

Care of adolescents with chronic conditions



Français en page 49

It is estimated that between 14.8% and 18% of all youths in North America have a chronic health condition or a special health care condition (eg, impairments, such as musculoskeletal impairments, speech defects, deafness and hearing loss, blindness and visual impairments; and diseases, such as asthma and heart disease) that affects them and their families (1,2). They may have survived life-threatening illnesses that, until recently, had a high mortality rate, or survive longer with improved medical care and technology. It is estimated that up to 98% of children diagnosed with a chronic health condition may now reach the age of 20 years (3,4), depending on the condition. Some may also have physical and mental disabilities resulting from their primary illness. Many have to deal with the psychological consequences of their condition and the continuing involvement of numerous medical and paramedical personnel in their lives.

The care and follow-up of many of these adolescents are often fragmented, and relies heavily on subspecialists and therapists who may practice far from their home. Adolescents with chronic health conditions that are less obvious or less serious may not get the support they need from physicians or other adults. This position statement is intended to assist specialists, subspecialists and primary care physicians who provide care to youth with chronic conditions.

DEVELOPMENTAL ISSUES

Independence and assertiveness

The Council on Child and Adolescent Health for the American Academy of Pediatrics has stated, "Children with disabilities, regardless of the cause, should be encouraged to develop the highest level of independence based on a realistic and objective evaluation of their abilities and limitations." The concepts of independence, dependence and interdependence are well described by Peterson et al (5) in their developmental framework for young adults with spina bifida, in which interdependence is referred to as "recognizing and distinguishing from each other situations in which one needs to rely on others and situations in which one needs to rely on oneself."

Preparing parents for separation from their teenager is an essential part of long-term management and may allow parents to think about their children surviving into and beyond adolescence. A number of factors make separation and independence more difficult for adolescents with chronic conditions

and for their parents. These factors include the adolescent's need for treatment, parental overprotection, and a physical appearance that is more youthful than the adolescent's chronological age and limited physical freedom.

Disease control measures should take adolescent behavioural needs into consideration. Adolescents need to be aware of treatment choices and should be encouraged to be assertive by discussing and participating in this decision-making. Allowing the adolescent to take control in simple ways, such as choosing the form of medication (eg, pill or liquid), will foster autonomy and improve adherence to proposed treatment plans. This may increase parental anxiety over the well-being of the child. Physicians are encouraged to help parents strike a balance between the increased control of care by the adolescent and parental supervision.

Learning self-care skills is an important way to enhance self-esteem and autonomy, and to empower the adolescent to become a responsible individual as she or he gets older. If the adolescent can participate in his or her own personal care, self-esteem will be enhanced and the mechanics of separation eased. If the youth requires assistance, it is appropriate to seek a caregiver who is not a family member, preferably someone of the same sex.

Adolescents often achieve autonomy by engaging in behaviours that parents may perceive as dangerous; adolescents with chronic illness are no different. Parents need help to recognize and accept safe forms of self-expression and discourage those likely to be harmful. Paediatricians and other health care providers should screen youths with special health care needs for risk behaviours and protective factors as they do for healthy youth (ie, using the Home, Education, Activities, Drugs, Sex, Suicide [HEADSS] method [6]).

The adolescent with a chronic health condition may have a greater need for coping skills, such as a good sense of humour and a positive view of life. Combined with supportive teachers, these can greatly reduce the risk of dysfunction. They may also need to be encouraged to pursue interests and hobbies. Occupational therapists can help these adolescents to achieve goals, such as learning to drive or participating in a sport.

Peer relationships

At adolescence, the young person's focus shifts from family to peers. This important move should be no different for

adolescents with chronic health conditions. However, it can be difficult for them to maintain friendships. Hospitalization, frequent appointments and restrictions, both inherent to the condition and those imposed by parents and others, may lead to social isolation.

Physicians can help the adolescent develop strategies to deal with being teased. Humour, for instance, can often help defuse a painful situation. Potential friends may be intimidated by the nature of the disease. Physicians can advise adolescents how to find supportive friends and to explain the disease and the restrictions it poses.

