



The relationship between psychosocial care and attitudes toward illness in adolescents with epilepsy

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ABSTRACT

Epilepsy is a significant health problem in Iran and other countries. Previous epilepsy studies conducted in Iran have often focused on physiological aspects and pharmacological therapy, and little attention has been paid to the psychological and social aspects of care, particularly in adolescence. This paper aims to fill this gap by assessing the relationship between psychosocial care and attitudes toward illness in adolescents with epilepsy. A descriptive correlational design was adopted, and 74 adolescents who experienced generalized seizures and were treated at the neurology clinic affiliated with the Tabriz University of Medical Sciences in 2010 were examined. The data were collected using instruments including (1) the patient demographic characteristics, (2) the Child Report of Psychosocial Care Scale, and (3) the Child's Attitude Toward Illness Scale. There was a significant positive correlation between psychosocial care and attitudes toward illness ($p < .05$). There is no evidence for routine psychological consultation for our sample; it would be helpful if psychological consultation with and without parents made available to adolescents with epilepsy.

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1. Introduction

Epilepsy is one of the most common and serious neurological disorders of childhood [1,2]. It leads to abnormally excessive or synchronous neuronal activity in the brain [3]. Worldwide, epilepsy occurs cumulatively in 3.8 individuals per thousand [4]. The point prevalence of epilepsy varies from 2.1 to 4 per 1000 individuals in Iran [5]. Epilepsy is a chronic condition, and attention to the physical, psychological, and social dimensions of chronic conditions is important [6]. If patients with epilepsy are provided with the correct treatment and care in a timely manner, they are at lesser risk of physical, mental, and social and family complications [7]. The multidisciplinary team that supports patients with epilepsy consists of doctors, psychologists, social workers and others [6], and nurses can play an important role as consultants and educators in the facilitation of self-management [8], which can affect the above-mentioned three dimensions.

Epilepsy care in children has been criticized for its lack of impact. Various service models and strategies have been developed in response to the perceived inadequacies in the care provision for children with epilepsy and their families. In a systematic review, Lindsay and Bradley assessed four trials and five reports in which they reported four different education and counseling programs for children, children and their parents, or teenagers and their parents. Each of the programs in this review showed some benefit to children with epilepsy, but their effects were extremely variable. The review concluded that no program showed benefits across the full range of outcomes. No study appears to have demonstrated any detrimental effects, but evidence in favor of any single program is insufficient to recommend one program over another. More trials, performed by independent research teams, are necessary [9]. This study revealed a necessity for additional investigations and assessments of educational and counseling interventions for clients with epilepsy.

Furthermore, the psychosocial care requirements of children with epilepsy are unknown. This issue was considered in 1998 by Austin et al. through describing and developing a psychosocial care need scale for clients with epilepsy [10]. Additionally, Shore et al. [11] conducted a study with 8- to 14-year-old children 3, 6, 12, and 24 months after their diagnosis and observed that although psychosocial care needs were the highest at the 3-month data collection, worries, concerns, and a need for information and support persisted for 24 months.

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These needs included an explanation of the disease and its expected control provided by a nurse or a doctor, the individual feelings concerning epilepsy as a condition, and living with a seizure condition. Therefore, the authors suggested that nurses should assess children for these needs at every encounter with a healthcare system to address their needs [11]. This study was conducted with a mixed sample of school-age children and adolescents. An additional important result was that more psychosocial care needs were associated with more negative attitudes toward having epilepsy [11].

A child's attitude toward epilepsy may affect their psychological balance [12]. Lagreca et al. and Heimlich et al. observed that adolescents have the most negative attitude toward epilepsy [13,14]. Research results demonstrate that the attitude of a patient with epilepsy is based on successful and failed experiences which are gradually gained through correct treatments. Performing daily tasks and adhering to condition-related treatments can affect the positive or negative attitudes of patients with epilepsy [7].

Furthermore, the school performances of children with epilepsy are notable. A study by Adewuya et al. [15] assessed the school performance of Nigerian adolescents (12–18 years old) with epilepsy compared to healthy controls and examined the variables correlating with their academic difficulties. One of the six variables that significantly predicted poor school performances in adolescents with epilepsy was the adolescents' attitudes toward the illness, and the researchers concluded that the determinants of poor school performances in adolescents with epilepsy in Nigeria are multivariate, with psychosocial factors as the most important. These psychosocial factors should be noted for early identification and screening of those children with the greatest risk for academic failure and the greatest need for appropriate educational remediation services [15]. Therefore, studies must focus on the attitudes of this population to help to prevent their academic failure. It appears necessary to prepare information included as a package of materials for the psychosocial care for adolescents.

