



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.

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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, Martellosi, 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 be 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,

parents, and pediatric providers agreed on what was most important to successful transition. Chi-square analyses with Bonferroni corrected post-hoc comparisons identified significant differences in the percentage of patients, parents, and pediatric providers who selected an item in their top five. Post-hoc comparisons were only conducted for those TRAQ items with a significant omnibus test. To account for alpha inflation and the likelihood of obtaining a spurious significant finding due to chance, the criterion value of significance ($p < 0.05$) was divided by the number of comparisons conducted in the post-hoc analyses and set to $p < 0.016$ ($0.05/3$). In order to quantify our data and see to what extent patients, parents, and providers shared views with one another, we calculated rates of agreement between groups. Percent agreement between two stakeholder groups was calculated by first identifying the number of overlapping top five items between each comparison group (i.e., parents and patients) by the number of total items possible to overlap (5).

Results

Participant Demographics

Participant demographics are reported in Table 1. In total, 190 individuals participated. The mean patient age was 19.31 ± 1.81 years and most accompanying caregivers were mothers. Health care providers were primarily physicians and nurses with an average of $11.86 \pm$ years of experience in IBD. In general, the outpatient IBD population at the two recruitment sites is primarily Caucasian, well-educated, and from a high socioeconomic background. Approximately three-quarters of patients at both sites are diagnosed with Crohn's disease (76%). These demographics are comparable to that of pediatric IBD populations reported in other research (Kunz, Greenley, & Howard, 2011; Mackner & Crandall, 2007; O'dell, Sander, Denson, Baldassano, & Hommel, 2011).

Table 1
Demographic characteristics of participant population.

	Site #1 (M \pm SD or %)	Site # 2 (M \pm SD or %)	Total Sample (M \pm SD or %)
Patients			
n	46	40	86
Age in years	18.00 ± 2.40	18.15 ± 1.87	18.08 ± 2.11
Gender			
Male	50.00%	60.00%	54.65%
Female	26.09%	40.00%	32.56%
Diagnosis			
Crohn's disease	50.00%	75.00%	61.63%
Ulcerative colitis	23.91%	25.00%	24.42%
Indeterminate colitis	2.17%	–	1.16%
Parents			
n	44	20	64
Relationship to patient			
Mothers	63.64%	85.00%	70.31%
Fathers	15.91%	10.00%	14.06%
Grandparent	0.00%	5.00%	1.56%
Health providers			
n	20	20	40
Age	48.30 ± 13.22 years	39.45 ± 9.50 years	42.40 ± 11.46 years
Gender			
Male	20.00%	30.00%	25.00%
Female	35.00%	70.00%	52.50%
Profession			
Physician	25.00%	35.00%	30.00%
Nurse	25.00%	65.00%	45.00%
Social worker	5.00%	0.00%	2.50%
Years of experience caring for patients with IBD	13.95 ± 11.92	10.81 ± 8.36 years	11.86 ± 9.60 years

TRAQ Items Identified by All Groups as Most Important to Successful Transition

Top 5 items selected by patient, parent, and health provider groups are presented in Table 2, with items unique to each group in bolded text. Only two items on the TRAQ were in the Top 5 rankings of all groups. "Calling the doctor about unusual changes in health" was selected by all with no significant difference in rates of endorsement between groups. For the second item, "taking medications correctly and independently," a significantly larger percentage of providers selected this item compared to patients or parents (see Table 3).

TRAQ Items Unique to Each Stakeholder Group

Only among patients did "knowledge of health insurance coverage" make it into the Top 5 rankings. Significantly more patients than health providers selected this item (46.51% vs. 15.00%). There was no significant difference between patients and parents.

"Knowing what to do when having a bad reaction to medications" was exclusive to the Top 5 rankings of parents. Although there was no significant difference between patients and parents in terms of the percentage of individuals who chose this item, parents were almost twice as likely to do so than health providers. Parents were also unique in selecting "following up on referrals for tests/labs/check-ups" as a Top 5 item and a larger percentage of parents selected this item than patients.

One TRAQ Top 5 item was unique to providers: "answering questions asked by the medical staff." This item was selected by almost three times as many providers as parents. Rates of endorsement did not significantly differ between patients and providers.

