

CHRONIC PHYSICAL ILLNESSES: PREVENTION AND SERVICES

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CHRONIC PHYSICAL ILLNESSES: PREVENTION AND SERVICES

Introduction

Despite the common perception that U.S. adolescents are among the healthiest of Americans, evidence from a variety of sources discussed below indicates that many adolescents experience acute or chronic conditions that adversely affect their lives (see definitions in box 6-A). Acute conditions experienced by adolescents include injuries (e.g., sprains, lacerations, and fractures)¹ and illnesses ranging from colds and influenza to appendicitis. Chronic conditions include a wide spectrum of physical and mental health problems (e.g., hay fever, acne, cancer, diabetes, cardiovascular disease, epilepsy, orthopedic impairments due to injury, hearing impairments, visual impairments, emotional problems, and mental retardation). Nevertheless, in the 1988 National Health Interview Survey (NHIS) conducted by the U.S. Department of Health and Human Services (DHHS), 97.1 percent of 10- to 18-year-olds were reported to be in good to excellent health (105). NHIS data generally reflect parents' perceptions of adolescents health status,² but other evidence suggests that, for the most part, adolescents also regard themselves as healthy.³

This chapter raises some important issues related to the prevention and treatment of chronic physical health problems among U.S. adolescents.⁴ First, it provides background on physical health problems of adolescents using a variety of data. Next it provides an overview of chronic physical illnesses and disabilities among adolescents and discusses the

prevention and treatment of such problems. The chapter includes an in-depth discussion of cancer and of two physical health problems whose importance to adolescents is sometimes overlooked by parents, health care providers, and policymakers: acne and dysmenorrhea (painful menstruation). Finally, the chapter reviews major Federal programs pertaining to chronic physical illness and disability.

It is important to emphasize that this chapter is not designed to be a comprehensive assessment of all chronic physical health problems affecting adolescents. Rather, this chapter is intended to stimulate further discussion of issues such as how to assess the physical health status of adolescents; how to prevent and treat adolescents' chronic physical health problems; and what role the Federal Government can play in addressing the needs of adolescents with physical health problems. Other chapters in this volume cover a variety of specific adolescent physical health topics.⁵ Chronic physical illnesses that affect adolescents and merit policy analysis but are not covered in depth in this chapter include asthma, diabetes, hypertension, chronic renal disease, seizures, and visual and hearing impairments (14, 22, 78).

It is also important to note that this chapter does not cover generic issues related to the delivery of health care services to adolescents. The delivery of primary and comprehensive care to adolescents, adolescents' health insurance status and financial

¹Injuries are harms or hurts inflicted to the body by an external force (16a). Information on injuries among U.S. adolescents is presented in ch. 5, "Accidental Injuries: Prevention and Services," in this volume.

²NHIS has a number of limitations. As a household survey of a sample of the civilian noninstitutionalized population, it does not include individuals who are homeless or in institutions such as nursing homes or hospitals. For individuals under age 17, information is collected from a proxy, usually a parent or guardian. Older adolescents, 17- and 18-year-olds, may respond for themselves (105).

³A survey of Minnesota youth found, for example, that 91.4 percent of males and 85.9 percent of females believed that their health status was good to excellent (88).

⁴Following current mainstream usage, although not without occasional difficulty and ambiguity, this chapter defines *physical health problem* as problems "of or related to the body, and having material existence" and defines *mental health problems* as problems "pertaining to the mind." Information on mental health problems in adolescents is presented in ch. 11, "Mental Health Problems: Prevention and Services," in this volume. Some mental health problems have a physical basis, so the distinction between physical and mental health problems is somewhat arbitrary.

⁵For example, the prevalence, consequences, prevention, and short-term treatment of **accidental injuries** are covered in this volume in ch. 5, "Accidental Injuries: Prevention and Services"; **nutrition and fitness problems**, in ch. 7, "Nutrition and Fitness Problems: Prevention and Services"; **dental problems**, in ch. 8, "Dental and Oral Health Problems: Prevention and Services"; **AIDS and other sexually transmitted diseases**, in ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services."

Box 6-A—Examples of Definitions of Chronic Illness and Disability

The literature on chronic illness and disability—for adolescents and for individuals of all ages—contains a wide array of definitions. Although some of the differences cannot be resolved in this chapter, several definitions are provided below as a guide to OTA’s approach to assessing the prevalence and consequences of chronic illness and disability among adolescents.

For the purpose of the National Health Interview Survey (NHIS) conducted by the National Center for Health Statistics in the U.S. Department of Health and Human Services (DHHS), a **health condition** is a departure from a state of physical or mental well-being (104). A condition may be either an illness, an injury, or an impairment (see below). A condition is considered *acute* if it has lasted 3 months and is of sufficient consequence to have involved either a physician visit or at least 1 day of restricted activity; a condition is considered *chronic* if it has lasted 3 months or more or is a type of condition that normally lasts for at least 3 months (e.g., asthma, diabetes, heart conditions) (105).

NHIS defines a **disability as any** temporary or long-term reduction of a person’s activity as a result of an acute or chronic condition (104). Disabilities are sometimes caused by illnesses (e.g., spina bifida, cerebral palsy, severe asthma) and sometimes caused by injuries or impairments. In NHIS, an **impairment is** a chronic or permanent defect, usually static in nature, that results from disease, injury, or congenital malformation (107a).

NHIS measures disability in several ways. One way is in terms of the number of “disability days,” or days that a person’s activity has been reduced. NHIS identifies several types of disability days. “Restricted-activity days” (the most inclusive and least descriptive measure) are any days on which a person restricts his or her usual activities for more than half the day because of illness or injury. NHIS measures four types of restricted-activity days: bed-disability days, work-loss days, school-loss days, and cutdown days. “School-loss days” are a type of restricted-activity day determined only for children ages 5 through 17; basically these days are any days on which a child did not attend school for at least half the day because of illness or injury.

NHIS also measures disability in terms of “limitation of activity due to chronic conditions” (107a). A limitation of activity refers to a long-term reduction in a person’s capacity to perform the average kind or amount of activities associated with his or her age group. Individuals identified as having a chronic condition by NHIS are classified into categories that reflect the extent to which their activities are limited because of the conditions as follows: 1) unable to carry on the major activity for their age group (for children 5 to 17, major activity refers to school attendance; for individuals age 18 and over, it usually refers to a job, housework, or school attendance);

access to health services, consent and confidentiality issues affecting adolescents, and issues specific to the delivery of services to selected groups of adolescents (e.g., black, Hispanic, Asian-American, American Indian and Alaska Native, Native Hawaiian, rural, and poor adolescents) are topics addressed in Volume III of this Report.

Background on Physical Health Problems of Adolescents

There is no single comprehensive source of information about the physical health status of U.S. adolescents. Hence, a variety of sources must be used to identify the most important physical health problems facing adolescents. As noted in box 6-B, data available from the National Center for Health Statistics in DHHS include vital statistics data that provide information on causes of death for adolescents; data on reasons for visits to physicians’

offices and for hospitalizations; data from household interview surveys that gather information on health problems, including those that result in limitations in activity; and data from epidemiologic surveys that include clinical examinations. Physical health concerns of particular importance to adolescents may be identified through surveys of young people that ask directly about their most pressing health concerns. Data from all of these sources are presented below to identify important health problems for U.S. adolescents.

Physical Causes of Death

As noted in box 6-B, national mortality data are compiled from State death certificates by the National Center for Health Statistics in DHHS on an ongoing basis. National mortality statistics include information on the cause of death and demographic

2) able to perform *the* basic activity but limited in the amount or kind of major activity performed; 3) not limited in major activity but limited in the kind or amount of other activities; and 4) not limited in activity.

OTA has sometimes broadly defined a chronic condition as a problem or disease that is lingering and lasting, as opposed to acute. In its 1982 report *Technology and Handicapped People*, OTA defined **disability** as a functional limitation, noting that a person with a disability has a “limited ability or an inability to perform one or more basic [daily] life functions (e.g., walking) at a level considered ‘typical’ “ (92). Disabilities are often caused by impairments (92). According to OTA, an **impairment is a** physiological, anatomical, or mental loss or “abnormality” caused by accident, disease, or congenital condition (92). Visual impairments, for example, may limit the ability to see. A **handicap**, according to OTA, has to be defined within its environmental and personal contexts (92). Individuals are handicapped by their disability if it prevents them from performing one or more life functions at a “typical” level (92). “Handicaps are caused not by the disabilities themselves, but by the interaction between an individual’s disability and the social environments in which the individual is functioning or expected to function” (92). Thus, an adolescent with poor vision has an impairment which reduces her ability to see (a disability). However, if corrective lenses can adequately correct her vision or if she can communicate effectively through the use of oral interpreters and braille, the visual impairment may not prevent the adolescent from performing in school, at home, or socially (i.e., it may not become a handicap).

In this chapter, **chronic illnesses** are defined as diseases that persist over a long period of time. According to a current medical dictionary, **a disease** is “any deviation from or interruption of the normal structure or function of any part, organ, or system, or combination thereof, of the body that is manifested by a characteristic set of symptoms and signs and whose etiology, pathology, and prognosis may be known or unknown” (16a).¹ **Disabilities** refer to limitations, usually long-term, in an individual’s ability to perform basic activities of daily living. Mainstream distinctions between **physical** and **mental conditions** are adhered to in this Report, so that physical is generally defined as being “of or related to the body, and having material existence,” whereas mental is defined as “pertaining to the mind.” Some mental health problems have at least some biological component so the distinction between physical and mental health problems is rather arbitrary.²

¹Diseases are sometimes distinguished from *injuries*, which have been defined as “harms or hurts inflicted to the body by an external force” (16a). Information on injuries among U.S. adolescents is presented in ch. 5, “Accidental Injuries: Prevention and Services,” in this volume.

²Information on selected mental health problems that affect U.S. adolescents is presented in ch. 11, “Mental Health Problems: prevention and Services,” in this volume.

characteristics of the decedent. Recent mortality statistics indicate that the most frequent *natural cause* of death among U.S. adolescents ages 10 to 19⁶ is cancer.⁷

Reasons for Hospitalizations

The National Hospital Discharge Survey (NHDS), a survey sponsored by the National Center for Health Statistics, provides information on hospital discharges from a sample of short-stay non-Federal

hospitals in the United States (see box 6-B). According to the 1987 NHDS, injury and poisoning are the problems that most frequently lead to hospitalization for U.S. males and females ages 10 to 18. Childbirth is the most frequent reason for hospitalization for U.S. females ages 15 to 18.⁸ The types of physical illnesses that most frequently lead to hospitalization for U.S. males and females ages 10 to 18 are diseases of the respiratory system and diseases of the digestive system (see table 6-1).

⁶To the extent possible, this OTA Report focuses on adolescents ages 10 through 18. It also attempts, whenever possible, to present evidence for smaller age groupings of adolescents (e.g., 10- to 14- and 15- to 18-year-olds). Sometimes, however, data were not readily available for these age groupings, and OTA used other age breaks. As a prominent example, the National Center for Health Statistics typically makes mortality data available at 5-year age breaks; thus, this section reports on information for 10- to 14-year-olds and 15- to 19-year+ Ms.

⁷Natural causes of death refer to causes such as illness, disease, or chronic conditions as opposed to external causes of death such as accidental injuries, homicide, or suicide. As shown in figure 5-1 in ch. 5, “Accidental Injuries: Prevention and Services,” more adolescents die from external causes than from natural causes. These other problems are covered in other chapters of the Report. Age differences in causes of death in the U.S. population are covered in Vol. I of this Report.

⁸See ch. 10, “Pregnancy and Parenting: Prevention and Services,” in this volume for a discussion of the physical and other consequences of childbearing among U.S. adolescents.

Box 6-B—Federal Sources of Data on the Physical Health of U.S. Adolescents

National Center for Health Statistics

The National Center for Health Statistics (NCHS) of the U.S. Department of Health and Human Services (DHHS) is the primary Federal source of data on the physical health of U.S. adolescents. Through the National Vital Statistics System, NCHS collects and publishes data on births, deaths, marriages, and divorces in the United States (104). In addition, NCHS collects and publishes data from ongoing and special surveys such as the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, the National Health Interview Survey, the National Health Examination Survey, the National Health and Nutrition Examination Survey, and the National Survey of Family Growth. Some of these surveys are described below.

National Hospital Discharge Survey (NHDS)

NHDS is a continuing nationwide sample survey that gathers information each year on patients (excluding newborn infants) discharged from a sample of non-Federal short-stay and specialty hospitals located in the 50 States and the District of Columbia (108). The information collected includes data on personal information about the patient (e.g., birth date, race, sex, marital status), administrative information (e.g., dates of admission and discharge), and medical information (e.g., diagnosis and medical procedures performed). To be included in the sample, hospitals must have a minimum of six beds for patient use and average patient stays of less than 30 days.

Limitations—Relatively few adolescents are hospitalized each year. Because NHDS does not oversample for adolescents, the number of adolescents sampled in the survey is small. Consequently, NHDS does not provide reliable information on the incidence of hospitalization among adolescents for any but the most frequent reasons for hospitalization and does not allow for finer breakdowns such as by race, gender, or socioeconomic status. In addition, data are not reported using appropriate age breaks for adolescents.

National Ambulatory Medical Care Survey (NAMCS)

NAMCS is a continuing national probability sample survey of ambulatory medical encounters. It collects data on physician-patient encounters in the offices of a sample of non-federally employed physicians classified as “office-based, patient care physicians. Sample physicians are asked to complete a patient record information form for a systematic random sample of office visits occurring during a randomly assigned 1-week reporting period. Approximately 3,500 physicians provided data in 1985 (the last year for which data are available), submitting 71,594 patient record forms for patients of all ages. These data are used to develop estimates of the use of office-based visits by the U.S. population. Data are collected on patient characteristics (e.g., birth date, sex, race, ethnicity) and medical information (e.g., diagnostic services performed, diagnosis, reason for visit, medication provided or prescribed, and disposition of visit). Additional data are collected on the expected source of payment, referral status of the patient, and characteristics of the provider (e.g., specialty).

Limitations—NAMCS does not collect data on visits to hospital-based physicians. In addition, because there is no stratification of the sample on race or ethnicity and the sample sizes are quite small for racial and ethnic minorities, NAMCS does not present reliable information on office visits made by minority adolescents. The survey also includes information only on those individuals who seek care. Thus, adolescents who do not seek care for medical problems, or who use alternative sources of care, are not included in the survey. These adolescents may disproportionately include poor adolescents or those of nonwhite racial or ethnic backgrounds.

National Health Interview Survey (NHIS)

NHIS is a continuing nationwide survey of households (105,106). Data are collected from a probability sample of the civilian noninstitutionalized population residing in the United States on personal and demographic characteristics, restricted-activity days due to acute and chronic conditions, injuries, activity limitations due to chronic health conditions, and use of medical services. In 1988, 47,485 households, representing 122,310 persons, were sampled; 94.9 percent of these households were surveyed. The 1988 NHIS included a special focus

¹**The strengths and limitations of Federal data on U.S. adolescents’** accidental injuries nutrition and fitness problems; dental and oral health; cases of ArDs and sex* transmitted diseases; pregnancy; mental health problems; alcohol, tobacco, and drug abuse problems; delinquency; and hopelessness are discussed in the relevant chapters of this volume. Also see ch. 18, “Issues in the Delivery of Health and Related Services to Selected Groups of Adolescents,” in Vol. III of this Report and app. C, “Issues Related to the Lack of Information About Adolescent Health and Health and Related Services,” in Vol. I of this Report.

on the health status of children and adolescents. Since 1985, the survey has oversampled black persons in order to increase the precision of estimates for this population. Data have been collected continuously since 1957.

Limitations—The NHIS sample does not include homeless persons, persons residing in institutions, or members of the armed services. Proxy interviews are generally used for all persons under age 17. Because the adults interviewed may be unaware of, or be reluctant to report, certain health problems or use of health services of adolescents, this information may not reflect the true health status of and utilization of services by adolescents in the household. The NHIS adolescent sample is too small to provide adequate measures of low prevalence physical conditions. Data are generally not reported using age groupings appropriate to describe adolescents.

National Health Examination Survey (NHES) and the National Health and Nutrition Examination Survey (NHANES)

National clinical epidemiological information on the health status of today's U.S. adolescents is not available. There are no recent national population surveys that provide clinical data about the health status of adolescents. One of the most comprehensive sources of national clinical epidemiological data on adolescents was NHES (94). The third cycle of this survey, which was conducted from 1966 to 1970, gathered information through interviews and physical examinations on the health status of a representative national sample of 6,768 adolescents ages 12 to 17. However, because this information is now over 20 years old, it is difficult to generalize to today's adolescents. There are likely to be many similarities in the health status of adolescents today and those of 20 years ago, but there may be significant differences as well.

NHANES was initiated as a successor to NHES in 1971 but has not yet collected comparable information on the health of U.S. adolescents. To measure the health status and characteristics of a sample of the civilian noninstitutionalized population of the United States, ages 1 to 74, NHANES uses interviews and, for a subsample, clinical examinations. NHANES I took place from 1971 to 1974, with a subsample of persons ages 25 to 74 selected for in-depth examinations. NHANES II began in 1976 and ended in 1980; this study oversampled persons 6 months to 5 years of age and those ages 60 to 74 (96,104). NHANES III is underway and has child health as a special focus (99). However, the adolescent sample in NHANES III will be small in comparison to the 1966-1970 NHES sample, and although blacks and Mexican Americans are being oversampled generally, the numbers of such adolescents included in NHANES III will be small. A total of 3,200 adolescents ages 12 to 19 will be included in the survey, including 1,120 black adolescents, 1,120 Mexican-American adolescents, and 980 white and other adolescents (17). Data collection for NHANES III is not expected to be completed until 1994. Thus, at this time, there is no good source of national clinical epidemiological information on the health status of today's adolescents.

