



The Adolescent With a Chronic Illness

How to manage treatment issues and provide specialized services in this population

James J. Burns, MD; Matthew Sadof, MD; and Depak Kamat, MD, PhD

The busy clinician often is confronted with the daunting task of providing primary care for chronically ill adolescents. Providing effective service to these patients requires an understanding of the developmental process of adolescence, as well as the unique medical aspects of the particular disease. Advances in medicine and surgery have increased the number of children with chronic illnesses who are surviving into their teens and adulthood. For the adolescent with chronic illness, there are simultaneous issues including development of independence from parents, decision making around risk-taking behaviors, identity formation, and dealing with the physical and psychological effects of the disease and medication side effects. This article provides a general overview of how to approach this clinical challenge.

DEFINITION AND PREVALENCE OF CHRONIC ILLNESS

Stein et al.¹ propose a definition of “chronic illness” in which the patient is required to have

at least one problem for 12 months’ duration in any one of three spheres: functional limitations, dependence on compensatory mechanisms (eg, medications, special diets, equipment), or service use beyond routine care (eg, physical therapy, special educational arrangements). Applying this definition to 30,032 children and adolescents up to age 17, Stein identified 14.8% (18.4% of adolescents older than 12) with a chronic condition. A convenient parent-report measurement tool titled the Questionnaire for Identifying Children with Chronic Conditions – Revised (QuICCC-R) was developed from this research and is available for clinical use.²

Some common chronic diseases that are seen in outpatient settings include allergic rhinitis, dermatologic conditions, mental health problems, headaches, asthma, cerebral palsy, diabetes, Down syndrome, malignancies, cystic fibrosis, inflammatory bowel disease, epilepsy, HIV/AIDS, sickle cell disease, juvenile rheumatoid arthritis, developmental disorders, and congenital heart disease.³

Dr. Burns is associate professor, Pediatrics, Tufts University School of Medicine, Baystate Children's Hospital, Springfield, MA. Dr. Sadof is assistant professor, Pediatrics, Tufts University School of Medicine, Baystate Children's Hospital. Dr. Kamat is professor of pediatrics, vice chair of education, and Director, Institute of Medical Education, The Carman and Ann Adams Department of Pediatrics, Children's Hospital of Michigan, Detroit, MI.

Address reprint requests to: James J. Burns, MD Baystate Children's Hospital, 140 High Street, Springfield, MA 01199; or e-mail james.burns@bhs.org.

SPECIFIC DISEASE ISSUES

The primary care clinician must take time to perform a comprehensive history and physical examination, consult with subspecialists, review disease-specific guidelines, and use standard evidence-based interventions. The clinician should know whether the illness is congenital, genetic, or acquired, the age of onset, the severity of presentation, the amount and effectiveness of therapy, the predictability of the symptoms, triggers that can cause disease flare-ups, and the expected long-term prognosis and potential complications.

It is also important to assess how the illness affects the general well-being of the patient, the visibility of the illness, how it limits mobility, whether it is painful, and whether it involves the central nervous system directly. For the teen with rare or genetic diseases, specialized online databases can provide useful information for the clinician. These include the National Organization for Rare Disorders (<http://www.rarediseases.org>) and Online Mendelian Inheritance in Man (<http://www.ncbi.nlm.nih.gov>).

Continuity of Care

One of most important roles for the primary care clinician is to develop a therapeutic longitudinal relationship with the teen who has chronic disease. Knowing and connecting with the adolescent as a unique person in the greater context of family, school, and community yields significant benefits for the clinician. This continuity allows for the detection of subtle changes early on, prompting timely interventions.

The assessment of the teen with chronic illness needs to go beyond specific disease management to include a psychosocial evaluation and a review of the effects



Adolescents with chronic illness generally have 3 to 4 times higher rates of mental health disorders than their healthy peers, but the vast majority cope well and show amazing resilience.

of the condition on the process of puberty and adolescence. Although there are hundreds of chronic diseases, each with its unique challenges, there are many common issues when working with adolescents who have chronic conditions.

Puberty and Adolescence

Suris and Viner⁴ describe a reciprocal relationship between chronic illness and puberty. Chronic illness can cause delayed puberty and, in some cases, eventual short stature. Conversely, the nutritional and metabolic demands of pubertal growth can lead to poor disease control. Puberty

also can affect the pharmacologic properties of medications.

