



The Role of Health Advocacy in Transitions from Pediatric to Adult Care for Children with Special Health Care Needs: Bridging Families, Provider and Community Services

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Background Youth and young adults with special healthcare needs (YASHCN) experience challenges during transition from pediatric to adult care. Prior studies have not examined how community and healthcare resources can work together to assist YASHCN in transitioning from child-focused care and services to adult-oriented providers.

Objective: The aim of this study was to develop a theoretical understanding of how family, healthcare providers and community supports can assist YASHCN during the transition from pediatric to adult healthcare and services.

Design/Methods: We conducted 41 semi-structured interviews with YASHCN aged 16–25, their family members and healthcare and community providers. We focused our interviews on support mechanisms, both within the traditional healthcare system, and those available in the community. Using grounded theory methods, we performed a multi-step analysis process.

Results: The theoretical code “Transition Advocacy” was developed from the data. This theoretical perspective arose from three major categories, which were developed in the analysis: “Fighting for healthcare”, “Obtaining resources”, and “Getting ready to transition”. Transition Advocacy consists of the presence of, or need for, a healthcare “advocate” who did or can assist the YASHCN with the healthcare transition, particularly to navigate complex health or community services. The “advocate” role was performed by family members, healthcare or agency professionals, or sometimes the YASHCN themselves. If advocates were identified, youth were more likely to obtain needed services.

Conclusions: Parents, health providers, and community agencies are potentially well-poised to assist transitioning YASHCN. Efforts to encourage development of strong advocacy skills will facilitate better transitions for YASHCN.

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THERE ARE INCREASING numbers of adolescents and young adults who report having a chronic health condition, with over 18% of adolescents reporting a special healthcare

need (National Survey of Children with Special Health Care Needs; Perrin, Bloom, & Gortmaker, 2007). With improvements in medical care and technology, these children are living longer, healthier lives. It is expected that 90% of children with chronic illnesses will survive well into adulthood. The transition from pediatric to adult healthcare

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not only involves transferring care to an adult provider, but calls for facilitating appropriate levels of independence and support for youth, with the goal of achieving optimal health and quality of life (Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012). Unfortunately, youth and young adults with special healthcare needs (YASHCN) are often not well prepared for the transition process (Lotstein, McPherson, Strickland, & Newacheck, 2005; Rutishauser, Akre, & Suris, 2011). In fact, less than half of YASCHN receive comprehensive preparation for transition, and even fewer youth from ethnic and racial minorities receive these services (Anonymous). Multi-level barriers impede a patients' ability to maintain access to—and continuity of—chronic medical care as they transition from pediatric to adult-oriented systems (Ferris, Ferris, Okumura, Cohen, & Hooper, 2015; McPheeters et al., 2014). Many YASHCN lack appropriate transition planning and support, or lose access to insurance, and those with intellectual disabilities may never achieve a level of independence that is expected of most youth (Lotstein et al., 2005). Regarding providers, many adult-focused healthcare providers are not comfortable treating childhood-onset chronic conditions, and pediatricians may not have the resources to prepare youth for transition (Okumura et al., 2008; Sharma, O'Hare, Antonelli, & Sawicki, 2014). On the systems level, incompatible information technology platforms and siloed personnel and services prevent ease of information transfer and continuity between providers, insurers, and patients (Anonymous, 2005).

A basic level of knowledge regarding barriers to care transitions has been elucidated by previous studies, however, the best means for ensuring efficient resource utilization and decreasing barriers to care during this period remain unknown. Recent studies and systematic reviews of transition programs have highlighted a lack of understanding regarding factors facilitating transition outside the ambulatory care setting—factors which are effective in the promotion of healthy transitions, and the need for identification of the best potential targets for interventions to promote the transition process (McPheeters et al., 2014; Crowley, Wolfe, Lock, & McKee, 2011). In addition, few studies have focused on YASHCN themselves (e.g., asking YASHCN for input regarding what they needed for their own transition process) (Betz, Lobo, Nehring, & Bui, 2013). Most studies have focused on healthcare providers and clinical-level interventions. A critical, but rarely addressed question regarding YASHCN in transition is: How can the family, community and outside supportive services work together to impact the healthcare transition process? (Ferris et al., 2015; Reiss, Gibson, & Walker, 2005). In order to implement effective means to improve quality of care for youth with chronic diseases in a holistic manner, we must first expand our understanding of how families and youth overcome barriers, and we must identify facilitators to chronic illness management and care beyond the walls of the healthcare system. Current recommendations, based on current evidence, are limited to generation of suggested transition planning strategies and transition programs which, ultimately, have proven not to work for many YASHCN. For example,

programs that feature education or navigation strategies have mixed results in improving transition outcomes (Crowley et al., 2011). The failure of current attempts to improve healthcare transitions may be, in part, related to the myopic focus on ambulatory care and the medical system—rather than family and community assistance—as the target for intervention.

Strategies for involving community services in transition to adult services are a missing link toward the improvement of the transition process for YASHCN. Prior studies have not adequately examined how the integration of community and healthcare resources affect youth and young adults in their chronic illness care management or what gaps remain in their care (Reiss et al., 2005). Therefore, the purpose of this study was to explore the experiences of YASHCN, their parents, healthcare providers and community agency members using grounded theory methods. Our aims were: (a) to explore barriers and facilitators to the transition from child-focused to adult oriented healthcare and services, (b) to generate a theoretical understanding of how families and supportive professionals can decrease barriers to the transition from pediatric to adult-oriented care systems. This understanding can then be used to develop programs and interventions for future testing, and (c) to develop a project map based on situational analysis to use both in validating our theoretical understanding and as a guide for developing future interventions and programs. We focused this study not only on the medical aspect of transitions, but also included community organizations that promote health and wellness to YASHCN. Better understanding of potentially effective facilitators to transitioning will help clinicians to develop patient, provider, system, and community-level improvements to promote healthcare transitions and thus enable the delivery of continuous chronic illness care for YASHCN.

Research Methods

Identification of Persons for Interviews: Sampling, Inclusion Criteria and Recruitment

Initial recruitment for the study was purposive. Inclusion criteria were: (a) YASHCN age 16–25 who had either recently transitioned to adult healthcare providers, or were preparing to transition their care, (b) healthcare or community service providers who provided care to YASHCN in outpatient, inpatient, or community settings. Recruitment strategies included flyers posted in medical office and community agency settings and postings on listservs for two community-based statewide programs that offer case management and funding for programs directed toward children and young adults with chronic conditions. As data collection and analysis proceeded, sampling became more theoretical and patients and providers were recruited by asking for referrals from providers in specific clinical or service settings to more fully explore aspects of the theoretical framework that were being developed. For example, in order to fully explore advocacy efforts of parents and providers, we recruited parents and youth referred by specific providers, and providers identified by enrolled youth and families to participate in interviews.

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