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Title

Individual and family factors associated with self-esteem in young people with epilepsy: A multiple mediation analysis

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Abstract

Objective: As young people experience added demands from living with epilepsy, which may lead to poor psychosocial adjustment, it is essential to examine mechanisms of change to provide practitioners with knowledge to develop effective interventions. The aim of this study was to examine individual and family-level factors – stress and illness perceptions, coping behaviours and family resilience – that promote or maintain young people's self-esteem.

Methods: From November 2013 to August 2014, young people attending a neurology clinic in KK Women's and Children's Hospital, Singapore, participated in a cross-sectional survey ($n=152$; 13-16 years old). Multiple mediation analyses were conducted to evaluate whether these variables mediated the relationship between illness severity (i.e., low, moderate, high) and self-esteem.

Results: Multiple mediation analyses demonstrated that illness severity had a direct effect on young people's self-esteem. Compared to those with moderate illness severity (reference group), young people with low severity had significantly higher self-esteem ($c=3.42$, $p<0.05$); while those with high severity had a more negative view of themselves ($c=-3.93$, $p<0.001$). Illness severity also had an indirect influence on self-esteem through its effects on mediators, such as perceived stress, illness perceptions and family resilience (D1: *Total ab*=3.46, 95% *CI* 1.13, 5.71; D2: *Total ab* =-2.80, 95% *CI* -4.35, -1.30). However, young people's coping levels did not predict their self-esteem, when accounting for the effects of other variables.

Significance: The continued presence of seizure occurrences is likely to place greater demands on young people and their families: in turn, increased stress and negative illness perceptions, negatively affected family processes that promote resilience. As the mediating effect of these modifiable factors were above and beyond the contributions of illness characteristics and young people's levels of coping, this has implications for developing individual and family interventions aimed to support young people living with epilepsy.

Key words: Adolescents; Chronic illness; Psychosocial; Adaptation

1. Introduction

Young people with epilepsy are three to nine times more likely to have poorer psychosocial outcomes when compared to healthy peers, young people with other medical conditions and/or their siblings [1-3]. Several systematic reviews conclude young people with epilepsy have higher levels of psychiatric diagnosis, externalizing and internalizing problems, lower health-related quality of life, social competence and poorer academic achievements, compared to their peers [4-7]. However, young people with epilepsy do not necessarily have negative outcomes. Hence, it is essential to understand the factors and psycho-social mechanisms that account for such variations, which will provide practitioners with knowledge for developing effective interventions to support this group of young people.

Epilepsy-specific variables that influence young people's outcomes include seizure severity, number of medications and their side effects [8, 9]. However psychosocial adaptation may not be solely a function of seizure-related variables. In order to understand individual and family variables, which could account for variations of psychosocial outcomes, the Double ABCX Model of Adolescent Adaptation was used. This model posits that four main variables – demands (aA), resources (bB), definitions and meaning (cC), and coping – have direct and indirect influence on development and adaptation (xX) [10] and as such can be applied to chronic illness experiences of young people with epilepsy.

Stressor and pile-up of demands (aA): Chronic illnesses, such as epilepsy, have often been perceived as stressors for young people and their families due to changes required to manage the medical condition [11]. It has been proposed that having to cope with additional illness-related demands exceed their existing capacities and results in higher stress levels [12]. However, most researchers have not specifically measured the construct of stress. Instead, stress levels were inferred from outcomes related to individuals' psychosocial functioning.

New and existing resources (bB): Family factors have been posited as a potential resource and play a significant role in influencing psychosocial outcomes; however, these have seldom been included in studies that involved young people with epilepsy. Findings from limited

empirical evidence document associations between family functioning and a range of psychosocial and health outcomes. For instance, poorer levels of family functioning predicted higher levels of behavior problems, lower self-esteem, social competencies, academic achievement, and treatment adherence [13-16].

Definition and meaning (cC): According to Patterson and McCubbin [10], meanings young people and their families ascribe to their situations or stressors are made in relation to the availability of their resources. Greater negative illness perceptions predicted more depressive symptoms and behaviour problems [17]; and lower self-esteem [16] among young people with epilepsy.

Coping behaviours: Coping is viewed as young people's efforts in managing multiple demands (e.g., individual, family, illness-related demands). Similar to research in the area of illness perceptions, limited studies exist that examine how young people cope with epilepsy [18, 19], although it may be inferred that problem-focused coping styles support positive adaptation. Specific coping behaviours, such as being optimistic, seeking social support, focusing on competence and adhering to treatment, have been correlated with positive psychosocial outcomes [18, 19].

Adolescent adaptation (xX): Evidence regarding the impact of epilepsy on young people's self-esteem levels is equivocal. Some studies found that young people were at greater risk for lower self-esteem [15], while others did not reveal any difference in self-esteem between young people with epilepsy and their peers [16, 20]. As the role of self-esteem in young people's development has been well documented and widely used as an index for an individual's overall psychosocial functioning [21], further research is indicated.

In summary, factors such as epilepsy-related characteristics, stress, negative illness perceptions, coping and family processes are likely to exert an influence on young people's psychosocial outcomes. However, few studies have considered the collective influence of illness characteristics, individual and family factors on young people's adaptation. The present study aims to extend the current body of knowledge on individual and family factors that influence the self-esteem of young people with epilepsy, from their perspectives. The

following hypotheses were developed; (i) Young people with greater illness severity would have lower levels of self-esteem; (ii) greater illness severity predicts higher levels of perceived stress, negative illness perceptions, lower coping and lower family resilience. In turn, these four factors mediate the relationship between illness severity and self-esteem.