The psychosocial process of adolescence generates many challenges, including identity development, formation of moral values, development of sexual orientation, separation from parents (emotionally, physically, and financially), development of lifelong relationships, and future career planning. Throughout adolescence, there are periods of risk taking, alternating feelings of invincibility and self-consciousness, concrete thinking, impulsivity, problems with body image, and peer group alliances.⁵

Chronic illness creates ironic juxtapositions that must be appreciated and managed. For example, teens with chronic illness may be more dependent on their parents at a time when they need

to become autonomous. Adolescents may both require parents' assistance and react negatively to their coddling. Because of this conflict and the constant reminder of their chronic illness, teens may feel different and less adequate when compared with healthy peers. The struggle to fit in can lead to concealment of the condition, risk-taking behaviors, or poor compliance with essential medications.⁶ The presence of chronic illness also may lead to isolation from peers, as can happen when a teen with epilepsy is not allowed to drive, an aspiring athlete is disqualified from sports, or a teen with a visible deformity such as an ostomy becomes too self-conscious to attend social events.⁷

Psychological Effects

Adolescents with chronic illness generally have 3 to 4 times higher rates of mental health disorders than their healthy peers, but the vast majority cope well and show amazing resilience.⁷⁻¹⁵ All teens with chronic illnesses should

be assessed for psychosocial problems and risk behaviors. The HEEADSS assessment, proposed by Goldenring and Rosen,¹⁶ and the American Medical Association's Guidelines for Adolescent Preventive Services (GAPS)¹⁷ are recommended as screening tools.

Home Issues

Like their healthy peers, adolescents with chronic illness need to be asked about their home life, including any specific issues with parents, divorce, domestic violence, homelessness, or parenting style. The burden of chronic illness on parents is significant. They often have to miss work to help the teen get to medical appointments or accompany him or her to procedures. This can limit career advancement, take a financial toll, and lead to social isolation.¹⁸ They must learn how to navigate the medical system and provide support to the teen. Some parents may become overprotective or conversely become distant.

There is evidence that family competence has a strong influence on the adolescent's adaptation to chronic illness. Patients with sickle cell disease had fewer internalizing and externalizing behaviors if family function was high.¹⁹ Family cohesion also is associated with more adaptive coping in patients with sickle cell.²⁰ In patients with cystic fibrosis, family members were found to provide more tangible support than friends, while parental nagging was correlated with poor adjustment.²¹

Siblings of chronically ill adolescents can have significant distress, with reports that 50% experience psychological problems. They may feel resentment and abandonment because of the family's focus on the ill sibling.¹² Conversely, they also may be a source of strength and companionship for the sibling, acting as a "co-therapists."²²

It is important to give control to adolescents for at least some of the decisions on disease management.¹⁴ This becomes

more essential during the transition to adulthood and if end-of-life decisions need to be faced. Loss of autonomy, due to needless parental restrictions placed on the teen with chronic illness, has been proposed to be a preventable cause of depression.²³

On a positive note, there is some evidence that the stress of chronic illness can make a family closer.²⁴ As time progresses, most families become adapted and show significant resourcefulness.¹⁸

Education

All teens should be asked specifically about their grades, whether they have been suspended, required to repeat a grade, or needed special education. There is evidence in the literature that adolescents with chronic illness do not fare well academically. Forty-five percent of adolescents with chronic illness report falling behind in school, leading them to dislike school,²⁵ with 35% having failing grades.²⁶

Treatments for chronic illnesses can interfere with learning. Side effects from medications such as steroids and sedatives can affect emotional and cognitive function. In addition, disease-specific problems such as poor oxygenation, sensory deficits, and pain may undermine academic performance.²⁷

Sometimes, adolescents may wish to conceal chronic illness. This can lead to misunderstandings with teachers and peers when they avoid certain activities, or worse, may leave school authorities in the dangerous situation of being unaware of the condition when a medical crisis occurs.²²

A review by Thies²⁷ found absenteeism among adolescents with chronic illnesses is a major issue; 58% of students with chronic conditions miss school routinely, and 10% miss more than one-quarter of the school year.²⁷ Asthma alone accounted for 24 million lost school days per year. Thies cites studies that indicate that the patterns of

absenteeism are not usually long blocks of time but rather frequent and sporadic short absences. Additionally, frequent visits to the nurse's office significantly reduced classroom time.

Eating Disorders

Adolescents with chronic illness have higher rates of unhealthy eating practices, including binge eating, purging, laxative abuse, and diuretic abuse.²⁸ This can be especially problematic for patients with diabetes.

