Adapting Lugasi’s Core Conditions for Optimizing Transition of Pediatric to Adult Care in Inflammatory Bowel Disease

The incidence of pediatric-onset inflammatory bowel disease is rising. As this growing population nears adulthood, they are faced with transition of care (TOC) to adult gastroenterologists. This critical transition period has been studied in pediatric patients with chronic medical conditions and several core conditions for successful transition have been identified. In this paper we apply Lugasi’s conditions for successful transition of care specifically to patients with inflammatory bowel disease and suggest a blueprint for a successful TOC process.

INTRODUCTION

Transition of care, recently defined as the lengthy process of preparing the adolescent for a life as an adult and receiving care from adult health care providers, is a pivotal point in an adolescent’s life. It is essential that this process result in uninterrupted care, but frequently there are barriers to a successful transition. Patients and their families are often hesitant to leave their pediatric caregivers, and do not fully understand the meaning of - and reason for - transitioning to adult-centered care (ACC). Despite the increasing emphasis placed on this process, transitioning care often remains a stressful time for pediatric patients and their families. To address these concerns, in 2010 Lugasi et al. performed a metasummary of 46 qualitative and descriptive quantitative studies involving adolescents with chronic medical illness before and/or after their transfer to ACC. This comprehensive metasummary which included adolescents with cystic fibrosis, congenital heart disease, sickle cell disease, solid organ transplant and diabetes identified 5 core conditions (continued on page 50)
Perhaps the most consistent theme among transition-aged patients is their preference for being treated like adults. Transition aged patients described CCC as patronizing. They prefer the medical staff to address them as opposed to their parents. Despite their initial anxiety, adolescents appreciate taking responsibility for their own care and gain self-esteem and confidence from the transition. In the “patronizing” setting of CCC it is easy to forget the patient’s social environment and the decisions they are making without the assistance of their parents on a daily basis. In CCC, pediatric gastroenterologists do address the impact of tobacco use, drug use, and sex – as well as less hot-button topics such as sun exposure and stress - on their disease. Adult gastroenterologists reported that their newly transitioned patients were not sufficiently privy to these topics and transition-aged patients reported that they would like more information on these topics.

In counseling patients and families about transitioning to ACC, it is important to acknowledge and validate their concerns to ensure that transitioning care is not construed as abandonment by their pediatric care team. Instead, the pediatric provider should convey that transitioning care is an involved and lengthy process in which they will be educated and ushered toward ACC, as well as highlight the benefits of transitioning: engendering autonomy, responsibility and self-management skills.

II. Expectations

Pediatric patients and their families frequently have preconceptions about ACC (table II). This section describes the preconceptions that pediatric patients and their families have toward ACC and provides a general outline of the important differences between CCC and ACC that patients should be informed of in advance of initiating the transition process.

Table I. Hesitations voiced by parents and patients about transitioning to from CCC to ACC, and the benefits of that transition.

<table>
<thead>
<tr>
<th>Hesitations about Transition</th>
<th>Benefits of Transition</th>
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<tr>
<td>Adult gastroenterologist does not know patient well</td>
<td>Adult gastroenterologist is better equipped to treat chronic nature of disease</td>
</tr>
<tr>
<td>Parent role is diminished</td>
<td>Patient (child) gains confidence and self-efficacy</td>
</tr>
<tr>
<td>Patient anxiety about taking ownership for their healthcare</td>
<td>Patient is treated like adult, given responsibility for their own healthcare</td>
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Lugasi et al. describe that pediatric patients and family members generally think of ACC as cold, impersonal, and business-like, whereas CCC is familiar and friendly. Escher et al. describes the perceived differences between pediatric and adult gastroenterologists similarly. Though these differences are subjective and difficult to investigate, pediatric care for IBD tends to be provided at tertiary care centers with a multidisciplinary team in a family-focused arena, whereas adult care is often provided by a single doctor at a local hospital and is patient focused. Newly transitioned patients in a flare of their disease usually will be admitted to a general medicine floor at a local hospital, as opposed to the familiar setting of a pediatric unit.

