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Abstract

Objective: Stigma is reported to cause as much distress and effect on quality of life of individuals with epilepsy as the physical symptoms of seizures. Existing quantitative reviews have focused on describing levels of stigma in epilepsy, but no qualitative review has been undertaken despite the increasing number of relevant studies. We provide a qualitative synthesis to aid the understanding of stigma experiences in adults with epilepsy across different sociocultural contexts.

Methods: A systematic database search yielded an initial set of 3,032 relevant papers, of which 28 were included. A meta-synthesis was conducted according to a meta-ethnographic approach which has been adapted for health research.

Results: Five themes were generated: 1) Societal negative perceptions of epilepsy result in discrimination and rejection; 2) Internal attributions of blame lead to negative self-perception and shame; 3) Stigma impacts everyday life and contributes to reliance on others; 4) Stigma is managed through concealment and avoidance; 5) Support from others is beneficial but dependent on own and others' understandings of epilepsy. These themes highlighted the key individual experiences of epilepsy stigma, which appeared to some degree culture-specific. Culturally-informed misconceptions of epilepsy were readily internalised, resulting in emotional challenges and affecting participants' lives. Strategies for coping with this were also described.

Significance: This synthesis characterised the experiences of stigma among adults with epilepsy and highlighted key similarities and differences in these experiences across sociocultural contexts. Educational programmes to inform communities about epilepsy hold importance going forward.

Keywords: seizures, epilepsy, discrimination, experiences, qualitative

Epilepsy is a chronic condition characterised by risk of unprovoked seizures, which has multifaceted implications for the lives of individuals.[1] People with epilepsy (PWE) experience related cognitive, emotional and psychological difficulties,[2] including anxiety, depression and low self-esteem, as well as problems with family functioning.[3] PWE also experience social and legal restrictions with possible implications for their welfare, not least in relation to driving[4] and employment.[5]

Those who continue to experience seizures are more likely to report negative consequences of the condition than those who are seizure-free.[6] One contributor to this may be the stigma associated with seizures, which can cause as much distress and reduction in quality of life of PWE as the physical symptoms.[7] Higher levels of perceived stigma in PWE have been found to correlate with higher levels of anxiety[8] and depression,[3] as well as lower self-esteem.[9] In this meta-synthesis of qualitative studies, therefore, we seek to elucidate the experience of stigma in epilepsy and its effects on PWE.

Stigma in epilepsy

Stigma has been described as “an attitude that is deeply discrediting”.[10(p3)] Goffman, writing from a sociological perspective, emphasised the importance of societal norms in the development of stigma. He proposed that those who deviate from these norms are viewed as “not quite human”[10(p5)] and therefore become targets for social exclusion. Link and Phelan[11] conceptualised stigma as occurring when individuals with differences are labelled as separate and associated with negative stereotypes, resulting in loss of status and discrimination. They further argued that stigma occurs when individuals with status exercise their social power to impose their negative appraisals, disapproval and rejection of socially-different others on wider society. Stigmatised groups are then likely to be disadvantaged in social relationships, health, employment and education.[12]

Within health research, the conceptualisation of stigma has been extended to include anticipated, enacted and internalized (or felt) stigma.[13] Anticipated stigma is the degree to which individuals expect to be discriminated against or socially rejected. Enacted stigma is the extent to which a person experiences active discrimination from others. Internalized or felt stigma relate to the feelings associated with the acceptance and internal endorsement of the negative attributions or beliefs of others.[11,14] All three forms of stigma may be associated with poorer physical and psychological outcomes[15] and have a deleterious impact on health behaviours.[16]

Initial models of stigma in epilepsy were similar to those in the wider stigma literature, with similar described experiences of discrimination and internalisation of negative interactions.[17,18] Indeed, the label of epilepsy alone may incur stigma.[19] However, cultural differences in the social construction of epilepsy are apparent. One study conducted in Europe reported little overt discrimination, but significant levels of perceived stigma,[20] while more examples of enacted stigma have been reported in poorer, less resourced countries.[21] Further, until a recent campaign for change, the wording for epilepsy in China (dian xien) linked the disorder with ‘madness’, and the literal translation of epilepsy in Cambodia (Chhkourt chrouk) is ‘mad pig disease’.[22] Negative beliefs and lack of knowledge about epilepsy have also been described among those providing healthcare in some countries.[23,24] Epilepsy continues to be misrepresented in the media worldwide,[25] including significantly negative portrayals on social media.[26] While considerable effort has been invested in improving awareness of epilepsy globally,[27] recent reviews suggest that epilepsy stigma remains globally problematic.[28,29]

Qualitative research into stigma in epilepsy

A recent review of studies investigating stigma in epilepsy reported that quantitative questionnaire studies may fail to identify more subtle forms of stigma.[28] For example, one mixed methods review concluded that adolescents did not report experiencing stigma on questionnaire measures but, upon qualitative exploration, did describe keeping their epilepsy secret to avoid stigma.[30] Accordingly, qualitative studies offer an opportunity to uncover more subtle beliefs and behaviours than may be readily accessed via quantitative methods.

Qualitative reviews have only evaluated the impact of stigma on PWE in limited contexts. Although one recent meta-synthesis considered the experiences of adults with epilepsy,[31] its scope was restricted to particular countries in Africa, Asia, Eastern Europe and

Latin America and focused on perceptions of causes and treatments for epilepsy. Other reviews have explored experiences of stigma in children with epilepsy[32] and their families.[33] However, there may be distinct factors influencing stigma in adults with epilepsy, such as issues related to marriage or employment. In addition, due to the importance of sociocultural factors in experiences of stigma in PWE, individual qualitative studies are limited in generalisability by the setting and group of patients recruited. A cross-cultural perspective on effects of stigma on adults with epilepsy is consequently unavailable at present.

Study aim

Quantitative research on the effects of stigma on the quality of life of PWE has already been reviewed[34]. In order to provide a similar pan-study account of qualitative research in this area, this meta-synthesis of qualitative research explored the experience of adults living with the condition. Meta-synthesis is a generic term to describe a number of methods for systematically reviewing and integrating findings from qualitative studies. While methods for reviewing quantitative studies (such as meta-analysis) are relatively well-established within health care research, qualitative review methodologies are increasingly being seen as a valued method of not only collecting, analyzing, and interpreting results across studies, but also developing more overarching interpretations from the primary studies included in the synthesis. The following meta-synthesis of qualitative studies in adults with epilepsy provides a means of exploring themes across cultures, potentially providing new insights into living with epilepsy.

Method

Search strategy

Three systematic literature searches were conducted using four databases (PubMed, PsycINFO, Scopus and CINAHL), with the original search conducted in January 2017 and updated searches in May 2019 and February 2021. These particular databases were chosen on the advice of an academic librarian due to their relevance to the review question. The search strategy included separate searches for key search terms and thesaurus entries or Medical Subject Headings (MeSH) for the major concepts of “epilepsy”, “stigma” and “experiences” (except Scopus, which does not endorse a thesaurus). Search terms and thesaurus entries were then combined with the Boolean operator ‘OR’ for each concept. Finally, the three concepts were combined with ‘AND’ to create the final search terms. References of included papers were also hand searched, citation searches of included articles were conducted and contents of relevant journals were checked. Studies were screened for inclusion according to the following criteria: the study was written in English; it included human participants; it was epilepsy-focused; it employed qualitative research, supported by quotes, and was peer-reviewed; it was an empirical paper and not a review or other form of publication such as a letter or anecdotal report; it was stigma-specific; and people with epilepsy were the informants (i.e. not professionals or family members). The specific literature search terms are detailed in Table 1. No date restriction was applied.

Duplicates were removed. Titles and abstracts of identified studies were screened and those meeting inclusion/exclusion criteria excluded. Ninety-one full text articles were reviewed by the authors. Where there was uncertainty about inclusion (n = 12), this was discussed with a co-coder and a final decision agreed.

<insert Table 1 about here>

Selected studies

A flow chart of the search process is provided in Figure 1. Of 3,032 publications identified by the literature searches, 28 were eligible for inclusion. Twenty reported on original research. In four cases, two papers were identified which described the same study sample. All were included, as they focused on different research questions and thus provided complementary information (n = 8).[35–42]

<Insert Figure 1 about here>

The following data were extracted from each eligible study: author(s), date of publication, title of article, data collection method, method of analysis, sample size, population (including type of epilepsy), age range, and country in which the study was conducted.

Study characteristics

Characteristics of the 28 included studies can be found in Table 2. The final 28 articles identified for this review were published between 2002 and 2021, representing 24 samples. The studies describe experiences of stigma in people with a range of epilepsy diagnoses and seizure types, within a diverse range of settings. The countries of origin were upper income countries such as the UK (n = 6), US (n = 4), Sweden (n = 4), Australia (n = 2), Ireland (n = 1), Slovenia (n = 1), Japan (n = 1) and Canada (n = 1); upper middle income countries such as South Africa (n = 2) and Argentina (n = 1); and lower middle income countries such as Indonesia (n = 1), Nigeria (n = 1), Ghana (n = 1), Zambia (n = 1) and Iran (n = 1).

All articles focused on direct experiences of PWE. Data were collected via individual interviews (n = 22), focus groups (n = 5), or a combination of both (n = 1). Forms of qualitative analysis included: content analysis (n = 10), thematic analysis (n = 7), phenomenological approach (n = 7), grounded theory (n = 2), ethnographic approach (n = 1), and hermeneutic analysis with systematic interpretation (n = 1).

<Insert Table 2 about here>

Quality Appraisal

To assess the methodological and reporting quality of the included studies, the Critical Skills Appraisal Skills Programme (CASP) tool was administered.[43] The CASP tool was developed to appraise qualitative health research across ten domains reflecting rigour, credibility and methodological aspects considered vital in qualitative research. Each paper was scored 'yes', 'no', or 'can't tell' for the initial two screening questions. Further criteria were scored alongside a three-point rating system developed by Duggleby and colleagues[44] rating how well the study met each of the eight criteria (weak: 1 point; moderate: 2; strong: 3). Four papers (17%) were appraised by an external rater to ensure rigour. Inter-rater agreement was 88%. Where discrepancy was found, this was discussed and a final score agreed. For outcomes of the quality rating procedure, see Table 3.

CASP scores ranged from 10 to 24 (potential range 8-24), indicating considerable variability in reporting quality. Following Sandelowski,[45] studies were not excluded based on the appraisal score due to the lack of consensus around what makes ‘good’ qualitative research. For example, lower scores may be indicative of reporting quality rather than the actual research process.[46] Further, since multiple studies were the only source of information for a given culture or region, exclusion would significantly narrow the perspective of the analysis. Scores were however taken into account when interpreting evidence during synthesis.

<Insert Table 3 about here>

Data Analysis

Meta-synthesis systematically integrates the findings of qualitative research in an attempt to create new meaning.[47] For this review, qualitative data from the final 28 studies was analysed using Noblit and Hare’s meta-ethnographic approach.[48] This approach aims to retain the interpretative nature of qualitative studies (rather than simply summarising the findings) and identify new themes from the data.[49] Thus, an interpretive position was assumed throughout the synthesis.

Guidance for synthesizing qualitative literature[48] was followed alongside a worked example adapted for health research.[50] Recent guidance on the reporting of meta-ethnographies was also followed.[51] This seven-stage approach allows for the identification of higher-order themes which provide an interpretative account of the synthesised studies. Following this process, the papers were read and re-read to create familiarity with their content. In line with Atkins et al.,[46] studies were examined chronologically. The first iteration of themes was produced by identifying key themes and subthemes from the results section of each paper and summarising these using the original authors' language from the results and discussion sections. Key findings from each of the included articles are summarised in Table 4.

Next, studies were compared so that similarities and differences in themes and subthemes could be identified. Through reciprocal translation following Noblit and Hare,[48] similar concepts were grouped and second-order constructs were formed. These translated constructs were then grouped into new conceptual contexts to form final third-order constructs. 'Lines of argument' were generated to express our interpretation of the synthesised results, offering conceptual development beyond the individual studies.[52] To enhance rigour, details of the analytic process are provided in Table 5.

<insert Table 4 about here>

<insert Table 5 about here>

Results

Five main themes were generated from the synthesis.

Theme 1: Societal negative perceptions of epilepsy leading to discrimination and rejection

This theme illustrates how PWE described being viewed as different from what was culturally expected, and their experience of varying levels of discrimination from the public and those with whom they had relationships. This was often due to misconceptions about the nature of epilepsy, but also due to the physical manifestations of seizures, which were not well understood and negative attributions were common. Negative attitudes towards epilepsy were described across all studies, resulting in discrimination or rejection.

Participants described a lack of public understanding regarding epilepsy, including causation, which predominantly resulted in negative views of the condition. In some cultures, participants referenced others' misconceptions that epilepsy was caused by supernatural forces, such as witchcraft, demonic possession or another person attempting to harm them: "I think that it is a bad spirit that caused this sickness".[53(p.23)] This could cause fear of affected individuals. Religious beliefs often cast epilepsy as a punishment for wrongdoing and the person with the condition as "damned".[54(p.111)] Such perceptions may shift blame towards the affected individual, maintaining negative perceptions.[55] Further, in settings where supernatural causes for epilepsy dominated, a belief in non-medical treatments intended to 'cure' epilepsy was also reported: "they believe [in Nigeria] it was a spiritual attack…they might do some cleansing".[56(p.454)] PWE could be vulnerable to extreme forms of assault: "I know of a woman with epilepsy who was beaten with extensive bodily injuries because she was thought to be possessed of an evil spirit".[57(p.45)] Other studies described experiences of physical and sexual assault, rejection from the community, and public humiliation and ridicule. Such negative societal views regarding PWE could result in complete rejection, even from family. Participants described how women with epilepsy living in urban settings in Africa were "sent back to the village",[58(p.169)] which was perceived as a poorer and less privileged society.

