Children’s Experiences of Epilepsy: A Systematic Review of Qualitative Studies

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abstract

CONTEXT: Epilepsy is a common and severe neurologic disease associated with increased mortality, seizure-related injury, and adverse psychological and quality-of-life outcomes.

OBJECTIVE: To describe the perspectives of children and adolescents with epilepsy.

DATA SOURCES: Medline, Embase, PsycINFO, and CINAHL from inception to August 2015.

STUDY SELECTION: Qualitative studies on children’s experiences of epilepsy.

DATA EXTRACTION: Results from primary studies. We used thematic synthesis to analyze the findings.

RESULTS: Forty-three articles involving 951 participants aged 3 to 21 years across 21 countries were included. We identified 6 themes: loss of bodily control (being overtaken, susceptibility to physical harm, fragility of the brain, alertness to mortality, incapacitating fatigue), loss of privacy (declarative disease, humiliating involuntary function, unwanted special attention, social embarrassment of medicine-taking), inescapable inferiority and discrimination (vulnerability to prejudice, inability to achieve academically, consciousness of abnormality, parental shame, limiting social freedom), therapeutic burden and futility (unattainable closure, financial burden, overwhelming life disruption, exhaustion from trialing therapies, insurmountable side effects, awaiting a fabled remission), navigating health care (empowerment through information, valuing empathetic and responsive care, unexpected necessity of transition, fragmented and inconsistent care), and recontextualizing to regain normality (distinguishing disease from identity, taking ownership, gaining perspective and maturity, social and spiritual connectedness).

LIMITATIONS: Non-English articles were excluded.

CONCLUSIONS: Children with epilepsy experience vulnerability, disempowerment, and discrimination. Repeated treatment failure can raise doubt about the attainment of remission. Addressing stigma, future independence, and fear of death may improve the overall well-being of children with epilepsy.

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Ms Chong conceptualized the study, carried out the data collection and analysis, coded the data, drafted the initial manuscript, and drafted the manuscript; Mr Jamieson contributed to the data collection and initial analysis and reviewed and revised the manuscript; Drs Gill, Singh-Grewal, and Craig, Ms Ju, and Ms Hanson contributed to the analysis and reviewed and revised the manuscript; Dr Tong conceptualized and designed the study, contributed to data analysis, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.


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PEDIATRICS Volume 138, number 3, September 2016:e20160658
Epilepsy is the most common serious childhood neurologic condition, affecting half a million children in the United States alone.1,2 Up to 50% of children with epilepsy have symptomatic epilepsy, which is associated with a 10-fold increased mortality risk.3 Morbidity and mortality are mainly attributable to injury, developmental comorbidities, and an increased risk of sudden death that persists into adulthood.2,4–6 Although some children achieve remission, the overall risk of recurrence is close to 50%.4,5

Children with epilepsy often require antiepileptic medications and must avoid seizure triggers such as fatigue. An estimated 80% of patients have an associated behavioral disorder and/or cognitive impairment.1,7 Studies have shown that children with epilepsy report impaired quality of life (QoL), low educational attainment, social stigma, and low self-esteem.1,5,7–48 These measures are worse in children with higher frequency seizures.8–10,49,50

The significant consequences of epilepsy signal the need to understand how children perceive and cope with the disease and treatment, as well as their concerns and needs. Most existing qualitative studies have a limited number of patients and are conducted in a single setting. A systematic review and synthesis of multiple qualitative studies can compare data from different populations and settings to provide more comprehensive information for health care providers.51 This review aimed to describe children’s perspectives of living with epilepsy to inform strategies to direct health care toward improved patient outcomes and QoL.

**METHODS**

We followed the Enhancing Transparency of Reporting the Synthesis of Qualitative research framework.51

**Selection Criteria**

Qualitative studies on the experiences and perspectives of children and adolescents (≤21 years of age) diagnosed with epilepsy were eligible. We excluded quantitative epidemiologic studies (eg, randomized controlled trials, cohort studies), basic science studies, nonprimary research articles, economic studies, quantitative surveys, psychiatric assessments, studies that did not elicit or report data from children and adolescents with epilepsy, and non-English articles due to lack of resources for translation. Studies on parental perspectives were excluded, as parents may have perspectives different from children.

**Data Sources and Searches**

The search strategy is provided in the Supplemental Information. We conducted searches in Medline, Embase, PsycINFO, and CINAHL from inception to August 2015. We also searched Google Scholar and the reference lists of relevant studies and reviews. We screened the abstracts and excluded those not meeting the inclusion criteria, then assessed the full-text reports of potentially relevant studies.