Other Federal Agencies

Although NCHS is the primary source of national data on the physical health of U.S. adolescents, other DHHS agencies also collect and publish such data (104). The National Cancer Institute within the National Institutes of Health, for example, collects data from 11 population-based registries on people diagnosed with cancer through its Surveillance, Epidemiology, and End Results Program. That program is described below.

Surveillance, Epidemiology, and End Results (SEER) Program of Data Collection on Cancer

The SEER program provides information about the incidence of and the mortality due to malignant neoplasms in the United States (all ages included). Incidence data are based on information collected from a sample of 12 sites in the United States, plus one in Puerto Rico, representing approximately 13 percent of the total U.S. population. Participants in the program provide data annually to the SEER program. Mortality data are derived from mortality tapes obtained from NCHS, and include data on cancer mortality for the entire United States. The program began in 1972.

Limitations—SEER data are only limited if information is required on very specific cancers for smaller populations. In addition, although certain ethnic groups are oversampled (e.g., Japanese, Filipinos), small sample sizes make data on these groups somewhat unreliable.

Because relatively few U.S. adolescents are hospitalized each year for physical illnesses and thus few are represented in the NHDS sample, sample sizes for number of hospitalizations for most specific illnesses are too small to draw reliable conclu-

sions about the specific diseases for which adolescents are hospitalized. Nonetheless, a more detailed review of the leading causes of hospitalization for 10- to 18-year-olds indicates that asthma, chronic diseases of the tonsils and adenoids, and acute

Table 6-I—Rates of Different First-Listed Diagnoses^a for U.S. Adolescents Ages 10 to 18 Discharged From Short-Stay Non-Federal Hospitals, 1987

Diagnosis by ICD-9-CM category ^b	Number of first-listed diagnoses/1,000 inpatients			
	Males		Females	
	10 to 14	15 to 18	10 to 14	15 to 18
Injury and poisoning	24.8	33.1	16.3	8.2
Diseases of the digestive system	13.9	11.7	12.1	5.8
Diseases of the respiratory system	13.4	10.7	19.5	6.1
Mental disorders	6.9	14.3	8.8	7.1
Diseases of the nervous system and sense organs	5.9	— ^c	— ^d	— ^d
Diseases of the musculoskeletal system and connective tissue	5.2	5.8	— ^d	2.8
Diseases of the genitourinary system	5.2	— ^e	4.3	7.5
Endocrine, nutritional and metabolic diseases, and immunity disorders	4.7	3.4	— ^c	1.9
Infectious and parasitic diseases	4.0	— ^e	— ^d	1.8
Complications of pregnancy, childbirth	— ^c	— ^e	— ^d	12.1
Supplementary classification	— ^e	— ^e	5.0	39.7

^aIn the National Hospital Discharge Survey, a *first-listed diagnosis* is the diagnosis listed first on the face sheet of a patient's medical record.

^bICD-9-CM refers to the International Classification of Diseases, 9th Revision, Clinical Modification, which is used to code morbidity data.

^cEntries marked with an asterisk (*) did not meet the requisite standard of reliability.

^dFemales with deliveries are inducted under "Supplementary classifications."

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1987 data from the National Hospital Discharge Survey, Hyattsville, MD, 1989.

appendicitis are among the physical illnesses most frequently leading to the hospitalization of U.S. adolescents (see table 6-2).

Reasons for Visits to Office-Based Physicians

As noted in box 6-B, the National Ambulatory Medical Care Survey (NAMCS) gathers information periodically on visits made by patients to a sample of non-Federal physicians in office-based practice (106). Inferences from NAMCS data are limited because the number of physicians sampled in the survey is small; furthermore, adolescents are one of the groups least likely to visit physicians.⁹

The most recent available NAMCS data are from 1985. According to these data, diseases of the

respiratory system are the most frequent diagnosis for visits by adolescents to office-based physicians (17.0 percent of visits), followed by injury and poisoning (16.3 percent of visits), followed by diseases of the skin and subcutaneous tissue (9.9 percent of visits) (see table 6-3).

If one groups NAMCS data by more specific conditions, acne emerges as the most frequent diagnosis for an office visit for a physical problem (4.8 percent of visits) (see table 6-4).¹⁰ Acne is particularly prevalent among older adolescents, who received a diagnosis of diseases of the sebaceous glands (e.g., acne) for 7.4 percent of visits; acne was the 12th most common diagnosis for younger adolescents (1.9 percent of visits).¹¹

⁹For a discussion of barriers to adolescents' use of physician services, see ch. 15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents," in Vol. III.

¹⁰The need for a general medical examination is actually the most frequent specific principal diagnosis (5.8 percent of visits). The need for a general exam does not, however, reflect any specific health problem and is more likely to be part of general preventive health care.

¹¹A preliminary analysis by OTA suggested some interesting discontinuities in the NAMCS data using year-by-year age breaks, but because of the lower reliability and interpretability of information based on fewer numbers of adolescents, it was not possible to look at information using these fine breakdowns. Age breaks of 10 to 14 years and 15 to 18 years were used based on the recommendations of the National Center for Health Statistics (60), and analysis of the patterns of visits to office-based physicians using the NAMCS data. Analysis of visit rates for adolescents of different ages indicated that the rate of visits for adolescent females increases at about age 15, most likely reflecting the increase in pregnancy-related visits. Pregnancies generally involve more than one visit per pregnant female during the course of a year (including postnatal visits). Thus, 10- to 14-year-old females have fairly similar visit patterns, as do 15- to 18-year-olds. No clear pattern emerged for males. The age break between 10- to 14-, and 15- to 18-year-olds, then, is driven by the utilization of physicians by females, which is in turn driven by pregnancy-related visits.

Table 6-2—Number of Different First-Listed Diagnoses for U.S. Adolescents Ages 10 to 18 Discharged From Short-Stay Non-Federal Hospitals, 1987

Diagnosis	NHDS diagnostic code	Estimated number of discharges ^b			
		Males		Females	
		10 to 14	15 to 18	10 to 14	15 to 18
Other fractures	167	18,969	27,184	—*	—*
Appendicitis	91	16,843	16,727	—*	—*
Asthma	80	13,845	—	—*	—*
Other mental disorders	39	—*	21,174	13,485	24,190
Other injury	177	—*	15,307	—*	11,000
Lacerations/wounds	174	—*	14,847	—*	—*
Other psychoses	33	—*	11,570	—	10,747
Chronic disease of tonsils and adenoids	75	—*	—*	20,681	16,387
Females with deliveries	184	—	—	—	309,689
Other implications of pregnancy, childbirth, and the puerperium	137	—	—	—*	47,459
Other inflammatory diseases of the female pelvic organs	120	—	—	—*	20,532
Other disorders of the genital tract	125	—	—	—*	19,720
Other pregnancy with abortive outcome	128	—	—	—*	16,500
Poisoning by drugs, medicinal agents, and biological substances..	178	—*	—*	—*	15,443
Other neurosis and personality disorders	35	—*	—*	—*	11,569

^aEstimates with fewer than 60 sampled cases have been omitted from this table. Many of the specific diagnostic categories for males and females ages 10 to 14 and 15 to 18 had fewer than 60 sampled cases. Thus, many of the diagnostic categories listed here consist of aggregations of "other," rather than more specific categories.

^bEntries marked with an asterisk (*) did not meet the requisite standard of reliability.

SOURCES: Discharges: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1987 data from the National Hospital Discharge Survey, Hyattsville, MD, 1989. NHDS diagnostic codes: U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, "NHDS Diagnostic Recodes for ICD-9-CM," Hyattsville, MD, June 1987.

Table 6-3—Visits to Office-Based Physicians by U.S. Adolescents Ages 10 to 18: Number and Distribution by Diagnosis, 1985

Diagnosis by ICD-9-CM Category ^a	ICD-9-CM Code ^a	Number of visits in thousands	Percent distribution
All diagnoses		50,218	100.0
Diseases of the respiratory system	460-519	8,535	17.0
Injury and poisoning	800-999	8,177	16.3
Diseases of the skin and subcutaneous tissue	680-709	4,957	9.9
Diseases of the nervous system and sense organs	320-389	4,833	9.6
Infections and parasitic diseases	001-139	3,593	7.2
Diseases of the musculoskeletal system and connective tissue	71 0-739	2,280	4.5
Diseases of the genitourinary system	580-629	1,969	3.9
Diseases of the digestive system	520-579	1,607	3.2
Mental disorders	290-31 9	1,226	2.4
Endocrine, nutritional and metabolic diseases, and immunity disorders	240-279	587	1.2
Neoplasms	140-239	470	0.9
Diseases of the circulatory system	390-459	454	0.9
Supplementary classification	VO1-V82	8,467	16.9
Symptoms, signs, and ill-defined conditions	780-799	1,424	2.8
Unknown diagnoses		965	1.9
All other diagnoses		673	1.3

^aICD-9-CM refers to the International Classification of Diseases, 9th Revision, Clinical Modification, which is used to code morbidity data.

^bThis includes blank diagnosis, noncodable diagnosis, and illegible diagnosis.

^cThis includes diseases of the blood and blood-forming organs (280-289); complications of pregnancy, childbirth, and the puerperium (630-676); congenital anomalies (740-759); and certain conditions originating in the perinatal period (760-779).

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1985 data from the National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

Table 6-4—Visits to Office-Based Physicians by U.S. Adolescents Ages 10 to 18: Number and Distribution by the 15 Most Common Principal Diagnoses, 1985

Rank	Most common principal diagnosis by ICD-9-CM Category ^a	Number of visits in thousands	Percent of all adolescent visits
1	General medical examination	2,914	5.8
2	Diseases of sebaceous glands ^b	2,394	4.8
3	Acute pharyngitis	1,822	3.6
4	Acute upper respiratory infections of multiple or unspecified sites	1,627	3.2
5	Normal pregnancy	1,548	3.1
6	Earache or ear infection	1,368	2.7
7	Suppurative and unspecified otitis media	1,236	2.5
8	Disorders of refraction and accommodation	1,197	2.4
9	Other diseases due to viruses and chlamydiae	1,139	2.3
10	Certain adverse effects not elsewhere classified ^c	1,086	2.2
11	Contact dermatitis and other eczema	1,063	2.1
12	Health supervision of infant or child	1,000	2.0
13	Acute tonsillitis	799	1.6
14	Asthma	704	1.4
15	Open wound of other and unspecified site	659	1.4

^aICD-9-CM refers to the International Classification of Diseases, 9th Revision, Clinical Modification, which is used to code morbidity data.

^bChiefly acne other than varioliformis.

^cPrimarily allergy, unspecified.

SOURCES: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1985 data from the National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

Findings From National Population-Based Surveys

Judgments about the importance of particular health problems derived from health care utilization data are limited in that they do not reflect the health concerns of individuals who do not use the health care system.¹² Such concerns are more likely to be reflected in population-based surveys. As noted in box 6-B, the National Center for Health Statistics has used two types of population-based surveys. The National Health Interview Survey (NHIS) collects data from a sample of the civilian noninstitutionalized U.S. population through personal household interviews (108). The National Health and Nutrition Examination Survey (NHANES)—formerly the National Health Examination Survey (NHES)—collects health-related data by means of direct physical examinations, clinical and laboratory tests, and related measurement procedures (108). The latter two surveys have been conducted more rarely than NHIS, and no adequate sample of adolescents was included in NHANES I or II. (NHANES) III is collecting some adolescent-specific data, but the results are not expected until 1994.)

National Health Interview Survey (NHIS)

NHIS collects information on both acute conditions and chronic conditions. A physical or mental condition is considered “acute” for purposes of NHIS if: 1) it was first noticed 3 months before the reference date of the interview; and 2) it is not one of the conditions considered chronic regardless of the time of onset. To be counted in NHIS data, an acute condition must also have been of sufficient consequence to have been associated with at least 1 restricted-activity day or at least one visit to a doctor. A physical or mental condition is considered “chronic” for purposes of the NHIS if: 1) the respondent indicates it was first noticed more than 3 months before the reference date of the interview and it exists at the time of the interview, or 2) it is a type of condition that ordinarily has a duration of more than 3 months. Examples of physical conditions that are considered chronic regardless of their time of onset are diabetes, heart conditions, emphysema, and arthritis.

Acute Conditions—The impact of acute conditions on adolescent health is measured in terms of restricted-activity days (overall and due to specific problems) and school-loss days (overall and due to

¹²As noted in box 6-B, available health services utilization data are limited in other ways, particularly with respect to adolescent health.

Table 6-5-Number of Restricted-Activity Days^a Associated With Acute Conditions^b per 100 U.S. Adolescents for Noninstitutionalized Adolescents Ages 10 to 18, by Sex, Age, and Type of Condition, 1988

Type of acute condition	Both Number of restricted-activity days/100 adolescents in age group ^c							
	sexes, ages		Males			Females		
	10 to 18	10 to 18	10 to 14	15 to 18	10 to 18	10 to 14	15 to 18	
All acute conditions	659.6	606.7	629.2	580.6	714.4	664.7	770.7	
Infective and parasitic diseases	121.7	117.9	129.6	104.3	125.6	156.0	91.1	
Common childhood diseases	25.7	—	—	—	—	—	—	
Intestinal virus, unspecified	—	—	—	—	—	—	—	
Viral infections, unspecified	28.0	—	—	—	—	—	—	
Other	57.5	55.6	—	—	59.4	—	—	
Respiratory conditions ^d	307.0	287.2	325.7	242.3	327.6	319.6	336.7	
Common cold	72.5	71.3	83.2	57.4	73.7	81.6	64.8	
Other acute upper respiratory infections	35.4	35.6	—	—	35.3	—	—	
Influenza	175.0	152.2	169.0	132.5	198.7	179.5	220.6	
Digestive system conditions	23.3	—	—	—	—	—	—	
Injuries ^e	119.5	133.5	94.9	178.4	104.9	92.7	118.7	
Fractures and dislocations	40.8	51.7	—	—	—	—	—	
Sprains and strains	29.4	—	—	—	—	—	—	
Other current injuries	19.2	—	—	—	—	—	—	
Selected other acute conditions ^f	74.8	39.4	—	—	111.5	—	174.9	
Delivery and other conditions of pregnancy and puerperium	24.7	—	—	—	50.3	—	107.4	

^aFor the purposes of the National Health Interview Survey (NHIS), *restricted-activity day* is any day on which a person restricts his or her usual activities for more than half a day because of an illness or an injury (i.e., a school-loss, work-loss, or cut-down day or a bed-disability day). Restricted-activity days are measures used for both acute and chronic conditions. This table shows only the restricted-activity days associated with acute conditions.

^bA condition is considered "acute" for the purposes of NHIS if it has lasted under 3 months, is not a condition considered chronic regardless of time of onset, and is of sufficient consequences to have been associated with either at least one doctor visit or at least 1 day of restricted activity.

^cEntries marked with an asterisk (*) did not meet the requisite standard of reliability.

^dCategories not shown because of low reliability of estimates include acute bronchitis, pneumonia, and "other" respiratory conditions.

^eThis includes dental conditions; indigestion, nausea, and vomiting; and other digestive conditions. No specific category had enough sampled cases to be considered reliable.

^fCategories not shown because of low reliability of estimates include "open wounds and lacerations" and "contusions and superficial injuries."

^gCategories not shown because of low reliability of estimates include eye conditions, acute ear infections, other ear conditions, acute urinary conditions, disorders of menstruation, other disorders of the female genital tract, skin conditions, acute musculoskeletal conditions, headache (excluding migraine), and unspecified fever.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1988 data from the National Health Interview Survey, Hyattsville, MD, 1990.

specific problems). As noted in box 6-A, a restricted-activity day is any day on which a person restricts his or her usual activities for more than one-half day because of an illness or injury (106).¹³ A school-loss day, a type of restricted-activity day calculated for 5- to 17-year-olds, is any day on which a child did not attend school for half a day because of illness or injury.

The 1988 NHIS found the acute conditions causing the highest numbers of restricted-activity days among noninstitutionalized adolescents ages 10 to 18 were acute respiratory conditions (particularly influenza), followed by infective and parasitic diseases (see table 6-5). Acute respiratory conditions are also responsible for over half of the school-loss

days associated with acute conditions (see table 6-6). Other acute conditions that cause relatively high numbers of restricted-activity and school-loss days among U.S. adolescents are infective and parasitic diseases and injuries.

Although the reported average rate of restricted-activity days due to acute conditions for younger (10- to 14-year-old) adolescents is similar to that for older (15- to 18-year-old) adolescents, there are some interesting age differences by condition and general differences by sex and race. As shown in table 6-5, younger adolescents are more likely to have restricted-activity days due to acute physical illness (respiratory conditions, infective and parasitic diseases), and older adolescents are more likely

¹³ 'Restricted-activity days' are unduplicated counts of the following: 1) bed-disability days, during which a person spent more than half a day because of illness or injury; 2) work-loss days, during which a currently employed person 18 years of age and over missed more than half a day from a job or business; 3) school-loss days, during which a student 5 to 17 years of age missed more than half a day from the school in which he or she was currently enrolled; and 4) cut-down days, during which a person cuts down for more than half a day on the things he or she usually does. Note that a "day of restricted activity" due to an acute condition is not the same as a "limitation in activity" caused by a chronic condition (105).

