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Epidemiology of Chronic Illnesses in Adolescence

Since the beginning of the 20th century, the relative distribution of somatic illnesses in the population has changed. Acute illnesses such as infectious diseases and deficiencies such as malnutrition have lost much of their significance; today, chronic illnesses predominate. Progress in medical knowledge and improvements in living conditions have been responsible for this change. In this chapter, data on causes of death and rates of mortality are presented first, followed by rates of incidence (frequency of newly appearing cases within a certain time period) and rates of prevalence (frequency of an illness in a special population at a certain point in time or over a particular period of time) for chronic physical diseases in adolescence. Finally, an approach to categorizing chronic physical illnesses is presented.

Changes in the Spectrum of Illnesses and Causes of Death

Chronic diseases are the main cause of death in the population today. However, the mortality rates for chronic illness are not as high for adolescent populations as for adult populations. According to the German Federal Bureau of Statistics (Statistisches Bundesamt, 1994), 10- to 20-year-olds show the lowest mortality rates of all age groups. The likelihood of dying in this age range is therefore relatively low, compared with other age groups. In Germany, accidents, particularly those involving motor vehicles, are the major cause of death in this age group, not illness as in adults. Similar trends have been documented for other European countries (Seiffge-Krenke, 1998a). According to the National Center for Health Statistics (1993), accident-related injuries are also the leading causes of death in young people aged 15 to 24 years old in the United States; 78% of

all deaths caused by motor vehicle accidents are suffered by adolescents under 19 years old (National Safety Council, 1993). Sells and Blum (1996) have pointed out that accidents, together with violent injuries, homicides, and suicides, account for 77% of adolescent deaths in the United States.

The leading causes of death in adulthood, such as cancer and cardiovascular disease, also rank among the leading causes of death in adolescence, although the prevalence rates are comparatively lower. In Germany, 1 in 100,000 15- to 20-year-old adolescents dies from cancer or heart disease (Bundesminister für Gesundheit, 1991). Comparable rates have been reported in Scandinavian countries (Westbom & Kornfält, 1987). Similarly, in 1991, cancer and heart disease were the fourth and fifth leading causes of death among American adolescents, followed by the acquired immunodeficiency syndrome (AIDS). Thus, chronic illness in adolescents rarely becomes life-threatening. It is important, however, to take note of the morbidity rates for chronic illness in this age group. Various studies have reported incidence rates of chronic disease ranging from 5% to over 30% (Newacheck & Taylor, 1992; Westbrook & Stein, 1994). Underlying this large variation in estimates is a lack of consensus as to which forms of illness should be included in the category of chronic illnesses. It is therefore necessary to define chronic illness precisely before epidemiological studies can be presented.

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Chronic physical illnesses must be distinguished from acute illnesses on the one hand, and various forms of disability on the other. Both distinctions have been made by Petermann, Noecker, and Bode (1987b), who defined chronic illnesses exclusively as "…physical illnesses … that determine the planning, actions, and feelings of the child and his family in a more or less threatening way over the space of several years or a lifetime" (p. 5). The aspect of chronicity ("several years or a lifetime") in this definition allows sufficient distinction from acute forms of illness. In contrast, other definitions typically set a lower limit for the illness duration, for example, at around 3 months (Pless, Cripps, Davies, & Wadsworth, 1989; Westbom & Kornfält, 1987). A second element of this definition, referring to the ominous course of the illness, is appropriate for excluding the more static disabilities that are often equated with chronic diseases. Such a distinction is necessary, since a definition that encompasses both types of illness could lead to prevalence values of up to 30% in children and adolescents. This definition does not imply that chronic disease necessarily follows a threat-

ening course; rather, it states that this possibility always exists. For example, the development of life-threatening complications due to diabetes mellitus can never be ruled out. Some authors' definitions also refer to the onset of chronic illnesses to distinguish them from acute illnesses. For example, Schulz and Hellhammer (1991) have stated that "chronic illnesses as a rule develop slowly, last a long time, and have an unpredictable course" (p. 421). The reference to the slow onset, however, is not characteristic of all chronic physical illnesses.