Agreement Between Patients, Parents, and Pediatric providers

Eighty percent of the items that made the patient Top 5 list were also included in the list of health providers, representing the largest agreement between groups. Parents and health providers overlapped on 60% of items. The lowest level of agreement existed between patients and parents, with only 40% overlap.

Discussion

In order to develop a comprehensive health promotion program in transition to adult care, it is important to involve key stakeholders (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011; Leung et al., 2011; Shalowitz et al., 2009). Unfortunately, few studies in transition to adult IBD care incorporate the perspectives of multiple stakeholders despite increased prevalence of such approaches in transition research among other chronic illness populations. By using a clear and validated tool of transition readiness skills, this study presents a quantifiable side-by-side comparison of what patients, parents, and pediatric providers consider to be important for successful transition in IBD. Results suggest that patients, parents, and clinicians share many common beliefs regarding transition. However, there are also distinct differences in terms of what each stakeholder group perceives to be important.

Contrary to our hypothesis, patients did not exclusively focus on items related to the day-to-day management of IBD. Instead, they endorsed broader issues such as calling the doctor about unusual changes in health and being knowledgeable about insurance coverage. Patients may have selected these items because they represent self-management tasks they know least about or are least comfortable doing. There is some evidence for this hypothesis as these two TRAQ items were among the lowest mastered in a large sample of adolescents and young adults with pediatric IBD (Gray, Holbrook, et al., 2015). Knowledge of insurance coverage is not IBD-specific. In a study of patients with sickle cell disease, only 10% knew if their insurance would be accepted by an adult provider and knowledge of insurance coverage

Table 2
Comparison of Top 5 items selected by patients, parents, and providers as being most important to successful transition.

Ranking	Patient (% endorsed)	Parent (% endorsed)	Provider (% endorsed)
1	Calling doctor about unusual changes in health (47.50%)	Calling doctor about unusual changes in health (67.50%)	Taking medications correctly and independently (82.50%)
2	Knowledge of health insurance coverage (46.51%)	Knowing what to do when having a bad reaction to medications (51.56%)	Calling doctor about unusual changes in health (75.00%)
3	Telling a doctor or nurse what you are feeling (46.51%)	Taking medications correctly and independently (51.56%)	Answering questions asked by the medical staff (45.00%)
4	Taking medications correctly and independently (46.51%)	Reordering medications before they run out (45.31%)	Telling a doctor or nurse what you are feeling (40.00%)
5	Filling a prescription when needed (37.21%)	Following up on referrals for tests/labs/check-ups (57.50%)	Filling a prescription when needed (35.00%) ^a Reordering medications before they run out (35.00%) ^a

Note: Items in bold were endorsed by only one group (e.g., patients) and not others (e.g., parents or providers).

^a Item was tied for Top 5 endorsement.

was among the top two patient-identified concerns and questions regarding transition (McPherson, Thaniel, & Minniti, 2009). Across pediatric chronic illness groups, insurance issues emerge as one of the most common concerns and barriers to transition (Gray, Schaefer, Resmini-Rawlinson, & Wagoner, 2017; Reiss et al., 2005). This likely speaks to national changes and inconsistencies in insurance coverage in the United States but also to the need to better educate patients about insurance coverage. Introducing them to the GotTransition online radio episode on health insurance (<https://www.youtube.com/watch?v=7OyEs24nLi0>) as part of a transition preparation program may help to improve adolescent knowledge and reduce concerns in this area.

As expected, parents placed the greatest emphasis on skills requiring health maintenance behaviors (i.e., knowing what to do when having a bad reaction to medication, noticing unusual changes in health). These skills are areas in which parents are primarily responsible (Fishman et al., 2010) and thus, more salient to them. Providing education to parents on how to transition responsibility for these skills to their child may be helpful (Annunziato et al., 2008). Although research has found that self-management skills in adolescents with IBD is sub-optimal, new research using technology to develop this skill in transition-aged youth with hemophilia and IBD holds promise (Breakey et al., 2014; Huang et al., 2014).