2. Methods

This cross-sectional survey was the first strand of a mixed-methods study, which examined young people's experiences with epilepsy. Between November 2013 and August 2014, 176 young people who met the following criteria: (i) diagnosed with epilepsy, (ii) aged between 13 and 16 years old, and (iii) attending mainstream school, were recruited from the pediatric neurology services in KK Women's and Children's Hospital, Singapore (KKH). SingHealth Centralized Institutional Review Board approved this study. Consent was obtained from young people and their parents. Young people completed the survey while waiting to see their physicians at KKH.

2.1 Measures

Young people self-reported demographic data and responded to standardized scales that measured constructs of family resilience and self-esteem. The questionnaire was administered in English, which is the main language of instruction for schools in Singapore. Young people who participated would have received at least 6 years of English-medium instruction since Primary 1 (i.e., 7 years old), and therefore have adequate proficiency to comprehend the questionnaire statements. Parents provided family demographic data such as household income and family structure. Physicians provided clinical information on number of medications, seizure frequency, and their assessment of seizure control (i.e., whether seizures were effectively controlled by anti-epileptic drugs [AED]).

2.1.1 *Illness severity*

Young people's illness severity has been determined based on: (i) seizure types, (ii) seizure frequency, and (iii) number of AED and its side effects [9]. Often, composite scores were derived from these classifications. In this study, illness severity was operationalized as the

extent to which young people's seizures were controlled by use of AED: (i) No seizures, AED not required (Low); (ii) Seizures controlled with AED (Moderate); and (iii) Seizures despite AED (High).

2.1.2 *Perceived stress*

The 14-item Perceived Stress Scale (PSS) was used to assess young people's perceptions of stress, by examining the frequency of a respondent's feelings and thoughts related to events and situations that occurred within the past month [22]. PSS is a widely used measure in stress research, including young people aged between 12 to 17 years old, and has been found to demonstrate adequate reliability and validity [23]. An example of an item is, '*How often have you been upset because of something that happened unexpectedly?*'

Respondents were asked to indicate their responses to each question on a 5-point Likert scale that ranged from 1 (*Never*) to 5 (*Very often*). Higher scores are indicative of higher levels of perceived stress. Cronbach's alpha coefficient for this study was 0.97.

2.1.3 *Illness perceptions*

Illness perceptions were assessed using the 8-item Brief Illness Perception Questionnaire (IPQ), which examines perceived consequences, timeline, personal control, treatment control, identity, concern, emotional burden, and the understanding of one's illness [24]. The Brief IPQ has been tested in several illness groups and shows good reliability and validity [24, 25]. Respondents rated the extent to which they agreed with questions on a Likert scale that ranged from 1 to 11. For example, '*How much control do you feel you have over your illness?*' (1=*Absolutely no control*, 11=*Extreme amount of control*), with higher scores indicating greater agreement with the question. Higher scores are indicative of more threatening views of epilepsy. The Cronbach's alpha coefficient was 0.83.

2.1.4 *Coping levels*

The 54-item Adolescent Coping Orientation for Problem Experiences (ACOPE) inventory measures frequencies of specified coping behaviors of young people [10]. In a systematic review of standardised coping measures for young people, ACOPE was assessed to be a

well-established measure with good psychometric properties [26]. Respondents were asked to indicate on a 5-point Likert scale, which ranged from 1 (*Never*) to 5 (*Most of the time*), the frequency of using a specified coping behavior when faced with difficulties or experiencing tension (e.g., '*Try to think of the good things in your life*'). Higher scores are indicative of higher levels of positive coping patterns. The Cronbach's alpha coefficient was 0.83.

2.1.5 Family resilience

Family Resilience Assessment Scale (FRAS), a 54-item scale was used to assess family processes that support families' ability to cope successfully with adversity [27]. Good internal consistency and reliability have been previously demonstrated among parents with a child diagnosed with an autism spectrum disorder [28]. Respondents indicated on a 4-point Likert scale, which ranged from 1 (*Strongly disagree*) to 4 (*Strongly agree*), their level of agreement with statements that describe family processes (e.g., '*We show love and affection for family members*'). Higher scores are indicative of higher levels of family resilience. Cronbach's alpha coefficient was 0.92.

2.1.6 Self-esteem

Young people's global self-esteem was measured with Rosenberg Self-Esteem Scale (RSS) [29]. This widely used 10-item scale evaluates global self-esteem through positive and negative perceptions of self. This scale has been determined to be valid and reliable measure among young people [30]. Examples of positive and negative worded items are, '*On the whole, I am satisfied with myself*' and '*At times I think I am no good at all*', respectively. Respondents rated each item on a 4-point Likert scale ranging from 1 (*Strongly disagree*) to 4 (*Strongly agree*). Higher scores are indicative of higher levels of global self-esteem. Cronbach's alpha coefficient for this study sample was 0.90.

2.2 Statistical analyses

2.2.1 Preliminary analyses

Data distribution was examined by using boxplots and standardised scores (z -score < 3.29). With the exception of young people's coping scores, assumptions of normality were met, as

z-scores of skew and kurtosis for all other variables were not greater than 3.29. To reduce the positive skew, log transformation was performed on the values of ACOPE. As both FRAS and ACOPE have subscales and its psychometric properties have not necessarily been tested in a Singapore population, EFA with principal axis factoring were conducted to examine the scales' factor structures. Correlational analyses and multiple regression analyses were performed to establish the statistical significance of relationships between proposed mediators and dependent variable. Variables that did not significantly predict young people's self-esteem were excluded from the multiple mediation analysis. Missing variables were excluded list-wise.

