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I just want to be normal: A qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life

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Abstract

This qualitative study explores how children and adolescents with medically refractory seizures experience the impact of epilepsy on their quality of life (QOL) within the domains of physical, emotional/behavioral, social, and cognitive/academic function. Semi-structured, open-ended interviews were conducted with 49 participants (7–18 years old). These narratives constituted our data source. Analyses involved inductive generation of themes/subthemes and connection of these themes to generate a theoretical representation of their relationships. These themes reflected the negative impact of epilepsy on QOL: physical—excessive fatigue as a barrier to academic and social pursuits; emotional/behavioral—intermittent emotional distress heightened by epilepsy-related factors such as unpredictability of seizures; social—profound social isolation; and cognitive/academic—discontinuous, fragmented learning. Youths perceive seizures as the major barrier to their sense of normalcy, setting them apart from others. Findings provide direction for assessment and evidence for developing or enhancing clinical interventions and community/school-based programs that might mitigate some of these negative experiences.

Keywords: Children and adolescents; Epilepsy; Intractable seizures; Quality of life; Qualitative methodology

1. Introduction

The last decade has witnessed a steady evolution in the documentation of quality of life (QOL) in children and adolescents (youths) with epilepsy [1]. The majority of these studies have used various standardized measures to systematically examine the various conceptual components that now commonly constitute health-related quality of life (HRQOL) in childhood epilepsy [2–12]. While quantitative methods provide some measure of what life is like for youths with epilepsy, methodology using a qualitative approach yields personal narratives that inform us about individual experiences and perceptions [10,13–15]. Ronen et al. [15] found in their qualitative study that children with epilepsy revealed "meaningful and important issues in quality of life beyond what parents and health professionals expected" [p.71]. Data that are qualitative also illuminate important processes, linking elements that can otherwise appear static [16].

Although the application of qualitative methodology is becoming more common in the investigation of HRQOL in children and adolescents with other medical disorders, this methodology is infrequently reported in

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the childhood epilepsy literature. We found only five qualitative childhood epilepsy studies [10,13,14,17,18] that focused specifically on child or adolescent perceptions of their QOL. Of these, two reported qualitative data as a component in developing HRQOL instruments [10,17]. A third study [13] explored adolescent perceptions of QOL following epilepsy surgery.

We concluded that there was an opportunity to further build on our understanding of how children and adolescents with medically refractory epilepsy perceive the impact of epilepsy on their QOL using a qualitative approach. More specifically, we were interested in listening to, documenting, and re-representing what youths themselves had to say about their QOL. Although there is some acknowledgment in the literature regarding the need for research focused on the child's own experience of an illness [19], overall, the child's voice is not one that has been typically reported in clinical research [20]. Woodgate [19] provides evidence that children are "capable and willing to tell their stories" [p.160], but suggests that researchers require a paradigm shift in their thinking, one that "views children as competent beings with important contributions to their world" [p.160]. Consistent with the process of a grounded theory method [21] we used the findings from our study to generate a theoretical model of HRQOL that is more specific to the processes described by these youths and that reflected their experiences.

2. Theoretical orientation

This study was informed by a number of constructs that now commonly constitute subjective HRQOL in children and adolescents with epilepsy: physical and psychological well-being and social and cognitive/academic adaptation in daily life [2,5,17,22,23].

Knowledge of developmental theory [24–26] is also pertinent to the study of youths with epilepsy as it provides a framework for understanding the capacity of children to view themselves, their illness, and others. Furthermore, it distinguishes the various stages of physical, emotional, social, and cognitive development and the normative tasks associated with each stage [25]. Children are capable of evaluating their global sense of self-worth, as well as making domain-specific evaluations of their competence (scholastic, athletic) and selfhood (social acceptance, physical appearance, and behavioral conduct) [24]. A child's sense of competence is derived from his or her interactions with a defined reference group (e.g., children in the classroom, siblings) [27]. As children reach the adolescent years, they become increasingly self-reflective and sensitive to how others evaluate them [24]. The major task of adolescence is transitioning into a more integrated personality with a stronger sense of "self-identity" [25]. This comes about as youths become increasingly autonomous, spend more time with peers, and prepare for secondary education or employment after high school.

Our interview questions were informed by these aspects of developmental theory. It is important, however, to note that these developmental tasks were not used as the gold standard against which the child's or adolescent's functioning was measured. Instead, an assumption was made that developmental tasks represent normative standards that are internalized by children, their peers, parents, and significant others in their life. These tasks have the potential to become the standard against which youths compare themselves, as the dominant discourse about what is "normal" is an important one to consider in the interpretation of findings [28]. This is consistent with the interpretive nature of our study [29]. Each child makes sense of, organizes, and gives a voice to his or her social world in a manner that is relevant to him or her. It is this narrative that forms the basis of our study.

3. Methods

This qualitative study was part of a larger longitudinal, prospective, multimethod study that explored the different components of HRQOL and cognitive outcomes in children and adolescents undergoing epilepsy surgery and a comparable group of youths who had medically refractory epilepsy [30]. The multimethod design of the larger study used quantitative measures, as well as semistructured interviews with youths and their mothers. This particular study draws from interviews that were held at baseline with youths involved in the larger study, all of whom were still undergoing investigations for surgery. We chose to combine the interview data, as at the time interviews were conducted, sufficient medical information was not yet available for most youths to determine whether or not they would be candidates for surgery. Subsequently, 33 participants were considered for surgery and 16 were not surgery candidates.

3.1. Participants

Fifty-one children and adolescents (7–18 years old) with medically refractory seizures (intractable epilepsy) were consecutively recruited through the Epilepsy Monitoring Unit (EMU) at the Hospital for Sick Children in Toronto between 1997 and 1999 by a research assistant. Two participants did not provide adequate responses during the interviews and, therefore, were excluded from the analyses. Of the remaining 49 participants, 18 were 7 to 12 years of age (children), and 31 were 13 to 18 years of age (adolescents). Forty-six of the participants were Caucasian; two, Asian-Canadian; and one, African-Canadian.