**Appraisal of Transparency of Reporting**

We evaluated the transparency of reporting of each study by using the Consolidated Criteria for Reporting Qualitative Health Research.52 This framework included criteria specific to the research team, study methods, context of the study, analysis, and interpretations. Two reviewers (LC, NJJ) assessed each study independently, and consensus was reached after discussion with AT.

**Data Analysis**

We used thematic synthesis as described by Thomas and Harden.53 Thematic synthesis identifies and analyzes recurring themes in the primary literature, to draw conclusions in systematic reviews.53–55 The development of descriptive and analytical themes using coding invokes reciprocal translation and constant comparison.

One potential limitation in combining findings of qualitative studies is that the findings of individual studies may be decontextualized, and the concepts identified in 1 setting may not be applicable to others. However, context is able to be preserved by providing summaries of each study (Table 1) so that readers can judge for themselves on whether the contexts of the studies the review contained were similar to their own.53 Summarizing qualitative findings can also prove difficult, due to the ethical and logistical difficulties in accessing original transcripts.

For each study, all participant quotations and text under the “results/findings” or “conclusion/discussion” section were extracted and entered verbatim into HyperRESEARCH (version 3.7.3; ResearchWare, Inc, Randolph, MA) software for storing, coding, and searching qualitative data. LC conducted line-by-line coding of the text into concepts inductively derived from the data. Concepts were compared and transferred across studies by adding coded text into existing concepts, or creating additional codes for new concepts. Similar codes were then grouped into themes. The preliminary themes were discussed by LC, NJJ, AJ, and CSH who had read all the included articles, to ensure that the themes reflected the full range of experiences reported by all study participants (investigator triangulation). The data were recorded by LC according to the revised analytical framework and cross-checked by the research team. From this, an analytical thematic schema was developed by identifying
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Grounded theory, theories are grounded in the empirical data and built up inductively through a process of careful analysis and comparisons; phenomenology, to study peoples' understanding and interpretations of their experiences in their own terms and emphasizing these as explanations for their actions; ethnography, to discover and describe individual social and cultural groups. NS, not stated or not applicable.

n refers to number of participants aged <21 y with epilepsy.

Conference abstract.
patterns and relationships within and across themes. The schema was reviewed and discussed among the research team (LC/NJJ/AJ/CSH) to ensure that these reflected the data across all included studies.

RESULTS

Literature Search

Our search yielded 7310 articles. Of these, 43 articles from 21 countries involving at least 951 children with epilepsy were included (Fig 1). The number of participants was not reported in 1 study. The study characteristics are provided in Table 1. The age range of participants was 6 to 21 years, and 678 (54.0%) were boys or young men. At least 1180 (94.0%) had active epilepsy, 22 (2.0%) had had no seizures in the past 6 months, and 53 (4.0%) were in remission.

Completeness of Reporting

Studies reported between 3 and 18 of the 26 Consolidated Criteria for Reporting Qualitative Health Research criteria (Table 2). The participant selection strategy was described in 25 (58%) studies, and 22 (51%) studies reported researcher triangulation. Raw data in the form of quotations was provided in 35 (81%) studies.

Synthesis

We identified 6 main themes: loss of bodily control, loss of privacy, inescapable inferiority and discrimination, therapeutic burden and futility, navigating health care, and recontextualizing to regain normality. Empathetic and
responsive health care encouraged them to work through these personal impacts and their struggles with therapy. This support from clinicians, alongside the provision of relevant information, gave participants the capacity to manage their disease and distinguish it from their identity.

**Loss of Bodily Control: Being Overtaken**

During seizures, the unusual and intense physical symptoms, including dizziness and inability to breathe, contributed to participants’ sense of being vulnerable and overpowered. Seizures disturbed their “basic trust in their bodies and in themselves.” They described this as, “It felt like my insides sort of turned literally upside down, and this feeling like I was just going to die...and I sort of get, kind of a vision...the things I see are always really terrifying.”

**Susceptibility to Physical Harm**

Participants worried that seizures could place them in serious danger of injury. They feared that they would “knock [their] head,” “fall to the floor,” or “bite [their] tongue.” Several regained consciousness after seizures to find themselves unexpectedly in the hospital and undergoing procedures, which they found “so traumatizing.” Some participants dropped out of school due to safety concerns. For others, the fear of serious harm reduced over time.

**Fragility of the Brain**

Participants were fearful aware of the involvement of their brain in epilepsy, reminded by day-to-day learning and concentration difficulties, postictal confusion, memory loss, and fears of becoming a “vegetable.” Some participants reported that after a seizure they could forget “everything [they’d] done that day,” “everything that [they’re] going to say,” and that “usually it doesn’t come back.”

