Transitional Care for Patients with Inflammatory Bowel Disease: Japanese Experience

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Keywords

Adolescent · Inflammatory bowel disease · Joint clinic · Transition · Transitional care

Abstract

Background: Transition-related healthcare intervention has recently been receiving worldwide attention. Given the increasing incidence of pediatric inflammatory bowel disease (IBD) and its lifelong impact, transitional care has become an important issue. In Japan, guidelines to support the autonomy of IBD patients during transition were recently published.

Summary: Here, we review current issues regarding care for IBD patients during transition from the pediatric to adult period in order to identify the barriers and key elements for successful transition in the context of the Japanese system. Although no single optimal model of transitional care exists, crucial elements identified so far include a joint pediatric/adult clinic or alternating visits between pediatric and adult healthcare providers, a multidisciplinary approach, and good coordination among stakeholders. Self-reliance and independence of patients with childhood-onset IBD are also considered essential for successful transition. Various tools for assessment of transition readiness have been validated and are considered useful. Better outcomes are expected for individually tailored transition, including improvements in

medication adherence, perceived health status, quality of life, and self-management. The timing of transfer from a pediatric to an adult gastroenterologist should not be fixed because the issue is not chronological age but rather the degree of individual maturity. We also propose a standardized medical summary with a checklist template for official referral of patients from a pediatric to an adult gastroenterologist. **Key Messages:** Transition programs require a multidisciplinary approach with a coordinator (IBD nurse) and optimal collaboration and communication. Lack of resources and funding are also pertinent issues.

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Introduction

In Japan, transition-related healthcare intervention is a relatively new medical concept that has been receiving attention only since around 2010, behind North America or Europe. This can be defined as the “purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems” [1]. Inflammatory bowel disease (IBD; Crohn’s disease, ulcerative colitis, and inflammatory bowel disease unclassified) is a chronic relapsing inflammatory disorder of the intestine, with

an increasing incidence and prevalence globally, including Japan [2, 3]. In 2013, the prevalence of Japanese pediatric Crohn's disease and ulcerative colitis was 7.2 in 100,000 and 15.0 in 100,000, respectively [3]. IBD is diagnosed before the age of 18 years in approximately 25% of all patients; approximately one-quarter of all affected children and adolescents are under the age of 10 years at diagnosis [4]. In other words, IBD occurs at a delicate time in a child's physical and psychosocial development and can impact on education, employment, and social integration [5]. Deficiencies in transitional care during a particularly critical phase can result in treatment interruptions, insufficient treatment adherence, and an increased frequency of complications that are probably avoidable [6]. Given the increasing incidence of childhood-onset IBD and the lifelong impact of the disease, transitional care for affected patients is critical to ensure continuity of the care and promote health literacy [5]. There is broad consensus that the transition process ought to be well coordinated with the support of a multidisciplinary team [7].

This article reviews current knowledge of transitional care for IBD patients in the context of the situation in Japan. The authors also propose a standardized transfer checklist for smooth official referral from a pediatric gastroenterologist to an adult gastroenterologist.

Methods

A literature search on PubMed was conducted covering the period from January 2010 to April 2020, using the keywords "inflammatory bowel disease" and "transition." This search brought up a total of 398 relevant articles. After screening the titles, the authors went through the articles and excluded those that were irrelevant. Secondary data sources were found through a bibliographic review of the selected articles. Handsearching of themes related to pregnancy was also conducted. The pertinent points were then summarized.

Current Issues Related to Transitional Care

There are some instances where childhood-onset IBD patients continue to be treated by pediatric healthcare providers even after reaching maturity, for example, when faced with medical issues unique to adulthood, such as lifestyle-related diseases (atherosclerosis, heart disease, etc.) and malignant neoplasms, especially when they have an increased risk of cancer secondary to long-standing intestinal inflammation or those secondary to

immunosuppressive therapies [8]. Many concerns among IBD patients exist regarding impact of the disease during pregnancy. Internists and obstetricians/gynecologists can appropriately address these conditions, whereas pediatricians cannot [9, 10]. On the other hand, adult gastroenterologists may not be familiar with vaccination issues or conditions associated with treatment using steroids, immunomodulatory agents, or biologics during periods of growth, and thus, the choice of treatments for childhood-onset IBD may be different from that of adults [11]. In addition, guardians often have a high level of trust in their pediatricians, not only for medical care but also for advice regarding social problems. As a result, patients and/or parents often hesitate to establish new relationships with adult healthcare providers. Patients with childhood-onset IBD require long-term outpatient care and/or hospitalization, and as a result, there may often be delayed psychological and social development or lack of self-care management involving drug adherence.