The Hollingshead Four Factor Index of Social Status was used to calculate the socioeconomic status (SES) of each family [31]. Eighty-two percent of the sample were in the middle to upper-middle socioeconomic group. Each child's neurologist had confirmed that seizures remained uncontrolled and were refractory to conventional antiepileptic drug therapy. This method of recruitment is consistent with purposeful homogeneous sampling [32] in which all participants are identified as having a similar characteristic, namely, refractory seizures. A more complete description of seizure frequency and other investigations can be found in a previously published article by the authors of this study [33].

Table 1 lists the demographic and seizure-related characteristics of the participants. Seizures in all had failed to respond to at least two antiepileptic drugs (AEDs). Exclusion criteria for the original study were as follows: (1) age less than 7 years, determined by the age appropriateness for interviews (the upper age limit was 18 years, the oldest age treated at the hospital); (2) a geographic location that would make the follow-up evaluation unfeasible (children from outside the province or from other countries); (3) inadequate English on the part of the child to complete the interviews; (4) impaired cognitive or language skills that limited the child's ability to understand and respond to interview questions.

Table 1
Group demographics and seizure-related variables

Sex	
Male	24
Female	25
Total	49
Numbers by age	
Children (7–12 years)	18
Adolescents (13–18 years)	31
Age at interview	
Mean(SD)	13.66 (2.97)
Range	7.35–18.28
Age at seizure onset	
Mean(SD)	6.18 (4.22)
Range	0–14
Number of AEDs	
0	1 (2.0%)
1	12 (24.5%)
2	28 (57.1%)
3	8 (16.4%)
Full scale IQ	
Mean (SD)	83.86 (19.00)
Range	46–137
Numbers across IQ ranges	
7	46–65
18	66–85
14	86–100
10	101–137

3.2. Procedure

This study was approved by the Research Ethics Board (REB) of the Hospital for Sick Children, Toronto, Ontario, Canada. Informed consent was obtained from the parents, and informed assent or consent from each child/adolescent, in accordance with the REB guidelines. A research assistant contacted families and children during the EMU admission. If they agreed to participate, outpatient appointments were arranged at the Hospital for Sick Children or in the family's home.

3.3. Data collection

We used a semistructured, open-ended interview with questions intended to elicit responses within the physical, psychological (emotional/behavioral), social, and cognitive/academic domains that constitute HRQOL. Younger children were generally more comfortable using a puppet to interact with the interviewer. Our previous experiences suggested this approach would likely elicit more information. All youths participated in the interviews. However, given the age range and variability in cognitive skills, some were better informants than others. We asked the participants to comment on how epilepsy impacted on each domain of functioning. Examples of interview probes are included in Appendix A. Interviews ranged from 20 minutes to 1.5 hours. The interviews were conducted by one of the investigators (I.E.) or a research assistant. The investigator (I.E.) is a nurse practitioner who had direct clinical involvement with most participants during their admission to the EMU or through the Neurology Clinic. The research assistant, a psychometrist, had previously administered neuropsychological tests during one or two visits. The dual role of clinician and researcher is not necessarily a problematic one in qualitative research. A previous relationship with youths can be considered a strength for two reasons. Participants are more likely to be comfortable with someone they already know. Second, prior knowledge of these youths informed the interviewers on how best to pose questions. Furthermore, in-depth knowledge of a population contributes to the trustworthiness of the analysis. Keeping the unique aspects of the researcher/participant relationship in mind, the interviewer (I.E.) was also sensitive to the unique ethical challenges this poses to the assent and consent process [34].

3.4. Data analysis

In qualitative research the "power" of an analysis depends on a number of factors such as the quality of the information obtained per participant, scope of the study, nature of the topic, and number of interviews held with each participant, as opposed to number in the sample per se [35,36]. Our sample size exceeds Morse's [37] recommendation for ethnographic and grounded theory studies. We chose to continue collection of data beyond when theoretical saturation may be obtained [38] because we were interested in the frequency with which themes and subthemes appeared as well as the salience of those themes.

Forty-nine of the fifty-one interviews were subjected to qualitative analysis. 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, the first phase of analysis, involved the inductive generation of codes and subcodes which emerged from the reading and rereading of text segments. During the second phase of analysis, we used axial coding to reorganize these codes conceptually and we identified salient themes that captured the essence of the representations that youths held of their life with epilepsy [39,40]. During the final selective coding phase of analysis, we organized core categories and subcategories within each conceptual domain and conceptually connected to one another, generating a theoretical representation of relationships among the concepts. We have chosen to address rigor in this study using the criteria developed by Lincoln [41] and Erlandson et al. [42]. In the qualitative paradigm, credibility, transferability, dependability, and confirmability are the equivalents to internal validity, external validity, reliability, and objectivity used in the quantitative paradigm [41]. Table 2 summarizes of how properties of rigor were established in this study.

4. Results

Findings from this study revealed much about the intrusive role of seizures on all aspects of youths' lives. Even younger children, and those with low IQs, indicated some appreciation of the meaning epilepsy had on various aspects of their lives. A summary of the results includes key themes that emerged within each domain of the analysis, together with representative quotes to illustrate themes (female = f, male = m, age = number), and a brief focused discussion.

4.1. Physical domain: excessive fatigue, sleep, and anergia/inertia as barriers to normal academic and social pursuits

A large proportion of youths in this sample (76%) reported excessive fatigue as their major somatic complaint. Although less frequently mentioned, other somatic complaints attributed to seizures or effects of antiepileptic drugs included headaches, hair loss, sore mouth from seizures, visual disturbances, clumsiness, increased appetite, weight gain, and dizziness.