Activities

All adolescents need to develop social skills, self-esteem, and physical fitness through appropriate activities. Adolescents with chronic illness may have a limited range of activities that are available to them. Despite this, they should avoid becoming isolated. It is important to assess what they do for fun. There is always something for even the most disabled teen, such as art or board games like chess. There is evidence that camps can increase the quality of life in teens with inflammatory bowel disease.²⁹ Experiences such as Special Olympics, Outward Bound,³⁰ and Boys and Girls Clubs could help teens find recreation and normal peer interaction.

Drugs, Alcohol, and Tobacco

Abuse of drugs, alcohol, and tobacco are major health hazards of healthy adolescents. The clinician should ask all adolescents about involvement with these health risk behaviors. There is evidence that adolescents with chronic illness have similar, and in some cases increased, risk for substance abuse when compared with healthy peers.^{31,32}

Sexuality

Clinicians should also inquire whether adolescents are sexually active and if they use condoms and contraception. There is evidence that teens with chronic disease have high rates of sexual activity and low

Useful Resources for Coordination of Care

- The **National Center of Medical Home Initiatives** (<http://www.medicalhomeinfo.org>) is an excellent resource for clinicians who wish to implement the medical home.
- **Title V programs** (<http://www.mchb.hrsa.gov/programs/default.htm>) support development of family-centered, community-based, coordinated systems of care, transportation, home visiting, and nutritional counseling.
- The **National Information Center for Children and Youth with Disabilities** (<http://www.nichcy.org>) compiles disability-related resources in each state.
- The **Utah Medical Home Collaborative** (<http://medhome.med.utah.edu>) provides tools and work sheets for clinicians and families.
- The **Massachusetts Department of Public Health** has created a “Directions” manual (with English and Spanish versions) to help parents organize their health records and locate resources for their child’s care (<http://www.mass.gov/dph/fch/directions>).

rates of contraceptive use.^{33,34} The consequences of sexually transmitted infections and pregnancy in this population make it especially important for clinicians to assess for unprotected sexual activity.

Depression and Suicide

Depression is a relatively common problem in adolescents, and suicide, which often is associated with depression, is a leading cause of adolescent death. Therefore, all teens should be screened for depression and the presence of suicidality. Adolescents with chronic diseases such as diabetes, inflammatory bowel disease, and asthma have higher rates of depression.¹¹ In addition, depression can exacerbate asthma: one study found depression was a significant risk factor for sudden death in children with asthma.³⁵

PROVIDING SERVICES FOR THE ADOLESCENT WITH A CHRONIC DISEASE

The care of the adolescent with chronic disease must take into account the developmental process of adolescence. It is important to communicate directly with the teen, rather than only with parents. Adolescents must be treated with respect, understanding, and encouragement, and without coercion.³⁶

Their feelings about prognosis should be addressed honestly and within the scope of the clinician’s expertise.

It is important to ask for input from the patient and family on difficult decisions. It is not appropriate to keep secrets or exclude information. Sometimes a piecemeal approach to information exchange is advisable to achieve optimal adjustment and prevent overwhelming the adolescent with negative information. Sometimes information has to be repeated many times before it is registered by the patient and family when denial is strong.

The teen with chronic illness, as with all teens, should be provided appropriate interventions based on the HEEADSS assessment. This should include contraceptive counseling, screening and therapy for sexually transmitted infections, treatment for depression, tobacco cessation, or alcohol and substance abuse counseling.

It is critically important that parents and siblings are supported and respected as important participants of the healthcare team. Offering psychological assistance through disease-specific support groups or mental health professionals is helpful. This becomes very important when end-of-life decisions have to be made.

Services are available to optimize

learning for teens with chronic conditions. Under the Individuals with Disabilities Education Act (IDEA), schools are required to provide eligible students “free, appropriate public education that emphasizes special education and related services designed to meet unique needs and prepare students for employment and independent living.”³⁷ Part B of IDEA ensures that eligible students receive this in the “least restrictive environment,” which means, whenever possible, in the same class as nondisabled students. For those in special education, there are individual education plans (IEP) that specify which services will be implemented. IEPs are required to specifically address transition to adulthood beginning at age 14, with specific services that prepare the youth for independence and employment starting at age 16. The teen has a right to participate in decisions made at IEP conferences.