2.2.2 *Multiple mediation analysis*

Multiple mediation modelling was used to examine the hypotheses that perceived stress, negative illness perceptions, coping and family resilience, mediate the relationship between illness severity and young people's self-esteem. Non-parametric bootstrapping procedures were used to test the statistical significance of indirect effects of these proposed mediating variables. Point estimates and confidence intervals of indirect effects (total and specific) were estimated and calculated from these bootstrapped samples. According to Preacher and Hayes [31], mediation was demonstrated if zero was not included within the 95% bias-corrected confidence interval, indicating that point estimates for indirect effects were statistically significant. In multiple mediation analysis, bootstrapping also allowed for the estimation of specific indirect effects of a mediator while controlling for other potential mediators [31]. For instance, the mediating effect of perceived stress was examined when effects of negative illness perceptions, coping and family resilience were controlled.

As the independent variable – illness severity – was a categorical variable with three levels, two dummy-coded variables (D_1 and D_2) were created for the purpose of multiple mediation analysis [32]. In this study, young people whose seizures were effectively controlled with AED (Moderate) was the reference category. D_1 represents comparison between young people who no longer require AED (Low) and the reference group: D_2 represents comparison between young people who continued to experience seizures despite medication (High) and the reference group.

Hayes and Preacher [32] appended the term *relative* to describe total, direct and indirect effects in multiple mediation models with a multi-categorical independent variable, as it quantifies the effect of being in one group relative to the reference category. Point estimates and confidence intervals of *relative indirect effects* (total and specific) were estimated from 10,000 bootstrapped samples. All statistical analyses were performed using SPSS version 21.0. SPSS macros (version 2.15) developed by Preacher and Hayes [31] for multiple mediation and bootstrapping procedures were used.

3. Results

A total of 156 young people with epilepsy participated in this study (response rate 88.6%). Scores from 152 young people were included in the analyses, as four questionnaires were incomplete. Clinical and demographic characteristics of this sample of young people are presented in Table 1.

(INSERT TABLE 1)

3.1 Preliminary analyses

The original factor structures of ACOPE and FRAS were not replicated. A 10-factor solution for ACOPE emerged from the analyses instead of original 12-factor structure found by Patterson and McCubbin [10]. These 10 factors accounted for approximately 75% of the total variance with factor loadings ranging from 0.45 to 0.90. Cronbach's alpha coefficients for total and sub-scales ranged between 0.68 and 0.94, suggesting moderate internal consistency. The EFA results for FRAS was previously reported [33]. A seven-factor solution, which reflected dimensions of family resilience put forward by Walsh's conceptual framework [27], accounted for approximately 83% of the total variance with factor loadings ranging from 0.40 to 0.91. Cronbach's alpha coefficients for the total and subscales, which ranged between 0.93 and 0.97, demonstrated that the FRAS had good internal consistency. These findings provide preliminary evidence that both ACOPE and FRAS are adequate measures for use among young people with epilepsy in Singapore.

Except for young people's gender and household income, there were no significant differences between demographic categories for scores obtained from the measures. Female participants ($M=160.28$, $SD=25.14$), reported significantly higher levels of mean total family resilience scores as compared to male participants ($M=151.12$, $SD=23.88$), $t(143)=-2.25$, $p<0.05$ [-17.21, -1.11]. Differences in young people's negative illness perceptions between income groups were statistically significant, $F(3, 141)=3.71$, $p<0.05$. Hochberg's GT2 post-hoc tests indicated that young people whose household income was '*Less than SGD 1,999*' ($M=55.35$, $SD=9.58$) had significantly higher levels of negative illness perceptions when compared to those whose household income ranged from '*SGD 2,000 to 4,999*' ($M=43.02$, $SD=14.01$).

Young people's age and the number of years since they were diagnosed with epilepsy were not significantly correlated with their self-esteem. Multiple regression analysis results showed that lower levels of stress, negative illness perceptions and higher levels of family resilience predicted higher levels of self-esteem among young people with epilepsy, $F(5, 133)=57.83$, $p<0.01$, $R^2=0.69$, $R^2_{\text{adjusted}}=0.67$. However, coping levels were not predictive of young people's self-esteem (refer to Table 2).

(INSERT TABLE 2)

3.2 Multiple mediation analyses

Gender and household income were included in the multiple mediation analysis as covariates due to significant group differences in family resilience and illness perception scores, respectively. The first hypothesis, which postulated that higher levels of illness severity was associated with decreased levels of self-esteem, was supported. As predicted, relative total effects of illness severity on young people's self-esteem were statistically significant (D_1 : $c=3.42$, $p<0.05$; D_2 : $c=-3.93$, $p<0.001$). In other words, compared to the reference group (moderate illness severity), young people with low illness severity had significantly higher levels of self-esteem. In contrast, young people who continued to have seizures despite AED (high illness severity) had significantly lower levels of self-esteem compared to the reference group.

The second hypothesis, which predicted that the impact of illness severity on self-esteem was mediated through perceived stress, negative illness perceptions and family resilience, was partially supported by findings from this multiple mediation analysis (refer to Figure 1).

(INSERT FIGURE 1)

In both D_1 and D_2 contrasts, the relative indirect effects of perceived stress and negative illness perceptions were statistically significant (refer to Table 3). Relative to those who had moderate illness severity (reference group), young people with low illness severity had significantly lower levels of stress and negative illness perceptions. On the other hand, young people with higher illness severity had increased levels of perceived stress and negative illness perceptions. In turn, higher levels of stress and negative illness perceptions predicted decreased self-esteem levels.

