

Say goodbye and say hello: The transition from pediatric to adult gastroenterology

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Pediatric and adult gastroenterologists have identified an important issue to be addressed which entails the process of transition of care for youth affected by chronic gastrointestinal disorders. The adolescent years are a time of change and development, and may be significantly affected by conditions such as Crohn's disease or ulcerative colitis. Health care providers need to advocate and provide comprehensive, developmentally appropriate care for youth and families to facilitate the transition from the pediatric to the adult setting. The present article will review important aspects of the transition from the pediatric to the adult care health system.

Key Words: *Adolescent; Chronic health condition; Inflammatory bowel disease; Transition of care; Youth*

Inflammatory bowel disease (IBD) in childhood carries a unique set of issues and concerns that requires the skill of trained pediatric gastroenterologists. Furthermore, the transition of care of the adolescent from the pediatric to adult gastroenterologist is a critical step in the ongoing care of that individual, and requires careful planning and a collaborative commitment of the adolescent, family and health care providers. To ensure the best possible health outcome, the transition process should begin long before the transfer of care becomes a reality, and should include a set of transition services and support that provides the adolescent with the knowledge and skills needed to effectively negotiate the adult health care system.

TWO DIFFERENT CULTURES – PEDIATRIC VERSUS ADULT HEALTH CARE

Adult health care providers have identified a number of concerns about patients who have transferred from pediatric clinics. Specifically, the lack of adherence to proposed treatments, lack of knowledge about the disease and limited self-care skills (1). These differences may be partially explained by the significant differences between the mandate and

Au revoir et bonjour! Du service pédiatrique aux soins pour adultes en gastro-entérologie

Les gastro-entérologues qui soignent les enfants et ceux qui soignent les adultes ont soulevé un problème de taille dont il faut s'occuper : la transition entre les soins pédiatriques et les soins pour adultes chez les jeunes atteints de troubles gastro-intestinaux chroniques. L'adolescence est une étape de transformation et de développement qui peut être sérieusement affectée par des problèmes comme la maladie de Crohn ou la colite ulcéreuse. Les professionnels de la santé doivent promouvoir et prodiguer des soins globaux appropriés, en tenant compte du stade développement des jeunes et de leurs proches pour faciliter la transition entre l'unité de soins pédiatriques et l'unité de soins pour adultes. Le présent article passe en revue les principaux aspects de ce transfert du système de soins de santé pédiatrique au système de soins de santé pour adultes.

functioning of pediatric and adult care services. Pediatric care is family-focused, relies on parental decision-making and prescribes care within the support of a multidisciplinary team. Adult care tends to be patient-focused and investigational, and requires autonomous, independent consumer skills (2). Pediatric providers and families have also expressed concerns about the level of training and experience that adult providers have with childhood-onset chronic conditions such as IBD, and that the services, when available through the adult system, are not comparable in scope and quality with those in the pediatric system (3). Adult health care differs significantly from pediatric care by virtue of the type and level of support, decision-making, consent processes and amount of family involvement (4). These, among many other factors, may play a role in a decrease in follow-up visits by the youth once transferred to the adult care system. Some authors believe that this decline of regular medical care can be attributed to the lack of transition planning and insufficient coordination with adult services (5).

Based on the previously described factors, health care providers must ensure that comprehensive and developmentally appropriate care for the adolescent patient is integrated

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into the current pediatric gastroenterology practice structures. It is essential for the adolescent, family and health care providers to work together early and in an ongoing fashion to develop a transition care strategy that is effective in fostering health-promoting behaviours and enhancing the long-term quality of the young adult's life. The present review will provide an overview of the journey for youth with gastrointestinal disorders, their families and health care providers, and the need for developmentally appropriate care to promote a smooth and positive transition of care.

GENERAL ADOLESCENT – PSYCHOSOCIAL DEVELOPMENTAL TASKS

Adolescence is a time of change and development that is strongly influenced by family and peers. It is well accepted in the adolescent health care field that adolescence can be divided into three stages: early adolescence – a time of physical growth and pubertal development; middle adolescence – a time for achieving psychosocial independence from family and developing peer relationships, and often associated with increased experimentation that may lead to health risk-taking behaviours; and late adolescence – a time during which there is further development of personal identity and life-long goals, as well as ethical and moral values (6). Adolescents need to be social and interact with others, and believe in their own potential for future success. Adolescents need to belong to a group that provides mutual support and caring relationships. The level of difficulty in addressing these needs may become magnified for youth with chronic gastrointestinal disorders. Satisfactory progress through these developmental stages contributes to the adolescent's self-confidence and self-worth. Families and health care providers play an explicit role in this developmental process by partnering with the adolescent to offer support and guidance.

