National Institute for Health and Care Excellence

FINAL

Epilepsies in children, young people and adults: diagnosis and management

[4] Evidence review: Information and support

NICE guideline NG217

Evidence review underpinning recommendations 2.1.1 – 2.1.10

April 2022

FINAL

Developed by the National Guideline Centre

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ISBN: 978-1-4731-4513-9

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1 Information and Support

1.1 Review question

What information and support is needed by people, parents or carers in relation to epilepsy, and when should this be provided?

1.1.1 Introduction

The need for up-to-date and accurate information and support when needed for anyone living with epilepsy is well recognised. People with epilepsy and their family and/or carers require information that explains their diagnosis, treatment and ongoing care. Such information must take into account their individual needs at each stage of the care pathway and be provided in an appropriate and accessible format. People with epilepsy and their family and/or carers often seek support on actions to reduce the risk of SUDEP, seizure-related risks and risks associated with anti-seizure medications. Communication on these topics requires sensitivity and skill in the methods and delivery of information about risk. The level and quality of information and support currently provided about epilepsy and epilepsy associated risk varies widely.

This updated guideline, reviews the evidence on what information and support is needed by people, parents and carers in relation to epilepsy, and when this should be provided.

1.1.2 Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	To determine what information and support do people and their families or carers need (for example, advice on lifestyle, driving, and their treatment).
Population and setting	Inclusion: children, young people and adults with epilepsy, their families and carers and health and social care professionals involved in their care
Context	A diagnosis of epilepsy can have wide ranging physical and psychological and social consequences which may be as difficult to deal with as the seizures themselves. It is therefore important that individuals with epilepsy, their family and / or carers have information that is individualised and appropriate for individual's developmental age, gender, culture, and stage of life.
Review strategy	• CERQual will be used to synthesise data from qualitative studies. The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings

1.1.3 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document.

Declarations of interest were recorded according to NICE's conflicts of interest policy.

1.1.4 Qualitative evidence

1.1.4.1 Included studies

We searched for qualitative studies exploring patients' and carer's perceptions of their experiences of having epilepsy their views, opinions and experiences in relation to information, education or support that will help people with epilepsy.

Forty one qualitative studies were included in the review; [3, 8-10, 16-18, 21-23, 27, 29-32, 36, 39-41, 43, 44, 47, 49-53, 56, 57, 60, 64, 65, 69, 71, 73-75, 79-82] these are summarised in Table 2 below. Key findings from these studies are summarised in the clinical evidence summary below (Table 3). See also the study selection flow chart in Appendix C, study evidence tables in Appendix D, and excluded studies lists in Appendix E.

1.1.4.2 Excluded studies

Excluded studies can be found in Appendix E.

1.1.5 Summary of studies included in the qualitative evidence

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim
Amjad 2016[3]	Semi – structured interviews with thematic and phenomenological analytical approach; thematic analysis Iran n=10	Parents with only one child with grand mal epilepsy who was between the ages of 1-18 years with a diagnosis of epilepsy made at least one year ago.	To explore the experiences of parents of children with epilepsy
Benson 2015[8]	Semi – structured interviews with thematic analytical approach; thematic analysis Ireland n=29	Children with epilepsy aged 6-16 years who had a diagnosis of epilepsy.	To address the gap in epilepsy literature by unearthing the contextual factors that present challenges for children with epilepsy in disclosing their epilepsy diagnosis to those external to the nuclear family. The nuclear family was defined as the family unit comprising the child's parents/guardians and siblings
Benson 2016[10]	Semi – structured interviews with thematic analytical approach; thematic analysis Ireland n=73 (33 children with epilepsy and 40 parents)	Children with epilepsy aged 6-16 years and their parents. Parent participants were required to be the parent or primary caregiver of the participating child.	To present the stigma experiences of children with epilepsy and their parents, in the context of communicating about epilepsy within and external to the family unit
Benson 2017[9]	Semi – structured interviews with	Parent(s)/ guardian(s) of a	To explore the challenges parents of children with

Study	Design	Population	Research aim
	thematic analytical approach; thematic analysis Ireland n=34	child aged 6–16 years with (i) a diagnosis of any type of epilepsy; (ii) a prescription for anti-epileptic drugs and (iii) no significant intellectual disabilities, learning difficulties and/or developmental delay	epilepsy experienced when deciding whether to disclose their child's epilepsy diagnosis to others external to the nuclear family (defined as the child's parent(s) / guardian(s) and sibling(s)), and identify factors that promoted concealment and / or selective disclosure management strategies among parents of CWE
Chen 2010[16]	Semi – structured interviews with thematic and phenomenological analytical approach; thematic analysis Taiwan n=15	Children aged 7-13 years old, had been diagnosed with epilepsy for at least 6 months and were not developmentally delayed, had well controlled epilepsy	To explore the lived experiences of school aged children with epilepsy
Chew 2018[17]	Semi – structured interviews with thematic analytical approach; thematic analysis Singapore n= 15	Young people (i) diagnosed with epilepsy, (ii) aged between 13 and 16 years old, and (iii) attending mainstream school were recruited,	To use a family resilience framework to explore young people's experiences of living with epilepsy. Key family processes that facilitate self-esteem – an indicator of adaptation and resilience – will be examined as such knowledge will be valuable to social workers and other professionals in supporting these young people and their families
Chiu 2014[18]	Semi – structured interviews with latent content analysis Taiwan n=11	Young people between 14-17 years and discontinued AEDs. Completely off AEDs for more than 6 months before interview	To present the personal views of children in adolescence who have successfully stopped taking AEDs
Eklund, 2003 [21]	Semi – structured interviews with latent content analysis Sweden n=13	Young adults diagnosed with epilepsy	To describe the lived experience of adolescents with epilepsy and how they cope with the disease
Elliot, 2005 [22]	Semi – structured interviews with open coding analysis, axial coding and finally selective coding Canada	Children and adolescents aged 7-18 years old with medically refractory seizures	To explore how children and adolescents with medically refractory seizures experience the impacts of epilepsy on their quality of life within the domains of physical,

Study	Design	Population	Research aim
	n=49		emotional/behavioural, social and cognitive / academic function
Gauffin 2015[23]	Focus group with open ended questions and analysis with meaning units were identified in the text and concentrated without changing the inherent meaning and the implicit meaning in the text was interpreted Sweden n=16	Adult parents with epilepsy aged 18-35 years old,	To describe aspects of what it means to be a parent with epilepsy, focussing the parent's perspective and their thoughts on having children
Harden 2015[27]	Semi-structured interviews with an inductive thematic method of analysis was adopted UK n=27	Participants aged 16-30 years old and only those who had already been informed about SUDEP	To develop a better understanding of how young adults view SUDEP and SUDEP information giving in order to inform the debate on disclosure of SUDEP to patients
Hightower, 2002 [29]	Semi – structured interviews with thematic analytical approach USA n=8	Children between the ages of 9-12 years old who had epilepsy	To gain a better understanding of children's personal experiences with epilepsy
Joung 2019[30]	Face-to-face in-depth individual interviews began with open-ended questions with Colaizzi’s phenomenological analysis South Korea n=12	Women with epilepsy who had given birth to a live infant within 36 months of the study	To explore the experiences of women with epilepsy throughout their pregnancies and childbirth
Kaddumukasa 2019[31]	Open-ended in-depth interviews with thematic analytic procedure, 6 separate focus group discussions Uganda n=27	Aged 18 years or older living with epilepsy and caregivers	To explore the perceived barriers to epilepsy care in people living with epilepsy and their caregivers in a Ugandan setting
Kampra 2017[32]	Semi – structured interviews with	Young people and children aged 5-17	To provide knowledge for healthcare professionals about the needs of young

Study	Design	Population	Research aim
	phenomenological analytical approach Greece n=91		people and children aged 5-17
MacLeod, 2009 [36]	Open-ended and semi – structured interviews with phenomenological analytical approach USA n=4	Young women aged 13-18 years old with a diagnosis of epilepsy and taking at least one seizure medication,	To describe the everyday experiences of young women with epilepsy
McEwan, 2004 [39]	Focus groups with thematic analysis UK n=22	Young people aged between 12-18 years with at least one seizure in the past year	In young people to describe the experience of having epilepsy, to describe its effect on perceived impact on QoL, its contribution to QoL as adolescent moves to adulthood and to examine the perceived impact of epilepsy on QOL in adolescence, and to present a conceptual framework for understanding the impact of epilepsy in adolescence
McNelis 2007[40]	Focus groups USA n=26	Children aged 7 to 15 years	To explore the concerns about the seizure condition and needs for information and support of children with epilepsy and their parents in greater depth than had previously been done
Mengoni 2016[41]	Semi – structured interviews with thematic analytic approach United Kingdom n=14	Diagnoses of intellectual disability and epilepsy, at least one seizure within the last 12 months, meaningful verbal or nonverbal communication enabling the participant to engage with the picture booklet intervention and a carer with sufficient English proficiency to complete the study questionnaires	To explore the impact and management of epilepsy in people with intellectual disability
Moffat, 2009 [43]	Focus groups and semi structured interviews analysed	Aged between 6-12 years, a diagnosis of epilepsy of at least 6 months	To investigate children's perceptions of the impact that epilepsy has on their quality of life by developing

Study	Design	Population	Research aim
	using grounded theory techniques UK n=22	duration and in main-stream schooling	a comprehensive list of themes through qualitative analysis
Mu 2008[44]	Semi – structured interviews with phenomenological analytical approach Taiwan n=20	A child with epilepsy between the ages of 3-7 years old living with his/her parents in the	To examine the essence of the lived experience of the health-illness transition process of parents during the first one and a half years following discovery of their child's epilepsy.
Ninnoni 2019[47]	Semi – structured interviews with thematic analytic approach UK n=28	Adults with mild learning disabilities with confirmed diagnosis of epilepsy, aged between 16-50 years receiving learning disabilities services as identified by the consultants	To give a voice to participants with learning disabilities and epilepsy to express in order to ascertain views regarding communication with doctors and nurses
O'Toole 2016[49]	Semi – structured interviews with thematic analytic approach Ireland n=34	Parent or primary caregiver of a child (aged 6-16 years) with a diagnosis of epilepsy for 6 months or more and with a prescription for AED at the time of interview	To explore the challenges that parents of children with epilepsy face experience when engaging in dialogue with their child about epilepsy and epilepsy related issues
Pashley, 2009 [50]	Open-ended questions and analysed using thematic content analysis United Kingdom n=37	Women with epilepsy prescribed AEDs at conception between 2001 and 2005	To explore why epilepsy-specific preconception advice may be suboptimal and to understand why some women with epilepsy are referred to epilepsy clinics already pregnant. Additionally, to compare the factors in women who planned their pregnancies with those who did not.
Prinjha, 2005 [51]	Interviewing continued until the sample included men and women with experience of different treatments and until no new themes emerged UK n=38	People with epilepsy and their carers	To explore why, at the turn of the 21st century, many people with epilepsy still want more information

Study	Design	Population	Research aim
Ramachandrannair, 2013 [53]	Focus groups and in depth one on one interviews with parents who had lost children to SUDEP because of the sensitive nature of the topic with textual analysis Canada n=63	Parents who lost children to SUDEP, of children with moderate to severe epilepsy, of children with mild epilepsy and of children with new-onset epilepsy	To understand the range of parental views on whether and how to approach the issue of SUDEP with families, to clarify the optimal timing and formulation of the information, and to learn from parents the optimal counselling strategies
RamachandranNair, 2016 [52]	Focus group and Semi – structured interviews with directed content analysis Canada n=23	Participants with epilepsy aged 18-65 years	To understand the range of adult patient views on whether and how to discuss the issue of SUDEP with patients with epilepsy and to clarify the optimal timing and formulation of this information
Roberts, 2011 [56]	Semi – structured interviews with thematic analytic approach Canada n=7	Caregivers of children with epilepsy (aged 5-12 years old)	To identify the perceptions and experiences of the primary caregivers of young children with epilepsy regarding their interaction with the schools' which impact both the child's and family's quality of life and to clarify how families think schools can best support, accommodate and prepare for these children and families
Ronen, 1999 [57]	Focus groups with textual analysis Canada n=71	Children (aged between 6 years and 12 years 11 months) with active epilepsy, defined as recurrent, unprovoked seizures (more than two seizures) within the preceding 24 months	To identify the burdens and concerns of children with epilepsy
Sample 2006[60]	Focus groups with thematic analysis USA n=41	Participants with epilepsy or family members	To explore individuals' experiences with accessing epilepsy-related services and health care, and what life with epilepsy is like
Smith 2014[64]	Semi-structured interviews with thematic and phenomenological analysis USA	Parents with one child with grand mal epilepsy between the ages of 1 to 18 years with a diagnosis of epilepsy made at	To explore the experiences of parents of children with epilepsy

Study	Design	Population	Research aim
	n=10	least one year before study	
Snape 2009[65]	Focus group and semi-structured interviews with thematic analysis China n= 151	Men and women with epilepsy and their families, ranging from 15-71 years old,	To present the experience and views of Chinese people with epilepsy and their families, and to identify knowledge gaps and uncertainties about epilepsy within selected urban and rural communities in China
Thompson, 2008 [69]	In-depth interviews with thematic analysis UK n=15	Women diagnosed with epilepsy aged between 20 and 40 years old	To explore the reproductive experiences of women with epilepsy and highlight the complexity of moral expectations as women seek to avoid questionable decisions and actions that might attract ascription of carelessness or deviance
Tonberg 2015[71]	Semi-structured interviews with thematic analysis UK n=27	Adults added 16-30 years with a HADS score <11 who had been told about SUDEP in the previous 2 weeks	To investigate young adults' responses to discussion on SUDEP in epilepsy
Varley, 2011 [73]	One to one open-ended interviews with phenomenology analysis Ireland n=19	Participants who had a scheduled appointment to attend epilepsy department, patients who did not attend the clinic previously or were discharged from the service	To document and interpret the experiences of people with epilepsy in Ireland as they journeyed along the epilepsy care continuum
Wagner, 2009 [74]	Focus groups with phenomenology analysis US n=7	Caregivers of children aged 1-21 years old with epilepsy	To provide an in-depth examination of the impact of paediatric epilepsy on youth, in an economically disadvantaged state.
Wallace 1999[75]	Focus groups with phenomenology analysis UK n=18	Women with epilepsy aged 24-66 years old	To explore, using focus group discussions, women's experience of and satisfaction with care and treatment for their epilepsy, and to seek views on how epilepsy services might be improved
Westin 2018[79]	Semi structured interviews with thematic analysis Sweden n=11	Parents to children admitted to a paediatric clinic due to a febrile seizure	To explore parents' experiences of their child suffering febrile seizures

Study	Design	Population	Research aim
Widnes 2012[80]	Semi structured interviews with thematic analysis Norway n=10	Women diagnosed with epilepsy and treated with one or more AEDs, undergone 18 weeks' pregnancy routine ultrasound screening without any teratogenic effects observed and aged 18 years or older	To examine risk perceptions and needs for medicines information in pregnant women with epilepsy
Wilde 1996[81]	interviews with thematic analysis UK n=24	Participants aged between 13-25 years attending outpatients' clinics	To explore the issues affecting young people with significant epilepsy who were attending outpatients' clinics
Wo 2018[82]	Semi-structured interviews with phenomenology approach and thematic analysis Malaysia n=33	Parents and their children aged 8-18 years old who had been diagnosed with epilepsy >6months, have ≤4 seizures in the past 6 months and attending regular school,	To explore the experiences of parents and their children, and to identify the needs and challenges faces by parents and children in childhood epilepsy care

See Appendix D for full evidence tables.

1.1.6 Summary of the qualitative evidence

Table 3: Review findings

Main findings	Statement of finding
Absence of information/support (Kampra 2017[32], Wallace 1999 [75], Sample 2006 [60])	Absence of experts who could offer them appropriate counselling about the psychosocial issues. Many parents stated they did not know where to seek help to cope with their child's illness, apart from their doctor.
Acceptance (Benson 2017[9])	For many parents on receiving the diagnosis of their child's epilepsy, a period of grief ensued as parents grappled with the loss of their 'healthy child'. Many parents verbalised that the diagnosis had a profound emotional impact, evoking 'devastation', 'upset', 'concern', 'worry' and 'shock'.
Activity restrictions (Benson 2017[9], Chen 2010[16], Eklund, 2003 [21], Elliot 2005 [22], Hightower, 2002 [29], McEwan, 2004 [39], Moffat, 2009 [43], Wilde 1996 [81], Wo 2018[82])	A number of participants felt their epilepsy had a direct effect on their independence and ability to participate in activities. Activity restrictions not only had implications for the children with epilepsy but also for their parents, with a number reporting that they felt others unnecessarily required them to be present during social and leisure activities.

Main findings	Statement of finding
Affects parents' life choices (Amjad 2016[3])	A father expressed his willingness to continue studying on his favourite course but felt prevented from doing so due to his daughter's condition. Some also felt the need to quit their jobs.
Assisting their child's re-integration (Mu 2008[44])	Parents hope their child can maintain normal social interactions and a healthy lifestyle. They discuss their child's needs, special concerns, peer relationships and activity limitations with their child's illness and comprehend the meaning of his/her behaviour and their child's place in the community
Being in control (Eklund, 2003 [21], Harden 2015[27], Snape 2009 [65], Westin 2018 [79])	A feeling of being in control was important for reducing anxiety. Some adolescents actively searched for information and wrote papers at school about epilepsy. these activities seemed to increase their self-confidence because they spoke proudly about it. participants also reported measures taken to safeguard themselves in the event of a seizure including avoiding potentially hazardous activities such as swimming or ironing.
Belief about what is normal (Chew 2018[17])	Young people's maturity of thought was evident when they spoke of normality. They recognized actual differences when they compared themselves to their peers, and family beliefs played a role in young people's positive views of themselves
Caregiver burden (Kaddumukasa 2019[31])	The burden of providing all basic needs in life and study participants cited performing most of the chores for the patients.
Clinical competence and skills (Wallace 1999 [75])	Problems due to the shortage of specialists with an interest in epilepsy were raised. Both the nurses and women with epilepsy described experiences of delayed diagnoses and misdiagnoses and inappropriate drug management by both neurologists and general physicians.
Cognitive (Elliot 2005 [22], Kaddumukasa 2019[31], Ronen 1999 [57])	Intermittent difficulties with memory were reflected in many narratives. Psychological distress symptoms such as sleep disturbances, were frequently reported by participants.
Communication issues and honesty and openness in provision of information (Mengoni 2016[41], Ninnoni 2019[47], Varley 2011 [73], Wallace 1999 [75], Wilde 1996 [81], Wo 2018[82])	Overall, service users and carers' communication purpose and needs with doctors and nurses were based on a wide range of things. However, involvement in decision making was central to their communication needs, they want to be more involved in communication.
Complexity of epilepsy - difficult to explain to others/challenging to understand (Benson 2015[8], Eklund 2003 [21], O'Toole 2016 [49])	Participants found it difficult to explain to others, with some (particularly those of a younger age) yet to establish how to appropriately describe their conditions to

Main findings	Statement of finding
	others. Some also felt it challenging for peers to understand.
Concealment (Benson 2016[10], Benson 2017[9], Moffat, 2009 [43])	A number of participants felt the need to actively hide their diagnosis from those external to the nuclear family, indicating their awareness of the potential for stigmatisation due to their epilepsy.
Contraception (Thompson 2008 [69], Prinjha 2005 [51])	Participants generally felt their attempts to perform the moral work of avoiding unplanned pregnancy were not always supported by effective healthcare practice and advice. While some women reported that their practitioners were helpful, those who received inaccurate or inadequate advice had to cope with varying consequences.
Coping strategies (Chen 2010[16], Chew 2018[17], Chiu 2014[18], Eklund, 2003 [21], Hightower, 2002 [29], O'Toole 2016 [49], Wo 2018[82])	The participants reported they would try self-management to prevent or manage seizures. This included several strategies such as activity restrictions, positivity or monitoring their general health.
Emotional distress (Elliot 2005 [22], Westin 2018 [79])	The majority of participants experienced periods of intense emotional distress that they attributed largely to the unpredictability of their seizures and loss of control over their bodies. Worry or fear and anger and frustration were often connected to experiencing seizures, medication side effects or extent of parental monitoring.
Epilepsy related risk (Harden 2015[27])	The risk of seizures was central to participants' accounts of their experience of living with epilepsy, both in terms of the risk of a seizure occurring and the risk of injury as the result of a seizure.
Experiences of employment (Wilde 1996 [81])	A significant issue for the majority of the interviewees was that of employment. Many recalled having been forced to send, in some cases, literally hundreds of application forms, with others being dissuaded or prevented from choosing careers they wanted because of their seizures.
Fear (Amjad 2016[3], Elliot 2005 [22], Gauffin 2015[23], McNelis 2007[40], Mu 2008[44], Snape 2009 [65], Roberts 2011 [56])	The fears and concerns of parents revolved around both the physical and emotional health of their children. Worrying about how the seizures would affect their child's development and the uncertainty of the future was identified as a concern. Caregivers discussed their continual worrying over the well-being of their child and the stress of explaining their child's condition to the school community
Fear of misinforming the child (O'Toole 2016 [49])	Fear of delivering misinformation in response to their child's epilepsy related questions was often a daily struggle. To answer their questions parents had to be readily knowledge about their child's epilepsy, however, often parents relayed that they

Main findings	Statement of finding
	themselves felt underinformed regarding their child's specific diagnosis.
Feeling different (Benson 2015[8], Eklund 2003 [21], Elliot 2005 [22], McNelis 2007[40]), Wo 2018[82])	For some disclosing the diagnosis elicited feelings of 'differentness'. Feelings of differentness were exacerbated by the fact very few participants had any contact with other people who also had epilepsy.
Feeling of inadequacy (Gauffin 2015[23]), Mu 2008[44])	The participants described a feeling of inadequacy when discussing parenthood. Some felt they were less important as parents than their spouses. They wished to take the same responsibility as other parents, but understood it was important to accept help from other people.
Food restrictions (Chiu 2014[18], Snape 2009 [65])	Adolescents were told they had to avoid beverages such as coffee or tea that contained caffeine, as well as chocolate and spicy foods.
Guilt (Gauffin 2015[23])	Parents often felt guilty because they could not be the parents they wanted to be. They also felt guilty because of all the difficulties their children had to experience when witnessing a seizure.
Healthcare system issues (Kaddumukasa 2019[31], McNelis 2007[40], Moffat, 2009 [43], Mu 2008[44], Wallace 1999 [75], Varley 2011 [73], Ronen 1999 [57])	Limited health care provider interaction and distance to health centres were major problems. Health facilities were reported to be located far from patients' homes and majority of people faced challenges in reaching these centres, as either they did not own or had difficulties with out of pocket to meet the transport costs.
Home environment (Mu 2008[44], Wo 2018[82])	Parents endeavour to establish appropriate family interaction patterns for their child's development, specifically in terms of routine and rules, as well as adapting their lifestyles to fit their child's treatment progress, special upbringing demands and safety.
Honesty and openness in provision of information (Ninnoni 2019[47])	Concerns that were repeatedly expressed by some service users were related to the issue of withholding or concealing information. Service users wanted more discussions regarding changes to medications to be openly and honestly discussed with them.
Information concealment (O'Toole 2016 [49])	Parents revealed instances of limiting the amount of information relating to epilepsy available to their child. Many parents felt that some information, particularly relating to medication side effects or SUDEP was inappropriate for their child's age (particularly 6–10-year age group).
Invisibility of epilepsy (Benson 2017[9], Wo 2018[82], Benson 2015[8], Chen 2010[16])	Participants discussed the fact it is not physically visible to others, and the silence around epilepsy in the public domain. A number of participants reported that the invisible nature of the condition acted as a barrier to disclosure because both they themselves and their peers struggled to

Main findings	Statement of finding
	reconcile their own perceptions of what an individual with an illness and/or disability should appear like with the seemingly 'normal' physical appearance of the children with epilepsy.
Knowledge sources about epilepsy (Snape 2009 [65], Prinjha 2005 [51])	Three main different sources from which informants drew knowledge and information regarding epilepsy were identified. 1) formal knowledge, which includes knowledge gained from reading medical publications or speaking with medical personnel. 2) informal knowledge, which is gained experientially or through word of mouth. 3) mass media.
Lack of understanding -SUDEP (Tonberg 2015 [71], RamachandranNair 2016 [52])	Most participants did not appear to have a clear understanding of SUDEP. Some were not able to describe or define SUDEP except in terms of its incidence "very low risk" or "very rare". Many associated SUDEP with a particular type of seizure and described it as an overloaded seizure. Many reported not altering their behaviour in terms of modifiable risk factors and adherence to medication.
Lack of understanding/knowledge (Benson 2017[9], Eklund 2003 [21], Wo 2018[82], Wagner 2009 [74], Sample 2006 [60])	Lack of public understanding and knowledge regarding what epilepsy is, the various presentation of seizures and what epileptic syndromes encompass (i.e., the physical, cognitive, and psychosocial consequences of epilepsy) inhibited parental openness about their child's epilepsy.
Lifestyle restrictions (Mengoni 2016[41], Sample 2006 [60], Kaddumukasa 2019[31])	Epilepsy was perceived to significantly limit participants' actions, work prospects, and activities in and outside their home. For participants who experienced multiple seizures a day, the occurrence and aftermath of the seizures could affect the entire day and prevent the participant from engaging in any activities.
Medication (Chen 2010[16], Chiu 2014[18], Eklund 2003 [21], Elliot 2005 [22], Hightower, 2002 [29], Kaddumukasa 2019[31], McEwan, 2004 [39], Mengoni 2016[41], Moffat, 2009 [43], Ninnoni 2019[47], Wo 2018[82], Wagner 2009 [74], Sample 2006 [60], Ronen 1999 [57], Prinjha 2005 [51])	Majority of participants took medication to help reduce seizure occurrence. Many reported side effects from medication, issues with compliance and problems with medical staff.
Minimising different treatment (Benson 2015[8], Benson 2017[9])	For some, disclosing their diagnosis to others was viewed as heightening the risk of others treating and perceiving them differently. Participants reported engaging in concealment and/or selective disclosure management strategies attempting to minimise the potential for others to treat them differently due to their epilepsy diagnosis.
Navigating the non-contingencies (Smith 2014 [64])	Non-contingency is defined as the lack of a perceived relationship between the person's actions and the outcomes experienced. Caregivers in each group echoed the non-contingencies experienced daily and over time in caregiving those with epilepsy in the

Main findings	**Statement of finding**
	home, school, community, and health-care settings.
Need for acknowledgement (Westin 2018 [79])	Parents appreciated that the healthcare staff allocated time to inform them of what was about to happen, listened to them, answered questions, checked in on them, asked them how they were doing and offered food and coffee during their time at the hospital.
Need for comfort (Westin 2018 [79])	The parents watched how the healthcare staff behaved, noticing that the paramedics and/or the staff working in the emergency room were calm and controlled. This helped to reassure the parents. Being told that the child's vital observations were fine also help reaffirm this feeling. Having had prior positive visits to the emergency room also raised the level of comfort.
Need for information (McNelis 2007[40], Mengoni 2016[41], Ninnoni 2019[47], Wo 2018[82])	Children wanted to be as informed as their parents. Most stated that physicians talked over them by using words outside their limited vocabulary or by ignoring them altogether and talking only to their parents. Parents described a need for information regarding all aspects of the disorder.
Need for support (Wilde 1996 [81], Westin 2018 [79])	Many parents felt that it was important to have support from the other parents during the seizure and reflected how much worse it would have been had they been there alone.
Negative feelings towards epilepsy (Benson 2016[10], Chen 2010[16], Eklund 2003 [21], Elliot 2005 [22], Hightower, 2002 [29], Ronen 1999 [57])	Many parents felt that it was important to have support from the other parents during the seizure and reflected how much worse it would have been had they been there alone. Some parents reported the epilepsy diagnosis evoked feelings of embarrassment and shame.
Negative responses to disclosure (Benson 2015[8], Benson 2016[10], Benson 2017[9], Wilde 1996 [81], MacLeod, 2009 [36], Chen 2010[16], Kaddumukasa 2019[31], Wo 2018[82], Elliot 2005 [22], McEwan, 2004 [39])	Many anticipated negative responses to disclosure whilst many had actual negative responses when disclosed. Some reported an unwillingness to disclose their epilepsy diagnosis to those external to the immediate family as they feared it would evoke worry and fear in others. Some participants relayed experiences of being bullied or teased by peers due to their epilepsy.
Outcomes of treatment (Wallace 1999 [75])	Issues concerning side-effects of treatment were a common cause of dissatisfaction for patients. There were complaints about doctors' lack of awareness of the side-effects of the different drugs; their failure to inform patients of the side-effects they might experience with a particular drug; their apparent disbelief of the side effects patients were reporting; and failure to seek patients' views on the desired balance between seizure frequency and side-effects.

Main findings	Statement of finding
Parental perceptions about who should receive routine SUDEP counselling (RamachandranNair 2016 [53])	Parents identified that both parents (as appropriate) should be present at the SUDEP counselling session. There was a consensus that it should be the parent's decision as to whether or not the child should be present at the meeting or when to inform the child about the risks of SUDEP.
Parental perspective of children's concerns and needs (McNelis 2007[40])	Parent participants talked about misinformation and misconceptions their children had about seizures and believed it was caused by lack of appropriate information.
Parental preferences for routine SUDEP counselling (RamachandranNair 2016 [53])	Parents expressed a need to be informed of the risk of SUDEP however some parents felt it is important for neurologists to stress that SUDEP is rare and to balance the message of risk with one of hope.
Parental understanding of SUDEP (RamachandranNair 2016 [53])	Among many parents there was a lack of understanding about the exact meaning of SUDEP and risk of a child dying. While many parents understood SUDEP was a rare condition they still overestimated the risk of SUDEP.
Parents and children's initial reactions (Wo 2018[82])	All parents experienced negative emotional reactions when their child first had a seizure. They were upset, shocked and worried. Many thought that their child was going to die. In some families' mothers blamed themselves for "causing" their child to have epilepsy or felt their in-laws blamed them.
Peers lack knowledge and understanding (Benson 2015[8])	A number of participants discussed how their peers lacked knowledge and understanding of the condition. Many adolescents highlighted how their peers relied heavily on stereotypes of epilepsy to inform the extent of their knowledge.
Practical/access difficulty (Chen 2010[16], MacLeod 2009 [36], Roberts 2011 [56])	Participants reported many problems with learning in their classes and some type of academic difficulty. Majority of the participants mentioned that they had to take time away from school, and sometimes multiple days in a row, in order to see specialists at a tertiary care facility.
Pre-conceptual planning (Thompson 2008 [69], Pashley 2009 [50])	The participants drew attention to the conflict between their initial understanding of the health behaviour—the moral work—of a 'good mother' and the learned moral work of becoming a 'good patient' as women with epilepsy. The majority of non-planners had misunderstandings about fertility.
Pregnancy (Pashley 2009 [50], Joung 2019[30], Widnes 2012[80], Wallace 1999 [75], Varley 2011 [73], Thompson 2008 [69])	Participants were overwhelmed with anxiety regarding possible abnormalities in the baby due to AEDs use, taken aback by unexpected changes in seizure severity and frequency. Participants mentioned struggling with the potential harm of AEDs and breastfeeding. There was an increased fear of passing down

Main findings	Statement of finding
	the disease, and management of the burdens of both childcare and seizure control.
Problems with diagnosis (Sample 2006 [60], Roberts 2011 [56])	A number of participants reported that it took them a long time to be diagnosed with epilepsy. Identification of the child's epilepsy did not come easily for many families, and many described themselves as noticing the symptoms, but not understanding what they meant.
Provoking factors (Chiu 2014[18], Eklund 2003 [21], Hightower, 2002 [29], Kaddumukasa 2019[31], Snape 2009 [65], Amjad 2016[3])	Parents believed that crowds and parties increase the risk of seizures, and some refused to attend parties and ceremonies due to the fear of disclosure of their child's illness. Alcohol use and financial constraints were reported as major impediments to epilepsy care and control.
Recovery after seizure (Mengoni 2016[41])	The effect of seizures varied widely, with some people recovering quickly after a seizure, whereas for others, this could take several hours or even several days.
Sadness, depression (Elliot 2005 [22])	Various degrees of sadness or dysphoria were experienced as fluctuating. In other instances, youths revealed more disturbed emotions that included thoughts of suicide.
School restrictions (Elliot 2005 [22], Moffat, 2009 [43], Wo 2018[82])	A large proportion reported excessive fatigue, making it difficult for them to think clearly and be available to participate in academic endeavours. For some the persistent fatigue and need for sleep that accompanied their seizures could last hours or a whole day; meaning youths either missed going to school or were unable to remain at school.
Self and others' perceptions of epilepsy (Roberts 2011 [56], Benson 2015[8], Prinjha 2005 [51])	Participants' own perceptions of epilepsy as well as their views on how others perceived the condition also seemed to impact their motivations to disclose (or not) the diagnosis to those external to the nuclear family and informed the disclosure management strategies they adopted. For many families, community support was also an important part of the families coping and they mentioned community organisations such as 'Victoria Epilepsy' which helped them become more aware of how they could support their child and spread awareness of epilepsy.
Signs of seizure onset (Hightower, 2002 [29], MacLeod, 2009 [36])	All the participants talked about not always being sure if they were having seizure activity. Sometimes they could tell that they were about to have or had already had a seizure. But at other times it was unclear.
Social exclusion (Benson 2016[10])	A number of participants relayed experiences of being excluded by their peers from parties, playdates and sleepovers, with some citing parental fear as a reason underlying their exclusion from such occasions.
Social restrictions (Benson 2017[9], Chew 2018[17], Ronen 1999 [57], Amjad 2016[3],	For some families, parental disclosure had resulted in the child with epilepsy receiving

Main findings	Statement of finding
	fewer invitations to social occasions, being excluded from participating in physical education in school or being denied enrolment in recreational activities. Detrimental impacts for parents included offensive reactions, e.g., others mimicking seizures, and difficulty finding someone to care for the child in their absence.
Stigma (Benson 2017[9], Kaddumukasa 2019[31], Mu 2008[44], Wo 2018[82], Sample 2006 [60], Ronen 1999 [57])	Several parents believed public perceptions of epilepsy were poor. Some parents felt that epilepsy is a condition that is stigmatised. Participants reported strongly about the need for increasing epilepsy awareness in the community as part of care and stigma reduction efforts.
Successes and barriers in obtaining care (Sample 2006 [60])	Once participants knew what help was available the next step was trying to obtain services, medications of treatments. Many described the ongoing problems they faced when trying to obtain the medication and services they needed: the high cost of medications, lack of money or insurance coverage to pay for them, dire consequences of not taking the medications.
SUDEP awareness (RamachandranNair 2016 [52], Prinjha 2005 [51], Harden 2015[27], Tonberg 2015 [71])	There was broad agreement that SUDEP information should be given to those with epilepsy. There was a sense that there would be something amiss if information was withheld by health care practitioners. Many participants reported they avoid searching for SUDEP information themselves online as they either felt like knew everything they needed to already or they deliberately avoided thinking about SUDEP.
SUDEP information delivery (RamachandranNair 2016 [52]), RamachandranNair 2016 [53])	The majority felt that the discussion should take place face-to-face in a verbal discussion or conversation followed by some written information to take home. Some suggested they would rather hear the information from their family doctor with whom they had a good relationship. Several participants suggested that it might be helpful to have a social worker involved along with the physician sharing the SUDEP information and have access to one after for any further questions or emotional support.
SUDEP information leading to behavioural changes (RamachandranNair 2016 [52], Tonberg 2015 [71], Harden 2015[27])	While some reported anxiety upon hearing about SUDEP for the first time, it was usually presented as being a temporary, rather than long-term concern. Some participants said that having information offered an opportunity for people to avoid or mitigate the risk of SUDEP by encouraging them to change any behaviour that may exacerbate the risk and referred to changes they had made in their lives.