**Alertness to Mortality**

The unpredictable timing, severity, and potentially dangerous locations of where they could have seizures.
TABLE 3 Illustrative Quotations

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<th>Theme</th>
<th>Quotations</th>
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| Bodily powerlessness from seizures | Being overtaken: I felt anxiety every day and I was afraid to lose control.  
I was talking and suddenly my arms started to shake and I fell off the chair on the floor. It turned dark and I don’t remember anything more until I woke up at the hospital. It was horrible.  
“It’s like” being in a nightmare really and you can’t really wake up or just something. | 10, 15, 17–18, 46  
20, 24, 28, 30, 33, 36, 37, 43 |
| Susceptibility to physical harm | 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 machines [EEG], I hate them, all you can feel is cold going onto your heads and jags going in your heads. | 10, 15, 17–18, 20, 25, 27, 32, 33, 37, 43  
30, 40, 42–44, 46 |
| Fragility of the brain         | The symbolic interpretation of the brain as a kind of superordinate bodily organ was central to many people’s accounts. The involvement of the brain in seizure activity led to deep fears about the fragility of the self. | 13, 14, 17, 18, 25, 37, 46 |
| Alertness to mortality         | Many people with epilepsy believed [they] should stay away from lakes, rivers, or ponds to avoid the risk of drowning during a seizure. Some participants recounted anecdotes about serious accidents that other people with epilepsy had had; most of these accidents, often involving drowning, had ended in death. | 13, 15, 18, 19, 33, 34, 36, 37, 44 |
| Incapacitating fatigue         | More commonly, children and adolescents experienced fatigue as a continuous occurrence that at times was made worse by a seizure. [This] made it difficult for them to think clearly and be available to participate in academic endeavors. | 10, 15, 17, 18, 20, 28, 33, 37, 46 |
| Loss of privacy                | Declarative disease: People with epilepsy might have the choice of either concealing or disclosing their disease unless the exposure is not deliberate and occurs during an attack.  
I didn’t like going to school if I had one so I would stay at home for about a week afterward...Because I was scared what people would say.  
My class knew that I was a little slower than the rest of the class. And so they kind of figured out on their own.  
I hate when I fall down...I get mad at my seizures because I don’t like them...sometimes I kind of hit people...I don’t really mean to hit people.  
What really gets you is if they see you having a fit. I find that really embarrassing, my hands start getting all jerky and then I just get really self-conscious of it and that can be really embarrassing.  
There is no part of your being that wants to even think to make up something as humiliating as having a seizure!...Wetting yourself, which is the most horrifying thing you could ever do in public.  
I can’t do some of the stuff in gym class because I might get hurt. I hate not being able to do some things because of the seizures.  
The teacher asks my schoolmates to care for me more.  
I thought if I take one lots of children will get scared and I don’t like it when lots of people say ‘you OK?’...too many times or crowd me.  
I have people make fun of me at a lot school because I have to take medicine and go to the doctor. | 10, 15, 18–20, 28–30, 33, 37, 44  
10, 15, 18–20, 34, 36, 38, 43, 46 |
| Humiliating involuntary action | I hate when I fall down...I get mad at my seizures because I don’t like them...sometimes I kind of hit people...I don’t really mean to hit people. | 10, 15, 18–20, 34, 36, 38, 43, 46 |
| Unwanted special attention     | There is no part of your being that wants to even think to make up something as humiliating as having a seizure!...Wetting yourself, which is the most horrifying thing you could ever do in public. | 10, 15, 18–20, 34, 36, 38, 43, 46 |
| Social embarrassment of medicine taking | I thought if I take one lots of children will get scared and I don’t like it when lots of people say ‘you OK?’...too many times or crowd me. | 10, 15, 18–20, 34, 36, 38, 43, 46 |
| Vulnerability to prejudice     | No one likes me because I’m a geek...Because I’m in the weird class.  
Yeah, the first 2 years were just absolute, sheer hell, with losing your job, friends stay away...people seem to disappear.  
In the past 2 years, because of my epilepsy and everything...the thought of suicide has been in my head...I’d say 4 to 8 times...once, I had the knife at my wrist and my mother came in and I just pretended I was drying it.  
In interviews for work, I don’t tell. I know that people have pre-conceived notions.  
I hope that there is a better understanding of epilepsy throughout England, so other children with the condition can lead normal lives and everyone around them will understand their condition. | 10, 15, 18–20, 34, 36, 38, 43, 46  
30, 37, 43, 44, 46 |
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<td>Consciousness of abnormality</td>
<td>I'm not really sure if I can go through with things... I just don't feel that... I'm able to do some of the things that other kids are able to do. 11&lt;br&gt;[I wish]. I didn't have seizures... I would be a normal kid and it would feel great. 18&lt;br&gt;Because I am cured, no need to tell anyone... I don't like to be different from my friends... I also will not let my future boyfriend know my past because he may think I am strange. I want to be a normal person. 16&lt;br&gt;I am afraid of holding my own children in my arms in case I have a seizure and let my child fall many times when I was holding. 13&lt;br&gt;It could affect different jobs that I do because I want to go into nursing and I have to be careful that shift work doesn't affect me because lack of sleep can trigger mine as well. 20</td>