4.1.1. Fatigue

Youth narratives revealed how intermittent or continuous fatigue made it difficult for them to think clearly and be available to participate in academic endeavors. For some youths, excessive tiredness was experienced only at the time of a seizure and might last for a short period, minutes to less than a half-hour, and, thus, they were then able to quickly return to normal classroom

Table 2
Establishing rigor for this qualitative research study [41,42]

Quantitative term	Qualitative term	Components in this study	Process in this study
Internal validity	Credibility	Prolonged engagement	In-depth knowledge and experience in the field of childhood epilepsy >15 years
		Triangulation	Different sources used: (1) a second reader with previous qualitative research experience independently read several representative transcripts (grouped by age and sex) for emerging themes and subthemes; (2) maternal interviews (subject of another paper); (3) results of other studies
		Peer debriefing	Repeated consultations with co-investigators and other clinical experts in the field of epilepsy (pediatric neurologists, psychiatrists, nurses, social workers)
		Member checking	Feedback: focus groups with youth participants and their parents
		Reflexivity	Self-reflective description of potential bias and perspectives due to relationship with participants
External validity	Transferability	Thick description	Detailed description of sample, including methods, timing of data collection, and location
Reliability	Dependability		Two co-investigators independently scrutinized data (quotes) and assigned themes or subthemes that were then compared with those of the first reader
			Second/third reader confirmed quotes matched themes and subthemes with those of the first reader
Objectivity	Confirmability	Audit trail	Audit trail of tapes, transcripts, reflexive notes, data reduction and analysis, as well as theme construction, maintained throughout study and available for review

activities. For others, the persistent fatigue and need for sleep that accompanied their seizures could last hours or a whole day. This meant youths either missed going to school or were unable to remain at school. More commonly, children and adolescents experienced fatigue as a continuous occurrence that at times was made worse by a seizure. Both scenarios made it difficult for youths to fully participate in classroom learning, as illustrated in these quotes:

"Sometimes when I'm at school if I'm working ... I have to put down my pencil and put my head down for a sec cause I can't hold my head up I'm so tired" [*f*, 11].

"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" [*m*, 17].

4.1.2. Need for more sleep

Fatigue meant that youths needed more hours of sleep than usual. Extended naps during the day and earlier bedtimes further reinforced how, physically, these youths were different from their siblings or peers:

"[I'm] tired a lot ... sometimes [take] naps after school ... two to three hours ... not everyday ... [my] brother and sister don't need naps, neither do other kids" [*m*, 10].

"[S]ome kids go to bed at 10 o'clock and I go to bed at 8:30" [*m*, 10].

"I think I am more tired. Do you find that out often [with other kids]? I went to bed one day at 5 (p.m.) and then woke up in the morning ... I went to bed yesterday at 6 at night ... I get tired and I sleep on the bus often." [*m*, 15].

The tone of the above statements hints at the sense of frustration and unfairness with which these children viewed needing more sleep than others.

4.1.3. Anergia, inertia

Fatigue was also represented as anergia or inertia, which negatively affected youths' ability to participate fully in typical age-related physical and social pursuits. The participant in the following example, when asked to comment on what, if any, effect seizures had on her physical activity, explained how her endurance for swimming and running was compromised:

"I can do a few laps but then I have to stop and just take a break ... also long endurance running is a big one 'cos when I was in grade 8 they made us run around the block and they would time us. By the time I was around the block I just ... was basically falling down" [*f*,14].

Participants who experienced inertia used words such as "draggy" and "lazy" and ascribed this state to a variety of factors including seizures, antiepileptic drugs, or a personal flaw:

"I kind of feel draggy like I if I don't try to I don't often get up and do new things um so I guess uh I'd be a bit draggy, couch potato ... whatever ... I stay at home I don't go out that often" [*m*, 15].

"I think that, that's because I am especially lazy, and don't want to go out and just sit on the couch instead, depending on how much sleep I have gotten ... I'd rather just be in bed, but um ... sometimes I'll just come home and sprawl on the couch and fall asleep if I'm really tired, or I'll just lay down forever" [*f*, 17].

4.2. Emotional/behavioral domain: intermittent emotional distress heightened by epilepsy-related factors

Intermittent heightened emotional suffering emerged as an important theme. Although 63% of participants identified feeling "happy" some of the time, the 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. Narratives were punctuated with words that powerfully identified their suffering: "worry," "fear," "anger," "pain," "sadness," "depression," "trauma," "frustration," and "embarrassment." Worry or fear (associated with the unpredictability of seizures) (49%), sadness, dysphoria, or depression (45%), and anger and frustration (67%) were often connected to and, therefore, appraised as emanating from the experience of having seizures, medication side effects, or extent of parental monitoring.

4.2.1. Unpredictability of seizures and loss of control

Emotions surrounding the unpredictability of seizures and loss of control reflected youths' worry about "what if" a seizure happens and this concern overshadowed their lives. In the following three examples, the apprehension and worry about injury, or even death, that surrounded an anticipated seizure are apparent:

"I panic almost every time they go happen to me" [*m*, 10].

"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" [*f*, 16].

"I thought that I was gonna ... I was maybe I wasn't going to be able to breathe 'cause I got tripped [with the seizure] ... sometimes I worry if I go down [with a seizure] ... I'm going to get hurt more ... that I may die or something" [*m*, 11].

In another example, this adolescent reported that she had no memory of what actually happened during her nocturnal seizures (hypermotor activity and screaming). Yet at some level she experienced emotional distress. The experience of sleep, usually viewed as a restful, restorative experience, was for her fraught with moments of terror:

"[It's like] being in a nightmare really and you can't really wake up or just something ... [it's] so traumatizing [that] this [seizure] has happened" [*f*, 14].

