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**Living with Epilepsy in Adolescence – A Qualitative Study of
Young People’s Experiences in Singapore: Peer
Socialisation, Autonomy, and Self-Esteem**

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Abstract

Background: Systematic reviews of quantitative research on the effects of childhood epilepsy have established its association with higher levels of psychiatric diagnosis, externalising and internalising problems, lower health-related quality of life, social competence and poorer academic achievements, compared to their peers. However, much less is known about young people's experiences of living with epilepsy and its impact on their development from their own perspectives.

Methods: Semi-structured interviews were conducted with 15 young people aged between 13 and 16 years. Participants were recruited as part of a larger mixed-methods study examining individual and family influences on outcomes for young people with epilepsy. These young people attended an epilepsy clinic in KK Women's and Children's Hospital, Singapore. The Framework approach to data management and analyses involved both inductive and deductive generation of themes.

Results: Findings from young people's interviews provided in-depth descriptions of stressful circumstances encountered. Interconnectedness between severity of the impairment and its impact on key developmental tasks, such as independence, autonomy, and social development, were emphasised. Seizures and illness-related demands disrupted their day-to-day functioning and challenged their abilities to meet these tasks. In addition to these impairment effects, young people's experiences of social exclusion were also affected by social and environmental factors, which act as systemic barriers to participation. In turn, this has an effect on their self-esteem. Nevertheless, young people reported positive experiences, such as support from both family and friends, which served as protective factors against the stress of living with a chronic medical condition.

Conclusion: The demands of epilepsy affect various domains of young people's lives. In order to obtain a holistic understanding of young people's inclusion or exclusion to participation, it is necessary to consider '*impairment effects*', '*barriers to doing*' and '*barriers to being*'.

Keywords: Epilepsy, Disabled adolescents, Chronic illness, Qualitative research, Participation, Disability

Living with Epilepsy in Adolescence – A Qualitative Study of Young People’s Experiences in Singapore: Peer Socialisation, Autonomy, and Self-Esteem

Young people experience varying degrees of adjustment during adolescence, which is characterised as a time of rapid growth in the domains of biological, psychological and social development. During this period of development, young people consolidate their identity and advance their understanding of the self in relation to the social world (Smetana, Campione-Barr, & Metzger, 2006; Steinberg & Morris, 2001). Successful adaptation during adolescence is reflected in young people’s ability to cope with challenges arising from these changes and achievement of age-appropriate developmental tasks such as increasing autonomy, differentiation from the nuclear family, development of self-identity, and increasing focus on peer relationships (Christie & Viner, 2005; Patterson & McCubbin, 1987). Those with a chronic disease, such as epilepsy, have to adjust these normative tasks and challenges of living with a chronic seizure condition (e.g., uncertainty of seizure occurrence, treatment adherence). Managing additional demands simultaneously is likely to be more stressful for young people and their families compared to peers without a chronic medical condition. In turn, their ability to cope with these multiple demands is likely to influence young people’s adaptation, including maintaining positive self-esteem (DuBois et al., 2002; Fergus & Zimmerman, 2005).

Self-esteem, the value that an individual places on his or herself, has been viewed as a critical developmental outcome in adolescence (Harter, 2005). It has been posited to be a factor through which negative effects of risk factors are reduced (Ekeland, Heian, Hagen, Abbott, & Nordheim, 2004). Evidence regarding the impact of epilepsy on young people’s self-esteem is equivocal. Some studies found that young people living with epilepsy were at greater risk for lower self-esteem (Austin et al., 2010; Hoare & Mann, 1994), while others did not reveal any difference between young people with epilepsy and their peers (Baker, Spector, McGrath, & Soteriou, 2005; Lee, Hamiwka, Sherman, & Wirrell, 2008; Rätty, Larsson, & Söderfeldt, 2003). Quantitative studies have shown that seizure-related factors, illness perceptions, and family functioning were likely to have a significant influence on young people’s self-esteem and other psychosocial outcomes (Austin et al., 2010; DiMatteo, 2004; Lee et al., 2008; Rätty et al., 2003; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005; Stanton, 1999). However, little is known about the impact of epilepsy on the psychosocial domains of adolescence development from young people’s own perspectives. A recent review of 17