Teens with disabilities not eligible for an IEP may be provided accommodations under Section 504 of the Rehabilitation Act of 1973.³⁸ Examples of these accommodations include use of assistive technology, special seating arrangements, wheelchair ramps, permission to type assignments instead of writing them by hand, or permission to hand in assignments late due to illness or hospitalization.

Although legally funded and reimbursed special education stops after age 22, the young adult with chronic disability can receive continued services under various programs. The Rehabilitation Act, the Americans with Disabilities Act, and Supplemental Security Income provide continued support for the disabled young adult in obtaining employment, workplace accommodations, and financial assistance.

COMPLIANCE

Clinicians can assess compliance by using several techniques, including direct but supportive questioning, biological assays such as medication levels, pill

counts, and even the new medication event monitoring system (MEMS), which records the number, date, and time of bottle openings. When asking the teen about compliance, it is important to be supportive and to avoid responding with frustration or disappointment when their performance is less than ideal.

Factors affecting compliance include intervention efficacy, side effects, severity of disease effects, organizational skills of the teen, rapport with the clinician, and financial cost of the intervention. Because adolescents may not have fully developed abstract cognition with future orientation and consequential thinking, it may be hard for them to comprehend the benefit of compliance. Additionally, the stigma of having to comply with conspicuous interventions, such as inhalers or orthopedic braces, may be too high a social cost for the teen to pay.²²

Providing written instructions, reminder systems, and behavioral techniques with specific, clearly defined goals and a reward system can help improve compliance. Giving the adolescent some autonomy in the process of self-management is important. Cognitive-behavior therapy and systematic desensitization can be helpful in coping with painful interventions.³⁹

COORDINATION OF CARE

The primary care clinician can help ensure coordination of services and monitor for compliance with prescriptions. This entails communicating with the multiple subspecialists these teens often need. Pain management is another challenging issue for the adolescent who is chronically ill and should be a very high priority for the clinician. Also, these patients frequently are prescribed several medications, requiring regular reviews to discover drug–drug interac-



Adolescents with chronic diseases such as diabetes, inflammatory bowel disease, and asthma have higher rates of depression.

tions and adverse effects.

As a guide for the primary care physician, the American Academy of Pediatrics has published a Medical Home Policy Statement that emphasizes the need for continuous, family-centered, culturally effective care.⁴⁰ The clinician should be aware of useful resources to aid in this endeavor (Sidebar 1, see page 210).

TRANSITION TO ADULT MEDICAL SERVICES

Early on, when a diagnosis is made of a chronic illness in a child, the primary care provider or specialist controls most of the medical decisions. As the family learns more about the illness, they can become “the expert” on the child’s condition. They know the peculiarity of an insulin regimen, the best way to break or prevent an asthma attack, or how to

manage the gastrostomy-tube feedings. Over time, there is a shift towards self-management as the teen becomes more capable and independent.

Clinicians should provide guidance and support as the adolescent with chronic illness prepares for transition into the adult medical system. In a review of nine studies of the transition process, age often was the sole criterion for transfer to adult settings, with preparation of the families and the patients late in the process. Questions about insurance coverage, unfamiliarity in a new setting, loss of a longstanding trusting relationship, and a lack of communication between adult and pediatric providers are factors

that may lead to anxiety and avoidance of planning.⁴¹

Starting at age 14, the clinician, parents, and teen should start developing a written plan for transition. This would include, for example, the creation of a portable medical record, a checklist of needed services, plans for insurance coverage, and identification of adult-oriented providers.⁴² Multiple conversations, instead of a one-time “transition talk,” offer families and patients the time they need to adjust to the planned changes.

Asking the teen to take a “conversational walk” through a typical day can help the teen and family anticipate environmental accommodations that the illness or disability requires. Questions about getting around the house can give insight into an adolescent’s ability to get out of bed, take medications, bathe, go to the toilet, dress, eat, and do housework. This can help identify the need for ramps, railings, wider doorways, special bathroom/kitchen adaptations, and mobility equipment, in addition to required medical devices. Questions relating to school may identify the need for transportation, assistive technology,

Management Issues to Consider When Treating the Adolescent With a Chronic Illness

Specific Disease Issues

- Comprehensive history and physical exam
- Disease-specific management guidelines
- Side effects/efficacy of interventions
- Complications
- Prognosis

Coordination of Care

- Continuity
- Consultations
- Community programs
- Communication
- Patient education

