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Healthcare System Supports for Young Adult Patients with Pediatric Onset Chronic Conditions: A Qualitative Study

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Over 90% of children with chronic conditions survive into adulthood necessitating primary care teams to care for adults with pediatric-onset chronic conditions. This study explores practice supports and barriers to care for this population via qualitative techniques. Using in depth interviews with twenty-two healthcare providers practice supports identified include: formalizing intake processes, interoperable electronic medical records, and leveraging care coordination. Barriers identified included: definition of the medical team, lack of appropriate medical records, time and administrative burden, lack of training, and financial constraints. Themes may be utilized to design interventions and improve care coordination for patients with pediatric-onset chronic conditions.

RECENT ADVANCES IN the treatment of pediatric chronic illness necessitate adult primary care teams to facilitate the transition and ongoing care of adults with pediatric onset chronic illness into adult healthcare systems (Newacheck & Taylor, 1992). Currently, over 90% of pediatric patients with chronic medical conditions are living into adulthood with approximately 500,000 patients entering adulthood each year (Blum, 1995). Once fatal conditions such as cystic fibrosis (CF), sickle cell disease (SCD) and complex congenital heart disease now have life expectancies well into adulthood. For some pediatric onset chronic conditions there are more adults living with an illness than children (Elborn, Shale, & Britton, 1991; Platt, Brambilla, Rosse, et al., 1994; Reid et al., 2006). Despite improvements in pediatric care, adult patients with pediatric onset medical conditions often have complex medical and social needs as adults due to accumulated complications from decades of illness and treatment (Blomquist, 2006; Kirk, 2008).

Transitioning from pediatric to adult oriented healthcare has been set as a core performance outcome for patients with chronic medical conditions by multiple professional organizations, yet adult providers feel poorly equipped to manage this growing population (AAP, 2002; Blum, Garell, Hodgman, et al., 1993; AAP 2011; Lotstein et al., 2009; Okumura, 2009; USDHHS, 2010). Previous surveys of adult providers identified barriers to transition including patient and provider characteristics and health system constraints (Okumura et al., 2008; Okumura et al., 2010; Peter, Froke, Ginsburg, & Schwartz, 2009). Qualitative studies have explored the perspectives of patients, parents and pediatric

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providers on the topic of transition and ongoing care in adult healthcare systems. However, these studies have been limited by their lack of representation of adult providers and thus may not aid primary care teams who accept responsibility for these patients and provide their ongoing medical care (Huang et al., 2011; Reiss, Gibson, & Walker, 2005; Scal, 2002).

The purpose of this study was to examine current practices in the care of adult patients with childhood onset chronic illness by adult providers who have experience caring for these patients in order to elicit barriers and facilitators to their care. We also aimed to compare this population to other patients with chronic illness in order to elicit existing facilitators that may be used or adapted for this group.

Methods

Study Design and Population

This was a cross sectional study consisting of qualitative open-ended, semi-structured, in-depth interviews with twenty-two providers who care for adults with pediatric onset chronic conditions. The study was approved by the IRB at the University of Pennsylvania. All participants provided verbal consent at the onset of their interview. Interviews were conducted between March 2011 and August 2011.

We purposively sampled providers who care for young adults with congenital or pediatric-onset chronic conditions in an ambulatory setting. Seventeen initial providers were invited to participate if they were known by the study team to care for these patients. Another 50 participants were recruited by the snowball method, that is, referred by study participants. Sixty-seven providers were invited to participate in the study. Ten providers declined interviews and thirty did not respond to request for interview. Twenty-seven providers agreed to participate. Five did not complete interviews because of scheduling difficulties or because clinical duties were primarily hospital-based. Twenty-two providers completed an interview.

Data Collection

Through a detailed review of relevant literature and consultation with outside experts, an interview guide was developed to elicit provider experience regarding the process of initial transfer of care, current clinical care, and practice supports for adults with pediatric-onset chronic conditions. Qualitative techniques are particularly well suited for this study to explore physician experience and practices in detail to elicit care innovations not previously identified (Maxwell, 2005). Questions were primarily open-ended and not leading. A single interview lasting 30–60 minutes began by having the subject walk through their last interaction with a patient with pediatric onset chronic illness and identify facilitators and barriers to their care. Follow up questions aimed to highlight other facilitators and barriers not previously identified and compare these facilitators and barriers to patients with chronic illness that is not pediatric in onset. The complete interview guide is available from the authors on request.

Before the start of the study, the interviewers (an MD and two research assistants) were trained by members of the study team experienced in qualitative research and interviewing. Interviewers were then observed conducting mock interviews. All interviews were conducted by phone. The team met biweekly throughout the study to ensure interview consistency and data quality and to modify the interview guide to explore emerging themes. Recruitment was discontinued when no new themes were identified during interviews (thematic saturation) (Saldana, 2009).

We collected demographic data on providers. Contents of interviews were recorded digitally, transcribed, and entered into NVivo 10.0 software (QSR International, Melbourne, Australia) to facilitate data management.

Data Analysis

We used inductive content coding to analyze the interviews, identifying themes without using an a priori set of codes (Kelle, 2007). Five research team members read the first five interviews and developed an initial coding scheme. An iterative process of revision was utilized to revise the coding scheme that was then approved by the entire study team. Two research team members then independently coded each transcript. Differences in coding were reconciled collaboratively. Representative verbatim comments were selected for presentation.

Results

Study Population

Twenty-two providers completed interviews: sixty percent were female and the mean time since completing training was 11.6 years. The twenty-two participating providers were primary care physicians (n = 20) or subspecialists (n = 2) who provided primary care for their patients. Providers represented practices in five different states, 8 different institutions and 11 different clinical practices. The majority of participants identified themselves as being affiliated with an academic medical center; 2 respondents worked in a federally qualified health center; and 1 respondent worked in a private practice.

Existing or Proposed Healthcare System Facilitators to Care of the Adult Patient with Pediatric-Onset Chronic Illness

Participants identified facilitators to care for adult patients with pediatric-onset chronic conditions. Major