Misunderstandings regarding the neurobiological underpinnings of epilepsy were also commonplace. A study conducted in Slovenia described concerns regarding contagion; one participant reported “she asked me if it is contagious and if she can get ill”.[59(p.7)] Similarly, a Ghanaian participant described the reaction of their family: “They don’t even allow me to touch anything belonging to someone…I was even asked to buy my own cup and bucket to use”.[53(p.33)] Physical manifestations of seizures might also be misperceived as side-effects of using illicit substances.[60] Public lack of knowledge regarding different types of epilepsy could also impact on others’ perceptions: “I mean if you go down on the floor and shake people know what’s going on… but when you’re just talking a load of rubbish you know, they just think you’re totally mad”.[40(p.667)] Indeed, reports from several studies described a perceived association between epilepsy and mental illness, for example: “People in my neighbourhood think that I am crazy because I got this epilepsy, they told my family and me that this is mental health illness”.[61(p.624)] Such misconceptions regarding epilepsy could result in enacted stigma, although less overt. For example, those who were viewed as being under the influence of drugs might be inappropriately treated or not treated at all: “They told her that they wouldn’t call an ambulance for someone on drugs”.[59(p.6)]

When epilepsy was not viewed as a medical condition, treatment was often withheld. Even when epilepsy was viewed as having a biological cause, the perception that it might be hereditary could prevent others forming intimate relationships with PWE, in case it was passed on to their children.[59] Medication burden and visiting psychiatric clinics for support were also described as distressing or “weaknesses” in multiple studies:[62,63] “I don’t want my children to see me weak. They must feel that mum is strong”.[63(p.3)]

Discriminatory behaviour was also experienced from healthcare professionals, whom participants expected to understand the causes and consequences of epilepsy better. Accounts reported doctors as not having the time to listen to the concerns of PWE, lacking empathy, or behaving as if they “don’t care”.[55(p.55)] Participants also experienced discrimination due to the hidden nature of the illness. For example, participants reported being viewed as “lazy”,[35(p.31)] perhaps for not working or not recovering quickly, because their symptoms were usually invisible to others.

Thus, epilepsy was referred to as a “taboo”.[59(p.5)] Across cultures and contexts, PWE were not accepted within society and appeared to be marked as lower in social value. The extent of this varied, often depending on local social and cultural perceptions regarding epilepsy.

Theme 2: Internal attributions of blame lead to negative self-perception and shame

This theme describes how societal stigma towards epilepsy could be internalised, resulting in negative self-perception. Participants described distress at identifying as someone with epilepsy and feelings of shame, often due to its impact on others.

Accounts indicated that cultural or societal beliefs about the nature of epilepsy influenced how individuals learned to perceive themselves as a PWE. Negative associations with epilepsy could become internalised. For example, participants from African cultures, in which epilepsy was viewed as having supernatural causes, reported viewing themselves as "witches".[56(p.455)] Similarly, where epilepsy was viewed as a curse for wrongdoing, this resulted in participants blaming themselves for their condition.

In contrast, in cultures such as the US or Europe which have dominant medical or neurological explanations for epilepsy, participants described more readily accepting this explanation. However, lack of public knowledge about epilepsy and resultant unclear individual cognitions about the nature of the condition could still result in PWE questioning whether they were to blame. One participant in Sweden commented: "I think that I got the epilepsy due to the incident when my boyfriend died… He killed himself… I don't follow him home the night it happened… I don't think I would have it if I had… and then I got my epilepsy 2 weeks later".[35(p.206)] Such accounts provide insight into how PWE appeared to make sense of their condition, often influenced by dominant narratives within their society.

Therefore, cultural and individual perceptions about the nature of epilepsy, and related negative associations, led PWE to feel different within society. In many studies, this sense of difference was described to endure beyond the acute seizures themselves: "It's not the seizures, it's that effect of feeling different. It's not the physical reality, it's that psychological effect that just doesn't go away".[64(p.283)] One study described a women's word for her epilepsy, "iyandiguqula", meaning 'epilepsy makes her a different person'.[42] This enduring sense of being different often led to negative self-perceptions, including low self-worth and disgust: "I thought it was a miracle that there are people out there who would even talk to us";[59(p.5)] "I felt like a 'mongo', epilepsy is yucky, people that have it are dirty".[35(p.205)]

Participants reported an expectation of societal rejection: “I’m a reject you know, basically, I’m one of nature’s rejects”.[40(p.669)] A study of immigrants in Sweden additionally highlighted that such self-stigma could be exacerbated by language barriers, membership of a minority group and socioeconomic deprivation, heightening the sense of being different.[63]

Shame was also commonly associated with stigma. This appeared related to negative associations with epilepsy and fears about the diagnosis becoming known to others: “I don’t want anyone to know that I have it… it is shameful… and I am afraid that it will come out that I have it”.[35(p.206)] Ghanaian participants described the shame of experiencing seizure episodes at school or church: “I think it (epilepsy) is a bad illness that wants to disgrace me just like that … It is a disgraceful illness”.[53(p.22)] In a Japanese study, participants’ negative beliefs about epilepsy included feeling abnormal and ashamed: “I think everyone has a bad image of epilepsy”.[62(p.5)] Such self-stigmatising beliefs were described in the majority of studies but varied in severity across cultures and settings. In collectivist cultures, participants demonstrated greater distress and concern about the potential impact of their epilepsy on family members and communities, than about personal emotional distress. For example, in a Zambian study: “The shame on me, it was too much [on her] and the name on the family…. Another family doesn’t want anything to do with your family.”[56(p.454)] Participants expressed a sense of responsibility for others’ responses to their epilepsy.

Furthermore, experiencing seizures in public led to feelings of guilt due to the perceived negative impact on witnesses or the risk of injuring others. Participants described how others could experience seizures as frightening, particularly children.[65] This appeared to result in an emotional conflict due to the perceived need to take personal responsibility for their epilepsy, over which they felt they had limited control.

Theme 3: Impact of stigma on everyday life and associated reliance on others

The third theme describes how epilepsy affected all areas of daily life. Participants described the impact on fulfilling their expected societal roles, and the reduced possibilities for education and employment. Reliance on others and externally-enforced decisions about their lives often resulted in individuals feeling that their epilepsy was in control.

Participants described experiencing restrictions in many areas due to overwhelming epilepsy stigma, which made living a socially-conventional lifestyle more challenging. Such experiences appeared to create a sense of diminished and limited life: “When you are whole, you can do anything… When epilepsy is on your record, all doors close”.[59(p.5)] Participants in Deegbe and colleagues’[53] study described overprotective relatives restricting their freedom in an apparent attempt to protect the affected individual, such as by preventing them from cooking, handling electrical gadgets or attending social gatherings or school.

In all studies, epilepsy was described as significantly affecting individuals’ ability to form and maintain relationships. Participants also described epilepsy causing the ending of marital relationships, expressed fears that partners would abandon them, or perceived epilepsy as a potential deterrent to marriage. Therefore, some participants described feeling thankful to their partner for being “still here”.[66(p.756)] or described surprise at their partner’s positive and protective response to their condition: “My partner says to me, you are special.

You are not like all the rest… Yes it's a good match".[66(p.756)] Such differences appeared to result from partners having a good understanding of epilepsy, which protected against stigma.

The majority of female participants also described restrictions in their aspiration to become parents. Participants held inaccurate beliefs that pregnancy could worsen their condition, that they may harm their developing baby or that their baby would also develop epilepsy.[35] For example, a Ghanaian women in one study commented "Because of this illness … anytime I get pregnant I lose it".[53(p.23)] This often appeared attributable to a lack of sufficient information, due either to limited access to healthcare or professionals not taking time to discuss it. In some cultures, the perceived inability to provide children within a relationship was described as being deeply shaming[58] and a cause of grief and sadness: "It really hurts, knowing that I will never experience pregnancy, I will never have a child of my own".[35(p.206)] However, the impact of epilepsy on parenting in male participants was only clearly described in one study.[38] This study reported three types of changes in participants' perception of their role within the family – role marginalization, role dependency and role enmeshment. Marginalisation was evident through not being consulted about everyday life activities, role dependency by their previous decisional role shifting towards their spouses/ partners and children, and role enmeshment by being perceived by spouses/partners as adult–children and by their children as a parent–child.

Participants also described difficulties with making and sustaining friendships, often due to fear of rejection and the need to explain a condition which might not be well understood. Some participants described experiencing rejection or distancing from others after witnessing a seizure: “I even had friends that [witnessed me when] I’ve had a seizure, and now they’re no longer my friends”.[66(p.260)] Participants also described the discriminatory behaviour of others within wider society, such as friends from exercise settings,[67] religious groups or their place of residence,[68] which reduced opportunities for social activities and interaction.

Participants across studies described significant restrictions in finding employment: “I didn’t get a job because I have epilepsy and it was made very clear that that was the reason”[64(p.283)] For some, employment opportunities were limited by disrupted education due to epilepsy in childhood, for example due to rejection or inability to access school.[55,63] Additional limitations such as not being able to drive were also described as problematic.[65] Lack of employment opportunities could have a devastating impact, including damage to self-image, rejection from partners or family units, poverty and further exclusion.[57,63]

In societies where such systems were available, participants described reliance on public benefits. However, this was often complicated by the hidden nature of epilepsy and lack of understanding, meaning participants often struggled to prove they “deserved” assistance. Not being able to work and relying on assistance could also increase shame around participants feeling they were not satisfactorily contributing to society.

Participant accounts described significant difficulties with loss of role, autonomy and independence. Participants described needing to rely heavily on others for financial, practical and emotional support, which could result in disappointment and guilt about burdening others.[36,55,60] For example, one person in an Indonesian study explained that ”I am afraid to become a burden to my family… my parents always accompany me everywhere”.[61(p.624)] Moreover, participants frequently reported feeling their decisions were dictated by healthcare professionals, family or employers,[41] although such decisions were sometimes believed incorrect due to others’ “ignorance” regarding epilepsy.[65] Thus, PWE expressed a sense of powerlessness over their own lives.[59] Interestingly, participants often described conflict between appreciation of offered support and finding their dependence restrictive and infantilising, particularly in cultures in which independence was encouraged.[38]

Theme 4: Attempts to manage stigma through concealment and avoidance

This theme illustrates how participants coped with the stigma associated with epilepsy. Participants described differences in accepting or denying their diagnosis, and the related behavioural strategies they used. For some these strategies were protective, while others recognised the potential to maintain inadvertently the stigma.

Differences in the extent to which PWE accepted and adjusted to their condition were evident. Several participants’ accounts described denial of an epilepsy diagnosis. This often appeared related to their own perceptions regarding epilepsy. For example, one individual denied the diagnosis despite their seizures: “I don’t have epilepsy because I do not foam from the mouth”.[57(p.41)] Others described protectively separating themselves from the negatively-perceived condition: “unlike me, he has those…terrible seizures”.[70(p.110)] Some participants described engaging in more drastic behaviours to reject their condition, including relocating, in order to live “as though nothing has happened”.[39(p.28)]

Even those who accepted their condition often chose to hide it from others to avoid stigma. Participants described fear of their epilepsy being known to others, often anticipating negative reactions following previous negative experiences around disclosure.[62,67] In some accounts, participants reported going to great lengths to conceal their epilepsy and present themselves as 'normal': "I would get an aura [perceptual disturbance preceding a seizure], and I would get up and run to the bathroom, and I could hide it for years".[64(p.284)] Further concealment behaviours were described, such as avoiding taking medication in public, and participants expressed aversion to informing family, employers and even healthcare professionals.[62] Concealment appeared particularly prevalent in employment situations. Indeed, even in societies with stronger anti-discriminatory employment laws, participants described the direct experience of colleagues or employers witnessing a seizure which then resulted in dismissal.[64]

In contrast, other participants described being open about their epilepsy. For some this was on a need-to-know basis, for example regarding safety concerns and managing risk: "I tend to tell people, if they ask and if it's important".[40(p.671)] For others, disclosure allowed a sense of liberation and the potential to be better understood. However, participants described being selective regarding who they disclosed to and the benefit of practicing telling beforehand.[70] Moreover, concealment was often context-dependent; participants from societies where they might be more vulnerable to extreme discrimination and abuse rarely described voluntary disclosure.

The majority of participants described fear of forced disclosure of their epilepsy, for example by having a seizure in public, which carried potential for further discrimination. As a result, social withdrawal and self-isolation were common: “in the end I will end up going nowhere in case of having a seizure… the risk is that one becomes… well… kind of isolated”.[36(p.1998)] While most accounts described this as protective, some identified how such behaviour further limited life and the ability to form relationships.

