

Strategies to Promote Better Outcomes in Young People with Chronic Illnesses

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Abstract

Introduction: This paper aims to provide an overview of chronic illness and disability in young people, focusing on the developmental needs of young people and the impact of chronic illness on adolescence. The emotional well-being of the young person with chronic illness is explored and strategies that promote better health outcomes for the young person through health, family and school settings are discussed. **Methods:** Literature was searched using Medline from 1980 to 2002 using the keywords chronic illness, chronic disease, disability, psychological, social, outcomes and transition. Articles were also hand searched from retrieved articles. **Conclusions:** Young people with chronic illness have the same developmental needs as other adolescents. Traditional health care is focused on disease outcomes; however, young people do not necessarily share the same focus. Improving health outcomes for young people involves health professionals having an understanding of adolescent development and broadening the medical perspective to incorporate the developmental perspective. Building competence in young people with chronic illness, strengthening connectedness within the family, school and peer group and building the capacity of the health care team in different settings will provide opportunities to enhance resilience in young people with chronic illness. In doing so, their health outcomes will hopefully also be improved.

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Epidemiology of Chronic Illness

The epidemiology of child health in the developed world is changing. Mortality from infectious diseases has fallen sharply over the past century due to public health measures, such as sanitation and immunisation, better housing and sweeping improvements in health care. Advances in medicine and surgical techniques have meant that children diagnosed with chronic conditions that previously limited life expectancy, such as congenital heart disease, renal disease and cystic fibrosis, are now surviving into their teens and adult life.¹ However, despite reduced mortality, young people with chronic illness still face significant morbidity.

The prevalence of chronic illness in young people has been estimated to range between 5% and 30%.² This wide variance reflects a lack of consensus in the literature about how chronic illness is defined and measured. Firstly, there is little agreement regarding the criteria used to define chronic illness. Chronic illness has been defined by some researchers as a condition that has lasted, or is expected to last 6 months or more; others use the time period of 3 months. The diversity in conditions also contributes to

problems of definition. Some studies include only chronic physical conditions, while others include both physical and mental conditions. Secondly, estimates of prevalence have ranged from population samples to hospital-based or clinical samples. The sampling frame is likely to significantly alter disease severity, with clinical samples weighted towards more severe or disabling conditions than population samples. Thirdly, a number of different methods of data collection have been used, ranging from self-report and parent-report to the analysis of medical records by medical experts. These methodological differences limit the capacity to compare different studies.

An example of a cross-sectional study using parental report and self-report of chronic illness utilised data from a large US population-based sample, the National Health Interview Survey. Analysis revealed that an estimated 31% of children under the age of 18 years were affected by a chronic condition (lasting 3 months).² However, the use of parent-report and self-report of illness is likely to have resulted in the inclusion of many young people with relatively mild conditions.

Data from the Australian Bureau of Statistics indicate

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that 45% of males and 42% of females aged 0 to 14 years suffered from a “long-term condition”, defined as having lasted or expecting to last 6 months or more. In this study, the proportion of young people with chronic illness tended to increase with age.³ Interestingly, 58% of 10 to 24-year-old Australian males and 64% of females reported they had a chronic illness.⁴ The leading causes of long-term conditions were asthma, hayfever, allergies and disorders of vision (far and near sightedness) in both the 0 to 14 and 10 to 24 years age groups. The absence of severity criteria and the inclusion of a large number of different conditions suggest that the data probably lie at the upper range of prevalence of chronic illness in children and young people.

Disability

Notwithstanding these definitional differences, a significant number of children and adolescents have a chronic illness. A smaller proportion of these will experience disability, defined as a restriction or lack (resulting from an impairment) of an ability to perform an activity in the manner or within the range considered normal for a human being.⁵ In the case of children and adolescents, activities of daily living and social roles such as school or play, are affected because of a physical or mental condition.⁶ In the United States, an estimated 7% of children experience some degree of disability. The Australian data are similar, with 8% children aged 0 to 14 years reported as disabled. In this age group, intellectual and mental disorders are the most commonly reported disabling condition, followed by respiratory illnesses (such as asthma).³ As with chronic illness, the rate of disability increases with age, being 8% and 9% for the 15 to 19 years and 20 to 24 years age cohorts, respectively.⁴

Psychosocial Outcomes

Despite improved medical outcomes for many young people with chronic illness, the impact on psychosocial sequelae is less clear despite a high level of interest over the past 30 years. The term ‘psychosocial outcome’ can best be understood as referring separately to psychological outcome and social outcome.⁷ Psychological outcome can be interpreted as the presence or absence of psychopathology, such as depression, anxiety and behavioural problems, as measured by instruments such as depression and anxiety scales, behaviour checklists, or through the use of structured clinical interviews. Other psychological outcomes have included measures of self-esteem and coping. Social outcome has been variously defined as the level of education attained, employment, social relationships, marital status and whether the subject continues to reside with his or her parents (as a proxy for level of independence achieved).