SELF-ESTEEM AND IDENTITY ISSUES

Previous studies (7) have demonstrated low self-esteem and additional psychological problems in adolescents with chronic health conditions. The McCreary Centre Society survey (8), performed in 1994, observed that a group of British Columbia adolescents with chronic health conditions expressed lower self-esteem three times more often than did their nondisabled peers. In addition, researchers comparing youth with and without chronic health conditions found more psychological problems, twice as many symptoms of depression, an increased incidence in social problems and higher levels of stress about death, body image, school and the future in general among adolescents with chronic conditions (9). Being listened to, being understood and feeling like a valued member of the family group are important determinants of emotional well-being. Youth living with chronic health conditions need to be involved in activities and behaviours that project their needs, limitations and abilities to those around them. Self-esteem can be fostered through helping adolescents acquire knowledge about themselves and their health condition as well as by developing skills to express their needs and strengths, and developing a plan for achieving life goals. Promoting wellness behaviour is also important in the care of these individuals (10). Good self-esteem, self-acceptance, knowledge and understanding about their disease,

the opportunity to discuss their health condition with others and allowing the adolescent to advocate for him or herself without parental involvement empowers the adolescent, promotes healthy behaviours and helps to assure a smooth transition to adult care.

AUTONOMY, INDEPENDENCE AND INTERDEPENDENCE CONCEPTS

As stated by the Council on Child and Adolescent Health for the American Academy of Pediatrics and the Adolescent Health Committee of the Canadian Paediatric Society, "Children with disabilities, regardless of the cause, should be encouraged to develop the highest level of independence based on realistic and objective evaluation of their abilities and limitations" (11-14). Peterson et al (15) expanded on the American Academy of Pediatrics statement by including dependence and interdependence, as well as independence in their developmental framework for young adults with spina bifida. Peterson et al defined 'interdependence' as "recognising and distinguishing from situations in which one needs to rely on others and situations in which one needs to rely on oneself". This framework can be readily applied to patients with IBD. Finding the appropriate balance between independence and interdependence is a critical task for the developing adolescent and their family. Many parents who have been the primary caregiver for years have difficulty fostering independence in their adolescent with a chronic health condition and in relinquishing responsibility for decision-making to their child (16). Blum (17) found that adolescents whose health problems have been "cared for" since early childhood may develop a false assumption that the condition is the responsibility of others and, therefore, care of the illness or condition is not their responsibility. Thus, the most significant barrier preventing the adolescent from gaining a sense of autonomy and personal responsibility for his/her own health management may be the behaviours of those trying to help.

Difficulties in adhering to treatment arise when other priorities, such as school demands, peer interactions and social engagements, interfere with medication and treatment schedules. The adolescent's psychosocial and cognitive development will significantly impact his/her ability to understand, accept and adhere to advice on medication and treatment. All of these factors will affect the ability of the adolescent to adhere to the treatment plan and independently adopt health-promoting practices to maintain health. Dependency, limited knowledge of their health condition and a lack of understanding of the limited roles and responsibilities of health care professionals may hinder independent and autonomous decision-making by the youth. Under these circumstances, the adolescent with chronic gastrointestinal disease may be reluctant to move to the adult health care system.

SEXUAL DEVELOPMENT AND SEXUAL BEHAVIOURS

Sexual development and maturation may be delayed in adolescents with IBD. Sexual education has a pivotal role for youth in general. Information and research specifically related to sexuality for youth with certain chronic health conditions or disabilities are limited (18,19). The lack of current research in this area may be explained by findings that show the public perceives

persons with chronic health conditions and physical disabilities as not being interested in sex or unable to participate in sexual activity. Parents have offered reasons for avoiding sexual health discussions with their youth. They view the youth as nonsexual, without sexual thoughts, desire or questions; they are uncomfortable with emerging sexual behaviours by the youth; or they discourage dating or the development of intimate behaviours to protect the youth from disappointment (20).