Main findings	Statement of finding
SUDEP information needed (RamachandranNair 2016 [52])	Patients wanted a general overview of what SUDEP was, their odds of being victims, risk factors, causes and prevention strategies.
SUDEP worries (RamachandranNair 2016 [53]), Harden 2015[27])	SUDEP was rarely expressed as a worry by some of the participants. Several participants contextualised the risk of SUDEP within the wider risk of death that everyone faces.
Support (Hightower, 2002 [29], McNelis 2007[40], Wo 2018[82], Eklund 2003 [21], Elliot 2005 [22], Chen 2010[16], Chew 2018[17])	Participants sought support from parents and siblings when they needed help or felt that something went wrong. Participants also described maintaining good relationships with their siblings, which facilitated getting help and emotional support from them. Best friends seem to provide children with a feeling of acceptance and advocacy. In addition to having best friends, every child in the study reported that educating their peers about seizures led to greater acceptance of them and their seizures.
The future (McEwan, 2004 [39], Moffat, 2009 [43], Wo 2018[82])	This theme encompassed leaving home, choosing careers and having children. From older and younger adolescents alike, concern was expressed regarding having children and some were concerned about their prognosis.
Timing and setting of SUDEP discussion (RamachandranNair 2016 [52])	Many believed that the best time to be told about SUDEP was at diagnosis. They felt it should be part of basic information about epilepsy and if shared in a matter-of-fact manner it would not be overwhelming.

1.1.7 Narrative summary of review findings

Review finding 1: Absence of information/support

Absence of experts who could offer them appropriate counselling about the psychosocial issues that arose due to their child epilepsy. "…it would be a blessing if there some kind of help from the school, the doctors or anyone else to help me cope with the way I should handle epilepsy and my daughter's social life without being scared for her...". Almost all parents stated they did not know where to seek help to cope with their child's illness apart from their doctor. There was a need from participants for social support and assistance with everyday needs and professional or peer emotional support. Obtaining information about epilepsy and antiepileptic medication from their doctor was often perceived to be a struggle and many looked to other sources for information. This was particularly apparent at diagnosis which several women commented had been very poorly handled: "She [the doctor] was so blasé about it, oh you've got epilepsy, just take the drugs, and we'll see you next month". The same problems were identified in the discussion with the nurses: "That's the difficulty with doctors, they see it very much from the medical point of view: 'How many seizures are you having, have some more carbamazepine'. [They] don't look at the other issues: the non-medical care, the advice, the information, the education, the much more practical issues that worry women." Women were concerned at the lack of advice and information they had received about contraception. A further issue that clearly caused confusion was the question of the inheritance of epilepsy. "They keep telling me it is not hereditary. That's another thing that is very misconceiving, it's the first thing they ask you, "is it in the family?'. If it's not hereditary, what difference does it make?" Participants found that the state epilepsy foundations website had not been updated for a while. "We checked it recently and it looked the same as 4 years ago..." Another way to gain information was further internet searching.

One participant stated "she's gotten help with her medication, this time from a website. I think it was Web MD." "The seizure clinic... I can call 24 hours a day, and they have somebody there to answer my questions. And that helps a lot." Other sources of help were personal rather than professional and included their spouse or the church.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants' not being adequately considered.

Review finding 2: Acceptance

For many parents on receiving the diagnosis of their child's epilepsy, a period of grief ensued as parents grappled with the loss of their 'healthy child'. Many parents verbalised that the diagnosis had a profound emotional impact, evoking 'devastation', 'upset', 'concern', 'worry' and 'shock'. Parents reported struggling to maintain composure when speaking with others about their child's diagnosis. Furthermore, parents expressed difficulties with adjusting their hopes and expectations for their child due to the epilepsy diagnosis. During this period of parental struggle (which varied considerably in length across families), many parents reported that disclosure was problematic. They consequently adopted concealment and/or selective disclosure management strategies.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 3: Activity restrictions

A number of participants felt their epilepsy had a direct effect on their independence and ability to participate in activities. Unnecessary restrictions were imposed on some participants due to other's fear of a seizure occurring. Some parents recounted incidents in which their child experienced elements of activity restriction by adults (such as teachers and coaches) due to their epilepsy. "I had to tell the teacher and she made a big scene. She wouldn't let her out to play P.E., she kept her in the hall. She wouldn't let her outside for a walk-in case she'd fall or hurt herself or bang her head on the wall...while the whole class was playing P.E., she made her go into third and fourth class and sit and do her work...She'd come home crying." Activity restrictions not only had implications for the children with epilepsy but also for their parents, with a number reporting that they felt others unnecessarily required them to be present during social and leisure activities. Another complained "I can't play computer games! That makes me angry!" The children reported some teachers restricted children's activities whereas others chose to help. "the teacher would offer me 10 more minutes to finish my diction test...". All adolescents described limitations of leisure activity. They also described frustration about not being able to do things their peers do, such as driving a moped or obtaining a driver's license. Although they viewed close parental monitoring as necessary because of safety concerns, they often felt frustrated by the restrictions that diminished their autonomy and opportunities to engage fully in age-appropriate social and recreational activities. "...I've missed a lot...camps, school trips, things like that...a lot of fun stuff...". Children expressed concern about the social impact of epilepsy and its anticipated impact. Sleepovers and going to friends' houses appeared to be major areas of concern for many children. Missing out on social outings and organised trips was a concern. Respondents commonly recalled that one parent, (usually the mother) was more anxious, and they often turned to the less worried parent for support and advice. Many respondents' parents did not restrict what their children did socially, or they tried hard not to, the main exception being swimming. Going out at night, however, especially if it involved drinking alcohol or going to night clubs or being with friends who were not 'in the know' often led to conflict, and frustration with parental overconcern.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 4: Affects parents' life choices

A father expressed his willingness to continue studying in his favourite course "I would have loved to continue into higher education in nursing and work in an operating room too, but my daughter's disease prevented me from doing that". Some also felt the need to quit their jobs. "when my wife realised my son was having seizures again, she left work and began spending more time to take care of him. If she didn't do that and was working instead, we would have a better economic status."

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 5: Assisting their child's re-integration

Parents hope their child can maintain normal social interactions and a healthy lifestyle. Parents serve as a communication mediator for the child, helping to establish caring patterns and a support network at school in order to help the child adapt to social life. They discuss their child's needs, special concerns, peer relationships and activity limitations with their child's illness and comprehend the meaning of his/her behaviour and their child's place in the community. One participant mentioned "I told the other children that he behaves like that because he doesn't feel well. You are not like that, but please understand his feelings. I encourage the other children to play with him."

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 6: Being in control

A feeling of being in control was important for reducing anxiety participants felt. They had enough knowledge of the importance of taking medication regularly and sleeping enough. Several also experienced a link between seizure frequency and stress and diet. Some adolescents actively searched for information and wrote papers at school about epilepsy. These activities seemed to increase their self-confidence because they spoke proudly about it. Participants also reported measures taken to safeguard themselves in the event of a seizure including avoiding potentially hazardous activities such as swimming or ironing, using safety non-spill mugs and hot water dispensers, having showers instead of baths and ensuring high levels of supervision. A number of both urban and rural participants stated that epilepsy was impossible to cure especially if it was inherited. Epilepsy was characterised as a chronic and often unstable condition, which required long-term treatment. The unpredictability of seizures and their potential to cause injury led participants to believe that effective seizure management was essential to maintaining quality of life. Many felt that if epilepsy was controlled it did not constitute anything serious as it was not contagious or fatal, and importance was placed on the need for treatment compliance. Personal and lifestyle interventions used to maximise seizure control and beliefs about the causes of seizures or triggers varied. Parents described the first febrile seizure as chaotic, and some had trouble thinking straight while waiting for the seizure to pass and unable to do anything. Not knowing what to do made parents feel powerless and out of control. To regain control of the situation, the parents performed different actions at home, e.g., cooling the childing and making sure they had open airways or did not harm themselves during the seizure. Some stated they shook the child to receive a reaction, and i was common to pound the child in the back in the belief that the child was choking. After the seizure many parents wanted to keep observing and often would sleep in the same room, frequently taking the child's temperature. To keep the temperature down, some parents gave the child antipyretics early and regularly, regardless of the child's temperature. One stated "...There was a time when we didn't dare leave him in his own room, because I was so afraid that he would get another seizure without us knowing it."

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There were no concerns regarding the applicability of this finding to the overarching question. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants' not being adequately considered and unclear recruitment strategy.

Review finding 7: Belief about what is normal

Young people's maturity of thought was evident when they spoke of normality. They recognized actual differences when they compared themselves to their peers. Family beliefs played a role in young people's positive views of themselves. Being told they were just like others and being encouraged to lead a normal life contributed toward their sense of normalcy and confidence in their abilities to carry on with life, respectively. One young person further elaborated that her parents would likely echo her sentiments. "I think they [parents] will agree with me. Because they also tell me that I must lead a normal life, like others. And sometimes they will say that don't think I have epilepsy and I can get away with things. Like PE (physical education). They also say that everyone is different, but everyone has to do what they have to do. So, I have epilepsy, other people may have other things. Everyone will have their strengths and weakness. So, it's like we are different, but also same."

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 8: Caregiver burden

The study participants were quite vocal about the onerous burden faced in the day-to-day efforts in caring for persons living with epilepsy. The lack of correct information about epilepsy care left most caregivers to resort to 'trial and error' methods. This was aggravated by changes in their roles, decreased household income, and increased caregiver responsibilities, often resulting in physical and emotional stress for the caregivers. The burden of providing all basic needs in life and study participants cited performing most of the chores for the patients. "I have to take care of her because most people find them (patients) disgusting because when it attacks, they drip saliva. Some people think that it is contagious." One stated how "they never explain to you whether it is this or that, the doctor just writes down the drugs. They started giving me medicine, so he started on that medication". Another discussed increased responsibilities: "well I have to take care of him such that he doesn't get an attack in my absence and yet I have a job to attend to. You see it is that job that sustains me, so it gets really hard for me. The challenge is with my job. If I am to leave in the morning, I would have to first give him his medicine”.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There were no concerns regarding the applicability of this finding to the overarching question. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered and lack of detail regarding the recruitment strategy.

Review finding 9: Clinical competence and skills

With all participants problems due to the shortage of specialists with an interest in epilepsy were raised. Both the nurses and women with epilepsy described experiences of delayed diagnoses and misdiagnoses and inappropriate drug management by both neurologists and general physicians. The women also commented on the frustrating process of finding the right drug for their seizures. While they clearly accepted that this was often a process of trial and error, they drew a line between careful changes in medication and what they perceived to be ‘messing around’ or ‘playing’ with drugs and haphazard, somewhat directionless prescribing. Across the groups, there were also comments about GPs’ lack of knowledge about the different types of seizures and the appropriate drug treatment for them. Accident and Emergency (A&E) departments were highlighted as an area for concern. It was felt that there was lack of awareness among clinical staff about the appropriate treatment of patients with epilepsy, particularly following a seizure. The women described how recovery was hindered by staff being insensitive to their needs, whether, for example, it was being left on a trolley under the glare of lights or not being allowed to sleep off the effects of the fit.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 10: Cognitive

Intermittent difficulties with memory were reflected in many narratives. One participant stated, "I don’t remember well both for school and other things…forget stuff at school...homework and writing things down". Seizures and postictal confusion often contributed to difficulties in being able to attend to what was being taught. Psychological distress symptoms were frequently reported by participants and these included sleep disturbances, mood changes, stress, and post-traumatic stress disorder (PSTD). These participants also reported poor appetite and low energy as well as living in a constant fear of having a seizure. “With this illness, suddenly you feel like you are about to have an attack and then get frightened and then the heart beats fast”. Another participant mentioned; “She did at one point think that she was actually stupid. That was the word, the terminology she used, I’m stupid. Because she used to be so good at math, she used to be so good at everything.”

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There were no concerns regarding the applicability of this finding to the overarching question. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered.

Review finding 11: Communication issues and honesty and openness in provision of information

Participants with intellectual disability had mixed levels of communication. Some carers considered their family member or client to have good understanding and expressive skills, whereas other carers and participants noted difficulties in expression and/or understanding. "She can't express how she feels, and stuff a lot of the time”. Overall, service users and carers’ communication purpose and needs with doctors and nurses were based on a wide range of things. However, involvement in decision making was central to their communication needs, they want to be more involved in communication. Service users have consistently expressed concerns regarding their lack of involvement in communication although this appears to vary among doctors and nurses. Similarly, carers expressed their wishes to be more involved in decision-making regarding patients and to be able to advocate for patients when necessary but felt they have often been side-lined by the doctors when making decisions for service users. ‘I would just like to be able to talk a lot more about her so that if I am worried, I can discuss it with them and between us we can put it right hopefully.' Poor communication between specialists and GPs was identified to be a common source of error in patients’ medication. Delays in letters being sent to GPs left patients without medication once they had finished their hospital supply and GPs without clear instructions as to which drugs they should be prescribing. Many participants expressed that although empathetic to their illness, GPs lack the expertise to manage their condition or continue to remain passive with respect to patient needs. Most participants, the GPs role was confined to refilling prescriptions of antiepileptic drugs. For some the interaction with the health care provider is intimidating, while the lengthy time scale between specialist review and onset of symptoms may negatively the patient’s ability to recall relevant clinical information. 33% of participants from one study described their doctors as having been helpful, offering advice, and encouraging, however, others were critical. The main criticisms included doctors did not discuss or explain their diagnosis or condition adequately, especially when the subjects were younger, and that doctors seemed overly concerned with the medical management of the respondents' condition, at the expense of giving practical advice about living everyday with epilepsy. Some subjects remarked that they had known little about epilepsy when they were diagnosed, and their present knowledge had been gained by their own efforts. One respondent commented "That's what I'm annoyed about really, 'cos I've felt, every time I come here, that I know they do their best, but it's just I feel as if I'm being palmed away a bit, and I feel as if they're using me as a bit of a guinea-pig, putting me on loads of new medication…and I feel as if I'm getting nowhere". Furthermore, other concerns related to conflicting information from doctors and nurses and the need for consistency in the provision of information. Service users and carers would value consistency in making decision where both carers and services are aware of decisions that are taken: ‘They have put a stop to my other tablets that I used to take but I don’t know why, I think the…. [nurse] said the learning disabilities team agreed on that but when I spoke with my Mum, my Mum said I was best taking two at lunch time instead of the one’. ‘But sometimes I just wish that there was a bit more communication with the support workers from the doctors and nurses but then everybody is busy’.

Other concerns that were repeatedly expressed by service users were related to the issue of withholding or concealing information. Service users wanted more discussions regarding changes to medications to be openly and honestly discussed with them. It appears there is conflict between autonomy and paternalism. “There was one doctor I think last week I have been on medication for my depression and one doctor tries to reduce it because I have not been getting the truth that ok... [doctors] have reduced it and all that my antidepressant but on Friday I have to go past and get it put back to normal”. Doctors rarely focused on this aspect and parents felt they merely ordered tests to confirm or exclude the diagnosis or epilepsy and prescribe medications for seizures. Although they provided more information in subsequent visits, parents felt the information should be more understandable and doctors should be franker about the side effects of AEDs.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 12: Complexity of epilepsy - difficult to explain to others/challenging to understand

Participants found it difficult to explain to others. Some (particularly those of a younger age) had yet to establish how to appropriately describe their conditions to others. "It is just kind of hard to explain…well maybe when I am older, I might be able to explain it a bit better." Participants also found it challenging for peers to understand. Participants reported experiencing a dilemma whereby their peers grappled with the medical jargon they used to describe epilepsy; they felt they had no option but to employ such language in explaining the diagnosis to peers as they found it challenging to simplify their explanations. "I talked to my friends and tried to make them understand. But it is hard when you don’t know what to say. It is hard to explain. But they were always there in some way. They tried to understand. They listened." Parents found some epilepsy related topics difficult to converse about with their child. The three most frequently referred to be the seizure free period, growing out of epilepsy, and difficulty relating to the disclosure of the child’s epilepsy to others. The seizure free period was a sensitive topic given the unpredictability of seizures, the possibility of circumstances changing suddenly and the fact that their seizure free period was not something they were accountable for. Parents found it challenging when reaffirming to their child that their epilepsy was not guaranteed to go away with age despite lengthy periods of seizure freedom. Some parents felt they should be selective as to whom they disclosed their child’s epilepsy to, considering their child’s wish to not disclose his/her condition to others. However, they understood the potential implications of not disclosing their child’s epilepsy.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 13: Concealment

A number of participants felt the need to actively hide their diagnosis from those external to the nuclear family, indicating their awareness of the potential for stigmatisation due to their epilepsy. Incidences of parents' unwillingness to disclose their child's diagnosis to others was recounted in several interviews, with some parents solely disclosing the condition to others on a need-to-know basis due to the fear of their child encountering epilepsy related stigma. Some parents, albeit often inadvertently, actively relayed to children with epilepsy the stigma that surrounds their condition. Many parents emphasised the importance of their child availing of the same opportunities and partaking in the same activities as their peers, and/or continuing to pursue activities (e.g., competitive sports) they had engaged in prior to the epilepsy diagnosis. Concealment and/or selective disclosure strategies were deemed desirable in instances where parents were concerned that life opportunities or participation in activities would be compromised due to the imposition of unnecessary restrictions on their child by others if they were to learn of the diagnosis. Some discussed their unwillingness to disclose their epilepsy to their peers. All participants from one study had told their best friend. They discussed disliking people staring at the during seizures and how other people's reactions made them feel. One mentioned how "she kept it a secret until I decided to tell everyone else in case, I was near anyone else, and my best friend wasn’t there".

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 14: Contraception

The women generally felt their attempts to perform the moral work of avoiding unplanned pregnancy were not always supported by effective healthcare practice and advice. While some women reported that their practitioners were helpful, those who received inaccurate or inadequate advice had to cope with varying consequences. One respondent reported that lack of information from her GP lead to termination of pregnancy at 5 months: In my opinion, they didn’t give me the information I should have been given when I was younger. I mean, for a start, nobody told me that the pill wouldn’t work. Women with epilepsy have needs related to childbearing. Some we interviewed were concerned about the effect of drugs on contraception, pregnancy and the unborn child. For example, a woman had not been told that anti-epileptic drugs could reduce the effectiveness of the contraceptive pill.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 15: Coping strategies

Participants reported they would try self-management to prevent or manage seizures. One said, "I would squat or sit down…, take more time to rest". Another said, "don’t do exercises that are too exciting; play other games…". Often, young people’s beliefs about living with epilepsy mirrored that of their parents. For instance, a participant spoke of recognizing and accepting the uncontrollable aspects of epilepsy. "… just enjoy life, I can’t do anything about it [epilepsy], to change it, so I have to just accept. And since I can’t do anything, never mind, just take it... I tell myself, don’t need to be bothered about it [restrictions]. I think that is more helpful." Young people with a sense of mastery regarded ‘positivity’ as a coping mechanism, emphasizing it was unproductive to dwell upon the negative aspects of living with epilepsy. Instead, they highlighted that it was essential to look forward to good things in life. These young people focused on their abilities, accepted that certain aspects of epilepsy were beyond their control, they channelled their efforts toward fulfilling their responsibilities (e.g., adherence to medication) and actively pursued their interests. This in turn reinforced a personal sense of control over their lives. Most of the participants said they were not worried about seizure recurrence but would use caution against a possible relapse. One said, "I would try spicy food but eat just a little each time" and would check the ingredients on food labels before eating or drinking anything. A positive attitude strengthened the feelings of control such as "I'm like everybody else. I take my epilepsy medication while others take aspirin." Some retained a restricted lifestyle such as participating in less strenuous activities. Routines helped to maintain a feeling of control, such as installing an alarm on the cell phone as a reminder to take the medication. Relating to others who may have more severe diseases also makes the feeling of control stronger. Also mentioned was exercise, good diet, plenty of rest, used cold packs on face, drank plenty of fluids, taking medication. Another said, "I don’t do anything except pray." Another ate honey, which his mother believed would prevent seizures. Participants also mentioned having a regular bedtime and not getting angry. Parents and children both adopted problem solving and effective emotional coping strategies in dealing with challenges. Many parents recounted about how they reinforced to their child that his/her epilepsy did not restrict him/her in any way or make them different to other children and that they can achieve just as much as children without epilepsy. The majority of parents felt that being treated differently as a result of epilepsy was a major concern for their child. Parents faced a challenge when communicating about epilepsy as they often did not wish to treat their child differently by engaging in dialogue with them about their condition. Similarly, they did not wish for their actions to infer differences between their child with epilepsy and his/her siblings.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 16: Emotional distress

Although most participants identified feeling happy some of the time, majority also experienced periods of intense emotional distress that they attributed largely to the unpredictability of their seizures and loss of control over their bodies. Worry or fear and anger and frustration were often connected to experiencing seizures, medication side effects or extent of parental monitoring. When the parents saw their child experiencing a seizure, becoming unresponsive and blue around the lips, they experienced anxiety, fear, panic and shock. Many could not identify what the child suffered from, and many thought they were suffocating due to choking. Many of the parents imagined their child dying. Even those who identified it as a febrile seizure were worried that the seizure would be dangerous, even though they knew it was not. "...You begin thinking. If it’s not a febrile seizure, what is it? What happens then and how dangerous could it be?". Nearly all parents described apprehension over recurring seizures and anxiety could last for a couple of days or up to several years. Anxiety peaked at night-time, especially if the child felt warm or seemed ill. Parents described that the anxiety faded with time, generally because the child had not suffered anymore seizures or because they had had multiple febrile seizures, so they did not seem so frightening. Ensuing thoughts and emotions after the acute phase were described as reflections over a terrifying experience and thoughts on what could have happened had they not been there when the seizure started.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered.

Review finding 17: Epilepsy related risk

The risk of seizures was central to participants’ accounts of their experience of living with epilepsy, both in terms of the risk of a seizure occurring and the risk of injury as the result of a seizure. Many had experienced some form of bodily harm as a result of having fallen during a seizure.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 18: Experiences of employment

Another very significant issue for the majority of the interviewees was that of employment. Of 24 subjects, four were in full-time employment at the time of the interview, nine were still at school or in higher education, four female subjects were housewives, looking after young children, and seven were unemployed. Seventeen respondents (71%) commented that having epilepsy made getting a job more difficult, either from personal experience or thinking prospectively. Many of them recalled having been forced to send, in some cases, literally hundreds of application forms, others that they had been dissuaded or prevented from choosing careers they wanted because of their seizures. Five recalled incidents where they had been invited for interview, but that at the mention of their epilepsy, the interviewers seem to lose their interest, and they nearly always failed to get the job. Many of the respondents who described difficulties while trying to obtain employment remarked that in most cases, their epilepsy had been the main reason why they had not succeeded, and a lack of success had led seven of them to conceal their diagnosis on application forms. However, a few subjects reported sympathetic interviewers, and when they did finally obtain employment, they generally had few problems in coping with it. Many of them described having been obliged to educate colleagues and employers but went on to report that fellow staff were usually understanding and helpful when seizures occurred.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 19: Fear

Participants discussed unfamiliarity with other cities and the fear of basic health care unavailability as reasons for not travelling, so they are afraid of taking journeys and therefore travel less. A mother said “for example, when we want to go to a party, I'm scared, and I make sure we always take the medications with us. We do not travel because I'm afraid I won't know what to do if a seizure happens.” A father said “I would like to go on overseas tours, but I am afraid. If he has seizures, what could I do in a strange country? I do not know their language”. Emotions surrounding the unpredictability of seizures and loss of control reflected youths' worry of a seizure occurring. "I worry about having seizures and what will happen 'cuz I'm not awake…probably knock my head or fall to the floor or I'd bite my tongue". The embarrassment and stigma associated with having a seizure and the uncertainty of when and where, made if uncomfortable for some youths to be around their peers. The participants in the focus-group interviews talked about the difficulties for and dangers to the child of a parent with epilepsy. They described that they were always aware of the possibility of a seizure and tried to foresee what the consequences would be in each and every situation, so that the child would be safe if a seizure did occur. The participants took great care to prevent the child from being harmed and some of them explained that they were never left alone with their child. The fears and concerns of parents revolved around both the physical and emotional health of their children. Worrying about how the seizures would affect their child’s development and the uncertainty of the future was identified as a concern. One asked "can they play sports or sing in the choir?". While the child is having a seizure, parents do not know what is happening. They feel empathy for their child's pain, yet do not know what they can do to help. "She is hurt. I feel sorry, sad about her. Sometimes… one time I said that I couldn’t take anymore, I told my daughter: why don’t you just die." Informants expressed fears about the unpredictable and variable nature of seizure occurrence. However, there were differences in the descriptions of epilepsy with respect to fear in the urban and rural communities. Urban respondents often expressed themselves from a western biomedical viewpoint using terms such as idiopathic, grand mal and absence seizures and appeared to rationalise the fear portrayed by others witnessing a seizure by attributing it to lack of societal understanding. Caregivers discussed their continual worrying over the well-being of their child and the stress of explaining their child’s condition to the school community. Beginning school after diagnosis was a source of worry and parents spoke of countless times they were required to advocate for their child. Parents also experienced loss of control of their child’s safety when sending them to school and this creates anxiety and uncertainty. Many of the parents viewed their children's experience at school as stressful and commented on the anxiety their children felt. Many families expressed feelings of uncertainty in terms of prognosis for their child and the unpredictable nature of the condition.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants' not being adequately considered and unclear recruitment strategy.

Review finding 20: Fear of misinforming the child

Fear of delivering misinformation in response to their child's epilepsy related questions was often a daily struggle. To answer their questions parents had to be readily knowledgeable about their child's epilepsy, however, often parents relayed that they themselves felt underinformed regarding their child's specific diagnosis. Parents revealed they often relied on online information which they acknowledged was potentially untrustworthy. The complexity and uncertainty of the information received particularly at the point of diagnosis made it difficult for parents to retrieve information specific to their child's diagnosis/seizure type. Parents often felt unsure of where to access reliable information and/or often found information they sourced difficult to understand, consequently, this made it challenging to communicate about epilepsy related issues.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 21: Feeling different

For some, disclosing the diagnosis elicited feelings of differentness. One stated they felt 'they are all normal and I am not'. Feelings of differentness were exacerbated by the fact very few participants had any contact with other people who also had epilepsy. There were reports by participants of isolation and feeling that they had nobody to identify with because within their social circles there were no individuals in the same position as them. "It's hard to talk about it...I don't know, it's just...well not much people I know have epilepsy so it's hard to talk about it...that like no one else has it." Epilepsy was perceived as something that isn't normal or typical, and not knowing others with epilepsy made it harder. All expressed feelings of being different. Some adolescents thought they would have made friends more easily if they did not have epilepsy. Feelings of injustice about having contracted epilepsy were common. There were also adolescents who felt discriminated against at school because they thought the teachers were afraid of seizures. "I'm always kind of…separated from people that I know, in a way." The children expressed concerns about seizures making them different from their friends and limiting their activities and abilities. Some felt isolated socially and viewed by others as "different, weird or contagious".

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants' not being adequately considered.

Review finding 22: Feeling of inadequacy

The participants described a feeling of inadequacy when discussing parenthood in the group. Some of them felt they were less important as parents than their spouses. They wished to take the same responsibility as other parents, but understood it was important to accept help from other people. They expressed that it was difficult to accept that they could not be part of all aspects of parenthood. For some participants this meant that they felt they did not have the same value or importance as other parents. One mentioned "I had a seizure at a parents' meeting in school. The teacher was there, and it was really bad. The teacher did not say anything, but the other parents did. After that my wife wanted me to stay at home on such occasions. I really felt insulted … I was side-stepped. My role in the family was affected by epilepsy. I did not have the energy to do all the things that I wanted to, and my opinion was not always asked for. I was side-stepped." Reframing parental roles was an element mentioned. Developmental features include enhancing parental abilities, monitoring and mastering the process of treatment and establishing a mutually respectful and accepting family environment.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 23: Food restrictions

Adolescents were told they had to avoid beverages such as coffee or tea that contained caffeine, as well as chocolate and spicy foods. The restrictions had a major effect as drinking beverages with schoolmates is a very common social activity in Taiwan. Only a few stressed the importance of a nutritious diet, while a number agreed that stimulants such as alcohol, tea, coffee and smoking should be avoided. Drinking plenty of water to aid digestion (as indigestion was thought to be a trigger), and avoidance of eating beef, mutton or spicy foods was also recommended.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 245: Guilt

The parents in the focus-group interviews often felt guilty because they could not be the parents they wanted to be. They also felt guilty because of all the difficulties their children had to experience when witnessing a seizure. They thought about what the seizure would look like and wondered if the child would be afraid when observing it. The parents were also worried about how these experiences in childhood would affect their children in the long run. They discussed whether the seizures would scare the children and how the children would react to them. The participants also experienced subjective memory decline and they believed that this affected the situation of their children. They explained that they often forgot to keep their promises and forgot to give information and they regarded this as being difficult for their children. They felt that they often let their children down and the children were often disappointed. "I have been worried, and I am so anxious. How will it be when she gets older and how will she cope with it when I have a seizure? I feel I am the worst mum. What will happen if I have a seizure…if it is just me and my children?"

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 256: Healthcare system issues

Limited health care provider interaction and distance to health centres were major problems for participants. Health facilities were reported to be located far from patients' homes and majority of people faced challenges in reaching these centres, as either they did not own or had difficulties with out of pocket to meet the transport costs. This was compounded by long waiting times to see a doctor and sometimes being triaged to another hospital. Participants reported limited patient-health worker interaction at the health centres they attend. "The care providers should work on their manners too; if I speak to you calmly, I don't want you to yell back. Care providers should work on that." Most parents stated that that paediatricians did not give enough information concerning medications, consultants and specialists, questions to ask and how to find answers to the most pressing concerns. Parents reported they often felt unable to talk to healthcare providers. "I had difficulty talking to the doctors and nurses; I did not feel part of the team; the doctors and nurses never talked to my child either." Other parents described healthcare interactions as a 'dictatorship'. Parents discussed the difficulties with not being fully informed about the diagnosis. It was a struggle to coordinate care when so many different healthcare providers were involved. Parents also talked about feelings as if they were working against the physicians rather than with them. Parents monitor whether doctors are providing credible care. "I asked him (the doctor) to check the level of medicine in his blood and figure out which of the medicines are lower than the baseline." The importance of continuity of care, i.e., seeing the same doctor at the hospital on each visit, was emphasized in all four groups. Continuity of care was seen to be important not only for establishing trust and confidence in the doctor but also for rationalizing treatment. As one participant described: 'one doctor will put you on one tablet, and then the next doctor will say 'I don't think you should be on that, I'll take you off that, put you on another'. The amount of time spent in a consultation was also of concern. The women felt that consultations were often rushed and there was never enough time to discuss all that they wanted, although this experience was not shared by everyone. It was agreed that if doctors did not have the time to give patients longer consultations, the opportunity to see a specialist nurse or counsellor would be welcomed. The NICE guideline for epilepsy recommends that all patients with a recent onset of suspected seizure should be reviewed by a specialist within 2 weeks. All participants including those with significant clinical risk endured significantly protracted waiting times. Many participants had waiting times of 2 years. "I thought it was very bad to have to wait 2 years", "it was 2 years from when he had the first seizure... I thought it was a typing error". For many the delay in accessing specialist care prompted negative psychological emotions, feeling "disappointed and shocked" and enduring "fear and worry". Participants do not experience a sense of empowerment or have insight into the concept of integrated shared care. Rather they interpret their care journeys linearly, culminating in review with specialist neurology services. One mother who cared for her 18-year-old son following a traumatic brain injury felt that her sons care "would not happen unless I went chasing things" and the transition from paediatric to adult epilepsy was "a very difficult time." The majority of participants reported little of no interaction with formal epilepsy support groups, relying predominantly on their GP or friends and family members. "He was more upset with all the testing and having to go through the blood work and he had to have a double CT scan. They had to put the dye in, and he was more upset about the testing than he was actually (about) having epilepsy."

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 26: Home environment

Parents endeavour to establish appropriate family interaction patterns for their child's development, specifically in terms of routine and rules, as well as adapting their lifestyles to fit their child’s treatment progress, special upbringing demands and safety. "He needs encouragement. Sometimes, he asked me, 'how is my painting?' and I try to maintain his motivation and tell him, 'you have done a good job'". They establish reasonable parenting and disciplining styles for their child and appropriate interaction patterns between siblings. A mother mentioned the way they discipline their child: "I told his younger brother to learn to respect him. He is your younger brother no matter what. I decided that if his own brother does not accept him, then nobody will accept him or respect him." The parent’s narratives reflected family resilience as the most important resource working at the individual, dyad and family systems levels that helped them to cope with their stress and to maintain family functioning and integrity. In some families, family members felt more united, however in others, parents developed health or mental health issues, and some were forced to give up their jobs to take care of their child. All parents reported they were constantly worried. They worried about their child’s health, school performance and the future (would they be able to live independently or gain employment). All parents agreed that their experiences handling their child with epilepsy improved with time. Most children did not report any significant changes to their family before or after their diagnosis. Some felt that their relationships with their siblings grew closer because of epilepsy.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 27: Information concealment

Parents revealed instances of limiting the amount of information relating to epilepsy available to their child. Many parents felt that some information, particularly relating to medication side effects or SUDEP were inappropriate for their child’s age (particularly 6-10-year age group). Parents felt that by lessening the level of information they could reduce their child’s level of worry and limit their child’s ability to dwell on their epilepsy.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 28: Invisibility of epilepsy

Participants discussed how it is not physically visible to others and that there is silence around epilepsy in the public domain. A number of participants reported that the invisible nature of the condition acted as a barrier to disclosure because both they themselves and their peers struggled to reconcile their own perceptions of what an individual with an illness and/or disability should appear like with the seemingly 'normal' physical appearance of the children with epilepsy. Some reported they would only disclose their diagnosis if others witnessed them having a seizure as this increased their credibility. The invisible nature of epilepsy both in terms of how the condition is often not immediately physically apparent to others and the silence that surrounds the condition within the public arena acted as a deterrent to disclosure for many parents. Parents also referred to dissimilarities between epilepsy and other ‘more visible’ conditions, commenting on how these conditions are viewed more favourably than epilepsy. The invisibility of epilepsy encouraged some parents to conceal and/or selectively disclose their child’s epilepsy diagnosis. Parents felt epilepsy was invisible within the public domain. They believed that there was a lack of dialogue about epilepsy, it received limited media attention and few public figures advocated for it. Parents thought this silent message, reflective of how epilepsy is perceived by society, was not a positive one. It suggested to them that others were uncomfortable with and fearful of epilepsy. This caused reluctance among several parents to disclose their child's epilepsy diagnosis to others. Not knowing the cause was difficult for children to understand. One participant reported "I don't know, maybe my thinking has some trouble. My parents took me to visit the clinic. My brain has something wrong." Others chose not to disclose they have epilepsy with the two main barriers identified as stigma and "invisibility of epilepsy".