Finally, the embarrassment and stigma associated with having a seizure and the uncertainty of when and where the next seizure might occur made it uncomfortable for some youths to be around their peers:

"I worry about having seizures in very large crowds um and at school especially it's often embarrassing" [*m*, 15].

4.2.2. *Intermittent feelings of sadness, depression*

Various degrees of sadness or dysphoria were experienced as fluctuating from hour to hour or day to day. Attempts to label or define differences between sadness and depression and pain did not always yield clear distinctions, as indicated in the next few quotes:

"I would get sad about nothing ... I get a sad feeling 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" [*f*, 13].

One young boy used a puppet's voice to explore his own pain and sadness:

"[S]ometimes he feels a lot of pain ... well, sadness, normal sadness ... right here (points to his head) ... it just makes him feel sad, or cry or something" [*m*, 11].

In other instances, youths revealed more disturbed emotions that included thoughts of suicide:

"[I] tell you in the past two years, because of my epilepsy and everything ... the thought of suicide has been in my head ... I'd say four to eight times ... I don't want it going through my head anymore and that's why I want the surgery to be successful ... once, I had the knife at my wrist and my mother came in and I just pretended I was drying it" [*f*, 15].

4.2.3. *Frustration and anger*

Children and adolescents expressed feelings of frustration and anger that they often attributed to their seizures, medications, or their perception of excessive parental monitoring. The following example clearly captures this particular adolescent's frustration with her seizures:

"I could have any number in a day, anywhere from 5 to 10 in a day ... that's just so frustrating, especially when I'm like sitting in class or something ... I hate having seizures" [*f*, 17].

In another example, a youth revealed how antiepileptic medications affected her mood state, increasing her irritability. She further described how often her feelings were usually directed toward family members:

"I have all the medication effects ... [I'm] miserable ... I wanna claw somebody's eyes out ... and the usual person ... usually the first person to cross my path is my dad or my brother" [*f*, 13].

Some youths depicted how they became angry at the time of a seizure. Angry feelings sometimes escalated to physical aggression. In the following passage, this young boy was able to clearly explore his feelings about the experience of having a seizure and provided further insights into his subsequent physical aggression:

"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 but sometimes I'm kind of mad at my seizures, not the mean thing ... I'm not meaning to hit people ... I'm just mad at my seizures" [*m*, 7].

Finally, a small proportion of youths reported frustration and anger that were triggered by parental monitoring (seizure safety issues and compliance with medications). Two participants depicted their experiences:

"[E]verything [makes me angry] ... when I'm in a ... angry mood, I can get along really bad, with mum and dad, especially dad ... they [parents] say all kinds of things like ... no, I can't leave you swimming here because, um, the other parents don't know your medical history ... it makes me feel ... angry, frustrated" [*m*, 12].

"I used to be a happy-go-lucky guy and all this but now, because, I have to take my medication all the time, and my mom and dad are constantly on my back for it ... I'm pretty angry. I had to go to anger management there, about a month ago" [*m*, 15].

4.3. *Social domain: profound social isolation*

In this study, both children and adolescents discussed aspects relating to the quality and quantity of their social interactions with friends and the larger peer group. Even as youth described the presence of and satisfaction with meaningful friendships, at the same time, social isolation presented as a dominant theme in their narratives. Their sense of social isolation arose from (1) internal constraints (lack of self-confidence, feeling alien or different), and (2) external constraints (exclusionary behavior by peers and perceived excessive parental monitoring and limit setting). However, not all experiences were negative. Some participants reflected their resilience by taking positive action in response to teasing by peers.

4.3.1. Variability in the meaning of close friendships

Although 65% of youths described "close friendships," there was considerable variability in how they defined a "close friend." For some, a close friendship meant socializing with a single peer at school. This was particularly true among the younger children, who rarely identified close friendships beyond the school setting. Adolescents, on the other hand, defined "close friendships" as having access to a number of friends both at school and at home. For many youths, satisfaction with friendships incorporated epilepsy-specific support. This took the form of "physical support" (knowing what to do during a seizure) or "psychological support" (protecting and advocating for the youths). In the following quotes, the first statement highlights the comforting experience of physical support from friends, while the second example characterizes the experience of psychological support:

"I'm okay at school ... like my friends know what to do if something happens and they know where the Ativan is if something were to happen and one of my friends has seen me have one before so she knows what to do ... so ... I'm okay there" [*f*, 14].

"[M]y friends are pretty nice ... they kind of like stick up for me or something, like if someone else sees it [seizure], or something, they'll go over and talk to them or something ... yeah, I've explained it basically to all my friends, and that's why they don't really say anything" [*m*, 15].

Even participants who had relatively close friendships sometimes experienced a sense of profound separateness and isolation. The barriers to social inclusion that they identified were either directly or indirectly connected to having seizures. These barriers were personal (e.g., aspects specific to the youths) and environmental (e.g., exclusionary behaviors by others and limits imposed by parents and others).

4.3.2. Barriers to inclusion: personal

Youths described aspects of their emotional self that influenced the degree to which they were able to participate in their social milieu. They referred to lacking self-confidence, hesitating and restraining themselves in social interactions as they experienced uncertainty regarding their ability to be successful and to feel safe. Consequently, some youths identified feeling separate from, even alien from, their peers and, therefore, not belonging in a social sense. Quotes from two female adolescents clearly illustrate their lack of self-confidence. They attributed this to not always being able to count on their bodies (as they might have a seizure) and, therefore, restricting themselves from engaging fully in social activities:

"I think my seizures kind of affect the confidence part because 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" [*f*, 17].

"I feel like it's not it's almost like there's not a day that goes by that I don't think about it and it's not like I obsess over it's just there's something somewhere that makes me realize oh yeah I can't do that because of this [seizures]" [*f*, 14].

