



Impact of choice of coping strategies and family functioning on psychosocial function of young people with epilepsy

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ABSTRACT

Both medical and psychological factors have an important impact upon the psychosocial functioning of young people with epilepsy. The purpose of this study was to identify factors that distinguish young people with epilepsy and high psychosocial functioning from those with lower levels. The participants were 114 young people (40 males, 74 females) with active epilepsy and a mean age of 17.92 years ($SD = 3.90$) who completed either a paper (60.5%) or a web-based survey (39.5%) comprising demographic, medical, and psychosocial measures. Psychosocial measures included family functioning, adolescent coping, anxiety, depression, and quality of life. A latent class analysis produced two psychosocial functioning groups based on participants' scores for anxiety, depression, and quality of life. Young people were more likely to be members of the group with poor psychosocial functioning if they had a seizure in the last month ($Wald = 5.63, p < .05$), came from families with lower levels of communication and problem solving ($Wald = 5.28, p < .05$), and made greater use of non-productive (emotion-focused) coping strategies such as wishful thinking, withdrawal, and worry ($Wald = 12.00, p < .01$). The findings suggest that, in addition to standard medical treatment, clinicians may promote better outcomes by strengthening family functioning and encouraging less use of nonproductive coping strategies.

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1. Introduction

The transition from childhood to adulthood has been described by Lerner and Galambos [1,2] as a period of first experiences, including some or all of the following: being out of the direct control of parents, living away from home, having first sexual experience, transitioning from school to work, and moving from the role of being cared for to providing care. Most young people view the transition from childhood to adulthood as a positive experience during which they tackle an impressive range of demands, conflicts, and opportunities [3] and build on their psychological strengths, such as resilience, optimism, and hope [4].

However, for a young person with a chronic illness, the difficulties of achieving the developmental transition can be compounded by the physical manifestations of the illness and its treatment [5], and this has been shown for epilepsy [6]. Generally, young people with epilepsy have been found to experience poorer quality of life and have more psychosocial problems than the general population [7,8], even when their epilepsy is well controlled [9–11].

For young people who have epilepsy, a specific developmental challenge relates to difficulties in balancing anticonvulsant medication in the context of puberty, with associated hormonal and weight changes

which can lead to poorer seizure control [12]. The condition may also impede normal opportunities for social interaction through restrictions in activities such as computer use and swimming [13]. Young people with epilepsy may have difficulties gaining and maintaining a driving license or obtaining education and employment [14], thus hindering their ability to gain independence and maintain their social connections.

Empirical research that examines psychosocial factors associated with chronic illness for young people remains limited. Research that is specific to psychosocial factors in young people who have epilepsy is even rarer. The lack of this research has implications for the provision of high quality health care to young people with epilepsy and for their willingness to adhere to treatment recommendations.

The rationale for this study was to better understand the relationships between health-related quality of life, anxiety, and depression so that targeted interventions can be designed that will minimize detrimental psychosocial outcomes, provide a strong evidence base to underpin the provision of effective high-quality multidisciplinary person-centered care, and support young people with epilepsy to reach their full potential.

The aim of this study was to examine the psychosocial functioning of young people (aged between 10 and 24) with epilepsy through the identification of medical and psychological factors that distinguish higher and lower psychosocial functioning. It was expected that psychological factors such as family functioning and coping styles would be of equal or greater importance to the severity of the illness in determining the young person's level of anxiety, depression, and quality of life. It is

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argued that factors that distinguish between good and poor psychosocial functioning should be the focus of future targeted intervention programs, as they have the most likelihood to lead to positive outcomes.

2. Method

2.1. Measures

2.1.1. Medical information

The epilepsy-specific medical questions were derived from previous epilepsy research performed by Jacoby and Baker in the United Kingdom and Europe [15–18] and covered epilepsy type, seizure frequency, family history of epilepsy and medication use, and related issues.

2.1.2. Family functioning

The general function subscale from the Family Assessment Device (FAD) developed by Epstein et al. [18,19] was used to measure family functioning. The scale's specific emphasis is on assessing communication and problem solving via two subscales that form an overall indicator of effective family functioning. Sample items include 'Planning family activities is difficult because we misunderstand each other' and 'We can express feelings to each other'. Using a four-point Likert scale, 12 items are rated from 'strongly agree' to 'strongly disagree' based on how the participant's family reacts most of the time. Scores on the 12 items are summed to produce a total ranging from 4 to 48. Lower scores indicate healthy functioning in terms of communication and problem solving, and higher scores reflect unhealthy family functioning. This study found good reliability with a Cronbach's alpha (α) of .91.

