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Multi-Site Comparison of Patient, Parent, and Pediatric Provider Perspectives on Transition to Adult Care in IBD

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ABSTRACT

Purpose: This multi-site study examines patient, parent, and pediatric provider perspectives on what is most important for successful transition.
Design and Methods: Using the Transition Readiness Assessment Questionnaire, 190 participants recruited from two pediatric IBD centers selected the top five skills they considered "most important for successful transition." Rankings were summarized and compared by group.
Results: While patients, parents, and clinicians all identified "calling the doctor about unusual changes in health" and "taking medications correctly and independently" as being important, each stakeholder group qualitatively and statistically differed in terms of transition readiness skills emphasized. Patients endorsed "calling the doctor about unusual changes in health" and "being knowledgeable about insurance coverage," as being most important to successful transition while parents emphasized health monitoring and problem solving. Pediatric providers emphasized adherence to treatment and reporting unusual changes in health. There were statistically significant differences in endorsement rates across participants for seven transition readiness skills. Patients agreed with providers 80% of the time and with their parents 40% of the time. Parent-provider agreement was 60%.
Conclusions: Although there was some overlap across groups, areas of emphasis differed by informant. Patients emphasized skills they need to learn, parents emphasized skills they most likely manage for their children, and providers emphasized skills that directly impact their provision of care.
Practice Implications: Patient, parent, and provider beliefs all need to be considered when developing a comprehensive transition program. Failure to do so may result in programs that do not meet the needs of youth with IBD.

Introduction

Inflammatory bowel disease (IBD) refers to a collection of chronic conditions (i.e., Crohn's disease, ulcerative colitis, indeterminate colitis) characterized by unpredictable periods of disease activity (e.g., diarrhea, abdominal pain, delayed growth, rectal bleeding) and remission. One-quarter of IBD cases are diagnosed in children and adolescence and IBD occurs at an incidence of 71 per 100,000 in those younger than 17 years (Auvin et al., 2005). Because IBD is a chronic, lifelong disease, pediatric IBD patients must eventually transition to adult care to continue to receive developmentally appropriate medical care (Baldassano et al., 2002).

Adult patients with inflammatory bowel disease (IBD) are expected to manage their health independently (Hait et al., 2009) yet many adolescents on the brink of transferring to adult care lack the important self-management skills to do so (Fishman, Barendse, Hait, Burdick, & Arnold, 2010; Gray et al., 2015). For example, Fishman and colleagues found that less than 15% of patients on the verge of transferring to adult care were fully responsible for their IBD self-management (Fishman et al., 2010). In another study, a clinic-wide assessment of transition readiness found that less than 6% of patients met institutionally-set benchmarks of transition readiness (Gray, Holbrook, et al., 2015). The impact of not being prepared for the adult care world can have serious consequences such as doubled rates of surgeries and

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hospitalizations in adult care (Cole, Ashok, Razack, Azaz, & Sebastian, 2015).

Unfortunately, the IBD transition literature has lagged far behind that of other chronic conditions, such as diabetes, cystic fibrosis, and other youth with special health care needs (see McPheeters and colleagues for a review (McPheeters et al., 2014). While much can be learned from transition work in other populations, IBD differs significantly from most of these conditions. Youth with conditions typically diagnosed at birth or in early childhood (e.g., cystic fibrosis, sickle cell disease, diabetes) have more time to adjust to their illness and are able to follow expert recommendations that preparation for adult care begin in early adolescence (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians - American Society of Internal Medicine, 2002). In IBD, however, the mean age of diagnosis for IBD is 15 years (Kappelman et al., 2007). This is well after transition planning is recommended to begin. Thus, youth with IBD must undergo an accelerated transition process while at the same time struggle to adjust to a demanding chronic illness that fosters feelings of vulnerability, embarrassment, lack of control, and social isolation (Nicholas et al., 2007).

Several limitations exist with regard to the current IBD transition literature. First, qualitative, single-site research dominates, bringing issues of generalizability into question. Second, studies tend to be selective in their study sample, focusing on one key group of stakeholders (e.g., patients) and excluding other important groups with a vested interest in transition (e.g., nurses, parents). Inclusion of multiple stakeholders is common in other chronic illness populations and provides a more comprehensive, relevant discourse on transition (Clarizia et al., 2009; Reiss, Gibson, & Walker, 2005; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004; Westwood, Henley, & Willcox, 1999). However, only a handful of transition studies in IBD have included more than one stakeholder, limiting our understanding of the transition process from multiple relevant perspectives (Cervesi, Battistutta, Martelossi, Ronfani, & Ventura, 2013; Gray et al., 2015; Houston et al., 2012).