<td>16, 10, 19, 23, 28, 30, 33 – 35, 38, 40, 43, 44, 46, 48&lt;br&gt;18, 12, 15, 19, 23, 30, 33 – 35, 38, 40, 43, 44&lt;br&gt;10, 16, 19, 23, 28, 30, 33 – 35, 38, 40, 43, 44&lt;br&gt;10, 16, 19, 23, 28, 30, 33 – 35, 38, 40, 43, 44&lt;br&gt;</td>
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<td>Inability to achieve academically</td>
<td>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. 18&lt;br&gt;When it comes to schoolwork or anything like I feel stupid... I say to myself I'm stupid because I can't remember what I'm doing. 18&lt;br&gt;People with epilepsy reported disruption to their education, failing to attend classes on a regular basis, with most patients having incomplete primary school education. 35</td>
<td>16, 10, 11, 15, 16 – 19, 23, 28, 32, 35, 38, 39, 41&lt;br&gt;10, 11, 15, 16 – 19, 23, 28, 32, 35, 38, 39, 41&lt;br</td>
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| Navigating health care                                              | Now I've been handed over to this [new doctor] and he seems like he is doing it because it is a job, but the other doctor cared about the patient... He wouldn't just tell you what you wanted to hear to get you out of the room. 29  
With changing doctors... 'cause I'm not having [fits] right now, he might decide to take me off [my current meds] and I will go doolally again. 29 | 28, 29, 64                                                                                                             |
| Valuing empathetic and responsive care                              | If I have a poor emotional balance, there is no sense in giving me any information or practicing some skills. Health care providers should be able to recognize the need for emotional support and to respond to that. 53  
[T]here also needs to be access to counseling, or therapy. That needs to be a part of treatment also. 53 | 10, 11, 13, 22, 24, 28, 30, 31, 33, 34, 44, 30, 36, 42, 44, 46, 47, 53                                                                 |
| Empowerment through information                                     | I have an understanding doctor, so, whenever I go to the doctor, we sit down and talk. I've found a good one... It's a blessing. 38  
I expected the nurses and physicians to teach me the skills that I need to take care of myself. Also, I expected them to give to me so much knowledge that I could understand my disease and its treatment. I know that the more skills and knowledge I have, the more independently I can live. 5, 53 | 10, 11, 13, 15, 22, 24, 28, 30, 31, 33, 34, 42, 44, 46, 47, 53                                                                |
| Fragmented and inconsistent care                                    | I was misdiagnosed for 7 years, and I faced a lot... going through the depression issues. The doctors questioned 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. 30  
Nervous that it (appointment) would be cancelled or something... and that's worse... waiting all that time and then they cancel it. 42 | 17, 19, 27, 29, 30, 31, 32, 33, 34, 42, 44                                                                                      |
| Recontextualizing to regain normality                               | I have missed quite a lot of school due to my epilepsy but I don't want it to stop me doing anything. 14  
That's what I do, I try not to let it run my life... I try to just forget about it, I go out with my friends a lot, and just feel like a normal person, I don't feel like a different person to everybody else... 'cos I know I'm normal. 14 | 10, 13, 14, 16, 17, 20, 22, 24, 28, 30, 31, 32, 33, 44, 46, 47                                                             |
| Delineating disease from identity                                   | I think any finding out, I've probably done myself. I felt that there wasn't... enough information... he gave me no telephone help lines... or anything like that. 24  
I expected the nurses and physicians to teach me the skills that I need to take care of myself. Also, I expected them to give to me so much knowledge that I could understand my disease and its treatment. I know that the more skills and knowledge I have, the more independently I can live. 5, 53 | 10, 11, 13, 15, 22, 24, 28, 30, 31, 33, 34, 42, 44, 46, 47, 53                                                                |
| Taking ownership                                                    | The only benefit of the illness is a better coping with life. I definitely control my disease. 10  
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's better people know. So I told my teacher at school. 17  
I was having seizures and some people were laughing at me they went, "isn't this funny,"... eventually I got the guts to get up in front of the class and explain exactly what happens when I have a seizure. 17 | 10, 13, 15–20, 22, 24, 28, 30, 31, 33, 34, 35, 37–39, 43, 44, 47, 48, 49, 50 |
| Gaining perspective and maturity                                   | Today my attitude is different. I'm another person. It happened for the best. The illness encouraged me to grow up and develop. 10  
And I feel like I have been chosen for this; this is my reason. This is what I'm here for. One thing I have to remember, too, is that everybody's got something... they've got to struggle with. That's why we all have a purpose, you know. 10 | 10, 11, 22, 24, 40, 42, 43, 44, 47, 53                                                                                         |
| Social and spiritual connectedness                                 | I used to sit... beside my friend and he was dyslexic and... we would... do the same sort of easy subjects together with the teacher... that made me feel... like I was not the only really slow coach there. 35  
Grandmother visits us almost every day. But she hardly ever has seizures. But we talk about it a lot. She is the only one who knows how it feels. She and I understand each other, because we have the same experiences. 17 | 10, 13, 15–18, 20, 22, 23, 28, 30, 33, 34, 42, 44, 46, 47, 49, 50                                                        |