Family resilience was found to be a significant mediator in the D_2 contrast, but not in the D_1 contrast (refer to Table 3). These findings indicate that family resilience levels between low and moderate illness severity were not significantly different; however, young people with high illness severity reported significantly lower family resilience compared to those with moderate severity. In turn, young people with higher levels of family resilience reported higher self-esteem levels.

(INSERT TABLE 3)

4. Discussion

4.1 Impact of illness severity on young people's self-esteem

This study sought to understand the relationships between young people's self-esteem, illness severity, their stress and negative illness perceptions, levels of coping and family resilience. Illness severity was found to be negatively associated with young people's self-esteem: young people who continued to have seizures despite taking AED had significantly lower self-esteem compared to those without. This finding was consistent with prior studies [16,20, 34-36].

It could be suggested that young people might have had existing negative views of themselves prior to their illness, and on this basis conclude that self-esteem does not vary as a function of illness severity. However, there is little empirical evidence to support such a conclusion. On the contrary, findings from the limited number of longitudinal studies involving young people with new-onset seizures, demonstrate that epilepsy does have a negative impact on a sub-group of young people [15, 37, 38]. Illness severity was one of the factors that characterised this group. Findings from a previously discussed study by Austin and colleagues [15] showed that as a group ($n=135$, 4-12 years old), there was no significant change in young people's self-reported esteem scores between baseline ($M=84.4$, $SD=15.5$) and after 36 months ($M=86.6$, $SD=12.5$). However, among those who experienced worsening of cognitive functions, there was a significant decline in self-esteem levels. These studies, which document changes in young people's psychosocial outcomes since the onset of seizures, provide support for current conclusions that young people with epilepsy are not homogenous. Epilepsy has a negative impact on young people's self-esteem and its effects vary depending on illness severity levels.

4.2 Young people's levels of coping behaviors

The statistical association between coping and self-esteem scores was no longer significant when young people's perceived stress, negative illness perceptions, and family resilience factors were taken into consideration. One possible explanation is that the direct effects of perceived stress, negative illness perceptions, and family resilience on young people's self-esteem were much greater than coping behaviours. Another explanation is that the measure used did not capture relevant aspects of the young people's response to living with epilepsy. ACOPE was designed to measure generic coping styles of young people in meeting multiple demands. As such, its items reflect young people's behaviours when coping with individual and family stressors, this in turn underscored the premise that young people manage multiple demands simultaneously, and that their coping responses are not role or situation-specific [10].

It is possible that young people with chronic illnesses develop different coping styles compared to their peers, and a generic coping instrument, such as ACOPE, may be less

sensitive in measuring the actions taken to manage illness-related stress. Compas et. al. [39] reviewed the evidence on coping with chronic illness among young people and surmised that secondary control coping (e.g., cognitive reappraisal, distraction) was associated with better adjustment. They concluded that these coping strategies, which were efforts to *adapt* to stress, were more suitable to meet the demands of uncontrollable aspects of chronic illness, as opposed to primary control coping (e.g., problem-solving, emotional modulation) that attempts to *change* the source of stress or reactions to it. Thus, in order to have a more comprehensive understanding of coping, future studies could include additional illness-specific coping measures. However, the issue of research burden placed on respondents would need consideration; this could be addressed by integrating specific and generic coping into a single measure.

4.3 Factors that mediated the relationship between illness severity and self-esteem

With the exception of coping, young people's perceived stress, negative illness perceptions, and family resilience were found to be significant mediators. Young people who experienced greater illness demands and seizures were more likely to report correspondingly higher levels of stress and negative illness perceptions. In turn, these young reported correspondingly lower self-esteem. These findings were consistent with extant literature [9, 16, 34, 36].

Family resilience explained variations in self-esteem of young people who continued to experience seizures despite taking medication (high illness severity), but not for the others. In other words, this group of young people with severe illness reported significantly lower levels of family resilience, and in turn, significantly lower self-esteem compared to young people who did not have seizures (low and moderate illness severity). These results suggest effective seizure control has a significant impact on young people and their families.

Compared to demands from treatment regimens (e.g., taking AED timely), the continued presence and uncertainties of seizure occurrences are likely to assert greater demands on young people and their families, increase stress and negatively influence family processes that promote resilience [12, 40]. In addition to illness demands, families also have to manage demands arising from negative psychosocial outcomes frequently associated with the presence of epilepsy. For instance, higher levels of behavior problems could lead to

increased strains experienced for other family members, poorer quality of parent-child relationships and increased family stress [8, 14]. Families' reduced ability to manage these demands and insufficient support are likely to exacerbate the impact of illness severity on young people's self-esteem. These findings suggest the importance of considering both individual and family factors when examining possible mediating effects between illness characteristics and young people's psychosocial outcomes such as self-esteem.

4.4 Limitations

This study used an exploratory cross-sectional design, thus, causality between variables cannot be inferred. As relationships between perceived stress, negative illness perceptions, coping, family resilience and young people's self-esteem are likely bi-directional, longitudinal research with multiple time point measurements is required to determine strength and direction of effects. One of the strengths of this study was the use of young people's self-reports rather than parent-reports. This provided a unique view on young people's stress levels, illness perceptions, family resilience, coping and self-esteem. Consequently, these may be more valid as intervention targets with young people. However, the exclusive reliance on self-reports may give rise to common method variance, e.g., social desirability and acquiescence [41]. Future research could minimize such variances by obtaining data from various sources, such as their family members, friends, and teachers. Findings from this study cannot be generalised beyond its current sample population, as young people were recruited from an outpatient clinic at a single tertiary medical facility and a convenience sampling was used. It is possible that young people who participated in the study may be different from those who defaulted their medical appointments or sought treatment at private medical centres. By extension, inferences regarding young people from other cultures, will also be limited. Therefore, additional research with culturally diverse populations is required in order to determine if current findings can be generalized. Lastly, a survey approach is constrained by data collected from closed-ended questions in the questionnaire. As such, it is limited in its ability to provide information about social and cultural contexts within which behaviours are embedded. In order to obtain a more comprehensive understanding, future studies employing qualitative methodologies will be required to explore potential cultural

influences on young people's psychosocial adaptation. Data collection methods, such as semi-structured interviews, provide opportunities to understand the meanings young people give to their situations and behaviours, which may differ from existing literature generated primarily in the West.