Table 6-6—Number of School-Loss Days^a Associated With Acute Conditions^b per 100 U.S. Adolescents for Noninstitutionalized Adolescents Ages 10 to 17, by Sex, Race, Family Income, and Types of Condition, 1988

Type of acute condition	Number of school-loss days/100 adolescents ages 10 to 17C								
	All ages 10 to 17	Sex		Race		Family income			
		Male	Female	White	Black	Less than \$10,000	\$10,000-\$19,999	\$20,000-\$34,999	\$35,000 or more
All acute conditions	379.6	362.8	397.1	399.9	302.8	483.1	403.2	419.3	349.1
Infective and parasitic diseases ^d	79.9	82.6	76.9	84.8	—*	—*	—*	84.3	83.8
Common childhood diseases	22.0	—*	—*	—*	—*	—*	—*	—*	—*
Viral infections, unspecified	17.3	—*	—*	20.5	—*	—*	—*	—*	—*
Other	33.0	36.7	—*	39.3	—*	—*	—*	—*	42.8
Respiratory Conditions ^e	210.0	199.8	220.7	226.2	137.8	235.1	196.2	236.5	200.2
Common cold	48.4	47.8	49.1	48.9	—*	—*	—*	61.7	—*
Other acute upper respiratory infections	23.7	—*	—*	26.7	—*	—*	—*	—*	—*
Influenza	122.3	110.0	135.3	132.2	—*	151.5	119.0	133.3	123.1
Digestive system Conditions ^f	15.4	—*	—*	—*	—*	—*	—*	—*	—*
Injuries ^g	32.3	42.4	—*	35.5	—*	—*	—*	—*	—*
Selected other acute conditions	34.3	22.2	46.9	29.8	—*	—*	—*	—*	—*
All other acute conditions	—*	—*	—*	—*	—*	—*	—*	—*	—*

^aFor the purposes of the National Health Interview Survey (NHIS), a school-loss day is a day on which a student 5 to 17 years of age missed more than half a day from the school in which he or she was currently enrolled. A school-loss day is one type of restricted-activity day.

^bA condition is considered "acute" for the purposes of NHIS if it has lasted under 3 months, is not a condition considered chronic regardless of time of onset, and is of sufficient consequences to have been associated with either at least one doctor visit or at least 1 day of restricted activity.

^cEntries marked with an asterisk (*) did not meet the requisite standard of reliability.

^dCategories not shown because of insufficient reliability include: intestinal virus, unspecified.

^eCategories not shown because of insufficient reliability include: acute bronchitis, pneumonia, "other" respiratory conditions.

^fCategories not shown because of insufficient reliability include: dental conditions; indigestion, nausea, and vomiting; and other digestive conditions.

^gCategories not shown because of insufficient reliability include: fractures and dislocations; sprains and strains; open wounds and lacerations; contusions and superficial injuries; other current injuries.

^hSubcategories are not shown because of insufficient reliability.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1988 data from the National Health Interview Survey, Hyattsville, MD, 1990.

to have restricted-activity days due to injuries and pregnancy-related causes. Female adolescents in general (but particularly older female adolescents) are more likely than males to have days of restricted activity due to acute conditions; perhaps not surprisingly, this phenomenon is largely due to pregnancy.¹⁴ Black adolescents are less likely (506.6 days per 100 10- to 18-year-olds per year) than white adolescents (704.4 days per 100 10- to 18-year-olds per year) to have restricted-activity days reported for acute conditions.¹⁵

School-loss days and restricted-activity days generally show similar age, sex, and race patterns, except that 10- to 14-year-old females have fewer school-loss days than their male counterparts (107). As shown in table 6-6, adolescents in families with

annual incomes less than \$10,000 have higher rates of school-loss days (483.1 days per 100 adolescents per year) than adolescents in families with annual incomes of \$35,000 or more (349.1 days per 100 adolescents per year). Differences in school-loss days by family income level are more marked for adolescents ages 10 to 14 than for those ages 15 to 17, although they follow the same general pattern.¹⁶

Chronic Conditions--The 1988 NHIS found the most frequently reported chronic physical conditions for noninstitutionalized U.S. adolescents ages 10 to 18 were hay fever or allergic rhinitis without asthma, chronic sinusitis, acne, asthma, deformity or orthopedic impairment, chronic bronchitis, chronic disease of the tonsils or adenoids, dermatitis, and

¹⁴See ch. 10, "Pregnancy and Parenting: Prevention and Services," in this volume for a discussion of adolescent pregnancy.

¹⁵Interestingly, the number of restricted-activity days per 100 persons per year increases with age for black adolescents and decreases for white adolescents. Because of small sample sizes, it is not possible to be specific about race differences for specific conditions.

¹⁶The average number of school-loss days per 100 10- to 14-year-olds per year reported by families with annual incomes less than \$10,000 was 491.9 days; by families with annual incomes from \$10,000 to \$19,999 was 379.8 days; by families with annual incomes from \$20,000 to \$34,999 was 402.0 days; and by families with incomes of \$35,000 or more was 340.7 days. See ch. 18, "Issues in the Delivery of Services to Selected Groups of Adolescents," in Vol. III for a discussion of the health problems of adolescents in poor and near-poor families.

Table 6-7—Prevalence Rate for 20 Leading Chronic Physical Conditions^a Among Noninstitutionalized U.S. Adolescents Ages 10 to 18, 1988

	Number of chronic conditions/ 1,000 Persons ^b		
	Ages		
	10 to 14	15 to 18	10 to 18
Hay fever or allergic rhinitis			
without asthma	91.2	92.4	89.8
Chronic sinusitis	89.6	82.9	97.4
Acne	61.7	34.6	92.9
Asthma	58.1	62.1	53.5
Deformity or orthopedic impairment	54.2	39.3	71.3
Back	26.6	16.6	38.1
Lower extremities	26.5	23.0	30.5
Chronic bronchitis	38.8	33.8	44.5
Chronic disease of tonsils or adenoids	31.1	29.6	32.9
Dermatitis	31.1	32.3	29.8
Migraine headaches	28.6	27.4	29.9
Heart disease	22.4	20.4	16.1
Heart murmurs	16.7	19.8	13.1
Hearing impairment	20.7	19.7	22.0
Visual impairment	18.9	16.5	21.6
Trouble with ingrown nails	17.6	10.1	26.4
Color blindness	12.3	10.4	14.6
Trouble with dry, itching skin	10.1	—*	12.8
Speech impairment	9.0	11.3	—
Diseases of female genital organs	7.1	—*	13.0
Anemias	6.2	—*	—*
Arthritis	4.7	—*	—*
High blood pressure	4.5	—*	—*

^aA physical or mental condition is considered "chronic" for purposes of the National Health Interview Survey if it has lasted more than 3 months or is a type of condition that ordinarily lasts more than 3 months (e.g., diabetes, heart conditions, emphysema, or arthritis).

^bEntries marked with an asterisk (*) did not meet the requisite standard of reliability.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1988 data from the National Health Interview Survey, Hyattsville, MD, 1990.

migraine headaches (see table 6-7). Other physical chronic conditions with a rather high reported prevalence among adolescents were heart disease, hearing impairments, and visual impairments (see table 6-7).

Each person identified by NHIS as having a chronic physical or mental condition is classified according to the extent to which his or her activities are reported as limited.¹⁷ As shown in table 6-8, the 1988 NHIS found that 93.2 percent of U.S. adolescents were reported to have no activity limitation

due to a chronic physical or mental condition; 6.8 percent were reported to have some activity limitation. The 6.8 percent with activity limitation due to a chronic condition included 0.6 percent of U.S. adolescents who were unable to perform a major activity (e.g., attending school); 4.3 percent who were limited in the amount or kind of major activity; and 1.9 percent who were limited but not in major activity (see table 6-8). Among adolescents with chronic conditions, there was very little difference in reported degree of activity limitation by age, sex, race, or place of residence. However, there were some differences by income, with a larger proportion of adolescents (94.9 percent) in higher income families than in the lower income families (e.g., 90.2 percent in families with annual incomes under \$10,000) free of an activity limitation (107).

Newacheck conducted an in-depth analysis of 1984 NHIS data by type of serious chronic disorder (62). This analysis revealed that 75 percent of U.S. adolescents ages 10 to 18 with a reported limitation of activity due to a chronic disorder or disorders had a disorder in one of the five following categories:

- mental disorders (including mental retardation, psychoses, and substance dependence syndromes), 32 percent;
- respiratory conditions (e.g., asthma), 21 percent;
- diseases of the musculoskeletal system or connective tissue (e.g., arthritis or acquired limb deformities), 15 percent;
- diseases of the nervous system (e.g., multiple sclerosis, cerebral palsy, or epilepsy), 6 percent; and
- diseases of the ear and mastoid process (e.g., hearing impairments), 4 percent.

National Health Examination Survey (NHES)

A compelling source of information on the health status of any group is a population-based survey that includes clinical examinations by health care providers. Unfortunately, the last such survey to include sufficient numbers of adolescents for meaningful analysis was the NHES completed in 1970 by the U.S. Department of Health, Education, and Welfare (now the U.S. Department of Education and DHHS)

¹⁷Note that limitations of activity associated with chronic conditions differ from restricted-activity days discussed above. NHIS measured restricted-activity days for both acute and chronic conditions, but limitations of activity only for chronic conditions.

Table 6-8--Distribution of Noninstitutionalized U.S. Adolescents Ages 10 to 18 by Degree of Activity Limitation Due to a Chronic Physical or Mental Condition and Socioeconomic Characteristics, 1988

Characteristic	Total ^a	Percent with no activity limitation	Percent with activity limitation ^b	Percent with limitation in major activity ^{b,c}	Percent unable to carry on major activity ^c	Percent limited in amount or kind of major activity ^c	Percent limited, but not in major activity ^{b,c}
All 10- to 18-year-olds	100.00	93.2	6.8	4.8	0.6	4.3	1.9
Age:							
10- to 14-year-olds	100.0	93.2	6.5	5.3	—*	4.9	1.6
15- to 18-year-olds	100.0	93.3	6.7	4.4	0.9	3.5	2.3
Sex and age:							
Male							
All ages (10 to 18)	100.0	92.7	7.3	5.4	—*	4.9	1.9
10- to 14-year-olds	100.0	92.3	7.7	6.1	—*	5.8	1.6
15- to 18-year-olds	100.0	93.0	6.9	4.6	—*	3.9	2.3
Female							
All ages (10 to 18)	100.0	93.8	6.2	4.3	—*	3.6	1.9
10- to 14-year-olds	100.0	94.1	5.9	4.4	—*	4.0	1.5
15- to 18-year-olds	100.0	93.5	6.5	4.1	—*	3.2	2.3
Race and age:							
White							
All ages (10 to 18)	100.0	93.0	7.0	4.9	0.6	4.4	2.0
10- to 14-year-olds	100.0	92.9	7.1	5.4	—*	5.1	1.7
15- to 18-year-olds	100.0	93.2	6.8	4.4	—*	3.6	2.4
Black							
All ages (10 to 18)	100.0	93.2	6.8	5.1	—*	4.4	—*
10- to 14-year-olds	100.0	93.3	6.7	5.3	—*	4.3	—*
15- to 18-year-olds	100.0	93.2	6.8	—*	—*	—*	—*
Family Income and age:							
Under \$10,000							
All ages (10 to 18)	100.0	90.2	9.8	7.8	—*	6.9	—*
10- to 14-year-olds	100.0	88.8	11.2	9.5	—*	9.2	—*
15- to 18-year-olds	100.0	91.5	8.5	—*	—*	—*	—*
\$10,000 to \$19,999							
All ages (10 to 18)	100.0	91.1	8.9	6.6	—*	6.0	—*
10- to 14-year-olds	100.0	91.5	8.5	6.6	—*	6.2	—*
15- to 15-year-olds	100.0	90.5	9.5	6.5	—*	5.7	—*
\$20,000 to \$34,999							
All ages (10 to 18)	100.0	92.9	7.1	5.0	—*	4.3	2.1
10- to 14-year-olds	100.0	93.5	6.5	4.8	—*	4.4	—*
15- to 18-year-olds	100.0	92.0	8.0	5.2	—*	4.1	—*
\$35,000 or more							
All ages (10 to 18)	100.0	94.9	5.1	3.5	—*	3.1	1.6
10- to 14-year-olds	100.0	94.4	5.6	4.1	—*	4.0	—*
15- to 18-year-olds	100.0	95.5	4.5	2.7	—*	—*	—*
Geographic region:							
Northeast	100.0	94.1	5.9	4.3	—*	3.9	—*
Midwest	100.0	92.6	7.3	5.5	—*	5.0	1.8
South	100.0	93.0	7.0	5.0	—*	4.4	2.0
West	100.0	93.5	6.5	4.2	—*	3.6	2.2
Place of residence:							
Metropolitan statistical area	100.0	93.5	6.5	4.7	0.6	4.1	1.8
Central city	100.0	93.7	6.3	4.7	—*	4.0	1.6
Not central city	100.0	93.3	6.7	4.7	—*	4.2	2.0
Not metropolitan statistical area	100.0	92.5	7.5	5.3	—*	4.8	2.2

^aNote that the numbers in horizontal rows do not add up to 100 percent. The reason is that the last four columns show breakdowns of the overall Percentage with activity limitations shown in the third column. In addition, numbers in some rows may not add up because of rounding.
^bMajor activity (or usual activity) refers to the principal activity of a person or of a person of his or her age-sex group (e.g., school attendance, working at a job).
^cEntries marked with an asterisk (*) did not meet the requisite standard of reliability.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1988 data from the National Health Interview Survey, Hyattsville, MD, 1990.

(94,95).¹⁸ Because they are so old, estimates of adolescents' physical health problems based on NHES may not pertain to the health status of contemporary adolescents. Still, the data from NHES suggest that the physical health of American adolescents may not be as positive as is often assumed. Most troubling is the NHES' finding that *more than one adolescent out of five (about 22 percent) had "some illness, deformity, or handicap . . . affecting normal growth, development, or function—cardiovascular, neurological, musculoskeletal, or other"* (94). NHES found that the proportion of adolescents ages 12 to 17 with physical health problems was greater than the proportion of younger children (ages 6 to 11) with physical health problems.

NHES also recorded information by race, region, and family income. This survey found no differences in physical health status by race. Adolescents living in the South had more health problems than adolescents from other regions, and adolescents of lower income had more health problems than adolescents from families with higher incomes (94).

Physical Health Problems From the Perspective of Adolescents

Adolescents themselves are rarely asked to identify the physical (or other) health problems that they believe are most important. Even in adolescent health surveys, adolescents are infrequently asked to rate the importance of various health issues. The National Adolescent Student Health Survey conducted by a consortium of groups funded partially by the Federal Government in 1987, for example, questioned more than 11,000 8th and 10th graders nationwide but failed to ask respondents to identify the most important physical health issues for adolescents (4). Adolescents were asked to identify physical health issues in the Minnesota Adolescent Health Survey of over 36,000 Minnesotan students in grades 7 through 12, but reports of the Minnesota survey results emphasized nonphysical concerns

(88).²⁰ Thus, data are very limited on the specific physical health concerns identified as most important by adolescents.

Some evidence suggests, however, that adolescents do not always agree with adults on what adolescents' most important health needs are. A Canadian study that asked a random sample of 1,000 adolescents ages 12 through 20 and 100 school-based public health nurses and school psychologists or counselors to rate the seriousness and prevalence of a variety of health problems among adolescents found differences in the perceptions of adolescents and the professionals (32). The health providers identified menstrual problems, acne, and headaches as common, but not serious, problems; pregnancy, venereal diseases (i.e., sexually transmitted diseases), and chronic health problems as serious but not common; and nervousness or emotional, school-related, and birth control problems as serious and common problems. Adolescents concurred with the health providers that menstrual problems and acne were common complaints, but few of the adolescents identified birth control problems, venereal diseases, or chronic health problems as significant. The professionals cited substance abuse (alcohol and drugs) and sexual problems as the most serious, but relatively uncommon, psychosocial problems. Adolescents reported fairly high rates of alcohol use (49.0 percent), drug use (15.1 percent), and sexual intercourse (22.1 percent) but did not perceive these to be problems.

Another study conducted in Canada asked adolescents ages 13 to 18 what issues they would like to discuss or have covered when they visit primary care physicians and how often the issues were actually discussed during a visit (50). This study was somewhat flawed in that it asked adolescents both questions simultaneously; the results would have been more valid if the responses had been independent.

Nonetheless, the results of this Canadian study are consistent with the results of previous studies that

¹⁸pediatricians examined 12- to 17-year-olds using a standardized physical examination for problems with eyes, ears, nose, and throat; goiter; musculoskeletal and limited neurological evaluation; cardiovascular examination; grading of facial acne; assessment of sexual maturation through a genital examination and an appraisal of nutrition. The examination did not include an evaluation of mental health problems, except for an assessment of mental retardation by appearance.