The following section deals with the statistical distribution of chronic diseases in adolescence. In epidemiological studies, children and adolescents are frequently grouped together. Owing to this common practice, most of the epidemiological data presented here are based on groups of mixed ages. As compared with adults, children and adolescents are seldom affected by chronic physical illnesses (La Vecchia, Decarli, Negri, Ferraroni, & Pagno, 1992; Rakonen & Lahelma, 1992; Schellevis, van der Velden, van der Lisdonk, van Eijk, & van Weel, 1993). Nevertheless, even in this age group, the prevalence is considerable, amounting to about 10% in various countries (Eiser, 1990a; Offord, Boyle, & Racine, 1989; Seiffge-Krenke, 1998a); this indicates a significant increase since earlier decades. Results of the National Health Interview Survey in the United States (Newacheck, Budetti, & McManus, 1984) showed that rates of chronic illness and disability in children and youth under 17 doubled between 1960 and 1980. Similarly, Hurrelmann (1991) reported that since 1960, an increasing number of German adolescents have been affected by chronic disease.

These structural changes in pediatric epidemiology, marked by a relatively sharp increase in chronic illnesses in children and adolescents, cannot be fully explained by rising incidence rates for these age groups (Gortmaker, 1985; Perrin, 1985). Moreover, progress in medical treatment and diagnostics has contributed greatly to the decrease in childhood mortality rates. Nowadays, many children with life-threatening diseases survive, or at least reach adulthood (Newacheck, Stoddard, & McManus, 1993). Some formerly fatal illnesses have, consequently, become chronic illnesses. According to Blum (1992), this phenomenon is responsible for the marked rise in chronic disorders in adolescence. In addition, the range of chronic diseases in childhood and adolescence differs greatly from that in adulthood. Among adults, chronic illnesses include quite a large group of widespread illnesses (e.g., diseases of the circulatory system, hypertension, and diabetes mellitus) and a small number of rarer diseases. In contrast, the chronic illnesses of infants, children, and adolescents are characterized by

Table 1.1. *Prevalence Rates of Chronic Illnesses in Childhood and Adolescence*

	Prevalence Rate (%)	
Illness	Gortmaker et al. (1990) (0–15 Years)	Newacheck & Taylor (1992) (10–17 Years)
Asthma	2.93	4.68
Epilepsy	0.30	0.33
Gastrointestinal diseases	0.16	—
Diabetes mellitus	0.10	0.15
Sickle cell anemia	0.09	—
Cerebral palsy	0.09	0.12
Heart disease	0.07	1.74
Cancers and tumors	0.06	—
Cystic fibrosis	0.03	—

only a few frequently occurring illnesses and a large assortment of different diseases with low prevalence rates.

Prevalence rates for children and adolescents in the United States, estimated by Gortmaker, Walker, Weitzman, and Sobol (1990), are reproduced in Table 1.1, along with the results of the National Health Interview Survey (Newacheck & Taylor, 1992). Only the most common types of illness are recorded here. Table 1.2 displays estimates for the Federal Republic of Germany, taken from Petermann et al. (1987b).

Table 1.2. *Estimated Frequencies of Chronic Illnesses in Childhood and Adolescence in the Federal Republic of Germany (Petermann et al., 1987b)*

Illness	Approximate Incidence (Cases per Year)	Approximate Prevalence
Chronic bronchitis/asthma	30,000	500,000 children
Congenital heart defects	4,000–5,000	30,000 children
Epilepsy	3,000	47,000 children
Diabetes mellitus		6,000 children
Cancers	1,200	4,000 children
Celiac disease	280	6,000 children
Hypothyroidism	280	6,000 children
Cystic fibrosis	120	2,350 children
Muscular diseases	110	1,750 children

According to these results, bronchial asthma is the most widespread chronic disease of childhood and adolescence, with a prevalence of about 3 to 5%. All the other forms of illness show considerably lower prevalence rates of about 0.03 to 1.7%. Gender ratios for the entire group of chronic illnesses are balanced in adolescence (Cadman, Boyle, Szatmari, & Offord, 1987). The remainder of this section will discuss, in some detail, those diseases that have been studied more frequently in psychological research.

The course of bronchial asthma, along with the high likelihood of its occurrence, appears typical of childhood and adolescence. Most patients become ill within the first 5 years of life. If asthma begins in childhood, the prognosis for its further course is favorable, as one-third of the afflicted patients lose their symptoms spontaneously during puberty. Of the remaining patients, only about 10% suffer from severe or lasting asthma. Spontaneous remission occurs largely among boys. While the male-to-female ratio in childhood is 2:1 – figures may also range from 4:1 to 3:2 (Reinhardt, 1993) – the relation evens out to 1:1 after puberty.