Not surprisingly, different studies have examined different psychosocial outcomes using different methods at different

ages.⁷ Some have utilised longitudinal birth cohorts and measured outcomes in adolescence and adulthood. Others have utilised clinic, hospital, or population-based cross-sectional surveys, comparing those with chronic illness and/or disability with an age-matched control group of healthy subjects. Studies have investigated both disease-specific and non-categorical models of chronic illness. Limitations of many studies include small sample size, the nature of the comparison group (or lack of) as well as differences in how the information is collected (self-report, parent and teacher reports, or child completed questionnaire, face-to-face or telephone interviews). As already noted, clinical samples generally contain greater numbers of young people more severely affected by chronic illness, which might introduce various biases. For example, the measurement of emotional wellbeing within clinical samples may be poorer than when measured across the severity spectrum. On the other hand, specialist clinics may be more sensitive in identifying or treating psychological difficulties.

The relationships between chronic illness, disability and psychosocial functioning are complex. Indeed, there are conflicting results from the research literature. Some studies have found that young people with chronic illness and disability have higher levels of psychological problems compared with their healthy peers; others suggest no difference.⁸ More recent studies have suggested that the long-term sequelae of chronic illness is less gloomy than many have thought. A British birth cohort study found no difference in the frequency of medically-treated psychiatric disorders compared to healthy controls based on self-report at the age of 26 years and on clinical interview at the age of 36 years.⁹ Results from a large Finnish cross-sectional study comparing a sample of 18 to 25-year-old population with a history of chronic illness in childhood and a group of population controls found a similar prevalence of psychiatric disorder in both the ill and healthy groups.¹⁰

In contrast to overt psychiatric disorders, it is well recognised that chronically ill children and young people experience more age-related everyday health concerns, body image issues, and are at greater likelihood of poor emotional wellbeing than their healthy peers.^{8,11} This places them at the risk of participating in health risk behaviours common to other adolescents.¹² There is also evidence of mild impairment in social maturation in chronically ill young adults compared to the general population, particularly in the areas of educational achievement and employment, independence from family, marital status and sexual development.^{9,13}

Over the last three decades, there has been growing interest in the concept of risk behaviours, protective factors¹⁴ and the notion of resilience.¹⁵⁻¹⁸ Research has identified factors, both internal and external to the individual, that

TABLE I: DEVELOPMENTAL TASKS OF ADOLESCENCE¹⁹

1. Autonomy/independence from parents and other adults
2. Increasing role of peer relationships
3. Developing a realistic body image
4. Self-identity formation that is realistic, positive and stable
5. Sexual self-identity formation
6. Consolidation of a moral/value system
7. Educational/vocational goal development

mitigate against negative life experiences and stressful events. The challenge this raises for health professionals is how to build protective factors into the lives of young people with chronic illness with the hope of promoting greater resilience.

How do Health Professionals Promote Better Outcomes in Young People with a Chronic Illness?

Understanding of Adolescent Development and the Impact of Chronic Illness

Doctors often spend much time and effort trying to achieve control, minimise disease progression, and reduce complications of chronic illnesses. These goals, commonly shared by parents, generally focus on disease outcomes. Young people, on the other hand, are far more interested in achieving the developmental tasks of adolescence (Table I).¹⁹ When their behaviour appears at odds with their health, they often become labelled as “difficult adolescents”.

An understanding of adolescent development, the psychosocial issues affecting young people with chronic illness, and how the traditional disease-focused perspective can be broadened to incorporate the developmental perspective of the adolescent can be used by health professionals to achieve better health outcomes for this group.

Entry into adolescence is marked by puberty. At this time, rapid physical growth pre-empts the development of secondary sexual characteristics. Cognitive changes take place, with an emerging capacity for abstract thought and logical reasoning. Socially, young people move from a position of dependence on their family to one of relative independence as peer relationships assume greater importance. Enjoyment of more intimate relationships increases with the formation of a coherent sexual identity. A focus on educational and vocational goals, and increasing development of self-identity and an intrinsic value system contribute to the capacity for more mature roles. Young people with chronic illness face these same developmental tasks as healthy young people. However, they often have more obstacles to overcome to achieving these tasks.

