



Review

To tell or not to tell: A systematic review of the disclosure practices of children living with epilepsy and their parents



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ABSTRACT

Disclosing an epilepsy diagnosis to others is complex due to the condition's largely invisible nature and associated stigma. Despite this, little has been documented in terms of what this process involves for children living with epilepsy (CWE) and their parents. A systematic review was conducted to examine and synthesize evidence pertaining to: (i) the disclosure practices of CWE and their parents, (ii) enablers and barriers for disclosure, (iii) the impact of disclosure practices, and (iv) the relationship between disclosure management and other variables.

The electronic databases PsycINFO, PubMed, MEDLINE, CINAHL, Scopus, and Web of Science were searched systematically. Any empirical, peer-reviewed journal articles with findings reported regarding the self- or proxy-reported disclosure practices of children aged 0–18 years with any type of epilepsy and/or their parents were deemed eligible for inclusion. Two review authors completed all stages of screening, data extraction, and quality assessment independently with two additional review authors resolving any discrepancies.

A total of 32 articles were included in the review. Only one dated study examined disclosure as a primary focus; in the remaining studies, disclosure was a subfocus of larger studies or pertinent qualitative themes/subthemes incidentally emerged. The limited evidence suggests that: 1) CWE and parents adopt varying disclosure management strategies – from concealment to voluntary disclosure; 2) disclosure decisions are challenging for CWE and parents; 3) many barriers to disclosure exist (e.g., fear of stigmatization and rejection); 4) only a limited number of factors that enable disclosure are known (e.g., openness by others to engage with and learn about epilepsy); 5) disclosure management is significantly related to a number of variables (e.g., child/maternal perceived stigma and seizure control); and 6) there are varying outcomes for CWE and/or their parents in accordance with the adoption of specific disclosure management strategies (e.g., disclosure resulting in greater acceptance and the receipt of support or evoking anxiety/fear in others; and concealment resulting in misunderstandings, embarrassment, and stigma-coaching), but the evidence remains inconclusive in terms of which disclosure management strategy is optimal.

While some preliminary work has been conducted, disclosure of epilepsy is a topic that has been largely neglected to date. This is despite the fact that disclosure is a significant source of concern for CWE and parent populations. Future studies should focus on elucidating the unique contextual factors that inform disclosure decisions in order to develop a theoretical framework that can explain the epilepsy disclosure decision-making process.

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1. Introduction

Epilepsy is a common, largely invisible, chronic neurological condition, with estimated childhood prevalence rates ranging from 3.6 to 9.0/1000 population internationally [1–5]. On receiving a diagnosis of epilepsy during childhood or adolescence, the child/young person living with epilepsy (hereafter referred to as CWE) and his/her parents must not only contend with the medical aspects of the condition, but also

with the impact that the condition can have on psychosocial wellbeing. Compared with their healthy peers, CWE are at significantly greater risk of experiencing depression, anhedonia, internalizing behavior problems, and social anxiety [6,7].

Individuals with epilepsy (both adults and children) often experience discrimination and/or social exclusion because of epilepsy-related stigma [8–11]. Public perceptions of epilepsy are poor; only 31% of a population of 19,441 adolescents in the U.S. reported that they would date a person with epilepsy [12] while 46.2% of 1556 Italian adults deemed the potential for marriage to be limited due to an individual receiving a diagnosis of epilepsy, and 36.5% indicated that they perceived epilepsy as a form of insanity [13]. Furthermore, 21% of a

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sample of employers in the U.K. ($n = 204$) perceived hiring a person with epilepsy as being “a major issue” [14]. This finding was replicated within an Irish context with 19% of survey respondents aged 15 years + ($n = 1001$) stating that they would not employ an individual who had a diagnosis of epilepsy [15].

While epilepsy-related stigma remains rife and globally problematic, many individuals with the condition have the capacity to conceal the diagnosis from others [16,17]. Epilepsy is an example of a concealable stigmatized identity [18], with visibility of the condition contingent upon either: (i) disclosure of the condition or (ii) the manifestation of symptoms (i.e., seizures) or cues that indicate the presence of the condition (i.e., medication-taking) in a public setting. Quinn and Chaudoir [19] demonstrated that individuals with concealable stigmatized identities (including mental illness, epilepsy, and HIV) are at risk of experiencing poor psychosocial outcomes, particularly in instances where they anticipate experiencing stigma on disclosing their identity to others.