4.5 Clinical implications

Significant associations between seizure, individual and family related variables, emphasize the importance of targeting multiple variables when developing interventions to support young people and their families. Several authors have highlighted that existing research focuses extensively on minimizing the influence of risk factors and there was a lack of attention on processes promoting positive psychosocial outcomes [42, 43]. Findings from this study provide empirical evidence for developing psychosocial interventions that aim to support positive self-esteem by reducing stress, negative illness perceptions and enhancing family processes that promote resilience. Such interventions are likely to benefit young people and their families [44, 45]. Our findings also highlight that young people who continue to experience seizures might require additional support and help in learning new strategies to deal with their reduced sense of control over their illness and circumstances. As such, this group of young people may benefit from targeted psychosocial interventions [46].

4.6 Cultural considerations

There is a need to consider cultural influences developing interventions to target mediators, such as young people's negative illness perceptions and family processes. First, cultural norms, values and beliefs, are likely to influence the definition and meaning of illness. Studies involving adults with epilepsy have shown social representations of epilepsy varied across different cultures, even among European countries [47, 48]. Culturally specific beliefs, such as explanations for what caused the disease and treatment methods, played a significant role in influencing negative perceptions and attitudes toward epilepsy [49]. These findings suggest dominant ideologies and discourses within the wider community plays an important role in influencing perceptions and attitudes. Second, culture factors influence how young people and their families cope with epilepsy and its associated stressors. For instance, cross-cultural research has shown young people's coping behaviours differ across countries [50]. An

international resilience study, which involved 1,451 young people across 11 countries, found significant variation in young people's coping behaviours in spite of similar adversities faced [51]. Additionally, young people from collectivistic societies tend to use coping strategies that emphasise interconnectedness as opposed to responses that emphasise personal control and agency [52]. Therefore, when planning interventions to support young people, it is essential to bear in mind how culturally specific beliefs influence key processes that promote positive outcomes.

5. Conclusion

Current findings shed light on factors that accounted for differences in self-esteem levels. First, the significant association between illness severity and young people's self-esteem emphasizes that this group of young people were not homogenous. Young people with greater illness severity, which was characterized by higher seizure frequency and/or need for medication, were more likely to have lower self-esteem. In line with existing studies, this suggests illness characteristics have differing impact on young people's psychosocial outcomes. Second, findings from mediation analyses provide evidence on the possible processes through which illness severity affects self-esteem. The negative impact of illness severity on young people's self-esteem was mediated through higher perceived stress, more negative illness perceptions and lower family resilience. Differential impact of illness severity on family resilience suggests the presence of seizures was a significant risk factor that exerts stress on families. In turn, this had a negative impact on young people's self-esteem. Contrary to expectations, young people's coping levels were not found to be a significant mediator. These findings also underscore the importance of considering individual and family factors when examining the impact of epilepsy on young people's psychosocial outcomes and developing appropriate interventions.

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References

- [1] McDermott S, Mani S, Krishnawami S. A population-based analysis of specific behavior problems associated with childhood seizures. *Journal of Epilepsy* 1995;8: 110-118. doi: 10.1016/0896-6974(95)00019-A
- [2] Plioplys S, Dunn DW, Caplan R. 10-year research update review: Psychiatric problems in children with epilepsy. *Journal of the American Academy of Child & Adolescent Psychiatry* 2007;46: 1389-1402. doi: 10.1097/chi.0b013e31815597fc
- [3] Rodenburg R, Wagner JL, Austin JK, Kerr M, Dunn DW. Psychosocial issues for children with epilepsy. *Epilepsy & Behavior* 2011;22: 47-54. doi: 10.1016/j.yebeh.2011.04.063F
- [4] Rodenburg R, Meijer AM, Dekovic M, Aldenkamp AP. Family factors and psychopathology in children with epilepsy: A literature review. *Epilepsy & Behavior* 2005;6: 488-503. doi: 10.1016/j.yebeh.2005.03.006
- [5] Stevanovic D, Tadic I, Novakovic T. Health-related quality of life in children and adolescents with epilepsy: A systematic review. In: Gadze ZP, editor. *Epilepsy in children - Clinical and social aspects*. Rijeka, Croatia: InTech; 2011, p. 161-186.
- [6] Reilly C, Neville BG. Academic achievement in children with epilepsy: A review. *Epilepsy Research* 2011;97: 112-123. doi: 10.1016/j.eplepsyres.2011.07.017
- [7] Rantanen K, Eriksson K, Nieminen P. Social competence in children with epilepsy - A review. *Epilepsy & Behavior* 2012;24: 295-303. doi: 10.1016/j.yebeh.2012.04.117
- [8] Rodenburg R, Marie Meijer A, Deković M, Aldenkamp AP. Family predictors of psychopathology in children with epilepsy. *Epilepsia* 2006;47: 601-614. doi: 10.1111/j.1528-1167.2006.00475.x
- [9] Heimlich TE, Westbrook LE, Austin JK, Cramer JA, Devinsky O. Brief report: Adolescents' attitudes toward epilepsy: Further validation of the Child Attitude Toward Illness