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3 qualitative studies found that young people stressed the significance of peer interactions, particularly
4 regarding the disclosure of their medical condition (Authors). However, most studies were conducted
5 in the United Kingdom and North America, and there is limited information on cultural differences
6 relating to young people's experiences.
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11 Young people's experiences of living with epilepsy are likely to differ due to cultural
12 influences. Cultural norms, values and beliefs are likely to influence how an illness is depicted and
13 perceived, attitudes influence social responses and types of policies created pertaining to an illness.
14 Studies involving adults with epilepsy have shown social representations of epilepsy varied across
15 different cultures, even among European countries (Baker, Brooks, Buck, & Jacoby, 2000; Serdari et
16 al., 2009). Culturally specific beliefs, such as explanations for what caused the disease and treatment
17 methods, play a significant role in influencing negative perceptions and attitudes toward epilepsy
18 (Jacoby et al., 2008). In addition to shaping definitions and meanings of epilepsy, cultural factors also
19 influence how young people and their families respond to stressors arising from the illness (Gelhaar et
20 al., 2007; McCarty et al., 1999; Oláh, 1995). For instance, young people from East Asian collectivistic
21 societies tend to use coping strategies that emphasise interconnectedness as opposed to responses
22 that emphasise personal control and agency (Yeh & Inose, 2002).
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34 In addition to cultural influences, it is also important to consider social barriers that may affect
35 young people's experiences. Social model perspectives situate individuals' experiences of exclusion
36 and disadvantage within a wider external environment and not merely as consequence of physical or
37 cognitive deficits (Thomas, 1999). According to Thomas' social relational model of disability (1999),
38 impairments and chronic illnesses have a direct impact on an individual's participation in society , and
39 this is referred to as '*impairment effects*'. She further elaborated that restrictions of activities due to
40 impairment effects, such as fatigue or pain, do not constitute disability: instead, the experience of
41 disability is a result of '*barriers to doing*' and '*barriers to being*' (Thomas, 1999). '*Barriers to doing*'
42 refers to environmental and economic barriers, such as inaccessible transport systems that restrict
43 individuals from engaging in activities. Additionally, individuals with impairments also experience
44 disability within the context of social interactions, where negative responses from others can have an
45 adverse impact on their psycho-emotional well-being (Thomas, 2004). Therefore, in order to
46 understand the range of young people's experiences of living with epilepsy, it is necessary to consider
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3 effect of seizures (*'impairment effects'*), social barriers that restrict their participation in activities
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5 (*'barriers to doing'*) and fulfilling their potential (*'barriers to being'*). The objective of the present study
6
7 was therefore to use the social relational model to expand our understanding of the impact of epilepsy
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9 on salient developmental tasks of young people from a non-Western society, specifically from their
10
11 own perspectives. These tasks include expanding peer socialisation, increasing independence and
12
13 autonomy, and developing a positive self-esteem.

14 15 METHODS

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18 This study was part of a larger project that examined young people's experiences of living with
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20 epilepsy: semi-structured interviews with young people formed a second strand in a sequential mixed-
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22 methods research design. Between November 2013 and August 2014, 176 young people who met
23
24 the following criteria: (i) diagnosed with epilepsy, (ii) aged between 13 and 16 years old, and (iii)
25
26 attending mainstream school, were recruited from the paediatric neurology services in KK Women's
27
28 and Children's Hospital, Singapore (KKH). SingHealth Centralised Institutional Review Board
29
30 approved this study.

31 32 Characteristics of Participants

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34 Of the 152 young people who participated in the first part of the project – a quantitative survey
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36 administered in the clinic (Authors) – 31 agreed to be contacted again for interviews. Parents were
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38 first approached by telephone to obtain consent to contact their child as it would have been culturally
39
40 inappropriate to contact young people without first seeking their parents' permission. Sixteen parents
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42 declined stating that their child would be too busy, would not have much to say or that they were not
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44 interested. Fifteen parents consented to further contact and all the children concerned agreed to be
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46 interviewed.

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48 Ten young people were Chinese and five Malay (the proportions in the general population are around
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50 75 per cent and 15 per cent respectively) (Table 1). Their scores on the Rosenberg Self-esteem Scale
51
52 (RSS), taken from the initial survey are also included. Of which, nine had lower self-esteem scores
53
54 compared to the overall sample mean ($n=152$, $Mean=28.78$, $Standard\ deviation=6.04$; higher scores
55
56 indicative of higher levels of global self-esteem).