Unlike asthma, cancer seldom occurs in childhood and adolescence. Only 1% of all cancer manifestations occur in these age groups. Cancer ranks second after accidents as the principal cause of death among German adolescents; nevertheless, its morbidity rate in this age group is relatively low. According to Niethammer (1993), 14 new cases occur annually in every 100,000 children and adolescents up to the age of 15. Older children and adolescents show the lowest prevalence rate (10 in 100,000), whereas babies (23 in 100,000) and infants under 4 years (19 in 100,000) have the highest. In addition, large differences in the types of cancer manifested in childhood and adolescence are apparent as compared with adulthood. Whereas various types of carcinomas predominate among the adult population, the most frequent type of cancer in children and adolescents is acute lymphoblastic leukemia (ALL), which accounts for 27% of all cancer diagnoses in this population, followed by tumors of the central nervous system. Nowadays about half of all children suffering from cancer can expect to recover in the long term, although prognoses vary with the specific type. In the case of the most widespread form, ALL, the survival rate is generally estimated at about 70%.

Juvenile diabetes is the most common metabolic disease of childhood and adolescence (Struwe, 1991). Findings differ, however, with regard to the age of onset. The first manifestation is most frequently diagnosed in late childhood or early adolescence (Bremer, 1990). In contrast, Weber (1993) has proposed two peaks of first manifestation: the first between 3 and 6 years of age, the second between 9 and 13. The National Health Interview

Survey (Newacheck & Taylor, 1992) of a representative sample of the American population revealed a prevalence of 150 cases in 100,000 children and adolescents between the ages of 10 and 17 years. A much lower prevalence rate, 60 per 100,000 was reported for younger children in this study. Similar statistics are available for other countries. For example, Petermann (1994) reported that an estimated 17,000 children and adolescents under the age of 20 with diabetes live in Germany, of whom about 6,000 are no older than 15 years. It is well known that a north–south incline can be established in Europe, although its causes have not yet been adequately explained. According to Seiffge-Krenke (1998a), annual incidence rates vary considerably, ranging from 35 new cases per 100,000 children and adolescents in Finland to 6 in France and 8 in Germany.

Psychological Perspectives on Chronic Illness: From the Biomedical to the Categorical Approach

In this section, chronic disease will be examined from a primarily psychological perspective, with biomedical aspects only of incidental interest. From a medical standpoint, different forms of chronic illness would obviously have to be viewed separately, owing to their different etiologies. In contrast, a psychological discussion can identify many specific characteristics common to most forms of disease, as Pless and Pinkerton (1975, p. 52) have emphasized:

> The chronicity of the illness and the impact that it has on the child, his parents, and his siblings is more significant than the specific character of the disorder, be it diabetes, cerebral palsy, hemophilia, etc. In other words there are certain problems common to all illnesses over and above particular challenges posed by individual needs.

Perrin (1985) has highlighted several characteristics common to chronic illness, namely, the necessity for expensive treatment, the intermittent need for medical intervention, the experience of pain and physical complaints, and the possibilities of slow degeneration or premature death. In fact, for a range of psychological parameters, Stein and Jessop (1982; 1984) and Jessop and Stein (1985) found no significant differences between children with asthma, spina bifida, hemoglobinopathies, and various forms of disability. Rather, they identified much larger differences within the individual illness groups. Hence they have argued for what they term a noncategorical approach, which sees chronically ill children and adolescents as a more or less homogeneous group. Stein and Jessop (1982) have asserted that above

all, the advantage of this approach lies in its practical contribution to the health care system. In this regard they state:

> When chronic illness is viewed noncategorically, it is possible to begin to learn more about characteristics, attitudes, and behaviors of the affected children in relation to the total child population in given communities. Additionally, since local communities are more likely to contain children with a range of conditions, but only a small number within each disease category, the noncategorical approach facilitates the creation and evaluation of service programs targeted to meet the needs of those with diverse conditions. (p. 361)

As Stein and Jessop (1984) have argued, whether long hospital stays result from asthma or from sickle cell anemia, their psychological consequences are much the same. Moreover, since some universal features in coping with various kinds of chronic illnesses appear to exist (see chapter 3), it is reasonable to assume that there may be certain aspects of stress that are generic to most chronic illnesses.

However, in emphasizing the similarities among different illnesses, their differences should not be overlooked. Apart from biomedical distinctions, important psychosocial differences exist. It would be inappropriate to subsume all the many and varied illnesses under the global category of chronic illness. The expected outcome of an illness may illustrate this point: The cognitive developments that generally occur in adolescence allow the youth to reflect about the facts in an abstract manner (Piaget, 1970). In this way, a potentially fatal illness would affect the adolescent differently from an illness that as a rule is not life-threatening. A more appropriate view is the partial categorical approach (Pless & Perrin, 1985, p. 45). In contrast to the noncategorical approach, this perspective does distinguish between individual diseases, but along psychological rather than biomedical lines. Rolland (1984; 1987) has offered one interpretation of this approach. According to his categorization of illnesses in childhood and adolescence, chronic diseases can be described and classified according to four dimensions: (1) their onset, which may be acute or gradual; (1) their course (progressive, recurrent, or stable); (3) the expected outcome; and (4) whether a disability is present.