Endorsement from Organizations

In 2013, the Japan Society of Pediatrics published a consensus statement on healthcare transition for young adults with special healthcare needs [12]. The statement emphasized that the goal of transitional healthcare is to provide appropriate and uninterrupted healthcare services as the individual moves from adolescence to adulthood and to maximize lifelong functioning. It also states the goal is not always transfer to adult healthcare providers. Based on the patient's physical and/or intellectual disability, transfer from a pediatric healthcare system to an adult one may not be completely achieved.

Transition process itself is an important step allowing gradual adjustment according to the age and maturity of the patient. Structured transition has been endorsed by major international gastroenterology societies, including North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) and European Crohn's and Colitis Organization (ECCO) [7, 13]. The ECCO considers that IBD patients participating in a transition program are likely to have better adherence and less adverse outcomes after transfer to adult healthcare provider compared with those who do not become involved. In Japan, the Japanese Society for Pediatric Gastroenterology, Hepatology, and Nutrition (JSPGHAN) recently published guidelines on autonomy support for patients with IBD during the transitional period [14].

Stakeholders in Transposal Care

The transitional care for young IBD patients involves multiple stakeholders (i.e., parents/caregivers, school workers, nurses, dietitians, counselors, social workers, psychologists, healthcare systems, insurance providers, and pharmacists) whose roles are all essential for seamless continuation of an adolescent's healthcare. Recognition of the roles of these individuals in multidisciplinary care and maximization of communication between them is of strategic importance [15–18]. In particular, specialized IBD nurses are expected to coordinate various issues among pediatric healthcare providers, adult healthcare providers, patients, and the guardians and play an important role in multidisciplinary IBD unit for transitional care [17, 19]. Patients with IBD managed by a transition coordinator show significant better transition readiness and acquisition of self-management skills [20]. In China, IBD nurses provide instructions to patients in the hospital, visit patients at home, maintain social networking groups, and make phone calls to promote follow-up [21]. However, in the Japanese survey, poor coordination of care was identified [16].

Supporting Tools for Transition

It is considered that using transition readiness checklists and handouts are useful for clarification of patient's goal and regular assessment of his/her present level of achievement. The abovementioned Japanese Guideline for Autonomy Support of Patients with IBD includes a checklist of self-management skills for patients, a transition readiness checklist for guardians, educational materials for young teenagers regarding the digestive anatomy and physiology, a rough standard schedule for transfer to adult gastroenterologist, a template for patient's own medical record, and "path" which includes the time schedule of transition for each of the multidisciplinary professionals involved [14]. It is expected that using these tools will lead to a better understanding of each patient's status and make it easier to confirm the goals of not only the patient and guardians but also each professional care provider. However, validation of the guideline has not yet been evaluated. Other tools include Transition Readiness Assessment Questionnaire and the NASPGHAN checklist. The former consists of a 20-item self-report questionnaire regarding disease self-management skills [22]. It covers a range of knowledge and skills likely related to a patient's ability to transition from pediatric-centered to adult healthcare, but

it is not specified for IBD and is based on self-reporting without clinical correlation. The latter checklist aims to be a reminder of how and when to encourage IBD patients to take on more responsibility for a successful transition [23]. Other IBD-specified tools include the Short IBD Questionnaire [24], the IBD-yourself [25], and the "IBD Self-Efficacy Scale for Adolescents and Young Adults," which involves a 13-item disease-specific scale designed to aid in managing medical care, everyday life with IBD, feedings, and living with IBD in the future [26].

Barriers to Successful Transition

Many previous studies have identified various barriers to a seamless transfer of care, as shown in Table 1 [5, 13, 16, 18, 19, 27]. These cover a range of specialists such as healthcare providers, patients, guardians, and social systems and may be single or multiple. Recent and current development of guidelines and consensus statements suggests that awareness of providing good transitional care is developing on the basis of identified barriers.

Transitional Care and Pregnancy

Few studies have investigated pregnancy in patients with childhood-onset IBD in terms of transitional care, and limited information is available on the lifestyle of such patients. However, it is considered important to educate them or address sexuality and fertility issues with patients in transitional period, prior to any pregnancy. According to the Healthcare Provider Transitioning Checklist by NASPGHAN [23], providing information about sexuality should be started at the age of 12–14 years and discussion about the impact of IBD on sexuality and fertility should be started at the age of 14–17 years. The conversation should include details of self-prescribed diets and other interventions, such as steroids, immunomodulatory agents, and biologics, which may affect not only the patients but also their fetuses. On the other hand, it is reported that many women with IBD remain childless due merely to lack of information under the assumption that pregnancy would be medically dangerous and that parenting would be too challenging in addition to their illness [28]. It is recommended that pediatric healthcare professionals begin to provide information about the impact of IBD on reproduction and to start any conversation in the transitional period. Pregnancy in relation to IBD requires a holistic and multidisciplinary approach.