Pediatric practitioners focus on physical, developmental, and psychosocial milestones of their patients with IBD. The dynamic nature of IBD as well as medication side effects during critical stages of growth and development often result in failure to meet these milestones, and pediatric practitioners are keenly aware of this. Puberty is sometimes delayed due to malnutrition, and psychosocially patients suffer as they miss school during flares and commonly struggle with self-esteem and identity issues. Pediatric practitioners aim to alter the early disease course in their patients to minimize long-term sequelae. Adult practitioners also aim to minimize disease flares, but the focus of care begins to shift toward malignancy surveillance, new drugs/treatments, and long-term effects of IBD and IBD treatment, as well as family planning.

Patients and families develop expectations of endoscopy, radiation exposure and treatment of IBD based on the care they have received in CCC, though they should be made aware of potential changes to expect. Frequent endoscopic surveillance is an important aspect of ACC. Endoscopy is a means of monitoring for malignancy, evaluate response to therapy and predict future risk of recurrence. Endoscopies are more frequent in ACC and performed under moderate sedation, whereas in CCC endoscopy is usually performed under deep sedation or monitored anesthesia care. This change

<table>
<thead>
<tr>
<th>Aspects of Care</th>
<th>Child-Centered Care (CCC)</th>
<th>Adult-Centered Care (ACC)</th>
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<tr>
<td><strong>General Associations</strong></td>
<td>Familiar, child-friendly, nice, take more time</td>
<td>Cold, impersonal, patient one of many, business-like, less time</td>
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<tr>
<td><strong>Focus</strong></td>
<td>Nutrition, growth, puberty, physical and psychosocial milestones</td>
<td>Malignancy surveillance, long-term treatment side-effects</td>
</tr>
<tr>
<td><strong>Goal</strong></td>
<td>Early disease course modification, radiation minimization</td>
<td>Minimize flares and necessity for surgery, management of chronic complications</td>
</tr>
<tr>
<td><strong>Team/Setting</strong></td>
<td>Multidisciplinary team, tertiary care hospital</td>
<td>Single gastroenterologist, local hospital</td>
</tr>
<tr>
<td><strong>Hospitalizations for Exacerbations</strong></td>
<td>Pediatric specialty floor</td>
<td>General hospital</td>
</tr>
<tr>
<td><strong>Endoscopy</strong></td>
<td>Deep sedation, infrequent</td>
<td>Moderate sedation, disease surveillance</td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td>Missing school, exam stressors, college preparation, experimentation with drugs/alcohol/tobacco</td>
<td>Family planning, cessation of smoking and other triggors, long-term psychosocial effects</td>
</tr>
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alone may cause anxiety in a transition-aged patient, and therefore it is important for patients to be aware of this difference.

Children are considerably more sensitive to radiation than adults. A study from Columbia University in 2008 showed that earlier exposure to radiation was associated with a higher risk of developing cancer later in life. A study from Great Britain in 2012 showed a positive association between radiation dose from childhood CT scans and the subsequent development of leukemia.\textsuperscript{16,17} At the University of Michigan in 2013, pediatric patients with IBD had undergone 1.08 CT scans in their lifetime.\textsuperscript{18} In contrast, radiation exposure amongst all-comers with IBD in Ireland between 1999 and 2009 showed a trend toward more radiation exposure on over a ten-year period in adult compared with pediatric populations.\textsuperscript{19} These trends have been reproduced in studies of adult patients with IBD in Alberta, Canada,\textsuperscript{20} as well as a study of lifetime radiation exposure in adult IBD patients in the UK.\textsuperscript{21} There is significant variation in resource utilization depending on the local patterns of practice, but there is an overall trend toward significantly more diagnostic radiation in adult patients with IBD. Transition-aged patients must be made aware of the long-term risks associated with exposure to radiation during CCC and also of the trend toward more radiation in ACC.