Another youth, who had several close friends, described how she still experienced feelings of emotional alienation and isolation:

"I have thought that ... I don't really belong ... yeah like when I say I don't belong here I feel like ... I should have never been born ... sometimes I've thought that I could just be invisible and nobody would really care ... or I could not be here and nobody would notice and I just felt basically like a nobody" [*f*, 14].

4.3.3. Barriers to inclusion: peers

Even those who had close friends sometimes suffered from exclusionary behavior. This took the form of being labeled, teased, and bullied by their peers; being portrayed by their peers as "different"; and being excluded from social activities. The most frequently cited exclusionary behavior experienced by the participants (65% of youths) was that of being labeled, teased, and/or bullied by peers. The following quotes provide clear examples of these hurtful encounters:

"Yes, I've been teased ... people call me special ed ... like I'm a 'special ed' kid ... I'm one of the smartest kids, not bragging, in my class and having epilepsy or having encephalitis, seizures has nothing to do with how your mind works ... People say, 'hmm, you shouldn't be in my class ... you should be in a special ed. class the whole year with other people who have seizures,' and things like that ... and I think that's disgusting" [*f*, 13].

"[M]ost of my life ... I've been teased or ... beat up and the first week of high school, I was beat up ... I don't know 'cuz the female felt like it ... most of the people at the ... school know that I have ... epilepsy or seizures ... makes me upset really" [*f*, 15].

Youths sometimes depicted in their narratives how they thought others negatively portrayed them:

"Sometimes well some, some people ... just like think that I'm ... kind of like ... weird ... cause I have epilepsy" [*m*, 12].

"[T]hey think I'm really different ... how I have my seizures" [*f*, 13].

Younger children talked about being excluded from play. This young girl illustrates similar experiences described by other children.

"Sometimes ... all the time, they [kids at school] never play with me" [*f*,7].

4.3.4. Barriers to inclusion: limits imposed by parents and others

Approximately 80% of youths expressed an opinion that parents were excessively worried about them because of their seizures. They described parental vigilance and monitoring that occurred during the daytime and during sleep at night. Although youths 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. The following statements clearly reveal their frustrations:

"[W]ell, I can't really do all things ... I've missed a lot ... camps, school trips, things like that ... a lot of fun stuff ... they [parents] won't let me do a lot of things out on my own, because they've worried about what will happen ... oh, swimming, stay out longer, biking ... they just say, they say all kinds of things like ... no, I can't leave you swimming here because um, the other parents don't know your medical history" [*m*, 12].

"I am not allowed to be left alone at home by myself ... I have no privacy at all ... if I am left alone [and] one [seizure] hits ... I am sick and tired of it ... I want some freedom, I want to be able to go out with my teenager friends, I want to be able to go back to school ... sometimes I wish I could have a shower by myself but I know it's not safe" [*f*, 17].

4.3.5. Resilience: taking control

Despite their experiences with exclusion, some youths identified instances that demonstrated an inner resilience or defiance. These youths refused to succumb to victimization from their peers and took it on themselves to take control and find a solution. In the first example, an adolescent female explained how she had sought the support of a teacher to deal with her problem. In the second example, an adolescent female described how she assumed responsibility to change her situation by educating those who were teasing her:

"In school ... when I've had seizures ... the kids would say ... 'hey, there's the seizure female. Can you shake on the ground like how you used to?' and they would always make fun of me and call me names and ask me this and that and why this ... why that .... Finally, um, one day I said, 'I have to put a stop to it' so ... I told their teacher ... Their teacher talked to myself and them ... since then up to the last day of school they hadn't bothered me" [*f*, 13].

"Yes I do [get teased] and it's not from friends ... and so what happened ... is that 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]" [*f*, 14].

4.4. Cognitive/academic domain: discontinuous and fragmented learning

The majority (70%) of children and adolescents reported problems with memory and/or other aspects of learning. Analyses of the narratives revealed the most striking theme in the cognitive domain was that of youth not feeling they were physically or mentally available to learn and, therefore, unable to count on a continuous and integrated learning experience. We discussed earlier the problems with fatigue that decreased the quality and quantity of participation in the classroom. In addition to fatigue, problems with memory compromised their performance at school and had an impact on their sense of self-worth. This girl described the latter:

"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" [*f*, 14].

To better understand youths' experience of discontinuity in learning, a number of important concepts were identified, each of which shed some light on the processes involved.

4.4.1. Fixed or on-going memory deficits

Intermittent difficulties with memory were reflected in many narratives. Typical of younger children, this boy represented his experience with a terse statement:

"[I] don't remember well both for school and other things ... forget stuff at school ... homework and writing things down" [*m*, 10].

In contrast, adolescents generally provided more elaborate descriptions. The following two quotes portray how many of these youths experienced memory problems and provide some insights about their experiences with repetition as a learning strategy:

"[W]ell it's harder for me to remember stuff that I just learned ... I can barely remember what happened yesterday ... it just happens um for all the stuff I just learned but if I keep learning them again and again and again [so] I can't forget" [*m*, 15].

"[M]y memory ... I forget ... things and ... when the teacher's teaching me something ... those are only words coming out of his or her mouth so ... the teacher has to repeat it to me over and over and over, so finally I would get it and remember it, so like today they were teaching [me] something [and] teaching the same thing tomorrow so I wouldn't forget it" [*f*, 15].

4.4.2. Intermittent transient disconnections

Seizures and postictal periods frequently produced transitory memory impairments. This participant described how a brief seizure, in the context of a school day, would erase her memory for the whole day. Life for that period was forgotten, unrecorded for future recall:

"[Y]ou know I have the conversation and I have a seizure like this ⟨snaps her fingers⟩ just comes like that . . . I have the seizure . . . I complete it and then I forget everything . . . everything that I've done that day . . . everything that I'm going to say and usually it doesn't come back because it's almost like my mind has gone blank" [*f*, 13].