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 29: Knowledge sources about epilepsy

Participants discussed three different sources from which knowledge and information regarding epilepsy were identified. 1) formal knowledge, which includes knowledge gained from reading medical publications (books, journals, hospital information leaflets) or speaking with medical personnel. 2) informal knowledge, which is gained experientially or through word of mouth. 3) mass media, which included information provided via newspapers, radio television or advertising campaigns. Respondents appeared insightful to recognise good advice from health care professionals when it occurred, however they were equally insightful in recognition of practice they believed had failed them. This was seen as partly attributable to the doctor's ignorance of the condition and also compounded by their heavy workloads and time constraints. "Some doctors cannot listen to the whole thing you say, they have already prescribed the drug". Consultants played an important role in giving information, sometimes via a nurse. People also got information from other sources; through epilepsy organisations, first aid training, via leaflets, books, magazines, newspapers, videos and the Internet.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 30: Lack of understanding -SUDEP

Most participants did not appear to have a clear understanding of SUDEP. Some were not able to describe or define SUDEP except in terms of its incidence "very low risk" or "very rare". Many associated SUDEP with a particular type of seizure and described it as an overloaded seizure. Many also erroneously ascribed it to accidental deaths including suffocation or drowning, others were able to note that behavioural factors such as not taking medications could increase the risk of SUDEP. Many participants were also unclear about their risk status "I am low risk (I think)". Worryingly 41% had generalized tonic-clonic seizures (GTCS) and were either unaware that this may place them in a higher risk category or identified themselves as low risk. Participants mentioned several benefits to knowing about SUDEP including taking better care of themselves, reducing risk factors and being prepared for the possibility that it could happen. "I think it's just like the knowledge to know really and to be prepared almost I guess". Participants highlighted three disadvantages of being told about SUDEP including increasing fear or anxiety for the patient, others knowing about SUDEP may cause them to become overprotective and hypervigilant and finally a few felt that knowing about SUDEP may results in obsessive thoughts or dwelling on it too much.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 31: Lack of understanding/knowledge

Lack of public understanding and knowledge regarding what epilepsy is, the various presentation of seizures and what epileptic syndromes encompass (i.e., the physical, cognitive, and psychosocial consequences of epilepsy) inhibited parental openness about their child's epilepsy. Stereotypes, common misconceptions and the complexity and heterogeneity of the condition exacerbated this lack of understanding by others. Additionally, several parents reported that a perceived lack of desire from others to engage in discussion and learn about the child's epilepsy fostered their unwillingness to disclose. Several respondents also said one reason for the lack of experience of being different was the general lack of knowledge about epilepsy in the society. All participants were aware of legislation relating to driving and career limitations; however, their knowledge was not always accurate. In one example of this, four of the younger participants expressed different views on how long someone had to remain seizure free before they could drive: "I think it's you can only drive if you've not had a seizure for 5 years". "5 is it, I thought it was 2?" "Mm, no 5", "Yeah 5". There was a general sense amongst the groups that there was a lack of knowledge about epilepsy in society and that more accurate information should be provided to reduce the fear of epilepsy and promote accurate and realistic management of seizures. Three of the teenagers commented on the fact that media portrayals tended to be negative: "when you watch stuff like Casualty and Holby City they make it out that it's bigger than it is". Most children did not actively look for information on epilepsy, some tried to search on the internet but did not understand what they read. Knowledge about epilepsy was obtained from their parents. Parents reported lack of knowledge in the school setting about epilepsy related educational difficulties. For example, students are frequently inappropriately placed in classes for students with a variety of disabilities which are not adequately structured or equipped for children with epilepsy needs. "Like I had to fight to even get him in just a regular school. Cause they want to segregate him into one class no matter where you live - all the special needs kids are in one class. I'm not having that! He's going to school! He's going to learn; he's going to college...". Because teachers, students and school nurses tend to be uncomfortable with seizures the ignorance and discrimination against these students continue. Parents found their children are often "bounced around" different schools and state agencies. Participants were asked to think of recommendations for policy makers which might help those with epilepsy live normal lives. The primary response was the need for a public relations effort at both local and national levels. They noted that with other conditions advocates have put together public information campaigns that spotlight celebrities with the condition. This "celebrity validation" often increases people's awareness, compassion, and willingness to open-up and accept diversity. However too few if any celebrities have come forward to announce themselves as people with epilepsy.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 32: Lifestyle restrictions

Limitations in self-care as well as participating in home and community activities were also cited as barriers. One mentioned "Sometimes they say, she must not cook…". Participants cited financial constraints to meet the required basic needs and get medications as a major cause of stress in their lives and was reported to be one of the barriers to epilepsy care and management. "There is stress about finding money and the children's school fees also mixes in". The condition was perceived to significantly limit participants' actions, work prospects, and activities in and outside their home. For participants who experienced multiple seizures a day, the occurrence and aftermath of the seizures could affect the entire day and prevent the participant from engaging in any activities. Some participants craved more independence, which was significantly limited by seizures that were difficult to control. "It does get to the stage, where sometimes when she has had more than one in a day, that's it the days, you can't go out, you can't do anything, so it has that impact as well.” Participants discussed their loss of anticipated abilities and life dreams. The first time this manifested was when they learned they would not be allowed to drive unless they remained seizure free for a certain period. This minimalised the amount of socialising, community access, types of employment and romantic relationships. Although several participants acknowledged their epilepsy was too severe to be employed, some participants wanted to work, support themselves and live like other people in the community. some received unhelpful treatment from employers. "I've been through three jobs in 6 years [since the onset of epilepsy], where before that the shortest time was 5 and a half years."

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered and unclear recruitment strategy.

Review finding 33: Medication

To control their seizures participants would take anticonvulsant drugs. They regularly took medication on their own or with reminders from their families. One reported "I could take the drugs by myself, but sometimes my mum needs to remind me. " Some would negotiate to slightly lessen the dosage. Throughout their treatment they were required to follow strict medical regimens. Regular timely doses of medicine had to be taken on an empty stomach and one participant could not eat for 2 hours to facilitate absorption. Such a regimen often conflicted with school meal schedules. Another conflict was regarding the requirement of applying for school sick leave in order to attend regular clinic check-ups. "You felt trapped by medications. When I camped overnight, I had to take them. It was troublesome when you stayed outside". The side effects of AEDs such as drowsiness and sleepiness constantly interfered with daily life and affected academic performance. "I always felt sleepy just by sitting in the class...failed the exams...". Participants were aware of the good effects of the antiepileptic drugs. However, several adolescents described side effects from the medications, such as tiredness, a sleeping disorder, concentration difficulties and memory impairment. "Sometimes I sleep a lot and them I'm too tired to do anything. It is especially at school I sometimes feel tired, I would like to go home to bed. but I go on working. I can’t do anything else". Both appetite change and weight gain were described. The adolescents also expressed having a problem regulating the dose of the antiepileptic drugs during adolescence. Others reported hair loss, breathlessness, visual disorder and dizziness. One female wondered about fertility in relation to the medication and one revealed how AEDs affected her mood state, increasing her irritability.

Daily medication awareness, understanding the importance of taking medications, negative feelings about taking medications and adverse effects of medication were identified through interviews. Every child in the study had knowledge of the trade names of their medications and their medication schedule. 7 of the 8 children understood that taking medications helped their seizures, and most understood the relationship between having seizures and medication. 6 out of 8 had negative feelings about taking the medication. "I don’t feel okay with it because I think I’m going to get addicted to it or something." "...sometimes I take my medicine, it makes my stomach hurt." Some followed the advice of traditional healers, which opposed the use of mainstream medical care. “The reason why some people don’t swallow drugs, is that traditional healers say they can treat every illness, so some patients seek treatment there and quit taking their anti-epilepsy medication”. Both people living with epilepsy and caregivers also reported an inability to seek modern medical care and opt for traditional or cultural practices, which impacts drug compliance. The study participants also reported reluctance to refill their drugs when feeling better. Remembering to take medication was an issue for nine participants, across all age groups. However, comments seemed to reflect that these difficulties were due to lifestyle and not a cognitive deficit: “they’re up in my room and I’m downstairs watching TV and I just can’t be bothered going up to get them”. Three teenagers also commented that medication acted as a physical reminder of their condition, made them feel different and increased the risk of disclosure which, in turn, increased the risk of peer rejection and bullying. Seven mentioned that they felt medication placed restrictions on activities, particularly experimenting with alcohol. Seven participants or their carers reported that epilepsy was fairly stable and well controlled with AEDs. These participants still sometimes experienced seizures, but carers and participants felt that they were as well controlled as they could expect. Changing medications was considered stressful, occasionally causing worse seizures or side effects. The following side effects were described and considered difficult to manage tiredness and impairments to mood, cognitive, verbal, and physical skills. Most disliked taking AEDs whereas some were indifferent and some still adjusting. Taste was an issue for majority. Compliance was discussed by the children, some concerned they would lose their tablets, their parents would forget and some worried about having more seizures if not compliant. "Sometimes they get stuck, and I have to take more juice, they taste awful, I actually bring some of them up".

Service users expressed concerns regarding medication errors. This led to patients questioning whether they were getting the prescribed or wrong medication. This was reported to be affecting their trusting relationships with doctors and nurses. “Medication is funny, there are so many things going on with my medication. For instance, the doctors got mixed up between my medication and my brother’s medications, how is that? I try to understand whether I take different, medications”. This view regarding errors in medication was corroborated by the carer’s own observation of the error in the medication: “He [patient] asked me a few months ago to double check his tablets because he felt the tablets were wrong and I did, and the tablets were definitely wrong, and we both went down to the doctors to get everything sorted out”. Service users also reported that they are not being trusted by doctors especially when reporting their experiences with medications and side effects: “I am finding that I am sweating a lot because of the dizziness, I get angry because trying to explain to the doctors, sometimes when you are telling them you wonder if they believe you, it makes me cross sometimes. But is, you are going through it, and they are just sitting on the chair, and you wonder if they are taking it all in”. However, one reported that her child had significant hair and weight loss because of the AED. The women were satisfied with the follow-up and medicines information provided, and neurologists, were regarded as highly trusted providers of medicines information. Participants reported limited needs for medicines information due to long-standing use of AEDs and to restrictive use of other medicines. Despite this, the women appreciated medicines information both in written form and through oral communication with health care professionals, as supplement to each other. The credibility of the physician was further enhanced when they took the time to explain medical issues and answering questions, demonstrating professional competence by referring to conference attendance, or by consulting the medical literature or a specialist colleague during consultations. Most women browsed the Internet for health and pregnancy related information in general, although a few were determined not to use the Internet at all while pregnant. The Internet was presented as an instant, superficial source of information with inherent problems of inconsistencies and varying quality of information. ‘‘I have searched the internet, that was the first thing I did, though different sites give so much different information. Not all of it is good for you to read.’’ A number of participants discussed concerns regarding frequent changes and adjustments to medications which contribute to unusual, sleepy and preoccupied behaviours along with behavioural outbursts. This can leave parents to question whether behaviour is related to seizures, medications of the child’s personality. "So now you are on four medicines instead of three and then all the different side effects." Parents also discussed how students are sent home after a seizure and that this avoidance of seizures and treatment side effects interferes with the ability of youth to overcome the embarrassment of having drowsy episodes or seizures in school. One parent felt that students must be taught more about epilepsy in school. Although participants wanted to live as normally as possible, they could not escape the fact they lived on very strong medications and/or with medical technology inside their bodies. "And it may be on the tip of your tongue, and you can't say it. It is part of that memory thing, and part is of that is the medication."

Other medication issues mentioned were interrupting activities, management issues and feeling different due to medication. 'The medicine helps you. Sometimes the medicine isn't nice, (because of) the side effects that come with it. I get tired.' Many wanted to know why their drugs were chopped and changed. For example, R: "...why am I like this and why is this medication not working and what's happening with me. It's just them, just changing the medication from one dose to another dose or from one drug to another drug, that's how it is. And they don't say, 'Oh we did the scan and it showed this', and 'it showed that' because they think oh maybe she wouldn't understand what we said to her. But I have done biology! (laughs). If they explained to me, I would understand." Some people were worried about the long-term side effects of drugs, and whether their medication was affecting memory and other aspects of daily life. One woman asserted that if she had been given more information about her medication, she would have changed her lifestyle to prevent osteoporosis: R: "It was only when I changed my doctor, and got to see the consultant I'm seeing now, did anyone bother telling me that actually phenobarbitone withdraws calcium from the blood stream, and especially after the menopause there's a strong risk of osteoporosis.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 34: Minimising different treatment

For some, disclosing their diagnosis to others was viewed as heightening the risk of others treating and perceiving them differently. "…I didn't really want my teachers to know in case they treat me differently…I don't want them to think the minute I put my hand up and say, 'I just have a wee bit of a headache, can I go?' I don't want them to freak out because they wouldn't with anyone else." Many participants conveyed they did not want epilepsy to be a defining characteristic in their lives. Furthermore, they didn't want to be pitied or to receive special treatment as a result of their diagnosis. Participants reported engaging in concealment and/or selective disclosure management strategies to minimise the potential for others to treat them differently due to their epilepsy diagnosis. Several parents described striving to foster a sense of normality for their children with epilepsy by ensuring where possible that others did not treat or perceive the children with epilepsy differently because of his/her diagnosis. Some parents reported considering the perceived risk of disclosure resulting in consequences that would compromise this sense of normality, e.g., 'drama' arising, the children with epilepsy being 'labelled' or thought 'less of', or others viewing the diagnosis as infringing on the children with epilepsy ability to reach his/her ''potential'' and thus changing their treatment of the child. Among parents who perceived such risks existed, concealment and/or selective disclosure strategies were viewed as protective mechanisms to guard against such consequences.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 35: Navigating the non-contingencies

Non-contingency is defined as the lack of a perceived relationship between the person's actions and the outcomes experienced. Caregivers in each group echoed the non-contingencies experienced daily and over time in caregiving youth with epilepsy (YWEs) in the home, school, community, and health-care settings. Participants shared their frustrations about seizure occurrence despite best planning, adhering to the medication plan, and employing supportive lifestyle changes to avoid seizure triggers. Caregivers were also frustrated that as school years progressed, they were informed that their youth had learning, emotional, and/or social comorbidities that interfered with the school milieu or community activities. However, caregivers also shared positive outcomes as a result of navigating these non-contingencies such as becoming experts about epilepsy, mastering skills needed to provide care, and experiencing immense love and advocacy for their YWEs. Caregivers also recognized the need to adjust to the diagnosis over time in order to try to live a healthy life. Overall, the focus groups expressed frustration with obtaining community services, (e.g., social activities and summer camps), the large amount of time spent finding resources and information needed to best care for their YWEs, and the lack of awareness among health-care providers and the community about epilepsy. Group differences in time periods postdiagnosis highlighted how the frustrations were perceived. For example, caregivers of YWEs diagnosed at less than1 year shared that they were still adjusting to the diagnosis, had questions about possible causes, and experienced uncertainty regarding the non-contingency of seizures and treatment effects. Caregivers of YWEs who had been diagnosed between 1 and 5 years expressed uncertainty that the epilepsy diagnosis would ever have a positive impact. The mother of a preadolescent shared that there was “nothing positive about the diagnosis” for her, her child, or the rest of her family. The two focus groups with caregivers of YWEs diagnosed for more than 5 years expressed uncertainty regarding the future for their YWEs, being overwhelmed with the amount of time spent in informal care identifying resources and being advocates. All four of the groups shared and agreed that they had to learn to navigate resources and information, especially since the public is not informed about epilepsy or seizure first aid.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 36: Need for acknowledgement

The parents of those with epilepsy stated that they were happy with the treatment they received at the paediatric emergency room, and they felt that the staff were responsive and kind-hearted. They felt welcome and they had their own room so did not have to sit in the waiting room and felt positive the parents appreciated that the healthcare staff allocated time to inform them of what was about to happen, listened to them, answered questions, checked in on them, asked them how they were doing and offered food and coffee during their time at the hospital. By confirming their anxiety, the parents felt that the healthcare staff took them seriously and that they had not gone to the emergency room in vain. Some parents mentioned the importance of the child being seen, for example, when staff communicated directly with the child in a suitable manner, thus involving the child directly in the treatment.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered.

Review finding 37: Need for comfort

The parents watched how the healthcare staff behaved, noticing that the paramedics and/or the staff working in the emergency room were calm and controlled. This helped to reassure the parents. Being told that the child’s vital observations were fine also helped reaffirm this feeling. Having had prior positive visits to the emergency room raised the level of comfort as well. One parent talked about the importance of a child customised environment, e.g., one including toys to help the child feel secure. "When you see they're not reacting like there's anything to panic about, you feel that things are pretty ok." Parents previous knowledge about febrile seizures varied and ranged from never having heard the term, to knowing what it was and how to handle it. Most parents who did not have prior knowledge wished they had received information prior, but some were unsure if they would have even remembered this information. Parents were satisfied with the information they received in the emergency room. Receiving an explanation of what had happened and that it was not dangerous was of the greatest importance. Some parents struggled to understand all the information they received ad stated they needed to hear it again in a calmer setting. Many read about it on the internet afterwards and some still had unanswered questions. Most parents whose children had been through several seizures said that the experience and the information they gained from the first seizure helped them feel safe and prepared during recurring seizures. Some families felt safe after being prescribed a short acting benzodiazepine to abort prolonged seizure while others experience additional stress wondering when they will need it and always needing to keep it with them.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered.

Review finding 38: Need for information

Children wanted to be as informed as their parents. Most stated that physicians talked over them by using words outside their limited vocabulary or by ignoring them altogether and talking only to their parents. The children noted that their most basic questions were not addressed, such as knowing what was happening to them. When asked about her visits with the doctors and nurses one said, "I just look at the magazines in the office while my mom talks to them." Parents described a need for information regarding all aspects of the disorder. Many parents expressed the desire for a guide that gave advice on what to do when a seizure occurred. "It would be helpful to have a kind of cookbook to know 'if my child has a seizure, this is the first thing you'll see, and this is how you respond to that'".

Most agreed that descriptions of medication side effects were often not provided. Regarding information needs and support, participants and carers reported mixed experiences but, overall, described the absence of epilepsy-related information and support tailored to their needs. From the participants' perspectives, 12 participants or their carer indicated that they had not received any information about epilepsy specifically adapted to their needs. One participant indicated having received information about epilepsy but could not remember its content. Only two participants recalled having attended information or support groups about epilepsy, and they reported finding it helpful. Some participants and carers reported receiving accessible information about other topics but not about epilepsy.

One participant who had been recently diagnosed with epilepsy was struck by the lack of information and support provided by the hospital at the time of diagnosis. No information was shared with the participant or his wife; rather, it was shared with care home staff only. “They won't let me, the doctor won't tell me nothing, they keep it away, they don't want to tell me yet, so I know they told the staff.” Service users and carers expressed the desire to communicate effectively but appeared to be constrained by their limited knowledge regarding epilepsy, seizures and medication. They both expressed the need to know more about epilepsy and would value some form of training to improve their knowledge on epilepsy and seizures. ‘……a gap in knowledge because I don’t know obviously enough about as much as I should because I work with her and more knowledge for what to look out for, just general knowledge of epilepsy would be ideal’. Parents wanted doctors to provide them with sufficient information on how to care for a child with seizures. Some parents were aware of the importance of a parental support group and hoped to share and exchange information with other parents.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 39: Need for support

One study showed that despite support groups being available in Leicester, all apart from 5 participants were unwilling to join. The reasons given by the respondents for their refusal to join included comments that such groups were irrelevant to their lives, and that these groups tended to emphasise the negative aspects of having epilepsy. One male respondent remarked: 'At college they had a day where everyone with..., illnesses and disabilities could go and meet, but I never turned up... I'm not being elitist or anything, but I didn't want to be associated with that... "cos what I try doing is forget about it and pretend it's not there, even though it is, I try to get on with life as well as possible.' Many parents felt that it was important to have support from the other parents during the seizure and reflected how much worse it would have been had they been there alone. They would not want to be alone if it happened again. The first time the child suffered a febrile seizure the most common course of action was to call the emergency services, and some called the healthcare guide service for advice. The parents were then told how to act. In addition, knowing that help was on its way, or they could go to the paediatric emergency room was reassuring and helpful and when the child was being cared for parents felt relieved to hand over the responsibility to someone with proper competence. Parents were pleased to be offered the possibility to stay overnight in the hospital and those that chose to go home felt safe knowing that they could call or go back.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants' not being adequately considered.

Review finding 40: Negative feelings towards epilepsy

Many participants reported they had internalised negative feelings towards their epilepsy. Some relayed how it made them feel different from their peers and at times their siblings. This brought up issues of self-identity related to living with epilepsy, with a number of participants reporting they felt like the 'odd one out' amongst peer groups. "...it was quite shocking and annoying because it sometimes it feels like I'm the odd one out". Some parents reported the epilepsy diagnosis evoked feelings of embarrassment and shame. Seeking a sense of normalcy and 'sameness' was imperative to participants in light of their diagnosis. "...he said, 'I just don't want to be different; I want to be the same as everybody else'". Children often described negative feelings about their condition, which led to seizures, restricted activities and the need to take medicine. One participant said "I don't want to have any more seizures, not at school or at home. I am afraid someone will find out what happens with my illness". They reported anxiety about having seizures at school because there was a risk of embarrassing oneself. It was a burden to take the medication for a whole lifetime and a burden to be forced to take care of oneself and to think about one's health more than other peers of the same age do. Fear of future seizures caused sleeping disturbances and anxiety for some respondents. One participant did not tell her mother when she got the seizures, because she found it embarrassing, and another girl thought she was stupid before she understood it was absence seizures. "I think it is more difficult for those who have diseases to make friends, they feel more alone and as invisible persons". Participants referred to lacking self-confidence, hesitating and restraining themselves in social interactions. All participants expressed negative feelings about having seizures. One stated he felt bad about seizures because he hated going to the hospital and he hated that outcome. Another said he did not like people to know he had epilepsy because they started crying after witnessing his seizures. Participants reported self-confidence issues along with the physical impact of epilepsy. “Lack of confidence I think is the biggest part of having epilepsy for them because they don’t feel positive about themselves a lot of times”’ Physical impact; “Sometimes I don’t feel good and after school I feel sleepy.” They also felt different to others. “It feels like nobody’s like, everybody’s like way different than you, like everybody looks alike and you’re the only person in the world that’s different. That’s what it feels like.’

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 41: Negative responses to disclosure

Participants anticipated negative responses to disclosure and some experienced negative responses. Some reported an unwillingness to disclose their epilepsy diagnosis to those external to the immediate family as they feared it would evoke worry and fear in others. For others, disclosure was avoided because of the apprehension that it would result in bullying/teasing. Several participants recounted how disclosing their diagnosis to those external to the family had yielded unfavourable outcomes for them in the past, including judgemental behaviour, social exclusion and prejudice. "...like some people don't really like to sit beside me...in case I... in case I would get a seizure or something like that." Some witnessed others imitating their seizures while others had experienced bullying and teasing. Some participants relayed experiences of being bullied or teased by peers due to their epilepsy. "Em, I don’t like talking about seizures that I've had cause like in primary school like people used to talk about seizures I used to have, and they'd like be laughing about them." Parents were also largely aware of the threat that bullying, and teasing posed for children with epilepsy perceptions of epilepsy-related stigma amongst peer groups.

Fear of negative responses, as well as actual experiences of negative reactions by others to past parental disclosures of the children with epilepsy (CWE’s) diagnosis, presented challenges for some parents. Some parents relayed fearing that after disclosure of the CWE’s diagnosis they and/or their child would be subjected to stigmatisation, prejudiced attitudes, discrimination, and/or exclusion from social, recreational and/or sporting activities. A number of parents alluded to being apprehensive about how parents of their child’s peers would respond and whether this would limit future invitations to playdates, parties and sleepovers, and consequently negatively impact on their child’s friendships and socialisation. Several parents reported how prior disclosure exchanges had resulted in negative consequences for them and/or their child. Children perceived their peers responded negatively to their illness. Some children keep their illness secret to prevent being teased by peers. One said "no one plays with me. They play with each other, but seldom with me". Even those who had close friends sometimes suffered from exclusionary behaviour. This took the form of being labelled, teased and bullied by their peers and being excluded from social activities. "Yes, I've been teased…people call me special ed". "Sometimes well some, some people...just like think that I'm...kind of like...weird...cause I have epilepsy". Lack of family support and stigmatizing behaviour by immediate family members were perceived as important barriers to epilepsy care. Several study participants reported insults or name calling from their family members.

“At school, I can get just one attack and then my colleagues isolate me. My friend who used to help me, has stopped sharing a seat with me, they say that when they sit with me, I would infect them with epilepsy”. Majority of participants had experienced some type of bullying while at school. Sometimes the bullying took the form of physical violence and sometimes it was psychological tactics such as ignoring and excluding. Either way, the bullying was clearly upsetting to the young women in the study. “On April Food’s Day one time they went…I was wearing a white school shirt, and they went, and they sprayed ketchup on it.” She was not safe in the hallways at her school. All the participants in this study engaged in disclosure management strategies, and all wished that they had more control over who knew or found out about their diagnosis of epilepsy. All the participants in the study wanted to be selective about whom they chose to talk about their diagnosis of epilepsy, but sometimes they did not have a choice. They had different reasons why they didn’t want to tell others about their epilepsy, including not wanting other people to worry about them, not wanting others to judge them negatively, or not wanting to be picked on or bullied. Nineteen of the participants reported experiences of bullying and social isolation: “I feel left out because I can’t go sometimes with my friends and things like that”; “at school, the boys in my year and other boys in other years pick on me, they call me names and things just because I’ve got epilepsy, I’ve had that since I started school”.

Some parents reported their child had no friends in school and were called names and bullied. Many subjects reported having been bullied at school although after leaving school, the experiences of stigma seemed to decrease. Verbal teasing was the most common form of prejudice, i.e., name-calling and jeering, which was often very distressing. Subjects felt that people reacted in a negative way towards those with epilepsy as they were either afraid of epilepsy, or ignorant, or both. Many subjects also commented that epilepsy was not talked about among the population and because of this public unwillingness to understand what epilepsy was, the old attitudes lived on.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 42: Outcomes of treatment

Issues concerning side-effects of treatment were a common cause of dissatisfaction for patients. There were complaints about doctors’ lack of awareness of the side-effects of the different drugs; their failure to inform patients of the side-effects they might experience with a particular drug; their apparent disbelief of the side effects patients were reporting; and failure to seek patients’ views on the desired balance between seizure frequency and side-effects. Although the women ultimately wished for seizure control, they were not prepared to achieve it at all costs, several having experienced side-effects which were worse than the seizures themselves. The nurse specialists emphasized that enabling patients to lead a full life not only involved treating seizures and limiting side-effects, but also helping patients to cope with the impact epilepsy had on broader areas of their lives, whether it be, employment prospects, education or social relationships. In their opinion, too often this was overlooked by health professionals, and patients were left to come to terms with living with epilepsy without professional support. The four participants who had had surgical intervention for their epilepsy spoke generally positively of their experience. Three no longer had seizures, though they were still on medication, and were looking forward to the time when they might come off drugs altogether. Furthermore, the thought that they might soon be able to drive was an exciting prospect.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 43: Parental perceptions about who should receive routine SUDEP counselling

Parents identified that both parents (as appropriate) should be present at the SUDEP counselling session. There was a consensus that it should be the parent’s decision as to whether or not the child should be present at the meeting or when to inform the child about the risks of SUDEP. Factors which influenced the decision included the child’s age, level of understanding of epilepsy and cognitive abilities. In general, it was agreed they should share this information once the child was in early adolescence (e.g., >12 years) and possessed the maturity to process the information and was not developmentally impaired. Some stressed the importance that it should be shared before they begin to engage in potentially risky behaviours (underage alcohol consumption). There was a lack of agreement over who should explain SUDEP to a child. Some felt it should be the responsibility of the parents while others felt that the information should come from the paediatric neurologist. There was a consensus that older siblings should also be informed about the risk of SUDEP.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 44: Parental perspective of children's concerns and needs

Parent participants talked about misinformation and misconceptions their children had about seizures and believed it was caused by lack of appropriate information. "Oh yes, my son had imagined all sorts of bad things that had nothing to do with seizures." Parents also identified how children took their cues about the seriousness of the disorder from them and the importance of parents being role models. "I think that kids do observe the parent...parents need to be calm if they are going to help their kids".

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered.

Review finding 45: Parental preferences for routine SUDEP counselling

Parents expressed a need to be informed of the risk of SUDEP however some parents felt it is important for neurologists to stress that SUDEP is rare and to balance the message of risk with one of hope. Parents who had lost a child to SUDEP were best able to articulate the messages that should be communicated to parents including: (i) the actual risk of SUDEP, (ii) risk and protective factors associated with SUDEP, (iii) any known prevention strategies, and (iv) an acknowledgement that SUDEP may be beyond parents’ or physicians’ ability to prevent or stop. Parents also agreed that SUDEP counselling should occur in a face-to-face interaction between the neurologist and the parents rather than a phone consultation but with written information to follow to read in their own time along with a list of credible websites.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 46: Parental understanding of SUDEP

Among many parents there was a lack of understanding about the exact meaning of SUDEP and risk of a child dying. While many parents understood SUDEP was a rare condition they still overestimated the risk of SUDEP. Parents who had lost a child to SUDEP had a more in depth understanding and recognised that there was very little they could have done to prevent their child’s death.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 47: Parents and children’s initial reactions

All parents experienced negative emotional reactions when their child first had a seizure. They were upset, shocked and worried. Many thought that their child was going to die. In some families’ mothers blamed themselves for "causing" their child to have epilepsy or felt their in-laws blamed them. At this stage many parents did not look for information actively as they did not know that their child had epilepsy. Most parents knew their child was sick and needed some sort of care, some parents sent their child to a healthcare institution and others sent them to traditional healers. Children’s perspectives were mainly described by children aged 11 years and older, as younger children did not know they were having a seizure or were too young to recall. Fatigue and excessive tiredness were experienced by some children after their first seizure. Some children were conscious and felt like they were "stuck inside" their body during the seizure. Others reported that they lost consciousness or went blank during their seizure. Most children felt shocked, upset and scared during or after their seizure.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 48: Peers lack knowledge and understanding

A number of participants discussed how their peers lacked knowledge and understanding of the condition. Many adolescents highlighted their peers relied heavily on stereotypes of epilepsy to inform the extent of their knowledge. Several participants based their decision to disclose their diagnosis to others on how they thought others would perceive epilepsy.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 49: Practical/access difficulty

Participants reported many problems with learning in their classes. One said "…I could not concentrate on anything; my thoughts just kept on drifting". One mentioned regular serious headaches, especially when paying attention to a teacher's lecture. Majority described some type of academic difficulty. Despite their academic struggles, none of the young women from one study were enrolled in any special education classes or received extra help beyond the traditional classroom. Missing school for doctors’ appointments may also contribute to the girls falling behind in their classes. All the participants mentioned that they had to take time away from school, and sometimes multiple days in a row, in order to see specialists at a tertiary care facility. Many families were happy with their schools, and many believed that not having seizures during the school day contributed to this. Despite many positive experiences with schools some families felt unsatisfied, and this often stemmed from safety issues, particularly the teachers' lack of seizure first aid knowledge. Many parents discussed the specific learning difficulties that their child experienced in the classroom. Most complaints concerned cognitive impairments centred on attention and memory. Frequent absences from school were a recurring theme that emerged from discussions. For many children being sick puts them at greater risk of seizures, therefore parents choose to keep their child at home when they were feeling unwell. Additionally, other parents mentioned pulling children out of school due to frequent symptoms of epilepsy such as migraines. Medical experimentation to obtain seizure control created such medical complications that one child was unable to attend school. Most parents discussed the academic support their child received at school, and many parents mentioned having psycho-educational assessments conducted and receiving individualised education plan. Parents suggested that having a teacher familiar with inclusive practices and experience working with children with special needs is essential to their child's success. Families also mentioned the importance of the flexibility of the school if their child missed school or how long it took to complete assignments and being allowed to home school their child when necessary.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants' not being adequately considered and unclear recruitment strategy.

Review finding 50: Pre-conceptual planning

One woman described how information about reproductive health does not necessarily form part of the general pattern of treatment for epilepsy: "I went in to see [the specialist] and they just said, ‘Oh, you're pregnant. You're supposed to have told us before you were trying so we could do things about it,’ like change my tablets and put me on folic acid for months before, apparently. Well, nobody said a word, I didn't know". The women drew attention to the conflict between their initial understanding of the health behaviour—the moral work—of a ‘good mother’ and the learned moral work of becoming a ‘good patient’ as women with epilepsy. This involved coming to terms with counter-intuitive knowledge of risk avoidance through comprehension of the need for continued medication. Five non-planners had at least one other unintended pregnancy (in the conventional sense) and four of these had experienced adverse outcomes (miscarriage or major malformation). Four non-planners were using contraception, and all reported contraceptive failures, including two using barrier methods who had three or more failures with this method. Most non-planners had misunderstandings about fertility. Seven seemed genuinely surprised they were pregnant. Four thought they might be infertile as a result of taking valproate or having irregular menses. An underlying belief that they could not conceive may have affected contraceptive practice: “well I'd heard that the Epilim could make you infertile”. All planners expressed fears about pregnancy in relation to takin AEDs. “You're always tinged by a slight concern. Generally, it is a time of great happiness, and it is for me but always tinged with quite a lot of anxiety”. Non-planners were less likely to worry about the risks associated with AEDs despite having knowledge. Only two non-planners expressed concerns but went on to say “We were never overly bothered. We was like if it happens, it happens [pregnancy].”

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 51: Pregnancy

Participants were overwhelmed with anxiety regarding possible abnormalities in the baby due to AEDs use, taken aback by unexpected changes in seizure severity and frequency. There were mixed feelings about separation from the baby. Participants mentioned struggling with the potential harm of AEDs and breastfeeding. There was an increased fear of passing down the disease, and management of the burdens of both childcare and seizure control. Participants had greater illness awareness and self-growth and were thankful for the helping hands and support. "My neurologist told me that the medication I took was safe for the foetus and there was no need to worry. However, I had underlying anxiety about malformations. I had no one to talk to about my disease, so I usually got information from the internet." The saying that ‘no pregnant woman should take any medication with ease,’ and the fact that AEDs affect the brain, made the participants hesitant in taking their AEDs. Some participants were so anxious about having malformed babies that they stopped taking their medication but later became nervous about having a seizure.

Regarding breastfeeding, "The opinions of health professionals were different. The neurologist and obstetrician said it would be ok, but the paediatrician was against it. In a situation where the medical professionals didn't give me a united opinion, the decision was up to me. That's what made matters worse."

All participants stated that the benefits of taking AEDs to avoid seizures in pregnancy clearly outweighed teratogenic risks. Consequently, self-reported adherence to AED therapy was high, and some women reported to be even more attentive to taking AEDs during pregnancy: ‘‘I haven’t forgotten to take the medicine while I’ve been pregnant, but it has happened before. It doesn’t happen often, but when taking medicines for so many years you are bound to miss out sometimes.’’ Several women reported that their neurologist had imparted low teratogenic risks of AEDs, though they could not be ruled out, balancing these risks against the risk of seizures. The women were concerned for teratogenic effects as a result of increasing the dose of AEDs during pregnancy. This was of particular concern when dose escalation took place in large steps, compared to regular, small increases. Also, reducing the dose after childbirth caused concern, due to risks of triggering seizures. Important factors for reducing concerns regarding teratogenic effects of AEDs included ultrasound examinations during early pregnancy and regular controls of foetal heart rates and movements throughout pregnancy. Also, preconception counselling, aiming to find the optimal AED therapy, reduced concerns.

Most women had a restrictive attitude to taking other medicines than AEDs in pregnancy, even widely used medicines such as acetaminophen and antihistamines. In all three patient groups, the women were concerned at the lack of advice and information they had received about contraception and were therefore not clear what exactly the risks were. They were also worried that their doctors did not always seem to have a complete understanding of the effects of AEDs on the oral contraceptive pill. One woman had her first seizure 4 months postpartum and had a second child whilst waiting to see the specialist. She recalled being told "if I took a second fit they might put me on medication... but my own doctor said we'll wait until you go for more tests and then they'll see after that whether to go on medication." The patient waited years for neurology review and did not receive any epilepsy specific counselling during her second pregnancy. Another woman could not recall any specific epilepsy care during her first 2 pregnancies and was continued on phenytoin during them both. Anxieties about the effect of medication on their babies continued for some women during pregnancy, extending the conflict between the moral work of the ‘good mother’ and that of the ‘good patient’. Two women found that their delivery units seemed unprepared for their epilepsy.

All but one of the non-planners were aware of the need for folic acid, but only two took it, one believing it to be a contraceptive. One woman felt it unnecessary before conception because she knew as soon as she was pregnant: “straight away I know. Straight away I go to the doctors … I usually buy the folic acid … I take the normal amount then”. Women with planned pregnancies were more likely to seek information. All were aware of the national voluntary epilepsy organisations, six had used their services and four were members. One planner visited her GP for preconception counselling: “I knew what services were available and I insisted”.

