



Knowledge, attitudes, and practices among mothers of children with epilepsy: A study in a teaching hospital

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ABSTRACT

Objective: Knowledge about epilepsy and attitudes towards patients with epilepsy can affect measures taken to manage epilepsy and seizures. Support and understanding of mothers is invaluable in enabling children with epilepsy to develop normal life skills in living with epilepsy. In order to identify the educational needs of mothers of children with epilepsy, their knowledge, attitudes, and practices should be assessed. Therefore, we interviewed a group of mothers of children with epilepsy who were referred to a pediatric neurology clinic in a teaching hospital. The objective of this study was to assess knowledge, attitudes, and practices among mothers of children with epilepsy in order to identify their educational needs.

Methods: In the period of August 2014 to January 2015, mothers whose children were diagnosed with epilepsy for at least six months participated in this cross sectional study, while returning to the neurology clinic of a pediatric hospital for usual follow-up. Data were collected through face-to-face interviews, held by trained female general practitioners. The interviewer used questions from a questionnaire. The knowledge section of the questionnaire included questions regarding prevalence and general knowledge about epilepsy, its etiology, symptoms, and seizure provoking factors. The attitudes section included statements regarding the mother's attitudes towards epilepsy and patients with the disease. The practice section included questions about first-aid measures taken by mothers who had witnessed generalized seizures by the time of interview.

Results: Responses of 206 participants were analyzed. At least 83% of mothers knew that epilepsy is a noncontagious neurological disorder which can be treated by regular drug therapy. In spite of demonstrating good knowledge scores, the majority of mothers felt the need for further training in epilepsy. More than 98% of mothers were against the idea that patients with epilepsy should hide their disease. Though having been referred to physicians, 84% of mothers had provided their children with at least one ineffective treatment, mostly based on superstitions. **Conclusion:** Mothers' level of knowledge of epilepsy was good, and their attitudes towards epilepsy were mainly positive. Regarding the right first-aid measures at time of the last seizure, mothers' practices were acceptable. However, there is still room for improvement regarding avoiding the wrong measures. It is suggested that both practice-related issues and other aspects of epilepsy be taken into account in epilepsy-related education programs.

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1. Introduction

The prevalence of epilepsy among children is seven in 1000, which is two times greater than adults [1]. In many parts of the world, patients with epilepsy suffer from stigma and discrimination, which can influence their quality of life and even discourage them from seeking treatment. In some communities, the nature of disease is not well understood, and therefore epilepsy may be considered as

a spiritual or contagious disease [2]. Moreover, some people believe that epileptic seizures are associated with divine retribution [3]. Knowledge regarding epilepsy is inversely related to perception of stigma [4]. The stigma can become problematic in terms of education, employment, and marriage [5,6]. Poor knowledge about epilepsy and negative attitudes towards patients with epilepsy can affect measures taken to treat the disease [7,8].

People who are in contact with children with epilepsy on a daily basis, especially their parents, can deeply affect them [9]. Support and understanding of parents, especially mothers, is invaluable in enabling children with epilepsy to develop confidence and normal life skills in managing and living with epilepsy [10]. Thus, considering the role of

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mothers in the lives of their children with epilepsy, they can help ease the burden of the disease the most. Mothers' knowledge of epilepsy is associated with attitudes towards epilepsy [11]. In addition, it is a predictor of mothers' practices, when a seizure occurs. Proper first-aid behaviors can decrease the risk of trauma and premature death among patients with epilepsy [12].

The educational needs of mothers who have children with epilepsy should be identified. In this regard, knowledge, attitudes, and practices of these mothers need to be assessed. Since no studies have been found to assess practices of mothers of children with epilepsy, the objective of this cross sectional study was to assess knowledge, attitudes, and practices among a sample of these mothers in order to identify their educational needs.

2. Material and methods

This study was approved by Ethical Committee of Shahid Beheshti University of Medical Sciences. The study did not require that the participants reveal their identity and all responses remained confidential. The interview was held in a private room by female general practitioners. All participants provided an informed consent prior to taking part in the study. They were able to leave the study at any stage. In addition, we made sure that participants did not allocate too much time and did not miss their turn while waiting in the clinic.

2.1. Setting

This cross sectional study was conducted during the period of August 2014 to January 2015 in Mofid Children's Hospital. This hospital is a tertiary level, referral, and teaching hospital affiliated with Shahid Beheshti University of Medical Sciences, Tehran, Iran.