Chronic illness impacts on every sphere of adolescent development: biological, psychological and social. Short stature and pubertal delay are common correlates of severe chronic illness. Visible signs of the illness or of treatment, for example motor handicap, scars and weight gain, further highlight differences between young people who are chronically ill and their peers. Cognitive difficulties may be due to the condition itself, such as epilepsy, hydrocephalus and spina bifida, or to its treatment, such as craniospinal irradiation. Learning difficulties are not uncommonly experienced due to reduced educational participation. Sexuality and reproductive health are important for young people in general. These issues assume greater relevance for some young people, such as those with intellectual disability, spina bifida and cystic fibrosis. This might be due to increased vulnerability to sexual abuse^{20,21} or because of concerns or confusion regarding sexual and reproductive capacity.^{22,23} It is known that doctors and other health professionals find it difficult to discuss sexual health matters due to embarrassment, lack of training, lack of time and perceived lack of priority in the complex hierarchy of chronic illness management.²¹

Adolescence can equally impact on chronic illness and disease management. The physical care of young people with a disability can be more difficult due to physical growth with puberty. Certain diseases, such as diabetes, can become more unstable during adolescence for physiological reasons. Lung function commonly deteriorates during the adolescent years in those with cystic fibrosis, especially girls. Adolescence is a time when young people commonly learn by experimentation. Health risk behaviours that have their onset during adolescence are particularly concerning in certain conditions. For example, smoking can exacerbate health outcomes in young people with asthma, cystic fibrosis and diabetes, while alcohol binges and the subsequent lack of appropriate eating and sleeping can greatly complicate diabetes care and epilepsy. While many young people with chronic illness cope remarkably well emotionally and psychologically, doctors need to be attuned to emotional distress. This can be manifested in different ways, such as poor adherence with the treatment regimen, school refusal, social withdrawal, problems relating to physical appearance, and risk-taking behaviours.

Taking a psychosocial history allows the doctor to develop rapport with the young person and to help them understand the impact of the illness in different aspects of the young person's life. It allows doctors to assess the young people's cognitive abilities, identify risk and protective factors in their lives, and screen for health risk behaviours and mental health states, such as smoking, unsafe sexual activity or depression, factors which may further compromise health.

TABLE II: THE “HEADSS” APPROACH TO TAKING A PSYCHOSOCIAL HISTORY

HEADSS	Area	Questions
H	Home	Where do you live? Who do you live with?
E	Education	Are you at school? What year are you in? What are your grades like?
A	Activities	What do you do for fun? What do you do with your friends?
D	Drugs	Many people your age experiment with cigarettes, alcohol and drugs. Have you ever tried using them?
S	Sexuality	Most young people have become interested in sex at your age. Have you ever had a sexual relationship?
S	Suicide/Depression	Many people feel sad and down at times. Have you ever thought life not worth living?

Adapted from Goldenring and Cohen, 1990²⁴

The HEADSS approach is a well-known framework for taking a psychosocial history (Table II).²⁴

Building the Capacity of Young People

Young people cope with and adjust to the stresses of managing a chronic illness through a complex interaction of developmental, physical, social, and emotional factors. Doctors can more readily provide holistic care for the young person with a chronic illness if they have some understanding of this complexity.

As young people mature, they desire increasing privacy in their relationship with health professionals. Providing confidential health care to adolescents has been shown to be highly valuable in establishing trust and is more likely to facilitate honest communication.²⁵ Seeing young people on their own, for at least part of the consultation, helps affirm that they, and not their parent, are the patient. Educating the young person about the illness and its various impacts in a developmentally and cognitively appropriate manner can be a valuable step to better self-care. Although a young person may have had an illness for many years, it is generally their parents who have been actively managing the illness and who have received most of the health education over the years. Through negotiating a management plan with both the young person and their parents, doctors can help shift the balance of responsibility and the ownership of the illness to the young person, rather than the parents.

It is important to provide opportunities for the young person to ask questions, and discuss management issues and treatment options. Acknowledging the difficulties

young people face, and reframing issues (helping the young person see their problem in a different light) can enhance the young person's capacity for decision-making and problem solving.

Providing positive reinforcement to young people for taking on responsible roles or making behavioural changes, however small initially, is helpful motivation for further efforts. The key to positively influencing the health of the young people lies in engaging them successfully, understanding the context of their lives and motivating behaviour change. This approach in building capacity in young people can be used in helping to improve young people's adherence to treatment regimens.

