B1-8: Parental Experiences Of Transitioning Their Adolescent With Epilepsy And Cognitive Impairments From Pediatric To Adult Health Care

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Abstract:
Introduction: There are no studies that examine the experiences of parents as they transitioned their adolescent with epilepsy and cognitive impairments from pediatric health care to adult health care. The research question was: “What is the experience of parents as they transition their adolescent with epilepsy and cognitive impairments from pediatric to adult health care?”

Method(s): A qualitative grounded theory study was conducted, based on the philosophical underpinning of symbolic interactionism. Theoretical sampling techniques were used to recruit parents of adolescents’ 18 years of age or older with epilepsy and severe to profound cognitive impairments that had transitioned to an adult provider. Informed consent was obtained. Participants completed a demographic data form, and were interviewed in their homes using a semi-structured interview guide. Data were collected through audio-taped recorded interviews and transcribed verbatim in their entirety. Data collection and analysis occurred simultaneously
following the tenets of grounded theory. Constant comparative analysis was done and a final theory was generated. Trustworthiness was established through the process of theoretical sampling, analysis of demographic data, and regular meetings with the dissertation committee.

**Results:** Seven participants who ranged in age from 45 to 65 years completed this study. Adolescents were aged 20 to 33 years, predominantly male and non-ambulatory (N = 6) with severe (N = 2) or profound (N = 5) cognitive impairments. The average number of seizures each adolescent had varied. Journey of Advocacy is the substantive theory that was derived from the data analysis. This theory has five categories: crisis sparks transition, parents in turmoil, parents as advocates, web of information, and captive waiting.

**Discussion & Conclusions:** Transitioning this group of adolescents was multidimensional in nature and required parents to be strong advocates. This study affirms the need to develop a transitional program for this group of parents and their adolescent. Nurses can play a pivotal role in the development and implementation of such a program.

**Abstract History:**
This abstract has not been presented or accepted for presentation in whole or in part at the SNRS or other scientific meeting.

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