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Parent health literacy and adherence-related outcomes in children with epilepsy

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ABSTRACT

Background: The relationship between parent health literacy and adherence to treatment in children with epilepsy has not been fully explored. The purpose of this study was to determine whether parent health literacy and other variables predicted factors associated with adherence, such as missed medication doses, missed medical appointments, and seizure frequency, in children with epilepsy between 1 and 12 years old.

Methods: It was hypothesized that parents with adequate parent health literacy would report fewer missed doses, missed appointments, and seizure occurrences. Using a nonexperimental, cross-sectional study design, interviews were conducted with 146 parents and guardians of children with epilepsy who resided in rural communities. Univariate analyses, including ANOVA, and multiple linear regressions were conducted.

Results: Results indicated that parent health literacy was the strongest predictor of two of the adherence-related factors. Higher health literacy scores were associated with fewer missed medication doses and seizure occurrences. However, health literacy was not associated with missed medical appointments. Among other study variables, higher household income was also predictive of fewer missed doses.

Conclusion: The study findings suggest that inadequate health literacy among parents may serve as an independent risk factor for adherence-related outcomes among children with epilepsy. Further research, as well as effective, targeted parent health literacy strategies used to improve epilepsy management and care in children, is recommended.

1. Introduction

Nearly one-half of all American adults, including parents, have difficulty comprehending health information, which makes it difficult for many to use information effectively [1]. A national, representative sample of 6100 parents found that 39% had basic and below basic health literacy [2]. At least 70% of the parents in the study had difficulty filling out a health insurance form. Health literacy is defined as the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions to prevent or treat illness [3]. It involves one's ability to effectively act on and use health information and health-care services [1]. Health literacy impacts the ability of parents to navigate through health-care systems, obtain medical resources, and adequately manage the care of themselves and their children.

Parent health literacy has been associated with child health outcomes [2,4,5]. Parents with inadequate health literacy tend to have difficulty understanding basic health information and performing health-related activities for their children (e.g., reading a digital thermometer and understanding a growth chart) [2]. Compared with parents with adequate health literacy, those with inadequate skills tend to commit more medication dosing errors and have higher rates of emergency department visits and hospitalizations among their children [4,6,7]. They are more likely to have children with unmet health-care needs, even when adjusting for income, age, and English proficiency [2,8].

Parent health literacy has also been linked to adherence to medical treatment. For instance, inadequate parent health literacy has been associated with poor adherence among children with asthma and in adolescents with insulin-dependent diabetes [9,10]. Adherence is defined as the extent to which a patient's treatment-related behaviors (e.g., taking medication, following a prescribed diet, modifying health habits, and attending clinic appointments) correspond to a health professional's advice or treatment plan [11,12]. Consequences for nonadherence include increased mortality, morbidity, use of health-care services, and medical costs [13]. Nonadherence is higher among

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those with chronic diseases, such as epilepsy, than among those without chronic illnesses [9].

Epilepsy is a neurological disorder operationally defined as two or more episodes of unprovoked seizures occurring at least 24 h apart [14]. It is one of the most common, disabling neurological conditions [14,15]. It is estimated that between 6 and 7 children per 1000 in the U.S. have epilepsy [14,15]. In a recent study, the prevalence of epilepsy in two rural U.S. counties was 17 per 1000 [16].

Adherence has been examined in patients with epilepsy. For instance, in the U.S., nonadherence has been associated with inadequate knowledge about epilepsy and treatment among parents as well as in adolescents 12 to 17 years of age [17]. Research has also found a relationship between adherence and family support, mother's age, number of family members, and greater seizure frequency among adolescents 13–18 years of age in Saudi Arabia [18] Adherence to epilepsy treatment has also been associated with socioeconomic status in children [19,20].

Despite the rates of epilepsy in children and growing research on adherence, there are significant gaps in our knowledge about adherence in patients with epilepsy as it pertains to health literacy. Former studies examined parents' knowledge of epilepsy and treatment, specifically, but did not explore general health literacy [17–19]. Health literacy and epilepsy research studies in the U.S. have primarily focused on outcomes in adults and literacy assessments of [21–24]. Thus, the relationship between parent health literacy and certain outcomes related to adherence among children with epilepsy has not been fully explored. The purpose of the study was to determine whether parent health literacy and other variables predicted factors associated with adherence, such as missed doses, missed appointments, and seizure frequency, among children with epilepsy between 1 and 12 years old.