Data Collection Procedures

Young people determined the time and location for their interviews: all but one were conducted in their homes. Participants were interviewed individually with the exception of one who agreed to his parent's request to observe the interview. Young people were informed that their views would be kept confidential, even from their parents, unless information regarding abuse or harm was revealed. Written consent for participation and digital audio recording was requested from all but one participant who was uncomfortable with recording. Semi-structured interviews explored their experiences of living with epilepsy, such as leisure activities, relationships with peers, friends, and family members, and living with a chronic medical condition (the topic guide is available from the corresponding author upon request). Interviews lasted between 42 and 80 minutes, with an average duration of 50 minutes.

Framework Approach to Data Management and Analysis

All interviews, except for one, were audio taped and transcribed verbatim. NVivo 10, a computer assisted qualitative data analysis software, was used to aid with data management and analysis. The analytic approach for this study was guided by 'Framework' analysis (Ritchie & Spencer, 1994). It is considered to be a form of thematic analysis, an interpretive process whereby themes describing a phenomenon are described and patterns within the data are identified (Braun & Clarke, 2006). The Framework approach comprises two stages: (i) data management, (ii) abstraction and interpretation. Although this two-stage approach provided a structure for how data was managed and analysed, these processes were iterative (Spencer, Ritchie, Ormston, O'Connor, & Barnard, 2014). The first author carried out the qualitative data analysis, as described. In order to maintain rigor of the analytical processes and increase credibility of the research findings, both second and third authors reviewed the thematic framework and examined whether themes were derived from the data. This process ensured that the final themes remained true to young people's accounts.

FINDINGS

Young people's narratives broadened understanding of their ongoing efforts in negotiating illness-related demands and achieving normative development tasks of adolescence. The challenges of living with epilepsy permeated various social contexts, such as family, peer groups and school. These included the physical effects of seizures, including post-seizure effects on their physical wellbeing; the

LIVING WITH EPILEPSY IN ADOLESCENCE

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demands of illness management, such as adherence to medication regimens and physician-recommended lifestyle changes; and disruptions to their day-to-day functioning. Specifically, their experiences of 'impairment effects', social barriers 'to doing' and 'to being' challenged their abilities and efforts in achieving positive outcomes in three key developmental areas: (a) peer socialisation, (b) independence and autonomy, and (c) self-esteem.

Peer socialisation: Friendships

Friendships played a significant role in their lives, and young people had concerns regarding the disclosure of their medical condition and its potential effects on peer relationships.

- Disclosure of medical condition

The fear of stigmatisation and discrimination due to disclosure of a medical condition is not uncommon among young people with chronic illnesses (Davidson, Penney, Muller, & Grey, 2004; Graetz, Shute, & Sawyer, 2000; MacLeod & Austin, 2003; Michaud et al., 2009). Not surprisingly, young people in this study raised similar concerns. For example, Participant 1 (P1) feared she might be overlooked for a leadership position in school and P2 was afraid others would avoid her. On the contrary, some were apprehensive of having to cope with excessive displays of concern.

Approximately half experienced unintended disclosure of their condition when they had a seizure in school. Seizures were often sudden and unexpected, particularly when occurring for the first time. Some did not feel ready for their medical information to be known and most were embarrassed by these experiences. Another example of an unintended disclosure was when medical information was discussed and overheard in public areas. Several young people chose to disclose in response to questions about their absences from school or exemption from activities. The quality of friendships influenced young people's decisions and most disclosed only after developing closer relationship with friends.

'Well, we were having those heart to heart talks with my friends... And they also because they asked me why am I taking medicine almost every day, so I told them, "Epilepsy"' (P6)

The relationship between quality of friendship and disclosure was also evident in other participants' decision to withhold information from some classmates.