4.4.3. Impaired attention or concentration

Seizures and postictal confusion often contributed to difficulties in being able to attend to what was being taught and is clearly illustrated in the following example:

"[W]ell, it's kind of like because when I have those [seizures] . . . I get the disorientation and everything, so it's hard to focus on what the teacher's saying, or on what they are teaching at that moment. Or if I'm working, I kind of lose my train of thought, like in English or something like that, if you're writing an essay" [*f*, 17].

4.5. Overarching theme: seizures as a barrier to normalcy

The above analysis identifies some important aspects of how youths experience living with epilepsy. Put together, these aspects suggest that for many youths, seizures play a large role in their identity. These experiences are internalized in such a manner that the youths themselves feel "not normal" and "different" from their peers. The major perceived barrier to their normalcy is seizures. This sets them apart from others. One older adolescent male described his experience:

"I'm always kind of . . . separated from people that I know, in a way" [*m*, 17].

This feeling of alienation occurs at a time in their lives when the desire to be "normal", not "different" is highly valued. The tone of some of the narratives reflected an underlying sense of sadness or grief associated with their seizures and a steadfast belief that remission of seizures would confer on them a state of normalcy. It reflected their hope for an idealized "normal" self (Fig. 1).

"[I wish] I didn't have seizures . . . just to be a normal kid like everybody else. I would be a normal kid and it would feel great" [*f*, 12].

Finally, this sense of the abnormal self (with seizures) permeated all areas of physical (extreme fatigue), emotional (heightened distress), social (profound isolation), and academic (fragmented, discontinuous learning) aspects of their lives:

"[W]hy do I feel different I don't know . . . I just I know it shouldn't be like that and no one necessarily makes me feel that, but I think it's 'cause . . . everything I do . . . I guess with school or even if I just go out, I have to think about if I'm by myself, I have to think about . . . am I gonna be okay" [*f*, 17].

Removing the seizures reflected the importance of the "body" not being abnormal, not defying one, the rebirth of a new self, as clearly illustrated by another participant:

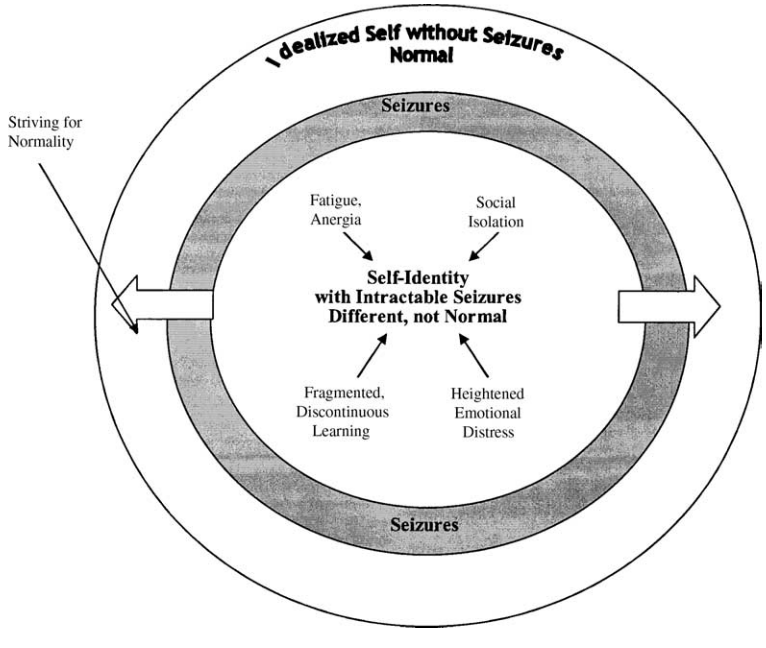

Fig. 1. (Intractable) seizures as a barrier to normal self.

"I would be a clean girl . . . like have nothing wrong with me . . . fixed, not broken . . . normal, just a normal person" [*f*, 17].

Their narratives suggested that they were in a continuous state of pursuit of "normal," reaching for but never quite arriving at that place where they would be like their peers. At the same time, the fact that youths upheld this idealized state as a destination to which they strove was perhaps not a negative, but rather a positive process insofar as it provided them with a sense of hopefulness for the future:

"[S]ooner or later if I don't have any seizures, I'll be able to be off the pills. And I'll like maybe have more energy and, you know, it'll be better. Schoolwork, hoping that I'll be able to do it better, like science. Um, like not needing as much help just like without any help at all maybe. 'Cos, I get so much help. It'll be better. They'll [peers] think I'm just a normal person" [*f*, 14].

5. Discussion

Overall, the youths in this study drew on their day-to-day life events and were able to generate a portrait of their competence and identity. Experiences attributed to their physical body, feelings and behavior, and social and academic worlds provided information that they could summon forth to represent to themselves and to others who they were and how they were. We were astonished and at times overwhelmed by the degree of suffering and distress that these children and adolescents endure. The patterns and rhythms of their lives were discontinuous, not as it should be, and seemed to generate a tension between that which is and that which should or could be. These sources of information yielded a sense of self that was "other than," "not normal," and "separate from" a self that would be without epilepsy. In this way, epilepsy was not integrated into their identity to a degree that allowed them to experience themselves as intact and good enough.

5.1. Physical domain

The critical elements of fatigue identified in this study (excessive daytime fatigue, increased sleep requirements, low energy) reflect a definition of abnormal fatigue proposed by Aaronson et al. [43]: "the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization, and/or restoration of resources needed to perform activity" [p. 46]. Few studies have examined self-perception of physical well-being in children and adolescents with epilepsy. More specifically, sleepiness and fatigue in children with intractable epilepsy are only beginning to emerge as a documented problem [13,16,44,45]. We found only one quality-of-life study [18] in which youths specifically reported on their somatic symptoms. The authors described excessive tiredness as the most common physical complaint among the 13 adolescent participants, with one individual reporting that "she had been asleep during all her primary school years" [p. 44]. Similar to our study, these authors report less frequently mentioned somatic symptoms that included weight gain, breathlessness, visual disorder, and dizziness.