Women with planned pregnancies were more assertive and questioning about their condition, for example: “I made the decision come what may I was not going to stay on valproate”. It was clear that the more articulate and determined women were usually successful in finding information, whereas non-planners were vulnerable to poor care. Planners were more likely to be at the centre of any decision-making processes about their epilepsy, preconception planning, and pregnancy, and to feel in control. Ten of the women felt their GP had not provided adequate advice before pregnancy. GPs initiated a preconception prescription for folic acid in only two women. Most non-planners did not seek advice from elsewhere.

The women identified several factors that they felt would be useful. 1) Information should be given at diagnosis. 2) Counselling teenagers “because accidents happen”. 3) Information should be repeated. 4) Information leaflets were helpful, but no substitute for discussion. 5) GPs were identified as having a role in discussing the issue and referring for specialist advice.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 52: Problems with diagnosis

A number of participants reported that it took them a long time to be diagnosed with epilepsy. "The first one misdiagnosed me for 3 years. The second one, who happened to be in the same practice… I went to him, and he found out that I was having a seizure disorder. And he probably treated me very nice because they did not want to get sued." Another participant explained; " I was misdiagnosed for 7 years, and I faced a lot of what others went through with depression issues. The doctor’s question whether I was making this up in my head. My family was even taught to ignore my seizures. That I was making them up, that I was doing it as an attention seeking device... It was the most breakthrough free thing in the world when they said you have epilepsy!"

Identification of the child’s epilepsy did not come easily for many families in this study, and many described themselves as noticing the symptoms, but not understanding what they meant. Many families described the false interpretations that were made about their child’s symptoms. Some were thought to have attention deficit disorder. Families described the importance of the school in identifying seizures early and communication with home as well as monitoring symptoms to report to the doctor. Errors with medication had many consequences for children’s experience at school and many missed school due to medication errors. Caregivers expressed the need for schools to assist with the monitoring of process during medication changes so that parents and physicians know exactly how a child is reacting as well as weather seizures have been eliminated.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered and unclear recruitment strategy.

Review finding 53: Provoking factors

Parents believed that crowds and parties increased the risk of seizures, and some refused to attend parties and ceremonies due to the fear of disclosure of their child's illness. Adolescents reported they felt alienated from their friends by having to avoid seizure-triggering factors such as strenuous activities and fatigue. Several reported they more commonly had seizures when they drank alcohol or when they were exposed to flashing lights such as at a disco. Some refrained from going to discos or drinking alcohol, but none ceased watching television or working with the computer. Some also reported they are not allowed to stay outdoors as long as their friends. "I am not allowed to go out by myself, not even with friends, Mum wants to come with us. And I am not allowed to bike without a helmet so that I won't fall in the middle of the street." One mentioned getting angry, dehydration, too much sun and running too much exacerbates his seizures. Another found if he stayed up too late watching football, he would have a seizure the next day. Alcohol use and financial constraints were reported as major impediments to epilepsy care and control. The study participants highlighted alcohol use as a major hindrance to epilepsy care and control, “Things got worse because when I took alcohol after swallowing the medicine, they told me to stop”. Noise was a commonly cited trigger and participants also expressed the need to reduce social and psychological burdens by avoiding anger, excitement, stress and by maintain a good mood and regulating one’s lifestyle to ensure a balance between work, exercise and rest. Attention to diet was also mentioned however there were opposing beliefs.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered and unclear recruitment strategy.

Review finding 54: Recovery after seizure

The effect of seizures varied widely, with some people recovering quickly after a seizure, whereas for others, this could take several hours or even several days. Some participants and carers reported falls and injuries during seizures. Fatigue and confusion were commonly reported after a seizure.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 55: Sadness, depression

Various degrees of sadness or dysphoria were experienced as fluctuating. "I would get sad about nothing…I get a sad feeing and I don’t know why…my mum thinks it’s kind of like depressed or something…me too maybe, I'm not sure…I don’t know what depressed is". In other instances, youths revealed more disturbed emotions that included thoughts of suicide.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 56: School restrictions

A large proportion reported excessive fatigue, making it difficult for them to think clearly and be available to participate in academic endeavours. For some the persistent fatigue and need for sleep that accompanied their seizures could last hours or a whole day; meaning youths either missed going to school or were unable to remain at school. "I'm constantly tired... in the morning and once I take them [seizures] during school...I just sit there, and I want to fall asleep during every class...it just wears me down." Teacher reactions seemed to vary. Some did not let children join in school activities and some were helpful and supportive. "My headmistress in junior school kind of worries and they're all trying to help me. A lot found missing lessons owing to seizures problematic and some reported being slower at schoolwork since diagnosis. In terms of school performance, some noted no changes while other parents reported a negative impact as they missed school or examinations frequently or had problems with understanding what they were taught in school. Some children reported that there was a negative impact on their academic achievement. Some children had a seizure during school resulting in loss of consciousness and they experienced difficulties concentrating on what was being taught in class. Some children had a seizure after school hours often meaning they were absent from school the following day.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 57: Self and others' perceptions of epilepsy

Their own perceptions of epilepsy as well as their views on how others perceived the condition also seemed to impact their motivations to disclose (or not) the diagnosis to those external to the nuclear family and informed the disclosure management strategies they adopted. Some perceived it as a private matter for family members only; this was either informed by the child’s own negative attitudes towards their epilepsy or by parental attitudes towards epilepsy. Several participants had negative perceptions of epilepsy - some reporting it as embarrassing, upsetting, unpleasant and something they would rather not have. "I just don’t like talking about it mostly...it’s just a kind of...eh...not a very nice thing to talk about, you know?" While some people thought that their seizures had been caused by accidents, head injury, meningitis, measles, or stress, many said that their doctors had not confirmed this. Historically, the devil, other supernatural spirits, and mental illness have all been credited with causing seizures and some respondents believe that this view still persists. “I think that the only thing that I’ve never really had answered is why I actually got the condition in the first place. I mean there’s just no reason for it, there’s no history of it, I didn’t do anything bad, I didn’t bang my head. I didn’t have any of these other classic type symptoms, so that’s really the only thing I don’t have the answer to.” Many families shared that they were required to tell the school of their child’s epilepsy when registering or after diagnosis. For some family’s disclosure about diagnosis and medication elicited a fear that their child would be treated differently. One frustration of the disclosure process was the multitude of forms they were required to fill in. Upon disclosure parents appreciated teachers who were open to learning about epilepsy. Families often commented on the anxiety that some teachers felt when they learned about their child’s epilepsy diagnosis. This anxiety stemmed from feeling responsible for maintaining the student safety in the event of a seizure. Parents also found it more complicated to have their children visit friends as they were required to explain medication routines and safety procedures. Misunderstandings of what it means to have epilepsy created frustration among parents who believed that educating teachers about epilepsy and what to do in the event of a seizure would alleviate this problem. Every family spoke of the importance of having all staff members aware of their child’s epilepsy and not just the classroom teacher. Parents felt that informing each staff member ensured the safety of their child during all aspects of the day. Parents suggested one way to inform the entire school was to participate in Purple Day for epilepsy awareness. Communication was a recurring topic and parents felt that communication with their children allowed their child to be involved in decision making processes and safety procedures and contributed to the positive school experience. Home to school communication was essential, as not only did it allow parents and schools to provide information to each other, but it also gave parents an opportunity to contribute their ideas and suggestions as to how to promote positive experiences at school. For many families, community support was also an important part of the families coping and they mentioned community organisations such as Victoria Epilepsy which helped them become more aware of how they could support their child and spread awareness of epilepsy.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants’ not being adequately considered and unclear recruitment strategy.

Review finding 58: Signs of seizure onset

All of the young women talked about not always being sure if they were having seizure activity. Sometimes they could tell that they were about to have or had already had a seizure. But at other times it was unclear. "I can tell when I’m going to get a seizure because I get really, really hot. It is usually when I’m asleep." "Mostly, like, whenever I’m tired or I get upset about something is whenever I mainly have them. 6 out of 8 described auras, a feeling, occurring before seizure onset. Two stated they felt tired before a seizure. Some felt sick, had a headache, stomach-ache and vomiting before a seizure.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 59: Social exclusion

A number of participants relayed experiences of being excluded by their peers from parties, playdates and sleepovers, with some citing parental fear as a reason underlying their exclusion from such occasions. "…there is a change because I don't get invited to as much sleepovers as i used to because the parents are afraid...It makes me feel a bit sad, but I suppose my parents would be afraid too..."

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 60: Social restrictions

Participants mentioned going to social functions was limited. One participant explains these limitations caused by illness 'we cannot visit any places to attend fun events, or visit anyone, for fear that someone will find out about this disease. We cannot attend ceremonies that are being held in a crowded space because it is possible, he will have a seizure.' For some families, parental disclosure had resulted in the CWE receiving fewer invitations to social occasions, being excluded from participating in physical education in school or being denied enrolment in recreational activities. Detrimental impacts for parents included offensive reactions, e.g., others mimicking seizures, and difficulty finding someone to care for the child in their absence. These experiences elicited negative emotions among parents (e.g., anger, concern, sadness, disappointment) and played a role in promoting parental disclosure decisions of concealment or selective disclosure.

Most young people engaged in regular social activities with their friends and had similar curfews as their siblings and friends. However, they felt that parents unnecessarily limited the types of activities and time spent with friends. Parental control and overprotectiveness were perceived as barriers to participation, and young people often used strategies, such as bargaining, reasoning, and persuading, to influence their parents' decisions. "I feel and I think they would say "well you can't come to a birthday party because it's swimming", that kind of thing." Timing of seizures, frequency, severity, location, aftereffects, seizure control and the handling of seizure situation by others; 'I had a seizure on the playground, and they all ran away, and I just sat down and I was sitting here until school ended and I didn't know what to do.'

Interviews discussed social aspects of school. Many families appreciated the school's opportunities to help out at the school and praised their school's openness and friendly community, however many felt lack of available time prevented them from becoming involved. Many positive experiences stemmed from feeling respected, particularly when parents expressed their ideas ad concerns on how to best support their child with epilepsy. Alternatively, many families felt disrespected and did not have a voice at school. Most parents felt their child had positive relationships with their peers at school. Some pointed out their child had a few close friends, while others mentioned their child often played with other children who have special educational needs. Some parents mentioned social isolation of their child after having a seizure at school in front of their peers. "When she had a seizure at school... all the kids stopped playing with her, period. Everybody she played with the year before... all of a sudden were no longer friends with her why? Because they thought they could catch it." In addition to social isolation some parents reported incidences of bullying both emotional and physical. An important aspect of school was their child's feeling of normalcy and despite various adjustments to their everyday life they wanted their children to understand these differences did not make them abnormal. One obstacle to reaching a sense of normalcy was the need to place restrictions and limitations on activities the children could participate in, and many parents spoke of the decreased independence that their child experienced after being diagnosed.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants' not being adequately considered and unclear recruitment strategy.

Review finding 61: Stigma

Several parents believed public perceptions of epilepsy were poor. Some parents felt that epilepsy is a condition that is stigmatising, and others made reference to the dearth of knowledge and understanding about epilepsy among the general population. Parents asserted that negative perceptions of epilepsy were difficult to contend with and contributed to their reluctance to disclose their CWE's diagnosis to others. Many parents discussed how, to their dismay, they felt that antiquated misconceptions of epilepsy persisted in modern day society, e.g., the notion of epilepsy as contagious and associated with mania and witchcraft. Parents highlighted how epilepsy-related stigma manifests itself in others as fear and/or discomfort.

Stigmatization from the community, as well as from family, compounded the lack of support and increased isolation felt by participants. The study participants felt strongly that there was a lack of attention to educating the community about epilepsy. The study participants reported strongly about the need for increasing epilepsy awareness in the community as part of care and stigma reduction efforts. Participants suggested various ideas regarding how to disseminate epilepsy information like holding community education meetings and seminars, door to door visits by health workers, engaging local leaders to spearhead projects, as well as using print and local media to spread the word about epilepsy. when parents were notified by their doctors that their child had epilepsy, they suffered from the negative social connotation of this disease. They perceived epilepsy as an unacceptable illness, feeling shock, anger, despair and/or guilt.

Parents perceive seizures as having a negative meaning and stigma in a traditional society. Parents do not want many people to know that their child has epilepsy and are concerned that in the future they, their child and their family will be stigmatised. Participants described the effort they felt they had to exert to educate the people around them. "Just trying to be accepted as a normal person. That is very, very challenging. The other thing is trying to get the stigmatisms that are put toward peopled with seizures changed…" Others stated that the decision to tell others about their condition involved a personal and deliberate thought process. "Make sure they (employers and co-workers) know what to do when you have one [seizure]. And if you don't tell them, so that you can get the job, they just won't be honest and fair with you." On diagnosis, 'My mom, she thought I was ignoring her, but I was really staring into space. They had a test done on me and that's how I found out.' Child's knowledge of epilepsy; 'She doesn't know she has epilepsy, by that word. We call it twitching because I was afraid to say epilepsy because there is a stigma.'

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 62: Successes and barriers in obtaining care

Once participants knew what help was available the next step was trying to obtain services, medications of treatments. "[Vocational rehabilitation counsellor] is the one that helped me… the place where I worked went bankrupt. He made sure I got my medicine and he paid for that. He did all kinds of stuff for me. Constantly calling me at home asking if I was okay. And then took me to this job, I had a seizure during the interview! And I still got hired". Conversely many described the ongoing problems they faced when trying to obtain the medication and services they needed: the high cost of medications, lack of money or insurance coverage to pay for them, dire consequences of not taking the medications. Sometimes even if participants were able to get the prescriptions for the medications, they required they found that many pharmacies did not carry the type of amount of medication prescribed. Additionally, the ongoing use of various medications was a concern for some participants along with the lack of any psychological therapy or counselling. Other participants talked about problems with physical and transportation requirements of visits for professional care, while others mentioned problems accessing support and benefits of government programmes due to confusing eligibility requirements.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 63: SUDEP awareness

There was broad agreement that SUDEP information should be given to those with epilepsy. There was a sense that there would be something amiss if information was withheld by health care practitioners as highlighted here by Sarah (21), 'I think, everyone should have access to information and not be, like, have things withheld from them cos I think it kind of causes a bit of mistrust…being told what you should and should not know isn't good'. There was disagreement concerning the timing of SUDEP information giving. Some participants felt that people should be told everything about their condition at their first diagnosis, including information about SUDEP, reflected in Phoebe's (23) comment that there was 'no point buttering it up'. 81% of participants thought that everyone should be told about SUDEP, and many felt that this should be given at an early stage in relation to diagnosis. 64% said not in the first meeting but soon after "the one after [diagnosis]... cos getting epilepsy's a bit of a shock to everybody never mind finding out you could die from it".

The magnitude of SUDEP risk within the context of their own epilepsy was the most important information to impart and many felt that this information should be given face-to-face. Some identified the epilepsy nurse specialist (ENS) as the caregiver understanding the experiences of people with epilepsy better and able to give more time to these discussions. Many participants reported avoiding searching for SUDEP information themselves online as they either felt like knew everything they needed to already or they deliberately avoided thinking about SUDEP.

There was consensus among all participants that all individuals diagnosed with epilepsy and their caregivers should be informed about SUDEP. The majority expressed that this topic should be incorporated into the general information patients receive about diagnosis, management and prognosis. Participants agreed that all adult patients should be told and most felt that young children should not be told until they reached their teens, although this should be on a case-by-case basis. People had other information needs too. Some wanted to know more about tests, about different kinds of epilepsy, and SUDEP. “One of the questions, which I’m sure all epileptics would like to have answered, is more concrete answers on SUDEP, which is a very worrying question but it’s something that seems to be very hazy, but we have absolutely no idea what the concrete cause of it is. It’s just quite scary to think that one night we, any one of us, might just go to sleep and never wake up.”

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 64: SUDEP information delivery

The majority felt that the discussion should take place face-to-face in a verbal discussion or conversation followed by some written information to take home. "I think you should hear it face-to-face… that’s why my mums with me. Because she’s getting it all in. But I think you should get a book or something, something explaining everything.” Nearly all of the participants felt that the information about SUDEP should come from the neurologist. "I just think that they should know all about epilepsy, anything to do with epilepsy if they're giving out medication. And any of the risks, side effects, anything like that they should know all about it". Some suggested they would rather hear the information from their family doctor with whom they had a good relationship.

Several participants suggested that it might be helpful to have a social worker involved along with the physician sharing the SUDEP information and have access to one after for any further questions or emotional support. Participants identified it was helpful to have another person present so that nothing important was missed. There was full agreement that routine counselling about SUDEP should be provided by paediatric neurologists, either during the appointment when the diagnosis of epilepsy is shared with parents or in a follow-up appointment several weeks later. They agreed there should be opportunities for short-term follow-up and discussions with clinical nurses or social workers to "translate what the doctors say".

Parents explained it is important to have a comprehensive understanding of all of the risks associated with epilepsy as this enables them to "prepare for the worst". Parents identified that with this information they would possibly be motivated to place monitors or alarms in their child’s room. Another parent felt understanding the risks of SUDEP would increase compliance with treatment regimens and minimise consumption of alcohol and nonprescription drugs. All parents agreed that not knowing about the possibility of SUDEP would be worse and they would be angry if they were not informed.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 65: SUDEP information leading to behavioural changes

While some reported anxiety upon hearing about SUDEP for the first time, it was usually presented as being a temporary, rather than long-term concern. Some participants said that having information offered an opportunity for people to avoid or mitigate the risk of SUDEP by encouraging them to change any behaviour that may exacerbate the risk and referred to changes they had made in their lives. For example, Paige (19) said ‘I got a wee bit more strict…about when I take my tablets’.

However, most participants reported not changing the way in which they managed their epilepsy, in light of their awareness of the risk of SUDEP. The majority of participants expressed the view that SUDEP could not be controlled and referred to its occurrence as more a matter of chance or fate. "There’s not a lot you can do. If you’re gonna die, you’re gonna die." "You just put it to the back of your mind". Forty eight percent of participants stated they were untroubled when they were told about their SUDEP. "I’m more worried about getting hit by a car during a seizure than I am actually having like an overload seizure". Fifty nine percent said that the information about SUDEP made no difference to their behaviour in terms of improving medication adherence or avoiding risk factors for seizures as it was considered by many as unpreventable. "If its gonna happen it’s gonna happen there’s not much I can do".

While all participants had been asked to read an information leaflet on SUDEP prior to the study none of the individuals could articulate the exact meaning or definition of SUDEP. Nearly half shared that had been shocked or scared on finding out this information. Some felt frightened initially but then came to accept the situation and carried on with their lives and others perceived the information was not relevant to their type of seizures. After hearing about SUDEP most participants went looking for more information using online resources.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 66: SUDEP information needed

Patients wanted a general overview of what SUDEP was, their odds of being victims, risk factors, causes and prevention strategies. They wanted as much information as possible and also information about how to access more information.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 67: SUDEP worries

SUDEP was rarely expressed as a worry by the participants. Only one of those interviewed offered SUDEP as a concern unprompted, saying it had been something they had thought about only since being reminded about it during recruitment for this study. ‘Dr X told me I was low risk cos I don’t have many [seizures]’. While they seemed fairly certain in that respect, their accounts demonstrated a limited knowledge of SUDEP. When asked what they understood SUDEP to be, many prefaced their answer by saying they knew little about it, or were not able to say what they thought caused it. Several participants contextualised the risk of SUDEP within the wider risk of death that everyone faces. Phoebe (23) said, ‘everything kind of has some kind of risk of death, doesn’t it? To a degree…so might as well just get on’. Similarly, Glenn (19) said that despite his initial fear when he found out about SUDEP, he did not want it to be something that changed his life, saying, ‘You can’t live like, well: ‘when’s the day?’’

Parents discussed their experiences of having their child diagnosed with epilepsy. Mothers disclosed a number of mental health issues after their child’s diagnosis: depression, anxiety, guilt, worry, whilst fathers felt worried, angry and concerned. Both parents were fearful their child would die (particularly in bed at night) and they were highly vigilant of their child - wanting to monitor all their activities. Many disclosed that their child slept in their bed as part of a coping strategy.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 68: Support

Participants sought support from parents and siblings when they needed help or felt that something went wrong. "I would tell my mum if I felt uncomfortable". Participants also described maintaining good relationships with their siblings, which facilitated getting help and emotional support from them. "My younger brother reminds me to take medicines; he has a good memory." Most young people described their relationships with family members as ‘close’ or ‘good’. Correspondingly, these young people described strong relationships among family members. Family connectedness was perceived low in three families as their interactions were often conflictual or distant. Features that characterized strong family connectedness were engagement in shared activities; validation and acceptance of young people’s feelings; providing and receiving both emotional and instrumental support in times of need; demonstrating affection and warmth; and successful management of family conflict. Family members serve as important sources of emotional and instrumental support, which buffered the effects of stress on young people’s well-being. Strong family connectedness is likely to correspond with greater support received in times of need. An example from a participant, illustrates contrasting relationships and support from each parent. "I think it’s because we spend time together, we depend on each other and have to be there for each other. Family right, so when there are problems, we have to support each other." This included emotional and practical support from parents, siblings, teachers, health professionals, other adults and in particular peers.

The adolescents wanted people around them to stay during a seizure and to give shelter. It gave them a sense of relief to know that most of the people around them had cell phones. "My mother always wanted to keep it in the family. She didn’t want the school to know. But to me it wasn’t hard. I think it is better people know. So, I told my teacher at school." For many, satisfaction with friendships incorporated epilepsy specific support. This took the form of physical (knowing what to do during a seizure) or psychological support. "I'm okay at school…like my friends know what to do if something happens…". Loving and supportive relationships with friends were related in 6 out of 8 interviews. Best friends seem to provide children with a feeling of acceptance and advocacy.

In addition to having best friends, every child in the study reported that educating their peers about seizures led to greater acceptance of them and their seizures. Steven's mother educated his classroom about epilepsy and "everybody stopped picking on me about having seizures and stuff". All parents talked about the need to be in touch with people who could offer advice or help when dealing with their children. Participants were part of a regular support group that met monthly. "We are lucky; we've got these meetings, and we've got resources and books and information, a place to turn, to ask questions of people who've lived it for most of their lives." Some children reported they had several close friends in school who gave them constant emotional and social support.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 69: The future

This theme related to leaving home, choosing careers and having children. Thirteen teenagers from all age groups expressed awareness that epilepsy may impede the opportunity to follow certain careers and worried “about discrimination and stuff”. Moving away from home was raised as an issue by five participants, both younger and older, with concerns voiced about safety and the risks of having a seizure if alone: “if you don’t have a boyfriend or a husband, what would happen if you had a fit in the bath, if you had drowned or that”; “if you’re wanting to leave home what would you do, would you go and have a friend to live with so you’re not on your own if something happens? I would rather have someone with me just in case something happens”.

From older and younger adolescents alike, concern was expressed regarding having children and eight reported specific worries about offspring having epilepsy, such as “there’s like a chance, a percentage of it having epilepsy and that". Some were concerned about their prognosis. Transitional stages were discussed. Some were concerned about having seizures if they lived alone, banned from driving and career choice impact. "I'm not worried about anything as long as my epilepsy goes away." Many adolescents reported they wanted to make their own decisions about their life: such as driving and what they want to be in the future. One mentioned she wanted to be communicated with directly rather than just asking her mother. Most children hoped they would be seizure free in the future and would like to be independent and fulfil their dreams.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 70: Timing and setting of SUDEP discussion

Many believed that the best time to be told about SUDEP was at diagnosis. They felt it should be part of basic information about epilepsy and if shared in a matter-of-fact manner it would not be overwhelming. "Maybe right away, I think. Just you can never be too safe. So, I think it is scary but like I said you have to be prepared for these things and it’s good to know". Some felt it was too soon to be told at diagnosis and they would prefer some time to process the information of the diagnosis and be told after a certain number of visits with the neurologist or after 6 months or a year. Nearly half felt that this information should be shared in the neurologist’s office.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

1.1.8 Qualitative evidence summary

Table 4: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Absence of information/support					
3 studies	A combination of interviews and focus groups	A number of participants felt their epilepsy had a direct effect on their independence and ability to participate in activities. Activity restrictions not only had implications for the children with epilepsy but also for their parents, with a number reporting that they felt others unnecessarily required them to be present during social and leisure activities.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship and ethical considerations.
[2] Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Acceptance					
1 study	Individual interviews	For many parents on receiving the diagnosis of their child's epilepsy, a period of grief ensued as parents grappled with the loss of their 'healthy child'. Many parents verbalised that the diagnosis had a profound emotional impact, evoking 'devastation', 'upset', 'concern', 'worry' and 'shock'.	Limitations	No or very minor	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Activity restrictions					
9 studies	A combination of interviews and focus groups	For many parents on receiving the diagnosis of their child's epilepsy, a period of grief ensued as parents grappled with the loss of their 'healthy child'. Many parents verbalised that the diagnosis had a profound emotional impact, evoking 'devastation', 'upset', 'concern', 'worry' and 'shock'.	Limitations	No or very minor	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Affects parents' life choices					
1 study	Individual interviews	A father expressed his willingness to continue studying on his favourite course but felt prevented from doing so due to his daughter's condition. Some also felt the need to quit their jobs.	Limitations	No or very minor	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Assisting their child's re-integration					
1 study	Individual interviews	Parents hope their child can maintain normal social interactions and a healthy lifestyle. They discuss their child's needs, special concerns, peer relationships and activity limitations with their child's illness and comprehend the meaning of his/her behaviour and their child's place in the community	Limitations	No or very minor	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Being in control					
4 studies	A combination of interviews and focus groups	A feeling of being in control was important for reducing anxiety. Some adolescents actively searched for information and wrote papers at school about epilepsy. these activities seemed to increase their self-confidence because they spoke proudly about it. participants also reported measures taken to safeguard themselves in the event of a seizure including avoiding potentially hazardous activities such as swimming or ironing.	Limitations	No or very minor	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Belief about what is normal					

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
1 study	Individual interviews	Young people's maturity of thought was evident when they spoke of normality. They recognized actual differences when they compared themselves to their peers, and family beliefs played a role in young people's positive views of themselves	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Caregiver burden					
1 study	Individual interviews	The burden of providing all basic needs in life and study participants cited performing most of the chores for the patients.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[3]	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

[2] Please see narrative summary of review findings for explanation of quality assessment

[3]downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Clinical competence and skills					
1 study	Focus groups	Problems due to the shortage of specialists with an interest in epilepsy were raised. Both the nurses and women with epilepsy described experiences of delayed diagnoses and misdiagnoses and inappropriate drug management by both neurologists and general physicians.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Cognitive					
3 studies	A combination of interviews and focus groups	Intermittent difficulties with memory were reflected in many narratives. Psychological distress symptoms such as sleep disturbances, were frequently reported by participants.	Limitations	Moderate limitations[1]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

2 Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Communication issues and honesty and openness in provision of information					
6 studies	A combination of interviews and focus groups	Overall, service users and carers' communication purpose and needs with doctors and nurses were based on a wide range of things. However, involvement in decision making was central to their communication needs, they want to be more involved in communication. Service users wanted more discussions regarding changes to medications to be openly and honestly discussed with them.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Complexity of epilepsy - difficult to explain to others/challenging to understand					
3 studies	Individual interviews	Participants found it difficult to explain to others, with some (particularly those of a younger age) yet to establish how to appropriately describe their conditions to others. Some also felt it challenging for peers to understand.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Concealment					
3 studies	A combination of interviews and focus groups	A number of participants felt the need to actively hide their diagnosis from those external to the nuclear family, indicating their awareness of the potential for stigmatisation due to their epilepsy.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Contraception					
2 studies	Individual interviews	Participants generally felt their attempts to perform the moral work of avoiding unplanned pregnancy were not always supported by effective healthcare practice and advice. While some women reported that their practitioners were helpful, those who received inaccurate or inadequate advice had to cope with varying consequences.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Coping strategies					
7 studies	Individual interviews	The participants reported they would try self-management to prevent or manage seizures. This included several strategies such as activity restrictions, positivity or monitoring their general health.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Emotional distress					
2 studies	Individual interviews	The majority of participants experienced periods of intense emotional distress that they attributed largely to the unpredictability of their seizures and loss of control over their bodies. Worry or fear and anger and frustration were often connected to experiencing seizures, medication side effects or extent of parental monitoring.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship and ethical considerations

2 Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Epilepsy related risk					
1 study	Individual interviews	The risk of seizures was central to participants' accounts of their experience of living with epilepsy, both in terms of the risk of a seizure occurring and the risk of injury as the result of a seizure.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Experiences of employment					
1 study	Individual interviews	A significant issue for the majority of the interviewees was that of employment. Many recalled having been forced to send, in some cases, literally hundreds of application forms, with others being dissuaded or prevented from choosing careers they wanted because of their seizures.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Fear					
7 studies	A combination of interviews and focus groups	The fears and concerns of parents revolved around both the physical and emotional health of their children. Worrying about how the seizures would affect their child's development and the uncertainty of the future was identified as a concern. Caregivers discussed their continual worrying over the well-being of their child and the stress of explaining their child's condition to the school community	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy
2 Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Fear of misinforming the child					
1 study	Individual interviews	Fear of delivering misinformation in response to their child's epilepsy related questions was often a daily struggle. To answer their questions parents had to be readily knowledge about their child's epilepsy, however, often parents relayed that they themselves felt underinformed regarding their child's specific diagnosis.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Feeling different					
5 studies	A combination of interviews and focus groups	For some disclosing the diagnosis elicited feelings of 'differentness'. Feelings of differentness were exacerbated by the fact very few participants had any contact with other people who also had epilepsy.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Feeling of inadequacy					
2 studies	A combination of interviews and focus groups	The participants described a feeling of inadequacy when discussing parenthood. Some felt they were less important as parents than their spouses. They wished to take the same responsibility as other parents, but understood it was important to accept help from other people.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Food restrictions					
2 studies	A combination of interviews and focus groups	Adolescents were told they had to avoid beverages such as coffee or tea that contained caffeine, as well as chocolate and spicy foods.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Guilt					
1 study	Focus groups	Parents often felt guilty because they could not be the parents they wanted to be. They also felt guilty because of all the difficulties their children had to experience when witnessing a seizure.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Healthcare system issues					
7 studies	A combination of interviews and focus groups	Limited health care provider interaction and distance to health centres were major problems. Health facilities were reported to be located far from patients' homes and majority of people faced challenges in reaching these centres, as either they did not own or had difficulties with out of pocket to meet the transport costs.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Home environment					
2 studies	Individual interviews	Parents endeavour to establish appropriate family interaction patterns for their child's development, specifically in terms of routine and rules, as well as adapting their lifestyles to fit their child's treatment progress, special upbringing demands and safety.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Information concealment					
1 study	Individual interviews	Parents revealed instances of limiting the amount of information relating to epilepsy available to their child. Many parents felt that some information, particularly relating to medication side effects or SUDEP was inappropriate for their child's age (particularly 6–10-year age group).	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] *downgraded for small sample size*

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Invisibility of epilepsy					
4 studies	Individual interviews	Participants discussed the fact it is not physically visible to others, and the silence around epilepsy in the public domain. A number of participants reported that the invisible nature of the condition acted as a barrier to disclosure because both they themselves and their peers struggled to reconcile their own perceptions of what an individual with an illness and/or disability should appear like with the seemingly 'normal' physical appearance of the children with epilepsy.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Knowledge sources about epilepsy					
2 studies	A combination of interviews and focus groups	Three main different sources from which informants drew knowledge and information regarding epilepsy were identified. 1) formal knowledge, which includes knowledge gained from reading medical publications or speaking with medical personnel. 2) informal knowledge, which is gained experientially or through word of mouth. 3) mass media.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Lack of understanding -SUDEP					
2 studies	A combination of interviews and focus groups	Most participants did not appear to have a clear understanding of SUDEP. Some were not able to describe or define SUDEP except in terms of its incidence "very low risk" or "very rare". Many associated SUDEP with a particular type of seizure and described it as an overloaded seizure.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Lack of understanding/knowledge					
5 studies	A combination of interviews and focus groups	Lack of public understanding and knowledge regarding what epilepsy is, the various presentation of seizures and what epileptic syndromes encompass (i.e., the physical, cognitive, and psychosocial consequences of epilepsy) inhibited parental openness about their child's epilepsy.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Lifestyle restrictions					
3 studies	A combination of interviews and focus groups	Epilepsy was perceived to significantly limit participants' actions, work prospects, and activities in and outside their home. For participants who experienced multiple seizures a day, the occurrence and aftermath of the seizures could affect the entire day and prevent the participant from engaging in any activities.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

2 Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Medication					
15 studies	A combination of interviews and focus groups	Majority of participants took medication to help reduce seizure occurrence. Many reported side effects from medication, issues with compliance and problems with medical staff.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Minimising different treatment					
2 studies	Individual interviews	For some, disclosing their diagnosis to others was viewed as heightening the risk of others treating and perceiving them differently. Participants reported engaging in concealment and/or selective disclosure management strategies in an attempt to minimise the potential for others to treat them differently due to their epilepsy diagnosis.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Navigating the non-contingencies					
1 study	Focus groups	Non-contingency is defined as the lack of a perceived relationship between the person's actions and the outcomes experienced. Caregivers in each group echoed the non-contingencies experienced daily and over time in caregiving those with epilepsy in the home, school, community, and health-care settings.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Need for acknowledgement					
1 study	Individual interviews	Parents appreciated that the healthcare staff allocated time to inform them of what was about to happen, listened to them, answered questions, checked in on them, asked them how they were doing and offered food and coffee during their time at the hospital.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[3]	

[1] downgraded for lack of information on; participant/researcher relationship and ethical considerations

[2] Please see narrative summary of review findings for explanation of quality assessment.

[3]downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Need for comfort					
1 study	Individual interviews	The parents watched how the healthcare staff behaved, noticing that the paramedics and/or the staff working in the emergency room were calm and controlled. This helped to reassure the parents. Being told that the child's vital observations were fine also help reaffirm this feeling. Having had prior positive visits to the emergency room also raised the level of comfort.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[3]	

[1] downgraded for lack of information on; participant/researcher relationship and ethical considerations

[2] Please see narrative summary of review findings for explanation of quality assessment.

[3] downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Need for information					
4 studies	A combination of interviews and focus groups	Children wanted to be as informed as their parents. Most stated that physicians talked over them by using words outside their limited vocabulary or by ignoring them altogether and talking only to their parents. Parents described a need for information regarding all aspects of the disorder.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Need for support					
2 studies	Individual interviews	Many parents felt that it was important to have support from the other parents during the seizure and reflected how much worse it would have been had they been there alone.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship and ethical considerations

[2] Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Negative feelings towards epilepsy					
6 studies	A combination of interviews and focus groups	Many parents felt that it was important to have support from the other parents during the seizure and reflected how much worse it would have been had they been there alone. Some parents reported the epilepsy diagnosis evoked feelings of embarrassment and shame.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Negative responses to disclosure					
10 studies	A combination of interviews and focus groups	Many anticipated negative responses to disclosure whilst many had actual negative responses when disclosed. Some reported an unwillingness to disclose their epilepsy diagnosis to those external to the immediate family as they feared it would evoke worry and fear in others. Some participants relayed experiences of being bullied or teased by peers due to their epilepsy.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Outcomes of treatment					
1 study	Focus groups	Issues concerning side-effects of treatment were a common cause of dissatisfaction for patients. There were complaints about doctors' lack of awareness of the side-effects of the different drugs; their failure to inform patients of the side-effects they might experience with a particular drug; their apparent disbelief of the side effects patients were reporting; and failure to seek patients' views on the desired balance between seizure frequency and side-effects.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Parental perceptions about who should receive routine SUDEP counselling					
1 study	A combination of interviews and focus groups	Parents identified that both parents (as appropriate) should be present at the SUDEP counselling session. There was a consensus that it should be the parents' decision as to whether or not the child should be present at the meeting or when to inform the child about the risks of SUDEP.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Parental perspective of children's concerns and needs					
1 study	Focus groups	Parent participants talked about misinformation and misconceptions their children had about seizures and believed it was caused by lack of appropriate information.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[3]	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

[2] Please see narrative summary of review findings for explanation of quality assessment.