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3 *'For classmates that are not so close, I don't feel like I needed to tell them. Like, there is no*
4 *need for them to know, that's why I didn't tell them... For K and the others, they were my*
5 *friends, so when they asked [about the hospitalisation], I just told them the truth. I did not want*
6 *to lie to them and not tell them. And it's also nothing to hide' (P8)*
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11 Most friends and classmates wanted to know more about epilepsy. Some young people took
12 the opportunity to educate their peers, addressing misconceptions because the terms 'epilepsy' and
13 'seizure' were not commonly understood and advising what to do when a seizure occurred. Others,
14 who did not take the initiative to educate their friends and classmates, tended to be younger. Despite
15 their willingness, younger adolescents lacked skills in communicating medical information to others.
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21 • Support from friends and peers
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24 Most young people experienced support from their friends and felt that disclosure did not negatively
25 affect their friendships. On the contrary, friends demonstrated concern by enquiring about their well-
26 being, particularly after a seizure occurred. Few shared that revealing personal information enriched
27 their relationships with friends. Overall, young people's relationship with friends seemed not to be
28 negatively affected by the disclosure of their medical condition. Instead, most gained additional
29 support and were encouraged by positive responses shown by their friends. Although existing
30 Western literature indicated that some young people experienced rejection and bullying (Elliott, Lach,
31 & Smith, 2005; McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004; Wilde & Haslam, 1996), only one
32 person in this study reported such experiences.
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42 **Independence and autonomy: Illness management and participation in social activities**
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44 • Illness management
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47 Negotiating independence and autonomy during adolescence, such as increasing control over daily
48 activities and decision-making, was complicated by young people's health care needs. An indicator of
49 young people's growing autonomy was the transition of responsibilities of illness management from
50 parent to child. Young people explained that their parents expected them to assume greater
51 responsibility for self-management.
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LIVING WITH EPILEPSY IN ADOLESCENCE

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3 *'As usual, my mother reminded to take medication at night, and my father said that I should*
4
5 *not be needing reminders already...'* (P12)
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7 Transfer of responsibilities from parent to child occurred in stages. It progressed from parental
8 administration of AED, to supervising their child when they took AED, and subsequently to monitoring
9 medication adherence.
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14 *'... my mother lets me do it [take medication on his own], and sometimes she will remind me.*
15
16 *Since, maybe I was 13, she stopped standing there and watching me take medicine'* (P5)
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19 Although young people were generally autonomous with regard to self-management, parents retained
20 a dominant role in deciding which activities were appropriate for them.
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24 • Participation in social and leisure activities
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26 The majority of the young people engaged in a range of social activities with their friends common to
27 Singapore such as going to the movies, hanging out with friends and interacting through social media.
28 Nevertheless, these young people felt that opportunities to engage with their friends were constrained
29 by disruptions caused by seizures (*impairment effects*), parent-imposed restrictions, and other social
30 *barriers to doing and being*. In turn, this affected young people's sense of independence and
31 autonomy.
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38 Seizures: Impairment effects
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41 Seizures and their effects interfered with young people's participation in school, leisure and social
42 activities. Constant fatigue prevented several from being in school for an extended period time. As a
43 result, they either stopped participating or switched to less demanding Co-Curricular Activities (CCA).
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47 *'I just sat down suddenly. I was running from the other side of the court, then after that*
48 *[seizure] I just sat down suddenly and the game [basketball] stopped'* (P5)
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52 Parental restrictions
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55 Most young people engaged in regular social activities with their friends and had similar curfews as
56 their siblings and friends: however, some considered that parental control and overprotectiveness
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3 acted as '*barriers to doing*' as parents unnecessarily limited the types of activities and time spent with
4 their friends. Although young people were mostly perceptive of their parents' anxieties and of possible
5 adverse consequences (e.g., drowning, falling off a bicycle), they did not necessarily share their
6 concerns and estimations of risk. Young people also described feelings of anger, irritation, frustration,
7 or resignation when their views diverged.
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13 *'I understand that they don't want me to be injured or to have more seizures. But sometimes*
14 *even after explaining, and even if I know those reasons, it's still a bit frustrating not to be able*
15 *to do the things I want to do' (P8)*
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19 A few participants reported a lessening of parental restrictions, influenced by several factors. First,
20 young people were granted greater independence when the frequency of seizures decreased.
21 Second, parents imposed fewer restrictions when their fears regarding the risk of seizures were
22 assuaged by physicians or by learning through experience that activities did not trigger seizures. As a
23 result, they were more willing to accede to young people's requests for permission to participate in
24 activities.
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32 *'It's like, at first, they [parents] said that I cannot swim or cycle, and follow what the doctor*
33 *said. But I said, "Can, can, can"... Then, when we went to the beach, they tried and let me do*
34 *it but my brother or father must follow me. So, we tried and I've got no seizure. Then, the next*
35 *time, they also allowed me' (P11)*
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40 Finally, some parents' fears were reduced when they were convinced that others had the ability to
41 manage their child's seizures.
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45 *'I think because they [parents] got to know my friends better. And oh, there was once, when*
46 *some of them [friends] were at my house doing some project, I had it [a seizure]. My mum*
47 *saw that they cleared the floor, you know, the area around me. Then after that, she said*
48 *something like, "Oh your friends knew what to do", and I was like, "I told you before, they*
49 *know what to do and what not to do". So, I think after that, she trusts my friends more' (P12)*
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55 However, reduced parental restrictions were not a common experience in this sample. Three
56 participants who lived with epilepsy for two years or less reported more examples of parental
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3 restrictions, such as constant reminders to take their medication and direct supervision of daily
4 activities.
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7 *Institutional barriers*
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10 Several young people related how attitudes of others and institution policies prevented them from fully
11 engaging in activities aimed at helping them to achieve their potential (i.e., a *barrier to being*). For
12 instance, one participant was barred from a youth development programme because he had not been
13 seizure-free for at least three years.
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19 *P6: If you have epilepsy or any of the other listed medical conditions, you cannot participate.*