¹⁹OTA included 10- and 11-year-olds in the adolescent age group, but NHES aggregated many of its findings by two age groups: 6- to 11-year-olds and 12- to 17-year-olds. Fewer 6- to 11-year-olds than 12- to 17-year-olds were found to have "significant abnormal findings" on examination by the physician (one in eight 6- to 11-year-olds v. one in five 12- to 17-year-olds). Much of the difference between the rate of problems for children and adolescents was attributed to "the conditions associated with the onset of puberty or other aspects of maturation" (94).

²⁰Physical health concerns were not, however, listed as a possible response in the Minnesota survey item concerning things students "worry about."

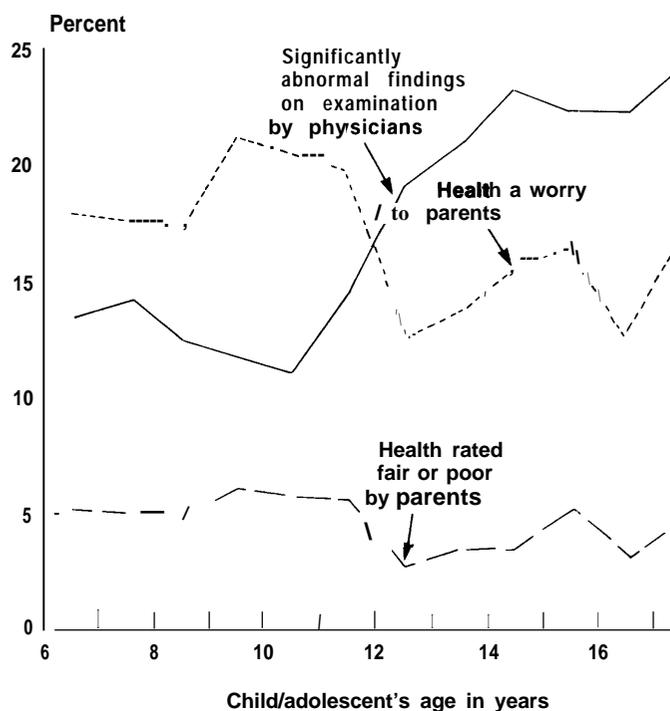
found diverging interests of health care providers and adolescents (see 50, for a review) and suggest that, at least from the adolescents' perspective, adolescents' real concerns are not being attended to by health care providers. In almost all cases, the adolescents who were questioned in this study reported that discussion of issues of interest to them took place considerably less frequently than the adolescents desired (50).²¹ For example, while over 80 percent of responding adolescents were interested in discussing physical fitness, nutrition, and growth, discussion of these topics reportedly took place in only 40 to 50 percent of visits. From 60 to 70 percent of adolescents were interested in discussing sexually transmitted diseases, contraception, acne, fear of cancer, and obesity, but these topics were reported to be discussed only 12 to 30 percent of the time. Almost 60 percent of adolescents were interested in discussing feelings of depression and lack of confidence, but such discussion took place only 16 and 11 percent of the time, respectively. Interestingly, the only topic with a close match between adolescents' desire for discussion and how often it actually took place was the topic of menses (of interest to adolescents 55 percent of the time and discussed 49 percent of the time); no specific details of the content of discussions about menses were provided.²² Dysmenorrhea (painful menstruation) has been identified through surveys of small samples of adolescent girls as a leading cause of pain and absence from school due to physical problems (44,120).

Physical Health Problems From the Perspective of Parents

As discussed above, some surveys (e.g., NHIS and part of NHES) use adolescents' parents as a source of information about the health of their adolescent children. It is important to note that parents may not be a valid source of information on the health of their adolescent children.

No current data are available on this issue, but the 1963-65 and 1966-70 NHES, conducted by the U.S. Department of Health, Education, and Welfare, was able to compare parents' ratings of their children's

Figure 6-1—Parents' Ratings of Child and Adolescent Health Compared to Physicians' Findings on Examination, U.S. Children Ages 6 to 17, 1963-65 and 1966-70a



^aChildren ages 6 to 11 were examined from 1963 to 1965 and adolescents 12 to 17 were examined from 1966 to 1970.

SOURCE: U.S. Department of Health, Education, and Welfare, "Examination and Health History Findings Among Children and Youths, 6-17 Years: United States," *Vital and Health Statistics: Data From the National Health Survey, Series 11, No. 129*, DHEW Pub. No. (HRA) 74-1611 (Rockville, MD: November 1973).

(including adolescents') health with findings from physicians' physical examinations²³ of the adolescents (94). As shown in figure 6-1, parents' worries about their children's health dropped considerably at about age 13, but there was a large increase in significantly abnormal findings on examination beginning at age 11 through age 17 (the last year of age included in the survey). Parents of 12- to 17-year-olds tended to rate their children's health significantly better than did parents of children ages

²¹The American health care system's competence to treat the health needs of adolescents is discussed more fully in ch. 15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents," in Vol. III.

²²For example, the "discussion" could have consisted merely of a question about whether menses had begun.

²³As noted above, the physical examination was generally limited to the identification of primarily physical abnormalities, although apparent mental retardation would have been noted.

6 to 11,24 both when giving a categorical statement of their child's health status and when indicating whether or not aspects of their child's health were a concern or worry.²⁵ In contrast, *surve*, pediatricians, who actually examined the children and adolescents, rated substantially more adolescents than children as having some significant abnormality. The National Center for Health Statistics could not come to definitive conclusions about the reasons for the reduction in parents' concern but suggested that the reduction probably reflected "a change in attitude or concern." The National Center for Health Statistics was not able to tell if this change occurred because of increased maturity of the child, because more of the abnormal conditions were under care, or because of some other factor.

Unfortunately, children and adolescents themselves were not asked to report on their overall health status or specific health concerns in a survey comparable with that given to parents.

Background on Chronic Physical Illnesses and Disabilities of Adolescents

Trends in the incidence and prevalence of chronic illness and disability among adolescents are reviewed below. Also discussed are consequences common to many chronic illnesses, with a focus on psychosocial consequences. Two other chronic physical health problems of importance to adolescents themselves—acne and dysmenorrhea—are also reviewed in this section.

Trends in the Incidence and Prevalence of Chronic Physical Illnesses and Disabilities Among Adolescents

A small but significant number of U.S. adolescents are believed to experience very serious chronic physical conditions such as severe asthma, juvenile-onset diabetes, congenital heart disease, leukemia, cystic fibrosis, and chronic kidney diseases (70). Unfortunately, however, it is difficult to determine

the incidence and prevalence of such illnesses among adolescents. Most studies of chronic illness among children do not report information separately for adolescents. Furthermore, many serious chronic illnesses are not of sufficient prevalence in adolescents to reliably measure in national epidemiological and health services utilization surveys that sample only a small number of adolescents (e.g., NHIS, NAMCS, NHDS, and NHANES). Estimates of the prevalence of serious chronic disorders among all children under age 20 range from 10 to 20 percent (27,72,80) (see box 6-C).

In 1984, using published prevalence estimates for 21 types of chronic conditions, Gortmaker and Sappenfield estimated the prevalence of chronic conditions in U.S. children under the age of 20 (see table 6-9). In aggregate (assuming that each child had no more than one of the specified problems), Gortmaker and Sappenfield estimated that 13.3 percent of U.S. children ages 0 to 20 had a chronic physical or mental condition. If one excludes some chronic mental disorders (i.e., mental retardation, Down's syndrome, and autism),²⁶ the figure for the remaining chronic conditions drops to 10.6 percent of U.S. children ages 0 to 20. If one assumes that 90 percent of children experiencing these 18 chronic conditions survive to age 20 (as Gortmaker and Sappenfield estimate) and thus experience a chronic condition during adolescence, the prevalence of these 18 remaining chronic conditions among adolescents would be 9.5 percent. Not all of these 18 conditions result in major activity limitations. If one excludes the chronic physical conditions that do not result in a major activity limitation (i.e., mild asthma, nonsevere congenital heart disease, mild and moderate hearing impairments, and mild visual impairments), one could estimate that 4 to 5 percent of U.S. adolescents have chronic physical conditions that make them either unable to carry on a major activity (e.g., attending school) or limited in the amount or kind of major activity. It is important to note that this prevalence estimate by OTA does *not* include chronic mental disorders.

²⁴OTA refers to 10- and 11-year-olds as adolescents, but the National Center for Health Statistics reports on NHES referred to 6- to 11-year-olds as children and 12- to 17-year-olds as "youths" or, less frequently, "adolescents." When comparisons by age were made in the narrative, the National Center for Health Statistics typically aggregated data for these two age groups. However, detailed tables also provided results by each year of age from 6 through 17 (94).

²⁵Differences between reports of abnormalities in the medical history (taken from parents) and findings on examination were also reported. Large differences were found for hearing trouble, walking trouble, arm or leg limitations, with more findings on examination than reports of abnormality. (It is important to note, however, that reports of any abnormality in the medical history were compared with *specific* abnormalities on examination (94).)

²⁶AS noted at the beginning of this chapter, some chronic mental disorders have a **physical basis**.

Box 6-C—Trends in the Prevalence of Chronic Physical Conditions Among U.S. Adolescents

During the 1960s, an estimated 4 percent of U.S. children's visits to primary care practices were for chronic health problems (27). By 1980, some 13 percent of visits to pediatric practices by children under the age of 15 and 18 percent of their visits to all physicians were for chronic problems, both routine and flareup. The increase in proportion of primary care visits by children for chronic conditions reflects a decrease in the incidence of acute illnesses (e.g., infectious diseases¹) and in the proportion of children with chronic conditions who survive through adolescence (27).

Over the last several decades, technological and medical advances have greatly increased the survivability into adolescence of children with certain chronic illnesses. For example, chances of survival to age 21 for children with cystic fibrosis increased from an estimated 5 percent between 1945 and 1959 to an estimated 70 percent during the 1970s (25). Less dramatic, but significant, improvements in the survivability of children with acute lymphocytic leukemia, sickle-cell anemia, congenital heart disease, and chronic kidney diseases have also been noted (25).

According to data from the National Health Interview Survey (NHIS), the prevalence of chronic conditions that limit activity more than doubled between 1960 and 1981 among U.S. children under 17 years of age (63). There is some disagreement about whether these prevalence changes are real or due to changes in questionnaire design, parent and physician perceptions, and other factors (63). Thus, the degree to which the prevalence of chronic conditions has actually increased among children is somewhat unclear (64).

Gortmaker suggests that dramatic increases in the absolute numbers of children and adolescents with chronic illnesses should not be expected during the coming decades for several reasons (25,26). First, there is little room for improvement in levels of survivability, given current rates of greater than 90 percent survival to age 20. Second, even if higher levels of survivability are achieved, smaller birth cohorts since the post World War II "baby boom" have resulted in lower absolute numbers of children with chronic illnesses, thus tending to offset any increases. The only substantial evidence for increases in the incidence of chronic physical conditions in children is the evidence of an increasing number of infants infected with human immunodeficiency virus (HIV).² There is also increasing concern about the disabling long-term effects of crack cocaine use during pregnancy on children.

¹Unlike the incidence of some infectious diseases, the incidence of sexually transmitted diseases has increased. For further discussion, see ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services," in this volume.

²Current problems associated with HIV infection among adolescents are discussed in ch. 9.

As noted earlier, data from the 1988 NHIS suggest that 6.8 percent of noninstitutionalized U.S. adolescents ages 10 to 18 are limited in a major or other activity by a chronic physical or mental condition: 4.8 percent are limited in or are unable to perform a major activity (e.g., attending school), and 1.9 percent are limited in an activity other than major activity as the result of a chronic condition (see table 6-8). Although OTA's estimate (based on Gortmaker and Sappenfield's work) that between 4 and 5 percent of U.S. adolescents have a chronic physical condition that limits major activity is similar to the NHIS estimate (4.8 percent), it is important to emphasize that the NHIS estimate *includes* mental disorders, while the OTA estimate does not. If mental disorders were included in the OTA estimate, it would be higher. Another difference between the OTA and NHIS estimates is that the OTA estimate (based on Gortmaker and Sappenfield's work) includes at least some institutionalized populations, while the NHIS estimate does not. Individuals who

are institutionalized are probably more likely to have seriously disabling chronic conditions than individuals who are not institutionalized.

Differences in estimates of the prevalence among adolescents of chronic conditions that significantly limit their ability to perform a major activity of daily living) are difficult to resolve. As Gortmaker and Sappenfield noted in their review, "Widely varying estimates concerning the population prevalence of chronic childhood disorders exist, depending upon the definitions used, the methods of study, and the population under investigation" (27).

Consequences of Serious Chronic Conditions for Adolescents

There are significant differences in the physical (and thus the emotional and social) consequences of specific types of chronic physical conditions. Still, the experiences of adolescents with various types of

Table 6-9-Estimated Prevalence of Serious Chronic Conditions in U.S. Children Ages 0 to 20, 1980

Disorder ^a	Prevalence estimates/1,000	Range of prevalence estimates/l ,000
Arthritis	2.2	1.0-3.0
Asthma	38.0	20.0-53.0
Moderate to severe...	10.0	8.0-15.0
Autism	0.44	0.40-0.48
Central nervous system injury		
Traumatic brain injury.. . . .	0.05	—
Paralysis	2.1	2.0-2.3
Cerebral palsy	2.5	1.4-5.1
Chronic renal failure	0.080	—
Terminal	0.010	—
Nonterminal	0.070	—
Cleft lip/palate”	1.5	1.3-2.0
Congenital heart disease	7.0	2.0-7.0
Severe congenital heart disease”	0.50	—
Cystic fibrosis”	0.20	—
Diabetes mellitus	1.8	1.2-2.0
Down’s syndrome”	1.1	—
Hearing impairment	16.0	—
Deaf	0.1	0.06-1.5
Hemophilia”	1.5	—
Leukemia		
Acute lymphocytic leukemia’	0.11	—
Mental retardation	25.0	20.0-30.0
Muscular dystrophy”	0.06	—
Neural tube defect’	0.45	—
Spinabifida”	0.40	—
Encephalocele”	0.05	—
Phenylketonuria’	0.10	—
Sickle-cell disease*	0.46	—
Sickle-cell anemia’	0.28	—
Seizure disorder	3.5	2.6-4.6
Visual impairment.	30.0	20.0-35.0
Impaired visual acuity	20.0	—
Blind	0.6	0.5-1.0

^aEntries marked with an asterisk (*) designate estimates that were made using specific prevalence at birth and survival data, as well as incidence and duration data, which are described in detail in the original study.

SOURCE: S.L. Gortmaker and W. Sappenfield, "Chronic Childhood Disorders: Prevalence and Impact," *Pediatric Clinics of North America* 31(1):3-18, 1984, reprinted by permission.

serious chronic conditions show at least some similarities (72).

As discussed below, adolescents with such conditions may experience consequences ranging from lost school days to limitations in major activity. They also may experience psychosocial consequences. The families of adolescents with such conditions (and society) may have to bear substantial financial costs (see the section of this chapter on services and interventions for the treatment of chronic physical illness).

Activity Limitations

As noted earlier, the 1988 NHIS found that 6.8 percent of noninstitutionalized U.S. adolescents ages 10 to 18 have limitations of activity due to chronic physical or mental conditions (see table

6-8). About 0.6 percent of noninstitutionalized U.S. adolescents (or about 1 in every 200) are unable to carry on their major activity (i.e., attending school or working) because of a chronic condition; an additional 4.3 percent are limited in the amount or kind of major activity; and an additional 1.9 percent are limited in an activity other than major activity.