Some participants identified how their choice not to disclose might contribute to others’ lack of knowledge: "I don't speak about it so maybe that's the problem".[69(p.89)] It was felt that concealment may inadvertently maintain stigma,[69] generating feelings of ambivalence in some participants. However, in many contexts the risk of exposure continued to outweigh this perceived responsibility, and was therefore not sufficient to change disclosure behaviour.

Theme 5: Support from others is beneficial but dependent on own and others’ understandings of epilepsy

Contrary to the many difficulties described by participants in adjusting to challenges around epilepsy and stigma, this final theme describes the strategies and resources adopted by PWE. Participants described the need for support, mostly from family but also from wider society, which was improved by better knowledge about epilepsy. Participants therefore perceived a need for better education and more accurate media representation.

Participants described relying on others for practical and emotional support: “When you’ve had a seizure and wake up, you want to be near a person you like, someone you know”.[63(p.4)] Perhaps due to the aforementioned dependency on others, participants expressed that a supportive family was critical to managing epilepsy and stigma: “whatever my condition is, my family always support me and be my side”.[61(p.624)] Indeed, supportive others could improve access to healthcare which might otherwise be difficult for PWE to access or navigate independently. Furthermore, participants described family support helping them to manage the emotional impact of stigma and practical limitations of epilepsy.[71]

Participants in many studies described the ongoing need for education about epilepsy both for themselves and others, as it was believed that: “a lot of stuff people don’t understand, scares them.”[73(p.110)] Participants hoped that this would help to reduce fear and negative beliefs about epilepsy.[61] Participants thought that increased awareness about the heterogenous nature of the condition and potential invisibility of epilepsy might reduce negative misperceptions and increase empathy.[68] Several felt that it was the collective responsibility of wider society to educate and correct misinformation about epilepsy. One participant described ongoing epilepsy stigma as a consequence of what is “seen on TV”,[73(p.11)] identifying a potential contributing role of media misrepresentations of epilepsy in maintaining stigma.

Individual coping strategies were also reported. One participant described restructuring negative cognitions to view the self as a survivor.[39] Others described the importance of improved self-care or resilience.[68] However, these were often dependent on social circumstances and appeared predominantly in descriptions from those who also reported sufficient support from others, and who thus perceived themselves as having better quality of life.

While few participants described the benefits of professional emotional support, support groups, in which others shared knowledge and experiences of epilepsy and stigma, were discussed, describing a unique opportunity for care. As many participants experienced social isolation, support groups provided opportunities for social interaction and expression of negative feelings: "So we need a place where people can go to open up. Some kind of group or something";[67(p.261)] "I want more places to talk about epilepsy".[62(p.7)] Unfortunately, these were not available to participants in most studies and were mentioned rarely across accounts.

Furthermore, participants in several studies described feeling let down by members of their community. Descriptions were commonplace regarding the responsibility of institutions, such as churches and schools, to educate society about epilepsy. This was particularly evident in collectivist cultures, or settings in which particular institutions were significantly influential on community views. Interestingly, even when misperceptions about the causes of epilepsy remained, positive attitudes towards epilepsy in a particular group or setting could be protective.

Discussion

This review aimed to understand and synthesise experiences of stigma in adults with epilepsy across cultures and contexts. The meta-ethnographic method of synthesis allowed incorporation of individual perspectives of epilepsy across a variety of contexts, and for key experiences to be identified. The developed themes highlight the adverse experiences of PWE resulting from stigma and discrimination. Although this has been evidenced in previous studies, this review conceptualises individual experiences of epilepsy-related stigma, dependent on sociocultural representations of epilepsy. The findings showed that misconceptions regarding epilepsy were readily internalised, leading to negative self-perceptions and widespread implications for participants' lives. Participants demonstrated a process of psychological and practical adaptation to overcome these challenges, and support from others also appeared crucial. The need for improved societal understandings regarding epilepsy was consequently highlighted.

While misconceptions about epilepsy were common, the degree of discrimination associated with negative representations was influenced by sociocultural context. Extreme acts arising from stigma were more common in lower middle income countries, such as parts of Africa, whereas participants in studies conducted in high income societies such as the US and Europe described more subtle experiences. It has been proposed that experiences of felt stigma might be more problematic for PWE in countries with improved seizure control than experiences of enacted stigma, and vice versa in regions with poorer healthcare.[6] In this review, however, PWE across cultures experienced both felt and enacted stigma – although sociocultural factors clearly still affected individual experiences.

Culturally-informed misconceptions about epilepsy were internalised, resulting in significant negative self-perceptions. It has been suggested that felt stigma, or fear of enacted stigma, may be more of a burden and have a greater influence on PWE than enacted stigma itself.[73] Indeed, this review highlighted the extensive perceived implications of felt and anticipated stigma on participants' lives and their attempts to overcome it.

Participants described restrictions in many aspects of daily life as a result of stigma, dependent on sociocultural context. Some significant restrictions were perceived as externally-enforced, including the impact of stigma on forming and maintaining relationships, the ability to marry and start a family, and potential for social activity, education and employment. Social models of disability are, therefore, also likely to be of relevance in understanding distress in PWE,[74] such as models relating to people with mental health difficulties,[75] intellectual impairment[76] and neurological conditions.[77] Thomas' model of psycho-emotional disablism bears particular relevance.[78] This social-relational definition of disablism identifies two dimensions that can disable people: environments that may exclude what people can 'do' (e.g. lack of healthcare services or inappropriate workplaces, as described by participant accounts here), and social interactions that can impact on psychological wellbeing and what people can 'be'.[79]

Consistent with this concept, most barriers described by participants appeared socially enforced. Negative social interactions, such as avoidance and rejection from others, resulted in negative self-perceptions and shame. Accordingly, participants described reduced social interaction and increased concealment of epilepsy, often through non-disclosure. Three modes of disclosure or non-disclosure have been identified;[81] ‘pragmatic’, in which people advise those who need to know; ‘secret’, in which epilepsy is concealed; and ‘quasi-liberated’, in which the condition is disclosed to educate others about their prejudices. In this review, significant cultural differences were evident in disclosure behaviour. While participants in some studies and countries identified potential for disclosure to reduce stigma through education, others felt unsafe to do so due to lack of legal protection and/or potential for abuse in their culture. In social relational definitions of disablism, such adaptive concealment behaviours are described as ‘passing’[82] and used in attempts to appear ‘normal’. However, passing can have negative psychological consequences, such as fear of exposure, and requires significant physical and emotional effort.

Participants in several studies described the shame experienced when their epilepsy affected others, particularly their family. This is consistent with the concept of ‘courtesy stigma’. Goffman originally argued that individuals can be subject to stigma through their association with a stigmatised person, as opposed to an attribute of their own. Courtesy stigma has been shown in HIV/AIDS[83] and may partially explain the rejection of PWE by close others. This is an important consideration for improving the negative impact of stigma, as seeking support was described as a key coping strategy and reducing rejection could improve the availability of support.

Participants described a range of negative cognitive and emotional experiences resulting from stigma. This is consistent with quantitative studies that correlate epilepsy stigma with poorer psychosocial wellbeing.[84] Psychotherapeutic interventions have consequently been recommended to address the spectrum of difficulties experienced by PWE.[85] Our findings suggest that such interventions may help to reappraise cognitions and enhance self-directed emotions and self-care in relation to felt stigma. However, few participants reported access to such support.

Psychosocial interventions for the impact of epilepsy is a developing field,[86] with recommendations for the psychological treatment of PWE recently developed.[87] These recommendations promote individual-based approaches to improve social and communication skills, or psychoeducation. The findings in this review, however, suggest that it may be valuable to incorporate the impact of sociocultural factors in addition to individual interventions. Furthermore, such approaches may inadvertently maintain stigma by focusing the blame (or responsibility for improvement) on the individual. Instead, this review highlights a need for ongoing educational programmes to improve epilepsy awareness worldwide. This could help to combat misconceptions in affected and unaffected populations, and hopefully reduce psycho-emotional disablism over time, although change in deep-seated perceptions is unlikely to be swift.[88] Lessons could also be applied from interventions aimed at reducing stigma in other conditions, such as HIV/AIDS.[89] Consideration of target audience (e.g. family members, healthcare professionals) and intended outcome (e.g. stigma-related knowledge, attitudes, and intended behaviour) will be crucial.[84]

Several participants also described the benefit of support groups, which provide a space to be open about their condition and offer safe social interaction. Many epilepsy charities in the high income countries offer such opportunities, but not all societies do.

Programmes offering safe discussion about epilepsy in different sociocultural contexts would, therefore, be of benefit.

Strengths and limitations

This qualitative meta-synthesis allowed for the voices of a larger number of participants to be considered in understanding cross-cultural experiences of epilepsy stigma. The meta-ethnographic approach allowed for individual participants' experiences to be preserved. However, synthesis relies on not only the language of the participants, but the interpretations of the authors of individual studies and the meta-synthesis. Many study interviews were also not completed in English, which required use of interpreters and so their voices may also be introduced. Additionally, while our literature search identified an increase in qualitative studies exploring epilepsy stigma over time, earlier investigations were confined to a relatively small number of researchers.[90] This may have limited the scope of our understanding, as existing models may have relied heavily on the experiences and assumptions of these authors.

Variability in study quality according to the CASP tool may also affect the findings presented here, with key qualitative information often missing. Notably, few authors provided reflexive information regarding their own role and influence on the research process, making it is difficult to judge the integrity of the findings.[91] Further, many studies were limited in the transparency of their analysis.[92]

The variation in sample selection may be considered both a strength and limitation to this review. For example, within studies, experiences of stigma were explored according to seizure type. Incorporating studies which contained experiences of participants with different forms of epilepsy provides insights into varied perspectives (e.g. those who experience tonic-clonic seizures may have different experiences from those with other forms of seizure), but may fail to identify important distinctions. Similarly, studies were conducted at different time points ranging from 2002 to 2019 and their findings may have been influenced by socioeconomic changes over that time – for example, the World Health Organization (WHO) Global Campaign against Epilepsy "Out of the Shadows"[27] was ongoing throughout this period.

In conclusion, this meta-synthesis describes experiences of stigma in adults with epilepsy and highlights variability in these experiences across sociocultural contexts. Culturally-informed misconceptions of epilepsy were readily internalised, which resulted in emotional challenges for participants and had far-reaching implications on their lives. While individual strategies to cope with the impact were utilised, opportunities for educational programmes to improve understanding in both affected and non-affected populations are a priority.

References

1. Kerr MP. The impact of epilepsy on patients' lives. *Acta Neurol Scand*. 2012;126:1-9. doi:10.1111/ane.12014
2. Quintas R, Raggi A, Giovannetti AM, et al. Psychosocial difficulties in people with

epilepsy: A systematic review of literature from 2005 until 2010. *Epilepsy Behav*. 2012;25(1):60-67. doi:10.1016/j.yebeh.2012.05.016

3. Jacoby A, Baker GA, Steen N, Potts P, Chadwick DW. The clinical course of epilepsy and its psychosocial correlates: Findings from a U.K. Community study. *Epilepsia*. 1996;37(2):148-161. doi:10.1111/j.1528-1157.1996.tb00006.x
4. Krumholz A, MD. Driving issues in epilepsy: Past, present, and future. *Epilepsy Curr*. 2009;9(2):31-35. doi:10.1111/j.1535-7511.2008.01283.x
5. Elwes RD, Marshall J, Beattie A, Newman PK. Epilepsy and employment. A community based survey in an area of high unemployment. *J Neurol Neurosurg Psychiatry*. 1991;54(3):200-203. doi:10.1136/jnnp.54.3.200
6. Baker GA. The psychosocial burden of epilepsy. *Epilepsia*. 2002;43 Suppl 6:26-30. doi:10.1046/j.1528-1157.43.s.6.12.x
7. Jacoby A. Stigma, epilepsy, and quality of life. *Epilepsy Behav*. 2002;3(6):10-20. doi:10.1016/S1525-5050(02)00545-0
8. Jacoby A. Felt versus enacted stigma: A concept revisited. Evidence from a study of people with epilepsy in remission. *Soc Sci Med*. 1994;38(2):269-274. doi:10.1016/0277-9536(94)90396-4
9. Westbrook LE, Bauman LJ, Shinnar S. Applying stigma theory to epilepsy: A test of a conceptual model. *J Pediatr Psychol*. 1992;17(5):633-649. doi:10.1093/jpepsy/17.5.633
10. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall; 1963.
11. Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol*. 2001;27(1):363-385.

doi:10.1146/annurev.soc.27.1.363

12. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health*. 2013;103(5):813-821. doi:10.2105/AJPH.2012.301069

13. Earnshaw VA, Chaudoir SR. From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS Behav*. 2009;13(6):1160-1177. doi:10.1007/s10461-009-9593-3

14. Link BG, Cullen FT, Struening E, Shrout PE, Dohrenwend BP. A modified labeling theory approach to mental disorders: An empirical assessment. *Am Sociol Rev*. 1989;54(3):400. doi:10.2307/2095613

15. Quinn DM, Chaudoir SR. Living with a concealable stigmatized identity: The impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *J Pers Soc Psychol*. 2009;97(4):634-651. doi:10.1037/a0015815

16. Earnshaw VA, Quinn DM. The impact of stigma in healthcare on people living with chronic illnesses. *J Health Psychol*. 2012;17(2):157-168. doi:10.1177/1359105311414952