Data from adolescent health surveys (AHS-I, 1994 [8] and AHS-II, 1998 [21]) performed by the McCreary Centre Society in British Columbia indicated that up to 50% of grade 12 students reported being sexually active. In a different survey conducted in the state of Minnesota (22), the numbers for youths with a chronic condition having had intercourse ranged from 38% to 45%. Among all groups of youth with and without chronic health conditions, the average age of first intercourse was 13.2 to 14.1 years. Sexual health seems to be the most misunderstood and limited area of health care for youth with chronic health conditions. It is important for youth and their families to understand the alterations in normal physiological sexual development that may be caused by certain chronic health conditions (23). It is also important for parents to acknowledge that their child's sexual behaviours are emerging and encourage discussions around this topic. Parents and providers should also support dating and the development of intimate relationships.

SOCIAL ASPECTS OF ADOLESCENT DEVELOPMENT

Adolescence is a time when social conformity and acceptance by peers is important. Not being able to conform, fit in or belong to an accepting peer group may result in self-rejection by the youth with chronic gastrointestinal disease. Attempts to participate actively in a group may be hampered by health limitations, which may reduce their identification with their peer group (24). Health regimens or illness such as IBD that interrupt normal participation in daily activities, school and social gatherings interfere with the continuity necessary to establish meaningful peer relationships. An adolescent with IBD, who has to spend time between classes and at lunch attending to personal self-care needs or taking medications, misses invaluable time for relaxed informal social learning with peers. These youth commonly experience social isolation, yet have a normal desire for acceptance, peer relationships and dating. Isolation, which may be self-imposed or due to rejection by peers, is a major predicament for many adolescents with chronic gastrointestinal conditions, which can lead to depression and further isolation. Families need to be sensitive to prejudices imposed by others and provide social opportunities that ensure inclusion and promote adolescents' strengths rather than their differences. Health care professionals need to teach and support families to provide social opportunities for their youth and challenge the prejudices that exist by seeking out positive role models and events that encourage their abilities (25).

EDUCATIONAL AND VOCATIONAL FACTS

The AHS-I in British Columbia found that youth living with a chronic health condition often have problems with school attendance, vocational planning, economic support and physical activity (8). The same researchers found that repeated

hospitalizations and exacerbations of the medical condition may reduce school and/or work attendance by the youth by as much as one-third compared with their healthy peers. These factors have been linked to further isolation, lower levels of academic achievements and higher dropout rates. Adolescent IBD patients will require ongoing health care, and must realistically plan to secure employment that will provide adequate health insurance or other means to pay for that care. Young adults with chronic health conditions are less likely to attend college, succeed at a job or live independently. Adults with disabilities may have up to 50% to 75% unemployment rates in the United States, compared with 5% for the general population (26). A long-term follow-up study of 246 adults with juvenile idiopathic arthritis with a mean disease duration of 28.3 years showed that the study group achieved better education standards than the control group and their siblings. In contrast, the rate of unemployment was double that of the national population (27,28). Another study (29) looking at outcomes in adults with juvenile idiopathic arthritis with a median age of 30 years and median disease duration of 21 years showed that the education level of the patients was comparable with that of the control group, but unemployment rates for patients were threefold higher than that of controls. Data as they related to employment for adolescents and young adults afflicted by IBD were not known to the authors at the time of writing the present article, but extrapolating from other conditions, it may be inferred that without employment, young IBD patients will remain dependent on their parents and the social service system for medical coverage and all costs of living. Adolescents and young adults with chronic health conditions rely on continual access to health insurance and benefits to cover or supplement the cost for medication, psychological support and counselling. It is important that health care professionals, youth and families are aware of the adolescent's eligibility for medical, dental and extended health benefits while living with the family, as a student, living independently or in applying for employment (30,31).

TRANSITION: WHAT DOES IT ALL MEAN?

