

Psychiatric aspects of chronic physical illness in adolescence

Significant numbers of chronically ill adolescents have problems coping with their illness.

SEAN HATHERILL, MB ChB, MRCP, MRCPsych, FCPsych (SA)

Senior Registrar, Division of Child and Adolescent Psychiatry, University of Cape Town and Red Cross War Memorial Children's Hospital

Sean Hatherill originally specialised in paediatrics in the UK before turning to psychiatry, and maintains a special interest in the psychiatric aspects of medical illness in children and adolescents.

Survival rates for children who suffer chronic physical illnesses have increased dramatically in recent decades, resulting in a growing population of chronically ill children surviving into adolescence and eventually making the transition to adult medical services. The majority of adolescents with a chronic physical illness cope well and adjust to the stress and limitations imposed by the illness. For a significant minority, however, chronic physical illness is associated with emotional, behavioural and developmental problems, which may have a profound impact on development, quality of life, treatment adherence, morbidity, and even mortality.

What is a chronic physical illness?

The term 'chronic illness' has been variably defined but generally refers to illness that requires at least 6 months of continuous medical care, permanent adjustments to lifestyle, and continuous behavioural adaptation to the unpredictable course of the illness. Commonalities in the proposed definitions are emphasis on ongoing interference with daily functioning and significant lifestyle adaptation in addition to mere chronicity of illness. Typical examples of chronic illnesses diagnosed and managed in adolescence include asthma, diabetes, epilepsy, chronic renal failure, cystic fibrosis and a variety of cancers. As more and more children perinatally infected with HIV survive into their teenage years, HIV/AIDS can also be added to the preceding list. These illnesses are typically characterised by a chronic course punctuated by periods of acute crisis. The sufferer is required to accommodate physical changes, lifestyle restrictions, changes in social roles, complicated medication regimens, painful procedures and frequent medical appointments, while remaining prepared for the possibility of further acute crises.

Why focus on adolescents?

The onset of adolescence coincides with an increase in risk-taking behaviours, antisocial behaviours, treatment non-adherence and a rise in the prevalence of mood, substance, eating and personality disorders. The onset of chronic illnesses with an unpredictable course in adolescence appears to herald poorer psychosocial outcomes. As a group, adolescents have traditionally been neglected in the planning and provision of medical and psychiatric services, with a tendency to 'fall between the cracks.' The interaction between the experience of chronic illness, its management, and the normal developmental tasks associated with adolescence presents unique challenges for the adolescent, his/her family, and the professionals who manage him/her. An appreciation of the

psychological aspects and developmental tasks associated with adolescence is crucial to the holistic and effective medical care of this population. Demographic studies estimate that between 10% and 20% of children may suffer a chronic illness, the most common of which is probably asthma. In addition to the stressors common to sufferers of chronic illnesses of all age groups, those diagnosed in youth may face delays or deviations in all domains of development, school absenteeism, academic failure, peer group exclusion, and difficulties in both physical and emotional separation from carers. At a time when their healthy counterparts are attempting to carve out their separate identities, make intimate attachments, and grapple with pubertal physical changes, separation and the quest for greater independence, adolescents with a diagnosis of chronic illness are confronted with an array of profound losses, both real and imagined. They may mourn, in addition to loss of health, the loss of freedom, friends, physical attractiveness, and the sense of invulnerability so characteristic of this period. They may have realistic fears about pain, perpetual dependency and an increased likelihood of a foreshortened future.

Resilience and vulnerability

Maladjustment and psychopathology may arise when the demands imposed by illness prove too great for the available coping resources to accommodate. Resilience in this context does not equate with innate hardiness or invulnerability, but reflects the capacity to struggle effectively with adversity, adapt positively, integrate, and learn from the experience. It is a dynamic and potentially modifiable process rather than a stable trait.

The interaction between illness and psychosocial adjustment is better conceptualised as a complex system of feedback loops rather than a simple unidirectional influence. While chronic illness in adolescence may increase the risk of emotional and behavioural problems, these may in turn have a profound influence on the morbidity and even mortality associated with the physical illness.

A variety of factors, other than disease-related parameters, may influence psychosocial adjustment and the risk of emotional and behavioural sequelae in chronically ill adolescents (Table 1). Through their impact on adherence, risk-taking behaviours, motivation, parenting and coping capacity, the psychosocial effects of illness may affect the management and outcome of chronic illness dramatically. Disease-related parameters have generally demonstrated few and inconsistent associations with adjustment to chronic illness in youth, and the bulk of the literature seems to suggest that these factors, with the exception of direct CNS involvement, are not central to psychosocial outcomes.