Table 1. Barriers to successful transition*Patient*

Psychological immaturity, delay of independence
 Disease non-remission (active phase)
 Emotional/cognitive delay
 Attachment to pediatric healthcare providers, medical setting, or practice
 Lack of knowledge about disease concept and own medical history
 Unstable social situation
 Presence of diseases other than IBD

Caregiver

High parental involvement
 Emotional/cognitive issue
 Lower socioeconomic status
 Underestimation of the child's capability
 Reduced parental assistance
 Attachment to pediatric healthcare providers, medical setting, or practice

Pediatric healthcare provider

Attachment to patient or family
 Inadequate medical summary
 Poor care coordination with adult gastroenterologist
 Lack of manpower or time to prepare for transition

Adult healthcare provider

Reluctance of patients and parents due to their close relationship with pediatric healthcare provider
 Cultural difference from pediatric healthcare providers
 Poor care coordination with pediatric gastroenterologist
 Lack of awareness of importance of transitional care

Health system organization

Lack of defined transition protocol (manual), planning difficulties
 Lack of manpower (e.g., coordinator, IBD nurse), time/space or funding

IBD, inflammatory bowel disease

Timing of Transfer to an Adult Gastroenterologist

Transfer from a pediatric to an adult gastroenterologist should ideally take place during the disease remission phase. However, there is no clear cutoff for transfer. The abovementioned Japanese survey indicated that adult gastroenterologists considered an age of 16 years to be reasonable to transfer point [16]. However, another Japanese survey of pediatric gastroenterologists revealed some discrepancy in their views regarding the timing of transfer in comparison to adult gastroenterologists: the majority of the former considered an age of 18 years or above to be ideal [29]. Both surveys showed that complex issues, such as psychological immaturity and autism spectrum disorders, presented a considerable barrier to successful patient transition and might necessitate some delay before transfer. Developmental milestones in adolescence may be reached at different times. Stollon et al. [30] reported that self-management skills were not mastered un-

til after 18 years of age. In any event, the timing of transfer should not be fixed because the issue is not one of chronological age but rather when each individual achieves maturity [31].

Joint Clinic and Alternative Visit

One of the ideal models for support of patients with childhood-onset IBD during the transition period is to implement an outpatient-based transitional care clinic run by a multidisciplinary team [27]. Although there is no common definition of a transition clinic and the settings are notably heterogeneous [17], a multidisciplinary approach and good interaction among the various stakeholders are potential keys of the success of transition [5]. In some circumstances, it may be difficult to set up a transitional clinic in some institutions due to territorial dispersion (regional specifics) or lack of medical resources.

Table 2. Key elements for successful transition

Good coordination between pediatric and adult healthcare provider
Initiation of planning and education of patients and parents at least 1 year before transfer
Discussion with the patient and caregiver regarding self-management of the disease
Consideration of the patient's sentiment in transition planning
Providing an opportunity to attend the office alone
Setting up a patient's meeting with an adult gastroenterologist before official transfer (joint clinic, alternating visits)
Provision of a medical summary by a pediatric gastroenterologist before the first visit to an adult gastroenterologist