Transition, as a general term, describes the movement from one stage or place to another; a process of change or a passage from one life phase to another. In 1993, the Society for Adolescent Medicine defined transition as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems" (10). This statement was reaffirmed in 2003 with specific recommendations provided for the health care providers involved in transition planning (32). Health care transition for youth with chronic gastrointestinal disorders encompasses the health concerns and issues that affect youth as they prepare to and carry out the move from pediatric to adult health care services. A successful transition process involves providing health care that is uninterrupted, coordinated and developmentally appropriate and psychologically sound both before and throughout the transfer into the adult system. By providing youth with developmentally appropriate knowledge and skills, they will learn to advocate effectively for themselves, maintain health-promoting behaviours, and access and use health care services as young adults.

GENERAL PRINCIPLES FOR TRANSITION PLANNING FROM PEDIATRIC TO ADULT HEALTH CARE

The literature contains reports on a number of transition projects and programs throughout North America. The National Center for Youth with Chronic Disabilities completed a survey of approximately 140 pediatric centres that self-identified as incorporating or developing transition programs into their health care services (33). The surveyors categorized the transition programs into four common models:

1. The disease-focus model, that involves intermediary clinics to direct the transition from pediatric care to adult care based on the management and care needs surrounding a specific disability or chronic condition;
2. The primary care model, in which the family physician or general practitioner provides ongoing medical care and care coordination into adulthood;
3. The transition coordination model, that uses a multi-disciplinary team created to assess the adolescent's transition needs, act as a case managers and, if necessary, make referrals to community services; and
4. The adolescent-focused model, that transitions youth from pediatric to adult health care services through the use of an adolescent clinic coordinated by primary care specialists with consultation from subspecialists.

The Society for Adolescent Medicine (34) has stated that "All individuals whether receiving primary preventative care or tertiary care, deserve services that are appropriate for their age and developmental stage". Thus, the goals of providing health care to youth with chronic health conditions should include:

- optimal medical management;
- adolescent involvement in the management of their health condition;
- adolescent and family understanding of the condition;
- acknowledgement of personal potential for activity, education, recreation and functioning;
- completion of adolescent developmental tasks;
- the attainment of self-esteem and self-confidence; and
- the acknowledgement of personal potential for a vocation or career.

The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition developed a position statement on "Transition of the patient with inflammatory bowel disease from pediatric to adult care" (35). Specific recommendations for the youth, family and care givers are clearly set in this document, and include examples of practical issues such as a summary of the health concern and medical history to be given to the youth at the time of transfer of care. Through the past decade it has become apparent that the goals set up by different organizations, as they relate to transition planning in providing collaborative, coordinated and integrated services for adolescents and young adults with chronic health conditions, have not been achieved. In 1999, 122 programs providing transition services to youth with chronic health conditions were surveyed (36). The primary barriers identified by these

programs were related to lack of adequate funding and trained staff in the area of transition, rather than family and adolescent resistance.

A TRANSITION PROGRAM: THE ON-TRAC MODEL

The period of instability or the potential for instability for youth in response to their transition provides a rationale for transition planning. Transition planning is conceptualized as a process that encompasses the medical, psychological, social, sexual, emotional and vocational needs of the adolescent. Six principles are suggested for transition planning (37):

- focus on abilities and competencies;
- remain family-centred;
- ensure cultural sensitivity;
- ensure teaching and resources are community based;
- coordinate services required by the youth and family; and
- ensure accountability through ongoing evaluation.

These principles can be used as a guide for adolescent health care providers in the development of programs that support transition planning and developmentally appropriate care for youth with chronic gastrointestinal conditions (38). The ON-TRAC model (Taking Responsibility for Adolescent/Adult Care project) was started at the British Columbia's Children's Hospital in 1996 to address the transition concerns facing over 1200 youth/year leaving the institution for the adult system. An advisory committee of youth, parents and health care providers from pediatric, rehabilitation and adult centres met regularly for two years to work together to develop a model to support all of those involved in transition. For more information, please refer to <<http://www.cw.bc.ca/youthhealth/transition.asp>>.

FACTORS ASSOCIATED WITH SUCCESSFUL TRANSITION STRATEGIES

Health promotion

The World Health Organization defines health promotion as "The process of enabling individuals to increase control over and improve their own health – a mediating strategy between people and their environments, synthesizing personal choices and social responsibility in health" (38). Youth with chronic gastrointestinal conditions require holistic care that not only maintains their medical and physical stability, but also prepares them for the future as participating consumers of adult health care. Health promotion is aimed at improving health potential or maintaining health balance. It is essential to health promotion that the adolescent and his/her family understand the condition and reasons for treatment, and have realistic expectations for the future.

