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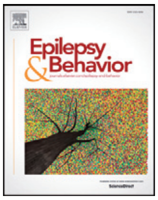

Individual and family factors associated with self-esteem in young people with epilepsy: A multiple mediation analysis

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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 behaviors 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 (D_1: *Total ab* $= 3.46$, 95% CI 1.13, 5.71; D_2: *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.

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 diagnoses, externalizing and internalizing problems, lower health-related quality of life, decreased 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, and 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.

1.1. 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

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researchers have not specifically measured the construct of stress. Instead, stress levels were inferred from outcomes related to individuals' psychosocial functioning.

1.2. 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].

1.3. 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 behavior problems [17]; and lower self-esteem [16] among young people with epilepsy.

1.4. Coping behaviors

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 behaviors, such as being optimistic, seeking social support, focusing on competence and adhering to treatment, have been correlated with positive psychosocial outcomes [18,19].

1.5. 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, as well as individual and family factors, on young people's adaptation. The present study aimed 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 and 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 standardized 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