Building the Capacity of the Family

Family connectedness is associated with emotional wellbeing in both the young people with chronic illness⁸ and in their healthy peers.¹⁶ It is therefore concerning that young people with chronic illness report lower levels of family connectedness. There are many reasons for this.

Parenting an adolescent provides many challenges as the roles of both parent and adolescent change. However, parenting an adolescent with a chronic illness often brings additional stresses to families. Increased time and physical effort is required to care for a child who is chronically ill or disabled. Commonly, the physical and emotional burden of caring for a chronically ill child falls onto one parent, usually the mother. It is important for doctors to encourage both parents to be involved in caring for and supporting the young person with chronic illness. Additional time off work for medical care simply adds to the fiscal burden that most families carry in managing a chronically ill child.

Emotionally, parents often experience the spectrum of disbelief, anxiety, distress and uncertainty over the diagnosis and prognosis of the illness. Anger and frustration at the lack of cure may be directed towards medical staff for perceived misdiagnosis, failure to provide information or better communication.²⁶ Parents of young people with chronic illness may experience greater tension than parents of healthy children between the desire to support and promote the growing autonomy of their adolescent and the desire to protect. Normal parental concern can become relative over-involvement when excessive involvement and assistance inhibits the young person's capacity to make decisions and inhibits moves towards greater independence. For example, in a study of young people with spina bifida and cerebral palsy, those who reported being over-protected by parents showed greater self-consciousness, lower self-perceived popularity, lower self-esteem and higher anxiety.²⁷ Doctors can support appropriate parenting styles that encourage growing independence and competence in the young person. For example, young

people with chronic illness should be encouraged to take on appropriate responsibilities within the family, such as household chores, which demonstrates their capacity to contribute to the family like other members of the household.

It is important for parents not to lower expectations of their child just because they have a chronic illness. Low expectations can be just as damaging as expectations that are inappropriately high, as this can subtly transmit the message that the young person is not capable. Many studies show that having clear expectations from parents and opportunities to participate in the life and work of a warm and caring family contribute significantly to a young person's competence and resilience.^{16,17}

Physicians frequently underestimate parents' desire for information about their child's condition and its implications.^{28,29} While the Internet has created new opportunities to access information, doctors will continue to be called on to interpret material in order to help parents advocate for their child's health. Doctors remain too often unaware of parents' desire (mothers, in particular) for social contact for themselves and for their children with other families that have a child with a chronic condition. This highlights the importance of social support for families and the opportunities it provides for information sharing and discussion of common issues. Social support can be provided in different ways, ranging from information seminars and facilitated support groups, to supportive and family therapy. Practical support, in the form of respite facilities, financial assistance, environmental modifications to the home and transport assistance can also be valuable and should be advocated for by the primary care physician.³⁰

Building the Capacity of Schools

The education of chronically ill children and adolescents is frequently compromised. Ill health, frequent outpatient attendances and prolonged hospital admissions contribute to school absence and poor learning. It is estimated that 23% of those with disabling chronic conditions were limited in their ability or unable to attend school on a long-term basis.⁶ Among those who attended secondary school, the results obtained by students with chronic illness were significantly lower than healthy students.^{13,31} Illnesses that impair cognitive function play a small role. Rather, school absenteeism and other factors, such as low socioeconomic status and underachievement, appear pertinent. Like parents, teachers may set lower goals for children and young people with chronic illnesses, setting up an expectation of underperformance.³²

School, however, provides more than simply an opportunity for education. The school setting provides opportunities for social interaction with peers, supportive relationships with teachers and opportunities to succeed,

academically, or in other extracurricular activities.³³ Periods of absence from school are likely to disrupt connections with the peer group, will reinforce disconnection from school and lead to social isolation.

Health professionals can support teachers' understanding of various education and health issues for young people with chronic illness. Practical assistance includes educating the staff about the nature of the illness and issues they may expect. Teachers often need more reassurance than health professionals recognise. The health-education interface can be specifically promoted through the provision of educational services and re-entry support for children and young people with particular health and development needs. An example is the education officers of the Royal Children's Hospital Education Institute, who assist young people maintain links with their school while they are in hospital through various innovative means, such as desktop videoconferencing, and the use of e-mail. One-on-one assistance can also be provided to assist young people succeed in making the transition back to school after significant time away due to illness.