Support groups allow both parents and adolescents to share experiences, challenge misconceptions and fears about the illness, and develop methods of coping. Adolescent groups also foster the acquisition of age-appropriate social skills.

School and work

Teenagers spend a large portion of their days in school and, later, at work. Attention should be paid to the concerns of adolescents with chronic health conditions about absenteeism resulting from medical care. The Adolescent Health Survey in British Columbia (7) found that youth living with a chronic health condition often had problems with school attendance, vocational planning, economic support and physical activity, to the point that they had a 30% reduction in school attendance compared with their healthy peers. Physicians can help students explain their medical problems to teachers, either by phone or by providing them with literature.

If ignored or not properly diagnosed, learning disabilities can become an increasingly serious problem during the more demanding junior and senior high school years. Appropriate remedial education may be needed; the paediatrician can often help to achieve this in an otherwise reluctant school system.

Parents may need help in arriving at realistic expectations for their adolescent. Some may continue to expect achievement beyond the teen's abilities, while others may have settled for goals much below their adolescent's potential. Prevocational skills training can be introduced in junior high school. A realistic, meaningful goal improves the quality of life: the adolescent, family and physician can work together to formulate this goal and strategies to achieve it. Adults with disabilities have a 50% to 75% unemployment rate in the United States, compared with 5% for the general population. It is important for health care professionals, youth and their families to be aware of eligibility for medical, dental and extended health benefits to optimize potential coverage, while living with the family and preparing for the transition to independent living (8).

Physical appearance

All adolescents are self-conscious about their physical appearance and pubertal development. Concerns about delayed puberty and physical abnormalities may be heightened in adolescents with chronic conditions. It is important for the

physician to anticipate these issues and address them early, in a manner appropriate to the teen's developmental age.

While minor physical changes, such as body odour, may concern adolescents, they may also be seen as concrete evidence of maturation. A physician who points out these changes, discusses the adolescent's sexual maturity rating or undertakes a bone age measurement to establish any growth delay can reassure adolescents with chronic conditions who are concerned about their physical development. Delays in growth and development may be due to nutritional factors that can be corrected or to medication that can be modified. Maturation delays caused by disease may respond to hormonal treatment.

Medication that alters physical appearance (causing hirsutism, acne, obesity, etc) heightens body image anxiety and may affect adherence to treatment. Professional advice about hair, clothing and makeup and consideration of alternative therapy often have a positive effect.

Sexuality

Common myths about adolescents with chronic health conditions and disabilities are that they are asexual, suppress their sexual needs because of their condition, are not subject to sexual abuse and do not need any type of sex education (9). As mentioned earlier, up to 98% of children diagnosed with a chronic health condition may now reach the age of 20 years. These children go through the same stages of adolescence as their peers – stages that incorporate concepts of human sexuality.

Sexual health appears to be a neglected issue for youths with a chronic health problem. In British Columbia, 54% of grade 12 students reported being sexually active (10). In a different population sample, the reported prevalence of sexual activities for adolescents with chronic health conditions and disabilities has been estimated to be higher than the prevalence for their healthy peers (11).

Adolescents with chronic conditions have the same need for sexuality counselling as other adolescents their age, and it is important for youths and their families to understand the alterations in normal physiological sexual development that may be caused by certain chronic health conditions.

In an effort to 'prove' normalcy, an adolescent may engage in sexual activity before he or she is emotionally ready. Suris et al (11) reported that 45% of youths with visible conditions (cerebral palsy, muscular dystrophy and arthritis) and 39% of youths with nonvisible conditions (diabetes, asthma and seizure disorders) reported having had intercourse. In that study, among all groups of youths with and without chronic health conditions who were sexually active, the estimated age at first intercourse was between 13.2 and 14.1 years. Males and females with chronic health conditions were more likely to report having had a sexually transmitted infection than the control groups.

In addition, adolescents with chronic health conditions and disabilities are more than twice as likely to report a history of physical or sexual abuse (11,12).

Some diseases, such as Turner syndrome, delay maturation and development, while others, such as spina bifida, cerebral palsy and some endocrine conditions, may cause premature development (13). A variety of sexual dysfunctions may develop in adolescents and young adults with chronic health conditions, such as cystic fibrosis, where male infertility is commonly found as a result of the disorder itself. This population requires ongoing counselling on sexually transmitted infections and sexual health in general (14).