Some of my close friends stayed with me so I would not feel bored. We chatted and listened to music. They made me feel happy. 16
caused some participants to believe that they may suddenly die. Participants were “afraid to die” and this was expressed particularly among adolescents who lived alone or had a limited support network. However, some participants indicated that they would prefer to die during a seizure than live a “life ruined by” brain damage.

**Incapacitating Fatigue**

The seizures could result in extreme daytime fatigue and increased sleep requirements. Consistently low energy reduced participation in academic and social activities, something participants found especially frustrating: “I just sit there and I want to fall asleep during every class...it just wears me down.” One participant stated that “she had been asleep during all her primary school years.”

**Loss of Privacy: Declarative Disease**

Participants resented the embarrassingly exhibitive nature of seizures that put them on public display. Some were frustrated that they were unable to selectively disclose their disease. They “didn’t want to have any more seizures, not at school or at home...afraid someone will find out what happens with [their] illness.” In school, participants also believed their “slowness” revealed their disease to their classmates.

**Humiliating Involuntary Action**

The complete loss of motor control during seizures was described by participants as “disgraceful,” especially if they knew others had seen them. They were “self-conscious” of “wetting themselves... in public,” “throwing things around,” and “saying strange things.” Due to sudden mood changes, some felt they became irrespressibly aggressive, and afterward felt ashamed.

**Unwanted Special Attention**

Some wanted privacy and felt that others’ incessant “worrying,” “overprotectiveness,” or questioning about their seizures, medications, and absenteeism was tiresome and intrusive. Perceived parental overprotection in the form of constant monitoring also made participants feel misunderstood. They resented having people “crowd” and fret over them during schoolground seizures. Some were “annoyed” when teachers restricted their physical activity (eg, gymnastics or school trips) or imposed special rules such as sitting at the front of class. Others felt they were teased because they were in a special education program.

**Social Embarrassment of Medicine Taking**

Some participants were required to take medications at school or during social gatherings such as sleepovers. They were embarrassed when asked “how many [tablets they] had to take” and became “mad” when others teased or interrogated them about their treatment: “I am on the ketogenic diet and kids keep asking...
me ‘What is that you are eating? Why do you gotta take a syringe, is that a shot?’”

Inescapable Inferiority and Discrimination: Vulnerability to Prejudice

Participants believed that others viewed people with epilepsy as contagious, “dangerous” or “weirdos,” and as having a “mental illness.” They reported prejudice, exclusion, and bullying from friends, neighbors, and employers. Some avoided using the “epilepsy word” at job interviews because they would “fail to get the job” or even among their “good friends” because it “repels people.” Many younger participants experienced “shame,” isolation, and grief daily. Several withdrew socially and wanted to leave their current school, move house, or take their life.

Consciousness of Abnormality

Some older participants defined themselves by their disease, feeling “less of a person” and “unable to do anything.” As sexual intercourse could trigger seizures and epilepsy could be inheritable, they worried about being unable to find a partner or begin a family. Female participants expressed concerns about fertility, fetus malformation, breastfeeding while on antiepileptic drugs, and dropping their baby during myoclonic jerks. Older participants felt their lives disrupted by the loss of meaningful roles and having to depend more on their family and friends compared with others. Participants thus were in constant pursuit of an idealized “normal self,” which they believed would be achieved at remission.

Inability to Achieve Academically

Cognitive impairment, memory difficulties, and attention problems cause participants to feel “slow” compared with their classmates, unable to “catch up” and requiring teachers to repeat things “over and over.” This perceived intellectual inferiority was discouraging, and some participants believed that their “schooling had gone to waste.” Participants also missed school due to hospital admissions or doctor appointments.