Many contend that it is as a result of such anticipated stigma (i.e., felt stigma) that some individuals living with epilepsy choose to conceal their condition from others [16,20–23]. Other disclosure strategies adopted by persons living with epilepsy as evidenced in studies examining disclosure among adult populations include: (a) preventive disclosure (i.e., telling others prior to the occurrence of a seizure in order to avoid the inherent risk of detection and/or to forestall stigmatization) [16]; (b) selective disclosure (i.e., restricting to whom and/or what information about the diagnosis is disclosed) [24]; (c) voluntary disclosure (i.e., voluntarily disclosing epilepsy to others between seizures) [25]; and (d) social broadcasting (i.e., broadcasting the epilepsy diagnosis in an effort to educate others) [26]. In addition, disclosure of an epilepsy diagnosis can be forced in two circumstances: 1) in the event of an unplanned revelation (i.e., others witnessing seizures or drug-taking) [27] and 2) when others broadcast the person's diagnosis [28].

Despite the fact that epilepsy is a concealable stigmatized identity, there is a paucity of evidence pertaining to the disclosure experiences of CWE and their parents. It is particularly salient to examine disclosure experiences in child/adolescent populations because childhood and adolescence are critical periods for identity formation and self-definition; therefore, experiences of felt and/or enacted stigma can significantly affect the present and future psychosocial health of children/young people [8]. The disclosure experiences of parent populations are also worth attention because CWE often take cues from parents in terms of how they perceive their own epilepsy. If negative attitudes towards epilepsy are endorsed by parents, this may result in stigma coaching of the child (i.e., parents relaying to the child the perception that epilepsy is something to be ashamed of and should not be spoken about) [29].

More needs to be known about the situational context of CWE's and parents' disclosure practices because the fear of how others will react, and the associated feeling of differentness, may impact on CWE's and parents' perceived stigmatization, self-concept, perceptions of the illness, quality of life, and epilepsy management. Additionally, while concealment and selective disclosure practices may be perceived as protective strategies for the person living with epilepsy in the short-term, such approaches can contribute to the silence and lack of public knowledge surrounding epilepsy in the long-term, potentially reinforcing and exacerbating epilepsy-related stigma [30–32].

The aim of this paper was to conduct a systematic review of the evidence on the disclosure practices of CWE and their parents. The specific objectives for the review were to:

- 1) synthesize research evidence on disclosure of a child's epilepsy diagnosis from child and parent perspectives (either self- or proxy-reported);
- 2) identify enablers and/or barriers to disclosure for CWE and their parents;
- 3) examine the consequences of various disclosure practices for CWE and their parents;

- 4) investigate the relationship between demographic, clinical, and psychosocial factors and disclosure practices in CWE and their parents; and
- 5) identify and review any preexisting quantitative measures of disclosure of epilepsy employed for use in CWE and/or their parents.

2. Methods

This systematic review was conducted and reported in accordance with guidelines outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [33].

2.1. Search strategy

Eligible papers for inclusion in this review were identified through searches of the following electronic databases in March 2015: PsycINFO (1957–present), Medline (1946–present), PubMed (1940s–present), Scopus (1966–present), Web of Science (1900–present), and CINAHL (1937–present). Search terms using both controlled vocabulary from databases (e.g., MeSH) and free text words were used in various combinations as displayed in Table 1. No limiters were applied. Ancestry searching was also undertaken (i.e., a manual search of bibliographies was conducted for (i) all studies deemed eligible for inclusion and (ii) any relevant review papers identified).

2.2. Study selection criteria

Prior to commencing the search, inclusion and exclusion criteria were specified for types of studies, types of participants, and types of outcomes. All types of research designs were considered across quantitative, qualitative, and mixed method paradigms. Peer-reviewed publications of English language studies comprising original research were considered for inclusion provided they addressed one or more objectives of the review. Editorials, books, book chapters, commentaries, dissertations, and review papers were excluded.

Studies with children/young people aged 0–18 years of either sex with epilepsy of any type (idiopathic, cryptogenic, and/or symptomatic) were deemed eligible for inclusion. Manuscripts were excluded if they combined results for adults (18 years +) and children with no delineation of child-specific or adult-specific findings. Any studies examining the disclosure practices of parents of CWE (aged 0–18 years) were also included.

In terms of study outcomes, studies were included that (a) explicitly examined disclosure of an epilepsy diagnosis from child and/or parent perspectives (self- and/or proxy-reported) as the primary focus of the study, (b) examined disclosure of an epilepsy diagnosis from child and/or parent perspectives (self- and/or proxy-reported) as a subfocus of a larger study, or (c) yielded incidental emergent themes and/or

Table 1
Search terms and strategy.

Key search terms	Search strategy
Epilepsy	• Epilepsy OR epilept* OR epileps* OR epilepsies OR seizure disorder OR seizure condition AND
Family, parent, child	• Family OR familie* OR parent* OR father* OR mother* OR caregiver* OR stepparent* OR child* OR infant* OR adolescen* OR teen* OR young* OR young person* AND
Disclosure	• Disclosure OR disclos* OR tell* OR talk* OR letting know OR informing OR conversat* OR conversing OR self-disclosure OR truth disclosure OR information disclosure OR duty to warn OR parental notification OR health communication OR mandatory reporting OR public disclosure OR diagnosis disclosure OR conceal*

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