Table I. Mediators and moderators of adjustment and psychopathology in chronically ill adolescents

Disease-specific factors	Family factors
Chronicity	Family history of psychiatric disorder
Predictability	Current psychopathology in carers
Lethality	Family conflict
Age of onset	Family cohesion
Visibility	Family expressiveness
Stigma	Parenting style
Functional disability	Social-environmental factors
Deformity	Peer support
Treatments	Poverty
CNS involvement	Practical resources
Individual factors	Relationship with treating team
Temperament	Cultural aspects
Gender	Stigma
Coping strategies	Developmental factors
Pre-existing emotional and/or behavioural problems	Timing and tempo of pubertal changes
Substance abuse	Emotional development
Previous experiences with illness	Cognitive development
	Social competence

Adjustment, maladjustment and adjustment disorder

Psychosocial adjustment is a multidimensional construct with behavioural, emotional, cognitive and social elements. Regardless of how 'maladjustment' is operationalised, the body of literature to date suggests that, on average, approximately twice the number of youth with chronic physical disorders are maladjusted when compared with groups without such disorders. Despite the prevalence being higher, only a minority of youth with chronic disorders are maladjusted. Although youth with chronic physical illnesses constitute a population at risk of maladjustment, this is not the most common outcome.

The psychiatric diagnosis of adjustment disorder is, however, still the commonest diagnosis encountered in the context of chronic illness in adolescence. It is characterised by emotional and/or behavioural symptoms that are clearly linked to the onset of a stressful event, that are transient, and that result in marked distress or significant functional impairment. The diagnosis can be specified as being chronic if it lasts longer than 6 months, but usually heralds a benign prognosis.

Psychiatric disorder

Pathways to psychopathology in this population may be multiple and complex, and direct cause-and-effect relationships are difficult to establish. The diagnosis of physical illness in a child, for example, may

trigger psychiatric disorder in a parent, which in turn may lower the resistance of the young person to the development of emotional problems.

Although the majority of young people diagnosed with chronic illnesses successfully adapt and even flourish despite their limitations, there remains an increased risk for the development of psychiatric disorder in a significant minority. In children, epidemiological studies estimate that those with chronic illness are 2.0 - 2.4 times more likely to develop diagnosable psychiatric and behavioural disorders than those without. Much of the increased prevalence is accounted for by disorders directly affecting the brain – epilepsy being a prime example. Associated intellectual impairment may be an important contributory factor. By comparison, young people with chronic illnesses not affecting the brain have a considerably lower risk, possibly only slightly increased above general population expectations.

Disentangling temporal relationships between emotional and behavioural problems, physical disorder and its treatment is often difficult. The relationship may be quite indirect. Physical, sexual, and emotional abuse are as likely, if not more likely, to occur in children and

adolescents with chronic physical illness. Psychological problems may predate the physical disorder in some cases.

Common referrals to consultation liaison psychiatry services for adolescents with chronic illnesses include depressed mood, excessive anxiety, and problems with adherence and risk-taking behaviours that compromise medical management.

Differential diagnosis of low mood

Normative transient mood fluctuation in response to stress
Adjustment disorder with depressed mood
Major depressive disorder
Dysthymia
Substance-induced mood disorder (e.g. steroids)
Mood disorder due to a general medical condition (e.g. epilepsy)
Bipolar depression
Pain
Delirium

Differential diagnosis of anxiety

Normative transient response to stress
Adjustment disorder with anxiety
Acute stress disorder
Post-traumatic stress disorder
Specific phobia
Anxiety disorder due to a general medical condition
Substance-induced anxiety disorder
Pain
Delirium

Other psychological problems

Regression and developmental delay
Excessive risk taking
Suicidality
Low self-esteem
Social withdrawal
Overdependence on sick role
Sabotage of illness management
Ambivalence
Eating disorders
Personality disorders
Somatisation and factitious 'overlay'

Typical examples of chronic illnesses diagnosed and managed in adolescence include asthma, diabetes, epilepsy, chronic renal failure, cystic fibrosis and a variety of cancers.

Treatment adherence

Treatment non-adherence is associated with significantly increased morbidity and mortality. A number of studies have demonstrated that approximately 50% of adolescents with long-term conditions do not comply with treatment recommendations. Medication non-adherence has been estimated as being four times greater in adolescents than in adults. Many studies have shown that long-term allograft survival is least successful in adolescent transplant recipients, in large measure due to poor adherence. Family support is a crucial factor in adherence. Emotional and behavioural problems such as depression and substance abuse are closely associated with treatment adherence.