2.1.3. Coping strategies

The short version of the Adolescent Coping Scale – General Short Form (ACS) was developed in Australia by Frydenberg and Lewis [20] and is a measure of 18 coping strategies that combine to form three general coping styles used by adolescents. The three styles are 'productive coping', 'reference to others', and 'nonproductive' coping. The productive coping style includes items referring to problem solving, working hard, belonging, positive thinking, relaxation, and physical recreation. This style combines strategies that focus on solving the problem or acting on the concern while remaining physically healthy. The reference to others style includes strategies for seeking support from others in the social, spiritual, and professional domains. The nonproductive coping style encompasses items relating to worry, spending time with friends, belonging, wishful thinking, not coping, tension reduction, ignoring the problem, keeping to self, and self-blame. All these strategies tend to distract from the problem and attempt to manage the emotional reaction to the problem. Using a five-point Likert scale, the 18 items are rated from 'doesn't apply or don't do it' to 'used a great deal' based on how the participant typically reacts in life. Each scale is used separately, and lower scores indicate a reduced use of coping strategies related to each particular coping style. A cluster analysis on the items using Ward's method and squared Euclidean distance produced dendrograms that support two factors rather than three factors for the ACS, with the factors reflecting productive and nonproductive coping styles. Item five (spending more time with friends) and item six (improving one's relationship with others) did not form the expected reference to others coping style cluster. Similar findings for these two items were also reported by Frydenberg and Lewis [21] and Cunningham [22]. Moreover, the internal reliability for the reference to others subscale was unacceptable ($\alpha = .48$). As a result, the reference to others subscale was excluded from this study, and only the constructs for productive ($\alpha = .77$) and nonproductive coping ($\alpha = .68$) were used.

2.1.4. Psychological well-being

Anxiety and depression levels were used as indicators of psychological well-being and were operationalized by the Hospital Anxiety and

Depression Scale (HADS) developed by Zigmond and Snaith [23]. This scale has been used in previous epilepsy research [24] and was selected because it does not include items that refer to physical symptoms of anxiety or depression that could be confused with symptoms of epilepsy. The HADS is rated on four-point Likert scales and includes both an anxiety subscale ($\alpha = .81$) and a depression subscale ($\alpha = .80$), each with 7 items. Higher scores represent greater levels of anxiety and depression.

To provide a humanistic perspective on psychological well-being, the short version of the Orientation of Life Scale developed by Antonovsky [25–27] (SOC-13) was also included in the survey. This scale examines the global orientation of individuals in terms of their perception of the world as comprehensible, manageable, and meaningful (also known as sense of coherence). A high sense of coherence predicts being able to handle stress better and has been found to decline over time for young people with epilepsy [28]. Sample items include 'Has it happened that people whom you counted on disappointed you?' and 'Do you have the feeling that you are in an unfamiliar situation and don't know what to do?' There are four items related to meaningfulness, five related to comprehensibility, and four to manageability. All 13 items are added together to provide a total sense of coherence score. The possible range of scores is 13 to 91, with higher scores indicating a stronger sense of coherence ($\alpha = .81$).

2.1.5. Health-related quality of life

The Quality of Life in Epilepsy for Adolescents (QOLIE-AD-48) scale developed by Cramer et al. [29] was used to examine health-related quality of life. This scale is divided into two elements—general health and effects of epilepsy and anticonvulsant medications—and has eight subscales: the impact of epilepsy in general, the impact of epilepsy on memory and concentration, the impact of epilepsy on physical functioning, attitudes toward epilepsy, stigma, social support, school behavior, and health perceptions. All subscales were scored in accordance with the instructions provided by Cramer et al. [30] to produce a weighted total score. Possible scores range from 16 to 98, with higher scores indicating a better quality of life. All analyses used the overall score and additional concerns about epilepsy QOLIE-AD-48 items, and hence, no modifications to the subscales were made ($\alpha = .94$).

2.2. Procedure

Data for this study were collected via paper and web-based versions of a self-report survey. Out of a total of 114 participants, 45 (39.5%) completed the web-based survey. Fourteen participants (12.2%) who did the paper survey required assistance from parents or carers to complete it.

Participants were primarily recruited through epilepsy organizations both in Australia and overseas, private practices of selected Australian neurologists, and social media.

2.3. Data analysis

Latent Gold 2.0 was used to perform a latent class analysis [31] that resulted in two psychosocial functioning groups (good and poor). Statistical Package for the Social Sciences (SPSS) was used for all descriptive statistics and a logistic regression analysis with the results of the cluster analysis as the dependent variable.

3. Results

3.1. Participants

In order to attract the most representative sample possible, the selection criteria for participation were that the participants had self-reported epilepsy, were aged between 10 and 24, and were able to complete the survey in English. The final sample included 114 young people, aged between 10 and 24 years, and who had self-reported

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