17. Scambler G, Hopkins A. Generating a model of epileptic stigma: The role of qualitative analysis. *Soc Sci Med*. 1990;30(11):1187-1194. doi:10.1016/0277-9536(90)90258-t

18. Muhlbauer S. Experience of stigma by families with mentally ill members. *J Am Psychiatr Nurses Assoc*. 2002;8(3):76-83. doi:10.1067/mpn.2002.125222

19. Baker GA, Jacoby A, Buck D, Stalgis C, Monnet D. Quality of life of people with epilepsy: A European study. *Epilepsia*. 1997;38(3):353-362. doi:10.1111/j.1528-

1157.1997.tb01128.x

20. Baker GA, Brooks J, Buck D, Jacoby A. The stigma of epilepsy: A European perspective. *Epilepsia*. 2000;41(1):98-104. doi:10.1111/j.1528-1157.2000.tb01512.x

21. de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy Behav*. 2008;12(4):540-546. doi:10.1016/j.yebeh.2007.12.019

22. Kim HD, Kang H-C, Lee SA, Huh K, Lee B-I. Changing name of epilepsy in Korea; Cerebroelectric disorder (noi-jeon-jeung, 뇌전증,腦電症). *Epilepsia*. 2014;55(3):384-386. doi:10.1111/epi.12516

23. Alaqeel A, Alebdi F, Sabbagh AJ. Epilepsy: What do health-care professionals in Riyadh know? *Epilepsy Behav*. 2013;29(1):234-237. doi:10.1016/j.yebeh.2013.07.009

24. Ekenze OS, Ndukuba AC. Perception of epilepsy among public workers: Perspectives from a developing country. *Epilepsy Behav*. 2013;26(1):87-90. doi:10.1016/j.yebeh.2012.10.016

25. Kerson TS, Kerson LA. Truly enthralling: Epileptiform events in film and on television--why they persist and what we can do about them. *Soc Work Health Care*. 2008;47(3):320-337. doi:10.1080/00981380802174069

26. McNeil K, Brna PM, Gordon KE. Epilepsy in the Twitter era: A need to re-tweet the way we think about seizures. *Epilepsy Behav*. 2012;23(2):127-130. doi:10.1016/j.yebeh.2011.10.020

27. De Boer HM. “Out of the shadows”: A global campaign against epilepsy. *Epilepsia*. 2002;43 Suppl 6:7-8. doi:10.1046/j.1528-1157.43.s.6.4.x

28. Herrmann LK, Welter E, Berg AT, Perzynski AT, Van Doren JR, Sajatovic M. Epilepsy misconceptions and stigma reduction: Current status in Western countries.

Epilepsy Behav. 2016;60:165-173. doi:10.1016/j.yebeh.2016.04.003

29. Kaddumukasa M, Kaddumukasa MN, Buwembo W, et al. Epilepsy misconceptions and stigma reduction interventions in sub-Saharan Africa, a systematic review. *Epilepsy Behav*. 2018;85:21-27. doi:10.1016/j.yebeh.2018.04.014

30. MacLeod JS, Austin JK. Stigma in the lives of adolescents with epilepsy: A review of the literature. *Epilepsy Behav*. 2003;4(2):112-117. doi:10.1016/s1525-5050(03)00007-6

31. Tanywe A, Matchawe C, Fernandez R. The experiences of people living with epilepsy in developing countries: A systematic review of qualitative evidence. *JBI Database Syst Rev Implement Reports*. 2016;14(5):136-192. doi:10.11124/JBISRIR-2016-002182

32. Chong L, Jamieson NJ, Gill D, et al. Children's experiences of epilepsy: A systematic review of qualitative studies. *Pediatrics*. 2016;138(3). doi:10.1542/peds.2016-0658

33. Harden J, Black R, Chin RFM. Families' experiences of living with pediatric epilepsy: A qualitative systematic review. *Epilepsy Behav*. 2016;60:225-237. doi:10.1016/j.yebeh.2016.04.034

34. Baker D, Eccles FJR, Caswell HL. Correlates of stigma in adults with epilepsy: A systematic review of quantitative studies. *Epilepsy Behav*. 2018;83:67-80. doi:10.1016/j.yebeh.2018.02.016

35. Räty LKA, Larsson G, Starrin B, Larsson BMW. Epilepsy patients' conceptions of epilepsy as a phenomenon. *J Neurosci Nurs*. 2009;41(4):201-210. doi:10.1097/jnn.0b013e3181aaaa75

36. Räty LK, Wilde-Larsson BM. Patients' perceptions of living with epilepsy: A

phenomenographic study. *J Clin Nurs*. 2011;20(13-14):1993-2002. doi:10.1111/j.1365-2702.2010.03572.x

37. Keikelame MJ, Swartz L. “The others look at you as if you are a grave”: A qualitative study of subjective experiences of patients with epilepsy regarding their treatment and care in Cape Town, South Africa. *BMC Int Health Hum Rights*. 2016;16:9. doi:10.1186/s12914-016-0084-0
38. Raffaele M. A qualitative study exploring family life in men following neurosurgery for adult onset epileptic seizures. *Aust J Rehabil Couns*. 2018;24(2):55-66. doi:10.1017/jrc.2018.11
39. Raffaele M, Mpofu E, Smith-Merry J, Mackey M. Men with adult onset epileptic seizures: Their coping strategies and sense of subjective wellbeing following elective neurosurgery. *Aust J Rehabil Couns*. 2017;23(1):19-36. doi:10.1017/jrc.2017.1
40. Kilinç S, Campbell C. “It shouldn’t be something that’s evil, it should be talked about”: A phenomenological approach to epilepsy and stigma. *Seizure*. 2009;18(10):665-671. doi:10.1016/j.seizure.2009.09.001
41. Kılınç S, van Wersch A, Campbell C, Guy A. The experience of living with adult-onset epilepsy. *Epilepsy Behav*. 2017;73:189-196. doi:10.1016/j.yebeh.2017.05.038
42. Keikelame MJ, Swartz L. "I wonder if I did not mess up….": Shame and resistance among women with epilepsy in Cape Town, South Africa. *Seizure*. 2018;61:50-56. doi:10.1016/j.seizure.2018.07.021
43. Critical Appraisal Skills Programme. CASP Qualitative Studies Checklist. https://casp-uk.net/referencing/. Accessed July 8, 2021.
44. Duggleby W, Holtslander L, Kylma J, Duncan V, Hammond C, Williams A.

Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qual Health Res*. 2010;20(2):148-158. doi:10.1177/1049732309358329

45. Sandelowski M, Docherty S, Emden C. Focus on qualitative methods. Qualitative metasynthesis: Issues and techniques. *Res Nurs Health*. 1997;20(4):365-371. doi:10.1002/(sici)1098-240x(199708)20:4<365::aid-nur9>3.0.co;2-e

46. Atkins S, Lewin S, Smith H, Engel M, Fretheim A, Volmink J. Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Med Res Methodol*. 2008;8:21. doi:10.1186/1471-2288-8-21

47. Harden A, Thomas J. Methodological issues in combining diverse study types in systematic reviews. *Int J Soc Res Methodol*. 2005;8(3):257-271. doi:10.1080/13645570500155078

48. Noblit GW, Hare RD. *Meta-Ethnography: Synthesizing Qualitative Studies*. Sage Publications; 1988.

49. Campbell R, Pound P, Pope C, et al. Evaluating meta-ethnography: A synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med*. 2003;56(4):671-684. doi:10.1016/S0277-9536(02)00064-3

50. Britten N, Campbell R, Pope C, Donovan J, Morgan M, Pill R. Using meta ethnography to synthesise qualitative research: A worked example. *J Health Serv Res Policy*. 2002;7(4):209-215. doi:10.1258/135581902320432732

51. France EF, Cunningham M, Ring N, et al. Improving reporting of meta-ethnography: The eMERGe reporting guidance. *BMC Med Res Methodol*. 2019;19(1):25. doi:10.1186/s12874-018-0600-0

52. Reid B, Sinclair M, Barr O, Dobbs F, Crealey G. A meta-synthesis of pregnant

women's decision-making processes with regard to antenatal screening for Down syndrome. *Soc Sci Med*. 2009;69(11):1561-1573. doi:10.1016/j.socscimed.2009.09.006

53. Deegbe DA, Aziato L, Attiogbe A. Beliefs of people living with epilepsy in the Accra Metropolis, Ghana. *Seizure*. 2019;73:21-25. doi:10.1016/j.seizure.2019.10.016

54. Molavi P, Sadeghieh Ahari S, Fattahzadeh-Ardalani G, Almasi S, Karimollahi M. The experiences of Iranian patients with epilepsy from their disease: A content analysis. *Epilepsy Behav*. 2019;96:109-113. doi:10.1016/J.YEBEH.2019.03.028

55. Sarudiansky M, Korman GP, Scévola L, Oddo S, Kochen S, D'Alessio L. A life with seizures: Argentine patients' perspectives about the impact of drug-resistant epilepsy on their lives. *Seizure*. 2018;63:52-61.

56. Sonecha S, Noble AJ, Morgan M, Ridsdale L. Perceptions and experiences of epilepsy among patients from black ethnic groups in South London. *Prim Heal Care Res Dev (Cambridge Univ Press / UK)*. 2015;16(5):450-460.

57. Komolafe M, Sunmonu T, Fabusiwa F, et al. Women's perspectives on epilepsy and its sociocultural impact in south western Nigeria. *African J Neurol Sci*. 2012;30(2). doi:10.4314/ajns.v30i2.

58. Birbeck GL, Chomba E, Atadzhanov M, Mbewe E, Haworth A. Women's experiences living with epilepsy in Zambia. *Am J Trop Med Hyg*. 2008;79(2):168-172.

59. Mlinar S, Petek D, Cotič Ž, Mencin Čeplak M, Zaletel M. Persons with epilepsy: Between social inclusion and marginalisation. *Behav Neurol*. 2016;2016:1-10. doi:10.1155/2016/2018509

60. Crooks RE, Bell M, Patten SB, et al. Mind the gap: Exploring information gaps for the

development of an online resource hub for epilepsy and depression. *Epilepsy Behav*. 2017;70(Pt A):18-23. doi:10.1016/j.yebeh.2017.03.005

61. Nurjannah E, Nurdin N, Andriani, Kadar K. Perception and psychosocial burden of people with epilepsy (PWE): Experience from Indonesia. *Enferm Clin*. 2020;30:622-625.
62. Kuramochi I, Horikawa N, Shimotsu S, et al. The self-stigma of patients with epilepsy in Japan: A qualitative approach. *Epilepsy Behav*. 2020;109:106994. doi:10.1016/j.yebeh.2020.106994
63. Andersson K, Strang S, Zelano J, Chaplin J, Malmgren K, Ozanne A. Multiple stigma among first-generation immigrants with epilepsy in Sweden. *Epilepsy Behav*. 2021;115:107638. doi:10.1016/j.yebeh.2020.107638
64. M B. Barriers to employment among people with epilepsy: report of a focus group. *J Vocat Rehabil*. 2002;17(4):281-286.
65. Gauffin H, Flensner G, Landtblom A-M. Living with epilepsy accompanied by cognitive difficulties: Young adults' experiences. *Epilepsy Behav*. 2011;22(4):750-758. doi:10.1016/j.yebeh.2011.09.007
66. Chung K, Liu Y, Ivey SL, et al. Quality of life in epilepsy (QOLIE): Insights about epilepsy and support groups from people with epilepsy (San Francisco Bay Area, USA). *Epilepsy Behav*. 2012;24(2):256-263. doi:10.1016/j.yebeh.2012.02.003
67. Collard SS, Ellis-Hill C. "I'd rather you didn't come": The impact of stigma on exercising with epilepsy. *J Health Psychol*. 2019;24(10):1345-1355. doi:10.1177/1359105317729560
68. Yennadiou H, Wolverson E. The experience of epilepsy in later life: A qualitative

exploration of illness representations. *Epilepsy Behav*. 2017;70(Pt A):87-93. doi:10.1016/j.yebeh.2017.01.033

69. Paschal AM, Ablah E, Wetta-Hall R, Molgaard CA, Liow K. Stigma and safe havens: A medical sociological perspective on African-American female epilepsy patients. *Epilepsy Behav*. 2005;7(1):106-115. doi:10.1016/j.yebeh.2005.03.020

70. Pembroke S, Higgins A, Pender N, Elliott N. Becoming comfortable with "my" epilepsy: Strategies that patients use in the journey from diagnosis to acceptance and disclosure. *Epilepsy Behav*. 2017;70(Pt A):217-223. doi:10.1016/j.yebeh.2017.02.001

71. Jacoby A, Ring A, Whitehead M, Marson A, Baker GA. Exploring loss and replacement of loss for understanding the impacts of epilepsy onset: A qualitative investigation. *Epilepsy Behav*. 2014;33:59-68. doi:10.1016/j.yebeh.2014.02.015

72. Sleeth C, Drake K, Labiner DM, Chong J. Felt and enacted stigma in elderly persons with epilepsy: A qualitative approach. *Epilepsy Behav*. 2016;55:108-112. doi:10.1016/j.yebeh.2015.12.026

73. Scambler G, Hopkins A. Being epileptic: Coming to terms with stigma. *Sociol Health Illn*. 1986;8(1):26-43.

74. Simpson J, Thomas C. Clinical psychology and disability studies: Bridging the disciplinary divide on mental health and disability. *Disabil Rehabil*. 2015;37(14):1299-1304. doi:10.3109/09638288.2014.961656

75. Beresford P. Thinking about “mental health”: Towards a social model. *J Ment Heal*. 2002;11(6):581-584. doi:10.1080/09638230020023921

76. Goodley D. “Learning difficulties”, the social model of disability and impairment:

Challenging epistemologies. *Disabil Soc*. 2001;16(2):207-231. doi:10.1080/09687590120035816

77. Simpson J, McMillan H, Reeve D. Reformulating psychological difficulties in people with Parkinson's disease: The potential of a social relational approach to disablism. *Parkinsons Dis*. 2013;2013. doi:10.1155/2013/608562

78. Thomas C. *Female Forms: Experiencing and Understanding Disability*. McGraw-Hill Education (UK); 1999..

79. Reeve D. Towards a psychology of disability: The emotional effects of living in a disabling society. In: D. Goodley, R. Lawthom, eds. *Disability and Psychology: Critical Introductions and Reflections*. London: Palgrave; 2006:94-107.