[3]downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Parental preferences for routine SUDEP counselling					
1 study	A combination of interviews and focus groups	Parents expressed a need to be informed of the risk of SUDEP however some parents felt it is important for neurologists to stress that SUDEP is rare and to balance the message of risk with one of hope.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Parental understanding of SUDEP					
1 study	A combination of interviews and focus groups	Among many parents there was a lack of understanding about the exact meaning of SUDEP and risk of a child dying. While many parents understood SUDEP was a rare condition they still overestimated the risk of SUDEP.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Parents and children's initial reactions					
1 study	Individual interviews	All parents experienced negative emotional reactions when their child first had a seizure. They were upset, shocked and worried. Many thought that their child was going to die. In some families' mothers blamed themselves for "causing" their child to have epilepsy or felt their in-laws blamed them.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Peers lack knowledge and understanding					
1 study	Individual interviews	A number of participants discussed how their peers lacked knowledge and understanding of the condition. Many adolescents highlighted how their peers relied heavily on stereotypes of epilepsy to inform the extent of their knowledge.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Practical/access difficulty					
3 studies	Individual interviews	Participants reported many problems with learning in their classes and some type of academic difficulty. Majority of the participants mentioned that they had to take time away from school, and sometimes multiple days in a row, in order to see specialists at a tertiary care facility.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

2 Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Pre-conceptual planning					
2 studies	Individual interviews	The participants drew attention to the conflict between their initial understanding of the health behaviour—the moral work—of a 'good mother' and the learned moral work of becoming a 'good patient' as women with epilepsy. The majority of non-planners had misunderstandings about fertility.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Pregnancy					
6 studies	A combination of interviews and focus groups	Participants were overwhelmed with anxiety regarding possible abnormalities in the baby due to AEDs use, taken aback by unexpected changes in seizure severity and frequency. Participants mentioned struggling with the potential harm of AEDs and breastfeeding. There was an increased fear of passing down the disease, and management of the burdens of both childcare and seizure control.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Problems with diagnosis					
2 studies	A combination of interviews and focus groups	A number of participants reported that it took them a long time to be diagnosed with epilepsy. Identification of the child's epilepsy did not come easily for many families, and many described themselves as noticing the symptoms, but not understanding what they meant.	Limitations	Moderate limitiations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

2 Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Provoking factors					
6 studies	A combination of interviews and focus groups	Parents believed that crowds and parties increase the risk of seizures, and some refused to attend parties and ceremonies due to the fear of disclosure of their child's illness. Alcohol use and financial constraints were reported as major impediments to epilepsy care and control.	Limitations	Moderate limitiations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

[2] Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Recovery after seizure					
1 study	Individual interviews	The effect of seizures varied widely, with some people recovering quickly after a seizure, whereas for others, this could take several hours or even several days.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Sadness, depression					
1 study	Individual interviews	Various degrees of sadness or dysphoria were experienced as fluctuating. In other instances, youths revealed more disturbed emotions that included thoughts of suicide.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
School restrictions					
3 studies	A combination of interviews and focus groups	A large proportion reported excessive fatigue, making it difficult for them to think clearly and be available to participate in academic endeavours. For some the persistent fatigue and need for sleep that accompanied their seizures could last hours or a whole day; meaning youths either missed going to school or were unable to remain at school.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Self and others' perceptions of epilepsy					
3 studies	Individual interviews	Participants' own perceptions of epilepsy as well as their views on how others perceived the condition also seemed to impact their motivations to disclose (or not) the diagnosis to those external to the nuclear family and informed the disclosure management strategies they adopted. For many families, community support was also an important part of the families coping and they mentioned community organisations such as 'Victoria Epilepsy' which helped them become more aware of how they could support their child and spread awareness of epilepsy.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

[2] Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Signs of seizure onset					
2 studies	Individual interviews	All the participants talked about not always being sure if they were having seizure activity. Sometimes they could tell that they were about to have or had already had a seizure. But at other times it was unclear.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Social exclusion					
1 study	Individual interviews	A number of participants relayed experiences of being excluded by their peers from parties, playdates and sleepovers, with some citing parental fear as a reason underlying their exclusion from such occasions.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1]downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Social restrictions					
4 studies	A combination of interviews and focus groups	For some families, parental disclosure had resulted in the child with epilepsy receiving fewer invitations to social occasions, being excluded from participating in physical education in school or being denied enrolment in recreational activities. Detrimental impacts for parents included offensive reactions, e.g., others mimicking seizures, and difficulty finding someone to care for the child in their absence.	Limitations	Moderate limitations[1,2]	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

[1] downgraded for lack of information on; participant/researcher relationship, ethical considerations and recruitment strategy

[2] Please see narrative summary of review findings for explanation of quality assessment.

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Stigma					
6 studies	A combination of interviews and focus groups	Several parents believed public perceptions of epilepsy were poor. Some parents felt that epilepsy is a condition that is stigmatised. Participants reported strongly about the need for increasing epilepsy awareness in the community as part of care and stigma reduction efforts.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Successes and barriers in obtaining care					
1 study	Focus groups	Once participants knew what help was available the next step was trying to obtain services, medications of treatments. Many described the ongoing problems they faced when trying to obtain the medication and services they needed: the high cost of medications, lack of money or insurance coverage to pay for them, dire consequences of not taking the medications.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
SUDEP awareness					
4 studies	A combination of interviews and focus groups	There was broad agreement that SUDEP information should be given to those with epilepsy. There was a sense that there would be something amiss if information was withheld by health care practitioners. Many participants reported avoiding searching for SUDEP information themselves online as they either felt like knew everything they needed to already or they deliberately avoided thinking about SUDEP.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
SUDEP information delivery					
2 studies	A combination of interviews and focus groups	The majority felt that the discussion should take place face-to-face in a verbal discussion or conversation followed by some written information to take home. Some suggested they would rather hear the information from their family doctor with whom they had a good relationship. Several participants suggested that it might be helpful to have a social worker involved along with the physician sharing the SUDEP information and have access to one after for any further questions or emotional support.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
SUDEP information leading to behavioural changes					
3 study	A combination of interviews and focus groups	While some reported anxiety upon hearing about SUDEP for the first time, it was usually presented as being a temporary, rather than long-term concern. Some participants said that having information offered an opportunity for people to avoid or mitigate the risk of SUDEP by encouraging them to change any behaviour that may exacerbate the risk and referred to changes they had made in their lives.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
SUDEP information needed					
1 study	A combination of interviews and focus groups	Patients wanted a general overview of what SUDEP was, their odds of being victims, risk factors, causes and prevention strategies.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
SUDEP worries					
2 studies	A combination of interviews and focus groups	SUDEP was rarely expressed as a worry by some of the participants. Several participants contextualised the risk of SUDEP within the wider risk of death that everyone faces. Some participants put disclosure to the back of their minds	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Support					
7 studies	A combination of interviews and focus groups	Participants sought support from parents and siblings when they needed help or felt that something went wrong. Participants also described maintaining good relationships with their siblings, which facilitated getting help and emotional support from them. Best friends seem to provide children with a feeling of acceptance and advocacy. In addition to having best friends, every child in the study reported that educating their peers about seizures led to greater acceptance of them and their seizures.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
The future					
3 studies	A combination of interviews and focus groups	This theme encompassed leaving home, choosing careers and having children. From older and younger adolescents alike, concern was expressed regarding having children and some were concerned about their prognosis.	Limitations	No or very minor concerns	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No or very minor concerns	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Timing and setting of SUDEP discussion					
1 study	A combination of interviews and focus groups	Many believed that the best time to be told about SUDEP was at diagnosis. They felt it should be part of basic information about epilepsy and if shared in a matter-of-fact manner it would not be overwhelming.	Limitations	No or very minor concerns	MODERATE
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[1]	

[1] downgraded for small sample size

1.1.9 Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

1.1.9.1 Included studies

None.

1.1.9.2 Excluded studies

None

1.1.10 The committee's discussion and interpretation of the evidence

1.1.10.1 The quality of the evidence

The quality of the evidence was moderate to high, with the majority of the evidence being high. Thus, it is highly likely that the majority of the review's findings is a reasonable representation of the phenomenon (theme) of interest. The CERQual (Confidence in the Evidence from Reviews of Qualitative Research approach was used. Quality assessment was examined over four domains. Methodological limitations were examined based on overall assessment of the primary studies contributing to the review finding. Coherence was determined by the identification of a clear pattern across the studies included in the review. Relevance considered the applicability to the context specified in the review protocol. Overall adequacy determined richness and quantity of the evidence supporting the review finding. In the minority evidence that was of moderate quality the evidence was downgraded due to methodological limitations.

1.1.10.2 Findings identified in the evidence synthesis

Additional suggestions to include with themes highlighted in the review:

In total, 70 themes were identified from 41 studies. From these themes the committe decided to prioritise those that fell into the following categories; activities of daily living (ADL), caregivers, cognition, contraception and pregnancy, general information giving, medication, mental health and sudden unexpected death in epilepsy (SUDEP). The committee agreed that these areas affected a lot of people with epilepsy and in their experience people wanted to discuss their concerns or asked for more information.

Under the cateogory of general information giving, one barrier was that parents / carers stated they did not know where to seek help other than their doctor. The committee discussed that it was usual practice to signpost people to epilepsy organisations and charities as an additional source of information, and decided to make the recommendation that people with epilepsy and their carers should be given details of local and national epilepsy information and support groups.

On the theme of communicating information, people with epilepsy, parents and carers thought that information was often withheld. A second finding in this category was that service users and carers felt that involvement in decision making was central to their communication needs and they wanted to be more involved in discussions. The committee considered that a recommendation was warranted on providing information and support to the person with epilepsy (and their family or carers where appropriate) according to their individual needs and circumstances. Children wanted to be as informed as their parents / carers and many stated that physicians talked over them by using words outside their limited vocabulary or by ignoring them altogether and talking only to their parents / carers. The committee noted that a child's need for information varies according to the age of the child. The committee decided therefore to make a recommendation on ensuring that children and young people are given opportunity to participate in discussions about their information and support needs and the information provided is appropriate for their developmental age.

The committee discussed the information needs of people with learning disabilities, and that longer appointments may be required to allow enough time to explore what support and information the person needs and to give the person and their family or carer opportunity to fully participate in discussions. The committee recognised that information may need to be provided in a different format from what is typically given in order to meet individual need.

The committee highlighted the NICE guideline on shared decision making and the Patient experience in adult NHS services and agreed both of these had generic recommendations that were applicable to people with epilepsy and cross reference to these should be made.

The committee discussed providing information in a timely manner when a person is first diagnosed with epilepsy and identified four core issues to be discussed at the first appointment. Three were identified within the evidence, namely, medication adherence, mediating epilepsy related risk and triggers provoking seizures. The committee agreed that these were key to enable the person to self-manage their epilepsy and maintain everyday activities. The fourth on driving and driving activities was identified through committee discussion as regulations around driving and concerns with not being able to drive with epilepsy were commonly raised.

The evidence described barriers to compliance in taking epilepsy medication were mainly due to side effects experienced. Themes that emerged from the evidence in relation to mediating epilepsy-related risk, were descriptions of how the risk of seizures was central to participants’ experience of living with epilepsy, both in terms of the risk of a seizure occurring and the risk of injury as the result of a seizure. Another theme described was the negative emotional reactions parents / carers experienced when their child first had a seizure. Many thought that their child was going to die. Triggers provoking seizures was identified as a core issue by the committee because the evidence described uncertainty about what could provoke a seizure. This included parents / carers believing that crowds and parties increase the risk of seizures, and reports of some people who refused to attend parties. It was felt by some people that epilepsy had a direct effect on their independence and daily activity. Activity restrictions not only had implications for children and young people with epilepsy but also for their parents / carers, with a number reporting that they felt other people unnecessarily required them to be present during social and leisure activities. Children and young people reported not being allowed to participate in some sports or leisure activities along with their peers because of safety concerns. Studies reported people would try self-management to prevent or manage seizures. This included strategies such as implementing safeguarding measures or making adaptations to activities such as showering rather than bathing, and monitoring their general health.

The committee acknowledged the diverse range of concerns raised and requests for advice or information raised by patients, their families or carers during consultations. The committee agreed a check list of commonly raised issues may be a helpful guide to enable the person, families or carers to come prepared to discuss the aspects of the condition that are most important to them, rather than it being clinician led. Drawing on the themes identified by the evidence and on their own experience the committee incorporated a series of headings and topics to aid discussion into the recommendations.

Quite a number of themes were identified in the evidence concerning the category of activities of daily living. The committee discussed these and considered that a list should be provided in the recommendations of the most important ones identified from the themes in the evidence. These included impact on social life, lifestyle restrictions, and social exclusion. While triggers of seizure should be discussed at the first appointment it was also considered by the committee that opportunities to raise this should be repeated at future appointments because it is a topic commonly asked about and can cause anxiety. Barriers identified in the evidence were that epilepsy was perceived to significantly limit participants' actions, work prospects, and activities in and outside their home. For participants who experienced multiple seizures a day, the occurrence and aftermath of the seizures could affect the entire day and prevent the participant from engaging in any activities. Further barriers were that parental disclosure had resulted in a child with epilepsy receiving fewer invitations to social occasions, being excluded from participating in physical education in school or being denied participation in recreational activities. The committee agreed safety issues should be discussed, including activities or situations that should where possible be avoided, but they agreed consideration of adaptations or safety measures that could be introduced should also be explored. For example, ensuring children are supervised when swimming or participating in water sports. The committee considered that information on employment was important because evidence showed people perceived having epilepsy precluded them from certain jobs, and stated they had difficulties while trying to obtain employment, citing epilepsy as the main reason why they had not succeeded.

The committee considered a recommendation should be made to provide information and support for caregivers. This was based on evidence that carers considered a lack of correct information about caring for someone with epilepsy left them to resort to ‘trial and error’ methods. This was aggravated by changes in their roles, decreased household income, and increased responsibilities as a carer, often resulting in physical and emotional stress for the caregivers. The committee agreed reference to the NICE guidance on supporting adult carers should be made.

The committee agreed another important category to include was contraception and pregnancy. The committee recommended that opportunities to raise sexual health and pregnancy during appointments should be provided. This should include advice and information on contraception and pregnancy, postnatal care and breastfeeding, including prescribed anti-seizure mediation and any potential interactions with contraception and support for changes in epilepsy medications. All these recommendations came from themes identified in the evidence. Women reported feeling overwhelmed with anxiety regarding possible abnormalities in their baby due to anti-seizure drug use. The consequences of reduced efficacy of hormonal contraception due to drug interactions with some ASM’s, were issues not always discussed with women and girls. The avoidance of unplanned pregnancy was not always supported by effective healthcare practice and advice. While some women reported that their practitioners were helpful, those who received inaccurate or inadequate advice had to cope with varying consequences. The committee also recommended that information on pre-conception planning should be given because the evidence found that women reported increased anxiety when planning for their pregnancies. The committee noted the findings of the MBRRACE report on maternal death in epilepsy which highlighted the negative consequences of failing to provide adequate information about the importance of planning pregnancy

Difficulties with memory and concentration was a theme identified in the included studies. Children cited difficulties with memory and concentration as a consequence of medication side effects. The committee discussed that impairments in cognitive function was a subject often raised in discussions with patients, and the impact this can have on education and work. Recommendations for discussing educational attainment, performance, and communication issues came from the committee s experience of children and young people’s concerns about coping with school or college, and being able to keep up with their peers, and also feeling not being able to raise issues or ask for the support they need. Evidence for the recommendation for difficulties in learning arose from the finding that children reported many problems with learning in their classes and some type of academic difficulty.

Epilepsy medication was a theme often raised within the evidence. In particular a need for more open and honest discussions regarding changes to medications. Side effects from medication were reported including tiredness, sleeping disorders, concentration difficulties and memory impairment. Issues with compliance in taking epilepsy medication often due to side effects were reported within the evidence, and also a lack of empathy from medical staff. The committee therefore decided that information and advice should be provided on medication and side effects, and the opportunity to discuss adherence and changes to medication.

Themes raised within the area of mental health included sadness, depression, fear and anxiety. The evidence described parents/carers concerns for their children's mental health, in particular depression, anxiety or low mood after their child's diagnosis. Parents / carers also reported experiencing depression, anxiety, guilt, worry, and anger. Children had anxiety about having seizures at school because there was a risk of embarrassing oneself. The fears and concerns of parents / carers revolved around both the physical and emotional health of their children. Studies reported fear of future seizures causing sleeping disturbances and anxiety, worrying about how the seizures would affect their child's development, and the uncertainty for the future were identified as concerns. Caregivers discussed their continual worrying over the well-being of their child and the stress of explaining their child's condition to the school community. Based on these findings the committee recommended that discussion and information on mental health problems should be included as a category. The committee also included psychiatric co-morbidities such as ADHD, and behavioural issues based on their experience and expertise.

Studies also reported parents and carers felt epilepsy was stigmatising and there was a need for increasing epilepsy awareness in the community as means of helping reduce stigma. Emotional distress was also identified as a theme, with people reporting periods of intense emotional distress that they attributed largely to the unpredictability of their seizures and loss of control over their bodies. The committee agreed these were important issues to broach in appointment and decided these should be included within recommendations.

Quite a number of themes were identified in the evidence on sudden unexplained death in epilepsy (SUDEP). These was a lack of understanding or awareness of SUDEP, parental perceptions and concerns, including access to routine SUDEP counselling, different information needs and how information is delivered, and the timing and setting of SUDEP discussion. The committee recognised all of these themes as concerns commonly raised in discussions with patients and their families or carers. The committee noted the timing of a discussion about epilepsy related risk factors, particularly SUDEP was very important and agreed this should be raised early in consultations. Evidence found that there was broad agreement that SUDEP information should be provided, and service users wanted a general overview of what SUDEP was, risk factors and prevention strategies. Preference was expressed to have a face-to-face conversation with a health professional followed by some written information to take home. Parents and carers appeared to have a lack of understanding about the exact meaning of SUDEP and the level of risk of a child dying. Whilst many parents and carers understood SUDEP was a rare condition they still overestimated the risk. While some reported anxiety upon hearing about SUDEP for the first time, it was usually a temporary, rather than long-term concern. Parents and carers felt that some information, particularly relating to SUDEP was inappropriate for their child's age and it was the parent's decision as to whether or not the child should be present at the meeting or when to inform the child about the risks of SUDEP. The committee decided to focus their recommendations on offering opportunity for people to raise their concerns about SUDEP, provide information on the risk factors and mitigating risk and advice on the availability of SUDEP counselling.

Overall, the majority of the recommendations were made based on identification of themes in the evidence.

1.1.10.3 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this was a qualitative review.

The recommendations generally provide guidance regarding the content of information and support specific to people with epilepsies. This is in line with the general principles of provision of information already established in existing NICE guidelines (Patient experience, Supporting adult carers, Medicines adherence, Medicines optimisation, Depression in adults with a chronic physical health problem, Depression in children and young people, and Mental health problems in people with learning disabilities). Therefore, the recommendations were not considered likely to have a substantial resource impact over and above this. The committee also noted that free good quality information relating to epilepsies was available from patient charities and organisation websites and helplines.

1.1.10.4 Other factors the committee took into account.

The committee acknowledged the lack of evidence found describing the experience of older people with epilepsy and their information and support needs. The committee agreed the numbers of people living with epilepsy into older age is increasing, but their needs are often not recognised or addressed. The committee decided older people should be included within the recommendation to address the support and information needs of particular groups such as people with learning disabilities or other complex needs.

The committee also discussed the recording of information about their care for people and their family or cares where appropriate in the form of a care plan to give to the person. Committee members own experience on what information was included and in what format varied, but they agreed a recommendation to provide this should be included in the guideline.

1.1.11 Recommendations supported by this evidence review

This evidence review supports recommendations 2.1.1 - 2.1.10.

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Appendices

Appendix A Review protocols

A.1 Review protocol for information and support needs

ID	Field	Content
0.	PROSPERO registration number:	CRD42020167499
1.	Review title	What information and support is needed by people, parents or carers in relation to epilepsy, and when should this be provided?
2.	Review question	What information and support is needed by people, parents or carers in relation to epilepsy, and when should this be provided?
3.	Objective	To determine what information and support do people and their families or carers need (for example, advice on lifestyle, driving, and their treatment). A diagnosis of epilepsy may have a significant effect on activities of daily living and give rise to health difficulties over long periods of time. Epilepsy can affect people in different ways, everyone's experience of living with the condition is different but there universal educational and support needs.
4.	Searches	The following databases (from inception) will be searched: • Embase • MEDLINE • PsycINFO • CINAHL Searches will be restricted by: • English language studies • Human studies Other searches: Inclusion lists of systematic reviews The searches may be re-run 6 weeks before the final committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.

5.	Condition or domain being studied	People with epilepsy, their family/carers and health and social care professionals involved in their care.
6.	Population	Inclusion: children, young people and adults with epilepsy, their families and carers and health and social care professionals involved in their care Exclusion: New-born babies (under 28 days) with acute symptomatic seizures
7.	Intervention/Exposure/Test	Views, opinions and experiences in relation to information, education or support that will help people with epilepsy.
8.	Comparator/Reference standard/Confounding factors	Not applicable.
9.	Types of study to be included	Qualitative studies using any appropriate methodology (e.g., semi-structured interviews or focus groups with ethnography or grounded theory-based analysis) and systematic reviews of qualitative studies will be considered for inclusion.
10.	Other exclusion criteria	Non-English language studies. Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias.
11.	Context	A diagnosis of epilepsy can have wide ranging physical and psychological and social consequences which may be as difficult to deal with as the seizures themselves. It is therefore important that individuals with epilepsy, their family and / or carers have information that is individualised and appropriate for individual's developmental age, gender, culture, and stage of life.
12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and may include provoking factors (for example alcohol and illicit drugs), lifestyle access and restrictions (for example access to transport and driving), environment factors (for example showers versus baths), medication, mental health issues and cognitive outcomes (for example memory).
13.	Secondary outcomes (important outcomes)	Not applicable.
14.	Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations and bibliographies. All references identified by the searches and from other sources will be screened for inclusion. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. A standardised form will be used to extract data from studies (see Developing NICE guidelines: the manual section 6.4) https://www.nice.org.uk/process/pmg20/chapter/reviewing-research-evidence#reviewing-research-evidence

		Once saturation is considered to have been reached (all the themes are already covered in the data extraction) data from other included papers will not be extracted or critically appraised, but the paper will still be read to check for any additional themes and will be noted in the included studies. The point at which data extraction is reached will be noted within the review.	
15.	Risk of bias (quality) assessment	The methodological quality of each study will be assessed using the CASP qualitative checklist and the GRADE CERQual approach used to provide overall risk of bias at outcome level 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: papers were included /excluded appropriately a sample of the data extractions correct methods are used to synthesise data a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement	
16.	Strategy for data synthesis	CERQual will be used to synthesise data from qualitative studies. The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings	
17.	Analysis of sub-groups		
18.	Type and method of review	☐	Intervention
		☐	Diagnostic
		☐	Prognostic
		☒	Qualitative
		☐	Epidemiologic
		☐	Service Delivery
		☐	Other (please specify)
19.	Language	English	

20.	Country	England		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☑	☑
		Piloting of the study selection process	☑	☑
		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑
		Data analysis	☑	☑
24.	Named contact	5a. Named contact: National Guideline Centre 5b Named contact e-mail NGCepilepsies@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre		
25.	Review team members	From the National Guideline Centre: Gill Ritchie, Guideline Lead Angela Cooper, Senior Research Fellow Rafina Yarde, Systematic reviewer Margaret Constanti, Senior Health economist Joseph Runicles, Information specialist		
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.		
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for		

		declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.	
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10112.	
29.	Other registration details		
30.	Reference/URL for published protocol		
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: notifying registered stakeholders of publication publicising the guideline through NICE's newsletter and alerts issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords	Epilepsies, information, support	
33.	Details of existing review of same topic by same authors		
34.	Current review status	☒	Ongoing
		☒	Completed but not published
		☐	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35.	Additional information	[Provide any other information the review team feel is relevant to the registration of the review.]	
36.	Details of final publication	www.nice.org.uk	

Appendix B Literature search strategies

This literature search strategy was used for the following reviews:

- What information and support is needed by people, parents or carers in relation to epilepsy, and when should this be provided?
- How should the transition from children's and young people's services to adults' epilepsy services be managed?

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[46]

For more information, please see the Methodology review published as part of the accompanying documents for this guideline.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 5: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 30 December 2019	Qualitative studies Exclusions
Embase (OVID)	1974 – 30 December 2019	Qualitative studies Exclusions
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 30 December 2019	
PsycINFO (ProQuest)	Inception – 30 December 2019	

Medline (Ovid) search terms

1.	exp epilepsy/
2.	seizures/
3.	exp status epilepticus/
4.	seizures, febrile/
5.	(dravet syndrome or epilep* or continuous spike wave or slow sleep or landau kleffner syndrome or lennox gastaut syndrome or infant* spasm* or seizure* or west syndrome).ti,ab.
6.	or/1-5
7.	letter/
8.	editorial/
9.	news/
10.	exp historical article/
11.	Anecdotes as Topic/
12.	comment/
13.	case report/

14.	(letter or comment*).ti.
15.	or/7-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animals/ not humans/
19.	exp Animals, Laboratory/
20.	exp Animal Experimentation/
21.	exp Models, Animal/
22.	exp Rodentia/
23.	(rat or rats or mouse or mice).ti.
24.	or/17-23
25.	6 not 24
26.	limit 25 to English language
27.	"patient acceptance of health care"/ or exp patient satisfaction/ or consumer health information/ or needs assessment/
28.	Patient Education as Topic/ or exp patients/ or exp family/ or caregivers/ or patient preference/
29.	((information* or advice or advising or advised or support*) adj3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)).ti,ab.
30.	(information* adj2 support*).ti,ab.
31.	((client* or patient* or user* or carer* or consumer* or customer* or parent* or famil* or spouse*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or preference* or focus group*)).ti,ab.
32.	or/27-30
33.	"Continuity of Patient Care"/
34.	Patient Transfer/
35.	Patient Care Planning/
36.	"Delivery of Health Care, Integrated"/
37.	shared care.ti,ab.
38.	shared service*.ti,ab.
39.	((healthcare or care or service*) adj3 integrat*).ti,ab.
40.	transition*.ti.
41.	(transfer? or transferred or transferral or transferring).ti.
42.	(transition* adj10 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department? or patient?)).ab.
43.	((transfer? or transferred or transferral or transferring) adj10 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department? or patient?)).ab.
44.	(transition* and (adult? adj3 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department?))).ab.
45.	((transfer? or transferred or transferral or transferring) and (adult? adj3 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department?))).ab.
46.	(transfer? or transferred or transferal or transferring or transition).ab. and (adult?.ti. or (adult focused or adult oriented).ti,ab.)
47.	(continuity adj3 (care or health care or healthcare or treatment? or therapy or therapies or patient? or "doctor-patient" or nurse patient)).ti,ab.
48.	or/33-47

49.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
50.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
51.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
52.	or/49-51
53.	26 and 52 and (32 or 48)

Embase (Ovid) search terms

1.	exp epilepsy/
2.	seizure/
3.	epileptic state/
4.	febrile convulsion/
5.	(dravet syndrome or epilep* or continuous spike wave or slow sleep or landau kleffner syndrome or lennox gastaut syndrome or infant* spasm* or seizure* or west syndrome).ti,ab.
6.	or/1-5
7.	letter.pt. or letter/
8.	note.pt.
9.	editorial.pt.
10.	case report/ or case study/
11.	(letter or comment*).ti.
12.	or/7-11
13.	randomized controlled trial/ or random*.ti,ab.
14.	12 not 13
15.	animal/ not human/
16.	nonhuman/
17.	exp Animal Experiment/
18.	exp Experimental Animal/
19.	animal model/
20.	exp Rodent/
21.	(rat or rats or mouse or mice).ti.
22.	or/14-21
23.	6 not 22
24.	limit 23 to English language
25.	patient attitude/ or patient preference/ or patient satisfaction/ or consumer attitude/ or needs assessment/
26.	patient information/ or consumer health information/ or patients/ or family/ or caregivers/
27.	((information* or advice or advising or advised or support*) adj3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)).ti,ab.
28.	(information* adj2 support*).ti,ab.
29.	((client* or patient* or user* or carer* or consumer* or customer* or parent* or famil* or spouse*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or preference* or focus group*)).ti,ab.
30.	patient education/

31.	or/25-30
32.	*patient care/
33.	*patient transport/
34.	patient care planning/
35.	integrated health care system/
36.	shared care.ti,ab.
37.	shared service*.ti,ab.
38.	((healthcare or care or service*) adj3 integrat*).ti,ab.
39.	transition*.ti.
40.	(transfer? or transferred or transferral or transferring).ti.
41.	(transition* adj10 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department? or patient?)).ab.
42.	((transfer? or transferred or transferral or transferring) adj10 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department? or patient?)).ab.
43.	(transition* and (adult? adj3 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department?))).ab.
44.	((transfer? or transferred or transferral or transferring) and (adult? adj3 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department?))).ab.
45.	(transfer? or transferred or transferal or transferring or transition).ab. and (adult?.ti. or (adult focused or adult oriented).ti,ab.)
46.	(continuity adj3 (care or health care or healthcare or treatment? or therapy or therapies or patient? or "doctor-patient" or nurse patient)).ti,ab.
47.	or/32-46
48.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
49.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
50.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
51.	or/48-50
52.	24 and 51 and (31 or 47)

CINAHL (EBSCO) search terms

S1.	(MM "Seizures")
S2.	(MH "Status Epilepticus+")
S3.	(MH "Epilepsy+")
S4.	(MH "Convulsions, Febrile")
S5.	(dravet syndrome or epilep* or continuous spike wave or slow sleep or landau kleffner syndrome or lennox gastaut syndrome or infant* spasm* or seizure* or west syndrome)
S6.	S1 OR S2 OR S3 OR S4 OR S5
S7.	(MH "Consumer Satisfaction+") OR (MH "Patient Education") OR (MH "Health Education")
S8.	((information* or advice or advising or advised or support*) n3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*))
S9.	(information* n2 support*)

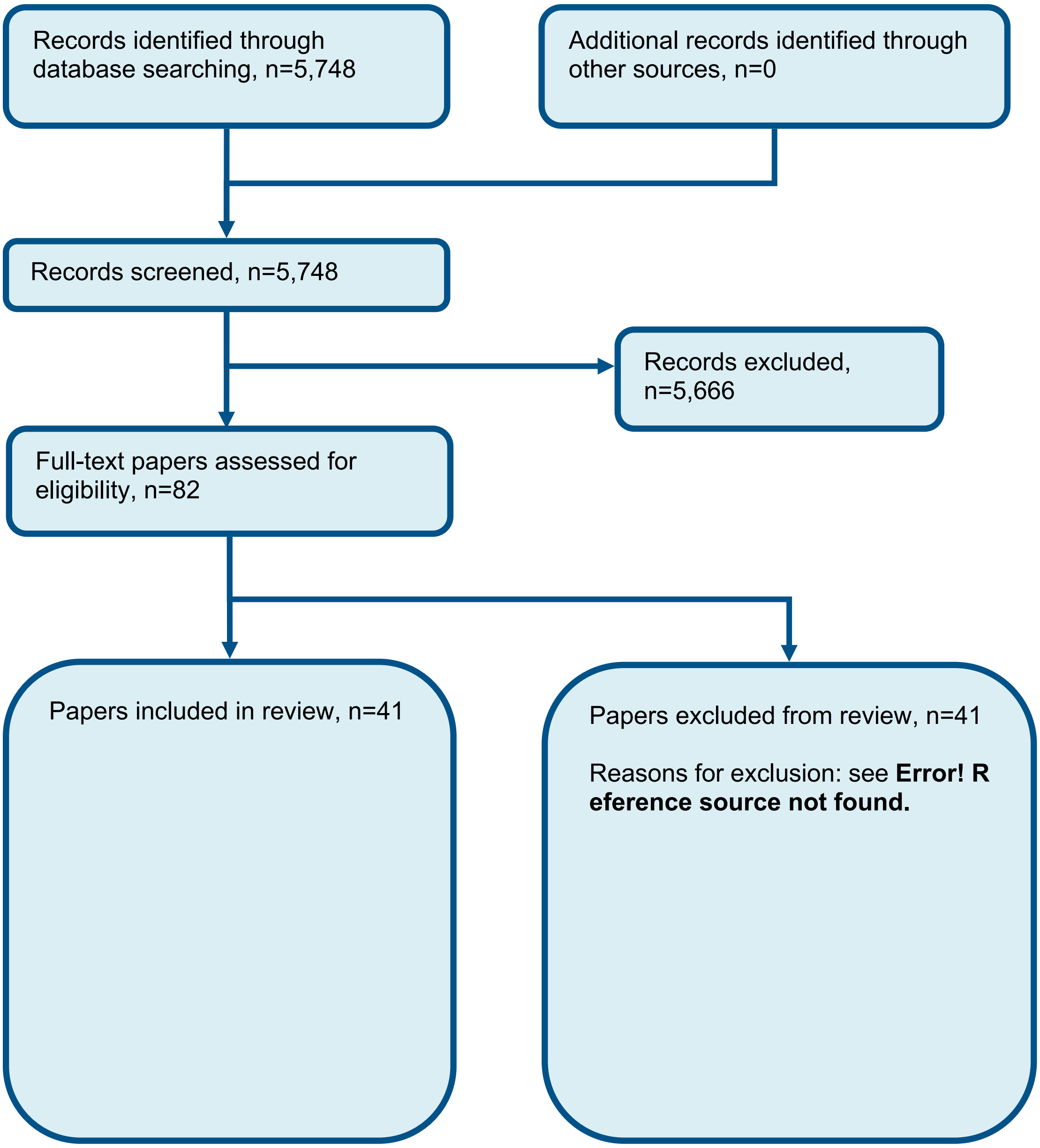
S10.	((client* or patient* or user* or carer* or consumer* or customer*) n2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion*))
S11.	S7 OR S8 OR S9 OR S10
S12.	(MH "Qualitative Studies+")
S13.	(MH "Qualitative Validity+")
S14.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S15.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S16.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* n3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
S17.	S12 OR S13 OR S14 OR S15 OR S16
S18.	S6 AND S11 AND S17

PsycINFO (ProQuest) search terms

1.	(MJMAINSUBJECT.EXACT.EXPLODE("Epilepsy") OR MAINSUBJECT.EXACT("Seizures") OR MAINSUBJECT.EXACT("Status Epilepticus") OR TI,AB(dravet syndrome OR epilep* OR continuous spike wave or slow sleep OR landau kleffner syndrome OR lennox gastaut syndrome OR infant* spasm* OR seizure* OR west syndrome)) AND (SU.EXACT("Client Education") OR SU.EXACT.EXPLODE("Client Attitudes") OR TI,AB((information* OR advice OR advising OR advised OR support*) NEAR/3 (patient* OR need* OR requirement* OR assess* OR seek* OR access* OR disseminat*)) OR TI,AB(information* NEAR/2 support*) OR TI,AB((client* OR patient* OR user* OR carer* OR consumer* OR customer*) NEAR/2 (attitud* OR priorit* OR perception* OR preferen* OR expectation* OR choice* OR perspective* OR view* OR satisfact* OR inform* OR experience OR experiences OR opinion*))) AND ((su.exact.explode("qualitative methods") OR su.exact("narratives") OR su.exact.explode("questionnaires") OR su.exact.explode("interviews") OR su.exact.explode("health care services") OR ti,ab(qualitative OR interview* OR focus group* OR theme* OR questionnaire* OR survey*) OR ti,ab(metasynthes* OR meta-synthes* OR metasummar* OR meta-summar* OR metastud* OR meta-stud* OR metathem* OR meta-them* OR ethno* OR emic OR etic OR phenomenolog* OR grounded theory OR constant compar* OR (thematic* NEAR/3 analys*) OR theoretical-sampl* OR purposive-sampl* OR hermeneutic* OR heidegger* OR husserl* OR colaizzi* OR van kaam* OR van manen* OR giorgi* OR glaser* OR strauss* OR ricoeur* OR spiegelberg* OR merleau*)))Limits applied

Appendix C Qualitative evidence study selection

Figure 1: Flow chart of qualitative study selection for the review of information and support needs



Appendix D Qualitative evidence

Study	**Amjad 2016**[3]
Aim	To explore the experiences of parents of children with epilepsy.
Population	For inclusion in the study, parents could have only one child with grand mal epilepsy who was between the ages of 1 to 18 years with a diagnosis of epilepsy made at least one year ago. The parents had to be literate, not separated, taking care of the child by themselves and agree to participate in the study, n=10
Setting, country	Imam Khomeini Hospital and Children's Medical Centre, Iran
Study design	Qualitative interview study
Methods and analysis	In depth semi-structured interviews conducted face to face with individuals in a quiet room. Conducted at a participants' place and time of choice, lasting 35 to 100 minutes. Thematic and phenomenological analysis - interviews were transcribed and to understand phenomenological relationships thematic analysis was performed with the data. The holistic and selective approach was used for exploring themes.
Findings	Fear: Parents reported that they were afraid of travelling due to fear of basic health care unavailability and the worry that their child would have a seizure in a 'strange' country and not know the language.
	Provoking factors: Parents believed that crowds and parties increase the risk of seizures, and some refused to attend parties and ceremonies due to the fear of disclosure of their child's illness so going to social functions were also limited.
	Social restrictions: One participant explained the limitations caused by the illness 'we cannot visit any places to attend fun events, or visit anyone, for fear that someone will find out about this disease. We cannot attend ceremonies that are being held in a crowded space because it is possible, he will have a seizure.'
	Affects parents' life choices: A father expressed his willingness to continue studying on his favourite course but felt prevented from doing so due to his daughter's condition. Some also felt the need to quit their jobs.