Summary and Checklist on Referral to an Adult Gastroenterologist	
Patient <ul style="list-style-type: none">Name _____ ID _____ Birthdate _____ Sex _____Age at onset: _____ Years _____ Months, Date (YYYY/MM) _____Age at diagnosis: _____ Years _____ Months, Date (YYYY/MM) _____Present age: _____ Years _____ Months	<ul style="list-style-type: none">Immunomodulatory agent (AZA _____ mg/day or 6-MP _____ mg/day)Cf. <i>NUDT 15</i> gene analysis ()Biologics (IFX/ADA/GLM/UST/VDZ/TOF/ ()_____ mg, every _____ weeks/monthsNutrition therapy ()Elemental diet (_____) _____ kcal/daySurgical History ()
Diagnosis <p>UC: proctitis/left-sided colitis/pancolitis CD: ileum/colon/ileocolon upper gastrointestinal perianal disease IBD-U: upper gastrointestinal/small intestine/colon/perianal ()</p>	Hystory <ul style="list-style-type: none">Number of exacerbation _____ (latest exacerbation: YYYY/MM _____)
Present manifestation <ul style="list-style-type: none">Abdominal pain ()Number of stools: _____/day Nocturnal stool: ()Stool consistency: formed/partially formed/completely unformedRectal bleeding: ()PUCAI: _____IOIBD score (CD): _____Laboratory data: WBC _____ μL, CRP _____ mg/dL, ESR _____ mm/hFecal occult blood _____ ng/mLFecal calprotectin (ELIZA) _____ μg/g, (FEIA) _____ mg/7kgLatest Endoscopy: Date (YYYY/MM/DD) _____Findings: _____	Complications or diseases other than IBD _____ Reason for transfer programmed/graduation/entering further education/employment/ moving away from familie and home/patient's willingness/age/ ()
Current treatment <ul style="list-style-type: none">Oral 5-ASA () _____ mg/dayEnema/Suppository 5-ASA () _____ mg/dayOral PSL () _____ mg/dayOral BUD () _____ mg/dayEnema/Suppository steroid () _____ mg/dayTotal amount of steroids integration value (PSL conversion) _____ mg	Familial background <ul style="list-style-type: none">Notable issues: _____ Particular points to note _____ Readiness Checklist <ul style="list-style-type: none">☐ He/She can explain own diagnosis and disease history.☐ He/She can explain the nature of a disease flare.☐ He/She can explain current medication and manage the treatment.☐ He/She can explain the purpose and side effects of current medication.☐ He/She has knowledge about the impact of diet and alcohol.☐ He/She is aware of contraceptives/safe sex.☐ He/She can attend office alone.☐ He/She can report symptomes to a health care professional.☐ He/She can communicate and prepare questions for consultation.☐ He/She has knowledge about the social support system for IBD.

Fig. 1. Proposed template for standardized medical summary with a checklist for referral. UC, ulcerative colitis; CD, Crohn's disease; IBD-U, inflammatory bowel disease unclassified; PUCAI, Pediatric Ulcerative Colitis Activity Index; IBD, inflammatory bowel disease; IOIBD, International Organization for Study of Inflammatory Bowel Disease.

In such cases, alternating visits between pediatric and adult healthcare services or email contacts may be useful approaches for encouraging patient autonomy and individual decision-making while still providing some reassuring support in the familiar background of the pediatric clinic [13, 17, 18, 20].

Key Elements for a Successful Transition

An international Delphi study conducted by experts of transitional care from 15 countries, including physicians, nurses, psychologists, transition program managers, and research director, presented key elements for,

and indicators of, a successful transition [32]. Similarly, a multinational expert panel made up of IBD nurses and pediatric and adult gastroenterologists investigated the outcomes that reflect successful transition in IBD patients using a Delphi method [33]. The principal key elements are shown in Table 2. The important points for successful transition are adequate teaching about the concept of transition to patients and guardians, early planning, and starting the program before it becomes too late. Of course, the ideal form of intervention involves a multidisciplinary team of specialized professionals. Moreover, it is very important to regularly monitor the transition process for both the patient and provider, in order to optimize and individualize the outcome. Transition takes time and should be personalized according to the needs, personality, and clinical history of the patients involved [5].

On official transfer from a pediatric to an adult gastroenterologist, proper provision of the patient's medical record to the latter was one of the most important points highlighted by the abovementioned Japanese surveys [16, 29]. JSPGHAN has presented a standardized template for the medical record which is also designed to allow the patient to be able to manage alone [14].

Proposal of a Standardized Medical Summary & Checklist for Referral

Poor coordination between pediatric and care providers and provision of an inadequate medical summary are known to be barriers to smooth transition [16, 29]. Therefore, provision of a proper medical record documented by a pediatric gastroenterologist is essential. However, redundant and pointless entries may be a source of irritation to an adult gastroenterologist. For this reason, the authors propose a standardized template for the medical summary and a checklist for eventual referral from a pediatric healthcare provider to an adult gastroenterologist (Fig. 1).

Conclusion

Due to differences in medical environments, resources, and culture, various societies require different levels of intensity for an IBD transition program. Transition programs should be tailored to and meet the individualized needs of patients that are identified through discussions with the patients and their families about their expecta-

tions and fears about transition. Better outcomes are expected from individually tailored transition planning, including improvements in medication adherence, perceived health status, quality of life, and self-management. Transition programs in Japan require a multidisciplinary approach with a coordinator (IBD nurse), thus improving collaboration and communication. Other issues that need to be discussed would include lack of resources and funding relevant to the cost-benefit balance during transitional care.

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Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

H.K. designed and drafted the manuscript; T.S. and Y.S. critically reviewed the manuscript. All authors read and approved the final manuscript.

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