80. Thomas C. *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*. Macmillan International Higher Education; 2007.

81. Schneider JW, Conrad P. Medical and sociological typologies: The case of epilepsy. *Soc Sci Med Part A Med Psychol Med Sociol*. 1981;15(3):211-219. doi:10.1016/0271-7123(81)90004-3

82. Reeve D. Psycho-emotional disablism: The missing link? In: N. Watson, A. Roulstone, C. Thomas, eds. *Routledge Handbook of Disability Studies*. London: Routledge; 2012:78-92. doi:10.4324/9780429430817-8

83. Herek GM, Mitnick L, Burris S, et al. Workshop report: AIDS and Stigma: A Conceptual Framework and Research Agenda. *AIDS Public Policy J*. 1998;13(1):36-47.

84. Gronholm PC, Henderson C, Deb T, Thornicroft G. Interventions to reduce discrimination and stigma: The state of the art. *Soc Psychiatry Psychiatr Epidemiol*.

2017;52(3):249-258. doi:10.1007/s00127-017-1341-9

85. Kerr MP, Mensah S, Besag F, et al. International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. *Epilepsia*. 2011;52(11):2133-2138. doi:10.1111/j.1528-1167.2011.03276.x

86. Mittan RJ. Psychosocial treatment programs in epilepsy: A review. *Epilepsy Behav*. 2009;16(3):371-380. doi:10.1016/j.yebeh.2009.08.031

87. Michaelis R, Tang V, Nevitt SJ, et al. Psychological treatments for people with epilepsy. *Cochrane Database Syst Rev*. 2020;2020(8). doi:10.1002/14651858.CD012081.pub3

88. Fernandes PT, Snape DA, Beran RG, Jacoby A. Epilepsy stigma: What do we know and where next? *Epilepsy Behav*. 2011;22(1):55-62. doi:10.1016/j.yebeh.2011.02.014

89. Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Educ Prev*. 2003;15(1):49-69. doi:10.1521/aeap.15.1.49.23844

90. Jacoby A. Thirty years of psychosocial research in epilepsy: Personal reflections of a social scientist. *Epilepsy Behav*. 2015;44:245-249. doi:10.1016/j.yebeh.2014.12.008

91. Yardley L. Demonstrating validity in qualitative psychology. *Qual Psychol A Pract Guid to Res Methods*. 2008.

92. Yardley L. Dilemmas in qualitative health research. *Psychol Health*. 2000;15(2):215-228. doi:10.1080/08870440008400302

Figure 1. Process of selecting papers for inclusion

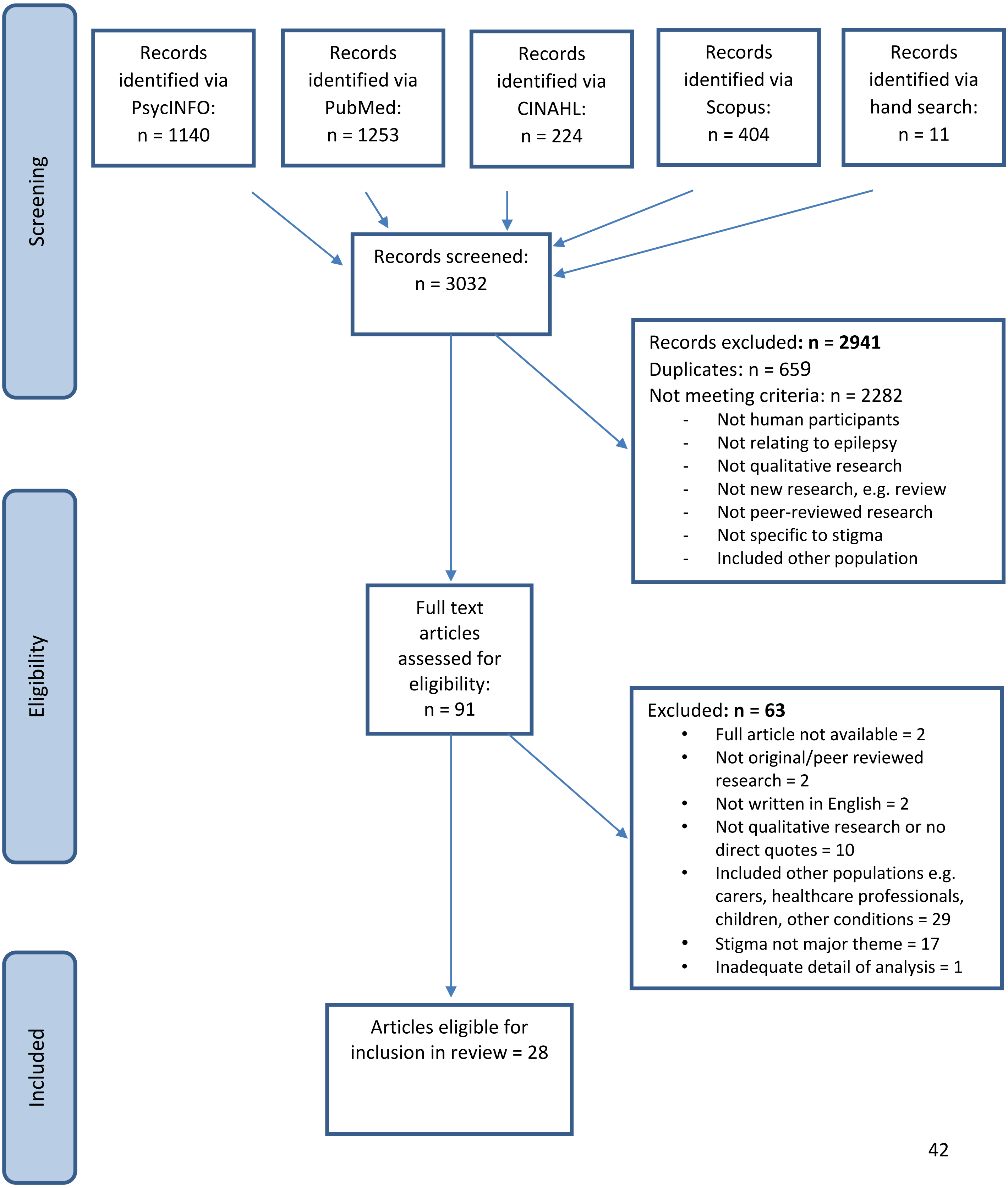

Table 1. Search terms used in literature search.

Major concept (combined with AND)	Key words	Database (combined with OR)	Thesaurus terms
Epilepsy	Epilep* or Seizure(s)	PsycINFO	DE "Epilepsy" OR DE "Epileptic Seizures" OR DE "Seizures"
		Pubmed	"Seizures"[Mesh] OR "Epilepsy"[Mesh]
		CINAHL	MH "Epilepsy" OR MH "Seizures"
		Scopus	n/a
Stigma	Stigma or discrimination or "social discrimination" or "social perception" "social adjustment" or stereotyp* or attitude or prejudice or ignoran* or shame or disgrace or dishonour or judgement or attitude	PsycInfo	DE "Physical Illness (Attitudes Toward)" OR DE "Health Attitudes" OR DE "Discrimination" OR DE "Attitudes" OR DE "Prejudice" OR DE "Social Acceptance" OR DE "Social Approval" OR DE "Social Discrimination" OR DE "Social Perception" OR DE "Stereotyped Attitudes" OR DE "Stigma"
		Pubmed	"Social Stigma"[Mesh] OR "Shame"[Mesh] OR "Prejudice"[Mesh] OR "Stereotyping"[Mesh] OR "Social Discrimination"[Mesh] OR "Social Behavior"[Mesh] OR "Attitude"[Mesh] OR "Attitude to Health"[Mesh] OR "Social Adjustment"[Mesh] OR "Social Perception"[Mesh] OR "Taboo"[Mesh]
		CINAHL	MH "Stigma" OR MH "Social Adjustment" OR MH "Social Attitudes" OR MH "Social Norms" OR MH "Social Behavior" OR MH "Social Conformity" OR MH "Social Inclusion" OR MH "Social Values" OR MH "Stereotyping" OR MH "Attitude" OR MH "Prejudice" OR MH "Shame" OR MH "Discrimination"
		Scopus	n/a
Experiences	Qualitative or ethnograph or experience or experiences or perception or perceptions or semi-structured or semistructured or "semi structured" or unstructured or in-depth or indepth or face-to-face or structured or guide or guides or interview or interviews or discussion or questionnaire or questionnaires or focus group or focus groups or survey or surveys or thematic or grounded theory or interpretative or narrative or case study or observation or phenomenology or	PsycInfo	DE "Grounded Theory" OR DE "Interviewing" OR DE "Qualitative Research" OR DE "Questioning" OR DE "Interview Schedules" OR DE "Interviews" OR DE "Structured Clinical Interview" OR DE "Feedback" OR DE "Life Experiences" OR DE "Experiences (Events)"

Major concept (combined with AND)	**Key words**	**Database (combined with OR)**	**Thesaurus terms**
	phenomenological or feedback		
		Pubmed	"Ethnology"[Mesh] OR "Grounded Theory"[Mesh] OR "Surveys and Questionnaires"[Mesh] OR "Narration"[Mesh] OR "Case Reports" [Publication Type] OR "Feedback"[Mesh] OR "Qualitative Research"[Mesh] OR "Focus Groups"[Mesh] OR "Interviews as Topic"[Mesh] OR "Interview" [Publication Type] OR "Interview, Psychological"[Mesh]
		CINAHL	MH "Qualitative Studies" OR (MH "Ethnographic Research" OR MH "Ethnological Research" OR MH "Grounded Theory" OR MH "Phenomenological Research" OR MH "Phenomenology" OR MH "Semi-Structured Interview" OR MH "Interview Guides" OR MH "Structured Interview" OR MH "Unstructured Interview" OR MH "Unstructured Interview Guides" OR MH "Structured Interview Guides" OR MH "Interviews" OR MH "Life Experiences" OR MH "Feedback" OR MH "Narratives" OR MH "Open-Ended Questionnaires" OR MH "Life Histories" OR MH "Biographies" OR MH "Surveys" OR MH "Survey Research" OR MH "Focus Groups" OR MH "Vignettes"
		Scopus	n/a

Table 2. Characteristics of the included studies

Authors	Year	Title	Research aim	Methodology	Participants	Setting
Andersson et al.	2021	Multiple stigma among first-generation immigrants with epilepsy in Sweden	To investigate the meaning of stigma among first-generation immigrants with epilepsy in Sweden.	Face-to-face interviews. Hermeneutic analysis with systematic interpretation	25 (15 female, 10 male) immigrants to Sweden with epilepsy Age: 20-62 years, mean 37.3	Swedish city suburb, recruiting from outpatient neurology department. High income country
Birbeck et al.	2008	Women's experiences living with epilepsy in Zambia	To identify relevant areas in lives of PWE for future quantitative studies.	Focus groups. Unspecified form of content analysis	Six groups of 8-15 women with epilepsy. Age: adult women	Zambia, urban clinic and rural (Tonga) region. Lower middle-income country.
Bishop	2002	Barriers to employment among people with epilepsy: Report of a focus group	To explore experiences of and barriers to employment faced by adult PWE	Single focus group. Form of thematic analysis (Creswell, 2003)	14 (8 female, 6 male) adults with epilepsy Age: 20-50 years	Two metropolitan areas (Ohio and Kentucky), USA. High income country.
Chung et al.	2012	Quality of life in epilepsy (QOLIE): insights about epilepsy and support groups from people with epilepsy (San Francisco Bay Area, USA)	To investigate perceived quality of life in PWE who do and do not attend support groups	Six focus groups: three of PWE who attend support groups, three of PWE who do not. Content and interpretative qualitative analysis by constant comparative method (Glaser & Strauss, 1967)	36 male and female PWE (18 who attended support groups, 18 who did not) Age: 24-65+ years	Community based, San Francisco Bay, USA. High income country.
Collard & Ellis-Hill	2019	'I'd rather you didn't come': The impact of stigma on exercising with epilepsy	To explore barriers to exercise for PWE; to understand how stigma is felt and enacted, in order to consider how it might be reduced	Focus groups and individual semi-structured interviews. Constructionist grounded theory	11 PWE Age: >18 years	Community setting in Bournemouth, UK. High income country.