Effects of Adolescence and Puberty

- Disease effects on puberty; puberty effects on disease
- Effects on autonomy
- Contraindications to driving/sports
- Exercise
- Sexuality, contraceptives, condoms, STI screening
- Depression, suicidality
- Tobacco, alcohol, substance abuse

Coping Issues

- Parents
- Financial considerations
- Navigation of the medical system
- Family competence
- Siblings
- Disordered eating
- Depression and suicidality
- Behavior
- Support groups
- Mental health medications

School Issues

- School performance
- Cognitive deficits
- School days missed
- Special education
- Individual education plans
- 504 plans
- Employment and transition plans

Compliance

- History
- Drug levels
- Pill counts
- Written plan with reminders and rewards

Pain Issues

Transition to Adult Medical Services

- Self-management
- Activities of daily living (bathing, toilet, dressing, eating, housework)
- Transportation
- Housing and assistive technology needs.

Management Team

- Social worker
- Mental health professional
- Physical/occupational therapist
- Special education teacher
- School administrators
- Community programs
- Insurance carriers
- National support groups
- Camp counselors

or connection to community recreational programs. The adolescent and family may decide they need the help of home nursing or personal care assistants. In implementing a successful transition, it may be necessary to enlist the help of many resources, including nurses, social workers, mental health professionals, physical and occupational therapists, teachers, and national support groups.

SUMMARY

The primary care clinician can play an important role in enhancing the qual-

ity of life for the adolescent with chronic illness through developmentally appropriate, individualized and compassionate coordination of care (Sidebar 2). Special attention to the process of adolescence, family, and psychological issues are required for successful management. Transition of care to adult services should be planned carefully with a multidisciplinary team.

REFERENCES

- Stein R, Silver EJ. Operationalizing a conceptually based noncategorical definition: a first look at US children with chronic conditions. *Arch Pediatr Adolesc Med.* 1999;153(1):68-74.
- Stein RE, Silver EJ, Bauman LJ. Shortening the questionnaire for identifying children with chronic conditions: what is the consequence? *Pediatrics.* 2001;107(4):E61.
- Suris JC. Global trends of young people with chronic and disabling conditions. *J Adolesc Health.* 1995;17(1):17-22.
- Suris JC, Michaud PA, Viner R. The adolescent with a chronic condition. Part I: developmental issues. *Arch Dis Child.* 2004;89(10):938-942.
- Christie D, Viner R. Adolescent development. *BMJ.* 2005;330(7486):301-304.
- American Academy of Child and Adolescent Psychiatry. The child with a long-term illness. May 1999. Facts for Families No. 19. Available at: <http://www.aacap.org/publications/factsfam>