Pediatric providers had a much stronger emphasis on items that directly impact their provision of care, such as adherence to treatment and reporting unusual changes in health. This is likely due to the fact that non-adherence to treatment and self-management deficits, which can undermine a provider's ability to successfully treat a patient's symptoms, is a common clinical problem (Hommel & Baldassano, 2010; Hommel, Davis, & Baldassano, 2009; Hommel, Greenley, Maddux, Gray, & Mackner, 2013) and has been noted as a highly relevant transition concern among pediatric providers (Nehring et al., 2015). Similarly, unusual changes in health may indicate the need for changes in treatment. As previously mentioned, technology-based self-management programs may be helpful in improving adolescents' understanding of their illness. Additionally, practical strategies for improving adherence

in patients with IBD are summarized by Greenley and colleagues (Greenley, Kunz, Walter, & Hommel, 2013).

This study had several strengths. First, this study is among the few in the IBD transition literature to incorporate the views of several key stakeholder groups. Using a quantifiable side-by-side comparison adds to our understanding of similarities and differences in stakeholder perspectives that have only been examined in a small number of qualitative research studies. We present a novel use of the TRAQ and illustrate a new way researchers and providers might be able to use this measure to quickly assess patient and parent needs in a standardized manner. This can be done in other populations to identify disease-specific priorities as well as across populations to identify items that transcend populations with special health care needs. The multi-site nature of our research is an additional strength as it allowed for a larger and more diverse sample. Most research focused on transition in IBD is single-site and therefore subject to site-specific bias. We collected data from two geographically and culturally distinct areas of the United States. Thus, our findings may be more generalizable to the broader IBD population.

Study limitations provide important directions for future research. Our study included multiple stakeholder groups, but was not all-inclusive. As this was an unfunded study, we were limited to including only those groups who were accessible within our own institutions: pediatric patients and their parents and providers. However, it is important to note that transition to adult care involves more than just pediatric parents, their parents, and their pediatric providers. We need to give additional attention to other key stakeholders, such as adult providers, post-transfer patients and parents, hospital administrators, and insurers. Our future work will move towards bridging the information gap between pediatrics and these other stakeholders.

Additionally, although we present a novel use of the TRAQ that allows for a quick and standardized method of assessing individual perspectives on what is important for transition, we acknowledge that this is a non-traditional approach that has methodological limitations. Limiting all participants to only five responses reduces variability. Further, restricting respondents' identification of areas important to

Table 3
Significant differences in the percentage of patients, parents, and Health providers endorsing TRAQ items.

TRAQ item	Patients (n = 86)	Parents (n = 64)	Providers (n = 40)	$\chi^2(2)$	p
Knowing what to do if having a bad reaction to medications	34.88%	51.56%*	27.50%	7.09	.006
Taking medications correctly and independently	46.51%**	51.56%**	82.50%	15.04	.002
Following up on referrals for tests or check-ups for labs	30.00%*	57.50%	32.50%	7.71	.02
Calling the doctor about unusual changes in health	47.50%*	67.50%	75.00%	6.96	.03
Keeping a calendar or list of medical and other appointments	40.00%*	20.00%	17.50%	6.35	.04
Answering questions asked by medical staff	25.58%	15.63%*	45.00%	11.00	.005
Knowing what health insurance covers	46.51%	34.38%**	15.00%**	11.88	.001
Managing money & budget	17.44%	3.13%*	2.50%*	11.64	.014

Note: One group bolded: this group endorsed this item at a significantly different rate than the other two groups; Two groups bolded: these groups significantly differed from one another in endorsement rate.

* p < .05.

** p < .01.

transition to those listed on the TRAQ limits the discovery of novel areas important to transition. If participants had been allowed to generate their own lists without being influenced by the TRAQ, they may have identified novel or different factors. Finally, due to differences in recruitment across settings, some data were collected anonymously and demographic information was missing for 15% of participants. While this may have reduced bias due to social desirability, we are unable to determine if specific characteristics of our sample, such as gender or disease status, may have influenced our findings. Although we used no specific recruitment strategy, we cannot rule out potential selection bias. Additionally, as is typical in pediatric IBD populations reported in the literature (Kunz et al., 2011; Mackner & Crandall, 2007; O'dell et al., 2011), the majority of our sample was comprised of patients with Crohn's disease. Because Crohn's disease and ulcerative colitis differ in factors such as symptom presentation and treatment options, patients may have different perceptions of what is important for transition. While our small sample of patients with ulcerative colitis precludes examination of this question in this study, future work should examine disease subtype differences.