Authors	**Year**	**Title**	**Research aim**	**Methodology**	**Participants**	**Setting**
Crooks et al.	2017	Mind the gap: Exploring information gaps for the development of an online resource hub for epilepsy and depression	To identify current gaps and barriers to online resources designed for PWE and depression	Individual interviews. Content analysis	10 PWE and depression Age: 27-53 years	Recruited via local epilepsy registry in Canada. High income country.
Deegbe et al.	2019	Beliefs of people living with epilepsy in the Accra Metropolis, Ghana	To explore epilepsy beliefs among PWE in Ghana	Semi-structured interviews. Content analysis	13 PWE without comorbid psychiatric diagnoses or intellectual disability Age: 18-40 years	Recruited via community mental health units in Accra, Ghana. Lower middle income country.
Gauffin et al.	2011	Living with epilepsy accompanied by cognitive difficulties: Young adults' experiences	To explore young adults' experiences of living with epilepsy and subjective cognitive decline	Four focus groups: two of women with epilepsy, and two of men. Content analysis following Graneheim & Lundman (2004)	14 PWE (7 female, 7 male) Age: 18-35 years	Eastern Sweden. High income country.
Jacoby et al.	2014	Exploring loss and replacement of loss for understanding the impacts of epilepsy onset: A qualitative investigation.	To gain in-depth understanding of lived experience of loss for PWE; to explore relationships between influences mediating loss and contributing to overall QOL	Individual interviews. Constant comparative method	67 PWE Age: 24-65 years	UK community setting. High income country.
Keikelame & Swartz	2016	"The others look at you as if you are a grave": a qualitative study of subjective experiences of patients with epilepsy regarding their teatment and care in Cape Town, South Africa.	To describe subjective experiences of how PWE in Cape Town understand their illness	Individual semi-structured interviews. Thematic analysis	12 PWE (4 female, 8 male) Age: >18 years	Urban township community in Cape Town, South Africa. Upper middle income country.
Keikelame, &	2018	I wonder if I did not mess	To provide an in-depth	Individual semi-	12 PWE (4 female, 8	Urban township

Authors	Year	Title	Research aim	Methodology	Participants	Setting
Swartz		up....: Shame and resistance among women with epilepsy in Cape Town, South Africa	understanding of how women with epilepsy experience shame and resistance	structured interviews. Thematic analysis	male) Age: >18 years (mean male age 47 years, females 37 years)	community in Cape Town, South Africa. Upper middle income country.
Kilinc & Campbell	2009	It shouldn't be something that's evil, it should be talked about: a phenomenological approach to epilepsy and stigma	To explore experiences of stigma for adult PWE	Two individual semi-structured interviews, 6-12 months apart. Phenomenological analysis (Lemon & Taylor, 1997)	52 PWE Age: 18+ years	UK community setting. High income country.
Kılınç et al.	2017	The experience of living with adult-onset epilepsy	To explore experiences of living with adult-onset epilepsy	Individual semi-structured interviews. Interpretative phenomenological analysis	39 PWE with onset at >18 years Age: >18 years	Recruited via epilepsy charity and support group in UK. High income country.
Komolafe et al.	2011	Women's perspectives on epilepsy and its sociocultural impact in South Western Nigeria	To explore sociocultural aspects of epilepsy for women in Southwest Nigeria	Six focus groups: three in urban areas, three in rural areas. Content analysis	Six focus groups of 8-15 women with epilepsy (mostly of the Yoruba population) Age: adult women	Rural and urban setting in Southwest Nigeria. Lower middle income country.
Kuramochi et al.	2020	The self-stigma of patients with epilepsy in Japan: A qualitative approach	To explore self-stigma and coping strategies in PWE in Japan	Semi-structured interviews. Content analysis.	20 PWE, although not all included in analysis Age: 20-65 years	Psychiatric outpatient clinic, Japan. High income country.
Mlinar et al.	2016	Persons with Epilepsy: Between Social Inclusion and Marginalisation	To explore subjective experiences of social inclusion in PWE in Slovenia	Individual semi-structured interviews. Content analysis using coding frames (Elo & Kyngas, 2008)	11 PWE (8 female, 3 male) Age: 27-64 years	Community setting in Slovenia. High income country.
Molavi et al.	2019	The experiences of Iranian patients with epilepsy from their disease: A content	To explore experiences of PWE regarding stigma	Semi-structured interviews. Content analysis	22 PWE Age: 21-59 years	Recruited from a neurology clinic in Iran. Lower middle income country.

Authors	Year	Title	Research aim	Methodology	Participants	Setting
		analysis				
Nurjannah et al.	2020	Perception and psychosocial burden of people with epilepsy (PWE): Experience from Indonesia	To investigate the perception of PWE and related psychosocial burden	Semi-structured interviews. Thematic analysis	7 PWE Age: unspecified	Recruited in Makassar City, Indonesia, via snowball sampling. Lower middle income country.
Paschal et al.	2005	Stigma and safe havens: a medical sociological perspective on African-American female epilepsy patients	To explore attitudes and behaviours of African-American women with epilepsy	Individual unstructured ethnographic interviews. Unspecified form of thematic analysis	10 African-American women with epilepsy Age: 29-58 years	Specialist and primary care centres, Midwest USA (Wichita). High Income county.
Pembroke et al.	2017	Becoming comfortable with "my" epilepsy: Strategies that patients use in the journey from diagnosis to acceptance and disclosure	To understand how people constructed their epilepsy	Individual interviews. Grounded theory analysis	49 people who felt comfortable with their epilepsy Age: >18 years	Community setting in Ireland. High income country.
Raffaele	2018	A qualitative study exploring family life in men	To explore family relations for men with adult-onset epileptic seizures	Semi-structured interviews. Interpretative phenomenological analysis	5 men with adult-onset epilepsy who had undergone temporal lobectomy neurosurgery Age: 24-45 years	Recruited via epilepsy charities in Australia. High income country.
Raffaele et al.	2017	Men with adult onset epileptic seizures	To explore family relations for men with adult-onset epileptic seizures	Semi-structured interviews. Interpretative phenomenological analysis	Sample size: 5 Sample: men with adult-onset epilepsy that had undergone temporal lobectomy neurosurgery Age: 24-45 years	Recruited via epilepsy charities in Australia. High income country.
Räty et al.	2009	Epilepsy patients' conceptions of epilepsy as a phenomenon	To explore the concept of epilepsy and related emotions in PWE	Individual interviews. Phenomenographic method (Alexandersson, 1994)	19 PWE (12 female, 7 male) Age: 20-65 years	Sweden, recruiting from county and private clinics. High income country.
Räty & Wilde-	2011	Patients' perceptions of	To describe how PWE	Individual interviews.	19 PWE (12 female, 7	Sweden, recruiting

Authors	Year	Title	Research aim	Methodology	Participants	Setting
Larsson		living with epilepsy: A phenomenographic study	perceive living with epilepsy	Phenomenographic method (Alexandersson, 1994)	male) Age: 20-65 years	from county and private clinics. High income country.
Sarudiansky et al.	2018	A life with seizures: Argentine patients' perspectives about the impact of drug-resistant epilepsy on their lives	To explore patients' perspectives of drug-resistant epilepsy from a developing nation	Semi-structured interviews. Thematic analysis	20 adults with drug-resistant epilepsy (8 female, 12 male) Age: 22-52 years	Recruited from hospital clinics in Argentina. Upper middle income country.
Sleeth et al.	2016	Felt and enacted stigma in elderly persons with epilepsy: A qualitative approach	To qualitatively assess effects of stigma on QOL of elderly PWE	Individual semi-structured interviews. Non-specified form of thematic analysis	57 older PWE (36 females, 21 males) Age: >65 years	USA (Southern Arizona), recruiting via flyers, public education sessions and referrals. High income country.
Sonecha et al.	2015	Perceptions and experiences of epilepsy among patients from black ethnic groups in South London	To explore perceptions and experiences of epilepsy among black African and Caribbean people	Individual semi-structured interviews. Thematic analysis (Green & Thorogood, 2004)	11 Black African and Caribbean PWE (7 female, 6 male) Age: 22-79 years	Recruited via UK (South London) hospitals. High income country.
Yennadiou. & Wolverson	2017	The experience of epilepsy in later life: A qualitative exploration of illness representations	To explore lived experience of epilepsy in later life through older peoples' appraisals of their condition	Individual interviews. Interpretative phenomenological analysis	10 older PWE Age: >65 years	Recruited from a neurological department in North of England, UK. High income country.

Abbreviations: PWE = people with epilepsy; QOL = quality of life

Table 3. Critical appraisal of the included studies

CASP criterion	Andersson et al., 2021	Birbeck et al., 2008	Bishop 2002	Chung et al., 2012	Collard & Ellies-Hill, 2019	Crooks et al., 2017	Deegbe et al., 2019	Gauffin et al., 2011	Jacoby et al., 2014	Keikelame & Swartz, 2016	Keikelame & Swartz, 2018	Kilinc & Campbell, 2009	Kılınç et al., 2017	Komola-fe et al., 2011
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims?	2	3	2	3	2	2	2	3	3	2	3	3	3	1
Was the recruitment strategy appropriate to address the aims?	2	3	2	2	2	2	2	3	3	3	3	2	2	2
Were the data collected in a way that addressed the research issue?	2	2	2	2	3	2	3	3	3	3	3	2	3	2
Has the researcher/participant relationship been considered?	1	1	1	1	2	1	1	1	2	3	3	1	3	1
Have ethical issues been considered?	2	3	2	3	2	1	2	2	3	3	3	1	2	2
Was the data analysis sufficiently rigorous?	2	2	2	2	2	3	3	3	3	3	3	3	2	2
Is there a clear	3	2	3	2	3	3	3	3	3	3	3	3	3	2

statement of findings?														
How valuable is the research?	3	2	3	2	3	3	3	3	3	3	3	3	3	3
Total Score	17	18	17	17	19	17	19	21	23	23	24	18	21	15

1 = weak, 2 = moderate, 3 = strong

CASP criterion	**Kuramochi et al., 2020**	**Mlinar et al., 2016**	**Molavi et al., 2019**	**Nurjannah et al., 2020**	**Paschal et al., 2005**	**Pembroke et al., 2017**	**Raffaele 2018**	**Raffaele et al., 2017**	**Räty et al. 2009**	**Räty & Wilde-Larsson, 2011**	**Sarudiansky et al., 2018**	**Sleeth et al., 2016**	**Sonecha et al., 2015**	**Yennadiou & Wolverson, 2017**
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims?	3	3	2	1	3	3	2	2	3	3	2	1	2	3
Was the recruitment strategy appropriate to address the aims?	2	2	2	1	3	2	2	2	2	3	1	2	1	3
Were the data collected in a way that addressed the research issue?	3	3	3	1	3	3	3	3	2	2	2	2	2	2
Has the researcher/participant relationship been considered?	2	1	1	1	2	1	2	1	1	1	1	1	1	1
Have ethical issues been considered?	3	2	2	3	2	3	2	2	3	2	1	2	2	2

Was the data analysis sufficiently rigorous?	3	3	2	1	2	3	2	3	2	3	2	2	2	3
Is there a clear statement of findings?	3	3	2	1	3	3	3	3	3	3	3	3	3	3
How valuable is the research?	3	3	3	1	3	3	2	3	3	3	3	3	3	3
Total Score	22	20	17	10	21	21	18	19	19	20	15	16	16	20

1 = weak, 2 = moderate, 3 = strong

Table 4. Summary of relevant findings of each individual study.

Study	Summation of findings
Andersson et al., 2021	Main theme: struggling to be appreciated as a person: reduced social networks, language barriers, status as an immigrant, effects on self-image. Struggling with negative self-image: shame related to the "epilepsy" label, guilt and embarrassment around effects of epilepsy, feeling undervalued, feeling or being seen as weak and less capable, being "the strange and crazy one"; distancing oneself from the stereotype. Searching for strategies to build self-confidence: seeking social support by informing others, concealing epilepsy; finding and maintaining work.
Birbeck et al., 2008	Seizure worries: shame caused by inadvertent taboo breaking (revealing themselves, indication of husband's regard, urinary/faecal incontinence), accidental injury, intentional injury, fear of sexual assault. Family responses to PWE: supportive families or extreme rejection. Role fulfilment: marital relationships (difficulty finding partner, married women abandoned or fear abandonment, lost children, sexual rejection leading to poverty and humiliation). Childbearing and rearing (fear children taken, prenatal or paediatric injury leading to ambivalence). Employment (limitations due to seizure worries, rejection if condition known, employment terminated as result of seizure). Social role in community (forced disclosure as result of seizure, social rejection and isolation, ridicule).
Bishop, 2002	Applying for a job as PWE: overt employer decisions, psychological impact of doubt, fear of disclosure, frustration about what to disclose. Maintaining employment: covert dismissal, hiding epilepsy, epilepsy a deterrent, empathy for witnesses. Factors that enable employment: supportive and knowledgeable employers and colleagues.
Chung et al., 2012	Barriers to employment: losing employment as result of seizure, discrimination at work. Invisibility/need to prove: proving deserving of aid, difficulty gaining financial assistance. Stigma toward people with epilepsy: negative attitudes, social rejection, rejection after disclosure, termination of employment, lack of knowledge in public sector workers, concern regarding caring for someone having a seizure. Psychological burden: medication for depression, lack of fulfilment, loneliness, difficulty maintaining relationships, limited social interaction, shame, frustration, guilt, support groups allowing positive coping strategies and increasing social interaction. Restricted activities and socialisation: support groups enable safe conversing without stigma. Social security and income: dilemma regarding aid or employment, impact on self-esteem and contribution to society, sustainability of financial support, unpredictable termination of employment. Value of support groups: gain knowledge, improve coping, build relationships.
Collard & Ellis-Hill, 2019	Disclosure to those in authority: feeling 'different' outweighed safety aspects. Disclosure not needed. Fear and experience that disclosure results in restriction. Feeling responsible to disclose to protect family. Disclosure to other members: fear of negative impact, hidden illness increases stigma, negative impact of limitations due to epilepsy, stigma improves with more knowledge.