Parental Shame

Participants felt disappointed by their parents’ shame regarding epilepsy, displayed in their attempts to hide the diagnosis from the participants, or keep the illness a family secret. They felt similarly isolated and abnormal when their families reacted fearfully to seizures or viewed epilepsy as a “strange illness.”

Limiting Social Freedom

Social limitations placed on participants by their family and practitioners made them feel excluded from their peer group. They were frustrated at not being allowed to attend parties, consume alcohol, and play sports or computer games, as these could trigger seizures. In some instances, they gave up on social activities: “I don’t go out anymore because I can’t do the things my friends do, so why bother?” Many teenage participants were frustrated by the longer length of time it would take for them to obtain their driver’s license.

Therapeutic Burden and Futility: Forging a Fabled Remission

Participants viewed epilepsy as “temporary and controllable.” Many believed they would “grow out of epilepsy” in late adolescence and no longer require medications. Holding hope for remission helped them cope with the present challenges of epilepsy, as 1 participant stated, “I’m waiting for the moment when I’ll speak about epilepsy as history.” Those who realized that they were unlikely to go into remission struggled with disappointment. Some adolescents felt they had been deceived by clinicians and refused to attend further appointments.

Financial Burden

Epilepsy was costly due to the ongoing high cost of medications and lack of money or insurance coverage to pay for them. Older participants in the United States believed it was unjust that epilepsy did not qualify for Social Security services, especially

Unattainable Closure

Due to prognostic uncertainty, participants felt insecure during periods of remission, were wary of therapeutic changes, and felt they could only “try” to withdraw from medication. Participants preferred to discontinue medications during stable life circumstances (ie, not while traveling or changing schools). Even after successful withdrawal of medications, many expressed apprehension that their seizures might return, and wanted to know “how long before [they could] start breathing.”

Exhaustion From Trialing Therapies

Participants had to invest time and energy to search for appropriate treatment. Those with active epilepsy were keen to “try anything if [they thought] it would work,” including both alternative and Western medicine. However, repeated treatment failure was mentally and physically draining. Some participants saw therapeutic success as a short-lived “honeymoon” and lost confidence in their abilities to overcome epilepsy.

Insurmountable Side Effects

The relentless side effects of medications, including poor concentration, weight gain, headaches, and abdominal pain interfered with participants’ daily life, academic performance, and self-esteem. They believed their medication to be “a dope,” “worse than the seizures,” and a “terrible but absolute necessity.” Some chose to discontinue drugs without consulting their doctors.
if controlled, and struggled to receive government assistance as a result. They wanted specific support in applying for disability status, concession for medications, and securing adequate employment.

**Overwhelming Life Disruption**

Several participants struggled initially with routinizing medications and remembering to take them as prescribed. Participants were “tired of the medicine,” due to the quantity, size, and unpleasant taste of the tablets. One participant explained, “Swallowing tablets at the start...I found it dead hard, I went through about 8 tablets a day before I could get the hang of it.”

**Navigating Health Care: Unexpected Necessity of Transition**

Some felt unprepared to transfer to adult services, as they had believed their epilepsy would resolve during childhood. They described this phase as particularly confusing and frightening. After transfer, participants felt forgotten and left “high and dry” by adult health care professionals due to infrequent clinic visits. Because they had not prepared for disease chronicity, many also did not feel capable of taking responsibility for self-management.

**Valuing Empathetic and Responsive Care**

Participants appreciated clinicians who provided “emotional support” by actively addressing social aspects of their disease, including stigma and depression, and sharing the experiences of other adolescents with chronic disease. Thus, they felt empowered to broach topics not discussed at home and to actively participate in self-management.

**Empowerment Through Information**

Being informed about epilepsy, seizure triggers, and self-management bolstered participants’ confidence in their ability to manage their disease, cope with stigma, and live independently. Participants felt insecure, disengaged, and excluded from their care when “doctors did not provide information about the condition” only “talked to my mum,” or used “hospital language.”

Teenage female participants wished for more information about fertility and pregnancy. Participants also desired verbal information to be reinforced with accessible, relevant written material, such as leaflets.

**Fragmented and Inconsistent Care**

Participants experienced diagnostic delays that made them feel anxious, depressed, and think they had inexplicable cognitive impairment. Several were “disappointed and shocked” at the prolonged waiting times to see a specialist, especially given the unpredictability of their seizures and difficulties with memory such that they may struggle to recall relevant clinical information.

Continuity of care provided by clinicians whom they trusted caused participants to feel more comfortable and secure.

**Recontextualizing to Regain Normality: Delineating Disease From Identity**

Over time, some participants, especially those with controlled epilepsy, accepted their diagnosis and began to see themselves as “people with epilepsy” as opposed to “epileptic patients.” They stressed that even though the disease had an influence on them, they did not want it to “stop [them] from doing anything.” They believed themselves to be normal and chose to live “in the moment.” Younger participants with less understanding of the possible serious ramifications of epilepsy saw themselves as “healthy individuals” whose health was only “coincidentally interrupted by seizures.”