Clinical Implications and Future Directions

Inclusion of all stakeholders is important in developing approaches to challenging health problems. Transition to adult care is no exception as stakeholders may have conflicting views or interpretations of the problem and what needs to be done. As stated by Kreuter and colleagues (Kreuter, De Rosa, Howze, & Baldwin, 2004), "we cannot expect to effectively resolve [these problems] by relying solely on expert-driven approaches." Such expert-driven approaches, which originate under special circumstances and are removed from the patient and parent perspective, may result in lower levels of acceptability among its target audience (Green & Mercer, 2001).

We suggest that interventions to improve transition focus on targeting tasks that are: 1) salient to key stakeholder groups (e.g., patients, parents, pediatric providers), and 2) associated with post-transfer success. Within a clinical setting, this might involve reserving a portion of the visit to discuss what patients and parents each believe will be important to the patient's successful transition to adult care. As time is a limited resource in a busy clinical setting, providers may consider using the TRAQ similarly to how it was used in this study to quickly assess individual perspectives in a standardized manner. We acknowledge that deviations in the administration of the TRAQ from original validation studies carry potential methodological threats to reliability and validity but contend that the face valid nature of individual TRAQ items allows for ready clinical utility. Using the TRAQ to identify patient and parent input on transition planning will help providers directly address needs that they otherwise might have considered less important (e.g., adolescent knowledge of insurance coverage). Recognition of these needs, along with discussing why certain items are important to an individual, can create opportunities for education and intervention. If such needs are ignored, they may serve as barriers to learning other skills. For example, a patient may be less receptive to providers emphasizing "taking medications correctly" if they are worried about whether or not they will have insurance a year from now or will be able to afford their medication.

With regard to future directions, we need to incorporate more mixed-methods approaches to improve our understanding of transition and identify the best approaches to optimizing patient outcomes. For example, a mixed-method approach would be helpful in examining not only what skills differ by stakeholder group but also why this is so. The clinical utility of each stakeholder's perspective on transition outcomes and how stakeholder perspectives change from pre- to post-transfer to adult care are other important areas to explore that are well-suited to a mixed-methods approach.

Our study examined what patients, parents, and providers think is most important for successful transition, not what is most important

or predictive of successful transition to adult IBD care. To date, our field has not identified those skills that are most predictive of successful transition outcomes. In order to move the IBD transition literature forward, it is important that we follow the example of more established transition research in other populations and first define what constitutes a successful transition outcome, and second, identify what modifiable factors are most predictive of success. Once this is accomplished, we can create programs that incorporate stakeholder perspectives of what is important and emphasize key predictors of success.

In our own program development efforts, our patient and parent collaborators have brought a unique perspective to transition and have made many important contributions that would otherwise not have been included had we relied solely on provider opinions. If we can design transition programs in a way that makes patients and parents feel that their voices are heard and their beliefs are important, while at the same time targeting skills backed by empirical data, we open the door to much more productive and fruitful partnerships.