Adolescents also need accurate information about fertility, the hereditary aspects of their disease, the consequences of sexually transmitted infections and unplanned pregnancy. Contraceptive options may be limited or contraindicated for youths with chronic conditions, such as congenital heart disease, diabetes, liver disease or post-transplantation. If pregnancy should occur, the young woman needs accurate information on the possible impact of the pregnancy on her health condition, and vice versa. A number of health conditions may be associated with sterility, such as cystic fibrosis, spinal cord defects and cancer in men; in the case with cancer, the treatments and medications may be the cause of the sterility. Sexual education has a pivotal role for youths in general (15).

Proper gynecological care for adolescents is important, regardless of their level of physical, mental or cognitive abilities. It should include developmentally appropriate education of the patient and caregiver (when the patient is unable to deal physically or mentally with such issues). If the patient is not sexually active, a pelvic examination is usually not indicated. However, an external genital examination should be done in all adolescents (16). Techniques for a pelvic examination in difficult adolescents (ie, those with mental retardation, and physical and/or mental disorders) have been described (16,17).

By addressing the youth's concerns directly and stressing his or her positive abilities, the physician may be able to help the adolescent modify inappropriate behaviour. Information and research related specifically to sexuality for youths with chronic health conditions and disabilities is limited. However, the sexual practices pattern demonstrated by Suris et al (11) contradicts and challenges the current societal beliefs that youth with chronic health conditions and disabilities are 'nonsexual', have no questions related to sexuality and have no desires commonly expected to emerge in their healthy peers.

The physician needs to be aware of the tendency either to see young people with chronic illnesses as asexual or to assume that they have a heterosexual orientation. By explaining normal sexual patterns to caregivers, physicians can prevent inappropriate interventions in the adolescent's sexual activity.

Death and dying

Some people with chronic conditions die in adolescence. The adolescent with a chronic condition may have to deal with the grief of losing friends with the same disease and the implications of those deaths and the possibility of facing his

or her own death. The issues of death and dying should be addressed both individually and through support groups. Chaplain services can provide support for individuals who are dying, their families and involved staff. Recognizing and acknowledging clinical situations where death has become inevitable is the first step to providing compassionate care during this process.

THE PRACTICAL APPROACH TO CARE

Age limits and office practice

Paediatricians must be flexible when deciding when to transfer adolescent patients to adult facilities and must take the adolescent's developmental age into consideration. The Canadian Paediatric Society (CPS) statement "Age limits and adolescents" (18) provides more information on this subject.

The adolescent should be involved in making decisions about when and to whom they will be referred. The CPS statement "Office practice guidelines for the care of adolescents" (19) discusses the topic. It provides suggestions on appointments, reading materials and office set-ups applicable to the care of youth with chronic conditions. Also, the Society for Adolescent Medicine stated that "all individuals, whether receiving primary preventative care or tertiary care, deserve services that are appropriate for their age and developmental stage" (20). The goals of providing health care to youths with chronic health conditions should include the following:

- optimal medical control;
- adolescent involvement in management of the 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 (20).

Legal and ethical issues are another important aspect of adolescent health care. Health care providers are encouraged to be knowledgeable about legal regulations in their local area. These aspects of adolescent health care include consent to treatment, confidentiality and competency (21). The Canadian Medical Association has developed a series of references for health care providers entitled "Bioethics for Clinicians" (22).

Networking

Physicians are encouraged to be informed about groups, organizations and Web sites that can provide physical and emotional support to patients and their families. They should also facilitate families' access to public health nurses, lay groups, home health providers, social service agencies

and educators. Physicians should also strive to foster broader community responsibility for the chronically ill by becoming community educators and advocates.

Education

Educating adolescents about their disease has three measurable beneficial effects:

- they learn how to avoid situations that exacerbate their condition;
- they learn how to minimize the severity of an exacerbation; and
- they learn self-care skills to minimize the daily effects of their illness.