20 *And I think it's because they don't want burdens. Who wants burdens right?*
21

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23 *I: Do you consider yourself a burden?*
24

25
26 *P6: No. But from this, it shows that other people do consider people with medical problems as*
27 *burdens and that's annoying.*
28

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30 Such institutional-level barriers not only perpetuate misconceptions of epilepsy, but it also send a
31 negative message to young people.
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35 In contrast, several young people related positive experiences where potential social barriers
36 were reduced. Several were able to participate in school camps because their teachers undertook the
37 responsibility of monitoring treatment regimens and provided additional supervision during sporting
38 activities. Similarly, some continued to participate in church activities and camps, as there was
39 adequate adult supervision. Parents' efforts in highlighting their children's abilities and educating
40 others about epilepsy also facilitated their participation. Another factor was inclusive attitudes held by
41 others, which prompted their requests for more knowledge about epilepsy. Such responses, which
42 were similar to young people's friends after disclosure, were likely to promote a greater sense of
43 acceptance and have a positive impact on young people's self-esteem. These examples highlight that
44 although impairment effects, such as seizure frequency and severity, have a direct impact on young
45 people's ability to engage in activities, social and institutional factors play a significant role in
46 determining their level of participation.
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Self-esteem: Comparisons with friends and peers

Most participants managed to cope successfully with the multiple demands of adolescence and they often had great support from family and friends. Others found it more challenging to achieve developmental tasks due to additional barriers such as parent-imposed restrictions and misconceptions of epilepsy held by others. These inter-related factors played an important role in influencing how young people viewed themselves. Based on their narratives, young people can be classified into three groups: (i) did not view themselves as different, (ii) felt different but had positive self-evaluations, and (iii) felt different and had negative self-evaluations.

Young people recognised that living with epilepsy was uncommon, yet most did not evaluate themselves negatively. As mentioned, a few perceived little or no difference between themselves and their peers. They used phrases, such as 'normal', 'same' or 'no difference', or 'not different'. Several young people focused on aspects of their lives similar to others and reasoned that differences among people were common. From this perspective, they did not see themselves different from friends.

'Maybe I have more things to cope with, but it's ok. Everyone has to deal with challenges, like how some classmates have to deal with going for remedial classes. Just an extra thing to do'
(P9)

Several young people felt different from friends but focused and valued their own strengths and abilities, and these attitudes were reinforced by parents.

'I don't really compare. I just think of what I can do. My mum also doesn't compare me with others. Like, if I get my results, she will ask if I can do better and not how well other classmates did' (P9)

Others, did not positively or negatively evaluate their feelings of difference.

'I just feel that I am different... It's not a good or bad thing, it's just a feeling of being different'
(P12)

Support and acceptance from friends also played an important role in shaping young people's perceptions of 'normal' and 'difference'. Positive interactions and inclusionary behaviours such as

reassurances from friends reinforced their beliefs that they were not different from others. On the other hand, young people also described 'barriers to being', such as negative responses from family, peer and other significant people, which affected their sense of competency and self-esteem. 'Barriers to being' does not necessarily refer to hurtful or insensitive remarks. Some young people highlighted that sympathetic responses may also reinforce perceptions of difference and this works in opposition to their efforts in being 'same as' others. A few participants explained that excessive displays of concern also acted as unwanted reminders of their illness and reinforced the notion that 'there is something wrong' with them.