Empowerment

Empowerment has been defined as a process of helping individuals to assert control over factors that affect their lives. Learning occurs in many ways. It may occur through repeatedly observing the behaviour of others and the consequences experienced as a result of that behaviour. Role modelling behaviour by individuals the youth admires or emulates tends to significantly influence his/her own behavioural patterns. An individual's knowledge, beliefs and values all influence the

TABLE 1
Clinical transition framework

| | Early (10 to 12 years of age) | Middle (13 to 15 years of age) | Late (16 to 18 years of age) |
|---------------------------------|---|---|---|
| Self-advocacy | <ul style="list-style-type: none"> Describe GI condition Learn about transition process | <ul style="list-style-type: none"> Name and describe the role of those involved in care Learn about rights and responsibilities | <ul style="list-style-type: none"> Review successful changes achieved in life Review GI condition and ways to stay informed |
| Independent behaviours | <ul style="list-style-type: none"> Name medications and doses Choose method to remember to take medication | <ul style="list-style-type: none"> Describe tests and reasons for them Plan and prepare for appointments Discuss differences in pediatric and adult care Encourage self-reporting | <ul style="list-style-type: none"> Demonstrate knowledge in dealing with own care needs (eg, booking appointments, refilling prescriptions) |
| Sexual health | <ul style="list-style-type: none"> Discuss puberty and changes related to GI condition and medication side effects | <ul style="list-style-type: none"> Discuss safer relationships and dating Name places for reliable sexual health information | <ul style="list-style-type: none"> Aware of sexual capability and ability to have children Understands sexual behaviours and its risks |
| Social supports | <ul style="list-style-type: none"> Describe role of family in transition process | <ul style="list-style-type: none"> Discuss family medical history Discuss ways to benefit from peer support | <ul style="list-style-type: none"> Enrolls in GI support associations Identifies contacts in case of need of emotional support |
| Educational/vocational planning | <ul style="list-style-type: none"> Discuss school attendance, goals and strengths Identify home chores and responsibilities | <ul style="list-style-type: none"> Review restrictions for education or work at school or community | <ul style="list-style-type: none"> Aware of work opportunities Discuss further plans for insurance coverage |
| Health and lifestyles | <ul style="list-style-type: none"> Review healthy active living Tobacco use or other substances | <ul style="list-style-type: none"> Review ways of coping with stress Learn of risks associated with driving and GI condition | <ul style="list-style-type: none"> Describes exercise/activity routines Discuss importance of planning ahead for trips and being away from home |

Adapted from the ON-TRAC (Taking Responsibility for Adolescent/Adult Care) model at the British Columbia Children's and Women's Health Center (37). GI Gastrointestinal

TABLE 2
Getting ON-TRAC with my care – Suggestions for youth, parents and health care providers during the transition process

| | |
|-------------------|--|
| About me | <ul style="list-style-type: none"> What I need to know about my health condition What would I tell a friend My treatment plan Family health tree |
| Doing it | <ul style="list-style-type: none"> A note to my family doctor/pediatrician Choosing a family doctor An emergency plan A personal care plan |
| The 'sex' word | <ul style="list-style-type: none"> My body, myself Who to question about 'sex' Where to find help about sexuality |
| Feeling connected | <ul style="list-style-type: none"> Me and my world Who can I talk to? Friends Staying connected |
| About my future | <ul style="list-style-type: none"> School: making it work for me Another meaning for homework What I need to tell my school or employer Future plans for living |
| Healthy choices | <ul style="list-style-type: none"> Driving yet? What are my activity restrictions? Designing your own exercise plan |
| Making the move | <ul style="list-style-type: none"> Getting ready for adult care Who will I need on my adult team? Questions for adult specialist Checking it out Graduation checklist |

Adapted from Getting ON-TRAC (Taking Responsibility for Adolescent/Adult Care) contents (37)

- Vocational and career planning with emphasis on health promotion and quality of life events may be coordinated with mental health providers such as

psychologists and social workers. This type of initiative is already part of routine practice in some institutions in Canada.

