views on the management of people with intellectual disability and epilepsy: A neglected population

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ABSTRACT

Little attention has been paid to the specific needs of people with intellectual disability and epilepsy despite evidence of increased prevalence of epilepsy, increased risk of complex epilepsy, and heightened use of health services among this group. In an attempt to address this gap, an online international survey was undertaken inviting health professionals and caregivers, both paid and family members, to share their views on the adequacy and quality of available treatment. This paper reports on the responses obtained from 113 individuals from the UK and Ireland. Findings revealed that professionals and carers differ in their expectations of treatment and with regard to maximizing communication during consultations. In addition, findings suggested that the potential of consultations to provide information for carers, as well as to allay concerns, may not be realized. Rescue medications were viewed favorably; however, respondents expressed less satisfaction with routine medications. These findings may reflect a failure by professionals to appropriately transfer knowledge of these treatments.

1. Introduction

Considerable evidence exists of marked disparities in health status and access to health services between people with intellectual disabilities and the general population [1–4]. Epilepsy, in particular, is found with increased prevalence among people with intellectual disabilities when compared with rates among the general population [4,5]. Recent population-based data from the United States, for example, cite estimates of 1% for self-reported active epilepsy in the adult general population [6]. This figure can be contrasted with a review of chronic health conditions among children with intellectual disabilities which identified epilepsy as the most prevalent comorbid condition, reporting a weighted prevalence of 22% [7]. Prevalence estimates among adults with intellectual disabilities availing of disability services throughout Europe are similarly high, with 30% of 19–34 year olds reporting a diagnosis of epilepsy [8]. This figure declined to 15% for those aged 65 years and over, a pattern which may reflect increased mortality among those with epilepsy and intellectual disability [9]. Population-based prevalence studies across all age groups for those with intellectual disability have reported rates of 20% for active epilepsy, ranging from 11% among those with mild intellectual disability and rising to 59% among those with profound levels of intellectual disability [10]. Epilepsy among those with intellectual disabilities is, thus, more prevalent than in the general population, declines with age, and is positively associated with the severity of the intellectual disability.

Disparities in the use of health care facilities for this population have been observed. Attendance rates for those with intellectual disability at inpatient, outpatient, and emergency services, for example, are elevated for those who have epilepsy [9]. Within primary care, epilepsy is the most commonly presenting health condition for people with intellectual disability [5], a situation which is likely to increase as this population transfer from institutionalized facilities to community-based living [11]. Anticonvulsant medication is among the most commonly prescribed medication for patients with intellectual disability by primary care physicians, even when excluding prescriptions for the control of challenging behaviors [5,12]. The complex presentation of epilepsy among this population is challenging for health care providers. Those with intellectual disability and epilepsy are more likely to present with more severe and treatment-refractory epilepsy [10,13–15], experience

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increased risk of prolonged seizures and status epilepticus [16], and experience higher mortality rates than their age-related peers who do not have epilepsy [17]. Challenges towards optimal care for this population include the fact that many are taking multiple medications for other conditions that may interact with their epilepsy medication [16], a general lack of expertise regarding the specific needs of those with intellectual disability (such as behavior disorder) among neurologists [12,18], and the challenges experienced by caregivers who advocate on behalf of those with intellectual disability and epilepsy who may have limited capacity to manage their condition [19,20].

Despite evidence of the increased prevalence of epilepsy among this population, of the increased risk of complex epilepsy, and of the heightened use of health services, little attention has been paid to the specific needs of people with intellectual disability and epilepsy [11,12,21]. The lack of recognition of the substantial needs of this population can result in a tendency to underestimate, and moreover, underfund the needs of those with intellectual disability and epilepsy [22]. Most recently, a substantive review of public health issues in epilepsy has noted the diminished quality of life experienced by this group and has called for greater collaboration between disability and epilepsy organizations to promote optimal management of the condition [23].

The research presented in this paper sought, through surveying professionals, paid caregivers and family members to examine the impact of epilepsy on individuals with intellectual disability and their caregivers and to garner views on the adequacy and quality of available treatment for this population.