Hospital-based care

Knowledge of adolescent development is important in planning health care delivery for youth in outpatient and inpatient settings, taking into account the physical and biological changes during puberty and the significant psychosocial and emotional milestones of adolescence. This will facilitate appropriate delivery of health care for hospitalized youths. Hospitals without an adolescent ward can become more 'adolescent-friendly' by providing an orientation pamphlet that explains the rules, regulations and privileges. Rules for adolescents about 'lights out', visitation policies and leaves from hospital should be different than those that apply to younger children. Appropriate snacks can also be made available. Institutions with a space dedicated for adolescents can provide a milieu of committed hospital staff to develop special expertise in caring for youths. These professionals may serve as a resource for program policy development, implementation and evaluation, in addition to staff education and training.

The physical organization and design of the space for youths facilitate aspects of their care for such issues as privacy, socialization and educational needs. Recreation time is particularly important for adolescents with chronic conditions because it may offer the opportunity to express fears and anxieties not revealed under other circumstances. Because hospitalization often triggers behavioural regression, socializing with peers in a teen lounge is important.

Transition and transfer of care

Youth with chronic health conditions face different stages of transition in their lives: a developmental transition from childhood through adolescence to adulthood; a situational transition from paediatric to adult health care; and, occasionally, a transition from relative health to illness.

Transition may be conceptualized as the process undertaken by the youth, his or her family, and health care providers that culminates with the transfer of care to an adult health care provider. Assessing readiness for transfer to an adult facility and preparing for that transfer must be discussed at leisure, well ahead of the event. The patient should be informed about the different types of care that

will be offered and the different resources available in an adult facility. Transition clinics staffed by youth-oriented professionals, as well as paediatric and adult subspecialists, can help in this transition.

The literature contains reports on a number of transition projects and programs around North America. In 1996, the National Center for Youth with Disabilities completed a survey of approximately 140 centres that self-identified as incorporating or developing transition programs into their health care services (23). Four models of care were identified: disease focus; primary care; transition coordination; and adolescent focus. The disease focus model is the most commonly seen across North America. Subspecialty clinics at tertiary care centres provide care to youths and their families with or without the support of a multidisciplinary team (rheumatology, cardiology, gastroenterology and cystic fibrosis clinics). In the transition coordination model, health care is provided to youths in a specific age range (18 to 25 years) with a particular health condition (eg, the young adult with rheumatic disease model). The adolescent focus model is usually run by adolescent medicine specialists, and comprehensive, coordinated support is provided based on the biopsychosocial model of care.

A copy of the transfer summary should be given to the adolescent. The paediatrician should follow up with the patient and the facility to which he or she has been referred to ensure that the transfer has gone smoothly. The aim of transition is to ensure that movement from paediatric to adult care is continuous, comprehensive and coordinated, both to minimize disability and to promote appropriate use of health care services (24). At BC's Children's Hospital, it is estimated that nearly 1200 youth with chronic health conditions transfer into the adult system annually; for this purpose, a service called "On Trac" was created (25). By providing youth with developmentally appropriate knowledge and skills, they learn to advocate effectively for themselves, maintaining good health behaviours and using health care services to maintain their health and prevent secondary disability (2,26).

RECOMMENDATIONS

The CPS makes the following recommendations for the care of the adolescent with chronic conditions and special health care needs:

- Physicians must encourage adolescents to develop the highest level of independence based on a realistic and objective evaluation of their abilities and limitations.
- Physicians must encourage parents to strike a balance between parental supervision and increased control of care by the adolescent.
- Physicians must help parents to recognize and accept safe forms of self-expression because adolescents often achieve autonomy by engaging in behaviours that parents may perceive as dangerous.