	Lack of understanding: "people just don't understand", hidden illness results in less awareness and fear in others, viewed as "weakness". Negative reactions to disclosure (distancing, increasing fear and stigma). Sharing understanding to decrease stigma: teaching others; disclosure improving felt stigma but increasing enacted stigma.
Crooks et al., 2017	Fear and anxiety: not understanding epilepsy. Fear of seizure in public due to others' perceptions and stigma (e.g. assuming drug withdrawal). Isolation due to staying at home for fear of stigma; impact on daily living such as driving and employment. Losing yourself: lack of control, lost independence and role, feeling a burden. Health journey and support: support from family 'critical'. Peer support keeps from feeling alone. Having understanding employers. Being positive and accepting. Seeking information: sought information primarily from health providers but also online and via community organizations. Short healthcare visits made obtaining information difficult. Healthcare professionals viewed as more credible, but also didn't know where else to get information. Online forums helpful for sharing experience but not reliable. Forgetting log-in information. Epilepsy organisations don't promote events sufficiently. Opportunities and filling a gap: desire for information to share with others to improve empathy.
Deegbe et al., 2019	Beliefs about signs and symptoms of epilepsy: falling and losing consciousness during a seizure, incontinence, shame of this occurring in public. Beliefs about causes of epilepsy: physical (hunger, starvation), spiritual (evil spirits, malevolent or envious other) and unknown causes. Beliefs about consequences of epilepsy: physical injuries (bruises, burns, miscarriages), effects on work/education (being stopped from going to school or sacked from work), stigmatising attitudes from others (but support from some relatives), disgrace, restrictions from general activities (cooking, using electrical gadgets, socialising), effects on relationships with family and romantic partners (e.g. partners refusing to marry the PWE, or relatives forcing the PWE to leave the home). Beliefs about cure or control of epilepsy: expectations of recovery and control, hope and belief in God for a cure, faith in medication, or acceptance that epilepsy can be coped with or prevented "to some extent" but not cured..
Gauffin et al., 2011	Affecting the whole person: personal development and fulfilment: developing a different personality, difficulties making friends and meeting partners, lifestyle adjustments, need to plan, giving up on dreams, driving restrictions and reliance on others, restrictions, life requiring more effort, impact on academic success, fatigue, impact on self-esteem. Limitation of potential and responsibility: not allowed, others enforcing restrictions due to ignorance, alienation, difficulty explaining and others not understanding symptoms of epilepsy, mistaken for mentally ill, embarrassment. Influencing daily life: memory: forgetting leading to embarrassment, impact on relationships and work, impact of seizures and medication. Memory ever-present (more difficult than intermittent seizures, decline); overcoming memory using strategies (aids, reminders and routine). Affecting relationships: family and friends (affecting whole family, family taking care, impact on other's work, sustaining friendships, impact of memory difficulties, not disclosing epilepsy, requiring support for seizures, mutual friendship, disregarded); dependence on others (dependence on relatives, close relationships, asking for help, frustration, fear of separation); guilt (causing family problems, impact on children, scaring children, keeping promises). Meeting ignorance in society: not helping with seizures, not recognising symbol for epilepsy, teaching others.
Jacoby et al., 2014	Explaining QOL impacts: linkage between psychological and social losses: psychological loss following seizure reoccurrence due to intrusion including loss of control, fear, anxiety, embarrassment, vulnerability and stigma. Social consequences such as loss of job, social activities and

	family roles. Externally enforced decisions such as family member decisions. Withdrawal behaviours to minimise expected harm. Restoring 'normality' and regaining good QOL: seizure control restoring normality and peace of mind via regaining self-confidence and former social/psychological status. Factors exacerbating loss: seizure factors; others' perceptions and responses to epilepsy and seizures; misperceptions and abuse. Public reaction to epilepsy, lack of empathy, others' fear and lack of knowledge. Employment factors. Factors limiting loss: Social/contextual factors. 'Resources' included personal psychological strategies and practical/emotional support from others.
Keikelame & Swartz, 2016	Difficulties on routine clinical visits: access to appropriate care inhibited. "You are not told anything". Need to be educated to understand. Professionals too rushed to listen. Lack of interpreters. Perceived healthcare professional factors affecting care: lack of empathy, respect, interest; poor listening, inadequate training. Disrespectful treatment, lack of required information. Counselling and information needs: insufficient information about medication and side-effects, sexual problems and pregnancy. Need for support to cope with epilepsy, impact on socio-economic circumstances.
Keikelame & Swartz, 2018	Processes of shame of living with epilepsy: disappointment and regret due to life disruption. Guilt, anger and shame at burdening others and affecting their relationships. Unable to fulfil role as mother/grandmother. Shame at incontinence which impacts relationships. Resistance strategies against discrimination: ability to devise individual strategies to resist injustice, prejudice and abuse. Retaliation as strategy against unfair treatment from spouse as result of epilepsy; fighting back.
Kilinc & Campbell, 2009	Misconceptions vs ownership: public negative misconception as mentally ill or using substances, public lack of awareness leading to not feeling 'normal', lack of own knowledge pre-diagnosis, impact of previous experience, reducing uncertainty of seizures and making adjustments. Avoiding versus sharing: hidden illness, concealing through avoidance and withdrawal, impact of seizures on others, disconfirming negative consequences of seizures, concealment contributing to public misconception, disclosure. Embarrassment vs normalising: confidence, seizures drawing attention, engaging in society, impact on identity, need for education.
Kılınç et al., 2017	The ripple effect: epilepsy is "life changing", affects all areas of life. Loss of independence, inability to drive and choose activities. Feeling restricted by externally-imposed decisions and need for supervision. Benefit of learning about own epilepsy and strategies to manage. Re-evaluating the future: epilepsy changed life for the better, make gains by adapting plans for future. Easier with diagnosis earlier in adulthood.
Komolafe, et al., 2011	Perception about epilepsy: denial of epilepsy, supernatural or contagion causes, traditional/spiritual treatments before Western care, costs of care. Family attitudes and social relationships: supportive vs rejecting, patrilineal distancing, concealment, social isolation, avoiding forced disclosure. Economic consequences: impact on education and future potential, employment restrictions, no financial contribution. Marital prospects and relationships: non-disclosure, separation or divorce, rejection/abuse from relatives, ceased financial assistance, poverty, turn to prostitution. Role fulfilment: difficulty being wives/mothers, limited roles due to fear of seizure injury, impact on fertility, fear of infecting/injuring children. Vulnerability or abuse: physical and sexual abuse, part of treatment, sexual assault during seizures, rituals.
Kuramochi et al., 2020	Self-stigma in PWE: negative beliefs about weakness, incapability, incurability, burden to others, fear of others' opinions, shame. avoidance. Social stigma associated with epilepsy: social prejudice, misconceptions, discrimination, lost ability to work or marry. Anxiety and distress: associated with lack of public understanding and incorrect information about epilepsy, fear of seizures, discouragement after seizures. Medication burden unhelpful due to adverse effects, especially when doses not reduced at medical assessments. Restrictions to social life

	(e.g. sports, driving, studying and certain occupations). Strategies for treating epilepsy: obtaining information, dealing with epilepsy on own, making own choices and self-ownership of the condition, avoidance of thinking about it, seeking friends and places to talk about epilepsy.
Mlinar et al., 2016	Physical consequences: draining seizures, injury, recognising triggers leading to control, avoiding situations leading to seizures. Emotional consequences: fear (reactions of friends, epilepsy worsening, unpredictability) leading to uncertainty about unpredictable future, self-confinement and social isolation, scaring others. Social consequences: disclosure impacting on social network, loneliness, rejection, employment implications, discrimination at work, impact on relatives, difficulty finding a partner, empathy for others with health concerns. Manging epilepsy information and social contacts: concealment, uncontrolled disclosure, hiding seizures, disclosure in close relationships or to enable help, fear of disclosure and non-disclosure with partners and employers, regrets of disclosure versus surprised by positive reactions. Experience: low self-worth, trusting others, others' fearing epilepsy, hurt at others' responses, distress due to epilepsy, powerlessness, desperation, insecurity, loneliness, self-confinement, disassociation, fear, dependence on others, anxiety, shame, feeling different, inferior, guilt from reliance on others, life changed, loss of autonomy, relatives dominance.
Molavi et al., 2019	Need for support: those supported by family experienced more positive reactions from others, continued education and positive mood. Support of important people (e.g. doctors, teachers, employers) increased quality of life. Those without support experienced many problems. Desire for increased public knowledge, reduction in superstitious beliefs, fewer presentations of fear in media, supported through early education. Defence mechanisms: trying to hide illness, fear of being labelled and deprived. Emigrating where no-one knew them, returning home for family support. Family shame: "my mother and father tried to hide my disease". Superstitious beliefs: belief of being 'damned', a punishment, need for faith healers. Negative feelings: shame, guilt, regret and fear. Frightened to be alone, not being accepted, effect on their lives, fear of their children getting the illness. Resulted in depression, low confidence and isolation. Experiences of rejection, deprivation resulting in regret.
Nurjannah et al., 2020	Perception of epilepsy: effects of community perception including concerns about contagion, viewing PWE as crazy, and loss of relationships. Self-perception in coping strategies, expectation and reality: value of support from friends/family; feeling positive and grateful as a coping strategy, avoidance due to others' fear of PWE, wanting community to understand epilepsy, wanting a job and marriage, wanting not to be seen as different. Psychosocial burden: emotional reactions to psychosocial burden (anger, sadness); anxiety about the future and experiences of teasing/bullying; restriction of enjoyed activities, work and marriage prospects due to family being overprotective.
Paschal et al., 2005	Financial resources: accessing and adhering to medication and treatment, impact of transport and dependence on others, affording medication, epilepsy putting into poverty. Knowledge about epilepsy: misconceptions (drug abuse), need to educate family, relationships ending, more stigma toward convulsions, mistaking symptoms due to lack of education and not seeking help. Patient-provider communication: better care received from tertiary than primary care, unaware of additional care, wanting more than medical care. Social networks and social support: support increasing access to transportation and finance (for medication), improved adherence to medication, family views of surgery, minimal community support (including church), not disclosing epilepsy, wanting church to educate and pray about epilepsy as similar to other conditions.

Pembroke et al., 2017	Meaning of "my" epilepsy: emotional reaction to diagnosis including felt and enacted stigma, due to lack of knowledge. Need to adjust life as it "dominate(s)"; reluctance to acknowledge diagnosis. Strategies: need to manage emotions by learning about epilepsy, meet others with epilepsy and talk about it to gain confidence and practice telling. Being comfortable with "my" epilepsy: way of interpreting diagnosis. Not allowing it to alter self-image; being selective about who to tell. Realising not alone aids positivity and removes shame.
Raffaele, 2018	Role marginalization: exclusion from normal life. Siblings embarrassed and minimising contact or isolating which affected happiness. Parents not showing care or concern. Spouse embarrassed to socialise with PWE. Role dependency: undue reliance on others. Reduced decisional role in family, resulting in enjoyed dependency and happiness. Others overprotecting. Having to rely on others, particularly for transport, experienced as negative. Financial dependence resulting in loss of relationship. Not being able to work affecting self-identity. Role enmeshment: treated by spouse like child, particularly for emotional support. Not able to maintain parent role, diminished responsibility.
Raffaele et al., 2017	Threat minimisation, self-blame, and social isolation: contending with many threats to personal functioning as a result of social role marginalisation. Anxiety about relationships. Threat from poor treatment from healthcare providers. Attempting to manage by living as normal life as possible, "as though nothing has happened", hiding epilepsy, relocating. Self-isolation to minimise negative social judgement. Self-blame. Cognitive reconstruction: trying to make sense of recovery and what mattered for self-management. Returning to valued activity. Supporting others in similar circumstances. Emotional acceptance and wish-fulfilling fantasy: self-acceptance improves wellbeing. See self as survivor. Using humour. Hope life will improve. Self-blame: over-loading partner with decisions. Impact on forming relationships. Relationship between self-blame and self-isolation. Not living up to others' expectations for recovery.
Räty et al., 2009	Illness/condition related to physical disturbances: chronic illness in the brain, condition associated with seizures, happy could be treated, not dangerous, hope might disappear, disappointment at seizures returning. Mental disturbance related to lack of capacity: something wrong in the brain/head, "disgusting", "queer", fear of exposure, anxious about social events, shame at not being entirely sane, not satisfactory member of society, denial of epilepsy. Handicap related to psychological and/or social aspects: a worry and restriction (including work), impact on relationships and childbearing, sorrow as result of obstacles to partnership, pregnancy and parenthood, guilt at suffering of others, shame and feeling of lower human value. Identity related to being epileptic: internalized, separate category of people, being abnormal, shame at not being normal and causing suffering to others by existing. A punishment: epilepsy result of wrongdoing and searching for explanations, sorrow and guilt at having done wrong.
Räty & Wilde-Larsson, 2011	Living with epilepsy means living a normal life - gaining and maintaining control: Accepting the person with epilepsy: accepting as part of daily life, not letting epilepsy rule, disclosing epilepsy so not to fear seizures, need for supportive family. Taking responsibility: listening to signs of a seizure and preparing so not to injure self or others, protecting family from harm by education, positive effects of epilepsy reducing feeling different and feeling normal, changing values becoming more understanding to own and others' difficulties. Living with epilepsy means living with focus on the condition - conflict and avoidance or resigning to fate: Struggling with stigma, prejudice and loss of control: restrictions on life and giving up dreams, fearing foetal damage, increasing seizures, avoiding disclosure, being observed and