**Taking Ownership**

Participants gained self-confidence by claiming responsibility for seizure prevention and disease management, such as by being adherent to medications or avoiding seizure triggers. Some educated their friends about the condition so they might have help during a seizure, whereas others educated peers in response to bullying. Participants also chose personal ways to emotionally cope with their illness. For instance, some ignored familial pressure to keep their disease a secret, and disclosed epilepsy to friends for social support.

**Gaining Perspective and Maturity**

Some participants believed they were more mature than their peers, as their disease had encouraged them “to grow up and develop” and appreciate “what is important in life.” Others saw their condition as giving them a “purpose,” providing them with the opportunity to empathize with and “change [others’] lives.” Participants also saw their disease from a broader perspective, relating their experience to others who may have more severe disease.

**Social and Spiritual Connectedness**

Understanding and support provided by family, friends, religion, other chronic illness sufferers, and support groups helped to reinforce coping strategies. Participants felt encouraged when they shared their experiences and when others assisted them in employment opportunities or during a seizure, such as by “holding [their] hand.” Several participants described counting on their parents to remind them to take medication, and felt they could tell their family “everything.”

**DISCUSSION**

Children and adolescents perceive that epilepsy forces them to relinquish their sense of privacy,
bodily control, normality, freedom, and confidence to participate in school and social activities. They are overwhelmed by the daily uncertainties attributed to the unpredictable timing and potential harm from seizures, side effects of ongoing treatment, and the impermanence of remission. The transition to adult services, which for some is unexpected, and the variability in care they receive intensifies the treatment burden. However, young patients feel empowered for self-management when provided with clinician support and relevant information about epilepsy, treatment, and broader psychosocial impacts (eg, family planning). To cope, some consciously disaggregate the disease from their identity, take control of their health, maintain hope for remission, and accept support from family and social networks.

Although many experiences and perspectives were common across patient populations, some differences were apparent based on age and disease severity. Feelings of loss and abnormality tended to be expressed more strongly by older adolescent patients. As young adults, they were aware of the potentially serious ramifications of epilepsy on their future, including their independence, school performance, vocation, and relationships. Teenage patients were more frustrated by social limitations on partying, drinking, and sleepovers that differentiated them from their peers. Patients with more severe, frequent, or uncontrolled seizures contended with disempowerment and seemed less able to delineate epilepsy from their identity. They seemed more willing to trial therapies that may work and some, on being told they would not achieve remission, chose to disengage from the health care system, deeming further treatment or follow-up to be futile. Those with milder, controlled epilepsy seemed better able to accept epilepsy, and were more optimistic about the future.

Children and adolescents with epilepsy report lower QoL compared with their well peers. This is especially so in older patients, or patients with frequent or severe seizures, such as partial epilepsy. Psychological, social, and behavioral domains are particularly affected, causing anxiety, poor self-esteem, and reduced social interactions. Our findings offer a detailed explanation for this observation; children and adolescents feel overshadowed by anxiety regarding seizure occurrence, fear of social exclusion, and anticipation of failure in future endeavors. They also experience physical, mental, and emotional fatigue due to the burden of disease and treatment. Hope for remission provides limited consolation, particularly for older adolescents, as they are unable to predict whether this will occur, or how long it may last.

A recent study found that peer and parental support is the most important factor in health-related QoL for children. Our findings concur with this, as children with epilepsy believed that strong social support enabled them to accept the disease. However, our study also highlights that stigma from family, peers, and employers may cause children with epilepsy to feel isolated and depressed. Familial shame is detrimental to children’s adjustment to their diagnosis and self-acceptance.

Children and adolescents with other chronic and life-limiting illnesses also experience a loss of normality and control over their bodies due to lifestyle restraints and transition difficulties. However, what may be unique in epilepsy is that children are conscious about the visibility of their condition, particularly because of seizures, and feel they suffer consequent discrimination. They are unable to protect their own privacy regarding their diagnosis, and constantly feel susceptible to injury.

Our review involved a comprehensive search and independent assessment of the transparency of study reporting. Research triangulation was achieved, enabling the breadth of data to be captured. Software was used to code the data, allowing for an auditable development of our findings. However, our study has some limitations. The views of patients with well-controlled epilepsy or those with severe mental health or cognitive comorbidities may be underrepresented, due to their limited participation in hospital-based studies and/or interaction with the health care system. Furthermore, our review included the experiences of children treated in low-income countries and different health systems. These views may be less applicable to certain contexts, influencing the transferability of our findings. However, to ensure transparency, we stated the countries in which these studies were conducted, and provided references to the studies. From this, the readers may assess the transferability of the findings to their own setting.

