



Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives



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ABSTRACT

Purpose: To examine the caregiving impact of those who support a family member with intellectual disability and epilepsy.

Methods: An online, qualitative international survey was conducted via the auspices of the International Bureau of Epilepsy with various stakeholders who support individuals who have intellectual disability and epilepsy. Qualitative comments were analyzed from respondents who identified themselves as family members ($n = 48$; 36%) who referred specifically to the impact of supporting a family member with these combined disabilities.

Results: Four main domains, which were comprised of ten themes, were derived from the qualitative data using Braun and Clarke's qualitative framework. These domains comprised (1) practical concerns, (2) disrupted family dynamics, (3) emotional burden and (4) positive experiences. In combination these themes illustrate the pervasive impact on family life for those supporting an individual with complex needs. Financial concerns, coordination and responsibility of care, diverted attention from other family members and social isolation all contributed a significant burden of care for family members. Positive aspects were, however, also cited including the closeness of the family unit and a fostering of altruistic behavior.

Conclusion: The study provides an insight into an under-researched area. The burden of caring for a family member across the lifespan has a largely negative and pervasive impact. Targeted service provision could contribute to an amelioration of the challenges faced by these families.

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1. Introduction

A considerable evidence base exists documenting the increased prevalence of epilepsy among those with intellectual disability when compared with the general population.¹ For families caring for a child with intellectual disability, epilepsy carries a significant burden; it is the most frequently reported co-morbidity,² it is typically severe in presentation and refractory to treatment² and it is incrementally more prevalent and complex among those who have more severe levels of intellectual disability.³ Epilepsy among

this population is also associated with the presence of other lifelong conditions including psychiatric disorder⁴ and autism spectrum disorder.⁵

The substantial burden of care for those supporting an individual with intellectual disability and epilepsy is reflected in increased attendance rates at inpatient, outpatient and accident and emergency facilities,² and at primary care where epilepsy is the most commonly reported presentation among those with intellectual disability.⁶ While health care providers themselves are challenged to coordinate the multi-disciplinary support required by those with complex disabilities,⁷ it is the family members of those with intellectual disability and epilepsy who carry much of the caregiving burden.⁸ The financial impact for families supporting an individual with complex disabilities, for example, can be considerable given the additional costs associated with disability and the loss or earnings for those unable to take up employment

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due to their caring duties.^{9–11} Somatic and psychological health, emotional health, quality of life and well-being have all been demonstrated to deteriorate among caregivers of those with complex disabilities.^{12–14} There is also a time-related burden for family members who provide round the clock direct care support or for those who spend considerable time coordinating home-based care while they remain in the workforce.^{7–9} In addition to the considerable responsibilities of caregiving, some families report that they are excluded from family and neighborhood activities which can further isolate them from wider social networks and supports.^{8,15,16} Members of the public who unwittingly behave in an awkward, scared or embarrassed manner in front of those with disabilities¹⁵ reinforce this sense of isolation and can arouse feelings of guilt and shame among family members.¹⁴ Despite these many challenges, and although less commonly reported, it is important to note the positive benefits of caregiving, which include feelings of altruism and fulfillment of family obligation.¹²

As most children and a large proportion of adults with intellectual disability now live in the family home,¹⁷ and given the increased prevalence and severity of epilepsy among this population,³ it is timely to consider the impact of caring for someone who has epilepsy and an intellectual disability on the family.

2. Aim

This study sought to conduct an international survey via the auspices of the International Bureau of Epilepsy with various stakeholders who support individuals who have intellectual disability and epilepsy. The aim of this paper is to report on how the wider family is impacted where a family member, whether child or adult, has an intellectual disability and epilepsy.

3. Methods

3.1. The survey

An online survey was developed using the Bristol Online Survey Software¹⁸ to examine the qualitative views of professionals, paid caregivers and family members who support people who have both an intellectual disability and epilepsy. The survey was anonymous requiring no demographic information from respondents other than whether they were over 18 years and were family members, paid caregivers or professionals. Respondents were also asked to indicate which country they lived in. Respondents were informed when reading the introductory material that by continuing to the survey they were consenting for their anonymized responses to be included in any subsequent analysis. Participants were given the option to exclude their direct quotes from being presented in any reporting of the survey.

The survey items comprised twelve open-ended questions exploring respondents' views on the needs of individuals with intellectual disability and epilepsy (see [Box 1](#)). The questions explored two key areas 'medical care and services' and 'the social impact of intellectual disability and epilepsy'. This paper reports on the latter area, the social impact (specifically drawing responses from questions 5–10), as findings relating to medical care have been published elsewhere (specifically responses to questions 1 and 2 in [Box 1](#)).¹⁹

Ethical approval for this research was obtained by the Research Ethics Committee of the School of Medicine at Cardiff University.

3.2. Sampling frame

The survey was distributed via a weblink to member organizations of the International Bureau for Epilepsy (IBE), the

Box 1. Survey questions as presented in the online survey.

Medical care and services

1. What are your views on the diagnosis and medical treatment of people with epilepsy and intellectual disability? What are the problems? What helps?
2. What are your views on anti-epilepsy medications (including rescue medications)? What are the problems? What helps?
3. What are your views on services provided to support the care of people with epilepsy and intellectual disability? What are the problems? What helps?
4. Do you think there is enough information available about treatment, management and support for people with epilepsy and intellectual disability? Where do you look for this kind of information? Is it easily available?

Social impact of intellectual disability and epilepsy

5. In your experience how does having epilepsy and intellectual disability impact on getting and keeping employment? What are the problems? What helps?
6. In your experience how does having epilepsy and intellectual disability affect schooling or other forms of education? What are the problems? What helps?
7. In your experience how does having epilepsy and intellectual disability affect engaging in social activities and developing friendship groups? What are the problems? What helps?
8. In your experience how does having epilepsy and intellectual disability affect romantic relationships? What are the problems? What helps?
9. How do you think people with epilepsy and intellectual disability are seen by other people? Can this cause problems? Can this cause good things?
10. In your experience how does having epilepsy and intellectual disability affect family life? What are the problems? What helps?

Miscellaneous questions

11. In your contact with people with intellectual disability and epilepsy, have they expressed any particular views that are relevant to this consultation?
12. Is there anything you would like to tell us that you think is relevant to this consultation that is not covered by the questions above?

international umbrella body for national epilepsy associations worldwide, between July 2011 and July 2012. Due to the available resources of the research team, the survey was only distributed among countries where English was an official or commonly spoken language. Member organizations were invited to distribute the weblink to their members and to other organizations, such as those providing support to individuals with intellectual disability, using a snowballing process.

3.3. Participants

Fifteen national epilepsy associations, support groups and professional networks across seven countries consented to promote the survey either on their website and/or by distributing documentation to their members. Valid responses were obtained from 133 individuals in 13 countries. Half of all respondents identified themselves as professionals ($n = 67$; 50%), over one third were family members ($n = 48$; 36%), with the remainder identifying themselves as paid caregivers ($n = 18$; 14%). See [Table 1](#) for a break down of family respondents by location. Although we did not explicitly ask for respondents to report the ages of the people they cared for, we were able to identify from the text that 24 (38.1%)

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