



Review

Systematic review of unmet healthcare needs in patients with epilepsy

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ABSTRACT

Objective: Patients with epilepsy (PWE) are more likely to have unmet healthcare needs than the general population. This systematic review assessed the reasons for unmet needs in PWE.**Methods:** Medline, Embase, PsycINFO, Cochrane, and Web of Science databases were searched using keywords relating to unmet healthcare needs, treatment barriers, and access to care. The search included all countries, adult and pediatric populations, survey and qualitative studies, but excluded non-English articles and articles published before 2001. Reasons for unmet needs were extracted.**Results:** Nineteen survey and 22 qualitative studies were included. Three survey and five qualitative studies excluded patients with comorbidities. There were twice as many studies on unmet mental healthcare needs than unmet physical care needs in PWE. Poor availability of health services, accessibility issues, and lack of health information contributed to unmet needs in both Western and developing countries. Lack of health services, long wait lists, uncoordinated care, and difficulty getting needed health information were prevalent in the United States (US) as well as countries with a universal healthcare system. However, unmet needs due to costs of care were reported more commonly in studies from the US.**Significance:** This systematic review identified reasons for unmet needs in PWE across different countries, which will inform specific interventions required to address these unmet needs. Unmet needs may have been underestimated due to exclusion of PWE with comorbidities in some studies. Additional studies are needed to understand the contribution of comorbidities on unmet needs and their interaction with caregiver and family factors.

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1. Introduction

Access to effective healthcare represents an essential determinant of health and is one of the 10 leading indicators of Healthy People 2010 [1]. When patients perceive that they do not receive the health services that they need to address their health problems, including physical and mental health problems, they have unmet healthcare needs. Assessing patients' perceived unmet needs has the advantage of incorporating patients' perspective of their healthcare needs [2]. Those with chronic diseases or self-reported poor health commonly cite more unmet needs than the general population [2]. Furthermore, those with two or more mental health conditions are more likely to report greater unmet needs than those with a single mental health condition [3]. Therefore, it is not surprising that patients with epilepsy (PWE), a common chronic neurological disorder that is frequently associated with psychiatric, behavioral, and social problems [4,5], have higher unmet needs relative to the general population [6]. The Institute of Medicine has highlighted

the urgency of addressing unmet needs in PWE by improving access to patient-centered care [7]. In the Global Campaign Against Epilepsy, the International League Against Epilepsy, International Bureau for Epilepsy, and the World Health Organization have stipulated that one of their long-term goals is to improve healthcare services for PWE [8].

It is important to understand the reasons for unmet needs, as this will provide the foundation for addressing those unmet needs. Broadly, reasons for unmet needs have been classified into several categories [9]. The first category is lack of availability of healthcare due to services not being available when required or not available in a particular geographic area or long wait times. The second is lack of accessibility due to cost of healthcare or transportation issues. Third, there is poor acceptability due to attitudes toward and knowledge about healthcare, including reasons such as patients were too busy to seek care, did not get around to or did not bother to seek care, felt that healthcare services would be inadequate, did not know where to seek care, or had language problems. Other reasons for unmet needs could include lack of access to health information. It is crucial to understand the reasons underlying unmet needs as different types of interventions are required to address the underlying factors.

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The aim of this study was to conduct a systematic review of unmet healthcare needs in PWE in order to evaluate the reasons for unmet needs.

2. Methods

2.1. Search strategy

The article search was conducted using the Medline, Embase, PsycINFO, Cochrane, and Web of Science databases. Search terms were based on the following keywords: epilepsy, unmet healthcare needs, unmet physical or psychiatric needs, access to care, and treatment barriers. All medical subject headings (MeSH terms) were combined with keywords, with explosions for subject headings and truncations for keywords used as necessary to create a comprehensive search (Supplementary Table 1). The search strategy was created with the assistance of a research librarian and collaboration among the authors. The search was performed on May 12, 2016. Citations were collected on EndNote basic and then exported to Mendeley Desktop. The titles and abstracts were screened to identify those reporting on original research, followed by a full-text screen of the remaining articles to determine which articles to include in the study. Duplicate articles were removed.

2.2. Inclusion and exclusion criteria

This study included articles published from the year 2001 and onwards. Articles included in the study had to be in English and reporting original research of unmet healthcare needs and/or reasons for unmet needs in PWE. No restriction was placed on country or study population. Surveys and qualitative and mixed method studies were included. Surveys included studies whereby data were derived from patient report, proxy report, or provider report within surveys, either from secondary analysis of population health surveys or primary data collection from clinical samples. Conference abstracts, theses, review articles, and non-English articles were excluded.