2. Methods

2.1. Survey protocol

An online survey was developed to qualitatively explore the views of professionals, paid caregivers, and family members who support individuals with intellectual disability and epilepsy. The survey was developed for online use using the Bristol Online Survey Software [24] and was piloted prior to data collection. Ethical approval for this research was obtained by the Research Ethics Committee of the School of Medicine at Cardiff University.

The online survey was anonymous in nature, requesting no demographic information from respondents other than whether they were family members, paid caregivers, or professionals. On reading the introductory material, respondents were informed that by moving to the survey proper, they were considered to have given consent to the researchers for their responses to be included in any subsequent analysis. The participants were given the option to exclude their direct quotes from being presented in the reporting of this survey. The survey proper comprised ten open-ended questions requesting information on respondents' views and experiences of the needs of people with intellectual disability and epilepsy. The questions explored two key areas, that of 'medical care and services' and the 'social impact of epilepsy and intellectual disability'. Two additional questions were included should participants wish to address any issues not covered by the survey.

This paper reports on participants' responses to questions relating to 'medical care and services'. Responses to the other key area, 'social impact of epilepsy and intellectual disability' will be presented elsewhere. The following open-ended items were used to elicit participants' responses to 'medical care and services':

> *What are your views on the diagnosis and medical treatment of people with epilepsy and intellectual disability? What are the problems? What helps?*
> *What are your views on anti-epilepsy medications (including rescue medications)? What are the problems? What helps?*

2.2. Sampling frame for distribution of survey

The International Bureau for Epilepsy, the international umbrella body for 126 national epilepsy associations in 95 countries worldwide, was asked to assist in providing contact details of national epilepsy associations in English-speaking countries and in countries where English is commonly considered a fluent second language. Due to the available resources of the research team, distribution and translation of the survey among non-English-speaking countries were not possible. National epilepsy associations within English-speaking countries were contacted directly by the research team and asked to place a notification of the survey on their website and, where practicable, on newsletters or emails distributed to their members. Through a snowballing process of recommendations from the research team and national epilepsy associations, the survey was also distributed to other support groups and professional networks primarily working within the intellectual disability field.

2.3. Survey participants

In total, 15 national epilepsy associations, support groups, and professional networks in seven countries consented to promote the survey either on their website and/or by distributing documentation to their members. Responses were obtained from 144 individuals in 13 countries. Responses from eleven of these participants were excluded at a preliminary stage in the analysis on the basis that the content indicated that these individuals had intellectual disabilities. This exclusion was based on the fact that ethical approval to include those with intellectual disabilities would require an assessment of capacity to consent, a process which was not possible given the anonymous nature of an online survey.

Of the remaining eligible responses, the vast majority were found to be of UK and Irish nationality (n = 113; 85%). Representation from other participating countries was poor. Given the skewed distribution of the nationalities represented in the survey, a decision was made to restrict data analysis in this paper to the responses of UK and Irish participants only. The analyses presented below are, therefore, based on responses from 92 participants from the UK and 21 respondents from Ireland. Further breakdown identifying these respondents as professionals, paid carers, or family members is presented in Table 1.

3. Results

In total, 281 statements were generated by 113 participants from the UK and Ireland in response to two items from the survey examining 'medical care and services'. Given the overlap in responses to the two items, the statements were combined for analysis and were coded by one author using thematic analysis to five broad themes; Attitudes and Expectations, Communication Issues, Knowledge of Epilepsy, Service Issues, and Medication Issues, the latter two themes accounting for the majority of statements. A second author was asked to code five percent of the statements generated from all participants in the survey and reported 80% agreement. Those statements which were not found to be similarly coded by the two authors were discussed until complete agreement was found.

Table 1
Survey participants by nationality and respondent category.

Nationality	Respondent category			Total
	Family	Paid carer	Professional	
Ireland	14	4	3	21 (19%)
UK	24	12	56	92 (81%)
Total	38 (34%)	16 (14%)	59 (52%)	113