	controlled by others including family and work, not having the same rights. Physical fears: injury or side-effects of medications. Psychological fears: being seen as different, judged, need for concealment and to avoid exposure. Social fears: being dependent and a burden, others' attitudes and knowledge, becoming isolated. Giving up hope of recovery, accepting loss of control: building and losing hope of seizure cessation, fear of exposure, vulnerability and mercy of others during seizures, nightmares about what might happen.
Sarudiansky et al., 2018	Characteristics of the illness: unpredictability of seizures impacting on life "I can't do anything". Interactions with the healthcare system: not having equal access to healthcare and benefits. Doctors not caring. Family members taking to traditional healers. Beliefs about the illness: medical illness and cause versus 'a defect', feeling ashamed or angry. Psychological or supernatural causes. Beliefs about how other people perceive them: others prejudiced. Called "lazy" or "crazy". Feeling a burden to others. Others over-protective and feeling dependent. Whether to reveal illness, only to minimise risk. Importance of social support for emotional support and navigating healthcare. Self-perception: accepting epilepsy influences disclosure. Feeling different from others. Not living up to societal expectations. Limiting life achievements such as marriage, parenting or employment aspirations. Not being able to financially support family. Lack of independence and autonomy. Hopeful for a cure. Impact of the illness on activities: restricted in employment and education which impacts on economy and autonomy. Restrictions on activities.
Sleeth et al., 2016	Felt stigma: experiencing stigma in daily life, others' reactions (including fear) particularly to tonic clonic seizures, stereotypes, affecting work and social life, not disclosing, perceived connection with mental state, not experiencing stigma. Enacted stigma: rejection from others, exclusion from social events, overt discrimination, worse in earlier life, others being more supportive. Effects of stigma: lack of disclosure, others not disclosing (including parents), refusing epilepsy diagnosis, avoiding terminology because of stigma, stigma not impacting on life. Reasons for stigma: lack of knowledge, belief epilepsy is contagious, negative stereotypes from previous experience. Addressing stigma: in community and patient education to increase knowledge (including explaining it is not contagious or harmful to others), teaching others how to live with stigma to mitigate adverse effects.
Sonecha et al., 2015	Beliefs about cause: African beliefs in supernatural causes (spirit possession), contagious disease (malaria type, airborne or sexually transmitted), related to stigma and shame and rejection of others. Caribbean belief that born with epilepsy, chronic condition and not necessary to conceal, generational differences (older beliefs similar to African). Felt and enacted stigma: African-born participants experienced persecution and discrimination, lack of care and social rejection, supernatural belief about self, social outcasts, impact on partnership, abuse as result of seizures, continued shame, stigma and social restriction. Caribbean not experienced discrimination, no impact on relationships, but embarrassment at seizures and impact on work so concealment when applying. Managing fits and social restrictions: Caribbean fear of seizures leading to avoidance and isolation, unpredictability being disabling, restricted activities and isolation. African restricted relationships, family, driving and occupation.
Yennadiou & Wolverson, 2017	The power of epilepsy: 'It's terrible… it's awful': traumatic experiences as physical consequences of seizures, concern for fear caused in others. 'They say you can live a normal life but you can't': The impact of society's attitudes: socially stigmatising condition. Negative lay beliefs result in negative attitudes and ignorance from others. Feeling ostracised and isolated. Feeling discriminated and excluded. Keeping their diagnosis concealed to avoid shame and exclusion. Own fragmented understanding of epilepsy. Concealment feeds stigma "I don't speak about it so maybe

	that's the problem".
	Loss of control: Epilepsy takes over life. Seizures take over the body. Multiple restrictions; not going out alone or avoiding risky situations.

Abbreviations: PWE = people with epilepsy; QOL = quality of life.

Table 5. Process of synthesis and emerging themes and concepts.

Relevant studies (first author)	**Key themes, first iteration**	**Key themes, final iteration (second-order constructs)**	**Core concept, first iteration**	**Core concept, final iteration (third-order constructs)**
Collard, Crooks, Deegbe, Gauffin, Jacoby, Kilinc, Komolafe, Kuramochi, Molavi, Nurjannah, Paschal, Pembroke, Sleeth, Sonecha	Beliefs about cause/public misconceptions/negative perceptions about epilepsy Ignorance/lack of knowledge about epilepsy/lack of understanding Mental illness/intellectual impairment/lack of capacity Caused by illicit substances/drunk/drugs Superstitious beliefs/possession/witchcraft/contagion	Misconceptions about epilepsy	Misconceptions about epilepsy	Societal negative perceptions of epilepsy result in discrimination and rejection
Andersson, Birbeck, Collard, Kuramochi, Nurjannah, Raty, Raty & Wilde-Larsson, Sonecha, Yennadiou	Different from society/societal expectations Taboo/strange/abnormal Person with epilepsy is weak/strange/crazy	Different from society	Different from society	
Birbeck, Chung, Collard, Deegbe, Komolafe, Mlinar, Molavi, Nurjannah, Paschal, Raffaelle, Sarudiansky	Experiencing rejection/abandonment/relationships ending/being avoided/distancing/disregarded/made to leave home	Rejected from society	Experiencing discrimination and rejection	
Birbeck, Collard, Komolafe, Mlinar, Nurjannah, Raffaelle, Sarudiansky, Sonecha	Experiencing ridicule/physical abuse/neglect/harm/cleansing/bullying/teasing	Experiencing discrimination		
Birbeck, Chung, Deegbe, Raty, Raty & Wilde-Larsson, Sarudiansky, Sleeth, Yennadiou	Own understanding Punishment for wrong-doing/my fault/deserving of epilepsy/Superstition/supernatural causes	Own misconceptions about epilepsy	Internalised stigma	Internal attributions of blame lead to negative self-perception and shame
Andersson, Chung, Collard, Gauffin, Mlinar, Pembroke, Raty, Sarudiansky, Sonecha	Self-perception Feeling different/abnormal/'yucky' Feeling of lower human value/low self-worth/disgusting Association between epilepsy and frailty	Feeling different		
Andersson, Chung, Gauffin, Keikelame, Kuramochi, Mlinar, Molavi, Raty, Sarudiansky, Sonecha, Yennadiou	Emotional reaction/shame/blame/guilt/shame on family	Shame	Shame	

Relevant studies (first author)	**Key themes, first iteration**	**Key themes, final iteration (second-order constructs)**	**Core concept, first iteration**	**Core concept, final iteration (third-order constructs)**
Gauffin, Jacoby, Komolafe, Mlinar, Raffaelle, Raty, Raty & Wilde-Larsson, Sleeth	Fear of harming others/injuring others/responsibility for others Scaring others	Risk to others		
Andersson, Collard, Crooks, Gauffin, Komolafe, Kuramochi, Mlinar, Molavi, Raty & Wilde-Larsson, Sarudiansky, Sonecha, Yennadiou	Fear of rejection//fear of assault/fear regarded stupid/fear of others' reactions	Fear of others' reactions	Fear of stigma	
Andersson, Chung, Deegbe, Gauffin, Jacoby, Keikelame, Komolafe, Kuramochi, Mlinar, Molavi, Nurjannah, Paschal, Raffaelle, Raty, Sonecha, Sarudiansky	Difficulties with relationships/effect on relationships/loss of relationship/fear of rejection/actual rejection Role fulfilment: marital relationships/unable to marry/fear of divorce/losing parent role/others unwilling to marry due to epilepsy Impact on friendship	Role fulfilment: relationships	Role unfulfillment	Impact of stigma on everyday life and associated reliance
Birbeck, Deegbe, Gauffin, Keikelame, Komolafe, Raffaelle, Raty	Fear of pregnancy/not able to parent/parenting/feeling a bad mother/not providing children/fear of harming baby/feeling epilepsy will cause miscarriage	Role fulfilment: parenting		
Andersson, Birbeck, Bishop, Deegbe, Gauffin, Jacoby, Kuramochi, Mlinar, Molavi, Raffaelle, Raty, Sarudiansky, Sleeth	Applying for employment/maintaining employment/limited opportunities Losing work/losing job Poor education/disrupted education/can't access school Feeling unvalued at work Fear of unemployment/unemployability	Role fulfilment: education and employment		
Bishop, Chung, Crooks, Deegeb, Jacoby, Kilinc, Kuramochi, Mlinar, Nurjannah, Pachal, Raffaelle, Raty & Wilde-Larsson	Diminished life/not being whole/daily restrictions/can't do what others do/impact on daily living/multiple restrictions Unable to drive, play sports, study, do specific occupations or desired hobbies	Restrictions on daily living	Impact of epilepsy and stigma	
Chung, Gauffin, Kilinc, Raty, Sarudiansky, Yennadiou	Not providing/not contributing/financial implications/unequal rights/not meeting potential	Not contributing		
Birbeck, Chung, Crooks, Keikelame, Klinic, Kuramochi, Raffaelle, Raty & Wilde-Larsson, Sarudiansky, Yennadiou	Relying on others/feeling a burden/requiring support/not wanting to be dependent/burdening others	Relying on others	Dependence on others	

Relevant studies (first author)	**Key themes, first iteration**	**Key themes, final iteration (second-order constructs)**	**Core concept, first iteration**	**Core concept, final iteration (third-order constructs)**
Andersson, Chung, Crooks, Deegbe, Gauffin, Jacoby, Kilinc, Kilinc and Campbell, Mlinar, Nurjannah, Pembroke, Raty, Sleeth	Loss of control/lack of autonomy Externally enforced decisions/family decisions/external restrictions Feeling powerless/feeling restricted/infantilising/other over-protective/being denied opportunities for responsibility	Lack of independence		
Keikelame, Kilinc, Kuramochi, Molavi, Pembroke, Raffaelle, Sleeth	Refusing diagnosis/rejecting epilepsy/avoiding the ‘E’ word/not understanding own epilepsy Accepting epilepsy, taking ownership of condition	Denial of epilepsy	Concealment	Attempts to manage stigma through concealment and avoidance
Andersson, Bishop, Chung, Collard, Gauffin, Kilinc, Komolafe, Mlinar, Molavi, Paschal, Raffaelle, Raty & Wilde-Larsson, Sarudiansky, Sleeth, Sonecha, Yennadiou	Hiding epilepsy/not disclosing/keeping epilepsy secret/concealment/not telling employers Choosing when to disclose/choosing who to tell/practicing telling/avoid explaining Fear of others knowing/disclosure resulting in discrimination Being open about epilepsy	Don't disclose epilepsy diagnosis		
Andersson, Birbeck, Chung, Crooks, Jacoby, Kilinc, Komolafe, Mlinar, Raffaelle, Raty & Wilde Larsson, Sonecha, Yennadiou	Social withdrawal/self-isolation /avoid relationships/choosing friends Avoiding exposure/preventing judgement/pretending to be normal/fear of forced disclosure/hiding seizures Decreased independence/restricting life/isolating	Social isolation	Social withdrawal	
Andersson, Birbeck, Bishop, Chung, Crooks, Deegbe, Keikelame, Komolafe, Kuramochi, Mlinar, Molavi, Nurjannah, Paschal, Pembroke, Raty & Wilde-Larsson, Sarudainsky, Sleeth	Receiving support/supportive family/supportive friends/needing family support/support groups/supportive employers/supporting each other/finding places to talk about epilepsy	Support	Support as protective	Support from others as beneficial but which is dependent on own and others’ understandings of epilepsy
Collard, Crooks, Jacoby, Keikelame, Kilinc, Kuramochi, Nurjannah, Pembroke, Raffaelle, Raty & Wilde-Larsson, Yennadiou	Taking control/managing/self-acceptance/self-care/professional support/resilience/adjustment/self-ownership of epilepsy/making own choices/feeling positive and grateful as coping strategy/accepting that epilepsy may be coped with or prevented but not cured/trusting in God/trusting in medication	Protective factors		

Relevant studies (first author)	Key themes, first iteration	Key themes, final iteration (second-order constructs)	Core concept, first iteration	Core concept, final iteration (third-order constructs)
Andersson, Chung, Crooks, Gauffin, Kilinc, Kuramochi, Molavi, Paschal, Raty & Wilde-Larsson, Sleeth, Yennadiou	Educating and informing others/increased awareness/need for understanding/ignorance/incorrect information Church as source of education/education means acceptance/schools should educate Media misrepresentation	Educating others	Need for education	