2.3. Data extraction

Information extracted from survey studies included authors, year published, country of study, study design (cohort or cross-sectional design), sample size, database if the study was from a population-based survey, population (adult or pediatric), study respondents (patients, caregivers, or providers), frequency and types of unmet needs (physical, mental and other) and the reasons for unmet needs which were categorized as availability, accessibility, acceptability, and other. Information extracted from the qualitative articles included authors, year published, country of study, data collection strategy (individual interview, focus group or both), sample size, population, and study respondents. Data on types of unmet needs and reasons for unmet needs were extracted from qualitative studies.

2.4. Study quality

The quality of the retrieved articles was assessed. For survey studies, a modified version of the Quality Index was used [10]. The modified Quality Index included 15 items and contained the following subscales: reporting, external validity, internal validity and study power, with each item scored as 0 (no/unable to determine) or 1 (yes), with a maximum score of 15 (Supplementary Table 2). There is no validated instrument to assess the methodological quality of qualitative studies. We used a modified quality checklist for qualitative studies [11], which included 13 items assessing the aim, validity, data collection and analysis, study result, and applicability to patient care, with each item scored as 0 (no/unable to determine) or 1 (yes), with a maximum score of 13 (Supplementary Table 3).

Our initial approach included conducting a meta-analysis for the survey studies, but because of the relatively small number of studies within each subcategory of reasons for unmet needs and the large confidence interval for the pooled data, we have opted to structure the findings as a systematic review.

3. Results

The total number of articles extracted by the search was 3386 (Fig. 1). Nineteen survey studies [6,12–29] with a total of 7165 respondents (Table 1), and 22 qualitative studies [30–51] with a total of 670 respondents (Table 2) were included. Studies were published from 2001 to 2015, with 17 (89.5%) survey and 17 qualitative (77.3%) studies published from 2005 to 2015. Respondents were PWE or proxies for PWE (parents of children with epilepsy or other caregivers) in 77% of survey and 91% of qualitative studies. Eleven (57.9%) survey studies originated from the USA, with the next most frequent country of origin being Canada ($n = 2$). Eight (36.4%) qualitative studies originated from the UK, and seven (31.8%) studies were from the USA. Three survey [16,21,27] and five qualitative [31,34,35,39,44] studies excluded patients with intellectual, developmental, or psychiatric comorbidities. The mean quality score of survey studies was 8.9 (range: 4–13). The mean quality score of qualitative studies was 9.5 (range: 4–13).

All the survey studies were cross-sectional in design. Six studies were undertaken using population surveys. Among the qualitative studies reviewed, data collection strategies were as follows: seven studies conducted focus groups, 13 conducted individual interviews, one conducted both focus group and individual interviews, and one used an open-ended questionnaire. Some qualitative studies took special interest in certain populations of PWE to highlight the unique challenges faced by these groups, including African–American women with epilepsy [33], African–American PWE [44], Pakistani–Muslim PWE in the UK [34], and South Asian PWE in the UK [35]. Other studies revolved around healthcare needs during specific life events: pregnancy [38], temporal lobe epilepsy surgery [39], and transition from adolescent to adult care [37,41].

An estimate of the proportion of PWE with overall unmet healthcare needs was presented by only two studies, in which 17.9% of PWE in a study from Canada [6] and 37.80% of PWE in a study from the US [13] report having overall unmet needs. Unmet physical care needs were reported in one Canadian study (12.53%) [6] and three US studies [12,20,27], with values ranging from 10.45% to 54.10%. Eight studies reported unmet mental healthcare needs, with a wide set of estimates ranging from 2.53% to 60.50%. Six of the eight studies on unmet mental healthcare needs originated from the US [12,14,16,17,20,27], one study was from Canada [6] and one from Sri Lanka [19]. Other unmet needs included difficulty with accessing care for routine check-up, care for injury, community-based care, home care, social worker services, and transitioning from pediatric to adult care.

3.1. Reasons for unmet needs

3.1.1. Lack of availability

Ten survey articles identified lack of availability of health services as a reason for unmet needs (Supplementary Table 4), and four of these were from the US. “Services not available at the time required” was reported in seven articles, two of which were from the US [20,27], two were multinational studies [24,28], and one study each was from Canada [25], Ireland [26], and Nigeria [21]. Estimates on “services not available at the time required” varied from 23.5% to 95.2%. Long wait times in getting mental health treatment were reported in 29.8% of those with epilepsy and psychological distress in a US study [17]. Two survey studies from the US [15] and Sri Lanka [19] found not enough consultation time contributing to unmet needs.

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