The 1988 NHIS also found that noninstitutionalized U.S. adolescents experienced an average of 8.7 restricted-activity days due to acute and chronic conditions per person (see table 6-10). Newacheck's analysis of 1984 NHIS data found that adolescents with a reported limitation of activity due to chronic illness experienced more restricted-activity and bed-disability days than other adolescents (62). In the Newacheck study, adolescents reporting some limitation of activity due to a chronic condition

Table 6-10-Number of Restricted-Activity Days Due to Acute/Chronic Conditions Among Noninstitutionalized U.S. Adolescents Ages 10 to 18, by Type of Restricted-Activity Day and Sociodemographic Characteristics, 1988^a

Characteristic	Number of days per person in year			Number of days in thousands		
	All restricted-activity days ^a	Bed-disability days ^b	Work- or school-loss days ^c	All restricted-activity days ^a	Bed-disability days ^b	Work- or school-loss days ^c
All persons ages 10 to 18	8.7	4.1	4.7	269,439	127,082	137,604
Age						
10 to 14 years	8.2	3.9	4.5	135,717	64,077	75,286
15 to 18 years	9.3	4.4	5.0	133,722	63,005	62,520
Sex and age						
Male						
All ages (10 to 18)	8.0	3.4	4.5	125,674	52,952	66,710
10 to 14 years	8.3	3.5	4.6	70,051	30,121	39,469
15 to 18 years	7.6	3.1	4.3	55,624	22,831	27,241
Females						
All ages (10 to 18)	9.5	4.9	5.0	143,764	74,130	71,096
10 to 14 years	8.1	4.2	4.4	65,666	33,956	35,816
15 to 18 years	11.0	5.6	5.7	78,098	40,174	35,280
Race and age						
White						
All ages (10 to 18)	9.3	4.4	4.9	233,185	109,763	116,810
10 to 14 years	9.9	4.2	4.8	119,105	56,355	64,751
15 to 18 years	9.8	4.6	5.0	114,080	53,408	52,059
Black						
All ages (10 to 18)	6.6	3.3	4.0	31,844	15,654	17,657
10 to 14 years	5.8	2.7	3.6	15,036	7,061	9,340
15 to 18 years	7.6	3.9	4.5	16,808	8,592	8,317
Family income and age						
Less than \$10,000						
All ages (10 to 18)	11.8	5.8	6.7	43,548	21,182	20,890
10 to 14 years	11.4	5.7	6.9	20,591	10,348	12,471
15 to 18 years	12.3	5.8	6.5	22,957	10,835	8,419
\$10,000-\$19,999						
All ages (10 to 18)	9.1	4.2	5.0	44,637	20,443	23,170
10 to 14 years	8.1	3.8	4.5	21,364	9,951	11,978
15 to 18 years	10.4	4.7	5.7	23,273	10,491	11,192
\$20,000-\$34,999						
All ages (10 to 18)	8.4	4.0	4.8	62,974	29,999	34,933
10 to 14 years	8.6	3.9	4.5	36,231	16,308	19,103
15 to 18 years	8.2	4.2	5.3	26,743	13,681	15,831
\$35,000 or more						
All ages (10 to 18)	8.0	3.9	4.1	84,720	41,411	42,116
10 to 14 years	7.5	3.8	4.2	42,540	21,805	23,891
15 to 18 years	8.6	4.0	4.1	42,180	19,603	18,539
Geographic region						
Northeast	6.7	3.2	4.1	37,896	18,141	21,891
Mideast	9.1	4.1	4.9	72,918	32,805	37,156
South	7.8	3.7	3.9	84,267	40,180	39,935
West	11.4	5.5	6.3	74,358	35,935	38,825
Place of residence						
Metropolitan statistical area	8.7	4.1	4.7	204,409	96,945	104,397
Central city	8.0	3.9	4.4	72,344	35,332	36,799
Not central city	9.1	4.2	4.9	132,065	61,613	67,597
Not metropolitan statistical area	8.7	4.0	4.8	65,030	30,136	33,409

^aFor the purposes of the National Health Interview Survey (NHIS), a *restricted-activity day* is any day on which a person restricts his or her usual activities for more than one half day because of an illness or an injury. Restricted-activity days are unduplicated counts of bed-disability days, work-loss days, school-loss days, and cut-down days.

^bA *bed-disability day* is defined by NHIS as any day on which a person stays in bed for more than half the daylight hours (or normal waking hours) because of an illness or an injury.

^cA *school-loss day* is defined by NHIS as any day on which a child did not attend school for at least half of his or her normal school day because of a specific illness or injury. School-loss days are determined only for children 5 to 17 years of age. A *work-loss day* is defined by NHIS as any day on which an individual did not work at his or her job or business for at least half of his or her normal workday because of a specific illness or injury. The number of work-loss days is determined only for currently employed persons.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1988 data from the National Health Interview Survey, Hyattsville, MD, 1990.

experienced an average of 27 restricted-activity days per year, while other adolescents experienced 7.7 restricted-activity days per year. Adolescents reporting some limitation of activity due to a chronic condition also experienced significantly more bed-disability days than other adolescents: 12.2 bed-days v. 3.7 bed-days (62).

Newacheck found that male adolescents in the 1984 NHIS were more likely to be reported as having a limitation of activity due to a chronic condition than females (7.2 percent of males v. 5.2 percent of females). Younger adolescents were more likely to be reported as having a limitation of activity due to a chronic condition than older adolescents (6.6 percent of 10- to 14-year-olds v. 5.7 percent of 15- to 18-year-olds). Newacheck also found that poor adolescents were 46 percent more likely to be reported as having limitations of activity due to a chronic condition than adolescents living in families with incomes above the poverty line (62).

Not surprisingly, several studies have found that children with chronic conditions miss more school days than healthy children (44). One study found that among children ages 6 to 17, those with chronic mental or physical conditions (e.g., mental retardation, cerebral palsy, or asthma) missed 8.7 days of school, while other children missed 5.8 days of school (17). Another study revealed that students with allergies in nursery school through 12th grade (15 percent of whom were in grades 8 through 12) experienced significantly more absences than non-allergic children (data on magnitude of differences were not presented) (53). Also, one study reported that asthmatic children ages 4 to 16 (one-third of whom were age 12 or older) had an absence rate approximately 24 percent higher than other children (19).

Psychosocial Consequences

McAnarney suggests that social experiences for adolescents with physical disabilities may differ from those of other adolescents in three ways: 1) their exclusion from school activities because of their high levels of school absence, 2) their inability to keep up with their peers physically and their exclusion from some activities because they feel different or ill, and 3) their lack of opportunity for

normal peer interactions, both in and out of school (52).

Only a few studies have examined the associations between chronic illness or disability and psychosocial outcomes for adolescents. Most of these studies suffer from various methodological limitations, including small sample sizes and lack of appropriate control groups (9). In addition, most studies are cross-sectional rather than longitudinal, making it difficult to draw conclusions about causality or about the process of adjustment through the course of an illness or disability. Despite these methodological limitations, existing studies do provide some useful information on young people with disabilities.

In the aggregate, adolescents with physical disabilities appear to be more like than unlike their able-bodied peers with respect to their social maturation (52), but the evidence is not consistent. For example, studies of large cohorts comparing adolescents with and without physical disabilities have generally found that these groups do not differ significantly in their levels of self-esteem. Other studies using samples of adolescents with the same types of disability have frequently found that disabled adolescents have lower levels of self-esteem than nondisabled adolescents (52). Still other research, such as a study of survivors of childhood cancer, have found that adolescents with chronic illness actually score higher on measures of self-concept than do normative samples (21).

A recent study found higher levels of emotional and behavioral problems among adolescents ages 12 to 17 with serious chronic physical conditions than among adolescents without such problems (28). Adolescents with serious chronic physical conditions in this study were particularly likely to be reported by their parents to be depressed and socially withdrawn. Although flawed in some ways,²⁷ this study is impressive in that it was able to disaggregate the effects of socioeconomic status from the effects of having a chronic physical disorder, demonstrating that both have independent effects.

An interview survey comparing matched samples of adolescents with diabetes (n = 31, mean age = 14.7 years) or cystic fibrosis (n = 31, mean age = 14.5 years) with healthy adolescents (n = 31, mean

²⁷A possible flaw not pointed out in the study is that the assessment of problems relied entirely on a child behavior checklist filled out by parents; children and adolescents themselves were not surveyed.

age = 14.5 years) found no statistically significant differences among the three groups on how often they used various strategies to cope with their social and emotional problems, their perceived degree of social support, their feelings of social competency, their perception of control over their life, or feelings of depression (9). However, results indicated that the adolescents with chronic illness were more concerned about their parents' reaction to their health than healthy adolescents were; believed that their parents experienced more stress because of their illness; and were more concerned about their future health (9). The survey found some differences between the adolescents with diabetes and those with cystic fibrosis; adolescents with cystic fibrosis rated their health worse than did adolescents with diabetes or healthy adolescents.

In a study examining depressive symptoms over time in a sample of 17 adolescents ages 13 to 19 with cancer, the mean level of depressive symptoms for adolescent cancer patients did not differ from a general population sample of adolescents (41). As in the general population of adolescents, depressive symptoms for the adolescents with cancer were associated with psychosocial events, such as arguing with parents, breaking up with a girlfriend or boyfriend, or being dissatisfied with one's appearance. Similarly, another study found that depression was uncommon among adolescent survivors of childhood cancer (21). (Other consequences associated with cancer during adolescence are discussed in the following section.)

Normal tasks of adolescence may be particularly difficult for adolescents with serious chronic physical conditions (52). Many of the concerns of adolescents with disabilities are the same concerns experienced by all adolescents, but the concerns may be exacerbated by a disability (52). Adolescents with some disabilities may experience more difficulty in achieving separation and independence from their parents than other adolescents, for example, if they rely heavily on their families for financial and personal assistance. And, although adolescents with disabilities have the same concerns about their sexuality as other adolescents, adolescents with some disabilities may have limited chances to develop their sexuality as a result of constraints that

include the lack of knowledge about or denial of their sexuality by their parents and the adolescents themselves (52). Lack of socialization with able-bodied peers, either because of limited contact or because of negative attitudes among peers towards developing romantic attachments with someone with a disability, also limits opportunities for some adolescents with disabilities to explore their sexuality.

Independence for people with disabilities requires access to the same opportunities afforded to people without disabilities and sufficient capacity to take advantage of those opportunities (87). Thus, independence may require access to a full range of residential alternatives, accessible transportation, and participation in the political process and may also require family support and assistance; personal-care assistance in the activities of daily living; social support from friends, neighbors, and communities; and the application of technology, such as computers. Some adolescents with disabilities need training to improve their capacities to make life choices, such as through life planning, instruction in problem solving, participation in the development of their individualized education program,²⁸ and participation in self-advocacy groups (87). The ability of disabled adolescents to achieve independence depends on the severity of their condition, the ability of their family to cope financially and psychologically with that condition, and their personal motivation to become independent (52).

Prevention of Chronic Physical Illnesses and Disabilities Among Adolescents

Many of the chronic physical illnesses and disabilities that U.S. adolescents experience (except those due to injuries) are not really preventable during adolescence. Some of the illnesses (e.g., cystic fibrosis, heart disease, spina bifida, sickle-cell disease) are congenital conditions that cannot be prevented during adolescence. Other chronic illnesses may develop during adolescence, but for many of them (e.g., cancer, arthritis, diabetes, renal failure), not enough is known to establish protocols for prevention for adolescents. Until effective means

²⁸An individualized educational program for each "handicapped" child is required under the Education for All Handicapped Children Act (Public Law 94-142), which was passed in 1975 (92). The program must include a statement of the child's present levels of educational performance; annual goals, including short-term instructional objectives; and other things specified in the regulations implementing Public Law 94-142.

of primary prevention²⁹ are developed, the emphasis for many chronic illnesses that adolescents experience must be on early intervention³⁰ and other forms of treatment. Clearly, however, efforts can be made to prevent adolescents' disabilities from becoming handicaps (see OTA definition of handicap in box 6-A).

It is important to note that health-compromising behaviors initiated in adolescence may lead to the development of chronic illness among adults. For example, smoking may lead to the development of lung cancer, engaging in unprotected sexual activity may lead to the development of acquired immune deficiency syndrome (AIDS) and other sexually transmitted diseases, and eating high fat diets may lead to an increased risk of heart disease. Attention to the prevention of these and other health-compromising behaviors during adolescence may be warranted.³¹

Services and Interventions for Adolescents With Chronic Physical Illnesses and Disabilities

Use of Health Services by Adolescents With Chronic Conditions

Adolescents with chronic conditions have more contact with the health care system than do other adolescents. According to 1984 NHIS data, adolescents with a chronic condition (mental disorders included) have more physician contacts annually than other adolescents (8.8 physician contacts v. 2.7 physician contacts) (62). They are also more likely to experience a hospitalization (0.181 hospitalizations per year v. 0.038 hospitalizations per year). Furthermore, when adolescents with a chronic condition are hospitalized, they spend nearly twice as long in the hospital as adolescents without such conditions (9.1 v. 4.8 days on average) (62).

A survey of 456 children ages 3 to 18 (no further age distribution was provided) with chronic physical conditions (i.e., cystic fibrosis, cerebral palsy, myelodysplasia, or multiple physical handicaps) found that these children were far more likely than a randomly selected comparison group of children from the same region to be hospitalized during the year (34 percent were hospitalized v. 6 percent of controls) and to have more lengthy periods of hospitalization (11.0 days v. 3.7 days for controls) (81). A relatively small subset of children in the study accounted for the majority of health care use; 75 percent of all outpatient use was accounted for by 25 percent of the sample, and all hospital care was accounted for by 33 percent of the sample.

Similar results were reported from an analysis of 1980 data from the National Medical Care Utilization and Expenditure Survey (NMCUES) by Newacheck and McManus (65). Children and adolescents with activity limitations due to chronic conditions (mental disorders included) were twice as likely to be hospitalized, made twice the number of visits to physicians, and saw nonphysician health care professionals (e.g., physical therapists, social workers) five times more frequently than children and adolescents without activity limitations due to chronic conditions.

Costs of Treatment for Adolescents With Chronic Conditions

Little is known about the total costs of medical services for chronically ill children in the United States (66). There is no single source of information on the full range of costs of care for people with chronic conditions, including adolescents. Total expenditures include personal expenses; expenditures reimbursed by insurance companies; services provided by private organizations; and costs of various

²⁹The traditional taxonomy of prevention distinguishes among primary, secondary, and tertiary prevention (see, e.g., 93a). *Primary prevention* refers to activities designed to avoid disease or other conditions that adversely affect health. *Immunizations* are one example of primary prevention but regulatory activities to protect health (health protection) are also forms of primary prevention. *Secondary prevention* includes efforts to identify existing conditions that could cause illness and disability before the appearance of clinical symptoms, or to minimize the progression of disease. Screening for the existence of disease is one form of *secondary prevention*. *Tertiary prevention* refers to efforts to control irreversible chronic conditions in order to avoid disability or death. Some have suggested that this typology does not adequately distinguish among preventive services (see 93a). Another way to characterize preventive services is by the target of an intervention (e.g., the environment, the individual) and the intended beneficiary (usually individuals).

³⁰As described above, *secondary and tertiary prevention (but especially tertiary prevention) can include treatment. In this Report, the term early intervention* is also used for treatment services delivered before a problem becomes serious and/or chronic.

³¹*Prevention of smoking is covered in this volume in ch. 12, "Tobacco, Alcohol, and Drug Abuse: Prevention and Services"; prevention of AIDS is discussed in ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services"; and nutrition and fitness problems among adolescents are covered in ch. 7, "Nutrition and Fitness Problems: Prevention and Services."*

Federal programs, such as Medicaid, that provide coverage for health care of people with disabilities.

One study that defined disability as having a reported long-term limitation in usual activities (e.g., school) estimated that U.S. children and adolescents with disabilities accounted for a relatively small proportion—\$ 3.9 billion in 1986 dollars (10.9 percent)—out of a total of \$35.7 billion in charges for health services provided to persons under the age of 21 (65).³² In this study, the four leading reported causes of disability for individuals under age 21 were mental and nervous system disorders (prevalence of 7.3 cases per 1,000), followed by respiratory diseases (6.0 cases per 1,000), musculoskeletal and connective tissue diseases (4.3 cases per 1,000), and eye and ear diseases and disorders (3.7 cases per 1,000).³⁵

Other evidence suggests that children and adolescents with chronic physical conditions have significantly higher health care costs than other children. For example, one report estimated that a sample of chronically ill and disabled children ages 3 to 18 with cystic fibrosis, cerebral palsy, myelodysplasia, or multiple physical impairments averaged 10 times the yearly expenditures for health care of a general population comparison group of children (81). Half of this difference was accounted for by the greater amount of hospitalization experienced by the children with chronic physical illness and disability.

The costs of care for children and adolescents with chronic conditions are not evenly distributed across this population. In a ranking of children and adolescents under age 21 who were reported to have activity limitations due to chronic conditions in the 1980 NMCUES according to their total health charges, the 10 percent who experienced the greatest health care expenses accounted for 65 percent of all charges accumulated by the children and adolescents with activity limitations (65). Those who

experienced the highest total health care costs were most likely to be between ages 16 and 20.

An estimated 14 percent of adolescents with chronic conditions do not have health insurance—about the same percentage as for adolescents without chronic conditions (62,93).³⁶ Because adolescents with chronic conditions often have high health care expenses, it is critical that they have health insurance. In addition to needing basic coverage provided by most health insurance policies, many adolescents with chronic conditions need more extensive coverage, such as for mental health services, prescription drug coverage, and long-term care benefits.³⁷ Even those who do have adequate health insurance coverage may incur significant related expenses that are not covered (e.g., travel to health care centers) (61). Thus, families shoulder a significant burden of costs of care for chronically ill children of all ages (7,37), although the extent of the family role is often not considered by policymakers (37). Moreover, excessive burdens to the family may be a factor in a family's decision to institutionalize a chronically ill child rather than attempt to care for the child at home.

Few studies have assessed the actual economic impact of caregiver costs on families with a seriously chronically ill or disabled child. Available studies use different methods and categories of costs and focus on children of different ages with different types of disabilities (sometimes including mental illness and mental retardation). Consequently, it is difficult to generalize the results to all children with chronic physical illness or disability, particularly adolescents, or to assess the overall economic burden to these families. Nonetheless, it is clear that substantial family **costs are** associated with the care of chronically ill or disabled children (37).

Analyses of the health care costs borne by families of chronically ill or disabled children in

³²Data were collected as part of the 1980 NMCUES. Figures were adjusted up to 1986 levels using the medical care component of the Consumer Price Index (65).

³³The population considered in this study is a subset of the population with chronic conditions, which also includes people who have chronic conditions but who do not suffer activity limitations.

³⁴In 1980, individuals under 21 constituted 34 percent of the U.S. resident population (93b).

³⁵These four categories accounted for just over half of reported disabilities in the survey. Note that individuals with disability as a result of mental and nervous system disorders, which include mental retardation and neurotic and personality disorders, are included in these analyses. It is not possible, however, to determine from the data presented (65) what the impact of these disorders is relative to other causes of disability.

³⁶These analyses included adolescents with chronic mental, as well as physical, disorders.

