



Health Care Transition Experiences of Young Adults With Cerebral Palsy

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Health care transition (HCT) describes the purposeful, planned movement of adolescents from child to adult-orientated care. The purpose of this qualitative study is to uncover the meaning of transition to adult-centered care as experienced by young adults with cerebral palsy (YA-CP) through the research question: What are the lived experiences of young adults with cerebral palsy transitioning from pediatric to adult healthcare? Six females and 3 males, aged 19–25 years of age, who identified as carrying the diagnosis of cerebral palsy without cognitive impairment, were interviewed. Giorgi's (1985) method for analysis of phenomenology was the framework for the study and guided the phenomenological reduction. The meaning of the lived experiences of YA-CPs transition to adult health care is *expert novices with evidence and experience-based expectations, negotiating new systems interdependently and accepting less than was expected*. More information and support is needed for the YA-CP during transition to ensure a well-organized move to appropriate adult-oriented health care that is considerate of the lifelong impact of the disorder. The nurses' role as advocate, mentor and guide can optimize the individual's response to the transition process.

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THE TRANSITION TO self-management and the negotiation of the adult health care model, coined health care transition (HCT) has evolved as a pivotal issue in the areas of adolescent and young adult health care. Adolescents and young adults with childhood diagnosed chronic conditions (AYA-CDC) are a growing population; more than half a million chronically ill youths cross the threshold to adulthood yearly due to the advent of innovative technologies and medical advances (Bryant & Walsh, 2009). Increased longevity means that many more young people experience the transition from adolescence to adulthood while dealing with chronic disease. The Society for Adolescent Medicine (Rosen et al., 2003, p.309) set the priority for “an organized, coordinated transition to adult health care for young people with chronic conditions” with the goal “to optimize health and

to facilitate each young person's attainment of his or her maximum potential” and promotes “proactive transition to the adult health care system” that, “encourages young people to be successfully integrated into a comprehensive care system to meet their complex needs”.

Cerebral palsy (CP) is the most common major disabling motor disorder of childhood and is a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain (Rosenbaum et al., 2007). Deaths in children with CP have in recent years become very rare; unless the child with CP is very severely disabled he or she will most likely survive into adulthood (Haak, Lenski, Hidecker, Li, & Paneth, 2009). Young adults with cerebral palsy (YA-CP) have carried their diagnosis and the subsequent health considerations from infancy and across the developmental stages; their transition to adulthood is negotiated with the inclusion of the physiologic factors

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associated with the disease (Drew, White, Ferguson, & Hay, 2009). The transition experience within the context of cerebral palsy, a relatively stable, chronic condition, provides an excellent source for the study of the lived experience of transition to adult care in the young adult experiencing a chronic condition or special health care needs. The higher frequency of health care utilization and longevity of chronic conditions in this cohort make them preeminent informants of the experience of transitioning to adult-centered health care.

The aim of this study was to uncover the meaning of transition to adult-centered care as experienced by YA-CP participants. Understanding the experience of health care transition for the YA-CP has potential to influence current thinking and planning regarding YA-CPs' maturation to adulthood and acquisition of an independent role in health care utilization. The purpose of the study was to engage YA-CP participants in an exploration of the meaning of this transition, through the research question: What are the lived experiences of young adults with cerebral palsy transitioning from pediatric to adult healthcare?

Method

Giorgi's Existential Phenomenological Method (1985) for analysis of phenomenology was used as a framework for the analysis of the data from interviews with YA-CPs concerning the lived experience of their health care transition. Giorgi's method involves four steps. Initially, the researcher read the entire description in order to get a (1) sense of the whole, (2) discriminate meaning units within a psychological perspective and focused on the phenomenon being researched, (3) transformation of subject's everyday expressions into psychological language with emphasis on the phenomenon being investigated and (4) synthesis of transformed meaning units into a consistent statement of the structure of the phenomenon.

In phenomenological studies of the lived experience the researcher shines a light on the experience so as to direct the flow of the interview to that phenomenon. Transition status is the relevant condition of this study as it confines the context of the lived experience under investigation; it pinpoints the area of interest of the study. For this study, transition is defined as having made a transition to an adult provider or having been notified of their transfer from pediatric/adolescent services to an adult provider that is expected to occur within 6 months. Clearly defining the experience to be explored in the phenomenological approach helps to engage the participant in a reflection of that lived experience in a more tangible way.

Sample Recruitment

Participants were invited by a flyer distributed in several private orthopedic offices and through referral by study participants. Each identified themselves to researcher directly, via email or phone, as young adults with CP who were interested in participating in the research study. To be included in this study participants needed to: 1) be 18–25

years; 2) carry the diagnosis of cerebral palsy, without cognitive impairment; 3) be able to articulate language; 4) report that an extended interview of approximately 1 hour will not pose a burden to them due to its reliance on language; and 5) must have made a transition to adult provider or have been notified of their transfer from pediatric/adolescent services into adult-centered care within 6 months.

The considerations for rights of human subjects were applied throughout the recruitment and for the duration of the research study. Informed consent was read aloud, alongside the participants and included restating the aim of the study, reviewing the voluntary and confidential nature of their participation and their ability to stop and drop out at any time. The processes for assuring confidentiality through the use of an alphanumeric code to identify participant interview audiotapes and transcriptions was reviewed and acknowledged at the start of each interview and in the introduction of the audiotape.

Data Collection Procedures

Interviews were used to bring the transition experience to the consciousness of the participant so that a rich description of that experience could be acquired for the phenomenological reduction. The researcher requested a description of the experience through the use of an unstructured interview initiated by the opening question, "You have been told that you will be moving from pediatric to adult provider"; or "you have already transferred to an adult healthcare provider- could you tell me what that experience has been like for you?" After the introduction, interviews evolved in response to the natural recall of the participant as the participant related descriptions of their experiences. The researcher's focus throughout the interviews was on attending to and being present with participants in dialog, to promote the unfolding of their individual experiences. Interviews were conducted in participants' homes, college dormitory and library meeting rooms; the interviews ran between 60 and 90 minutes.

Interviews were audio taped and replayed by the researcher while practicing reflective journaling. Journaling immediately after interview was used to capture gestures, tones or considerations that became apparent during the interview phase. The recordings were transferred to digital files and sent for professional transcription. Transcripts were available within 5 days and reviewed with the audio to ensure the accuracy of the data. Journal entries were simultaneously reviewed with transcripts to identify any recollected non-verbal gestures or tones that accompanied the descriptions.

Data Analysis

The phenomenological reduction followed the initial data collection as described by Giorgi (1985, 2005). The experimental environment for the descriptive phenomenological study is controlled through the Epoché (Giorgi, 2009) withholding prior knowledge and existential claims. The researcher used

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