Study	**Amjad 2016**[3]
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Benson 2015**[8]
Aim	To address the gap in epilepsy literature by unearthing the contextual factors that present challenges for children with epilepsy in disclosing their epilepsy diagnosis to those external to the nuclear family. The nuclear family was defined as the family unit comprising the child's parents/guardians and siblings.
Population	Children aged between 6 and 16 years who had a diagnosis of epilepsy and a prescription for antiepileptic drugs were recruited. Children/adolescents with an intellectual disability, developmental delay, significant learning, or behavioural deficits and or significant medical conditions were excluded to avoid confounding factors, n=29
Setting, country	Participants interviewed in a location of their choice, Republic of Ireland
Study design	Qualitative interview study
Methods and analysis	Participants were interviewed in a location of their choice at a time that suited them. The option of the child's parent being present was left to the discretion of the child. Most opted to be interviewed separate from their parents. Semi-structured interviews lasting approximately 20-40 minutes. The interviews were audiotaped, transcribed verbatim, and thematically analysed using Braun and Clarke's six phase framework for purposeful, systematic, and rigorous thematic analysis. Authors reviewed the entire dataset and manually coded line by line each transcript to generate a coding framework.
Themes with findings	Feeling different: For some disclosing the diagnosis elicited feelings of ‘differentness’. Feelings of differentness were exacerbated by the fact very few participants had any contact with other people who also had epilepsy.
	Minimising different treatment: For some, disclosing their diagnosis to others was viewed as heightening the risk of others treating and perceiving them differently. Participants reported engaging in concealment and/or selective disclosure management strategies in an attempt to minimise the potential for others to treat them differently due to their epilepsy diagnosis.

Study	**Benson 2015[8]**
	Invisibility of epilepsy: Participants discussed the fact it is not physically visible to others, and the silence around epilepsy in the public domain. A number of participants reported that the invisible nature of the condition acted as a barrier to disclosure because both they themselves and their peers struggled to reconcile their own perceptions of what an individual with an illness and/or disability should appear like with the seemingly 'normal' physical appearance of the children with epilepsy.
	Negative responses to disclosure: Many anticipated negative responses to disclosure whilst many had actual negative responses when disclosed. Some reported an unwillingness to disclose their epilepsy diagnosis to those external to the immediate family as they feared it would evoke worry and fear in others. Some participants relayed experiences of being bullied or teased by peers due to their epilepsy.
	Complexity of epilepsy - difficult to explain to others/challenging to understand: Participants found it difficult to explain to others, with some (particularly those of a younger age) yet to establish how to appropriately describe their conditions to others. Some also felt it challenging for peers to understand.
	Self and others' perceptions of epilepsy: Participants' own perceptions of epilepsy as well as their views on how others perceived the condition also seemed to impact their motivations to disclose (or not) the diagnosis to those external to the nuclear family and informed the disclosure management strategies they adopted.
	Peers lack knowledge and understanding: A number of participants discussed how their peers lacked knowledge and understanding of the condition. Many adolescents highlighted how their peers relied heavily on stereotypes of epilepsy to inform the extent of their knowledge.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Benson 2016[10]**
Aim	To present the stigma experiences of children with epilepsy and their parents, in the context of communicating about epilepsy within and external to the family unit.

Study	**Benson 2016[10]**
Population	Children with epilepsy were eligible to participate if they were aged 6-16 years, had a prescription for antiepileptic drugs and did not have any other significant medical condition and or developmental delay. Parent participants were required to be the parent of primary caregiver of the participating child, n=73
Setting, country	Participants interviewed in a location of their choice, Republic of Ireland
Study design	Mixed methods design, quantitative and qualitative
Methods and analysis	Mixed methods design. Interviews were conducted separately with children and their parents at a time and location convenient to them. The interviews were structured around an open-ended topic guide with probes on pre-defined issues to capture children with epilepsy and their parents' experiences of communicating about epilepsy and epilepsy-related issues, both within and external to the home environment. Interviews were digitally recorded and transcribed verbatim. Transcripts were imported into the Nvivo organisational software that facilitates the storage, retrieval, and manipulation of large quantities of qualitative data. Data were thematically analysed according to Braun and Clarke's six-phrased framework for thematic analysis.
Themes with findings	Social exclusion: A number of participants relayed experiences of being excluded by their peers from parties, playdates and sleepovers, with some citing parental fear as a reason underlying their exclusion from such occasions.
	Activity restrictions: A number of participants felt their epilepsy had a direct effect on their independence and ability to participate in activities. Activity restrictions not only had implications for the children with epilepsy but also for their parents, with a number reporting that they felt others unnecessarily required them to be present during social and leisure activities.
	Negative responses to disclosure: Some participants relayed experiences of being bullied or teased by peers due to their epilepsy. "Em, I don’t like talking about seizures that I've had cause like in primary school like people used to talk about seizures I used to have, and they'd like be laughing about them." Parents were also largely aware of the threat that bullying, and teasing posed for children with epilepsy perceptions of epilepsy-related stigma amongst peer groups.
	Negative feelings towards epilepsy: Many participants reported they had internalised negative feelings towards their epilepsy. Some relayed how it made them feel different from their peers and at times their siblings. This brought up issues of self-identity related to living with epilepsy, with a number of participants

Study	**Benson 2016[10]**
	reporting they felt like the 'odd one out' amongst peer groups. Some parents reported the epilepsy diagnosis evoked feelings of embarrassment and shame. Concealment: A number of participants felt the need to actively hide their diagnosis from those external to the nuclear family, indicating their awareness of the potential for stigmatisation due to their epilepsy.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Benson 2017[9]**
Aim	To explore the challenges parents of children with epilepsy experienced when deciding whether to disclose their child’s epilepsy diagnosis to others external to the nuclear family (defined as the child’s parent(s)/guardian(s) and sibling(s)), and identify factors that promoted concealment and/or selective disclosure management strategies among parents of CWE.
Population	Participants were required to be parent(s)/ guardian(s) of a child aged 6–16 years with (i) a diagnosis of any type of epilepsy; (ii) a prescription for anti-epileptic drugs and (iii) no significant intellectual disabilities, learning difficulties and/or developmental delay, n=34
Setting, country	Participants interviewed in a location of their choice, Republic of Ireland
Study design	Qualitative interview study
Methods and analysis	Data were gathered using exploratory semi-structured interviews, conducted at a location and time of parents’ choosing. If both parents wished to participate, they were given the option of being interviewed separately or together. In all instances of both parents participating, parents opted to be interviewed together. Interviews with parents were directed by a semi-structured interview guide which was developed collaboratively with the research team, an epileptologist, a professional from the national epilepsy association and two expert advisors in the field of epilepsy. The interview guide was developed following engagement with research literature pertaining to childhood epilepsy, the psychosocial impact of childhood epilepsy on CWE and their parents, and disclosure of epilepsy and/ or other concealable stigmatised identities.

Study	Benson 2017[9]
	Data were imported into NVivo 10 which is an organisational software platform that facilitates the storage, retrieval and manipulation of large quantities of qualitative data. Subsequently, data were thematically analysed. In undertaking thematic analysis of the data, Braun and Clarke's six-phase process and framework for thematic analysis was employed19 comprising (1) data familiarisation through transcription and reading/re-reading transcripts; (2) line-by-line coding of each transcript and generation of a coding framework; (3) creation of themes and sub-themes through synthesis of initial codes; (4) review of themes and subthemes for appropriateness by the research team, with theme interpretations validated through discussions with the research team and repeated referral to the coded extracts and original dataset; (5) labelling and defining themes; and (6) production of a written report of the analysis.
Themes with findings	Minimising different treatment: A number of parents described striving to foster a sense of normality for their child with epilepsy by ensuring where possible that others did not treat or perceive them differently because of his/her diagnosis. Some parents reported considering the perceived risk of disclosure resulting in consequences that would compromise this sense of normality. Among parents who perceived such risks, concealment and/or selective disclosure strategies were viewed as protective mechanisms to guard against such consequences.
	Concealment: Concealment and/or selective disclosure strategies were deemed desirable in instances where parents were concerned that life opportunities or participation in activities would be compromised due to the imposition of unnecessary restrictions on their child by others, if they were to learn of the diagnosis.
	Invisibility of epilepsy: The invisibility of epilepsy encouraged some parents to conceal and/or selectively disclose their child's epilepsy diagnosis. Parents believed that there was a lack of dialogue about epilepsy, it received limited media attention and few public figures advocated for it. Parents thought this silent message, reflective of how epilepsy is perceived by society, was not a positive one. It suggested to them that others were uncomfortable with and fearful of epilepsy.
	Negative responses to disclosure: Fear of negative responses, as well as actual experiences of negative reactions by others to past parental disclosures of the child with an epilepsy diagnosis. A number of parents alluded to being apprehensive about how parents of their child's peers would respond and whether this would limit future invitations to playdates, parties and sleepovers, and consequently negatively impact on their child's friendships and socialisation.

Study	**Benson 2017[9]**
	Social restrictions: For some families, parental disclosure had resulted in the child with epilepsy receiving fewer invitations to social occasions, being excluded from participating in physical education in school or being denied enrolment in recreational activities. Detrimental impacts for parents included offensive reactions, e.g., others mimicking seizures, and difficulty finding someone to care for the child in their absence.
	Stigma: Several parents believed public perceptions of epilepsy were poor. Some parents felt that epilepsy is a condition that is stigmatised. Participants reported strongly about the need for increasing epilepsy awareness in the community as part of care and stigma reduction efforts.
	Lack of understanding: Lack of public understanding and knowledge regarding what epilepsy is, the various presentation of seizures and what epileptic syndromes encompass (i.e., the physical, cognitive, and psychosocial consequences of epilepsy) inhibited parental openness about their child's epilepsy.
	Acceptance: For many parents on receiving the diagnosis of their child's epilepsy, a period of grief ensued as parents grappled with the loss of their 'healthy child'. Many parents verbalised that the diagnosis had a profound emotional impact, evoking 'devastation', 'upset', 'concern', 'worry' and 'shock'.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Chen 2010[16]**
Aim	To explore the lived experiences of school aged children with epilepsy in Taiwan.
Population	Children aged 7-13 years old, had been diagnosed with epilepsy for at least 6 months and were not developmentally delayed, had well controlled epilepsy, were able to communicate in Chinese or Taiwanese, were willing to be interviewed and agreed to be tape-recorded during the interview, n=15
Setting, country	In home visits, Taiwan
Study design	Qualitative interview study

Study	**Chen 2010[16]**
Methods and analysis	Interviews were conducted using a semi-structured interview guide. Questions in the guide were developed after an extensive review of the literature. Interviews lasted 60 to 80 mins. Breaks were taken every 30 mins to allow children to have a snack or visit their room and toys before resuming the interview. In-home visits were scheduled to conduct tape-recorded interviews. Data were analysed using the phenomenological method. The narratives were read thoroughly to gain an understanding. Meaningful statements and phrases were extracted from each transcript, then clustered to form categories and subthemes.
Themes with findings	Invisibility of epilepsy: Participants discussed the fact it is not physically visible to others. Not knowing the cause was difficult for children to understand. One participant reported "I don't know, maybe my thinking has some trouble. My parents took me to visit the clinic. My brain has something wrong."
	Negative feelings towards epilepsy: Children often described negative feelings about their condition, which led to seizures, restricted activities and the need to take medicine.
	Activity restrictions: Participants had may complaints about the restrictions on their activities because of their illness. Participants felt their epilepsy had a direct effect on their independence and ability to participate in activities. One stated "The teacher doesn't allow me to run and hang on the exercise bar…".
	Practical/access difficulty: Participants reported many problems with learning in their classes and some type of academic difficulty. Participants One said "…I could not concentrate on anything; my thoughts just kept on drifting".
	Negative responses: Children perceived their peers responded negatively to their illness. Some children keep their illness secret to prevent being teased by peers. One said "no one plays with me. They play with each other, but seldom with me".
	Coping strategies: The participants reported they would try self-management to prevent or manage seizures. This included several strategies such as activity restrictions, positivity or monitoring their general health.
	Medication: To control their seizures many would take anticonvulsant drugs. They regularly took medication on their own or with reminders from their families. Some would negotiate to slightly lessen the dosage.

Study	**Chen 2010[16]**
	Support: Participants sought support from parents and siblings when they needed help or felt that something went wrong. Participants also described maintaining good relationships with their siblings, which facilitated getting help and emotional support from them
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Chew 2018[17]**
Aim	To use a family resilience framework to explore young people's experiences of living with epilepsy. In particular, key family processes that facilitate self-esteem – an indicator of adaptation and resilience – will be examined as such knowledge will be valuable to social workers and other professionals in supporting these young people and their families.
Population	Young people (i) diagnosed with epilepsy, (ii) aged between 13 and 16 years old, and (iii) attending mainstream school were recruited, n= 15
Setting, country	All but one were conducted in participants' home, Singapore
Study design	Qualitative interview study
Methods and analysis	Young people determined the time and location for their interviews: all but one were conducted in their homes. Digital audio recording was requested from all but one participant who was uncomfortable with recording. Semi-structured interviews explored their experiences of living with epilepsy and of how individual and family factors might have influenced their adaptation to the condition. The interview guide was developed to reflect this objective. Interviews lasted between 42 and 80 minutes, with an average duration of 50 minutes. All interviews, except for one, were audio taped and transcribed verbatim. NVivo 10, a computer assisted qualitative data analysis software, was used to aid with data management and analysis. The analytic approach for this study was guided by 'Framework' analysis. It is considered a form of thematic analysis, an

Study	**Chew 2018**[17]
	interpretive process where themes describing a phenomenon are described and patterns within the data are identified. The Framework approach comprises two stages: (i) data management, (ii) abstraction and interpretation. Although this two-stage approach provided a structure for how data was managed and analysed, these processes were iterative. The first author carried out the qualitative data analysis. In order to maintain rigor of the analytical processes and increase credibility of the research findings, both second and third authors reviewed the thematic framework and examined whether themes were derived from the data. This process ensured that the final themes remained true to young people's accounts.
Themes with findings	Coping strategies: Often, young people's beliefs about living with epilepsy mirrored that of their parents. Young people with a sense of mastery regarded 'positivity' as a coping mechanism, emphasizing it was unproductive to dwell upon the negative aspects of living with epilepsy. Instead, they highlighted that it was essential to look forward to good things in life. These young people focused on their abilities, accepted that certain aspects of epilepsy were beyond their control, they channelled their efforts toward fulfilling their responsibilities (e.g., adherence to medication) and actively pursued their interests.
	Belief about what is normal: Young people's maturity of thought was evident when they spoke of normality. They recognized actual differences when they compared themselves to their peers, and family beliefs played a role in young people's positive views of themselves.
	Support: Most young people described strong relationships among family members. Family connectedness was perceived low in three families as their interactions were often conflictual or distant. Features that characterized strong family connectedness were engagement in shared activities; validation and acceptance of young people's feelings; providing and receiving both emotional and instrumental support in times of need; demonstrating affection and warmth; and successful management of family conflict.
	Social restrictions: Most young people engaged in regular social activities with their friends and had similar curfews as their siblings and friends. However, they felt that parents unnecessarily limited the types of activities and time spent with friends. Parental control and overprotectiveness were perceived as barriers to participation, and young people often used strategies, such as bargaining, reasoning, and persuading, to influence their parents' decisions
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Chiu 2014**[18]
Aim	To present the personal views of children in adolescence who have successfully completed withdrawal from antiepileptic drugs and, thus, are in the process of adjusting to their new present life without the constraints imposed by epilepsy.
Population	The participants age when AEDs were discontinued and at the time of the interview was between 12-18 years, the child was discontinued from AEDs at the time of the interview and had been completely off AEDs for more than 6 months and the child had no diagnosed cognitive or mental disabilities or disorders, n=11
Setting, country	At the participants' home, Taiwan
Study design	Qualitative interview study
Methods and analysis	Interviews were conducted with the eligible participants. All were in their adolescence at the time of their interview, ranging from 14 to 17 years of age. The 1-hour interview was conducted in the participants home, and according to a semi-structured interview guideline. The data were analysed using content analysis. Each transcript was carefully read line by line by the first two authors. Then open coding was performed with notes and headings written in the margins by each author. The research process was carefully conducted to ensure the trustworthiness of the study. The typed transcripts were carefully verified by the first two authors.
Themes with findings	Food restrictions: Adolescents were told they had to avoid beverages such as coffee or tea that contained caffeine, as well as chocolate and spicy foods.
	Medication: Throughout their treatment participants reported they were required to follow strict medical regimens. Regular timely doses of medicine had to be taken on an empty stomach. Such a regimen often conflicted with school meal schedules. The side effects of AEDs such as drowsiness and sleepiness constantly interfered with daily life and affected academic performance.
	Coping strategies: Most of the participants said they were not worried about seizure recurrence but would use caution against a possible relapse. Some retained a restricted lifestyle such as participating in less strenuous activities.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Eklund, 2003[21]**
Aim	To describe the lived experience of adolescents with epilepsy and how they cope with the disease.
Population	Young adults diagnosed with epilepsy, n=13
Setting country	At the participants' home, Sweden
Study design	Qualitative interview study
Methods and analysis	An interview manual with 12 open-ended questions was developed and reviewed by the paediatric epilepsy nurse and two paediatric nurses. Semi structured interviews were conducted from September to November 2001 and tape recorded. Each interview lasted 30 to 60 minutes and performed in the homes of the adolescents in 7 case and at the hospital in 6 cases. Latent content analysis means each passage is reviewed within the context of the entire text to identify the major intents and significant meanings. Transcripts were analysed according to the 14 stages described in Burnard.
Themes with findings	Activity restrictions: All adolescents described limitations of leisure activity. They talked about the need to take care of themselves. They also described frustration about not being able to do things their peers do, such as driving a moped or obtaining a driver's license.
	Provoking factors: Several reported they more commonly had seizures when they drank alcohol or when they were exposed to flashing lights such as at a disco. Some refrained from going to discos or drinking alcohol, but none ceased watching television or working with the computer.
	Medication: Many respondents were aware of the good effects of the antiepileptic drugs. Most found it important to take the medication regularly as they knew it decreased the risk of seizures. However, several adolescents described side effects from the medications, such as tiredness, a sleeping disorder, concentration difficulties and memory impairment. One female wondered about fertility in relation to the medication.
	Feeling different: All expressed feelings of being different. Some adolescents thought they would have made friends more easily if they did not have epilepsy. Feelings of injustice about having contracted epilepsy were common. There were also adolescents who felt discriminated against at school because they thought the teachers were afraid of seizures.

Study	**Eklund, 2003**[21]
	Lack of understanding: Several respondents also reported that one reason for the lack of experience of being different was the general lack of knowledge about epilepsy in the society.
	Negative feelings towards epilepsy: Some participants reported anxiety about having seizures at school, because there was a risk of embarrassing oneself. It was a burden to take the medication for a whole lifetime and also a burden to be forced to take care of oneself and to think about one's health more than their peers. Fear of future seizures caused sleeping disturbances and anxiety for some respondents.
	Support: This included emotional and practical support from parents, siblings, teachers, health professionals, other adults and in particular peers. The adolescents wanted people around them to stay during a seizure and to give shelter. It gave them a sense of relief to know that most of the people around them had cell phones.
	Complexity of epilepsy - Participants found it difficult to explain to others, with some (particularly those of a younger age) yet to establish how to appropriately describe their conditions to others. Some also felt it challenging for peers to understand.
	Being in control: A feeling of being in control was important for reducing anxiety. Some adolescents actively searched for information and wrote papers at school about epilepsy. these activities seemed to increase their self-confidence because they spoke proudly about it. participants also reported measures taken to safeguard themselves in the event of a seizure including avoiding potentially hazardous activities such as swimming or ironing.
	Coping strategies: Routines helped to maintain a feeling of control, such as installing an alarm on the cell phone as a reminder to take the medication. Relating to others who may have more severe diseases also makes the feeling of control stronger. The participants reported they would try self-management to prevent or manage seizures. This included several strategies such as activity restrictions, positivity or monitoring their general health.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Elliot, 2005[22]**
Aim	To explore how children and adolescents with medically refractory seizures experience the impacts of epilepsy on their quality of life within the domains of physical, emotional/behavioural, social and cognitive/academic function.
Population	Children and adolescents aged 7-18 years old with medically refractory seizures, n=49
Setting, country	At the Hospital for Sick Children, Canada or in the family's home.
Study design	Qualitative interview study
Methods and analysis	Semi-structured open-ended interview with questions. Interviews ranged from 20 minutes to 1.5 hours and were conducted by one of the investigators or a research assistant. Outpatient appointments were arranged at the Hospital for Sick Children or in the family's home. Secondary sampling followed rereading of the interviews. Audiotaped interviews were transcribed verbatim and imported into QSR NUD.IST 4.0, a computer software program designed to manage text-based data. Open coding was the first phase of analysis and involved the inductive generation of codes and sub codes which emerged from the reading of text segments. During the second phase of analysis, axial coding was used to reorganise the codes. During the final selective coding phase of analysis, core categories and subcategories within each conceptual domain.
Themes with findings	School restrictions: A large proportion reported excessive fatigue, making it difficult for them to think clearly and be available to participate in academic endeavours. For some the persistent fatigue and need for sleep that accompanied their seizures could last hours or a whole day; meaning youths either missed going to school or were unable to remain at school.
	Activity restrictions: Seizures had effects on their physical activity.80% of participants expressed that parents were excessively worried about them because of their seizures. Although they viewed close parental monitoring as necessary because of safety concerns, they often felt frustrated by the restrictions that diminished their autonomy and opportunities to engage fully in age-appropriate social and recreational activities.
	Emotional distress: The majority of participants experienced periods of intense emotional distress that they attributed largely to the unpredictability of their seizures and loss of control over their bodies. Worry or fear and anger and frustration were often connected to experiencing seizures, medication side effects or extent of parental monitoring.

Study	Elliot, 2005[22]
	Fear: Emotions surrounding the unpredictability of seizures and loss of control reflected youths' worry of a seizure occurring. The embarrassment and stigma associated with having a seizure and the uncertainty of when and where, made if uncomfortable for some youths to be around their peers.
	Sadness, depression: Various degrees of sadness or dysphoria were experienced as fluctuating. In other instances, youths revealed more disturbed emotions that included thoughts of suicide.
	Medication: Majority of participants took medication to help reduce seizure occurrence. One revealed how AEDs affected her mood state, increasing her irritability.
	Support: For many, satisfaction with friendships incorporated epilepsy specific support. This took the form of physical (knowing what to do during a seizure) or psychological support.
	Negative feelings towards epilepsy: Participants referred to lacking self-confidence, hesitating and restraining themselves in social interactions.
	Negative responses: Even those who had close friends sometimes suffered from exclusionary behaviour. This took the form of being labelled, teased and bullied by their peers and being excluded from social activities.
	Cognitive: Intermittent difficulties with memory were reflected in many narratives. Seizures and postictal confusion often contributed to difficulties in being able to attend to what was being taught.
	Feeling different: For some disclosing the diagnosis elicited feelings of ‘differentness’. Feelings of differentness were exacerbated by the fact very few participants had any contact with other people who also had epilepsy. "I'm always kind of…separated from people that I know, in a way."
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	Gauffin 2015[23]
Aim	To describe aspects of what it means to be a parent with epilepsy, focussing the parent's perspective and their thoughts on having children.

Study	**Gauffin 2015**[23]
Population	Young adults aged 18-35 years old, with epilepsy, treated in clinic, n=16
Setting, country	Not stated, Sweden
Study design	Qualitative focus group study
Methods and analysis	Focus group interviews, of 3 or 4 people. They were asked open ended questions and interviews lasted between 60 and 90 minutes. They were encouraged to explain their feelings about different situations. First, all the authors read the transcripts several times, in order to get a sense of the whole and a good grasp of the content. In the next step, meaning units were identified in the text. This analysis did not follow common grammatical or linguistic rules, but the text was divided when a shift in the sense of meaning could be found. In the next step, meaning units of what being a parent with epilepsy meant were identified. These meaning units were then concentrated without changing the inherent meaning and the implicit meaning in the text was interpreted. Following this the interpretations were grouped together.
Themes with findings	Guilt: Parents often felt guilty because they could not be the parents they wanted to be. They also felt guilty because of all the difficulties their children had to experience when witnessing a seizure. The participants also experienced subjective memory decline and they believed that this affected the situation of their children. They explained that they often forgot to keep their promises and forgot to give information and they regarded this as being difficult for their children. They felt that they often let their children down and the children were often disappointed.
	Fear: Participants described that they were always aware of the possibility of a seizure and tried to foresee what the consequences would be in each and every situation, so that the child would be safe if a seizure did occur. The participants took great care to prevent the child from being harmed and some of them explained that they were never left alone with their child.
	Feeling of inadequacy: The participants described a feeling of inadequacy when discussing parenthood. Some felt they were less important as parents than their spouses. They wished to take the same responsibility as other parents, but understood it was important to accept help from other people.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Harden 2015**[27]
Aim	To develop a better understanding of how young adults view SUDEP and SUDEP information giving in order to inform the debate on disclosure of SUDEP to patients.
Population	Participants aged 16-30 years old and only those who had already been informed about SUDEP, n=27
Setting, country	Participant's home or a room at the clinic, UK
Study design	Qualitative interview study
Methods and analysis	Semi-structured interviews were conducted in either the participant's home or a room at the clinic, depending on participant preference. Each interview was conducted using a topic guide and lasted 83 mins, were digitally recorded with the participant's permission, transcribed in full and participants allocated a pseudonym. An inductive thematic method of analysis was adopted. Transcripts were read independently by authors and then discussed in order to compare interpretations and to identify key themes across participants' accounts. A coding framework was developed and applied to the transcripts, based on the initial themes identified. From this descriptive stage, the data were interpreted further to establish links between themes, to abstract, conceptualise and develop possible explanations around such links, to unpack the situated nature of the themes, and to consider the similarities and differences in the research participants' accounts.
Themes with findings	Epilepsy related risk: The risk of seizures was central to participants' accounts of their experience of living with epilepsy, both in terms of the risk of a seizure occurring and the risk of injury as the result of a seizure.
	Being in control: Participants reported measures taken to safeguard themselves in the event of a seizure including avoiding potentially hazardous activities such as swimming or ironing, using safety non-spill mugs and hot water dispensers, having showers instead of baths and ensuring high levels of supervision.
	SUDEP worries: SUDEP was rarely expressed as a worry by some of the participants. Several participants contextualised the risk of SUDEP within the wider risk of death that everyone faces.
	SUDEP awareness: There was broad agreement that SUDEP information should be given to those with epilepsy. There was a sense that there would be something amiss if information was withheld by health care practitioners. Many participants reported they avoid searching for SUDEP information themselves online as they either felt like knew everything they needed to already or they deliberately avoided thinking about SUDEP.

Study	**Harden 2015**[27]
	SUDEP information leading to behavioural changes: While some reported anxiety upon hearing about SUDEP for the first time, it was usually presented as being a temporary, rather than long-term concern. Some participants said that having information offered an opportunity for people to avoid or mitigate the risk of SUDEP by encouraging them to change any behaviour that may exacerbate the risk and referred to changes they had made in their lives.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Hightower, 2002**[29]
Aim	To gain a better understanding of children's personal experiences with epilepsy.
Population	Children between the ages of 9-12 years old who had epilepsy, n=8
Setting, country	An inner-city neurology clinic office, USA
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews with 8 questions. They were interviewed in an inner-city neurology clinic office. Each interview lasted approximately 15 to 20 mins. The audiotapes were transcribed, and the content verified by interviewer, and examined to find common patterns and themes.
Themes with findings	Medication: Medication issues figured prominently in most participants interviews. Daily medication awareness, understanding the importance of taking medications, negative feelings about taking medications and adverse effects of medication were identified through interviews.
	Negative feelings towards epilepsy: All participants expressed negative feelings about having seizures. One stated he felt bad about seizures because he hated going to the hospital and he hated that outcome. Another said he did not like people to know he had epilepsy because they started crying after witnessing his seizures.

Study	**Hightower, 2002[29]**
	Activity restrictions: One felt bad about having epilepsy as she could no longer ride her bike as a result of breaking her leg in a bicycle accident caused by a seizure. However most participated in sports without restrictions.
	Support: Loving and supportive relationships with friends were reported in 6 out of 8 interviews. Best friends seem to provide children with a feeling of acceptance and advocacy. In addition to having best friends, every child in the study reported that educating their peers about seizures led to greater acceptance of them and their seizures.
	Signs of seizure onset: The majority of participants described auras, a feeling, occurring before seizure onset. Two stated they felt tired before a seizure. Some felt sick, had a headache, stomach-ache and vomiting before a seizure.
	Coping strategies: Most were aware of self-management behaviours that they perceived to be helpful in preventing seizures such as exercise, good diet, plenty of rest, used cold packs on face, drinking plenty of fluids and taking medication. Another participant mentioned regular bedtime and not getting angry.
	Provoking factors: One mentioned getting angry, dehydration, too much sun and running too much exacerbates his seizures. Another found that if he stayed up too late watching football, he would have a seizure the next day.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Joung 2019[30]**
Aim	To explore the experiences of women with epilepsy throughout their pregnancies and childbirth.
Population	Women with epilepsy who had given birth to a live infant within 36 months of the study; treatment with AEDs for at least 6 months before contraception, during pregnancy, and after childbirth, absence of any psychological disorders, ability to participate in an in-depth personal interview and willingness to share one's experience, n=12

Study	**Joung 2019[30]**
Setting, country	At the participants home or a secluded café, South Korea
Study design	Qualitative interview study
Methods and analysis	Face-to-face in-depth individual interviews began with open-ended questions. Each interview lasted one hour and forty minutes on average. Additional telephone interviews were conducted with two of the participants. The interviews were tape-recorded and transcribed verbatim as soon as possible. All interviews except one were performed at the participants' homes. One interview took place at a secluded café near the participant's home. Data were analysed following Colaizzi’s phenomenological analysis, in which the cyclical process of simultaneous data collection and analysis are conducted and repeated until no new information is obtained. The author read all of the participants' descriptions several times to acquire a general impression of their experiences and make sense out of them. Then, significant phrases and sentences that pertained to the experience of pregnancy and childbirth in WWE were extracted and eliminated repetitions. And the author transformed participants' statements into a more general formulation. In the third step, the author attempted to discover what was hidden in each significant statement and created formulated meanings. Then, formulated meanings were sorted into clusters of specific themes. In the fifth step, the author integrated all of the results into a narrative exhaustive description. Then, the author identified the fundamental structure of the experience in unequivocal statements. In the final step, the author validated the study by asking the participants if the findings captured the essence of their experience.
Themes with findings	Pregnancy: Participants were overwhelmed with anxiety regarding possible abnormalities in the baby due to AEDs use, taken aback by unexpected changes in seizure severity and frequency. Participants mentioned struggling with the potential harm of AEDs and breastfeeding. There was an increased fear of passing down the disease, and management of the burdens of both childcare and seizure control.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Kaddumukasa 2019[31]**
Aim	To explore the perceived barriers to epilepsy care in PLWE and their caregivers in a Ugandan setting.

Study	Kaddumukasa 2019[31]
Population	Inclusion criteria for participation in this study was, age 18 years or older, cognitively intact, and able to provide informed consent, n=27
Setting, country	The in-depth interviews were conducted at the respondents' homes while the FGDs were conducted at the local village chairperson's residence.
Study design	Cross-sectional qualitative mixed methods study, Uganda
Methods and analysis	Using both face-to-face in-depth interviews and FDGs, narrative data on perceived barriers to epilepsy care and coping with stigma were utilized to optimize credibility and validity of this qualitative study. We used open–ended questions so as not to limit the range or breadth of discussion among the participants. We positioned the study participants for adequate eye contact with others in the group and the discussion lasted approximately 1 hr. Six separate Focus Group Discussions (FGDs) were conducted consisting of four groups with PLWE (n = 19) and two with caregivers. The FGDs were conducted to give in-depth insights into the perceived barriers of epilepsy care. The in-depth interviews were conducted at the respondents' homes while the FGDs were conducted at the local village chairperson's residence. The interview was recorded, and then transcribed verbatim. Information collected from focus group sessions included interview and observation. A team of three investigators read the focus group transcripts in their entirety to gain familiarity with the data. Segments of text from the transcript were labelled and assigned codes that described meaning of content. The codes were subsequently collapsed into broad themes or categories. Authors independently coded each transcript to ensure consistency and transparency of the coding; discrepancies were resolved by discussion. Finalization of codes was based on the consensus of the qualitative team. We utilized the grounded theory approach to data analysis, involving open, axial and sequential coding, and the constant comparative method to generate constructs (themes) and elaborate the relationship among them. A separate coding dictionary was then constructed for the interviews and focus groups.
Themes with findings	Cognitive: Psychological distress symptoms were frequently reported by participants these included sleep disturbances, mood changes, stress, and post-traumatic stress disorder (PSTD). These participants also reported poor appetite and low energy as well as living in a constant fear of having a seizure.
	Medication: Some followed the advice of traditional healers, which opposed the use of mainstream medical care. People with epilepsy and caregivers also reported an inability to seek modern medical care and opt for traditional or cultural practices, which impact drug compliance. The study participants also reported reluctance to refill their drugs when feeling better.

Study	**Kaddumukasa 2019**[31]
	Provoking factors: Alcohol use and financial constraints were reported as major impediments to epilepsy care and control. The study participants highlighted alcohol use as a major hindrance to epilepsy care and control,
	Lifestyle restrictions: Limitations in self-care as well as participating in home and community activities were cited as barriers. Participant cited financial constraints to meet the required basic needs and get medications as a major cause of stress in their lives and was reported to be one of the barriers to epilepsy care and management.
	Negative responses: Lack of family support and stigmatizing behaviour by immediate family members were perceived as important barriers to epilepsy care. Several study participants reported insults or name calling from their family members.
	Stigma: Stigmatization from the community, as well as from family, compounded the lack of support and increased isolation felt by participants. The study participants felt strongly that there was a lack of attention to educating the community about epilepsy.
	Caregiver burden: The burden of providing all basic needs in life and study participants cited performing most of the chores for the patients.
	Healthcare system issues: Limited health care provider interaction and distance to health centres were major problems. Health facilities were reported to be located far from patients' homes and majority of people faced challenges in reaching these centres, as either they did not own or had difficulties with out of pocket to meet the transport costs.
Limitations and applicability of evidence	The study had moderate methodological limitations providing valuable research and findings. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants' being adequately considered and unclear recruitment strategy. There were no concerns regarding the applicability of the evidence.