³⁷See ch. 16, "Financial Access to Health Services," in Vol. III for further information on adolescents' health insurance status and health insurance benefits.

general (or by society) have been scarce (65). Newacheck and McManus' analysis, based on data from the 1980 NMCUES, suggested that only a small fraction of families incur "catastrophic costs, but that analysis was limited by NMCUES' small sample size (65). Of the 6,245 persons younger than age 21 in the sample, only 249 were reported to be limited in their activities. According to Newacheck and McManus, the small sample implies that few children with low prevalence, very serious and costly, chronic conditions will be represented in the sample. In addition, the NMCUES sample excludes the institutional population, and thus excludes a large segment of the most severely ill children and adolescents. Also, the NMCUES data were collected in 1980 and 1981, when children were often hospitalized rather than cared for at home and when health care costs were lower. Finally, NMCUES interviewers were instructed to indicate to survey respondents that limitation of activity refers to a limitation caused by long-term illness or disability *only* when a respondent asked for clarification; in some cases, therefore, a limitation reported in the NMCUES may have been caused by an acute, rather than a chronic, condition. Although Newacheck and McManus suggest that the number of such cases should be small (and that other features of the NMCUES questions could compensate for the ambiguity about chronicity), the small overall number with reported limitations in activity still invites cause for concern. Thus, a particular finding from Newacheck and McManus' analysis should be viewed very cautiously—namely, the finding that families of all children with limitations in activity averaged \$135 in 1980 dollars per child in out-of-pocket expenses for health care and that families of the 10 percent of children consuming the greatest amount of care averaged \$300, while families with children without activity limitations averaged \$76.

A study by Butler et al. examining sources of payment for physician visits by disabled children³⁸ (about a third of the 1,726 children in the study were ages 11 to 13) found that in families without health insurance, parents paid all of the costs of the visit 70.6 percent of the time (8). In families with private health insurance, parents paid all costs 30.7 percent

of the time and partial costs 44.3 percent of the time; in families with public health insurance, parents paid all costs 4.6 percent and partial costs 2.8 percent of the time. Whether children with disabilities had seen a physician in the past year was significantly associated with whether the children were covered by insurance, even after controlling for survey site, race and ethnicity, socioeconomic status, age, and type of disability. Disabled children with health insurance were 1.8 times more likely to have seen a physician than those without insurance.

Jacobs and McDermott's review of three studies of family caregiver costs for chronically ill and disabled children concluded that: 1) estimated *incremental money costs* (i.e., apart from the costs of therapy) to families of children (ages unspecified) with cancer ranged from \$1,121 to \$4,012, and 2) estimated *annual time costs* (e.g., family members giving up time from work and other activities) ranged from \$1,514 to \$4,697, for a total range of estimated incremental money costs from \$3,000 to \$9,000 annually (37). Two studies that met minimal methodological criteria and covered other serious chronic diseases were also subject to review. One of the studies, on cystic fibrosis, found an annual incremental money cost of \$334, but the reviewers were unable to estimate the incremental time or money costs to families of a child with spina bifida (37).

In conclusion, current estimates of the financial costs to families of chronic illness and disability among adolescents are highly variable, and more research on this topic is warranted.

/interventions To Treat Psychosocial Problems of Adolescents With Chronic Conditions

In a 1990 review of the association of chronic physical health problems and behavioral or emotional problems, Gortmaker and colleagues concluded that, despite general acceptance of the idea "that children with chronic conditions are at higher risk for developing behavioral problems," the literature contains few accounts of systematic, well-documented attempts to prevent or ameliorate these functional problems" (28).

³⁸This study classified children as disabled on the basis of enrollment in special education classes. The primary disabling condition of about a third of the children in the sample was a neuromuscular, orthopedic, or sensory impairment or a chronic disease. The remainder of the disabled sample included children with problems such as learning disabilities, attentional deficits, mental retardation, speech impairments, or emotional or behavioral dysfunctions (8).



Photo credit: Katherine Criss, New York, NY

Independence for adolescents with disabilities may require access to the same opportunities in life afforded to people without disabilities.

The Gortmaker review found only five accounts of systematic, well-documented attempts to prevent or ameliorate chronically ill children's psychosocial problems (28). All but one of the studies found beneficial effects, but only two of the programs included or focused on adolescents (28). Two studies with small samples documented the effectiveness of educational programs geared to increase health knowledge and self-care and to improve the functioning of children with asthma (18,46). A randomized controlled trial of a university hospital-based home care program for children with a broad range of long-term health needs demonstrated beneficial effects on the psychologic functioning of the children (82). Pless and Satterwhite found that a lay family counselor intervention also improved psychosocial functioning of children with chronic physical health problems (73). On the other hand, a randomized controlled trial of a social work intervention conducted by Nolan et al. at Montreal Children's Hospital indicated no effects from a 6-month intervention intended to improve psychosocial functioning for children with chronic physical conditions (68).

The two programs that included or focused on adolescents were the lay family counselor intervention (73) and the social work intervention in Montreal (68). Both of the programs focused on providing assistance to families as a whole (primarily parents), although it was the aim of the programs to improve the psychosocial status of the adolescents. Differences between these two programs may be helpful in evaluating why one failed and the other did not. The program reported by Nolan et al. was a

short-term (6-month) intervention in which social workers had minimal (an average of three times) personal contact with some member of the family (68). Half the families did not find the intervention helpful. Although the program reported by Pless and Satterwhite used lay volunteers rather than professionals, these lay volunteers were able to spend much more time with the families (an average of 4.6 hours per month with each of eight families) over the course of a year (73). Pless and Satterwhite found that children's psychological improvement increased with the amount of time spent by the lay counselor (73). In addition, the lay volunteers were chosen on the basis of their personal characteristics and proven success in childrearing, which Pless and Satterwhite asserted might not be possible to do with professional staff (73).

One of the main issues for adolescents with serious chronic physical illnesses or disabilities is the development of greater independence (49), and a number of programs have developed to enhance the capacities of adolescents with serious chronic physical illnesses or disabilities to be independent. Some programs employ interdisciplinary teams to assess and provide services to adolescents with chronic illness or disability. One such program is the Comprehensive Adolescent Medicine program at the Montefiore Medical Center in New York City. The program, originally funded by the Robert Wood Johnson Foundation in 1979, provides chronically ill young people ages 10 to 20 with comprehensive, interdisciplinary care designed to help them develop into independent adults. The program serves between 450 and 500 young people each year (77).

Another program, the Youth in Transition Project at the University of Washington in Seattle, is a demonstration project funded by DHHS' Bureau of Maternal and Child Health. This program is designed to facilitate transitions from high school and home to employment and independent living for individuals ages 17 to 21 with developmental disabilities, cognitive impairments, or chronic physical illness (10). Each participant in the project receives an extensive evaluation from an interdisciplinary team including a physician, nutritionist, psychologist, and a social worker. A transition plan is then developed that might include, depending on the needs of the adolescent, vocational planning, life skills training, sexuality education, and nutrition education and a diet plan. Followup is then provided to determine how clients are progressing in their

transition and whether assistance is needed in implementing the transition plan. Preliminary evaluations of the demonstration project based on the first 27 clients indicate that families found the assessment process useful.

Other types of programs focus on experiential learning for adolescents with chronic illness or disability to increase their sense of personal efficacy. Adventure, Inc. is a program that provided an Outward Bound experience, consisting of a 9-day wilderness and a 5-day urban experience, for chronically ill, physically disabled, and able-bodied adolescents (42). After participating in the program, both able-bodied adolescents and adolescents with disabilities or chronic illnesses, showed improved body image, declines in family conflict, and increases in individual recreational activities relative to family recreational involvement. Although the study is limited by a small sample size ($n=37$, 23 of whom were chronically ill or disabled), the study does indicate the potential of an Outward Bound type of program for developing independence for adolescents with chronic illness or disability.

Another program, the Adolescent Employment Readiness Center at Children's Hospital National Medical Center in Washington, DC, has provided vocational services, including vocational aptitude and aptitude testing and job placement, to over 100 young people ages 12 to 19 with chronic health problems such as juvenile rheumatoid arthritis, spina bifida, muscular dystrophy, kidney failure, diabetes, epilepsy, and cystic fibrosis (12). The program, which was funded by a grant from the DHHS Bureau of Maternal and Child Health, is designed to improve prevocational readiness and enhance independence. Through the program, adolescents are placed in volunteer or paid jobs ranging from clerical jobs to lifeguarding. An evaluation of this program is under way, but no outcome data are available yet (118).

State and Local Services for Adolescents With Chronic Conditions

Assistance may be available for adolescents with physical or mental disabilities from a variety of State agencies depending on the State (36). These agencies include State departments of education, which

provide special education services; offices of State coordinators of vocational education for handicapped students, which coordinate vocational education services; and State mental health departments. Other sources include State mental retardation agencies, programs that have received funding from the DHHS Bureau of Maternal and Child Health for direct medical and related services to children with special health care needs, and State developmental disabilities agencies. State protection and advocacy systems provide services to persons with developmental disabilities, and State vocational rehabilitation agencies provide services needed to prepare persons with disabilities for work. Finally, a number of universities have university-affiliated programs, which provide services and programs for children and adolescents with disabilities and their families. There is considerable variability across States in how these various services are provided, and in where the various functions are housed organizationally.

According to Blum, there are major problems in the care of adolescents with chronic illness and disabilities (5). These include the lack of coordinated care among subspecialist services; provider ignorance of the various health, education, and social services in the community; a lack of attention on the part of health care providers and policymakers to providing for adolescents' transition to the adult health care system; and failure to address the sexual and reproductive needs of adolescents with chronic illnesses and disabilities.

Some observers have noted that services to children with chronic illness are frequently disease specific (72). That is, often specialized services emerge to address the needs of persons with only certain types of disorders. Voluntary and advocacy organizations, which represent only one or a few disorders, rarely coordinate their advocacy efforts. The result is that policies are made or programs are developed that address specific concerns of advocates for specific problems, rather than the generic needs of people with varying types of disabilities. In addition, the needs of children with illnesses without effective advocates may not be addressed in the policy domain.

³⁹There are notable exceptions to this lack of coordination, for example, the Technology-Related Assistance for Individuals With Disabilities Act of 1988 (Public Law 100-407), which was actively backed by a broad coalition of organizations and individuals in the disability community. However, the coordinated effort was to encourage the passage of legislation not to actually provide services.

Examples of Chronic Physical Illnesses Among Adolescents

OTA has used the available information on the prevalence and importance of chronic physical health problems to identify for further discussion in this chapter one serious problem—cancer—and two problems with less dire consequences—acne and dysmenorrhea. Each of these illnesses illustrates certain important issues about services to treat physical illness in adolescents.

Cancer was chosen because it is the most frequent cause of natural death (i.e., death caused by illness, disease, or chronic conditions as opposed to death caused by external causes such as accidental injuries, suicide, or homicide) among U.S. adolescents. Adolescents with serious chronic illness such as cancer and their families merit public attention for these major reasons:

- significant public funds are consumed by these children, particularly for health care;
- the needs of children with chronic illness are not likely to be met by the existing health care system; and,
- thanks to the advances in technology and health care over the past several decades, significantly greater numbers of children with chronic illness are now surviving into adolescence and adulthood (72).

Cancer is a low prevalence disease that has very serious short- and long-term consequences for adolescent victims and their families.

Acne is a leading cause of adolescents' visits to office-based physicians, and it is identified by adolescents as an important concern. Usually thought of by adults as a minor problem, common acne (acne vulgaris) is experienced by the vast majority of U.S. adolescents.

Dysmenorrhea (painful menstruation) is a problem for many young women, and it contributes significantly to school-loss days among adolescent females (39,44,120). Although identified by adolescents as an important concern, dysmenorrhea may not be adequately addressed by health care providers.

Cancer Among Adolescents

Cancer is the leading cause of *natural death* among U.S. adolescents. For U.S. adolescents ages

10 to 14, malignant neoplasms (cancer) are the *second* leading cause of death, following accidental injuries; for U.S. adolescents ages 15 to 19, malignant neoplasms are the *fourth* leading cause of death, following accidental injuries, suicide, and homicide (103).

While the number of adolescents dying from cancer is small, and cancer treatment represents only a small portion of health care services delivered to adolescents, a number of issues specific to cancer are important to address. Adolescents with cancer, and their families, suffer devastating personal effects as a result of treatment, and the costs to families of cancer treatment are high. Cancer and cancer treatment put adolescents at risk for a number of short- and long-term physical problems, and death.

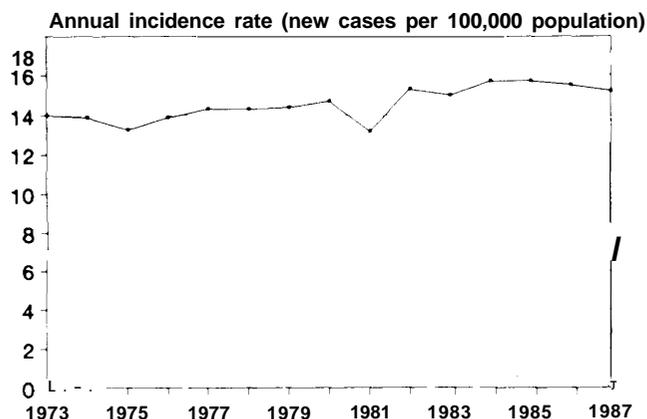
Trends in the Incidence and Prevalence of Cancer Among Adolescents

U.S. adolescents generally have lower cancer rates than Americans in other age groups. However, adolescents ages 10 to 19 experience the highest rate of bone cancer except for those ages 60 and above. And, they experience more acute lymphoblastic leukemia, the most common form of leukemia experienced by adolescents, than all Americans except those ages 9 or younger, or 80 and above (110). In general, the incidence of cancer among U.S. adolescents has remained relatively stable since the early 1970s (see figure 6-2), with the exception of acute lymphoblastic leukemia, which has increased in incidence (110).

Substantial advances in treatment of childhood cancers have led to declining death rates in recent years (see figure 6-3). Between 1960 and 1984, 5-year survival rates among children of all ages increased from 20 to 48 percent for bone cancer, from 52 to 91 percent for Hodgkin's disease, from 33 to 82 percent for Wilm's tumor, from 35 to 55 percent for brain and nervous system cancers, and from 18 to 60 percent for non-Hodgkin's lymphoma (110).

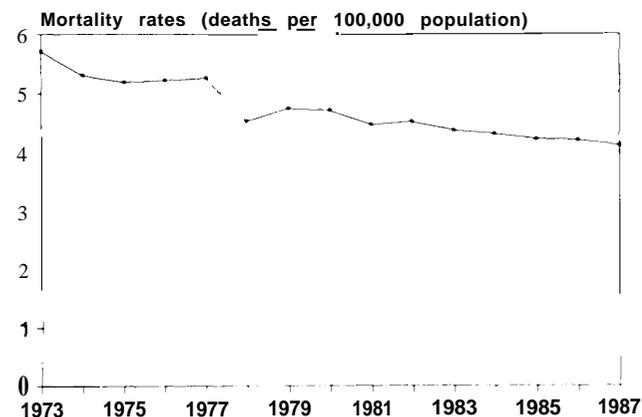
Dramatic increases in survival have also been realized for leukemia among young people. While as recently as 40 years ago nearly all children diagnosed with leukemia died of the disease (83), about half of the white males and females ages 0 to 14 diagnosed with leukemia in 1979 survived 5 to 6

Figure 6-2—incidence of Cancer Among U.S. Adolescents Ages 10 to 19, 1973-87



SOURCE: Office of Technology Assessment, 1991, based on U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, National Cancer Institute, unpublished Surveillance, Epidemiology, and End Results Program data, Bethesda, MD, 1989.

Figure 6-3-Cancer Mortality for U.S. Adolescents Ages 10 to 19, 1973-87



SOURCE: Office of Technology Assessment, 1991, based on U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, National Cancer Institute, unpublished Surveillance, Epidemiology, and End Results Program data, Bethesda, MD, 1989.

years (110). Nevertheless, leukemias, followed by brain and central nervous system cancers, are the most common cause of cancer deaths among U.S. adolescents.

Consequences of Cancer Among Adolescents

Increases in survival among cancer patients mean that more individuals contracting cancer during early childhood will survive into adolescence and that persons with cancer during their adolescence have a high probability of surviving into adulthood. There are a number of significant short- and long-term consequences of cancer for adolescents.

Short-Term Consequences for Adolescents--Short-term consequences of cancer include the side effects of treatments, interruptions in major academic and socializing activities, and the psychological distress that may arise from these more overt consequences.

The side effects of cancer treatments such as radiation and chemotherapy can be devastating for adolescents. In a study involving interviews with 40 survivors of childhood and adolescent Hodgkin's disease (70 percent of whom were ages 12 to 19 at the time of diagnosis), half of the respondents reported that the "worst" thing about having Hodgkin's disease was experiencing the side effects of treatment (115). A study by Wasserman et al. of survivors of childhood/adolescent Hodgkin's disease found that females, in particular, were likely to identify side effects of treatment (especially loss of hair) as the most traumatic part of their illness (115).

Immediate side effects of treatment include nausea and vomiting and pain associated with the administration of the chemotherapy agents. Ulceration of the mouth or gastrointestinal tract are also common side effects, appearing several days after a dose of chemotherapy (57). Radiation and chemotherapy frequently lead to loss of hair (alopecia), necessitating the use of a wig or appearing bald in public (33). These side effects of treatment can be particularly difficult for adolescents because of their heightened concern about their appearance and relationship to their peers.