Building Capacity in Different Health Settings

The Role of Peer Support Programmes

The peer group assumes more importance for young people as they gradually establish greater independence and autonomy from the family during adolescence. Through interaction with peers, young people acquire social skills, try out new roles and have an opportunity to test the values they develop from their families. Adolescents with chronic illnesses risk missing out on opportunities to socialise with their peers at school, at sporting and other recreational activities due to restrictions from illness. For many, their sense of being different, lack of self-confidence and worry about acceptance can inhibit participation. Many also report being bullied and teased about their condition or their appearance.³⁴

Peer support programmes allow young people with chronic illnesses to share their experiences (both negative and positive), vent their emotions, and develop peer relationships and a sense of social connectedness in a supportive environment. An example of a peer support programme is the Chronic Illness Peer Support or ChIPS, developed at the Centre for Adolescent Health in Melbourne.³⁵ Young people are referred to the programme by doctors or other health professionals. Doctors or other health professionals refer young people to the programme. This programme is for young people with all types of chronic illness, recognising that despite differences in illness types, young people share similar life concerns. The participants meet weekly for 8 weeks in sessions that are

led by a peer leader and a health professional. Following the 8-week programme, young people can subsequently participate in regular social events, including an annual camp, as well as a range of leadership activities. Peer support groups, such as ChIPS, increase young people's self-confidence, self-efficacy and their sense of control over their illness.³⁶

The Role of Hospital Inpatient Units

An audit of adolescent admissions to the Royal Children's Hospital, Melbourne showed that the two most common reasons for admissions to the Adolescent Ward were for the management of two chronic illnesses – diabetes mellitus and cystic fibrosis.³⁷ Adolescent inpatient wards, at the very least, provide a separate physical space for hospitalised young people, where an appropriate level of privacy can be achieved. Just as importantly, they cater to the developmental needs of this group.³⁸ Staff on adolescent wards can promote the growing independence of young people by encouraging young people to be appropriately responsible in self-care. Staff can identify psychosocial issues and co-morbidities through routine screening and observation, and can facilitate timely intervention. Young people's participation in education and psychosocial support programmes provides opportunities for identification of educational concerns, promotes informal socialisation and can provide valuable support between young people in similar circumstances.³⁹

Transition to Adult Health Care

Most young people receiving paediatric specialty health services who need care beyond adolescence will graduate to adult services. The concept of transition has been defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult oriented health care systems".⁴⁰ Transfer, by contrast, refers simply to the physical event. The developmental importance of transition is based on the fact that expectation by a young person that they will be treated as an adult within an adult health care setting will promote greater personal responsibility and independence.⁴¹ Generally, young adults with chronic illness are better managed in adult health care settings.

Common barriers that prevent successful transition to adult specialist services include factors relevant to the young persons and their parents. This includes anxiety related to leaving a specialised paediatric team and hospital that they know and trust. The paediatrician may be reluctant to transfer the patient because of concerns about the quality of care able to be provided within the adult setting, or there may be genuine lack of services available within the adult health care system. There are also barriers once young people have been transferred, such as acceptance of the

new system, because of the belief that the adult providers do not understand them as well as their paediatric providers.⁴² As multidisciplinary services become more established within adult hospitals, young people appear to better manage the transition process.⁴³

A number of different models that can be used to facilitate the transition process, although there is little evidence to suggest that one is superior over the others. Disease-specific models involve the transfer from a paediatric subspecialist to an adult subspecialist. This may be facilitated via an interim service located within the paediatric setting or the adult setting. In the primary care model, the general practitioner coordinates the transfer and the multidisciplinary needs of the young person and provides continuity. Another model involves the use of generic adolescent health services, with adolescent physicians coordinating the care. The choice of model should depend on the type and severity of disease, institutions and availability of facilities, including interested staff.⁴⁴ Regardless of the model, a set of principles underpin successful transition: young people and their parents should be given information about the process and time to prepare; good communication between the paediatric and adult team is important; and planning and coordination is required. A survey examining patients' perspectives on transition has shown that at a centre where patients are transferred directly to the adult system without a transition programme, patients and their families felt having a programme would be helpful.²⁸ Patients who have been through a transition have been found to be more satisfied with the adult clinic than those who had not.⁴⁵

Conclusion — Enhancing Capacity at Every Level

Improving health outcomes for young people with chronic illness is best achieved when the medical aspects of disease management are addressed within an understanding of the developmental context of the young person. In addition to their roles in disease management, health professionals can assist the development of stronger connectedness within the family, school and peer group. They can help build the capacity of the health care team to engage with young people, whether in paediatric or adult health care settings. In doing so, they will hopefully provide opportunities to enhance resilience in this group of young people and can improve their health and life outcomes.

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