While numerous publications express what providers clinicians think is most important for transition (Nehring, Betz, & Lobo, 2015), far less attention has been given to what patients and parents consider to be important. This issue has been noted as a limitation in IBD (Leung, Heyman, & Mahadevan, 2011) as well as across transition research among youth who have special health care needs (Betz, Lobo, Nehring, & Bui, 2013; Betz, Nehring, & Lobo, 2015; Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014). Failure to consider what patients and parents think is important for successful transition may a contributing factor to the conclusion of a recent Cochrane review that there is low evidence for the effectiveness of transition interventions (Campbell et al., 2016). Most IBD transition research involving patients and parents focuses on their concerns or worries pre-transition or their experiences post-transition. We have yet to ask them what they think is most important for successful transition. This is a critical gap in the literature as patients and parents, not health providers, are the only ones who undergo the transition process. Therefore, it is important to consider their views along with that of their health providers.

To address these limitations, the current study uses a standardized quantifiable approach to assess the perspectives of multiple stakeholders in transition to adult IBD care. Specifically, this study asks two questions; 1) What do transition-aged patients with IBD, their parents, and their pediatric providers consider most important for successful transition? and, 2) To what extent do these individuals agree on what is most important? We present a side-by-side comparison of the perspectives of patients, parents, and pediatric providers recruited from two major pediatric IBD centers. We predicted that stakeholders would emphasize factors that are most salient to them. For patients, this would mean emphasizing tasks they are most likely responsible for, such as taking medications (Fishman et al., 2010). Parents, on the other hand, would be more likely to emphasize higher-level tasks of managing IBD that they often manage for their child, such as coordinating appointments and monitoring symptoms (Fishman et al., 2010). Providers, on the other hand, would emphasize tasks that impact their own ability to care for patients with IBD: medication-taking, (re)filling prescriptions, and knowing ones' own medical history (Houston et al., 2012). We expected moderate agreement between groups regarding what is most important as prior research shows some commonality between different stakeholders but also the presence of unique perspectives (Gray, Resmini, et al., 2015).

Method

Procedure & Participants

Data were collected at two major children's hospital-affiliated pediatric gastroenterology clinics in the United States, one in the Midwest and one in the Southeast. Ethical approval was obtained at both sites, with the data collection at the Midwest site occurring as part of a larger quality improvement research effort. Eligibility criteria for patients included: 1) Being treated for Crohn's disease, ulcerative colitis, or indeterminate colitis, and 2) Age 16 or older (in order to coincide with existing transition efforts at one of the recruitment sites). Participating caregivers were required to be the parent or legal guardian of a child who met study eligibility criteria. Most patients (86.7%) participated along with their caregiver. Participating pediatric providers were required to be a pediatric gastroenterologist, nurse, or social worker directly involved in the care of adolescent patients with inflammatory bowel disease. All individuals ($N = 190$) who were approached for the study agreed to participate.

All participants were given a copy of the Transition Readiness Assessment Questionnaire (Sawicki et al., 2011; Wood et al., 2014) and asked to select the top five skills they consider to be “most important to successful transition.” Each participant completed their form independently and demographic information including IBD sub-type, gender, and age were obtained from the medical record (for patients) or via self-report (parents and providers).

Measures

The Transition Readiness Assessment Questionnaire (TRAQ) assesses an adolescent's/young adult's acquisition of skills believed to be critical to successful health care transition (Sawicki et al., 2011; Wood et al., 2014). This includes tasks such as taking medication as prescribed, scheduling appointments, monitoring symptoms, and seeking out health care when needed. Previous research has found the TRAQ to be a reliable ($\alpha = 0.93$) measure of transition readiness. It has been used in a number of studies examining transition readiness in IBD (Falaiye, Schaefer, Williams, & Chinchilli, 2016; Gray, Holbrook, et al., 2015; Romanova et al., 2013; Rosen, Annunziato, Colombel, Dubinsky, & Benkov, 2016) and is one of the most commonly used measures used by pediatric IBD providers in the US to measure transition readiness (Gray & Maddux, 2016). A copy of the TRAQ, along with information about its development and validation, can be found at: http://www.etsu.edu/com/pediatrics/traq/

Statistical Analyses

Data were examined by participant group (i.e., patients, parents, pediatric providers). The number of times each TRAQ item was endorsed was recorded. This was then divided by the number of participants in the sample to determine the percentage of patients, parents, and pediatric providers that endorsed each item. The top five most endorsed items for each class of participants were identified. In the event that two or more items tied for fifth place, both of these items were included in the fifth place position. These items were then compared across groups of participants to determine the extent to which patients,