Scale (CATIS). *Journal of Pediatric Psychology* 2000;25: 339-345. doi:
10.1093/jpepsy/25.5.339

[10] Patterson JM, McCubbin HI. Adolescent coping style and behaviors:
Conceptualization and measurement. *Journal of Adolescence* 1987;10: 163-186. doi:
10.1016/S0140-1971(87)80086-6

[11] Patterson JM. Families experiencing stress: I. The Family Adjustment and Adaptation
Response Model: II. Applying the FAAR Model to health-related issues for intervention and
research. *Family Systems Medicine* 1988;6: 202-237. doi: 10.1037/h0089739

[12] Oostrom KJ, Schouten A, Kruitwagen CLJJ, Peters ACB. Parents' perceptions of
adversity introduced by upheaval and uncertainty at the onset of childhood epilepsy. *Epilepsia*
2001;42: 1452-1460. doi: 10.1046/j.1528-1157.2001.14201.x

[13] Fastenau PS, Shen J, Dunn DW, Perkins SM, Hermann BP, Austin JK.
Neuropsychological predictors of academic underachievement in pediatric epilepsy:
Moderating roles of demographic, seizure, and psychosocial variables. *Epilepsia* 2004;45:
1261-1272. doi: 10.1111/j.0013-9580.2004.15204

[14] Austin JK, Risinger MW, Beckett LA. Correlates of behavior problems in children with
epilepsy. *Epilepsia* 1992;33: 1115-1122. doi: 10.1111/j.1528-1157.1992.tb01768.x

[15] Austin JK, Perkins SM, Johnson CS, Fastenau PS, Byars AW, deGrauw TJ, Dunn
DW. Self - esteem and symptoms of depression in children with seizures: Relationships with
neuropsychological functioning and family variables over time. *Epilepsia* 2010;51: 2074-2083.
doi: 10.1111/j.1528-1167.2010.02575.x

[16] Lee A, Hamiwka LD, Sherman E, Wirrell EC. Self-concept in adolescents with
epilepsy: Biological and social correlates. *Pediatric Neurology* 2008;38: 335-339. doi:
10.1016/j.pediatrneurol.2008.01.011

- [17] Dunn DW, Austin JK, Huster GA. Symptoms of depression in adolescents with epilepsy. *Journal of the American Academy of Child & Adolescent Psychiatry* 1999;38: 1132-1138. doi: 10.1097/00004583-199909000-00017
- [18] Austin JK, Patterson JM, Huberty TJ. Development of the coping health inventory for children. *Journal of Pediatric Nursing* 1991;6: 166-74. doi: Not available
- [19] Cengel-Kultur SE, Ulay HT, Erdag G. Ways of coping with epilepsy and related factors in adolescence. *The Turkish Journal of Pediatrics* 2009;5: 238-247. doi: Not available
- [20] Baker GA, Spector S, McGrath Y, Soteriou H. Impact of epilepsy in adolescence: A UK controlled study. *Epilepsy & Behavior* 2005;6: 556-562. doi: 10.1016/j.yebeh.2005.03.011
- [21] Trzesniewski KH, Donnellan MB, Moffitt TE, Robins RW, Poulton R, Caspi A. Low self-esteem during adolescence predicts poor health, criminal behavior, and limited economic prospects during adulthood. *Developmental Psychology* 2006;42: 381-390. doi: 10.1037/0012-1649.42.2.381
- [22] Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *Journal of Health and Social Behavior* 1983;24: 385-396. doi: 10.2307/2136404
- [23] Vera EM, Vacek K, Blackmon Sk, Coyle L, Gomez K, Jorgenson K, Luginbuhl P, Moallem I, Steele JC. Subjective well-being in urban, ethnically diverse adolescents: The role of stress and coping. *Youth & Society* 2012;44: 331-347. doi: 10.1177/0044118x11401432
- [24] Broadbent E, Petrie KJ, Main J, Weinman J. The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research* 2006;60: 631-637. doi: 10.1016/j.jpsychores.2005.10.020
- [25] Chong J, Mackey AH, Broadbent E, Stott NS. Children's perceptions of their cerebral palsy and their impact on life satisfaction. *Disability and Rehabilitation* 2012;34: 2053-2060. doi: 10.3109/09638288.2012.669021

- [26] Blount RL, Simons LE, Devine KA, Jaaniste T, Cohen LL, Chambers CT, Hayutin LG. Evidence-based assessment of coping and stress in pediatric psychology. *Journal of Pediatric Psychology* 2008;33: 1021-1045. doi: 10.1093/jpepsy/jsm071
- [27] Sixbey MT. Development of the family resilience assessment scale to identify family resilience constructs. In: University of Florida; 2005.
- [28] Plumb JC. The impact of social support and family resilience on parental stress in families with a child diagnosed with an autism spectrum disorder. In: *Social of Social Policy and Practice*: University of Pennsylvania; 2011.
- [29] Rosenberg M. *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press; 1965.
- [30] Ang RP. Effects of parenting style on personal and social variables for Asian adolescents. *American Journal of Orthopsychiatry* 2006;76: 503-511. doi: 10.1037/0002-9432.76.4.503
- [31] Preacher KJ, Hayes AF. Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods* 2008;40: 879-891. doi: 10.3758/BRM.40.3.879
- [32] Hayes AF, Preacher KJ. Statistical mediation analysis with a multicategorical independent variable. *British Journal of Mathematical and Statistical Psychology* 2014;67: 451-470. doi: 10.1111/bmsp.12028
- [33] Chew J, Haase AM. Psychometric properties of the Family Resilience Assessment Scale: A Singaporean perspective. *Epilepsy & Behavior* 2016;61: 112-119. doi: 10.1016/j.yebeh.2016.05.015
- [34] Rätty LK, Soderfeldt BA, Larsson G, Larsson BMW. The relationship between illness severity, sociodemographic factors, general self-concept, and illness-specific attitude in Swedish adolescents with epilepsy. *Seizure* 2004;13: 375-382. doi: 10.1016/j.seizure.2003.09.011