We used thematic synthesis to analyze our findings. The process of translation, through the development of descriptive and analytical themes, can be carried out in a rigorous way that facilitates transparency of reporting. Some may argue against thematic synthesis, as the findings of individual studies can be decontextualized and the concepts identified in 1 setting may not be applicable to others. However, reviewers are able to transfer themes from 1 situation and can check that each transfer is valid. Qualitative meta-syntheses have been used in other fields to improve understanding and practice,
including nephrology, geriatrics, and gastroenterology.\textsuperscript{61,64,75}

Both raw data from children (in the form of quotations) and discussion of the data from authors of the studies were included. Eight (19\%) studies did not provide quotations (ie, raw data from children) (Table 2), so we included the author’s summary and description of their experiences. We only included text in the discussion section that directly reflected children’s perspectives.

There are several challenges associated with pediatric epilepsy. Table 4 details suggestions for clinical practice. Nonadherence to treatment and problems with self-management remains a major challenge. It is estimated that 38\% to 50\% of children are nonadherent to their antiepileptic medication within the first 6 months of initiating therapy.\textsuperscript{62,63} This may be due to their desire to appear and feel normal, the unrelenting side effects of medication, and disempowerment. Treatment failure also can result in patients losing confidence in traditional health care and disengaging from the system. To promote empowerment and independence in self-management, we suggest involving children in age-appropriate discussions and education on the disease processes, self-management (such as avoiding sleep deprivation), and treatment options.

In epilepsy, there are some distinct difficulties with transition from pediatric to adult health care. Some adolescents believe their epilepsy will resolve during childhood, and therefore feel unprepared to accept the chronicity of their disease or assume responsibility for self-management. This suggests that clinicians need to address patient...
expectations regarding the likelihood of remission from the onset of care, as disappointment can potentially lead to disengagement from health services. This will also help in improving readiness for transition and self-management.

Our findings also confirmed the limited access to government organizations and assistance by health care providers, patient advocates, and patients themselves. We suggest practitioners and allied health professionals support adolescents and young adults with epilepsy in applying for disability status, attaining concession for medications, and securing adequate employment. In the United States, although epilepsy is included in the Americans With Disability Act, patients are not fully protected from employment discrimination, and Social Security disability benefits may be withheld in cases of controlled epilepsy.

Our findings also suggested that those with epilepsy face major challenges in attaining employment. Liaising with school career advisers to investigate “risks” associated with certain jobs, such as long hours and memory work, can combat this. Researching flexible job alternatives, such as those with the option to work from home, also can be helpful. Clinicians also may consider providing work-related guidance on managing the condition in the workplace, including sick leave and whether epilepsy is a recognized medical condition. A closer open dialogue among clinicians, patients, and employers can assist in introducing work adjustment policies, such as allocating those with epilepsy roles that do not involve extended time at computer screens or with machinery. To facilitate access to a broader range of jobs, community transport services can be used. Table 4 presents some additional suggestions.

Although our review identified a broad range of patient perspectives, there are some knowledge gaps. Comprehensive and validated epilepsy-specific QoL instruments, for example the Adolescent Psychosocial Seizure Inventory are available, but may be further adapted to capture patient-relevant domains relating to concerns about the fragility of the brain, familial reaction, satisfaction with health care (including information), and preparedness for transition to adult services. Parent-proxy report measures also may be a useful addition to the child’s self-assessment to provide insight into the family dynamics of coping with epilepsy.

Randomized controlled trials have demonstrated the efficacy of supportive and problem-solving programs in improving treatment adherence. Further randomized controlled trials are needed to investigate the impact of age-appropriate education on epilepsy and seizure management, and interventions to improve patient QoL. More research is recommended to assess perceptions and concerns about fertility and pregnancy in adolescent patients with epilepsy, as these topics had not been addressed in depth in current studies. Further research is also warranted to address patient concerns regarding the heritability of the disease.

Children and adolescents living with epilepsy experience vulnerability, disempowerment, and discrimination. Treatment failure and prognostic uncertainty can raise doubt about the attainment of remission or future independence. Treatment and management should address the psychosocial needs of patients regarding stigma, present lifestyle limitations, and future concerns. These suggestions may inform strategies for practice and research that may contribute toward the improved QoL, therapeutic satisfaction, and health outcomes of children and adolescents with epilepsy.

**ABBREVIATION**

QoL: quality of life
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Pediatrics 2016;138;
DOI: 10.1542/peds.2016-0658 originally published online August 10, 2016;

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