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References

- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians - American Society of Internal Medicine (2002). *A consensus statement on health care transitions for young adults with special health care needs*. *Pediatrics*, 110(6), 1304–1306.
- Annunziato, R. A., Emre, S., Shneider, B. L., Dugan, C. A., Aytaman, Y., McKay, M. M., & Shemesh, E. (2008). Transitioning health care responsibility from caregivers to patient: A pilot study aiming to facilitate medication adherence during this process. *Pediatric Transplantation*, 12(3), 309–315. <https://doi.org/10.1111/j.1399-3046.2007.00789.x>.
- Auvin, S., Molinié, F., Gower-Rousseau, C., Brazier, F., Merle, V., Grandbastien, B., ... Turck, D. (2005). Incidence, clinical presentation and location at diagnosis of pediatric inflammatory bowel disease: A prospective population-based study in northern France (1988–1999). *Journal of Pediatric Gastroenterology and Nutrition*, 41(1), 49–55.
- Baldassano, R., Ferry, G., Griffiths, A., Mack, D., Markowitz, J., & Winter, H. (2002). Transition of the patient with inflammatory bowel disease from pediatric to adult care: Recommendations of the north american society for pediatric gastroenterology, hepatology and nutrition. *Journal of Pediatric Gastroenterology and Nutrition*, 34(3), 245–248.
- Bartholomew, L. K., Parcel, G. S., Kok, G., Gottlieb, N. H., & Fernandez, M. E. (2011). *Planning health promotion programs; an Intervention Mapping approach*. San Francisco: Jossey-Bass.
- Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook*, 61(5), 311–336. <https://doi.org/10.1016/j.outlook.2013.01.008>.
- Betz, C. L., Nehring, W. M., & Lobo, M. L. (2015). Transition needs of parents of adolescents and emerging adults with special health care needs and disabilities. *Journal of Family Nursing*, 21(3), 362–412. <https://doi.org/10.1177/1074840715595024>.
- Breakey, V. R., Ignas, D. M., Warias, A. V., White, M., Blanchette, V. S., & Stinson, J. N. (2014). A pilot randomized control trial to evaluate the feasibility of an Internet-based self-management and transitional care program for youth with haemophilia. *Haemophilia*, 20(6), 784–793. <https://doi.org/10.1111/hae.12488>.
- Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., ... Gibson, F. (2016). Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews*, 4. <https://doi.org/10.1002/14651858.CD009794.pub2>.
- Cervesi, C., Battistutta, S., Martellosi, S., Ronfani, L., & Ventura, A. (2013). Health priorities in adolescents with inflammatory bowel disease: Physicians' versus patients' perspectives. *Journal of Pediatric Gastroenterology and Nutrition*, 57(1), 39–42. <https://doi.org/10.1097/MPG.0b013e31828b5fd4>.
- Clarizia, N. A., Chahal, N., Manlihot, C., Kilburn, J., Redington, A. N., & McCrindle, B. W. (2009). Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent and health care provider. *Canadian Journal of Cardiology*, 25(9), S317–S322. [https://doi.org/10.1016/S0828-282X\(09\)70145-X](https://doi.org/10.1016/S0828-282X(09)70145-X).
- Cole, R., Ashok, D., Razack, A., Azaz, A., & Sebastian, S. (2015). Evaluation of outcomes in adolescent inflammatory bowel disease patients following transfer from pediatric to adult health care services: Case for transition. *The Journal of Adolescent Health*, 57(2), 212–217. <https://doi.org/10.1016/j.jadohealth.2015.04.012>.
- Falaiye, T., Schaefer, M., Williams, E., & Chinchilli, V. (2016). P-224 variable levels of transition readiness in pediatric inflammatory bowel disease patients. *Inflammatory Bowel Diseases*, 22, S77. <https://doi.org/10.1097/01.mib.0000480339.61594.52>.
- Fegran, L., Hall, E. O. C., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult

- care: A qualitative metasynthesis. *International Journal of Nursing Studies*, 51(1), 123–135. <https://doi.org/10.1016/j.ijnurstu.2013.02.001>.
- Fishman, L. N., Barendse, R. M., Hait, E., Burdick, C., & Arnold, J. (2010). Self-management of older adolescents with inflammatory bowel disease: A pilot study of behavior and knowledge as prelude to transition. *Clinical Pediatrics*, 49(12), 1129–1133. <https://doi.org/10.1177/0009922810379042>.
- Gray, W. N., Holbrook, E., Morgan, P. J., Saeed, S. A., Denson, L. A., & Hommel, K. A. (2015). Transition readiness skills acquisition in adolescents and young adults with IBD: Findings from integrating assessment into clinical practice. *Inflammatory Bowel Diseases*, 21(5), 1125–1131.
- Gray, W. N., & Maddux, M. H. (2016). Current transition practices in pediatric IBD: Findings from a national survey of pediatric providers. *Inflammatory Bowel Diseases*, 22(2), 372–379. <https://doi.org/10.1097/mib.0000000000000642>.
- Gray, W. N., Resmini, A. R., Baker, K. D., Holbrook, E., Morgan, P. J., Ryan, J., ... Hommel, K. A. (2015). Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: Perspectives of patients, parents, and health professionals. *Inflammatory Bowel Diseases*, 21(7), 1641–1651.
- Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2017). Barriers to transition from pediatric to adult care: A systematic review. *Journal of Pediatric Psychology* jsx142–jsx142 <https://doi.org/10.1093/jpepsy/jsx142>.
- Green, L. W., & Mercer, S. L. (2001). Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *American Journal of Public Health*, 91(12), 1926–1929.
- Greenley, R. N., Kunz, J. H., Walter, J., & Hommel, K. A. (2013). Practical strategies for enhancing adherence to treatment regimen in inflammatory bowel disease. *Inflammatory Bowel Diseases*, 19(7), 1534–1545. <https://doi.org/10.1097/MIB.0b013e3182813482>.
- Hait, E. J., Barendse, R. M., Arnold, J. H., Valim, C., Sands, B. E., Korzenik, J. R., & Fishman, L. N. (2009). Transition of adolescents with inflammatory bowel disease from pediatric to adult care: A survey of adult gastroenterologists. *Journal of Pediatric Gastroenterology and Nutrition*, 48(1), 61–65. <https://doi.org/10.1097/MPG.1090b1013e31816d31871d31818>.
- Hommel, K. A., & Baldassano, R. N. (2010). Brief report: Barriers to treatment adherence in pediatric inflammatory bowel disease. *Journal of Pediatric Psychology*, 35(9), 1005–1010. <https://doi.org/10.1093/jpepsy/jsp126>.
- Hommel, K. A., Davis, C. M., & Baldassano, R. N. (2009). Objective versus subjective assessment of oral medication adherence in pediatric inflammatory bowel disease. *Inflammatory Bowel Diseases*, 15(4), 589–593. <https://doi.org/10.1002/ibd.20798>.
- Hommel, K. A., Greenley, R. N., Maddux, M. H., Gray, W. N., & Mackner, L. M. (2013). Self-management in pediatric inflammatory bowel disease: A clinical report of the north American Society for Pediatric Gastroenterology, hepatology, and nutrition. *Journal of Pediatric Gastroenterology and Nutrition*, 57(2), 250–257. <https://doi.org/10.1097/MPG.0b013e3182999b21>.
- Houston, Y., Lindsay, J. O., Jenkins, H., McCartney, S., Ahmad, T., Arnett, I., ... Sebastian, S. (2012). Perspectives of transition care in inflammatory bowel disease: A survey. *Gastrointestinal Nursing*, 10(1), 30–34.
- Huang, J. S., Terrones, L., Tompane, T., Dillon, L., Pian, M., Gottschalk, M., ... Bartholomew, L. K. (2014). Preparing adolescents with chronic disease for transition to adult care: A technology program. *Pediatrics*, 133(6), e1639–e1646. <https://doi.org/10.1542/peds.2013-2830>.
- Kappelman, M. D., Rifas-Shiman, S. L., Kleinman, K., Ollendorf, D., Bousvaros, A., Grand, R. J., & Finkelstein, J. A. (2007). The prevalence and geographic distribution of Crohn's disease and ulcerative colitis in the United States. *Clinical Gastroenterology and Hepatology*, 5(12), 1424–1429. <https://doi.org/10.1016/j.cgh.2007.07.012>.
- Kreuter, M. W., De Rosa, C., Howze, E. H., & Baldwin, G. T. (2004). Understanding wicked problems: A key to advancing environmental health promotion. *Health Education & Behavior*, 31(4), 441–454. <https://doi.org/10.1177/1090198104265597>.