- Physicians must question adolescents about their relationships with peers and advise them on any problems to ensure that they develop and maintain friendships.
- Physicians must help teachers understand the condition of the adolescent and facilitate integration into the school program. Also, physicians must help parents to have realistic academic expectations for their adolescent with a chronic condition.
- Physicians must anticipate issues of delayed puberty and physical appearance and address them early, in a manner appropriate to the teen's developmental age.
- Physicians must ask questions on sexuality, sexual orientation, sexual activities, and physical and sexual abuse. Information must be provided to the adolescent on the following topics: pregnancy, sexually transmitted infections, type of contraception allowed by the adolescent's condition, and fertility.
- Physicians must assess issues related to pain control in adolescents with certain chronic conditions, such as sickle cell anemia, juvenile idiopathic arthritis and neuromuscular conditions, in which pain may be underestimated and not treated appropriately.
- Hospital-based care must be adolescent-friendly and support the developmental issues involved.
- The issues of death and dying must be addressed whenever appropriate.
- Paediatricians must be flexible when deciding when to transfer adolescents to adult facilities and must take their developmental age into consideration, ensuring that the transition to an adult facility or new health professional is continuous, comprehensive and coordinated both to minimize disability and to promote appropriate use of health care services. Discussions about transition should start between the ages of 10 and 12 years.
- The adolescent must be involved in decision-making regarding treatment or referral. To do so, the physician must also educate the adolescent about his or her condition.
- Health care providers must be knowledgeable about legal regulations and aspects of consent and confidentiality in their province, especially when dealing with adolescents with chronic conditions.
- Physicians must be informed about organizations that can provide support to adolescents and their families. They must also facilitate the adolescents' and their families' access to needed services in the community.
- Physicians must foster broader community responsibility for the chronically ill and be community educators and advocates.

CONCLUSION

For physicians, caring for adolescents with chronic conditions and special health care needs can be interesting and rewarding. Physicians have more impact on their progression into adulthood than on patients seen less frequently and in less intense situations. The opportunity to have an effect on the life of these adolescents is invaluable, as are the lessons we learn from them.

APPENDIX RESOURCES FOR YOUTH AND PARENTS

- Canadian Paediatric Society: <www.cps.ca>, <www.caringforkids.cps.ca>
 - Kaufman M. *Easy for You to Say*. Toronto: Key Porter Books, 1995.
 - The Canadian Health Network: <www.canadian-health-network.ca/customtools/homee.html>
 - Ability OnLine: <www.ablelink.org/public/default.htm>
 - The McCreary Centre Society – Youth Health Resources: <www.mcs.bc.ca/>
 - Health Care Transitions: <<http://hctransitions.ichp.edu/>>
 - National Dissemination Center for Children with Disabilities: <www.nichcy.org>
 - The Society for Adolescent Medicine: <www.adolescenthealth.org/>
 - The Disability Resources Monthly Guide to Disability Resources on the Internet: <www.disabilityresources.org/index.html>
 - National Center for women with disabilities: <www.4women.gov/wwd>
 - Adolescent Health Transition Project: <<http://depts.washington.edu/healthtr/>>
 - Healthy & Ready to Work National Center: <www.hrtw.org>
 - Institute for Child Health Policy: <www.ichp.edu/>
 - SIECCAN – Sex Information and Education Council of Canada: <www.sieccan.org/>
-

REFERENCES

1. Coupey SM, Neinstein LS, Aelter LK. Chronic illness in the adolescent. In: Neinstein LS, ed. *Adolescent Health Care: A Practical Guide*. 4th edn. Philadelphia: Lippincott Williams & Wilkins, 2002:1511-2.
2. Blum RW. Overview of transition issues for youth with disabilities. *Pediatrician* 1991;18:101-4.
3. Gortmaker SL, Sappenfield W. Chronic childhood disorders: Prevalence and impact. *Pediatr Clin North Am* 1984;31:3-18.
4. van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. *Arch Pediatr Adolesc Med* 2004;158:884-90.
5. Peterson PM, Rauen KK, Brown J, Cole J. Spina bifida: The transition into adulthood begins in infancy. *Rehabil Nurs* 1994;19:229-38.
6. Goldenring JM, Rosen DS. Getting into adolescent heads: An essential update. *Contemporary Pediatrics* 2004;21:64-90.
7. McCreary Centre Society. *Adolescent Health Survey: Chronic illness and disability among youth in British Columbia*. Vancouver: McCreary Centre Society, 1994:15.
8. Nelson RP. Access to health care for adolescents and young adults with disabilities. *Adolesc Med* 1994;5:233-40.
9. Greydanus DE, Rimsza ME, Newhouse PA. Adolescent sexuality and disability. *Adolesc Med* 2002;13:223-47.
10. McCreary Centre Society. *Adolescent Health Survey I & II: Listening to BC Youth*. Vancouver: McCreary Centre Society 1993, 2000.
11. Suris JC, Resnick MD, Cassuto N, Blum RW. Sexual behavior of adolescents with chronic disease and disability. *J Adolesc Health* 1996;19:124-31.
12. Canadian Paediatric Society, Adolescent Medicine Committee. Sexual abuse of adolescents with chronic conditions. *Paediatr Child Health* 1997;2:212-3. <<http://www.cps.ca/english/statements/AM/am96-01.htm>> (Version current at December 9, 2005).