Study	**Kampra 2017**[32]
Aim	To provide useful knowledge for healthcare professionals about this populations needs.

Study	**Kampra 2017**[32]
Population	Children aged 5-17 years old with epilepsy during school age, child controlled with epilepsy and no significant intellectual disabilities, learning disabilities, and/or developmental delay and attending regular school, parent/caregiver who lived with the child and personally cared for them, parent/caregiver who was mentally and physically healthy, parent/caregiver willing and able to participate in the study, n=91
Setting, country	Evangelismos and Children's Hospital Panagiotis and Aglaia Kyriakou, Greece
Study design	Qualitative interview study
Methods and analysis	In depth semi-structured interviews with open ended questions to let parents express their concerns and share their experiences with us. A phenomenological approach was taken. The interviews took place in a quiet area of the hospital and lasted approximately 1 and a half hours. They were analysed in two steps. Following van Manen's process they identified two main themes followed by subthemes.
Themes with findings	Absence of information/support: Absence of experts who could offer them appropriate counselling about the psychosocial issues. Many parents stated they did not know where to seek help to cope with their child's illness, apart from their doctor.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**MacLeod, 2009**[36]
Aim	To construct a vivid description of the everyday experiences of adolescent girls with epilepsy. To describe the everyday living of adolescent girls with epilepsy.
Population	Young women aged 13-18 years old with a diagnosis of epilepsy and taking at least one seizure medication, n=4

Study	MacLeod, 2009[36]
Setting, country	Not stated, USA
Study design	Qualitative interview study
Methods and analysis	Open-ended and semi-structured interview techniques set up an interview at the time and place of their convenience. face-to-face, minimally structured, open-ended interviews. They participated in multiple interviews. The first and second interviews typically lasted about ninety minutes. The third interview with each young woman was short, lasting about thirty minutes. All interviews were audio-taped and transcribed verbatim. Analysis used overtones of phenomenology. Instead of following a prescribed method of data analysis, van Manen (2006) calls for the researcher to be sensitive, creative, and intimately involved with the text of interest.
Themes with findings	Signs of seizure onset: All the participants talked about not always being sure if they were having seizure activity. Sometimes they could tell that they were about to have or had already had a seizure. But at other times it was unclear.
	Practical/access difficulty: Participants reported many problems with learning in their classes and some type of academic difficulty. Majority of the participants mentioned that they had to take time away from school, and sometimes multiple days in a row, in order to see specialists at a tertiary care facility.
	Negative responses to disclosure: All of the participants in this study engaged in disclosure management strategies, and all wished that they had more control over who knew or found out about their diagnosis of epilepsy. All of the participants in the study wanted to be selective about whom they chose to talk to about their diagnosis of epilepsy, but sometimes they did not have a choice. They had different reasons why they didn't want to tell others about their epilepsy, including not wanting other people to worry about them, not wanting others to judge them negatively, or not wanting to be picked on or bullied.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**McEwan, 2004**[39]
Aim	1. To describe the experience of having epilepsy in adolescence. 2. To contribute to our understanding of the perceived impact of epilepsy on QOL in adolescence. 3. To explore any changes in QOL issues as the adolescent progresses towards adulthood. 4. To present a conceptual framework for understanding the impact of epilepsy in adolescence
Population	Participants were included if they were (a) aged between 12 years 0 months and 18 years 0 months with (b) a diagnosis of epilepsy of (c) at least 6 months duration, (d) had experienced at least one seizure in the past year and (e) were able to participate verbally in a group, n=22.
Setting, country	The Fraser of Allander Neurosciences Unit, Glasgow.
Study design	Qualitative focus group study
Methods and analysis	Six focus groups were conducted with between two and five participants in each. Participants were stratified into focus groups by age (12–13, 14–15 and 16+ years) to enable exploration of any changes in factors related to QOL at different points in adolescence. All focus groups were held on evenings or at weekends at the Fraser of Allander Neurosciences Unit in Glasgow. Groups lasted 2 hours with a 1/2-hour break in which participants were given refreshments. Each focus group comprised three main sections. Groups were audio-taped to enable verbatim transcription. Audio-taped data from each of the six focus groups were transcribed onto a word processing package. Thematic coding was used to code data from groups and written sheets. Data collection continued until theoretical saturation was obtained. Saturation was reached in the fourth group, however, given that one of the study's aims was to investigate age-related differences, it was felt necessary to conduct at least two groups per age band. Following initial analysis, the relationships between codes were studied and used to generate central themes. Later analysis investigated the similarities and differences between groups. QSR NUD*IST 4.0 for Microsoft Windows, a computer package designed specifically for the analysis of qualitative data, was used to facilitate analysis. Data from transcription of focus groups were triangulated with written information provided by participants and identified themes and representative quotes were fed back to participants by post for comment on their relevance.

Study	McEwan, 2004[39]
Themes with findings	Negative responses: Nineteen of the participants reported experiences of bullying and social isolation: "I feel left out because I can't go sometimes with my friends and things like that".
	Activity restrictions: Many participants described restrictions imposed by others. However, some also placed restrictions on themselves in order to keep safe or avoid possible embarrassment if they had a seizure. Parents were seen as over-protective by many participants, although this was not reported as a significant problem.
	The future: This theme encompassed leaving home, choosing careers and having children. From older and younger adolescents alike, concern was expressed regarding having children and some were concerned about their prognosis.
	Medication: The most important factors with respect to medication surrounded issues of compliance and others checking on whether they had taken their medication. Remembering to take medication was a particular issue, across all age groups. Some also commented that medication acted as a physical reminder of their condition, made them feel different, increased the risk of disclosure and placed restrictions on activities - particularly experimenting with alcohol.
	Lack of knowledge: There was a general sense amongst the groups that there was a lack of knowledge about epilepsy in society and that more accurate information should be provided to reduce the fear of epilepsy and promote accurate and realistic management of seizures.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**McNelis 2007[40]**
Aim	To explore the concerns about the seizure condition and needs for information and support of children with epilepsy and their parents in greater depth than had previously been done.
Population	Participants were children with seizures aged 7-15 years old, n=26
Setting, country	Conducted at locations where participants' existing support groups regularly met in the community, USA
Study design	Qualitative focus group study
Methods and analysis	Focus group design was used to explore concerns and needs of children with epilepsy and their parents. Interviews were conducted at locations where participants' existing support groups regularly met in the community. The primary investigator directed the inquiry and interaction among the group members in a semi structured manner, avoiding leading questions and all members were encouraged to participate through shared opinions and stories. After audiotapes were transcribed verbatim, the transcriptions were treated as a database, and the relevant field notes taken by the second moderator were added to this database. Data were analysed by 2 investigators, with each immersing herself in the data, followed by independent identification of themes and the supporting statements. The investigators then met to discuss the themes and statements and 100% agreement was reached.
Themes with findings	Need for information: Children wanted to be as informed as their parents. Most stated that physicians talked over them by using words outside their limited vocabulary or by ignoring them altogether and talking only to their parents. Parents described a need for information regarding all aspects of the disorder.
	Feeling different: The children expressed concerns about seizures making them different from their friends and limiting their activities and abilities.
	Parental perspective of children's concerns and needs: Parent participants talked about misinformation and misconceptions their children had about seizures and believed it was caused by lack of appropriate information.
	Healthcare system issues: Most parents stated that that paediatricians did not give sufficient information concerning medications, consultants and specialists, questions to ask and how to find answers to the most pressing concerns. Parents reported they often felt unable to talk to healthcare providers. Parents discussed

Study	**McNelis 2007**[40]
	the difficulties with not being fully informed about the diagnosis. It was a struggle to coordinate care when so many different healthcare providers were involved.
	Support: All parents talked about the need to be in touch with people who could offer advice or help when dealing with their children. Some participants were part of a regular support group that met monthly and felt very lucky to have this resource.
	Fear: The fears and concerns of parents revolved around both the physical and emotional health of their children. Worrying about how the seizures would affect their child’s development and the uncertainty of the future was identified as a concern.
Limitations and applicability of evidence	The study had moderate methodological limitations providing valuable research and findings. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants’ being adequately considered. There were no concerns regarding the applicability of the evidence.

Study	**Mengoni 2016**[41]
Aim	To explore the impact and management of epilepsy in people with intellectual disability (ID).
Population	Diagnoses of ID and epilepsy, at least one seizure within the last 12 months, meaningful verbal or nonverbal communication enabling the participant to engage with the picture booklet intervention and a carer with sufficient English proficiency to complete the study questionnaires, n=14
Setting, country	The participants home, UK
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews conducted in the participant's home ranging from 8-56 minutes. All interviews were conducted by a female postdoctoral psychology research fellow with experience and training in qualitative research and working with people with intellectual disability. The semi-structured interviews were transcribed and analysed using thematic analysis on the computer software program, NVivo. Two members of the research team coded the interviews, with 30% of the interviews being coded by both researchers. Codes were compared and discussed, and themes were derived through

Study	Mengoni 2016[41]
	discussion. The sample size was determined prior to analysis. Data saturation was not a factor in determining how many interviews were conducted. Because of time constraints, transcripts were not returned to participants for comments, and the analysis was not discussed with participants.
Themes with findings	Communication issues: Participants with ID had mixed levels of communication. Carers reported varying levels of understanding and expressive skills.
	Recovery after seizure: The effect of seizures varied widely, with some people recovering quickly after a seizure, whereas for others, this could take several hours or even several days.
	Lifestyle restrictions: Epilepsy was perceived to significantly limit participants' actions, work prospects, and activities in and outside their home. For participants who experienced multiple seizures a day, the occurrence and aftermath of the seizures could affect the entire day and prevent the participant from engaging in any activities.
	Need for information: Participants and carers reported mixed experiences regarding information and support needs but, overall, they described the absence of epilepsy-related information and tailored support. Despite this, in nearly half of all the interviews, participants and carers indicated that they did not feel the need for information anymore and they had developed a fairly good understanding of their condition.
	Medication: Several participants or their carers reported that epilepsy was fairly stable and well controlled with AEDs. These participants still sometimes experienced seizures, but carers and participants felt that they were as well controlled as they could expect. Changing medications was considered stressful, occasionally causing worse seizures or side effects. The following side effects were described and considered difficult to manage tiredness and impairments to mood, cognitive, verbal, and physical skills.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	Moffat, 2009[43]
Aim	To use qualitative methods to investigate children's perceptions of the impact that epilepsy has on their quality of life by developing a comprehensive list of themes through qualitative analysis.

Study	**Moffat, 2009**[43]
Population	Participants between the ages of 6-12 years old. Included if they had a diagnosis of epilepsy of at least 6 months duration, were able to verbally participate in a group and were in mainstream schooling, n=22
Setting, country	The playroom of an outpatient neurosciences unit at a regional children's hospital, UK
Study design	Qualitative focus group and interview study
Methods and analysis	Focus groups were utilised to facilitate the generation of key concerns. The number of focus group participants required to answer the research questions was determined during the process. Five focus groups and two semi structured interviews were conducted. Each group lasted for 45 mins plus a 15 min break. Sessions were held in a playroom of an outpatient neurosciences unit at a regional children's hospital after school during term time. Data analysed using grounded theory techniques. Recorded data were transcribed onto a word processing package. Open coding was used to closely examine the transcripts and to generate themes. Themes were then developed into meaningful categories. theoretical saturation was achieved after the fourth group.
Themes with findings	Activity restrictions: Children expressed concern about the social impact of epilepsy and its anticipated impact. Sleepovers and going to friends' houses appeared to be major areas of concern for many children. Missing out on social outings and organised trips was a concern. In terms of future worries, not being able to drive was an issue for some. Safety issues as well as the impact of going to parties and discos and going into town with friends.
	Concealment: Some discussed their unwillingness to disclose their epilepsy to their peers. All participants had told their best friend. They discussed disliking people staring at the during seizures and how other people's reactions made them feel.
	School restrictions: Teacher reactions seemed to vary. Some did not let children join in school activities and some were helpful and supportive. Many found missing lessons owing to seizures problematic and some reported being slower at schoolwork since diagnosis.

Study	**Moffat, 2009**[43]
	Medication: Medication seemed to be a major area of concern for all children. Most disliked taking AEDs whereas some were indifferent and some still adjusting. Taste was an issue for majority. Compliance was discussed by the children, some concerned they would lose their tablets, their parents would forget and some worried about having more seizures if not compliant.
	Future: Some were concerned about their prognosis. Transitional stages were discussed. Some were concerned about having seizures if they lived alone, banned from driving and career choice impact.
	Healthcare system issues: The emotional impact of medical experiences were discussed, with many describing the trauma of admissions and being taken to hospital by ambulance.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Mu 2008**[44]
Aim	To examine the essence of the lived experience of the health-illness transition process of parents during the first one and a half years following discovery of their child's epilepsy.
Population	Inclusion criteria: A child with epilepsy between the ages of 3-7 years old living with his/her parents in the Greater Taipei area, who had been diagnosed and medically treated within the past 6 months, who had no moderate-to-serious learning disability and where the parents were primary caregivers, n=20
Setting, country	Not stated. Taiwan
Study design	Qualitative focus group and interview study
Methods and analysis	Semi structured interviews with open questioning was used to encourage parents to reflect on their experiences and heighten their awareness of the first one and a half years following discovery of their epilepsy. The investigator conducted all the interviews. on average each interview took approximately one and a half hours.

Study	**Mu 2008[44]**
	Based on phenomenological principles. The interview contents from all interviews were recorded and transcribed verbatim for accuracy in order to preserve the original content of the parent's experiences. The results were subsequently analysed manually using Colaizzi's method, which involves integrating both the de-structured and restructured analysis principles of phenomenology.
Themes with findings	Stigma: When parents were notified by their doctors that their child had epilepsy, they suffered from the negative social connotation of this disease. They perceived epilepsy as an unacceptable illness, feeling shock, anger, despair and/or guilt. Parents perceive seizures as having a negative meaning and stigma in a traditional society. Parents do not want many people to know that their child has epilepsy and are concerned that in the future they, their child and their family will be stigmatised.
	Fear: While the child is having a seizure, parents do not know what is happening. They feel empathy for their child's pain, yet do not know what they can do to help.
	Feeling of inadequacy: Parents mentioned reframing of parental roles. This included: enhancing parental abilities, monitoring and mastering the process of treatment and establishing a mutually respectful and accepting family environment.
	Healthcare system issues: Parents reported monitoring whether doctors are providing credible care.
	Home environment: Parents endeavour to establish appropriate family interaction patterns for their child's development, specifically in terms of routine and rules, as well as adapting their lifestyles to fit their child's treatment progress, special upbringing demands and safety.
	Assisting their child's re-integration: Parents hope their child can maintain normal social interactions and a healthy lifestyle. They discuss their child's needs, special concerns, peer relationships and activity limitations with their child's illness and comprehend the meaning of his/her behaviour and their child's place in the community. One participant mentioned "I told the other children that he behaves like that because he doesn't feel well. You are not like that, but please understand his feelings. I encourage the other children to play with him."
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Ninnoni 2019**[47]
Aim	To give a voice to people with learning disabilities and epilepsy and to express their views regarding communication with doctors and nurses.
Population	Inclusion criteria were adults with mild learning disabilities with confirmed diagnosis of epilepsy; receiving learning disabilities services as identified by the consultants and aged 16–50 years. Only people who gave written informed consent were sampled, n=28
Setting, country	The surgery, Day centre or at their home, UK
Study design	Qualitative interview study
Methods and analysis	Data were collected using semi-structured interviews. Each interview lasted about 30–40 min. Interviews were taped with the participant consent. Participants were interviewed either at the Surgery, Day centre or at home as deemed convenient by the participant. Thematic data analysis approach was adopted. Data were transcribed verbatim. Transcripts of about 50 pages were printed. The transcripts were read through several times to obtain a sense of the whole. Participants experiences of communication and information provision with healthcare professionals and carers regarding epilepsy and related issues constituted the unit of analysis. Each interview was read, and margins and notes made to form initial codes. The interview was divided into meaning units that were condensed such as communication exchanges, information provision, involvement, listening and understanding. Significant statements and commonalties were organised into themes representing clearly define response category. Emergent themes were documented and discussed to ensure inter-rater reliability. In the event of disagreements regarding themes the transcripts were revisited and analysed until consensus was reached. Identified themes were matched with the initial category.
Themes with findings	Need for information: Service users and carers expressed the desire to communicate effectively but appeared to be constrained by their limited knowledge regarding epilepsy, seizures and medication. They both expressed the need to know more about epilepsy and would value some form of training to improve their knowledge on epilepsy and seizures.
	Communication issues: Overall, service users and carers’ communication purpose and needs with doctors and nurses were based on a wide range of things. However, involvement in decision making was central to their communication needs, they want to be more involved in communication. Other concerns related to conflicting information from doctors and nurses and the need for consistency in the provision of information.

Study	**Ninnoni 2019[47]**
	Honesty and openness in provision of information: Concerns that were repeatedly expressed by some service users were related to the issue of withholding or concealing information. Service users wanted more discussions regarding changes to medications to be openly and honestly discussed with them. Medication: Service users expressed concerns regarding medication errors. This led to patients questioning whether they were getting the prescribed or wrong medication. Service users also reported that they are not being trusted by doctors especially when reporting their experiences with medications and side effects.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**O'Toole 2016[49]**
Aim	To explore the challenges that parents of children with epilepsy face experience when engaging in dialogue with their child about epilepsy and epilepsy related issues.
Population	To be included participants had to be the parent or primary caregiver of a child (aged 6-16 years) with a diagnosis of epilepsy for 6 months or more and with a prescription for AED at the time of interview, n=34
Setting, country	At a location convenient to participants, Ireland
Study design	Qualitative interview study
Methods and analysis	Interviews were conducted with parents at a time and location convenient to them. They had the choice to be interviewed alone or with their partner. The interviews were semi structured around a topic guide to capture parents' experiences of family communication about epilepsy. Interviews followed the guide with prompts given by the interviewer to allow parents to discuss all aspects of epilepsy related communication until no more aspects were forthcoming, and the interview was terminated. The interviews lasted between 13 and 76 minutes and were digitally recorded and transcribed verbatim. Transcripts were imported into the NVivo qualitative data analysis software to facilitate data management. Data were thematically analysed according to Braun and Clarkes 6 step thematic analysis framework. It is an

Study	O'Toole 2016[49]
	inductive approach whereby themes are dependent on the emergent data itself rather than a priori theoretically determined identification of what potential themes should constitute.
Themes with findings	Coping strategies: Many parents recounted about how they reinforced to their child that his/her epilepsy did not restrict him/her in any way or make them different to other children and that they can achieve just as much as children without epilepsy. Parents faced a challenge when communicating about epilepsy as they often did not wish to treat their child differently by engaging in dialog with them about their condition.
	Information concealment: Parents revealed instances of limiting the amount of information relating to epilepsy available to their child. Many parents felt that some information, particularly relating to medication side effects or SUDEP was inappropriate for their child's age (particularly 6–10-year age group).
	Fear of misinforming the child: Fear of delivering misinformation in response to their child's epilepsy related questions was often a daily struggle. To answer their questions parents had to be readily knowledge about their child's epilepsy, however, often parents relayed that they themselves felt underinformed regarding their child's specific diagnosis.
	Complexity of epilepsy - difficult to explain to others/challenging to understand. Parents found a number of epilepsy related topics difficult to converse about with their child. The three most frequently referred to were: the seizure free period, growing out of epilepsy, and difficulty relating to the disclosure of the child's epilepsy to others.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	Pashley, 2009[50]
Aim	To explore why epilepsy-specific preconception advice may be suboptimal and to understand why some women with epilepsy are referred to epilepsy clinics already pregnant. Additionally, to compare the factors in women who planned their pregnancies with those who did not.
Population	All women with epilepsy prescribed AEDs who had conceived between 2001 and 2005 were invited for interview. Women in this study had been referred to the clinic either before, or during, the most recent

Study	**Pashley, 2009**[50]
	pregnancy. Women were excluded from the study if they were not prescribed AEDs at conception or if they had since moved to another part of the country, n=15
Setting, country	Participants' homes, UK.
Study design	Qualitative interview study
Methods and analysis	In-depth interviews were carried out by an interviewer who had not been involved in care of the women at the time of the pregnancy. Open-ended questions, derived from clinical knowledge and a literature review, were drafted into an interview guide. A pilot interview was conducted to check feasibility and these data were not used. Interviews were not constrained by the schedule. Interviews, averaging 60 minutes, were conducted in patients' homes, audio taped, and transcribed verbatim. Primary care and hospital medical records were reviewed for each woman after interview. The transcribed data were coded and analysed independently by the authors, using thematic content analysis. A second researcher independently analysed the dataset.
Themes with findings	Pregnancy: Women with planned pregnancies were more likely to seek information. Women with planned pregnancies were more assertive and questioning about their condition and were more likely to be at the centre of any decision making, whereas non-planners were vulnerable to poor care. Many of the women felt their GP had not provided adequate advice before pregnancy. GPs initiated a preconception prescription for folic acid in only two women. The women identified several factors that they felt would be useful; Information should be given at diagnosis; information should be repeated, and information leaflets were helpful but no substitute for discussion.
	Pre-conceptual planning: The majority of non-planners had misunderstandings about fertility, and some thought they might be infertile as a result of taking valproate or having irregular menses. An underlying belief that they could not conceive may have affected contraceptive practice. All planners expressed fears about pregnancy in relation to takin AEDs. Non-planners were less likely to worry about the risks associated with AEDs despite having knowledge.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Prinjha 2005**[51]
Aim	To explore why, at the turn of the 21st century, many people with epilepsy still want more information.
Population	Interviewed people with epilepsy and carers of someone with epilepsy, n=38
Setting, country	At participants homes, UK
Study design	Qualitative interview study
Methods and analysis	Interviewing continued until the sample included men and women with experience of different treatments and until no new themes emerged from the data. All but four participants were interviewed by one of the authors, an anthropologist of Indian descent, in their homes in 2002. After signing a consent form, they were asked to tell their story from when they first suspected a problem. Questions about specific issues were asked at the end of the interview. All interviews were audio-taped and lasted one to three hours. Interviews were then transcribed and sent to the respondents for review and verification. Two members of the research team (an anthropologist and a sociologist) read and re-read the data and constructed a coding frame. Thematic categories, such as ‘finding information’, were subdivided into lower-level categories such as ‘finding information/ unanswered questions’. Subsequent data analysis involved examining these themes across the whole data set as well as in the context of each individual’s interview. NUD.IST (a qualitative data-indexing package) facilitated the coding and analysis of data. Authors regularly discussed the coding and interpretation of results.
Themes with findings	Medication: Many wanted to know why their drugs were chopped and changed. Some people were worried about the long-term side effects of drugs, and whether or not their medication was affecting memory and other aspects of daily life. One woman asserted that if she had been given more information about her medication, she would have changed her lifestyle to prevent osteoporosis:
	Knowledge sources about epilepsy: Consultants played an important role in giving information, sometimes via a nurse. People also got information from other sources; through epilepsy organisations, first aid training, via leaflets, books, magazines, newspapers, videos and the Internet.
	Contraception: Women with epilepsy have particular needs related to childbearing. Some we interviewed were concerned about the effect of drugs on contraception, pregnancy and the unborn child. For example, a woman had not been told that anti-epileptic drugs could reduce the effectiveness of the contraceptive pill.

Study	**Prinjha 2005[51]**
	SUDEP awareness: Some participants reported wanting to know more about SUDEP and more concrete answers which was very worrying for them.
	Self and others' perceptions of epilepsy: While some people thought that their seizures had been caused by accidents, head injury, meningitis, measles, or stress, many said that their doctors had not confirmed this. Historically, the devil, other supernatural spirits, and mental illness have all been credited with causing seizures and some respondents believe that this view still persists.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Ramachandrannair, 2013[53]**
Aim	To understand the range of parental views on whether and how to approach the issue of SUDEP with families, to clarify the optimal timing and formulation of the information, and to learn from parents the optimal counselling strategies.
Population	Parents who lost children to SUDEP, of children with moderate to severe epilepsy, of children with mild epilepsy and of children with new-onset epilepsy, n=63
Setting, country	Not stated, Canada
Study design	Qualitative focus group and interview study
Methods and analysis	Six focus group interviews (separate groups for mothers and fathers) were conducted by an experienced interviewer using a semi structured interview guide each lasting 2 hours. In depth one on one interviews were conducted with parents who had lost children to SUDEP because of the sensitive nature of the topic. Textual analysis using qualitative software NVivo 8 occurred immediately following the transcription. The principles of directed content analysis were used to guide and categorise the focus groups and interview data. Key concepts from the interview guide were used as the first level of coding categories. However, through a process of line-by-line coding, new codes were also established to reflect emerging concepts.

Study	**Ramachandrannair, 2013[53]**
Themes with findings	SUDEP worries: Parents discussed their experiences of having their child diagnosed with epilepsy. Mothers disclosed a number of mental health issues after their child’s diagnosis: depression, anxiety, guilt, worry, whilst fathers felt worry, anger and concern. Both parents were fearful their child would die (particularly in bed at night) and they were highly vigilant of their child - wanting to monitor all their activities. Many disclosed that their child slept in their bed as part of a coping strategy.
	Parental understanding of SUDEP: Among many parents there was a lack of understanding about the exact meaning of SUDEP and risk of a child dying. While many parents understood SUDEP was a rare condition they still overestimated the risk of SUDEP.
	SUDEP information delivery: There was full agreement that routine counselling about SUDEP should be provided by paediatric neurologists, either during the appointment when the diagnosis of epilepsy is shared with parents or in a follow-up appointment several weeks later. They agreed there should be opportunities for short-term follow-up and discussions with clinical nurses or social workers to "translate what the doctors say". Parents explained it is important to have a comprehensive understanding of all of the risks associated with epilepsy as this enables them to "prepare for the worst". Parents identified that with this information they would possibly be motivated to place monitors or alarms in their child’s room. All parents agreed that not knowing about the possibility of SUDEP would be worse and they would be angry if they were not informed.
	Parental perceptions about who should receive routine SUDEP counselling: Parents identified that both parents (as appropriate) should be present at the SUDEP counselling session. There was a consensus that it should be the parents’ decision as to whether or not the child should be present at the meeting or when to inform the child about the risks of SUDEP. In general, it was agreed they should share this information once the child was in early adolescence (e.g., >12 years) and possessed the maturity to process the information and was not developmentally impaired. Some stressed the importance that it should be shared before they begin to engage in potentially risky behaviours (underage alcohol consumption). There was a lack of agreement over who should explain SUDEP to a child. Some felt it should be the responsibility of the parents while others felt that the information should come from the paediatric neurologist. There was a consensus that older siblings should also be informed about the risk of SUDEP.
	Parental preferences for routine SUDEP counselling: Parents expressed a need to be informed of the risk of SUDEP however some parents felt it is important for neurologists to stress that SUDEP is rare and to balance the message of risk with one of hope. Parents who had lost a child to SUDEP were best able to articulate the messages that should be communicated to parents including: (i) the actual risk of SUDEP, (ii) risk and

Study	**Ramachandrannair, 2013**[53]
	protective factors associated with SUDEP, (iii) any known prevention strategies, and (iv) an acknowledgement that SUDEP may be beyond parent's or physician's ability to prevent or stop.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**RamachandranNair, 2016**[52]
Aim	To understand the range of adult patient views on whether and how to discuss the issue of SUDEP with patients with epilepsy and to clarify the optimal timing and formulation of this information.
Population	Participants aged 18-65 years, n=23
Setting, country	Not stated, Canada
Study design	Qualitative interview study
Methods and analysis	Data were collected using in-depth, semi-structured, one-on-one telephone interviews and a single focus group interview. An experienced qualitative interviewer used a semi-structured guide to conduct both types of interviews. Transcribed data were stored and managed using qualitative software NVivo 8 immediately following the transcription. Directed content analysis was followed to code and categorise the interview data. First each transcript was read in its entirety. Then, using key concepts from the interview guide, the data analyst developed a preliminary codebook to guide the initial process of open coding. However, through a process of line-by-line coding, new codes were also established to reflect emerging concepts. Individual codes were then subsequently collapsed into broader analytic categories.
Themes with findings	SUDEP information leading to behavioural changes: Only half of the participants had heard about SUDEP before they were invited to the study. Nearly half shared that had been shocked or scared on finding out this information. Some felt frightened initially but then came to accept the situation and carried on with their lives and others perceived the information as not relevant to their seizures. After hearing about SUDEP most participants went looking for more information using online resources.

Study	**RamachandranNair, 2016[52]**
	SUDEP awareness: There was consensus among all participants that’s all individuals diagnosed with epilepsy and their caregivers should be informed about SUDEP. The majority expressed that this topic should be incorporated into the general information patients receive about diagnosis, management and prognosis. Participants agreed that all adult patients should be told and most felt that young children should not be told until they reached their teens, although this should be on a case-by-case basis.
	Lack of understanding SUDEP: Participants mentioned a number of benefits to knowing about SUDEP including taking better care of themselves, reducing risk factors and being prepared for the possibility that it could happen. Participants highlighted three disadvantages of being told about SUDEP including increasing fear or anxiety for the patient, others knowing about SUDEP may cause them to become overprotective and hypervigilant and finally a few felt that knowing about SUDEP may results in obsessive thoughts or dwelling on it too much.
	Timing and setting of SUDEP discussion: Many believed that the best time to be told about SUDEP was at diagnosis. They felt it should be part of basic information about epilepsy and if shared in a matter-of-fact manner it would not be overwhelming. Some felt it was too soon to be told at diagnosis and they would prefer some time to process the information of the diagnosis and be told after a certain number of visits with the neurologist or after 6 months or a year. Nearly half felt that this information should be shared in the neurologist’s office.
	SUDEP information delivery: The majority felt that the discussion should take place face-to-face in a verbal discussion or conversation followed by some written information to take home. Some suggested they would rather hear the information from their family doctor with whom they had a good relationship. Several participants suggested that it might be helpful to have a social worker involved along with the physician sharing the SUDEP information and have access to one after for any further questions or emotional support.
	SUDEP information needed: Patients wanted a general overview of what SUDEP was, their odds of being victims, risk factors, causes and prevention strategies.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Roberts, 2011**[56]
Aim	To identify the perceptions and experiences of the primary caregivers of young children with epilepsy regarding their interaction with the schools' which impact both the child's and family's quality of life and to clarify how families think schools can best support, accommodate and prepare for these children and families
Population	Caregivers of children with epilepsy (aged 5-12 years old), n=7
Setting, country	Not stated, Canada
Study design	Qualitative interview study
Methods and analysis	In depth semi-structured interviews were conducted with seven caregivers of children with epilepsy. Each interview lasted between 45 and 120 minutes. Interviews with each family were recorded and reviewed by a graduate research assistant. Each interview was transcribed verbatim and extensively reviewed. Statements that caregivers gave that represented how the family experienced school were extracted. These statements were used to identify patterns, or themes that created a deep understanding of the family's school experiences. Themes were identified if two or more participants discussed an issue or topic. themes were categorised and labelled based on their central meaning. photocopies of the transcribed interviews and initial analysis were by the caregivers during a second interview. Families had an opportunity to correct misunderstandings and include additional comments.
Themes with findings	Problems with diagnosis: Identification of the child's epilepsy did not come easily for many, and many described themselves as noticing the symptoms, but not understanding what they meant. Many families described the false interpretations that were made about their child's symptoms. families described the importance of the school in identifying seizures early and communication with home as well as monitoring symptoms to report to the doctor.
	Fear: Caregivers discussed their continual worrying over the well-being of their child and the stress of explaining their child's condition to the school community. Beginning school after diagnosis was a source of worry as parents experienced loss of control of their child's safety which created anxiety and uncertainty. Many of the parents viewed their children's experience at school as stressful and commented on the anxiety their children felt.
	Practical/access difficulty: Many parents discussed the specific learning difficulties that their child experienced in the classroom. Most complaints concerned cognitive impairments centred on attention and memory. Frequent

Study	**Roberts, 2011**[56]
	absences from school were a recurring theme. For many children being sick puts them at greater risk of seizures, therefore parents choose to keep their child at home when they were feeling unwell. Parents suggested that having a teacher familiar with inclusive practices and experience working with children with special needs is essential to their child's success. Families also mentioned the importance of the flexibility of the school if their child missed school, or how long it took to complete assignments and being allowed to home school their child when necessary.
	School restrictions: Some parents mentioned social isolation of their child after having a seizure at school in front of their peers. In addition, some parents reported incidences of bullying both emotional and physical. An important aspect of school was their child's feeling of normalcy and despite various adjustments to their everyday life they wanted their children to understand these differences did not make them abnormal. One obstacle to reaching a sense of normalcy was the need to place restrictions and limitations on activities the children could participate in, and many parents spoke of the decreased independence that their child experienced after being diagnosed.
	Self and others' perceptions of epilepsy: For some families disclosure about diagnosis and medication elicited a fear that their child would be treated differently. Families often commented on the anxiety that some teachers felt when they learned about their child's epilepsy diagnosis. This anxiety stemmed from feeling responsible for maintaining the student safety in the event of a seizure. Misunderstandings of what it means to have epilepsy created frustration among parents who believed that educating teachers about epilepsy and what to do in the event of a seizure would alleviate this problem. Every family spoke of the importance of having all staff members aware of their child's epilepsy and not just the classroom teacher. Parents suggested one way to inform the entire school was to participate in Purple Day for epilepsy awareness. For many families, community support was also an important part of the families coping, and they mentioned community organisations such as Victoria Epilepsy which helped them become more aware of how they could support their child and spread awareness of epilepsy.
Limitations and applicability of evidence	The study had moderate methodological limitations providing valuable research and findings. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations, the relationship between the researcher and participants' being adequately considered and unclear recruitment strategy. There were no concerns regarding the applicability of the evidence.

Study	**Ronen, 1999**[57]
Aim	To identify the burdens and concerns of children with epilepsy. Discussions were taped and textual analysis followed to extract, understand, explain, and categorize the health-related quality of life (HRQL) components.
Population	Entry criteria for the study were: (1) children with active epilepsy, defined as recurrent, unprovoked seizures (more than two seizures) within the preceding 24 months; and (2) children aged between 6 years and 12 years 11 months, n=71
Setting, country	McMaster University, Canada
Study design	Qualitative focus group study
Methods and analysis	Separate focus groups were established for children with epilepsy and for their parents. The focus groups for the parents were conducted according to Krueger (1994) and the process for the children was modified with pre-set activities to prompt the discussions, which were facilitated by child-life specialists. Activities included drawing maps of important places in the child’s daily life to elicit discussions about their external world, and forming playdough (a type of modelling clay) to trigger dialogues about their internal world. Each group discussion lasted 90 minutes. Four sessions of group discussions were held on different weekends, at McMaster University. Textual analysis of the taped and transcribed raw data using the Ethnograph V4.0 software (Seidel et al. 1995), began immediately after the first group discussions. This consisted of identifying the components of HRQL followed by a logic organisation and categorisation in the form of a code book related to the research question. The process of coding, categorizing, and reassembling the raw data was continuously revised as the field work continued. A higher level of textual analysis followed, discovering relationships and trends, and clustering the codes into smaller numbers of dimensions. The findings were validated 11 months later in focus groups with a subset of the original participants, and subsequently were replicated with new participants. The process was completed when all the data were classified, and the categories were saturated so that no new information emerged from successive focus groups, and a sufficient number of regularities emerged. Throughout this phase of the work, different independent measures (triangulation) of data source, methods, and researchers were used to prevent biases.
Themes with findings	Stigma: Participants discussed the discovery of having epilepsy, feeling trapped by the condition, keeping it as a secret, and the various emotional aspects associated with having epilepsy. One participant mentioned ‘She doesn’t know she has epilepsy, by that word. We call it twitching because I was afraid to say epilepsy because

Study	Ronen, 1999[57]
	there is a stigma. I feel and I think they would say “well you can’t come to a birthday party because it’s swimming”, that kind of thing.’
	Social restrictions: Some participants worried they would receive fewer invitations to social occasions. ‘I feel and I think they would say “well you can’t come to a birthday party because it’s swimming”, that kind of thing.’ Timing of seizures, frequency, severity, location, aftereffects, seizure control and the handling of seizure situation by others were also discussed; ‘I had a seizure on the playground, and they all ran away, and I just sat down, and I was sitting here until school ended, and I didn’t know what to do.’
	Medication: participants discussed medication issues such as Interrupting activities, management issues, feeling different due to medication. ‘The medicine helps you. Sometimes the medicine isn’t nice, (because of) the side effects that come with it. I get tired.’
	Cognitive: Intermittent difficulties with memory or other cognitive experiences were reflected in many narratives. ‘She did at one point think that she was actually stupid. That was the word, the terminology she used, I’m stupid. Because she used to be so good at math, she used to be so good at everything.’
	Healthcare system issues: One parent mentioned issues with all the testing to obtain diagnosis. ‘He was more upset with all the testing and having to go through the blood work and he had to have a double CT scan. They had to put the dye in, and he was more upset about the testing than he was actually (about) having epilepsy.’
	Negative feelings towards epilepsy: Participants reported self-confidence issues along with the physical impact of epilepsy. ‘Lack of confidence I think is the biggest part of having epilepsy for them because they don’t feel positive about themselves a lot of times.’ Physical impact: ‘Sometimes I don’t feel good and after school I feel sleepy.’
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	Sample 2006[60]
Aim	To explore individuals’ experiences with accessing epilepsy-related services and health care, and what life with epilepsy is like.