- Kunz, J. H., Greenley, R. N., & Howard, M. (2011). Maternal, paternal, and family health-related quality of life in the context of pediatric inflammatory bowel disease. *Quality of Life Research*, 20(8), 1197–1204.
- Leung, Y., Heyman, M. B., & Mahadevan, U. (2011). Transitioning the adolescent inflammatory bowel disease patient: Guidelines for the adult and pediatric gastroenterologist. *Inflammatory Bowel Diseases*, 17(10), 2169–2173. <https://doi.org/10.1002/ibd.21576>.
- Mackner, L. M., & Crandall, W. V. (2007). Psychological factors affecting pediatric inflammatory bowel disease. *Current Opinion in Pediatrics*, 19(5), 548–552. <https://doi.org/10.1097/MOP.0b013e3282ef4426>.
- McPheeters, M., Davis, A., Taylor, J., Brown, R., Potter, S., & Epstein, R., Jr. (2014). Transition care for children with special health needs. Retrieved from <http://www.effectivehealthcare.ahrq.gov/ehc/products/546/1920/children-special-needs-transition-report-140617.pdf>.
- McPherson, M., Thaniel, L., & Minniti, C. P. (2009). Transition of patients with sickle cell disease from pediatric to adult care: Assessing patient readiness. *Pediatric Blood & Cancer*, 52(7), 838–841. <https://doi.org/10.1002/pbc.21974>.
- Nehring, W. M., Betz, C. L., & Lobo, M. L. (2015). Uncharted territory: Systematic review of Providers' roles, understanding, and views pertaining to health care transition. *Journal of Pediatric Nursing*, 30(5), 732–747. <https://doi.org/10.1016/j.pedn.2015.05.030>.
- Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: A qualitative examination. *Health and Quality of Life Outcomes*, 5, 28. <https://doi.org/10.1186/1477-7525-5-28>.
- O'dell, S., Sander, E., Denson, L. A., Baldassano, R. N., & Hommel, K. A. (2011). The contributions of child behavioral functioning and parent distress to family functioning in pediatric inflammatory bowel disease. *Journal of Clinical Psychology in Medical Settings*, 18(1), 39–45. <https://doi.org/10.1007/s10880-011-9228-5>.
- Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics*, 115(1), 112–120. <https://doi.org/10.1542/peds.2004-1321>.
- Romanova, A., Armstrong, D., Brill, H., Chauhan, U., Halder, S., Moayyedi, P., ... Marshall, J. (2013). P-119 transition experience from pediatric to adult IBD care: Results of a pilot study. *Inflammatory Bowel Diseases*, 19, S71. <https://doi.org/10.1097/01.mib.0000438797.60250.61>.
- Rosen, D., Annunziato, R., Colombel, J. F., Dubinsky, M., & Benkov, K. (2016). Transition of inflammatory bowel disease care: Assessment of transition readiness factors and disease outcomes in a young adult population. *Inflammatory Bowel Diseases*, 22(3), 702–708. <https://doi.org/10.1097/mib.0000000000000633>.
- Sawicki, G. S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I. -C., Livingood, W., ... Wood, D. (2011). Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ—Transition readiness assessment questionnaire. *Journal of Pediatric Psychology*, 36(2), 160–171. <https://doi.org/10.1093/jpepsy/jsp128>.
- Shalowitz, M. U., Isacco, A., Barquin, N., Clark-Kauffman, E., Delger, P., Nelson, D., ... Wagenaar, K. A. (2009). Community-based participatory research: A review of the literature with strategies for community engagement. *Journal of Developmental & Behavioral Pediatrics*, 30(4), 350–361. <https://doi.org/10.1097/DBP.0b013e3181b50ef14>.
- Telfair, J., Alexander, L. R., Loosier, P. S., Alleman-Velez, P. L., & Simmons, J. (2004). Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *Journal of Health Care for the Poor and Underserved*, 15(3), 443–461.
- Westwood, A. T. R., Henley, L. D., & Willcox, P. (1999). Transition from paediatric to adult care for persons with cystic fibrosis: Patient and parent perspectives. *Journal of Paediatrics and Child Health*, 35(5), 442–445. <https://doi.org/10.1046/j.1440-1754.1999.355394.x>.
- Wood, D. L., Sawicki, G. S., Miller, M. D., Smotherman, C., Lukens-Bull, K., Livingood, W. C., ... Kraemer, D. F. (2014). The transition readiness assessment questionnaire (TRAQ): Its factor structure, reliability, and validity. *Academic Pediatrics*, 14(4), 415–422. <https://doi.org/10.1016/j.acap.2014.03.008>.