This perspective stands on intermediate grounds between a biomedical approach, which views each illness in isolation, and a noncategorical approach, which subsumes the different disorders under the global concept of chronic disease. On the one hand, this allows many sorts of illness to be drawn together; on the other hand, there is still the flexibility to adopt certain medically and psychologically driven distinctions.

This book focuses on insulin-dependent diabetes mellitus, a relatively common chronic illness in adolescence. In terms of Pless and Perrin's (1985, p. 45) partial categorical approach, this illness is characterized by a gradual beginning and a progressive, possibly life-shortening course, which poses no severe impairments for the affected adolescent. After a more labile initial phase, most patients with diabetes show a relatively stable course.

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Coping with Illness in Adolescence: An Overview of Research from the Past 25 Years

As mentioned in chapter 1, adolescents assume a middle position in morbidity rates in comparison with other age groups. Problems with health and illness rarely crop up in adolescents' spontaneous remarks, although – or perhaps precisely because – adolescents are so concerned with their physical development and want to be "as normal as possible." One should not forget, of course, that at least 10% of all families in Germany care for a chronically ill adolescent (Seiffge-Krenke, 1998a); comparable surveys in the United States and Great Britain have documented rates of 7 to 12% (Eiser, 1992; Gortmaker et al., 1990). Thus, chronic illness in adolescence is not a rare occurrence. In this chapter, research on adolescent coping with chronic illness will be reviewed. Thereby it will become evident that interest is growing in understanding the psychological processes and outcomes that are linked with chronic illness in this particular age group.

Current State of Research: Results of Two Meta-analyses

This chapter provides a brief overview of the current state of research on adolescents' coping with chronic illness, based on two meta-analyses. In the first meta-analysis, the period from 1970 to 1988 was studied. A literature search of the databases Psychinfo and Psyndex retrieved 249 publications on the topic of coping with illness in adolescence (for a summary, see Seiffge-Krenke & Brath, 1990). In a subsequent meta-analysis, Hanl (1995) found 85 studies published between 1989 and 1995. Generally, both analyses revealed a growing interest in theoretical and conceptual approaches as well as an increase in empirical studies. However, the proportion of empirical studies was meager in both analyses, amounting to 25% and 35%,

respectively. Most articles were overviews, descriptions of therapies, or works of a conceptual nature.

Adolescence was defined in the first meta-analysis as the age span of 12 to 18 years. However, only 30% of the 249 publications analyzed by Seiffge-Krenke and Brath (1990) were strictly confined to this age range; most studies included a broader range, lumping together children, adolescents, and young adults. This reflects the tendency to select mixed groups covering a wide age range, thereby neglecting to differentiate further within the phases of adolescence. In the following discussion the findings pertaining to adolescent population samples will be dealt with more specifically.

Early research on adolescents characteristically focused on rare, extremely burdensome illnesses, for which no suitable treatment was available and which often had serious, unavoidable outcomes, such as death or serious physical damage. Besides illnesses with high mortality rates, diseases that are associated with crises or life-threatening phases have also been researched (e.g., acute renal failure, asthma attacks, diabetic coma, and hypoglycemic shock). The larger volume of research in more recent years has devoted more attention to illnesses that are less often fatal, more easily treated, and in principle, more readily managed by the patient. Lately this approach has included diabetes and some types of cancer, which nowadays are not necessarily fatal but rather chronic, very stressful illnesses.

The studies analyzed varied with respect to their definitions, operationalizations, and assessments of coping with illness. In the first meta-analysis, 42% of the studies employed a very broad definition of coping with chronic illness and explored the ill person's general adaptation; 27% of these studies employed a very narrow definition, equating coping with compliance with physicians' instructions or adherence to a therapeutic regimen and only 31% of the studies listed under the entry "coping with chronic illness in adolescence" employed an adequate definition of coping or defense. The measures for assessing coping tended to vary with age. Whereas in children, predominantly family coping was examined, the focus for adolescents was on individual coping (see chapter 6).

Most studies were based on samples of individuals suffering from similar types of illnesses or belonging to the more undifferentiated group of "chronically ill," without including control groups. Because the illnesses studied were quite rare, most studies were based on small samples (from individual case studies to $N = 50$). A minority of studies incorporated samples greater than $N = 100$. Only 12% of the studies included a healthy control group, and 10% included a control group consisting of patients with