13. Boas SR, Falsetti D, Murphy TD, Orenstein DM. Validity of self-assessment of sexual maturation in adolescent male patients with cystic fibrosis. *J Adolesc Health* 1995;17:42-5.
14. Sawyer SM, Phelan PD, Bowes G. Reproductive health in young women with cystic fibrosis: Knowledge, behavior and attitudes. *J Adolesc Health* 1995;17:46-50.
15. Taniguchi MH, Schlosser GA. Adolescent spinal cord injury: Considerations for post-acute management. *Adolesc Med* 1994;5:327-44.
16. Quint EH. Gynecological health care for adolescents with developmental disabilities. *Adolesc Med* 1999;10:221-9, vi.
17. Bradshaw KD, Elkins TE, Quint EH. The patient with mental retardation: Issues in gynecologic care. Raritan: Ortho-McNeil, 1996.
18. Canadian Paediatric Society, Adolescent Health Committee. Age limits and adolescents. *Paediatr Child Health* 2003;8:577. <<http://www.cps.ca/english/statements/am/ah03-02.htm>> (Version current at December 9, 2005).
19. Canadian Paediatric Society, Adolescent Medicine Committee. Office practice guidelines for the care of adolescents. *Can J Paediatr* 1994;1:121-3. <<http://www.cps.ca/english/statements/AM/am94-04.htm>> (Version current at December 9, 2005).
20. Blum RW. Summary of conference recommendations. *J Adolesc Health* 1995;17:6-9.
21. Morton WJ, Westwood M. Informed consent in children and adolescents. *Paediatr Child Health* 1997;2:329-33.
22. Canadian Medical Association. Bioethics for Clinicians. <www.cmaj.ca/misc/bioethics_e.shtml>. (Version current at December 9, 2005).
23. National Center for Youth with Disabilities. Transition program from child to adult health care services: A national survey, 1996. Minneapolis: National Center for Youth with Disabilities, 1996.
24. Council of University Teaching Hospitals. COUTH report: The role of Vancouver hospitals in meeting youth needs. Vancouver: Council of University Teaching Hospitals, 1995.
25. Paone M. Setting the Trac: A resource for health care providers. Vancouver: Children's & Women's Health Centre of British Columbia, 2000.
26. Paone MC, Whitehouse S, Stanford D. The challenges of transition: Coping with a chronic condition. *Br Columbia Med J* 1998;40:73-5.

ADOLESCENT HEALTH COMMITTEE (2004-2005)

Members: Drs Sheri M Findlay, McMaster Children's Hospital – Hamilton Health Sciences Centre, Hamilton, Ontario; Jean-Yves Frappier, Hôpital Sainte-Justine, Montréal, Québec (chair); Eudice Goldberg, The Hospital for Sick Children, Toronto, Ontario; Jorge Pinzon, BC's Children's Hospital, Vancouver, British Columbia; Koravangattu Sankaran, Royal University Hospital, Saskatoon, Saskatchewan (board representative); Danielle Taddeo, Hôpital Sainte-Justine, Montréal, Québec

Liaison: Dr Karen Mary Leslie, The Hospital for Sick Children, Toronto, Ontario (Adolescent Health Section, Canadian Paediatric Society)

Principal authors: Drs Jorge Pinzon, BC's Children's Hospital, Vancouver, British Columbia; Johanne Harvey, Clinique de pédiatrie, Chicoutimi, Québec

The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate. Internet addresses are current at time of publication.