5.2. Emotional/behavioral domain

Our findings highlight the quality of emotional distress experienced by these youths. These emotional experiences correspond to findings from other qualitative studies [15,17] in which 48 children and adolescents ranked hatred of epilepsy, social embarrassment (including teasing, bullying), fear of seizures, and injuries as some of their most important concerns. The unpredictable nature of seizures may contribute to the development of a more general sense of helplessness and loss of control. In an effort to avoid potential embarrassment and stigma, youths may socially withdraw from their peers, isolating themselves and limiting their social interaction [46].

Children and youths in this sample had some difficulty regulating affect and behavior. Some struggled to interpret their symptoms, uncertain as to whether or not they were depressed. Low affect, irritability, and frustration are symptoms that are risk factors for depression and anxiety [47]. Of interest, none of the youths in our study who experienced these symptoms were specifically diagnosed or being treated for depression or anxiety. Underdiagnosis of depression in epilepsy is common [48]. When systematically evaluated, rates of self-reported depression range from 10 to 26% in children and adolescents with epilepsy [49]. In our study, almost half of the youths described intermittent states of sadness and unhappiness. However, our sample had intractable epilepsy and rates of depression are already established as being higher among those with chronic active seizures [50]. Finally, the strong feelings that youths described were not represented as pervasive, but rather intermittent, which may make the diagnosis of depression or anxiety more difficult as the symptoms they described do not follow well-established DSM-IV criteria [51]. This point has been previously been made for adults, but has not been documented for children [52,53].

5.3. Social domain

The importance of epilepsy-specific support in intimate friendships suggests that knowledge of epilepsy management by close peers is important. Lach [16] found that the presence of helpful and competent peers differentiated youths with epilepsy who had better social experiences from those whose social experiences were problematic. The social isolation that adolescents experienced is consistent with findings from a recent qualitative study of adolescents in which "limitations of leisure" and "feelings of being different" are identified as important epilepsy-related strains [18]. Another qualitative study of adolescents with intractable epilepsy also identified peer acceptance as a major concern [14]. The analysis in that study suggests an association between social isolation and lack of peer acceptance.

One of the most distressing aspects of the findings in this study was the extent to which participants reported being teased about their seizures and bullied by their peers. Unfortunately for most participants, disclosure of their epilepsy was not a choice because the intractable nature of their seizures meant that at some point they would have a seizure in the presence of peers or others. The definition of bullying described by Peplar and Craig [54] is consistent with how bullying was coded in the analysis. The problem of bullying and teasing is emerging in other studies of children with epilepsy [14,15,55]. Rates of bullying and teasing reported by these children and adolescents are similar to those reported by their mothers in our larger study [16], in which 85% of mothers reported that their child had been bullied or teased. The concern with repeated exposure to bullying and teasing, and even to social isolation and exclusion, is that over time these experiences reinforce more stable schemas and scripts that children then draw on for interpreting social cues and their social self-perception [56]. This means that in due course, they may begin to internalize messages about "self" and "other" in a way that is not particularly facilitative or helpful.

The limit setting and monitoring that youths described as constraining and contributing to their social isolation are consistent with what mothers reported about their own parenting behavior [16]. Monitoring is viewed as necessary for the purpose of safety, and mothers set limits on what they perceive to be potentially dangerous activities or situations. Unfortunately, this restricts youths' exposure to opportunities and building of skills necessary for their functioning as young adults.

Finally, the "taking control" approach described by some of the participants in this study is similar to the concept of self-efficacy [57], which has been identified as a protective factor in the childhood development literature [58]. This suggests that interventions targeting specific protective factors (such as self-efficacy) may improve psychosocial outcomes for youths at risk [59].

5.4. Cognitive/academic domain

Memory and learning issues identified by this group of youths correspond to objective neuropsychological findings from the same group of participants [30] and are consistent with literature on cognitive deficits in epilepsy [60–68]. What stands out as different from other studies is the rich portrayal of memory and attention problems by these youths and their accounts of how these difficulties negatively affected day-to-day learning in school. We found only one qualitative study [17] in which youths themselves ranked the negative effect of epilepsy on cognition as an important concern. In contrast, academic difficulties were not highlighted as an issue in a more recent qualitative study [14]. In this latter study, the fact that 19 of their 22 participants were in a mainstream school might account for this difference. More than 95% of our sample had some special education considerations/services, and given that our participants were being investigated for surgery, our sample might have included a more neuropathologically compromised group.

It has been documented that inattentiveness is a frequent observation of parents and teachers of children with epilepsy [69]. Our findings demonstrate that the youths themselves are aware of this impairment. Of interest, a number of youths in our study attributed aspects of memory and other learning problems to poor attention and concentration. This finding corresponds to a recently published childhood study in which cognitive and psychological predictors of everyday memory were explored in 37 children with intractable epilepsy between 7.3 and 17.9 years [70]. The authors found that a parent-report measure of attention was the most significant predictor of everyday memory ratings by both children and their parents.