Patients who are stable on certain drug regimens in CCC may be asked to change medications by their adult gastroenterologist, potentially adding uncertainty while transitioning care. Newly transitioned patients, when compared with their pre-transition counterparts, have poorer rates of medicine compliance, which may be an indication of discomfort and unfamiliarity with new treatment regimens.\textsuperscript{12} Adult gastroenterologists treating IBD typically present several therapeutic options to the patient in the hopes at arriving at a shared decision. In CCC the patient’s parent or guardian is much more likely to be the decision-making party regarding a particular therapeutic venture. Additionally, pre-conceptive counseling and more aggressive medical or surgical management of longstanding disease are more common in ACC. In ACC patients are expected to play a more active role in their management and often require re-education on the nature of their disease, the risks and benefits of their therapy, and counseling as to the possible consequences of medical non-compliance.

Pediatric patients and family members often have preconceived notions about ACC and the changes to expect. It is important to address these notions about the general environment of ACC, and to acknowledge that there are significant changes to be expected simply by transitioning from CCC to ACC. Speaking openly with patients and family members about these changes will help to reduce uncertainty during and after transition as well as to ensure that their expectations of transitioning care are realistic.

III. Level of Patient’s Knowledge/Skill

In a joint study published by the Journal of Pediatric Gastroenterology and Nutrition (JPGN) in 2008, adult gastroenterologists affiliated with the Crohn’s and Colitis Foundation of America (CCFA) were asked what they expected from young adult patients with IBD entering their care in terms of patient knowledge about their disease.\textsuperscript{6} Among the most important expectations were knowledge of the name, dose and major side-effects of the medications at the time of transition, procedures performed, their medical condition, and an understanding of their disease course and prognosis. Adult gastroenterologists routinely reported that these expectations were often unmet upon patient transition into their care.

The JPGN and adult gastroenterologists affiliated with the CCFA recommend early and repetitive teaching of these basic concepts. There are checklists based on chronological age of their patients for age-appropriate teaching. (continued on page 54)
knowledge of their disease. Readiness assessments based on disease knowledge such as “IBD yourself”, and “MyHealth Passport for IBD” have been devised but have not yet been validated for assessing readiness for transition. The Social–Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) is a more comprehensive readiness assessment tool that highlights the importance of patient, parent and provider components to a successful transition.

These assessment tools are limited and knowledge alone is not sufficient. Fishman et al. suggest that self-efficacy – an individual’s mental or cognitive state based on past or present experience determines his/her ability to organize and implement a pattern of behavior necessary for health promotion – which correlates better than knowledge alone. Similarly, in a recent study, healthcare providers caring for adolescents with IBD identified the patient’s developmental maturity as one of the greatest predictors of transition success, and identified difficulties with abstract reasoning as predictive of a failed transition. Patients have difficulty understanding that absence of symptoms may not correlate to disease activity emphasizing the need to take medications despite feeling “well”.

A patient’s knowledge of their disease and medications, as well as evaluation of a patient’s social understanding and self-advocacy would best predict a patient’s readiness for transition and determining the proper timing for transition.

IV. Planning/Timing
Transitioning to ACC must be broached early in the course of a young patient’s chronic illness. However, there is no consensus on the exact timing of transfer of care.

The age at which transfer must occur has varied from country to country based upon age. In the UK and France, the legal age limit for pediatric medical care is 18 years of age, whereas in the USA it is 21 years. In the UK, patients with cystic fibrosis and their parents reported frustration at the inflexibility of the legislatively determined age of transition. Since the legal age of transfer in the USA is 21, the transition timeline must not follow as “rigid” of a protocol as elsewhere.

The exact timing of transfer must be tailored to the emotional and cognitive competency level of the patient during a time of medical stability. Transfer should occur at a time of relative disease quiescence; active flares are contraindications to transitioning care. However, there is debate about the timing of transfer with regards to social stability.