Individuals receiving treatment for cancer also are particularly susceptible to secondary infections (83). Even after they receive treatment, some individuals experience anxiety about their condition. In a 1988 study, a quarter of the 41 survivors of childhood cancer interviewed were extremely preoccupied with their physical condition (21).

Young people with cancer may find it difficult to keep up with school. The need for frequent treatments, often at a distance from home, may result in high levels of school absence. Many school systems provide good in-home tutoring services, but the quality of services is not consistent across schools (69). Individuals interviewed in Wasserman et al.'s retrospective study of the effects of childhood and adolescent cancer missed an average of 6 months of school while they were undergoing treatment (115). Some may drop out of school after extended absences (115). Even when young people return to

⁴⁰Data presented are for white children only; data for black children are unreliable because of small sample sizes.

school, they may find that they are ostracized by their peers. Forty percent of those interviewed in the study by Wasserman et al. remembered being teased about their appearance or being treated as outcasts (115).

Long-Term Consequences for Adolescents--Long-term side effects of cancer can also be quite serious and include secondary cancers, sterility, and growth retardation (13,57,83,115). Chemotherapy and radiation can also result in gonadal damage, resulting in smaller testes for males (76). The long-term effects of gonadal damage resulting from chemotherapy and irradiation may not become evident until adulthood (e.g., sexual dysfunction, increased risk of heart disease) (76). Females treated for leukemia with chemotherapy and radiation have been found to experience significantly earlier breast development, to have a lower mean age of menarche than average, and to go through puberty in a shorter period of time than average. This early puberty and limited potential for growth can have a number of psychological effects on adolescents. Secondary cancers are also possible sequelae of cancer treatment (57).

Adolescent cancer can also have long-term social or emotional effects. For example, evidence indicates that survivors of childhood cancer often confront employment discrimination and discrimination in obtaining life and health insurance policies (111). For people who do not belong to group health insurance policies (e.g., through an employer), health insurance may be very expensive or even unobtainable (115). Discrimination may occur in other areas as well; Wasserman et al. found that 5 of their 23 male subjects reported being denied entry into the armed forces because of their cancer history (115).

Available evidence suggests that most adolescent survivors of childhood cancer do not experience higher levels of depression or lower levels of self-esteem than other adolescents (29). Survivors with severe long-term medical effects (e.g., physical disfigurement, loss of a limb, gonadal failure, or second malignant neoplasm) tend to experience greater levels of depression and to have a lower self-concept than survivors with no long-term cosmetic or organ dysfunction (29).

Many survivors of childhood cancer actually identify positive effects of their experience with cancer. One study reported that 61 percent of the adolescent survivors of childhood cancer interviewed identified positive effects, such as increasing their self-confidence, enabling them to be more empathetic, increasing their appreciation of life, and making them more mature (21). Likewise, Wasserman et al. found that 95 percent of adult survivors of child or adolescent Hodgkin's disease identified positive consequences (115).

Prevention of Cancer Among Adolescents

Most cancers that occur during adolescence could not have been prevented given the current state of knowledge. Except for the relationship between prenatal radiation of a pregnant mother and childhood leukemia (6,79), little is known regarding the cause of leukemia. The risk of secondary leukemia increases with certain types of cancer chemotherapy (110).

Discussions about preventing cancer in adolescents generally focus on the prevention of future cancers that are linked to engaging in health-compromising behaviors (e.g., 51). These behaviors, which may be initiated or established during adolescence, include smoking, drinking alcohol, using certain contraceptives, eating habits, and tanning. Results of the 1987 National Adolescent Student Health Survey of more than 11,000 8th and 10th graders found that these adolescents had a number of eating practices that may increase their risk of cancer later in life. These include high consumption of fatty foods (59 percent reported eating fried foods one to three times weekly and 39 percent did so more than three times weekly), and a lack of knowledge about some risk factors for cancer (e.g., few were aware of the role of dietary fiber in the prevention of colon cancer) (74).

Other behaviors common among U.S. adolescents, such as tanning, may increase the risk of developing cancer later in life. A survey including 126 adolescents, conducted by the American Academy of Dermatology, found for example, that 67 percent of adolescent females and 33 percent of adolescent males reported intentionally working on a tan and that they did not take precautions from the

⁴¹Adolescents' smoking and alcohol use is discussed in ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," their nutrition and eating habits are discussed in ch. 7, "Nutrition and Fitness Problems: Prevention and Services," and their contraceptive use is discussed in ch. 10, "Pregnancy: Prevention and Services," all in this volume.

sun (23). Although similar percentages of adults reported working on a tan, fewer (23 percent) took no precautions to protect themselves from the sun. Seventy-five percent of adolescents (compared to 66 percent of adults) believed tans make people look healthy. Overexposure to the sun, however, can have dangerous outcomes. In a study of melanoma in women, those who reported having five or more blistering sunburns between the ages of 15 and 20 were more than twice as likely to have developed malignant melanoma by ages 38 to 65 (the age group surveyed) as were those who had experienced no such burns (16). This exposure during the adolescent years was found to be a much more important determinant of melanoma incidence than exposure after the age of 30. Preventive efforts should focus on the behaviors of children and adolescents to reduce their intensive sun exposure.

There is evidence that many U.S. adolescents do not have accurate knowledge about the etiology, warning signs, prevention, and treatment of cancer. A survey of 870 inner-city junior and senior high school students (mean age = 14) found a significant lack of understanding about cancer (75). Although most (approximately 90 percent) recognized the association between cigarette smoking and cancer, fewer than half recognized the role of nutrition. Of the seven warning signs of cancer recognized by the American Cancer Society (ACS), only the sign of a lump or bump in the breast or elsewhere was identified as a warning sign of cancer by more than half the students.

The study found differences between white and black adolescents in their understanding of cancer. Only 9 percent of the black students and 3 percent of the white students knew that blacks are more likely than whites to get cancer and to die from cancer. In addition, fewer black than white students believed that they could get cancer. Perhaps most critically, the black adolescents were significantly less likely than whites to see the value of early treatment for cancer or to believe that cancer can be cured. Thus, there appears to be a need, particularly for some adolescents who may be at highest risk for developing cancer in the future, to increase knowledge about risk factors, warning signs, and the importance of early detection and treatment.

In 1985, the ACS appointed a National Public Education Subcommittee on Youth Education that developed a "Plan for ACS Youth Education

Program" (15). ACS initiated a campaign to increase awareness of childhood and adolescent cancer (83) that includes a book by humorist Erma Bombeck (40) and a "Peanuts" television special (16). ACS also sponsors a variety of public education programs, including programs targeted at elementary, intermediary, and secondary school students. The programs include educational strategies designed to promote good health habits among young people, help them make health-enhancing lifestyle decisions, and help them understand the relationships between health behaviors and cancer risk reduction (2).

Services and Interventions for the Treatment of Adolescent Cancer

Cancers in adolescents are most frequently discovered by primary care physicians (33). Most childhood cancers are detected at early stages, as parents are likely to seek medical care soon after observing a health problem (10). Current methods of treating cancer generally have to be offered in tertiary care facilities that provide sophisticated multidisciplinary care to cancer patients (55). Although much treatment must take place in these cancer centers, however, the primary care physician in the community can still play an important role. He or she can act as a link between the family and the cancer center, administer certain drug treatments (particularly during the maintenance phase), and monitor the adolescent with cancer during followup.

Because cancer centers are often some distance away from the adolescent home, families frequently incur extensive nonmedical costs when the adolescent is at the treatment center, such as travel and lodging costs and lost wages because of time away from work. It is believed that the use of community-based care, in coordination with treatment at a tertiary center, has the potential to greatly reduce these economic costs to the family (55).

Despite the difficulties inherent in undergoing treatment for cancer, some evidence indicates that adolescents are generally cooperative partners in treatment, although little research exists in this area. One study covering adolescents' compliance with treatment, however, found older adolescents to be less compliant than younger adolescents, suggesting that the transfer of greater responsibility for treatment from parent to adolescent may be associated with greater noncompliance in adolescents struggling to gain autonomy (85). Similarly, in a study

with 27 adolescents in remission from cancer (ages 12 to 18), adolescents were rated by nurses as being moderately cooperative with treatment, though older adolescents were rated as being less cooperative than younger adolescents (38). Compliance with orally administered chemotherapy agents may be increased if adolescents and parents agree on who is responsible for administering the medications, although older adolescents may still tend to be less compliant than younger adolescents even when they agree with their parents on medication instructions (85). (85).

There is evidence that while younger children with cancer may be more comfortable with not fully understanding the seriousness of their disease, adolescents appreciate being kept informed throughout their diagnosis and treatment and have a good understanding of their treatment (115). Efforts to improve the quality of life of adolescents with cancer by reducing the negative effects (e.g., loss of hair, nausea, risk of secondary cancers) of treatments are greatly needed. Strategies include developing mechanisms for best identifying leukemia patients at highest risk of relapse so patients at most risk may be targeted for more extensive treatments and patients at least risk will not have to endure longer courses of therapy (13).

Interventions for the Treatment of Adolescent Cancer—Substantial support for basic and clinical cancer research and patient activities comes from private sources such as ACS. ACS has an affiliation agreement with the Candlelighters Childhood Cancer Foundation that links over 250 parent self-help groups for families of children and adolescents with cancer (56). These groups can provide families a diverse range of support including funds for wigs or prostheses, educational information, peer counseling, and a forum for discussion of common concerns.

Supportive services provided by ACS include the provision of home-care items, transportation services, and patient and family education. Of the 1986-87 ACS budget of \$306.23 million, 28 percent went to research, 19 percent to public education, 13 percent to patient services, and 10 percent to professional education (2).

Barriers to Treatment for Adolescents With Cancer—A significant barrier to care for adolescents

with cancer is the current state of available treatment. Although significant advances have been made in the development of treatments that increase survivability, the treatments themselves may reduce the quality of life to the extent that adolescents and their parents may question their value.

Adolescent medicine specialists, and health care providers who feel competent to work with adolescents, are relatively few in number.⁴² Adolescents, however, have a number of special concerns related to their treatment for cancer that need to be addressed. For example, they must adjust to the impact of the illness and treatment on their relationships with their peers, their sexuality, and their developing independence. In addition, adolescents' understanding of the disease and its implications will be more sophisticated than those of young children because they are more advanced developmentally and more capable of abstract reasoning.

Costs of Cancer Treatment for Adolescents—Even for adolescents with health care coverage, the costs of cancer treatment can be staggering. For adolescents in geographically isolated areas, which are likely to be farther from pediatric cancer centers, these problems can be even more burdensome (3,69). Some families may even lose their homes. A witness at a hearing of ACS reported that his 13-year-old daughter was hospitalized 63 times in one year because of an abdominal tumor; the family was eventually evicted for falling behind in their rent because of medical bills (3).

Pendergrass et al. followed for 2 years the total hospital costs for 24 children (no ages specified) diagnosed with leukemia at a Seattle hospital in 1979 (69). They estimated that the first-year therapy costs for children with acute lymphoblastic leukemia averaged \$12,334, with a range from \$2,000 to \$40,825. For the 10 children who completed 2 years of therapy, costs averaged \$21,114 for 2 years, with a range from \$2,958 to \$52,343. Many of these costs were probably covered by insurance. However, these estimates included only treatment costs within the site where participants were identified; they did not include other physician fees or out-of-pocket expenses for the families. Thus, they are conservative estimates of the actual costs of care for these children.

⁴²For further discussion see ch.15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents," in vol. III.

Data for the study by Pendergrass et al. were collected in 1979 when bone marrow transplants for leukemia were extremely rare. Bone marrow transplants have been a major factor in improving leukemia survival rates. However, for a child with leukemia who requires a bone marrow transplant and does not have access to a compatible donor, the limited information available suggests that costs can go well beyond what insurance will cover. In interviews with four transplant centers for a 1990 staff paper, OTA found that the costs of locating an unrelated donor ranged from \$13,810 to \$20,475 (1 13). Information is scarce on the costs of the procedure itself; one transplant center puts the range at \$150,000 to \$250,000 (67).

In 1989, researchers examined the so-called ‘ ‘incremental’ costs to families of caring for children with cancer (no ages were specified) (37). Cost categories in the study included direct home costs, travel costs, durable equipment and other capital costs, and time costs (i.e., family members giving up time from work and other activities) but did *not* include costs of therapy. In analyzing the three studies that provided data on such “incremental” costs, the researchers found that estimated annual money costs ranged from \$1,121 to \$4,012 across the studies; estimated annual time costs ranged from \$1,514 to \$4,697. Overall, total incremental costs (including time costs) represented about 28 percent of family incomes.

Major Federal Policies and Programs Pertaining to Cancer Among Adolescents

The National Cancer Institute (NCI) within DHHS provides the major Federal support for research on cancer. Currently funded basic research includes study of the basic biology of normal and malignant hematopoietic cells to learn more about the origin and progression of leukemia, studies of drug metabolism in leukemia patients to learn more about disease and treatment-related changes in these patients, and studies to predict which patients might benefit most from additional therapy (1 11). NCI is also currently funding a followup study of childhood leukemia survivors through early adulthood to learn more about the effects (especially endocrinologic effects) of the disease and its treatment. Other epidemiologic studies are examining the environmental and genetic risk factors for developing leukemia (both acute lymphocytic leukemia and nonlymphocytic leukemia). Other studies focus on

different childhood cancers. One study is assessing the risk of developing leukemia and other cancers after intensive chemotherapy and radiation therapy for Hodgkin’s disease. Another is examining exposure to N-nitroso compounds as a risk factor for developing brain tumors during childhood and adolescence. Other studies are examining the effects of various treatment therapies on different cancers (111).

NCI also provides support for programs and research studies that focus on the physical and psychological health of cancer patients (1 11). These include teen support groups to aid adolescent patients, pain management and stress-reduction programs for young cancer patients, and programs that focus on reducing the psychological side effects of cancer treatments, including a study identifying and monitoring the effects of cancer and treatment on the neuropsychologic development of children with leukemia. Another focus of support for NCI is on interventions that minimize the social and academic difficulties of long-term childhood cancer survivors. One currently funded study is focusing on increasing school attendance of children with newly diagnosed cancer. It is anticipated that the provision of ongoing scholastic and peer involvement will help to counteract the anxiety and depression experienced by severely ill patients. Another main focus of NCI funding is on prevention. This includes support for antismoking efforts and nutrition studies.

Acne Among Adolescents

Acne vulgaris, or common acne, is a disorder of the sebaceous (or oil) glands, sebaceous ducts, and hair follicles that results in skin eruptions. The vast majority of American adolescents experience acne. An estimated 90 percent of adolescent males and 80 percent of adolescent females are affected with acne to some degree (33). Some adolescents experience only a few occasional pimples; others are plagued by persistent pustular acne that lasts for years, leaving disfiguring scars. Each case of acne follows its own individual course. Because acne is so prevalent among adolescents and is not life-threatening, many health care providers, policymakers, and others may minimize its importance to young people.

According to data collected during the 1985 NAMCS sponsored by the National Center for Health Statistics, the majority of U.S. adolescents who visited a dermatologist (60.1 percent) in 1985

did so because of acne (101). The percentage of older adolescents who went to a dermatologist because of acne was higher than the percentage of adolescents ages 10 to 12 who visited a dermatologist because of acne.⁴³ About two-thirds (66.4 percent) of visits to dermatologists by adolescents ages 16 to 18 were for acne (101). Only 1.2 percent of visits by 16- to 18-year-olds to general practice or family physicians were for acne, however for older adolescent males, acne was the most frequent reason for visiting a physician. Limitations in available data make comparisons by race impossible for specific conditions.

Myths about acne abound. These include beliefs that acne is caused by the consumption of certain foods (such as chocolate), by sexual activity or thoughts, or by poor hygiene. Actually, several factors are involved in the development of acne. Rising levels of certain hormones during adolescence increase the activity of oil glands. Heredity also plays a role; adolescents are more likely to develop acne if they inherit oily skin that is sensitive to the effects of hormones. Plugged oil glands are also a factor; oil glands can become plugged when cells lining the oil glands or pores shed and stick together. Finally, skin bacteria are a factor; plugged pores can become infected when bacteria are present, leading to the development of pustules or cysts (1,33).

An estimated \$120 million is spent each year on acne treatment, including \$100 million on over-the-counter acne medications (114). What portion of this is spent by or on the behalf of adolescents is unknown, but it is likely to be considerable given the high prevalence of acne among adolescents.

There is no cure for acne. The goal of treatment is generally to control the condition and prevent or limit scarring (33). A variety of treatments are available (30,33,84). A topical 5- to 10-percent benzoyl peroxide solution is a commonly used drying and peeling agent. It is available over-the-counter as a lotion, or by prescription as a gel. Another topical product used for more severe acne is tretinoin, which is available only by prescription. Antibiotics are also frequently part of the treatment regimen for severe acne. Oral antibiotics (e.g., tetracycline or erythromycin) or topical antibiotics (e.g., erythromycin or clindamycin) may be used.

Isotretinoin (13-cis-retinoic acid) is a relatively new treatment for severe cystic acne.