- /illness.htm. Accessed January 26, 2006.
7. King RA. Pediatric inflammatory bowel disease. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):537-550.
 8. Lewis M, Vitulano LA. Biopsychosocial issues and risk factors in the family when the child has a chronic illness. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):389-399, v.
 9. Forsyth BW. Psychological aspects of HIV infection in children. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):423-437.
 10. Szydlo D, Wattum P, Woolston J. Psychological aspects of diabetes mellitus. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):439-458, vi.
 11. Mrazek DA. Psychiatric symptoms in patients with asthma causality, comorbidity, or shared genetic etiology. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):459-471.
 12. Apter A, Farbstein I, Yaniv I. Psychiatric aspects of pediatric cancer. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):473-492, vii.
 13. Franks RP. Psychiatric issues of childhood seizure disorders. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):551-565.
 14. Casey R, Brown R. Psychological aspects of hematologic diseases. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):567-584.
 15. Vitulano LA. Psychosocial issues for children and adolescents with chronic illness: self-esteem, school functioning and sports participation. *Child Adolesc Psychiatr Clin N Am.* 2003;12(3):585-592.
 16. Goldenring JM, Rosen D. Getting into adolescent heads: an essential update. *Contemp Pediatr.* 2004;21(1):64-90.
 17. Elster AB, Kuznets N. *Guidelines for Adolescent Preventive Services.* Baltimore, MD: Williams and Wilkins; 1994.
 18. LeBlanc LA, Goldsmith T, Patel DR. Behavioral aspects of chronic illness in children and adolescents. *Pediatr Clin North Am.* 2003;50(4):859-878.
 19. Kell RS, Kliwer W, Erickson MT, Ohene-Frempong K. Psychological adjustment of adolescents with sickle cell disease: relations with demographic, medical, and family competence variables. *J Pediatr Psychol.* 1998;23(5):301-312.
 20. Hurtig A, Park K. Adjustment and coping in adolescents with sickle cell disease. *Ann N Y Acad Sci.* 1989;565:172-182.
 21. Graetz BW, Shute RH, Sawyer MG. An Australian study of adolescents with cystic fibrosis: perceived supportive and nonsupportive behaviors from families and friends and psychological adjustment. *J Adolesc Health.* 2000;26(1):64-69.
 22. Michaud PA, Suris JC, Viner R. The adolescent with a chronic condition. Part II: healthcare provision. *Arch Dis Child.* 2004;89(10):943-949.
 23. Boice MM. Chronic illness in adolescence. *Adolescence.* 1998;33(132):927-939.
 24. Eiser C. *Growing Up With a Chronic Disease: The Impact on Children and Their Families.* London, England: Kingsley; 1993.
 25. Lynch EW, Lewis RB, Murphy DS. Educational services for children with chronic illnesses: perspectives of educators and families. *Excep Child.* 1992;59:210-20.
 26. Valdes K, Williamson C, Wanger M. The National Longitudinal Transition Study (NLTS) of Special Education Students. Statistical Almanac, Volume 9, Youth Categorized as Other Health Impaired. Washington, DC: US Department of Education; 1990.
 27. Thies KM. Identifying the educational implications of chronic illness in school children. *J Sch Health.* 1999;69(10):392-397.
 28. Neumark-Sztainer D, Story M, Resnick MD, Garwick A, Blum RW. Body dissatisfaction and unhealthy weight-control practices among adolescents with and without chronic illness: a population-based study. *Arch Pediatr Adolesc Med.* 1995;149(12):1330-1335.
 29. Shepanski MA, Hurd LB, Culton K, et al. Health-related quality of life improves in children and adolescents with inflammatory bowel disease after attending a camp sponsored by the Crohn's and Colitis Foundation of America. *Inflamm Bowel Dis.* 2005;11(2):164-170.
 30. Kessell M, Resnick MD, Blum RW. Adventure, Etc. – a health-promotion program for chronically ill and disabled youth. *J Adolesc Health Care.* 1985;6(6):433-8.
 31. Miauton L, Narring F, Michaud PA. Chronic illness, life style and emotional health in adolescence: results of a cross-sectional survey on the health of 15-20-year-olds in Switzerland. *Eur J Pediatr.* 2003;162(10):682-689.
 32. Alderman EM, Lauby JL, Coupey SM. Problem behaviors in inner-city adolescents with chronic illness. *J Dev Behav Pediatr.* 1995;16(5):339-344.
 33. Valencia LS, Cromer BA. Sexual activity and other high-risk behaviors in adolescents with chronic illness: a review. *J Pediatr Adolesc Gynecol.* 2000;13(2):53-64.
 34. Choquet M, Du Pasquier FL, Manfredi R. Sexual behavior among adolescents reporting chronic conditions: a French national survey. *J Adolesc Health.* 1997;20(1):62-67.
 35. Strunk RC, Mrazek DA, Fuhrmann GS, LaBrecque JF. Physiologic and psychological characteristics associated with deaths due to asthma in childhood. A case-controlled study. *JAMA.* 1985;254(9):1193-1198.
 36. Woodgate RL. Adolescents' perspectives of chronic illness: "it's hard." *J Pediatr Nurs.* 1998;13(4):210-223.
 37. IDEA 2004 Resources. US Department of Education. October 6, 2005. Available at: <http://www.ed.gov/policy/speced/guid/idea/idea2004.html>. Accessed February 14, 2006.
 38. *Protecting Students With Disabilities: Frequently Asked Questions About Section 504 and the Education of Children With Disabilities.* US Department of Education Office for Civil Rights. March 4, 2005. Available at: <http://www.ed.gov/about/offices/list/ocr/504faq.html>. Accessed February 1, 2006.
 39. Fielding D, Duff A. Compliance with treatment protocols: interventions for children with chronic illness. *Arch Dis Child.* 1999;80(2):196-200.
 40. Medical Home Initiatives for Children With Special Needs Project Advisory Committee. American Academy of Pediatrics. The medical home. *Pediatrics.* 2002;110(1 Pt 1):184-186.
 41. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics.* 2005;115(1):112-120.
 42. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians – American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics.* 2002;110(6 Pt 2):1304-1306.