- [35] Gauffin H, Landtblom A-M, Råty L. Self-esteem and sense of coherence in young people with uncomplicated epilepsy: A 5-year follow-up. *Epilepsy & Behavior* 2010;17: 520-524. doi: 10.1016/j.yebeh.2010.01.167
- [36] Funderburk JA, McCormick BP, Austin JK. Does attitude toward epilepsy mediate the relationship between perceived stigma and mental health outcomes in children with epilepsy? *Epilepsy & Behavior* 2007;11: 71-76. doi: 10.1016/j.yebeh.2007.04.006
- [37] Modi AC, Ingerski LM, Rausch JR, Glauser TA. Treatment factors affecting longitudinal quality of life in new onset pediatric epilepsy. *Journal of Pediatric Psychology* 2011;36: 466-475. doi: 10.1093/jpepsy/jsq114
- [38] Ferro MA, Camfield CS, Levin SD, Smith ML, Wiebe S, Zou G, Speechley KN. Trajectories of health-related quality of life in children with epilepsy: A cohort study. *Epilepsia* 2013;54: 1889-1897. doi: 10.1111/epi.12388
- [39] Compas BE, Jaser SS, Dunn MJ, Rodriguez EM. Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology* 2012;8: 455-480. doi: 10.1146/annurev-clinpsy-032511-143108
- [40] Smith G, Wagner J, Andrews J, Austin J, Mueller M, Carter E, Griesemer K. Caregiving in pediatric epilepsy: Results of focus groups and implications for research and practice. *Epilepsy & Behavior* 2014;34: 34-41. doi: 10.1016/j.yebeh.2014.03.002
- [41] Podsakoff PM, MacKenzie SB, Lee J-Y, Podsakoff NP. Common method biases in behavioral research: A critical review of the literature and recommended remedies. *Journal of Applied Psychology* 2003;88: 879-903. doi: 10.1037/0021-9010.88.5.879
- [42] Hilliard ME, Harris MA, Weissberg-Benchell J. Diabetes resilience: A model of risk and protection in Type 1 Diabetes. *Current Diabetes Reports* 2012;12: 739-748. doi: 10.1007/s11892-012-0314-3

- [43] Kichler JC, Kaugars AS. Commentary: Applying positive development principles to group interventions for the promotion of family resilience in pediatric psychology. *Journal of Pediatric Psychology* 2015;40: 978-980. doi: 10.1093/jpepsy/jsu115
- [44] Snead K, Ackerson J, Bailey K, Schmitt MM, Madan-Swain A, Martin RC. Taking charge of epilepsy: The development of a structured psychoeducational group intervention for adolescents with epilepsy and their parents. *Epilepsy & Behavior* 2004;5: 547-556. doi: 10.1016/j.yebeh.2004.04.012
- [45] Frizzell CK, Connolly AM, Beavis E, Lawson JA, Bye AME. Personalised epilepsy education intervention for adolescents and impact on knowledge acquisition and psychosocial function. *Journal of Paediatrics and Child Health* 2011;47: 271-275. doi: 10.1111/j.1440-1754.2010.01952.x
- [46] Wagner JL, Smith G, Ferguson P, van Bakergem K, Hrisco S. Feasibility of a pediatric cognitive-behavioral self-management intervention: Coping Openly and Personally with Epilepsy (COPE). *Seizure* 2011;20: 462-467. doi: 10.1016/j.seizure.2011.02.010
- [47] Baker GA, Brooks J, Buck D, Jacoby A. The stigma of epilepsy: A European perspective. *Epilepsia* 2000;41: 98-104. doi: 10.1111/j.1528-1157.2000.tb01512.x
- [48] Serdari A, Tsalkidis A, Tripsianis G, Vadikolias K, Chatzimichael A, Piperidou C, Livaditis M. Epilepsy impact on aspects of school life of children from different cultural populations in Thrace, Greece. *Epilepsy & Behavior* 2009;15: 344-350. doi: 10.1016/j.yebeh.2009.04.025
- [49] Jacoby A, Wang W, Vu TD, Wu J, Snape D, Aydemir N, Parr J, Reis R, Begley C, de Boer H, Prilipko L, Baker G. Meanings of epilepsy in its sociocultural context and implications for stigma: Findings from ethnographic studies in local communities in China and Vietnam. *Epilepsy Behav* 2008;12: 286-97. doi: 10.1016/j.yebeh.2007.10.006
- [50] Gelhaar T, Seiffge-Krenke I, Borge A, Cicognani E, Cunha M, Loncaric D, Macek P, Steinhausen H-C, Metzke CW. Adolescent coping with everyday stressors: A seven-nation

study of youth from central, eastern, southern, and northern Europe. *European Journal of Developmental Psychology* 2007;4: 129-156. doi: 10.1080/17405620600831564

[51] Ungar M, Brown M, Liebenberg L, Othman R, Kwong WM, Armstrong M, Gilgun J. Unique pathways to resilience across cultures. *Adolescence* 2007;42: 287-310. doi: Not available

[52] Yeh C, Inose M. Difficulties and coping strategies of Chinese, Japanese and Korean immigrant students. *Adolescence* 2002;37: 69-82. doi: Not available

Table 1. Characteristics of young people who participated in the survey ($n=152$).