Each of these treatments has negative side effects (33,84). Benzoyl peroxide and tretinoin produce drying and peeling. About 2 to 3 percent of people may be allergic to benzoyl peroxide. Tretinoin can also be very irritating to the skin, sometimes resulting in exacerbation of acne during the initial stages of treatment. Sun exposure increases skin irritation for adolescents using tretinoin, necessitating either avoidance to sun exposure or use of a sunscreen. Oral antibiotics can irritate the stomach and, in young women, increase the chances of developing vaginal yeast infections. Topical antibiotics may cause a yellowish discoloration of the skin. Isotretinoin, which should be used for only the most severe cases of acne, can produce birth defects if used during pregnancy and should not be used for anyone who is pregnant or who is likely to become pregnant. Other side effects of isotretinoin include cracking and scaling of the lips (90 percent of users), severe drying of the skin (80 percent of users), and conjunctivitis (inflammation of the mucous membrane that lines the inner surface of the eyelids and the forepart of the eye) and difficulty with contact lens use (40 percent of users) (86).

The course of treatment for acne can be difficult for adolescents for other reasons. Weeks of treatment are frequently required before improvement is visible. In addition, some adolescents have difficulty effectively complying with complicated treatments that may involve washing their face several times a day, applying one solution to their skin in the morning and another at night, and taking oral antibiotics. Oral antibiotics are most effective when taken on an empty stomach, necessitating that adolescents remember to take their medication either an hour before or 2 hours after meals. Following such a regimen may be especially difficult for adolescents who snack throughout the day. Cosmetics, frequently used by girls to cover their blemishes, may actually exacerbate their acne. Thus, adolescents may become frustrated and give up on treatments that take weeks to show any effects, have undesirable side effects, do not actually cure their acne, and are complicated and time-consuming to administer (20).

⁴³The number of 10- to 12-year-olds visiting dermatologists was too small to retie a reliable numerical estimate.



Photo credit: © American Academy of Dermatology

There is no cure for acne, an almost universal problem among adolescents. An estimated \$124 million is spent each year on acne treatment. Health care providers should help adolescents understand that treatments designed to control the condition and prevent scarring maybe slow to work, cause side effects, or even temporarily worsen an adolescent's appearance.

Health care providers may fail to recognize the difficulties that adolescents experience in adhering to treatment regimens. It is important that they emphasize the slow course and complicated nature of treatment, ensure that adolescents realize there is no cure, and advise adolescents of potential side effects, including the possibility of a temporary worsening in appearance (20),

Dysmenorrhea Among Adolescent Females

Primary dysmenorrhea (menstrual pain in the absence of anatomic pathology such as endometriosis⁴⁴) usually has its onset in the first year or 2 following menarche, but its incidence increases through the adolescent period (11). Over half of those experiencing dysmenorrhea may experience moderate to severe menstrual cramps.

The 1966-70 NHES conducted by the U.S. Department of Health, Education, and Welfare

included taking menstrual history of adolescent females ages 12 to 17 (94). Almost 60 percent of the adolescents in this study reported some degree of menstrual pain, and 14 percent reported frequent school absenteeism due to dysmenorrhea (43).⁴⁵ Although there are no current national population-based studies of the prevalence and effects of dysmenorrhea for adolescent females,⁴⁶ studies with small samples indicate that dysmenorrhea remains a leading contributor to school absenteeism for adolescent females. For example, one-fourth of the 88 high school females surveyed by Wilson and Key reported that they had missed classes because of dysmenorrhea (120). A study involving middle-school students with excessive absences in Boston found that almost half of these students cited health problems as a reason for the absence; menstrual pain was one of the most frequently cited problems (44). Forty-five percent of 14- to 18-year-old adolescent females in two Midwestern communities reported some school or work absenteeism due to menstrual pain (39), and 59.7 percent of otherwise healthy females in an independent New England high school reported dysmenorrhea (119).

Even though the prevalence of dysmenorrhea appears to be high, less than 2 percent of visits to office-based physicians by adolescent females ages 15 to 18 are for "abdominal pain, cramps, or spasms" (which could possibly include menstrual cramps); fewer than 1 percent are for menstrual symptoms "other and unspecified" (101). Although the numbers are too low to be reliable because trouble with menstruation was reported for few adolescent females, 1988 NHIS data indicate that only 5.9 percent of females ages 5 to 18 (virtually all of whom must be age 10 or over) experiencing trouble with menstruation sought medical care. In comparison, 77.9 percent of women ages 18 to 44 with disorders of menstruation reported seeking medical care (101).

⁴⁴Dysmenorrhea due to endometriosis or other anatomic pathology is termed *secondary dysmenorrhea*. According to Litt, endometriosis (a condition in which tissue resembling the uterine mucous membrane occurs aberrantly in various locations in the pelvic cavity) has been underdiagnosed in adolescent females (47), another reason for paying serious attention to menstrual pain.

⁴⁵The parents of 2.5 percent of females ages 12 through 17 reported "genito- conditions" (no more specifics given) as having been the adolescents' most serious illness (94).

⁴⁶NHIS, for example, provides a poor measure of menstrual problems experienced by adolescent females because many of the proxy respondents (e.g., mothers) maybe unaware that the adolescent is experiencing problems. It seems likely that primarily the most severe difficulties, those resulting in medical intervention, will be reported. It is also difficult to use NAMCS data to assess the prevalence of dysmenorrhea because it only captures information on females who seek medical intervention for their menstrual cramps.



Photo credit: Education Week

Menstrual pain (dysmenorrhea) is a frequently cited reason for missing school. Adolescent females may need to be informed that dysmenorrhea is physically, not psychologically, caused and that it is easily treatable.

Only recently has the medical profession recognized a physiological basis for menstrual pain: elevated concentration of menstrual prostaglandins that cause painful uterine contractions. As late as the 1980s, menstrual cramps were believed to be a psychosomatic complaint caused by poor attitudes of women about their femininity (11). Psychotherapy was seen as an appropriate response to the problem.

Now **that** a physiological basis is known, however, treatment for dysmenorrhea can usually be straightforward. Nonsteroidal anti-inflammatory drugs (e.g., salicylates such as aspirin, propionic acids such as ibuprofen and naproxen sodium) inhibit the production of prostaglandins and have been effective in reducing uterine contractions (11). Ibuprofen, previously available only by prescription, is now available over-the-counter.⁴⁷

The low rates at which adolescent females seek care for dysmenorrhea may be due to beliefs by them, their mothers, or both that nothing can be done (39,48). Negative attitudes and erroneous beliefs may also be supported through misinformation received from peers and others. Because the medical community has only recently come to understand the physiological basis for dysmenorrhea (47), it is likely that some providers are not adequately informed about the importance of providing relief to young women suffering from menstrual cramps. Some of them, for example, may believe that exercise is an appropriate treatment, although recent evidence suggests that exercise is more directly associated with relieving stress which may reduce the intensity of dysmenorrhea (54). Even when providers are informed about the issues, they may not ask appropriate questions during health care

⁴⁷Thus, it may be that newer studies (conducted after ibuprofen was made more widely available) would indicate fewer problems with menstrual pain (39). This would only apply if more adolescents were aware that menstrual pain can be prevented or ameliorated.

visits to probe about suffering from this problem and to make appropriate interventions (39).

Major Federal Policies and Programs Pertaining to Adolescents With Chronic Conditions

Federal efforts to address the needs of U.S. adolescents with chronic conditions include a Federal law requiring that education be provided to all handicapped children and a Federal law authorizing the provision of financial assistance to States and private nonprofit organizations that offer services to persons with “developmental disabilities.” These efforts are managed by various Federal agencies within the U.S. Department of Education and DHHS.

Education for All Handicapped Children Act

Educational opportunities for U.S. adolescents with disabilities have been greatly enhanced by the Education for All Handicapped Children Act (Public Law 94-142), which was passed in 1975 and amended several times since then (e.g., Public Law 99-457 in 1986, Public Law 101-476 in 1990). This act is designed to guarantee free and appropriate public education for all children ages 3 to 21 with disabilities, including mental retardation; hearing, speech, vision, or orthopedic impairments; serious emotional impairments; autism; traumatic brain injury; multiple disabilities; specific learning disabilities and other health impairments (35; Public Law 101-476). Some Federal funds are provided to support these efforts, but State and local-educational agencies bear most of the burden.

The Education for all Handicapped Children Act also authorized a transition-from-school program for children and adolescents with disabilities. Amendments to the act in 1986 (Public Law 99-457) clarified that funded activities may serve students throughout their school years as well as those who have left secondary school, and it expanded the purposes of this provision to include improving vocational and life skills. The act also authorized funding for physical education and therapeutic recreation programs designed to increase community participation among adolescents with disabilities (89).

Developmental Disabilities Assistance and Bill of Rights Act

Services to persons with developmental disabilities are authorized through the Developmental Disabilities Assistance and Bill of Rights Act, which in 1970 amended the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (Public Law 88-164) (91). The act authorizes Federal financial assistance to States and public and nonprofit agencies for programs that help people with developmental disabilities to achieve their full potential through increased independence, productivity, and integration into the community. Funded programs also provide assistance to the families of people with developmental disabilities.

Under the act, the definition of “developmental disabilities” is based on functional limitations rather than specific disorders. These limitations must be manifest before age 22; be attributable to a mental or physical impairment; be likely to continue indefinitely; and result in substantial limitations in three or more major life activities, such as self-care, learning, receptive and expressive language, and mobility. Each State is required to have a State planning council that receives funds under the act. State planning councils serve as advocates for people with developmental disabilities and develop a State plan that identifies unmet service needs and services to be provided. The act also requires States to have in place a protection and advocacy system to provide information and referral services and to investigate reports of abuse and neglect of people with developmental disabilities. University-affiliated programs provide interdisciplinary training for people preparing to work with persons with developmental disabilities, conduct applied research, provide technical assistance to agencies working with people with developmental disabilities, and provide services for people with developmental disabilities.

Other Federal Efforts

A new disabilities prevention program has been established within DHHS at the Centers for Disease Control (34). Efforts will focus on the areas of developmental disabilities, injuries to the head and spinal cord, and secondary complications among people with physical disabilities.

There are some tax code provisions designed to alleviate the financial burden on the families of people with disabilities (90). The costs of sending a

dependent with mental or physical disabilities to a special school may be deducted if the main reason for using the school is that the school provides facilities for alleviating the handicap. The dependent-care tax credit can be claimed for expenses incurred in the care of a physically or mentally disabled dependent necessary for the primary care provider to be gainfully employed. This includes expenses for household services, day-care centers, and other noninstitutional care.

In addition, the U.S. Surgeon General has sponsored several campaigns and conferences on children and adolescents with special health care needs (formerly known as “crippled children” (see 24, 49,100). The 1989 Surgeon General’s Conference focused specifically on issues for individuals with special health care needs making the transition between childhood and adulthood (49). A main focus of DHHS’s Bureau of Maternal and Child Health is the dissemination of funds for programs assisting adolescents with disabilities.⁴⁸

Conclusions and Policy Implications

Available data suggest that there may be more U.S. adolescents with physical health problems than is generally assumed. The most recent intensive health examination survey of a number of adolescents was the National Health Examination Survey (NHES) completed in 1970. This survey found that about 22 percent of U.S. adolescents had *some illness*, deformity, or physical handicap affecting normal growth, development, or function (94,95). Although not all of these were serious and chronic conditions, they were judged to interfere with healthy adolescent development in some way.

As discussed in this chapter, OTA estimates (using Gortmaker and Sappenfield’s work) that roughly 5 percent of today U.S. adolescents experience chronic physical conditions that make them physically unable to carry on major activity (e.g., attending school) or limit the amount or kind of major activity they can perform.

Little can be done during adolescence to prevent many of the serious chronic physical illnesses of adolescence.⁴⁹ In the absence of effective preventive interventions, attention to treatment and to issues affecting the quality of life of affected adolescents is particularly important. Although adolescents with chronic illnesses and disabilities experience many of the same problems as their nondisabled peers, such adolescents face a number of additional problems. These range from concerns that are specific to certain chronic illnesses (e.g., the devastating effects of chemotherapy and radiation associated with cancer treatment) to concerns that are associated with a variety of chronic illnesses (e.g., problems related to having to be absent from school, difficulties in socializing with peers, and substantial economic costs for families and for society). Adolescents with some chronic illnesses or disabilities may have limited options for employment and marriage, may be unable to (or choose not to) have children, and may experience discrimination in obtaining life and health insurance.

Another problem is that even for families with adequate health insurance, many of the often substantial costs associated with care of adolescents with chronic conditions are not covered. As discussed elsewhere in this Report, there is generally a scarcity of personnel trained to provide services to adolescents and services for adolescents tend to be fragmented.⁵⁰ The problems of fragmentation are compounded for adolescents with a serious chronic condition, who are typically in need of a broad range of often specialized services. Additional personnel trained to identify the needs of adolescents with chronic illnesses and disabilities, and to provide them with services, are needed.

Some chronic physical health problems of U.S. adolescents are so common that they may be accepted by parents, health care providers, and policymakers as “normal” and not worthy of mention or intervention. Adolescents, on the other hand, may find them extremely troubling. Acne and dysmenorrhea are examples. The vast majority of U.S. adolescents experience common acne which,

⁴⁸ For further discussion of the role of the Bureau of Maternal and Child Health in adolescent health, see ch. 19, “The Role of Federal Agencies in Adolescent Health,” in Vol. III.

⁴⁹ As noted earlier, many physical health problems due to injuries are preventable. For further discussion, see ch. 5, “Accidental Injuries: prevention and Services,” in this volume.

⁵⁰ See ch. 15, “Major Issues pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents,” and ch. 19, “The Role of Federal Agencies in Adolescent Health,” in Vol. III.

although not physically disabling, negatively affects the day-to-day lives of many adolescents. Evidence from a variety of sources suggests that at least half of adolescent females report dysmenorrhea (painful menstruation) and about 1 in 7 miss school because of this pain. Dysmenorrhea is a problem that, in most cases, could be alleviated through the use of certain over-the-counter drugs. It appears that adolescents are not routinely made aware of current information about the causes of these and other disorders of importance to them, or of the fact that treatment is available.

There is no single comprehensive source of information about the physical health status of U.S. adolescents. Rather, a variety of sources must be used to identify the most important physical health problems facing adolescents. National surveys sponsored by the National Center for Health Statistics in DHHS that provide information on the health of adolescents include NHIS, NHDS, and NAMCS, but these data sources have a variety of limitations. Most do not include large enough samples of adolescents to provide reliable data on low-prevalence chronic conditions. Furthermore, NHDS and NAMCS measure utilization of services (e.g., the number of adolescents with hospital stays or visits to physicians' offices) rather than need. Thus, adolescents who do not seek care for services, or who use alternative services, are not included in the surveys. These data may disproportionately exclude racial and ethnic minority adolescents and poor adolescents who may not have access to services.⁵¹

National surveys do provide some information on differences in health status or health care utilization among adolescents of different ethnic or racial groups, between males and females, and among adolescents of varying socioeconomic status, but much of this information is not reliable for policymaking purposes because of limitations in these data sources (e.g., small sample sizes of minority adolescents). There are virtually no population-based data on the health status of minority adolescents and their utilization of health services. Even when minority groups are oversampled in some national surveys, the number of minority adolescents remains small. Similar problems exist for

describing the health of adolescents living in poverty. Although some useful data are collected on socioeconomic status and health,⁵² sufficient data are rarely collected to allow for analyses to determine the nature of relationships between socioeconomic status and health. Additional information is particularly needed on the health status of these groups of adolescents and their utilization of services.

As described elsewhere in this Report, programs related to adolescents with chronic illness and disability can be found in a wide range of Federal agencies and departments.⁵³ These include the U.S. Department of Education and, within DHHS, the Centers for Disease Control; the National Cancer Institute; the National Heart, Lung, and Blood Institute; the National Institute of Allergy and Infectious Diseases; the National Institute of Arthritis and Musculoskeletal and Skin Diseases; the National Institute of Neurological Disorders and Stroke; and the Office of Human Development Services. There is, however, no central place in the Federal Government that coordinates programs for children and adolescents with chronic illness or disability.

In summary, policy changes to improve the physical health of U.S. adolescents might include:

- improved data collection,
- additional support for coordinated services and services to improve the quality of life for adolescents with serious chronic physical conditions, and
- health education on issues of importance to adolescents.

NHANES III currently in the field will oversample children, but includes relatively few adolescents and will not include institutionalized adolescents. NAMCS, NHDS, and NHIS (which are conducted more regularly than the infrequent NHANES) could oversample so that more adolescents of a greater racial, ethnic, and economic diversity are included. Population-based interview surveys would be improved if they asked adolescents about their own health problems rather than relying on parents as

⁵¹Seech.18, "Issues in the Delivery of Services to Selected Groups of Adolescents," in Vol. III.

⁵²Some data, for example, are collected as part of the National Health Interview Survey. However, this survey is limited because adolescents themselves are not asked about their health problems.

⁵³See ch.19, "The Role of Federal Agencies in Adolescent Health," in Vol. III.

reporters of this information and if they included problems of importance to adolescents.

Adolescents who have serious chronic physical conditions are in need of a broad range of often specialized services. Additional personnel trained to identify the needs of adolescents with chronic illnesses and disabilities, and to provide them with services, are also needed. Many adolescents with chronic physical illnesses may be in need of supportive or mental health services, for example.

Although recent Federal efforts have addressed the needs of children and adolescents with special health care needs, there is no central place in the Federal Government that coordinates programs for adolescents with chronic illness or disability. More active support for the development and evaluation of programs, as well as for efforts to coordinate available programs, is needed.

Finally, health education for adolescents could be improved if it addressed health issues of importance to adolescents and provided information on how to get access to medicine and services.

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