2. Methods

2.1. Study design

Based on previous research, it was hypothesized that parent health literacy would be associated with adherence in children; specifically, parents with inadequate parent health literacy would report lower adherence in children. The study used an observational, cross-sectional study design with interviews to collect data. Purposive sampling was used to recruit parents and guardians of children with epilepsy who resided in rural counties in Alabama. The study protocol was approved by the Institutional Review Board at the University of Alabama.

2.2. Sample and setting

The study was conducted across the state of Alabama in the United States. Fifty-five of the 67 counties in the state are considered rural [25]. White non-Hispanics represent 77% of the total population in the rural counties [25]. Approximately 17% of the state's population which resides in these rural counties is economically below the poverty level [25]. Among those with epilepsy in Alabama, about 29% are racial/ethnic minority patients, and many are uninsured and lack sufficient neurology or specialty care for their conditions [25,26]. In the current study, adults who were at least 19 years old could participate if they were parents or legal guardians to children who met the following criteria: 1–12 years old; medically diagnosed with epilepsy or seizure disorder; with active epilepsy (defined as being currently treated for epilepsy); resided with the interviewing parent/guardian; and resident of rural county in Alabama.

2.3. Recruitment

Several recruitment strategies were used to identify and recruit participants. Convenience sampling was the primary recruitment strategy. University researchers partnered with the Epilepsy Foundation of Alabama (EFA) and the Children's Rehabilitation Service; both sent direct mails and/or emails about the study to eligible participants. Information was also posted on EFA's website. Both organizations allowed large posters to be posted and flyers to be distributed or made available at their facilities. In addition, two online support groups allowed information about the study to be posted on their websites, and one in-person epilepsy support group shared information about the study with its members. Flyers and posters were distributed at six individual neurology clinics and two hospitals in Alabama which had tertiary epilepsy centers. Word-of-mouth and snowballing techniques were also used; some parents shared information with others who had children with epilepsy. A $50 incentive was advertised as part of these efforts; funding was provided by a grant from the national Epilepsy Foundation in Landover, Maryland.

2.4. Interview guide

The researchers expanded upon an instrument which was originally created by Cramer, Glassman, and Rienzi [27] and later used and modified for another study [28]. The original instrument was designed to identify factors which influenced medication adherence in adults with epilepsy. The current instrument was adapted for parents of children with epilepsy and was expanded to address parent health literacy as a potential issue associated with epilepsy adherence. After a few iterations of the instrument, feedback was obtained from one of the community partners (the Epilepsy Foundation of Alabama) and a physician assistant who worked at an epilepsy care center. Subsequently, the instrument was piloted on five parents/guardians of children with epilepsy to evaluate language, terminology, survey length, missed questions, etc. The interview questions were modified accordingly. The resulting interview guide consisted of 68 questions presented in structured format using close-ended and open-ended response items. The instrument addressed the following six categories: child-level sociodemographic, family-level sociodemographic, administration of medication, medical appointments, seizures, and parent health literacy. The interviews were approximately 1 h in duration and were conducted by the university researchers (Table 1).

2.5. Adherence-related outcomes

The study used self-reported measures, which are the most commonly used methods in general research on adherence [12,29]. However, the aim was to determine whether parent health literacy and other participant characteristics would predict certain factors associated with adherence: i.e., missed medication doses, missed medical appointments, and seizure frequency. A frequency count for each outcome within the last 30 days was assessed.

2.5.1. Missed doses

The interview guide included the following question: “In the last 30 days, how many times would you say your child forgot, missed, or skipped a dose of any type of medication, including medication for epilepsy, seizures, and other conditions?” The current method does not assess intentional versus unintentional missed doses, which have been measured in some studies conducted among children with epilepsy using self-reported measures of adherence, and it does not specify a specific level at which “nonadherence” would be determined [18,30]. Nevertheless, similar measures of missed doses, coded as a continuous (interval) variable, have been used in previous studies conducted on adults with epilepsy [26,27]. The current approach provides information about the quantity or frequency of missed doses among participants. Furthermore, it does not limit its assessment to antiepileptic drugs (AEDs) or to specific types of AEDs, but rather assesses missed doses among all medications prescribed to and taken by the child. The purpose was to determine whether parent health literacy and other variables predicted factors associated with adherence, such as missed doses, missed appointments, and seizure frequency.