Psychological and social outcomes in adulthood

A recent review of the relevant literature concluded that, in general, adult survivors of chronic physical disorders in youth do not have elevated rates of psychiatric disorder. Outcomes may differ slightly according to physical diagnosis. Rates of adult psychiatric disorder are, for example, marginally higher in youth with chronic renal failure. As a group, adolescent cancer survivors are indistinguishable from healthy controls with regard to adult psychosocial outcomes. There is more commonality than difference in the psychosocial outcomes of different chronic physical disorders. Adult psychiatric outcomes may be better for men than for women. Objective measures of adult social outcome such as educational attainment and employment suggest mild impairment when compared with the general population.

Effects on psychosexual and social development

Historically, adolescents with chronic medical illnesses have been viewed as childlike and asexual, limited in their exploration of psychosexual issues by isolation from peers and parental overprotectiveness. Research has challenged this viewpoint. A large population-based survey published in 1996 examining sexual behaviours in more than 1 500 adolescents with chronic physical disorders found no differences between adolescents with and without chronic conditions in the proportion ever having had intercourse, age of sexual debut or contraceptive use. Adolescents with chronic conditions were, however, more likely to have been sexually

abused and to have contracted a sexually transmitted disease. Youth with chronic physical illnesses are less likely to be offered sexual education. A recent retrospective study from the Netherlands suggests that, as a group, youth with chronic physical illnesses achieve fewer developmental milestones, or achieve them at older ages than their healthy peers, in all domains, including social, psychosexual, and autonomy development. Curiously, they also display less antisocial behaviour and have lower levels of substance abuse than their healthy peers.

Caring for the chronically ill adolescent

Carers of medically ill adolescents must attempt to foster just the right amount of contextually appropriate dependency and normal illness behaviour (e.g. adherence to medication regimens, dietary restrictions, outpatient attendance) to facilitate adequate monitoring and treatment of their medical condition, while simultaneously avoiding entrenching the sick role and perpetuating inappropriate regression and excessive dependency. There are risks associated with not finding this delicate balance for each individual patient. The more immediate and tangible risk is the excess morbidity and mortality associated with inadequate supervision and treatment of the medical condition. On the other hand, provision of developmentally and contextually inappropriate levels of support and protection may hinder the normal developmental tasks of separation and individuation and impede recovery in the broader sense of successful adaptation. This applies equally to parents of ill adolescents and to the medical professionals who look after them, often over many years. Medical professionals may also run the risk of adopting an overprotective and infantilising style of 'parenting' their adolescent patients, particularly those who may appear far younger than their chronological age. In the same way that overprotective parents of ill adolescents may find it more challenging to facilitate physical and emotional separation, so caring paediatricians may find the transition of patients to adult services difficult, sometimes holding on to their patients well into their twenties. Even though many of these patients

The onset of chronic illnesses with an unpredictable course in adolescence appears to herald poorer psychosocial outcomes.

may achieve admirable stability of their medical conditions, they may remain severely disabled in the emotional and social domains.

Recommended reading

Freed GL, Hudson EJ. Transitioning children with chronic diseases to adult care: Current knowledge, practices, and directions. *J Pediatrics* 2006; 148: 824-827.

Gledhill J, Rangel L, Garralda E. Surviving chronic physical illness: psychosocial outcome in adult life. *Arch Dis Child* 2000; 83: 104-110.

Kyngas HA, Kroll T, Duffy ME. Compliance in adolescents with chronic diseases: A review. *J Adolesc Health* 2000; 26: 379-388.

LeBlanc LA, Goldsmith T, Patel DR. Behavioral aspects of chronic illness in children and adolescents. *Pediatr Clin North Am* 2003; 50: 859-878.

Stam H, Hartman EE, Deurloo JA, Groothoff J, Grootenhuys MA. Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood. *J Adolesc Health* 2006; 39: 4-13.

Smith BA, Shuchman M. Problem of nonadherence in chronically ill adolescents: strategies for assessment and intervention. *Curr Opin Pediatr* 2005; 17: 613-618.

Wallander JL, Varni JW. Effects of pediatric chronic physical disorders on child and family adjustment. *J Child Psychol Psychiatr* 1998; 39: 29-46.

In a nutshell

- More and more children with chronic diseases are surviving into adolescence and adulthood.
- Adolescence represents a period of increased risk for a number of psychiatric disorders.
- There is an increased prevalence of psychiatric disorder in youth with chronic physical illnesses.
- Emotional and behavioural problems can have a significant impact on the morbidity and mortality associated with chronic physical illness.
- The rate of treatment non-adherence in this population is approximately 50%.
- Adolescents with chronic physical illness are less likely to display antisocial behaviour and substance abuse, but are more likely to have experienced sexual abuse.