	n	(%)
Demographics		
Age, mean $\pm$ SD	15.0 $\pm$ 1.13	
Gender		
Male	79	(52.0)
Female	73	(48.0)
Ethnicity		
Chinese	95	(62.5)
Malay	37	(24.3)
Indian	18	(11.8)
Others (Arab, Burmese)	2	(1.3)
Household income ($n=146$)		
No working person	2	(1.4)
Less than 1,999 SGD	16	(11.0)
2,000 – 4,999 SGD	60	(41.1)
5,000 – 9,999 SGD	33	(22.6)
10,000 SGD and above	35	(24.0)
Medical information		
Age at which young person was diagnosed with epilepsy, mean $\pm$ SD	8.79 $\pm$ 3.94	
Number of years with epilepsy, mean $\pm$ SD	6.21 $\pm$ 3.68	
AED		
Not on medication	18	(11.8)
Single AED	86	(56.6)
Multiple AED	48	(31.6)
Seizures		
No seizures	95	(62.5)
At least once a month	35	(23.0)
Every three months	14	(9.2)
Single seizure episode within the past 3 months	8	(5.3)
Illness severity ($n=152$)		
No seizures, AED not required	18	(11.8)
Seizures controlled with AED	77	(50.7)
Seizures despite AED	57	(37.5)

¹Percentages for 'Ethnicity' and 'Household income' do not add up to 100% due to rounding errors.

N – population sample; n – study sample; SD – Standard deviation; NA – Not available; AED – Anti-epileptic drugs;

GCE 'O', 'N' and 'A' levels refers to Singapore-Cambridge General Certificate of Education Ordinary, Normal and Advance level, respectively; ITE – Institute of Technical Education; SGD – Singapore Dollars.

Table 2. Descriptive statistics for young people's self-esteem, perceived stress, illness perceptions, coping and family resilience.

	Total (<i>n</i> =152)		Low: No seizures, AED not required (<i>n</i> =18)		Moderate: Seizures controlled with AED (<i>n</i> =77)		High: Seizures despite AED (<i>n</i> =57)	
	<i>M</i>	(<i>SD</i>)	<i>M</i>	(<i>SD</i>)	<i>M</i>	(<i>SD</i>)	<i>M</i>	(<i>SD</i>)
RSS	28.78	(6.04)	33.56	(4.74)	29.95	(5.92)	25.70	(5.01)
PSS	38.30	(8.12)	31.83	(8.82)	37.24	(7.52)	41.79	(7.06)
IPQ	46.91	(14.29)	34.05	(11.25)	45.21	(14.39)	53.57	(11.09)
ACOPE	113.24	(18.76)	112.76	(12.82)	113.62	(19.14)	112.87	(20.06)
FRAS	155.48	(24.83)	164.94	(26.57)	158.63	(25.11)	147.43	(21.84)

* $p < 0.05$; ** $p < 0.01$; NS–Not significant; M–Mean; SD–Standard deviation

RSS–Rosenberg Self-esteem Scale; PSS–Perceived Stress Scale; IPQ–Brief Illness Perception Questionnaire;

ACOPE–Adolescent Coping Orientation for Problem Experiences; FRAS–Family Resilience Assessment Scale.

Table 3. Path coefficients for multiple mediation model: Relative direct and indirect effects of illness severity on self-esteem through perceived stress, illness perceptions and family resilience.

	Path coefficients (SE)				Indirect effects (SE)	
	Self-esteem (Y)	Perceived stress (M ₁)	Illness perception (M ₂)	Family resilience (M ₃)	ab	95% BC CI
D1: Low vs. Moderate (ref)						
Illness severity (X)	c' -0.04 (0.92)	a_1 -5.38 (1.98) **	a_2 -11.33 (3.44) **	a_3 5.47 (6.40)		
PSS	b_1 -0.26 (0.05) **					
IPQ	b_2 -0.16 (0.03) **					
FRAS	b_3 0.05 (0.01) **					
Relative total indirect effect					3.46 (1.18) *	1.13, 5.71
Specific: X→PSS→Y					1.42 (0.67) *	0.33, 3.02
Specific: X→IPQ→Y					1.76 (0.69) *	0.64, 3.37
Specific: X→FRAS→Y					0.28 (0.40)	-0.36, 1.30
D2: Moderate (ref) vs. High						
Illness severity (X)	c' -1.13 (0.65)	a_1 3.86 (1.40) **	a_2 7.93 (2.43) **	a_3 -10.79 (4.52) *		
PSS	b_1 -0.26 (0.05) **					
IPQ	b_2 -0.16 (0.03) **					
FRAS	b_3 0.05 (0.01) **					
Relative total indirect effect					-2.80 (0.77) *	-4.35, -1.30
Specific: X→PSS→Y					-1.02 (0.41) *	-1.95, -0.33
Specific: X→IPQ→Y					-1.23 (0.49) *	-2.49, -0.48
Specific: X→FRAS→Y					-0.55 (0.35) *	-1.49, -0.08

* $p < 0.05$; ** $p < 0.01$; BC CI–Bias corrected confidence intervals; SE–Standard error; $n=139$; 10,000 bootstrap samples
X–Independent variable (Illness severity); Y–Dependent variable (Self-esteem); M–Mediators (Perceived stress, illness perception and family resilience)
Ref: Reference category–Seizures controlled with AED (Moderate)
D1 contrast: Covariates (D2, Gender, Household income); D2 contrast: Covariates (D1, Gender, Household income)
PSS–Perceived Stress Scale; IPQ–Brief Illness Perception Questionnaire; FRAS–Family Resilience Assessment Scale