'... don't keep asking me how I am... [it's] reminding me that I have a medical problem... asking is a way of showing concern, but also a reminder... Asking in a normal tone is ok, but if it's over-concern, or over-worried tone, then it's like there is something wrong with me' (P10)

Two young persons examined their experiences across various social contexts, such school and peers, and compared themselves negatively based on poorer academic performance and the lack of friends. Barriers to participation were regarded as missed opportunities for developing friendships and also contributed to the sense of difference from their peers. In turn, these factors have negative implications for their self-esteem.

'... because I cannot do those things [activities] right. Then, I become very boring, like different from my classmates. As if I am very weak or very poor thing, you know. But I don't think I am, it's just that they [parents] don't allow me to do things. But sometimes I am also not sure if I can do those things or not, because I've never tried. But people will see me differently right? Like I cannot do things. So, if they choose friends, they will chose other people who is more fun and exciting, and not me.' (P15)

'... sometimes I miss school and class excursions, so I don't get to do the same things as my classmates. Then, we don't have the same things to talk about... But I would like to have more friends, just like other classmates. If not, now, I am the odd one out. Sometimes I feel like I am outside and they are inside, you know... Just feel like outsider...' (P13)

Their experiences contrasted with those who viewed themselves positively. These young people tended to display greater optimism and acceptance toward the effects of epilepsy, and did not

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2
3 perceive restrictions to be as limiting. For example, P8 adapted to restrictions imposed by parents by
4
5 adjusting how he characterised himself without necessarily evaluating his abilities.

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8 *'I see myself as the same as my friends. Just that I can't be a sporty person... Someone*
9
10 *whose parents don't allow him to play sports so much' (P8)*

11
12 Several young people proactively engaged in other forms of activities when they encountered barriers
13
14 to participation. Thus, their social interactions with friends were not necessarily reduced. In addition,
15
16 some made it a point not to let frustrations over restrictions impede their enjoyment of the time
17
18 spent with friends.

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20
21 *'... if I can't do something, like, go to (activity), then I'll do other things... There are so many*
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23 *things to do... I know that I can't do things, I get upset and then move on, don't let it continue*
24
25 *to bother you...'* (P6)