- Peer support initiatives may include IBD support groups, picnics, mentoring and Internet chat rooms.
- Communication and collaboration between pediatric and adult gastroenterology providers will ensure that the process of transition is optimal for the youth and family by closing the "gap between the two different cultures", and reducing the stress of transition. This process will likely:
 - reduce the risk for development of secondary diseases such as osteoporosis with associated complications;
 - introduce the concept of cancer surveillance;
 - improve the supervision of negative effects of long-term medication use;
 - allow for better long-term follow-up;
 - improved supervision and care of sexual health issues as they relate to pregnancy and the unborn fetus that may be overlooked in pediatric centres; and
 - may help decrease problems related to poor adherence to proposed treatment regimens and patients lost to follow-up seen in youth recently transferred to the adult health care system.

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final outcome of their behaviour. This places health care providers working in the gastrointestinal field in a predominant position to role model health-promoting strategies and empower youth and their families to advocate for themselves by providing opportunity and direction. However, a significant contribution to empowering youth to maintain health will be made by family members with whom the youth spends the majority of his/her time. Empowerment, future orientation and expectations of living as an independent young adult need to start when a child is young. Youth who have developed skills and knowledge to facilitate their health during childhood, supported by family and health care professionals, are much more likely to maintain their positive health habits and realize how their own contributions may improve their health and the way they perceive themselves.

Self-efficacy

Self-efficacy is an important concept in developing health-promoting and health-maintaining behaviours. The theory of social learning incorporates self-efficacy as an important determinant of health behaviour. As discussed by Bandura in 1977 (39), self-efficacy refers to an individual's perception that he/she has the capacity to perform specific activities or behaviours. Green and Kreuter (40) described self-efficacy "as an individual's mental or cognitive state, based on past or present experience that determines his/her ability to organize and implement a pattern of behaviour necessary for health promotion". Low self-esteem and low expectations are associated with low self-efficacy, which, in turn, will impact the youth to advocate for themselves and their health care needs. Attitude is a strong indicator of self-efficacy toward attempting new health-promoting behaviours. Attitude and self-efficacy develop over time, emerging from past personal experiences, social interactions and the adolescent's perception of the current situation. Adolescents with chronic gastrointestinal conditions will continue to view themselves as different and incapable as long as society, family and health care professionals focus on the disease and limitations rather than their capacity for success.

Partnerships

Health care that is developmentally appropriate for youth requires that health care professionals and families learn to share the responsibility for health with the maturing adolescent. The critical partnership for youth with chronic health conditions is between the youth, family and health care providers. This will require a shift in the therapeutic relationship from dominance and control to one of partnership between the adolescent, his or her family and the health care providers. Before any partnership can be formed, it is important to acknowledge the different perspectives each participant has before entering the relationship. The family's ability to cope and assist their adolescent to cope can significantly influence the youth's health behaviours, compliance and outcome. As care becomes more developmentally appropriate, encouraging the adolescent to increase independence and participation in decision-making may cause parents to feel threatened and fearful of the change. The adolescent may also feel overwhelmed by the shift in care.

Quality of life for adolescents with chronic gastrointestinal conditions has been identified as an important aspect for pediatric and adult gastroenterologists to address. A self-reported,

disease-specific, health-related quality of life questionnaire for patients with IBD (41) has been shown to be a valid and reliable tool for the pediatric population. This type of instrument may be used to complement other strategies used during the process of transition. Professionals caring for the youth and family must be attuned to these stresses and assist youth to develop strategies to cope with the changes.

SUMMARY AND RECOMMENDATIONS

Transition of care is an active process that requires a collaborative commitment by the adolescent, family and health care provider. Understanding the differences in patient care and providing the adolescent and family with the appropriate support and skills are essential to the smooth transition of care. Collaboration between pediatric and adult gastroenterologists is an important component in the process of transition of care.