5.5. Seizures as a barrier to normalcy

Participants in this study viewed their refractory seizures as a major barrier to feeling "normal" and "not different" from their peers. Removal of the seizures would confer on them a new "normal" self. The quest for a life that is considered normal, not different, is part of what adolescence is all about. Even young children compare themselves with their peers and worry about appearances that differentiate them from their peers. The concept of normalization has been applied to families of children with chronic health conditions [71] and to adults with disabilities [72]. This concept, however, has emerged from literature that is mostly adult- or parent-based. Little has been documented about how children experience this phenomenon of normalization. Unlike adults or parents, children and adolescents place a high value on that which is considered "normal" and tend to evaluate their life given their internalized construction of "normal." This is significant insofar as the extent to which children in this sample viewed their life as "normal" was part of what constitutes the evaluation of their quality of life [10]. It is important to acknowledge that what we consider normal is socially constructed [73] and that messages youths receive about the extent to which "difference" is tolerable are also informed by what is sanctioned by their social world as desirable and attractive. Therefore, their desire for normalcy is both a developmental (psychological) and social phenomenon.

5.6. Future directions: implications for research and practice

The subjective experiences of fatigue and lack of energy described by these youths should enlighten parents, teachers, and others, who in our experience, frequently label these youths as "lazy," or as "lacking in motivation," or, perhaps, "depressed." Given that researchers are now able to track and validate the disrupted sleep patterns of children with epilepsy [74], the next step should be to examine how this phenomenon influences the child's level of energy and behavior during the day. Furthermore, the impact of fatigue and decreased energy needs to be more systematically evaluated as a dimension of quality of life [11]. This remains an important area for further research as this seemingly "somatic" problem may have implications for the development of youths' sense of physical and scholastic mastery, social independence, emotional well-being, and, ultimately, self-identity.

These results highlight the need for diagnostic clarification (DSM-IV) of mood disorders in youths with epilepsy. Furthermore, the lack of documented interventions to assist children and adolescents suffering from anxiety and fear directly related to their seizures, as well as mood disorders, reinforces the need for research that explores clinical interventions that might help youths allay or manage their emotional angst [49,47,75].

Integrated school environments provide a natural laboratory for promoting supportive interactions between youths who have a chronic health condition and their peers [76]. However, Bell and Morgan [77] caution that health-related information may be stigmatizing and do little to change the attitudes of peers. We previously noted that self-efficacy has been identified as a protective factor [58], suggesting that interventions targeting self-efficacy may improve psychosocial well-being.

The implications of disruptions in learning for latency-aged children are the risk of failure to attain concrete thinking skills that provide the foundation for more complex learning during adolescence and the risk of undermining children's sense of scholastic competence, self-esteem, and eventual quality of adult life, that is, success in long-term educational and vocational goals [78–80]. Finally, there are social implications when children have learning disabilities. They are less liked by their peers and are more frequently rejected from social situations with peers than students without disabilities [81].

5.7. Limitations

Although there is literature that supports interviewing as a medium for eliciting views of children as young as 6 years of age [82], we found that the younger children in our sample were easily distracted and contributed less detailed responses than did older youths. This difference may be in part a function of their stage in development, as the younger group was not overrepresented with attention and memory/learning difficulties when compared with adolescents in this study. Although one-on-one interviews with younger children in this study indicated some appreciation of the meaning epilepsy had in their lives, utilization of focus groups and case vignettes successfully used by other researchers [10,83], potentially, could have yielded more fully the meaning of epilepsy in the lives of these children. We did not address the significance of gender in relation to quality of life in this article. Further exploration of this topic would add to a small base of evidence in the pediatric epilepsy literature, which at present contains mixed findings [3,5,84] and lacks youths' own perspectives. Finally, these findings can be applied only to children and adolescents with intractable epilepsy.

6. Conclusion

This study has contributed to research on how children and adolescents experience the effects of intractable epilepsy on their QOL. We recognize that this analysis provides further evidence of the extent to which intractable epilepsy is experienced as a personal tragedy. This "medical" perspective is challenged by the social model of disability, which locates the "problem" not in the individual, but rather in sociocultural factors [85]. Notwithstanding the significant contribution this model has made to our analysis of challenges experienced by individuals with disabilities, we believe that it is an adult-based model that is not informed by the voices of children and youths. Therefore, we cannot nor should not ignore the individual child's internal experience of their seizures, their body, and the world around them. Not only does this study provide some direction as to what should be evaluated in the psychosocial assessment of youths, it also provides evidence for the development of clinical interventions and community- or school-based prevention programs that might mitigate some of the sequelae that have been described. Future studies should more actively seek to validate the findings using measures that tap into the dimensions that have been elicited in this study. Prevalence of bullying and teasing, measures of friendship (quality) and peer group status, evaluation of depression and emotional distress associated with the unpredictability of seizures, as well as evaluation of parent–child relationships are needed to further substantiate some of the issues that have been described in this study.

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Appendix A.[1]

A.1. Examples of interview probes with younger children (7–12 years)

A.1.1. Physical domain

Do you think that you need to go to bed earlier or at the same time as other kids your age? Do you ever take naps after school? (If yes, why?). Do you ever feel sick, have pain or funny feelings in your body? Do you think your medicine or seizures cause any of these feelings or something else?

A.1.2. Emotional/behavioral domain

What are some things that make you happy? Sad? Mad? Afraid? How do your medicine and seizures make you feel?

A.1.3. Social domain

Tell me about the kinds of fun things you like to do with friends or by yourself; for example, some kids like to play hockey or ride a bike or play video games? Is there anything you're not allowed to do that other kids are allowed to do because of your seizures?

A.1.4. Academic/cognition school

What do you like best about school/least about school? Do you ever find it hard to remember things at school or do you find you remember things really easy? Do you think your medicine or your seizures ever make school more difficult for you?

A.2. Examples of interview probes with adolescents (13–18 years)

Can you describe for me what life has been like for you lately in the following areas? Physical well-being? Emotional well-being? Social relations and activities? Learning/academic performance. For each of these areas, the adolescent is asked for details of the experience, what it feels like to them, and the significance or meaning of that experience: Can you give me an example of when that happened and how it happened? What did it feel like for you? How would you explain it or make sense of it?

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[1] Interview probes were adapted throughout the interview, according to responses of the participants.

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