26 27 **DISCUSSION**

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30 Young people's narratives revealed the interconnectedness between epilepsy and its impact on key
31
32 developmental tasks of adolescence, such as social development, independence and autonomy, and
33
34 self-esteem. Young people's independence and autonomy varied across different contexts such as
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36 illness management and adherence, and socialisation with peers. Young people undertook
37
38 responsibility for a significant number of illness management tasks. This is in contrast to Western
39
40 studies, which found the transition of responsibilities impeded by young people's lack of confidence in
41
42 managing their illness or parents' resistance to their children's efforts to do so (e.g., hyper-vigilance
43
44 about adherence) (Reed-Knight, Blount, & Gilleland, 2014). On the contrary, parents expected young
45
46 people to be responsible for taking their medication as prescribed and in a timely manner. One
47
48 possible explanation is cultural differences in parenting practices and expectations of young people's
49
50 behaviours. For instance, Singaporean parents may have placed greater emphasis on the value of
51
52 responsibility and young people's adherence to treatment are likely guided by pressure to meet these
53
54 parental expectations. Ang et al. (2009) have argued that as members of culture characterised by
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56 collectivism, young people from Singapore are more likely to feel pressure to conform to expectations
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58 such as those from their parents.
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3 Young people had varying degrees of autonomy over their medical regimens and the shift of
4 responsibilities from parent to child occurred in stages. Findings from a systematic review of health
5 care transition among adolescents with chronic illnesses highlighted that the transfer of treatment
6 responsibilities to young people was associated with poorer health outcomes: these studies were
7 conducted mainly in United States (Pai & Ostendorf, 2011). Sustained parental involvement is likely to
8 promote adherence as higher levels of parental supervision and shared responsibilities were
9 associated with better treatment adherence and health outcomes among young people with chronic
10 illnesses in the United States (Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008; Modi,
11 Marciel, Slater, Drotar, & Quittner, 2008). While parental involvement may positively influence
12 treatment adherence, findings from this study suggests that differing expectations regarding parental
13 supervision contributes to negative experiences of living with epilepsy. Thus, it is important to strike a
14 balance between maintaining adequate supervision and facilitating young people's autonomy.
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26 The increased levels of independence and autonomy did not extend to other domains of
27 young people's lives in this sample, and they did not necessarily have greater responsibilities or
28 decision-making autonomy regarding their participation in social and leisure activities. This was often
29 due to parental restrictions, which is an example of '*barriers to doing*'. There is evidence from the
30 West that restricted socialisation with friends and peers, which occur as a result of parents' perception
31 of their child's vulnerability to injury or death, is likely to negatively affect young people's sense of
32 independence and autonomy (Chapieski et al., 2005; Holmbeck et al., 2002; Mullins et al., 2004).
33 However, these findings might not be generalisable to collectivistic cultures as the areas and
34 boundaries in which young people are expected to act autonomously are likely to vary depending on
35 different cultural contexts (Manzi, Regalia, Pelucchi, & Fincham, 2012). Recent cross-cultural
36 research has suggested that autonomy is a valued and universal developmental outcome for
37 adolescents across diverse cultures, however, cultural norms and values influence how autonomy is
38 expressed and experienced (Helwig, 2006; Lee, Beckert, & Goodrich, 2010; Luciano, 2010). For
39 instance, European and American young people expect and assert autonomy at earlier ages
40 compared to young people from Hong Kong (Feldman & Rosenthal, 1991) and American adolescents
41 from Mexican, Chinese, and Filipino backgrounds (Smetana, 2002). Culture also affects the meanings
42 young people ascribe to parental behaviour. In this study, young people occasionally perceived
43 parental control and restrictions to participation as overprotective parenting; however, most reasoned
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3 that it was part of parents' attempts to protect them from harm. This is unlike findings from studies
4 conducted in more individualistic societies, where such parenting behaviours might be experienced as
5 controlling and is associated with negative consequences (Ang, 2006; Houtzager, Möller, Maurice-
6 Stam, Last, & Grootenhuis, 2014; Taylor, Gibson, & Franck, 2008). Therefore it is necessary for
7 practitioners to adopt a culturally sensitive view of autonomy when working with young people and
8 their families as behaviours that appear dysfunctional in one context might not be so in others.
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15 In addition to '*barriers to doing and being*', this study highlighted that seizures and its effects
16 played a role in limiting young people's participation, and this is what Thomas (1999) considers as
17 '*impairment effects*'. This was similar to those with other chronic illnesses such as cerebral palsy,
18 juvenile idiopathic arthritis and Duchenne muscular dystrophy (Abbott & Carpenter, 2015; Cavallo,
19 Majnemer, Duffy, & Ehrmann Feldman, 2015; Shimmell, Gorter, Jackson, Wright, & Galuppi, 2013).
20 The experience of pain or fatigue, which necessitated rest, also limited their participation. Activities
21 were also avoided in order to prevent exacerbating disease symptoms. Therefore, notwithstanding the
22 importance of considering social and environmental factors that act as systemic barriers to
23 participation, it is also necessary to consider variability of disease characteristics and its impact on
24 young people.
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35 Positive self-concept and esteem is often associated with autonomy (Kagitcibasi, 2013). In
36 this study of Southeast Asian young people living with epilepsy, self-esteem was influenced by
37 various factors such as the medical condition itself, its impact on various normative developmental
38 tasks, and support received from parents and friends. This was similar to Western studies, which
39 reported young people who had positive outlook on life and received greater family and peer support,
40 were less affected by the disruptive effects of epilepsy (Eklund & Sivberg, 2003; Wilde & Haslam,
41 1996). Several young people considered friendships to be a hallmark of not being different in spite of
42 a medical condition. Others felt different but not necessarily inferior, in part, because of friendships
43 they had. However, there was two exceptions where young people had lower sense of self-esteem.
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Reduced participation in activities and engage in social interaction with their friends and peers
contributed to these feelings of difference and inadequacy. Furthermore, their inability to participate in
activities emphasised differences between young people and their peers, and reduced opportunities
for them to develop friendships, which in turn, reduced potential sources of support. Studies in both

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3 East and West have shown that young people with strong peer attachments or who participated in
4 activities had higher levels of self-esteem and psychological functioning (Chong, Huan, Yeo, & Ang,
5 2006; Kort-Butler & Hagewen, 2011; Viau & Poulin, 2014; Wilkinson, 2004; Yu, 2016). It was posited
6 that participation in structured activities provide opportunities personal and interpersonal development
7 such as leadership, problem-solving skills and peer relationships (King et al., 2003), which is likely to
8 have a bolstering effect on young people's global self-esteem. Hence, interventions that aim to
9 support young people with epilepsy should also be directed at reducing socially imposed '*barriers to*
10 *doing*', (e.g., parental restrictions and institutional policies). Additionally, interventions that promote
11 appropriate responses from family members, peers and other significant others is likely to reduce
12 '*barriers to being*' and in turn, increase young people's self-esteem.
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22 **LIMITATIONS**