- The process of transition needs to start during the early adolescent stage between 10 and 12 years of age and will culminate with the transfer of care to the adult health care system. During this period, the youth and the family are introduced to the transition process and the youth begins to participate in his/her care. During the middle adolescence transition stage between 13 and 15 years of age, the youth and the family gain understanding of the transition process and the youth practices skills, gathers information and sets goals to participate in his/her own care. By the end of high school or around 18 years of age, the youth and the family prepare to leave the pediatric setting with confidence and the youth uses independent health care behaviours and consumer skills in the adult system (Table 1). Please refer to <<http://www.cw.bc.ca/youthhealth/pdf/Transition%20Framework.pdf>> for additional information.
- Health care for the adolescent or young adult and the family should be developmentally appropriate and based on individual needs. This can be done in the context of different developmental stages, with goals that will include increasing youth involvement and participation in decision making and treatment plans. By empowering the adolescents to take charge over their gastrointestinal condition, family members and health care providers actively participate in the process of transition (Table 2). Please refer to <<http://www.cw.bc.ca/youthhealth/pdf/Components%20of%20Transition.pdf>> and <<http://www.cw.bc.ca/youthhealth/pdf/Getting%20ON%20TRAC%20Contents.pdf>> for additional information.
- During the early adolescence stages (10 to 12 years of age), educational sessions (related to the particular gastrointestinal condition) may be set up by the pediatric institution with involvement of nurses, physicians, nutritionists, occupational therapists, psychologists and social workers, among other multidisciplinary health care providers. These sessions will provide the youth and family with a forum to learn, share, support and start the process of transition that will continue throughout adolescence and will culminate with the transfer of care to the adult system.

APPENDIX

Other resources

1. American Academy of Paediatrics. Committee on Children with Disabilities. Sexuality education of children and adolescents with developmental disabilities. *Paediatrics* 1996;97:275-8.

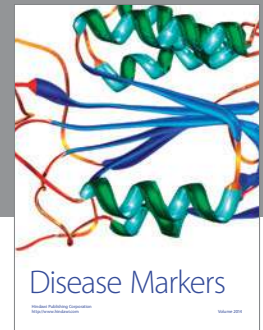
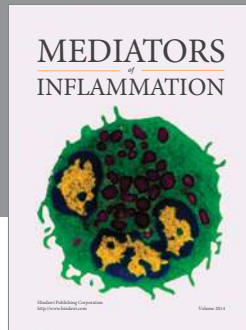
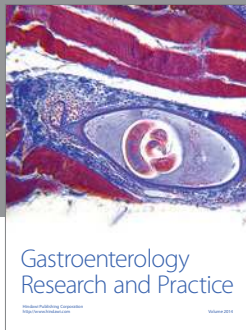
Web sites

1. Youth Health Program – Children's and Women's Health Centre of British Columbia – On-Trac Model – Transition Planning. <<http://www.cw.bc.ca/youthhealth/transition.asp>> (Version current at November 9, 2004).
2. The Society for Adolescent Medicine <<http://www.adolescenthealth.org/>> (Version current at November 9, 2004).
3. Healthy and Ready to Work National Center. Healthy and Ready to Work: A Transition Service for Youth <<http://www.hrtw.org/>> (Version current at November 9, 2004)
4. The Hospital for Sick Children. Adaptation to Childhood Chronic Illness: Research on Children and Families. <<http://www.sickkids.ca/kidscancope/default.asp>> (Version current at November 9, 2004).
5. GriefWorks BC. A site for issues related to death, bereavement and dying. <<http://www.griefworksbc.com>> (Version current at November 9, 2004).
6. Ability Online. A free Internet community where kids with disabilities or illness can meet role models, mentors and friends. <<http://www.abilityonline.org/public/default.htm>> (Version current at November 9, 2004).
7. National Clearinghouse on Rehabilitation Training Materials (NCRTM) <<http://www.nchrtm.okstate.edu/>> (Version current at November 9, 2004).
8. Adolescent Health Transition Project. A resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities <<http://depts.washington.edu/healthtr/>> (Version current at November 9, 2004).
9. National Center on Secondary Education and Transition. Creating opportunities for youth with disabilities to achieve successful futures. <<http://ici.umn.edu/ncset/unsubscribe.html>> (Version current at November 9, 2004).
10. Disability Resources. The Disability Resources Monthly Guide to Disability Resources on the Internet. <<http://www.disabilityresources.org/index.html>> (Version current at November 9, 2004).
11. Kids as Self Advocates (KASA). US network of youth with special needs and their friends, speaking on their own behalf. <<http://www.fvkasa.org/>> (Version current at November 9, 2004).
12. Health Care Transitions. Information on health care transition for youth with disabilities and special health care needs. <<http://hcttransitions.ichp.edu/>> (Version current at November 9, 2004).

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