Many patients that are “transition-aged” or otherwise deemed “ready” for transition are commonly 16 to 19 years old. Transferring medical care in the setting of other major life changes creates undue stress and be deleterious to the patient’s health. On the other hand, pediatric and adult gastroenterologists in the UK agreed that the age of 18 was an ideal time for transfer since 18 marks the end of secondary school and entry into university education or employment. Transfer therefore should occur not reflexively at a specified chronological age, but rather be assessed on a case-by-case basis (Figure 2).

V. Environment
Appropriate resources are integral to a successful transition environment. Currently there is no standardized
transition of care protocol in the US since transition programs are highly variable. Transition preparation ranges from brief educational sessions to more extensive visits with adult and pediatric gastroenterologists and a dedicated nurse or social worker to facilitate transition. Most important in transitioning care is the joint visit with the pediatric and adult gastroenterologist. These joint visits engender a sense of continuity and security with their new provider. Patients and family members surveyed after a joint meeting with their former and future provider felt that the visit was useful in terms of establishing confidence in the new physician.

As awareness of this critical transition period becomes more widespread, programs have helped ease the psychosocial stress that accompanies growing up with a chronic medical illness. At Duke University, the Adolescents Transitioning to Leadership and Success program (ATLAS) pairs college students living with a chronic disease with children also coping with an illness. The children and their mentors discuss issues pertinent to living with a chronic disease, how it may influence relationships with their family, their peers, as well as illness-related experiences. Children are paired with an empathetic friend and are equipped with a strong support system. Doctors, nurses and social workers help assist them in navigating a complex medical system.

In many pediatric practices it is not feasible to orchestrate a multidisciplinary transition process incorporating transition nurses, psychologists/psychiatrists and social workers. However, providing patients and families with information about available support programs and arranging joint meetings between pediatric and adult gastroenterologists positively impact the transition experience.

CONCLUSION

Transitioning from CCC to ACC is a critical event in a young person’s life. Pediatric practitioners have recognized the importance of this process but this process is not as yet optimized. The discussion about transitioning care must begin early in the pre-adolescent course of disease. The healthcare provider should validate and address the patient’s and family’s concerns about transition while highlighting the benefits of this transition. The pediatric care provider must educate the patient about their disease, the natural history of their illness and what to expect during and after the transition process. Joint meetings among pediatric and adult gastroenterologists, family and patient builds trust between patient and providers. By satisfying the 5 core conditions of TOC set forth by Lugasi, a potentially tumultuous time in a young patient’s life can be translated into an empowering event guiding their future health care.

References

8. Leung, Y et al., Transitioning the Adolescent Inflammatory Bowel Disease Patient: Guidelines for the Adult and Pediatric Gastroenterologist. Inflammatory Bowel Disease 2011; 17:2169-2173.
11. Hait E et al., Educate, Communicate, Anticipate—Practical Recommendations for Transitioning Adolescents With IBD to Adult Health Care. Inflammatory Bowel Disease 2006; 12:70-73.
14. Zijlstra M et al., Self-efficacy in adolescents with inflammatory bowel disease: A pilot study of the “IBD-
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18. Domina J, et al., Imaging Trends and Radiation Exposure in Pediatric Inflammatory Bowel Disease at an Academic Children’s Hospital. AJR 2013; 201:W133–W140.
22. Paine CW et al., Barriers and Facilitators to Successful Transition from Pediatric to Adult Inflammatory Bowel Disease Care from the Perspectives of Providers. Inflamm Bowel Dis 2014;20:2083–2091.
23. Benchimol E et al., Assessment of Knowledge in Adolescents with Inflammatory Bowel Disease Using a Novel Transition Tool. Inflamm Bowel Dis 2011;17:1131-1137.
27. ATLAS Mentorship Group for Teens with Chronic Illness. Information provided by Dr. Nancy McGreal and Amanda Rozyczki, as well as the DukeHealth.org website.