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25 A strength of this study was young people's involvement in interviews, however, none of the Indian
26 young people agreed to be interviewed. As young people's experiences did not seem to vary as a
27 function of ethnicity, it could be postulated that this group of young people would likely have similar
28 experiences. However, this has to be established by future research. Younger participants provided
29 less detailed responses and required more prompts than those who were older. This is likely due to
30 differences in development stages (Elliott et al., 2005). On hindsight, a variety of techniques, such as
31 task-based activities, could have been used to make the interviews more interesting for young people.
32 Different techniques could have catered to the diversity of preferences and competencies among
33 young people (Punch, 2002).
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43 **CONCLUSION**

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45 Despite the disruptive effects of epilepsy on peer socialisation and development of autonomy, most
46 young people did not evaluate themselves negatively in relation to their peers. Young people's
47 descriptions of their coping strategies relating to illness-related demands provide support that it was
48 more effective to engage in secondary control coping strategies such as positive thinking.
49 Additionally, their positive self-esteem was supported by positive outlook and support from both family
50 and friends. Collectively, these findings highlight the importance of young people's participation in
51 structured and leisure activities as it has a positive influence on development and is likely to serve as
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a protective factor against the stress of living with chronic medical condition. As such, there is a need support parents and young people in striking a balance between the over- and underestimation of risks and not overlook the benefits of participation. Additionally, continued efforts are required to increase awareness that young people with epilepsy can and should be as fully engaged in social and leisure activities as their peers.

KEY MESSAGES

- Impairment effects of epilepsy disrupt and challenge young people's abilities to meet key developmental tasks, such as social development, independence and autonomy, and self-esteem.
- Systemic barriers to participation are likely to have a negative influence on young people's self-esteem.
- Young people also reported positive experiences, such as support from both family and friends, which served as protective factors against the stress of living with a chronic medical condition.
- It is important for practitioners to adopt a culturally sensitive view of key development tasks of adolescence as cultural norms and values play a role in young people's experiences.
- It is essential to consider socially imposed '*barriers to doing*' and '*barriers to being*' when developing interventions to support young people with epilepsy.

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Table 1: Characteristics and family circumstances of young people interviewed (n=15).

No.	Ethnicity	Gender/Age	Family structure	Seizure frequency	Years with epilepsy	Self-esteem score ¹
1.	Chinese	Female/13 years old	2-parent household, 2 children	Seizures with AED	12 years	28
2.	Malay	Female/16 years old	2-parent household, 3 children	No seizures with AED	5 years	21
3.	Chinese	Female/16 years old	2-parent household, 2 children	No seizures with AED	6 years	30
4.	Chinese	Male/16 years old	2-parent household, 2 children	Seizures with AED	6 years	30
5.	Chinese	Male/16 years old	1-parent household, 2 children	Seizures with AED	11 years	26
6.	Chinese	Male/16 years old	2-parent household, 1 child	No seizures with AED	2 years	29
7.	Chinese	Male/14 years old	2-parent household, 1 child	Recent single episode	10 years	19
8.	Chinese	Male/13 years old	2-parent household, 4 children	Recent single episode	12 years	39
9.	Chinese	Male/15 years old	1-parent household, 2 children	Recent single episode	10 years	31
10.	Malay	Male/16 years old	2-parent household, 6 children	No seizures, no AED	6 years	35
11.	Malay	Male/13 years old	2-parent household, 11 children	No seizures with AED	1 years	25
12.	Malay	Female/15 years old	2-parent household, 2 children	Seizures with AED	6 years	25
13.	Malay	Female/16 years old	2-parent household, 4 children	Seizures with AED	13 years	23
14.	Chinese	Female/15 years old	2-parent household, 1 child	No seizures with AED	2 years	25
15.	Chinese	Male/15 years old	2-parent household, 4 children	Seizures with AED	8 years	14

AED: Anti-epileptic drugs

¹Rosenberg Self-esteem Scale (RSS) scores obtained previously from a survey: Quantitative sample – Mean=28.78, Standard deviation=6.04, Range=14-40 (possible score range: 10-40, higher scores indicative of higher levels of global self-esteem).