The adolescence stage of life is important because it is associated with considerable mental, physical (puberty), and psychosocial (identity, autonomy) changes. Adolescents with chronic conditions face many crises. Despite its developmental exclusivity because of adolescence, adolescents should be able to face the stress of a diagnosis and serious, long-term treatment. Developmentally, there is an effort for independence in teens, whereas dependence, surrender, and a lost sense of control lead to more difficult confrontations of this disease for adolescents [16]. The vulnerability of adolescents with epilepsy is well documented in the literature, and they exhibit a higher frequency of behavioral problems than healthy or chronically ill control groups [17–19], including more worries and less interest in competitive sports as well as the belief that epilepsy will prevent them from becoming parents, driving a car [17], or becoming successfully employed [20]. Many are concerned that the seizures will kill them [21] or lead to a poor health-related quality of life [22].

There are some contradictory findings in the literature regarding attitudes toward illness. Chiou [23] concluded there were attitude differences between age groups, but Westbrook [24] stated that older adolescents have more negative attitudes toward their epilepsy than younger groups, which suggests that this age group may be more vulnerable to the effects of possessing a stigmatizing disorder. Westbrook stated that the developmental tasks of this stage are more demanding because they require the more sophisticated cognitive processes involved in adult decision-making. Furthermore, the actions performed during this time may have more immediate and longer lasting implications for adulthood [24]. If the tasks of earlier stages are not satisfactorily achieved because of epilepsy-related problems, then the accumulation of both prior and current tasks may be overwhelming and contribute to the less positive perceptions of illness in older adolescents. In addition, older adolescents may have to display greater independence as their age-matched peers continue in their development [24].

In summary, attitude towards the illness is an important variable affecting and relating to other patient variables, such as psychosocial care, but its relationship with the other variables has not been assessed in a pure sample of adolescents.

According to statistics, epilepsy in Iran is a significant health problem, as it is in other countries. Research in this field can be useful for many, and it can reduce the numerous problems in the community that will be created from epilepsy complications [25]. However, the statistics related to Iranian adolescents with epilepsy were not assessed. Studies regarding epilepsy in Iran are more related to the physiological aspects of health and pharmacological therapy, and little attention has been placed on the relationship between psychological and social care, particularly in adolescents. Whether psychosocial care needs are associated with an adolescent's attitudes toward having epilepsy is unknown. This paper will focus on filling this gap; it answers the following questions:

1. What are the psychosocial care needs of Iranian adolescents with epilepsy?
2. What are the attitudes of Iranian adolescents with epilepsy toward their illness?
3. What are the relationships between adolescents' psychosocial care needs and their attitudes toward having epilepsy?

Previously published studies have either included the parents as participants or evaluated children from different age groups. By contrast, this study focused on adolescents and, in specifically, patients with generalized seizures.

2. Methods

This study adopted a descriptive correlational design in which the participants with epilepsy were 10–18 years old and experienced generalized seizures. They were seen in the neurology clinic affiliated with the Tabriz University of Medical Sciences in 2010 (total eligible = 74 participants).

The inclusion criteria were that the children had been prescribed antiepileptic medication and a definitive diagnosis of epilepsy. The exclusion criteria were a diagnosis of mental retardation or intellectual disability (a parent report of child placement in a mentally handicapped classroom), another major chronic physical disorder, or a progressive brain disorder.

The data were collected using an instrument consisting of three components: (1) patient demographic characteristics, (2) the Child Report of Psychosocial Care Scale, and (3) the Child Attitude Toward Illness Scale, which were used after obtaining permission. Demographic details were collected, including information on age, gender, current status, and year in school, for adolescents with epilepsy, and clinical details, including the age of onset and seizure types, were also collected.

2.1. The Child Report of Psychosocial Care Scale

The Child Report of Psychosocial Care Scale was used [10]. Acceptable levels of scale reliability have been reported elsewhere [26]. This scale has three parts: subscale 1 included an explanation of the disease and its expected control which were provided by a nurse or a doctor and is scored from 1 (less than expected) to 3 (more than expected). Subscale 2 is scored from 1 (never) to 5 (very often) and included six questions regarding individual feelings about having epilepsy as a condition. Each item indicated how much or how many times the participant worried about seizures and/or was scared about participating in activities that led to a deterioration in the epilepsy condition. Subscale 3 measures the information needs related to living with a seizure condition on a response scale of 1 (yes) to 2 (no).

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