Study	Sample 2006[60]
Population	Participants with epilepsy or family members, n=41
Setting, country	Not stated, USA
Study design	Qualitative focus group study
Methods and analysis	Six focus groups took place in 4 locations in South Carolina with a total of 41 participants either people with epilepsy or their family members. Focus group questions were developed with assistance from qualitative researchers, field experts, people with epilepsy and caregivers. Questions were pilot tested in an epilepsy support group and revisions were made based on the feedback. Discussion notes were transcribed and sent to the group facilitator to review. The group facilitator verified the transcripts by comparing them with the flipchart notes and audiotapes. To begin the analysis the primary analyst took the 4 initial steps. (1) Reading through the first transcript without taking notes, (2) going back through and coding the transcript, (3) creating a list of all codes from the initial transcript, (4) arranging the codes into content categories and then defining the categories. the remaining staff served as additional analysts as they reviewed the findings. This step of the review contributed to the triangulation if analysts, wherein no individual was responsible for the data analysis, generating results and offering recommendations. The steps were repeated with the other transcripts. The final step involved using the content categories to answer the studies main questions.
Themes with findings	Problems with diagnosis: A number of participants reported that it took them a long time to be diagnosed with epilepsy. "the first one misdiagnosed me for 3 years. The second one, who happened to be in the same practice… I went to him, and he found out that I was having a seizure disorder." Another participant explained; " I was misdiagnosed for 7 years, and I faced a lot of what you others went through with depression issues. The doctor's questions whether or not I was making this up in my head. My family was even taught to ignore my seizures."
	Absence of information/support: Once the participants were diagnosed with epilepsy, the next major step was finding help. the quickest way to find help was to find the epilepsy foundation of America online and at a more local level to be involved with state support groups. Participants found that the state epilepsy foundations website had not been updated for a while. Other sources of help were personal rather than professional and included their spouse or the church.
	Successes and barriers in obtaining care: Once participants knew what help was available the next step was trying to obtain services, medications of treatments. Many described the ongoing problems they faced when

Study	Sample 2006[60]
	trying to obtain the medication and services they needed: the high cost of medications, lack of money or insurance coverage to pay for them, dire consequences of not taking the medications. Other participants talked about problems with physical and transportation requirements of visits for professional care, while others mentioned problems accessing support and benefits of government programmes due to confusing eligibility requirements.
	Lifestyle restrictions: Participants discussed their loss of anticipated abilities and life dreams. The first time this manifested was when they learned they would not be allowed to drive unless they remained seizure free for a certain period. This minimalised the amount of socialising, community access, types of employment and romantic relationships.
	Medication: Although participants wanted to live as normally as possible, they could not escape the fact they lived on very strong medications and/or with medical technology inside their bodies.
	Lack of understanding/knowledge: Participants were asked to think of recommendations for policy makers which might help those with epilepsy live normal lives. The primary response was the need for a public relations effort at both local and national levels. They noted that with other conditions advocates have put together public information campaigns that spotlight celebrities with the condition. This "celebrity validation" often increases people's awareness, compassion, and willingness to open up and accept diversity.
	Stigma: Participants described the effort they felt they had to exert to educate the people around them. "Just trying to be accepted as a normal person. That is very very challenging. The other thing is trying to get the stigmatisms that are put toward peopled with seizures changed." Others stated that the decision to tell others about their condition involved a personal and deliberate thought process.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	Smith 2014[64]
Aim	To explore caregivers' perceptions of the caregiving process at different time periods post epilepsy diagnosis.
Population	Caregivers of those with epilepsy, n=19

Study	**Smith 2014[64]**
Setting, country	Not stated, USA
Study design	Qualitative focus group study
Methods and analysis	A total of 19 participants attended the focus group meetings and caregivers received a copy of the consent forms and received a $25 gift card for their participation in the study. A trained focus group leader (clinic paediatric nurse practitioner) and an assistant (neurology resident) led the focus groups. The questions were developed in consultation with an epilepsy nurse expert, psychiatric nurse expert, linguistics and content expert, and a paediatric psychologist. Focus group questions began with broad topics related to the caregivers' perceptions of the caregiving process regarding their YWEs followed by questions focused on the constructs of the Caregiving Process Model by Raina et al. The trained focus group assistant took field notes, and the sessions were digitally recorded and transcribed verbatim. Thematic analysis guided the data analysis. Using the Caregiving Process Model as the theoretical framework for the development of research questions, a deductive approach guided the thematic analysis. The six phases used in this thematic analysis were reflexive and recursive. First data were read, transcribed, and then reread by two investigators and the focus group leaders; next, the data set was coded and organized into potential themes by two investigators; once themes were reviewed by the investigative team, a thematic map was created; ongoing analysis was carried out to provide descriptions and identification of each theme; and then a final analysis with particular quotations was reflected back to the research question for the results. To further assist in coding and retrieval of themes, the NVivo 10 software program was utilized.
Themes with findings	Navigating the non-contingencies: Non-contingency is defined as the lack of a perceived relationship between the person's actions and the outcomes experienced. Caregivers in each group echoed the non-contingencies experienced daily and over time in caregiving those with epilepsy in the home, school, community, and health-care settings.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Snape 2009[65]check other Snape 2006 study!**
Aim	To present the experience and views of Chinese people with epilepsy and their families, and to identify knowledge gaps and uncertainties about epilepsy within selected urban and rural communities in China.
Population	Men and women with epilepsy and their families, ranging from 15-71 years old, n= 151
Setting, country	Not stated.
Study design	Qualitative interview and focus group study
Methods and analysis	‘Mini-ethnographies’ were used in rural and urban communities in China. In-depth interviews and focus group discussions with identified relevant informant groups, and review of local literature and media reports were used. 96 in depth interviews from men and women with epilepsy and their family members. All interviews were tape recorded. Interviews were conducted in informants’ homes; focus groups were conducted in local health or community facilities or places of work. All interviews and focus groups were conducted by local research teams led by two of the authors in their own languages. In both countries, all encounters were tape-recorded the recordings were then transcribed and translated into English by 3 researchers, then cross-checked for clarity of translation and meaning of any culturally specific terminology. Though some subtleties of meaning were almost inevitably lost in the process of translation, this allowed accessibility of all the ethnographic material to the whole research team. All checked and cleaned data were stored as Word files. The data were subjected to a process of thematic coding and charting, assisted by use of the qualitative data analysis package, ‘Framework’. A subset of transcripts were coded inductively by three of the authors, to develop an initial set of codes representing major and sub-themes raised; application of the initial set to subsequent transcripts generated additional codes which were then incorporated following discussion and agreement by all members of the coding team. To ensure quality of the coding process, every fifth transcript was double-coded and any inconsistencies arising were discussed by the coding team and reconciled. The coded data were then charted electronically using an Excel database, to allow easy transferability of files to all team members, regardless of geographical location.
Themes with findings	Being in control: A number of both urban and rural participants stated that epilepsy was impossible to cure especially if it was inherited. The unpredictability of seizures and their potential to cause injury led participants to believe that effective seizure management was essential to maintaining quality of life. Many felt that if epilepsy was controlled it did not constitute anything serious as it was not contagious or fatal. Importance was placed on the need for treatment compliance. Personal and lifestyle interventions were used to maximise seizure control and beliefs about the causes of seizures or triggers varied.

Study	**Snape 2009[65]check other Snape 2006 study!**
	Provoking factors: Noise was a commonly cited trigger and participants also expressed the need to reduce social and psychological burdens by avoiding anger, excitement, stress and by maintain a good mood and regulating one's lifestyle to ensure a balance between work, exercise and rest. Attention to diet was also mentioned however there were opposing beliefs.
	Food restrictions: A few participants stressed the importance of a nutritious diet, while a number agreed that stimulants such as alcohol, tea, coffee and smoking should be avoided. Drinking plenty of water to aid digestion (as indigestion was thought to be a trigger), and avoidance of eating beef, mutton or spicy foods was also recommended.
	Fear: Informants expressed fears about the unpredictable and variable nature of seizure occurrence. There were differences in the descriptions of epilepsy with respect to fear in the urban and rural communities. urban respondents often expressed themselves from a western biomedical viewpoint using terms such as idiopathic, grand mal and absence seizures and appeared to rationalise the fear portrayed by others witnessing a seizure by attributing it to lack of societal understanding.
	Knowledge sources about epilepsy: Three main different sources from which informants drew knowledge and information regarding epilepsy were identified. 1) formal knowledge, which includes knowledge gained from reading medical publications or speaking with medical personnel. 2) informal knowledge, which is gained experientially or through word of mouth. 3) mass media.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Thompson, 2008[69]**
Aim	To explore the reproductive experiences of women with epilepsy and highlight the complexity of moral expectations as women seek to avoid questionable decisions and actions that might attract ascription of carelessness or deviance.
Population	Women diagnosed with epilepsy aged between 20 and 40 years old, n=15
Setting, country	In participants' homes or via telephone, UK

Study	Thompson, 2008[69]
Study design	Qualitative interview study
Methods and analysis	In-depth interviews with 15 women were conducted either face to face in women's homes or by telephone, in the latter case to ensure that the wide geographical spread of participants was maintained. No differences were noted between the data obtained by the two methods. Interviews lasted a mean of 2h, with a range of between 1h and 3 h. The data were organized using a qualitative data software programme, QSR NVivo. Analysis was undertaken by 2 researchers and checked by a final researcher following the constant comparative method; no major disagreements occurred. Deviant cases were sought throughout the process of analysis. Using the framework of reproductive chronology, the data were scrutinized to identify women's accounts of healthcare experience, giving due regard to supportive encounters in addition to those of which women were critical.
Themes with findings	Contraception: The women generally felt their attempts to perform the moral work of avoiding unplanned pregnancy were not always supported by effective healthcare practice and advice. While some women reported that their practitioners were helpful, those who received inaccurate or inadequate advice had to cope with varying consequences.
	Pre-conceptual planning: One woman described how information about reproductive health does not necessarily form part of the general pattern of treatment for epilepsy. The women drew attention to the conflict between their initial understanding of the health behaviour—the moral work—of a 'good mother' and the learned moral work of becoming a 'good patient' as women with epilepsy. This involved coming to terms with counter-intuitive knowledge of risk avoidance through comprehension of the need for continued medication.
	Pregnancy: Anxieties about the effect of medication on their babies continued for some women during pregnancy, extending the conflict between the moral work of the 'good mother' and that of the 'good patient'. Two women found that their delivery units seemed unprepared for their epilepsy. Some women reported conflicting advice from the local hospital and specialist hospitals.

Study	**Thompson, 2008**[69]
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Tonberg 2015**[71]
Aim	To investigate young adults' responses to discussion on SUDEP in epilepsy
Population	Adults added 16-30 years with a HADS score <11 who had been told about SUDEP in the previous 2 weeks, n=27
Setting, country	Not stated, UK
Study design	Qualitative study
Methods and analysis	Semi-structured interviews with thematic analysis
Themes with findings	Perception of SUDEP and risk: most people did not have a clear understanding of risk and struggled with the understanding of the term SUDEP. Many considered SUDEP to be associated with a particular type of seizure and described it as an 'overloaded' seizure or too many seizures. Many described SUDEP as being a result of accidental death in people with epilepsy such as suffocation, drowning and being hit by a bus.
	Perceptions of individual risk factors: as with general understanding of SUDEP, many were unclear about their individual risk factors.
	Knowing about SUDEP: Only 2 people expressed a wish that they didn't want to know about SUDEP. Most participants thought that everyone should be told about SUDEP, and many felt that this should be given at an early stage in relation to diagnosis. Most said they only had a basic understanding of SUDEP. Strong consensus SUDEP should be discussed face-to-face.
	Independent information seeking: A few people described finding information online about SDEP but became alarmed at reading it. The majority said they didn't seek information about it as they didn't want to think about it or felt they already knew everything they needed to know.

Study	**Tonberg 2015**[71]
	Impact of finding out about SUDEP: ‘You just put it to the back of your mind’ Nearly 50% said they just put it to the back of their minds. Forty four percent expressed initial, though not longstanding, anxiety.
	The behavioural impact of SUDEP disclosure: some reported changes in their behaviour for example medication adherence and alcohol reduction, however, over 50% said that SUDEP disclosure made no difference to their behaviour in terms of medication adherence and modifiable risk factors.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Varley, 2011**[73]
Aim	The objective was to document and interpret the experiences of people with Epilepsy in Ireland as they journeyed along the epilepsy care continuum.
Population	Criteria included: patients who had a scheduled appointment to attend epilepsy department, patients who did not attend the clinic previously or were discharged from the service greater than 3 years ago, patients who had a diagnosis of epilepsy or suspected epilepsy at the time of referral, patients whose referral to the service was epilepsy related, lower age limit of 16 years, n=19
Setting, country	Research room
Study design	Qualitative interview study
Methods and analysis	One to one interviews were conducted at an outpatient’s clinic following their appointment. Interviews could last up to 1 hour and participants were guided by open ended questions. Where necessary the interviewer probed or asked for clarification. Data analysis was conducted by the lead researcher. No coding software was used to analyse the data. Data analysis was guided by interpretive phenomenology which facilitated the interrelated processes thematic analysis, analysis of examples, and search for paradigm cases.
Themes with findings	Healthcare system issues: All participants including those with significant clinical risk endured significantly protracted waiting times. Many participants had waiting times of 2 years. For many the delay in accessing

Study	Varley, 2011[73]
	specialist care prompted negative psychological emotions, feeling "disappointed and shocked" and enduring "fear and worry".
	Communication issues: Many participants expressed that although empathetic to their illness, GPs lack the expertise to manage their condition or continue to remain passive with respect to patient needs. For the majority of participants, the GPs role was confined to refilling prescriptions of antiepileptic drugs.
	Pregnancy: 10 women participated in the study and 9 had children under 18 years old. One patient waited years for neurology review and did not receive any epilepsy specific counselling during her second pregnancy. Other women could not recall any specific epilepsy care during her first 2 pregnancies and was continued on phenytoin during them both.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	Wagner, 2009[74]
Aim	To provide an in-depth examination of the impact of paediatric epilepsy on youth in an economically disadvantaged state.
Population	Caregivers of children aged 1-21 years old with epilepsy were included, n=7
Setting, country	Not stated. USA
Study design	Qualitative focus group study
Methods and analysis	Six small size focus groups were held and only data from the 7 participants who were caregivers of children with epilepsy aged 1-21 were included. Focus group questions were developed with researchers, field experts, caregivers and people with epilepsy and tested in a different support group. A facilitator asked the questions using probes and ensured no individual dominated the discussion. another researcher serving as recorder wrote the questions and responses. Discussion notes were transcribed and verified compared to the written notes and audio tapes. Responses were analysed using phenomenological tradition of qualitative data analysis. The primary analyst took the 4 following

Study	**Wagner, 2009**[74]
	steps; 1. Reading through the transcript of one of the focus groups, 2. going back through and coding the transcript, 3. creating a list of codes from the initial transcript, 4. arranging the codes into content categories. the steps were repeated with the other transcripts. the final step involved using the categories to answer the studies main questions and then combining them into one phenomenological question.
Themes with findings	Medication: Participants discussed concerns regarding frequent changes and adjustments to medications which contribute to unusual, sleepy and preoccupied behaviours along with behavioural outbursts. This can leave parents to question whether behaviour is related to seizures, medications of the child's personality.
	Lack of understanding/knowledge: Parents reported lack of knowledge in the school setting about epilepsy related educational difficulties. For example, students are frequently inappropriately placed in classes for students with a variety of disabilities which are not adequately structured or equipped for children with epilepsy's needs.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Wallace 1999**[75]
Aim	To explore, using focus group discussions, women's experience of and satisfaction with care and treatment for their epilepsy, and to seek views on how epilepsy services might be improved.
Population	Women with epilepsy aged 24-66 years old, n=18
Setting, country	Royal College of Physicians, UK
Study design	Qualitative focus group study
Methods and analysis	Three focus group discussions were held at the Royal College of Physicians, involving 18 women in total. Group size ranged from 4–8 people. As a means of validation, a further focus group discussion was held with six epilepsy nurse specialists from hospitals around England. The discussions lasted one-and-a-half to two hours. The focus groups were facilitated by two interviewers who asked a series of open-ended questions.

Study	Wallace 1999[75]
	The discussions were audio-taped and transcribed verbatim. Content analysis guided by grounded theory methodology was carried out to identify common themes and concepts.
Themes with findings	Healthcare system issues: The importance of continuity of care, i.e., seeing the same doctor at the hospital on each visit, was emphasized in all four groups. Poor communication between specialists and GPs was identified to be a common source of error in patients' medication. Delays in letters being sent to GPs left patients without medication once they had finished their hospital supply and GPs without clear instructions as to which drugs they should be prescribing. Women felt that consultations were often rushed and there was never enough time to discuss all that they wanted, although this experience was not shared by everyone.
	Absence of information/ support: Obtaining information about epilepsy and antiepileptic medication from their doctor was often perceived to be a struggle and many of the women had looked to other sources for information. This was particularly apparent at diagnosis which several women commented had been very poorly handled: In all three patient groups, the women were concerned at the lack of advice and information they had received about contraception.
	Pregnancy: Women worried that their doctors did not always seem to have a complete understanding of the effects of AEDs on the oral contraceptive pill. Some felt they had not been given enough information and were therefore not clear what exactly the risks were. Many of the women also expressed anxieties about the risk of AEDs in pregnancy. Some felt they had not been given enough information and were therefore not clear what exactly the risks were.
	Communication issues: women reported difficulty in obtaining the information they needed. In the discussion with the nurses: Nurse E: That's the difficulty with doctors, they see it very much from the medical point of view: 'How many seizures are you having, have some more carbamazepine'. [They] don't look at the other issues: the non-medical care, the advice, the information, the education, the much more practical issues that worry women.
	Clinical competence and skills: Problems due to the shortage of specialists with an interest in epilepsy were raised. Both the nurses and women with epilepsy described experiences of delayed diagnoses and misdiagnoses and inappropriate drug management by both neurologists and general physicians.
	Outcomes of treatment: Issues concerning side-effects of treatment were a common cause of dissatisfaction for patients. There were complaints about doctors' lack of awareness of the side-effects of the different drugs; their failure to inform patients of the side-effects they might experience with a particular drug; their apparent disbelief

Study	**Wallace 1999**[75]
	of the side-effect's patients were reporting; and failure to seek patients' views on the desired balance between seizure frequency and side-effects.The four participants who had had surgical intervention for their epilepsy spoke generally positively of their experience. Three no longer had seizures, though they were still on medication, and were looking forward to the time when they might come off drugs altogether.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Westin 2018**[79]
Aim	To explore parents' experiences of their child suffering febrile seizures
Population	Parents to children admitted to a paediatric clinic in southern Sweden due to a febrile seizure, n=11
Setting, country	Parent's choice of location.
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews with one or both of the children's parents. The interview was based on an interview guide that contained questions open ended questions about the parent's experiences during and after the febrile seizure. The interviews were performed during October-November 2013 in the location of the parents' choice. In autumn 2014 the first author conducted a small number of additional interviews. 3 additional interviews took place in Jan-Feb 2015. the mean interview time was 22 minutes. Interviews were analysed with latent context analysis. The interviews were transcribed verbatim by the first author on the same day or day after they were conducted. Upon completion the texts were read with the study aim in focus to gain a full sense of context. The meaning units were then identified, i.e., words or phrases that related to the aim of the study. The meaning units were shortened without losing the core content and labelled with code. Finally, all codes were divided into categories. Finally, the latent part of the analysis, the interpreted implications were connected in themes.
Themes with findings	Emotional distress: Many of the parents imagined their child dying. Nearly all parents described apprehension over recurring seizures and anxiety could last for a couple of days or up to several years. Anxiety peaked at night-

Study	**Westin 2018**[79]
	time, especially if the child felt warm or seemed ill. Parents described that the anxiety faded with time, generally because the child had not suffered anymore seizures or because they had had multiple febrile seizures, so they did not seem so frightening
	Being in control: Parents described the first febrile seizure as chaotic, not knowing what to do made parents feel powerless and out of control. To regain control of the situation, the parents performed different actions at home, e.g., cooling the childing and making sure they had open airways or did not harm themselves during the seizure. After the seizure many parents wanted to keep observing their child so many did not well for some time and often would sleep in the same room, frequently taking the child's temperature.
	Need for support: Many parents felt that it was important to have support from the other parents during the seizure and reflected how much worse it would have been had they been there alone. When the child was being cared for parents felt relieved to hand over the responsibility to someone with proper competence. Parents were pleased to be offered the possibility to stay overnight in the hospital and those that chose to go home felt safe knowing that they could call or go back.
	Need for acknowledgement: Parents appreciated that the healthcare staff allocated time to inform them of what was about to happen, listened to them, answered questions, checked in on them, asked them how they were doing and offered food and coffee during their time at the hospital.
	Need for comfort: The parents watched how the healthcare staff behaved, noticing that the paramedics and/or the staff working in the emergency room were calm and controlled. This helped to reassure the parents. Being told that the child's vital observations were fine also help reaffirm this feeling. Having had prior positive visits to the emergency room also raised the level of comfort.
Limitations and applicability of evidence	The study had moderate methodological limitations providing valuable research and findings. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants' being adequately considered. There were no concerns regarding the applicability of the evidence.

Study	**Widnes 2012**[80]
Aim	To examine risk perceptions and needs for medicines information in pregnant WWE.

Study	**Widnes 2012[80]**
Population	Women diagnosed with epilepsy and treated with one or more AEDs, undergone 18 weeks' pregnancy routine ultrasound screening without any teratogenic effects observed and aged 18 years or older, n=10
Setting, country	The neurology clinic, Norway
Study design	Qualitative interview study
Methods and analysis	All women were interviewed at the neurology clinic for approximately 1 h. The interviews were initiated with a short questionnaire where the participants were asked to provide information. The interview guide was semi-structured and contained open-ended questions regarding the women's risk perception and experiences with and needs for medicines information. The process of analysis was facilitated by use of the text analysis software NVivo. The analysis was performed in accordance with the principles of systematic text condensation, a four-step process. In the first step, the transcripts were read by all three authors to identify recurring themes within the transcripts. In the second step, the transcripts were analysed iteratively according to these themes. Step three involved further condensing and abstracting the text for its contents into subgroups and describing the content of each subgroup with an artificial quote. In the final step, the content of each subgroup was abstractly described, and the contents of the subgroups were compared to the original transcripts.
Themes with findings	Medicine: The women were satisfied with the follow-up and medicines information provided, and in particular neurologists, were regarded as highly trusted providers of medicines information. Participants reported limited needs for medicines information due to long-standing use of AEDs and to restrictive use of other medicines. Despite this, the women appreciated medicines information both in written form and through oral communication with health care professionals, as supplement to each other. The credibility of the physician was enhanced when they took the time to explain medical issues and answering questions. Most women browsed the Internet for health and pregnancy related information, which was presented as an instant, superficial source of information with inherent problems of inconsistencies and varying quality of information.
	Pregnancy:
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Wilde 1996**[81]
Aim	To explore the issues affecting young people with fairly significant epilepsy who were attending outpatients' clinics.
Population	Criteria: (1) aged between 13 and 25 years, (2) had epilepsy, and no other serious comorbidity (such as learning disabilities), (3) attending outpatients' clinics at the Leicester Royal Infirmary for their epilepsy (rather than having been discharged to their GP), n=24
Setting, country	Interviewed in clinic after their outpatient's appointment, if applicable, with the option to be interviewed at home if they preferred, UK
Study design	Qualitative interview study
Methods and analysis	Participants were interviewed in clinic (using an interview schedule developed during the project) after their outpatients' appointment, if applicable, with the option to be interviewed at home if they preferred. The interview schedule was designed to be flexible so that different subjects could discuss the issues that were especially relevant for them. The designated interview time period was from November 1994 until March 1995, inclusive. However, some of those who fulfilled the inclusion criteria above were found to have outpatient's clinic appointments outside the interview time period; they were also invited to be interviewed, either at home or in clinic, at a time and date suitable for them. All interviews were tape-recorded, transcribed onto a word processor and analysed by the researcher. The analysis of the verbatim data was moderated by the project supervisor. Analysis was carried out by sorting the verbatim material into key thematic categories, using the interview schedule as a framework.
Themes with findings	Negative responses to disclosure: Many subjects reported having been bullied at school although after leaving school, the experiences of stigma seemed to decrease. Verbal teasing was the most common form of prejudice, i.e., name-calling and jeering, which was often very distressing. Subjects felt that people reacted in a negative way towards those with epilepsy as they were either afraid of epilepsy, or ignorant, or both. Many subjects also commented that epilepsy was not talked about among the population and because of this public unwillingness to understand what epilepsy was, the old attitudes lived on.
	Activity restrictions: Subjects' parents were reported as being generally calm, practical and not overdramatic when seizures occurred; many described very open and supportive relationships with their parents, and were able to

Study	Wilde 1996[81]
	discuss their epilepsy, easily with them. Respondents commonly recalled that one parent, (usually the mother) was more anxious, and they often turned to the less worried parent for support and advice. Many respondents' parents did not restrict what their children did socially, or they tried hard not to, the main exception being swimming. Going out at night, however, especially if it involved drinking alcohol or going to night clubs, or being with friends who were not 'in the know' often led to conflict, and frustration with parental overconcern.
	Communication issues: 33% of participants described their doctors as having been helpful, offering advice, and encouraging, however, others were critical. Main criticisms included doctors did not discuss or explain their diagnosis or condition adequately, especially when the subjects were younger, and that doctors seemed overly concerned with the medical management of the respondents' condition, at the expense of giving practical advice about living everyday with epilepsy. Three respondents also mentioned a lack of continuity in their management, and complained that the rapid turnover of staff meant that they never saw the same doctor twice.
	Need for support: Despite support groups being available in Leicester, all apart from 5 participants were unwilling to join. The reasons given by the respondents for their refusal to join included comments that such groups were irrelevant to their lives, and that these groups tended to emphasise the negative aspects of having epilepsy.
	Experiences of employment: A significant issue for the majority of the interviewees was that of employment. Many recalled having been forced to send, in some cases, literally hundreds of application forms, with others being dissuaded or prevented from choosing careers they wanted because of their seizures. Many of the respondents who described difficulties while trying to obtain employment remarked that in most cases, their epilepsy had been the main reason why they had not succeeded, and a lack of success had led seven of them to conceal their diagnosis on application forms.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	Wo 2018[82]
Aim	The aim of the study was to explore the experiences of parents and their children, and to identify the needs and challenges faces by parents and children in childhood epilepsy care.

Study	**Wo 2018**[82]
Population	Parents and their children aged 8-18 years old who had been diagnosed with epilepsy >6months, have ≤4 seizures in the past 6 months and attending regular school, n=33
Setting, country	Participants' homes, Malaysia
Study design	Qualitative interview study
Methods and analysis	In depth interviews were conducted with parents and children at their respective homes in their preferred language. Interviews were audio recorded and lasted from 30-60 minutes for parents and 15-30 minutes for children. Additional notes including impressions and thoughts about the participants were recorded in a research diary. topic guides were used to structure the interviews. All interviews were transcribed verbatim by experienced transcribers. Data analysis was facilitated by using NVivo 10. Data were analysed using the descriptive phenomenology approach and thematic analysis in three phases. During the first phase one the researcher coded each interview line by line to develop an initial list of codes. Subsequent interviews were then coded using this list and new themes that emerged were added. During the 2nd phase open codes were organised and reorganised into broader categories based on thematic similarities. Finally core categories and subcategories were organised within each conceptual domain generating a theoretical representation of relationships among concepts.
Themes with findings	Parents and children's initial reactions: All parents experienced negative emotional reactions when their child first had a seizure. They were upset, shocked and worried. Many thought that their child was going to die. In some families' mothers blamed themselves for "causing" their child to have epilepsy or felt their in-laws blamed them. Children's perspectives were mainly described by children aged 11 years and older. Fatigue and excessive tiredness was experienced by some children after their first seizure. Some children were conscious and felt like they were "stuck inside" their body during the seizure. Others reported that they lost consciousness or went blank during their seizure. Most children felt shocked, upset and scared during or after their seizure.
	Home environment: In some families, family members felt more united, however in others, parents developed health or mental health issues, and some were forced to give up their jobs to take care of their child. All parents reported they were constantly worried. They worried about their child's health, school performance and the future (would they be able to live independently or gain employment). Most children did not report any significant changes to their family before or after their diagnosis. some felt that their relationships with their siblings grew closer because of epilepsy.

Study	**Wo 2018**[82]
	Activity restrictions: All parents imposed restrictions on their child's physical and social activities (such as sleepovers) as they were afraid no-one would know how to care for their child if they had a seizure. Some children with epilepsy placed restrictions on themselves in order to avoid triggering a seizure. Despite the restrictions children did not think their parents were overprotective.
	Stigma: Disclosing their child had epilepsy was not easy for parents due to fear of stigmatisation. Parents who did share this information often felt that a burden had been lifted. Some children with epilepsy disclosed they had epilepsy to people they trust. Others chose not to disclose they have epilepsy with the two main barriers identified as stigma and "invisibility of epilepsy".
	Coping strategies: Parents and children both adopted problem solving and effective emotional coping strategies in dealing with challenges. Some children sought help from siblings or close friends while others ignored their problems, hoping that they would go away.
	Feeling different: Participants reported they felt isolated socially and viewed by others as "different, weird or contagious".
	Invisibility: Participants discussed the fact it is not physically visible to others, and the silence around epilepsy in the public domain. Some children with epilepsy disclosed they had epilepsy to people they trust. Others chose not to disclose they have epilepsy with the two main barriers identified as stigma and "invisibility of epilepsy".
	Medication: All children were aware of the importance of taking their medications. One parent reported that her child had significant hair and weight loss because of the AED.
	Lack of understanding: Some children with epilepsy disclosed they had epilepsy to people they trust. Others chose not to disclose they have epilepsy with the two main barriers identified as stigma and "invisibility of epilepsy". Some felt isolated socially and viewed by others as "different, weird or contagious". Some parents reported their child had no friends in school and were called names and bullied.
	Future: Many adolescents reported they wanted to make their own decisions about their life: such as driving and what they want to be in the future. One mentioned she wanted to be communicated with directly rather than just asking her mother. Most children hoped they would be seizure free in the future and would like to be independent and fulfil their dreams.
	Need for information: Parents wanted doctors to provide them with sufficient information on how to care for a child with seizures. Doctors rarely focused on this aspect and parents felt they merely ordered tests to confirm or

Study	**Wo 2018**[82]
	exclude the diagnosis or epilepsy and prescribe medications for seizures. Although they provided more information in subsequent visits parents felt the information should be more understandable and doctors should be more frank about the side effects of AEDs. Some parents were aware of the importance of a parental support group and hoped to share and exchange information with other parents. Most children did not actively look for information on epilepsy, some tried to search on the internet but did not understand what they read. Knowledge about epilepsy was obtained from their parents.
	Honesty and openness in provision of information; Some parents were aware of the importance of a parental support group and hoped to share and exchange information with other parents.
	School restrictions: In terms of school performance, some noted no changes while other parents reported a negative impact as they missed school or examinations frequently or had problems with understanding what they were taught in school. Some children reported that there was a negative impact on their academic achievement. Some children had a seizure during school resulting in loss of consciousness and they experienced difficulties concentrating on what was being taught in class. Some children had a seizure after school hours often meaning they were absent from school the following day.
	Negative responses: In terms of interpersonal relationships most parents thought that their child had no problems in making friends. However, some parents reported their child had no friends in school and were called names and bullied.
	Support: Some children reported they had several close friends in school who gave them constant emotional and social support.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Appendix E Excluded studies

Table 6: Studies excluded from the qualitative review

Reference	Reason for exclusion
Abubakar 2015[1]	Incorrect population; included those without epilepsy
Alkhamra 2012[2]	Incorrect study design; questionnaire
Andrade 2017[4]	Incorrect study design; recommendations
Aytch 2001[5]	Incorrect population; included those without epilepsy
Baca 2018[6]	Incorrect study design; not qualitative
Baird 2003[7]	Quantitative study with some themes reported, doesn't mention qualitative analysis
Blank 2014[11]	Incorrect study objectives: addressing why elderly patients don't regularly attend clinic
Burke 2018[12]	Systematic review: references individually assessed, not all looked at epilepsy, those that did have already been ordered
Butau 1993[13]	Incorrect study design: close ended questions, no clear themes identified
Camfield 2017[14]	Incorrect study design; conference proceedings
Canvin 2006[15]	Incorrect objective; asking opinions on joining an epilepsy trial
Chong 2016[19]	Systematic review: not all qualitative studies, already have the ones that are
Collard 2019[20]	Systematic review, not all studies qualitative, ordered relevant ones
Geerlings 2015[24]	Systematic review: not all qualitative studies, already have the ones that are
Hames, 2009[25]	Incorrect study design; written accounts
Harden 2016[26]	Systematic review, not all studies qualitative, ordered relevant ones
Heath 2016[28]	Incorrect study objective; about surgery
Kuchenbuch 2013[33]	Incorrect study design; questionnaire
Lewis 2013[34]	Included in transition review
Louik, 2017[35]	Incorrect study design; questionnaire
Mc Govern 2018[37]	Incorrect study design; actual transition programme
McAuley, 2012[38]	Incorrect study objective
Miller, 2014[42]	Incorrect population; providers e.g., neurologists and doctors

Reference	Reason for exclusion
Nashef, 1998[45]	Incorrect population and study design; not all SUDEP, not qualitative data analysis
Nisbet, 2017[48]	Incorrect population; neurologists and doctors
Prinjha, 2005[51]	Duplicate
Ramachandran Nair, 2016[54]	Incorrect study comparisons
Ridsdale, 2012[55]	Incorrect study objective
Rushe, 2011[58]	Unavailable
Saburi 2006[59]	Incorrect study design; survey
Scheffer 2014[61]	Incorrect study design; not qualitative study
Schultz 2013[62]	Included in transition review
Shih 2018[63]	Incorrect study objective; discussing people considering surgery
Sonecha 2015[66]	Incorrect study objective
Swarztrauber 2003[67]	Incorrect study objective; more about surgery
Tanaka 2018[68]	Incorrect study population; people with mental health issues
Thompson 2013[70]	Incorrect study design; online survey
Van Naarden Braun 2006[72]	Incorrect study design; cross sectional study
Watkins 2006[76]	Incorrect study design; not qualitative
Webster 2016[77]	Included in information review; no information on transition
Weckesser 2013[78]	Systematic review: not all papers looking at epilepsy, relevant ones ordered/ we have