2.2. Participants

Among 237 mothers who met the study criteria, 208 agreed to participate in the study (87.7% response rate). Interviews of two participants were incomplete and therefore responses of 206 participants were analyzed. Since children were mainly accompanied by their mothers, and mothers become more involved in seizure-related issues, we decided to conduct the study on mothers. Therefore, all mothers whose children were diagnosed with epilepsy for at least six months and referred to the neurology clinic for usual follow-up were included in the study. The epilepsy diagnosis was based on the definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) [13].

2.3. Variables and data collection

Variables included socio-demographic status of children and their parents, mothers' knowledge of epilepsy, their attitudes towards patients with epilepsy, and their practices at time of the last seizure. Data were collected through face-to-face interviews by trained female general practitioners. The interview was held in a separate room in the neurology clinic. Each mother and child were led to the private interviewing room from the waiting room. We followed a structured interview approach to make sure that all questions were answered properly and completely. The interviewer would ask the mothers questions from the questionnaire and either mark their chosen items, or write their answers on special answer sheets in case further explanation was needed.

The study questionnaire consisted of five main sections regarding socio-demographic data of children and their parents, status of the disease, knowledge of epilepsy, attitudes towards patients with epilepsy, practices of mothers at time of the last seizure, and non-medical actions to treat epilepsy. The questionnaire was modified according to initial feedback from the first few interviews in the pilot phase of the

study. Appropriate questions for assessment of knowledge, attitudes, and practices of mothers were developed using previously published studies investigating parents [14,15], patients with epilepsy [16,17], healthcare professionals [18,19], teachers [20,21], students [22,23], and the public [24,25]. Content validity of the questionnaire was evaluated by a group of five pediatric neurology and public health experts.

Test-retest correlation over a two-week period was 0.89; coefficient alpha, used to estimate internal consistency reliability, was 0.91.

The knowledge section included 43 questions regarding prevalence and general knowledge about epilepsy, its etiology, symptoms, and seizure-provoking factors. In addition, participants were asked how they evaluated their own knowledge about epilepsy, their sources of information, and whether they felt the need for further training.

The attitudes section included twenty statements regarding mother's attitudes towards epilepsy and patients with the disease. In response to this set of statements, participants could choose "I strongly agree", "I agree", "I disagree", "I strongly disagree", or "No opinion".

The practice section included 14 questions about first-aid measures taken by mothers who had witnessed generalized seizures by the time of the interview. Among all mothers, 170 (82.5) met this criterion. In addition, mothers were asked how they reacted at the onset of seizures and whether they sought treatments for epilepsy, other than those recommended by a doctor.

2.4. Data analysis

To analyze mothers' knowledge, one point was awarded to each correct answer to these questions. Thus, the total knowledge score of mothers related to epilepsy varied from 0 to 43. Based on mothers' knowledge score quartiles, their level of knowledge was categorized as poor, fair, good, and very good.

To analyze mothers' attitudes, "I strongly agree" and "I agree" responses were considered together, "I disagree" and "I strongly disagree" responses were put in the same category, and the no opinion responses were excluded.

To analyze mothers' practices at the time of the last seizure, mothers' first-aid measures were categorized as helpful or potentially harmful. One point was awarded to taking each helpful measure, or not taking each potentially harmful measure. Therefore, the total score in this section varied from 0 to 14. Based on mothers' practice score quartiles, their level of practice was categorized as poor, fair, good, and very good.

Qualitative variables were analyzed using Chi-Square test. *t*-Test and one-way analysis of variance (ANOVA) test were used to analyze the differences among means of two groups and three groups or more, respectively. Statistical analyses were performed using IBM SPSS Statistics 21. A probability level of <0.05 was considered significant.

3. Results

Of 208 participants, responses of 206 were analyzed. The mean (SD) age of mothers, fathers, and children was 32.5 (6.1), 37.4 (6.8), and 7.1 (3.5) years, respectively. The age range of children was 2–18 years. Almost all mothers (99%) were married, one was divorced, and one was widowed. Other socio-demographic characteristics of parents and their children with epilepsy are presented in Table 1.

Of 93 children who were school-aged, 85 (91.4) went to school, four had never attended school, and four had left school for any reason. Among those who attended school, four went to special schools. Of those who attended school, 10 (11.7) had failed to pass at least one grade at school. Among those mothers whose children attended school, 80 (94.1) had informed school teachers of their child's disease. Seizure type of 180 (87.4) children was generalized, eight had partial seizures, seven mixed seizures, and 11 had other types of seizures.

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