

Adolescent Health 5



Adolescents with a chronic condition: challenges living, challenges treating

Susan M Sawyer, Sarah Drew, Michele S Yeo, Maria T Britto

In this review, we aim to focus attention on the interaction between adolescents with chronic conditions and the health systems that support them. At least 12% of adolescents live with a chronic condition. Some conditions are characterised by increasing incidence (eg, diabetes) or improving survival rates (eg, cystic fibrosis), while others are concerning because of differentially poorer outcomes in adolescents in comparison to both children and adults (eg cancer). Growing evidence suggests that young people with chronic conditions are doubly disadvantaged—engaging in risky behaviours to at least similar if not higher rates as healthy peers, while having the potential for greater adverse health outcomes from these behaviours. In addition to efforts at improving survival, in order to improve their life chances, we need to better understand how the social and emotional outcomes of young people with a chronic disease can be improved, and better support young people's emerging capacity for self-management.

Increasing appreciation of the growing burden of chronic illness in adults is based on estimations that at least 80% of heart disease, stroke, and type 2 diabetes could be avoided through the combination of healthy diet, regular physical activity, and refraining from use of tobacco. This appreciation has led to integrated policy responses that focus on prevention, such as the WHO Global Strategy on Diet, Physical Activity and Health,¹ together with calls for innovative, cost-effective models of care in adults with chronic disease that focus on self-management.² However, children and adolescents with chronic disease have been remarkably absent from this discourse. Most chronic conditions of childhood, unlike those of adults, are not preventable by lifestyle changes, but there is every reason to suppose that the socially-mediated co-morbidities experienced by adolescents with chronic conditions can be modified.

Numbers of young people with chronic conditions are growing. Improvements in survival typify many previously fatal conditions of childhood, such as cystic fibrosis, congenital heart disease, and spina bifida. Increasing incidence in adolescence is a feature of other conditions such as diabetes, mental disorder, HIV/AIDS, and cancer. Not only is cancer in young people on the rise, but also improvements in outcomes in adolescents and young adults for this disease lag behind advances that have been achieved for children and older adults.^{3,4}

The health issues of adolescents with chronic conditions are reported to be “linked to the illness they suffer from, to adolescence in general, and to psychosocial problems generated by the interaction between the illness, the adolescent and his immediate environment”.⁵ Certainly, many health professionals report that managing the complexity and range of health concerns in adolescents is more challenging than for other age groups.⁶⁻⁹

In this review, we aim to focus attention on the interaction between adolescents with chronic conditions and the health systems that support them. Following a description

of the epidemiological challenges of measuring chronic conditions in adolescents, we review the value of measuring health and developmental burdens, and investigate the benefits and challenges of self-management support in adolescents with chronic conditions. We wish to bring attention to what is common in young people's journey through adolescence with different chronic conditions, by contrast with the many disease-driven divisions that characterise much current practice, policy, and research.

Challenges in definition and epidemiology

The shortage of age-specific epidemiological data is one factor limiting more focused policy and planning considerations for adolescents with chronic conditions. Many surveys and reports of chronic disease fail to recognise adolescence as a developmental stage by grouping adolescents with children (0–14 years) or with adults (15–34 years).^{10,11}

When adolescence is recognised, the choice of lower and upper age limits is variable. This inconsistency limits national, let alone international, comparability. For example, even within the USA, where health surveys of relevance to adolescents are most advanced, the National

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Centre for Adolescent Health, Royal Children's Hospital, Parkville 3052, Melbourne, Victoria, Australia

(Prof S M Sawyer MD,

S Drew PhD, M S Yeo MBBS);

Department of Paediatrics, University of Melbourne,

Victoria, Australia (S M Sawyer,

S Drew, M S Yeo); and

Cincinnati Children's Hospital

Medical Centre, Cincinnati,

Ohio, USA (M T Britto MD)

Correspondence to:

Prof Susan Sawyer

susan.sawyer@rch.org.au

Search strategy and selection criteria

We searched MEDLINE (2000–06) and the Cochrane Library (any age or date) using the search terms “chronic illness”, “adolescence” or “adolescents” (“adol*”), “risk factors”, “psychosocial outcomes”, “self-management”, “self-efficacy”, “adherence”, “compliance”, and randomised controlled trial interventions in various combinations. No language restriction was used. Key references published before this period were identified through scrutiny of commonly cited papers and review articles that showed particular insight into the area of psychosocial wellbeing for young people with chronic conditions.

Health Interview Schedule Child Health Supplement defines adolescents as individuals aged 10–17 years, the National Health and Nutrition Examination Survey as those aged 12–17 years, the National Adolescent Hospital Discharge Survey groups 15–24-year-olds together, whereas the National Longitudinal Study of Adolescent Health explores the causes of health-related behaviours of adolescents in school grades 7 through 12, who range in age from 12 years to 20 years.

Prevalence data have typically been derived from one of three sources: checklists of medical disorders or disease types (eg, diabetes) have been used to identify chronic illness; functional status assessment has been used to identify chronic conditions that cause impairment in basic functions (eg, vision, hearing, activities of daily living); and limitation in socially defined roles (eg, schooling) has identified children with disabilities.¹²

Sources of data will affect prevalence results. For example, reports from doctors and parents differ as to the presence of a chronic condition,¹³ whereas doctors' and adolescents' reports differ in relation to the importance of physical symptoms.¹⁴ Comparison of parents' and adolescents' report suggests greater congruence between parents with older (age 15–17 years) rather than younger (age 12–14 years) adolescents¹⁵ and less similarity between parents and adolescents for reports of mental health and behavioural needs.^{15,16}

Checklists commonly vary between surveys and include only the most common conditions. With few exceptions (such as asthma and allergy), most individual chronic conditions of adolescence are uncommon but together comprise a substantial proportion (31%) of all US children.¹⁷ Many less common conditions, such as

achondroplasia, are likely to cause major limitations in daily activities, which further highlights the importance of accurate ascertainment.¹⁸ Importantly, checklists identify children with several chronic conditions who have increased morbidity across a range of measures.¹⁹ However, many checklists do not include mental, behavioural, or cognitive disorders, resulting in an underestimation of chronic conditions in adolescence. The extent of co-morbidity makes this omission relevant, especially in older adolescents, in view of the relatively large contribution of mental illness to their burden of disease and the complex ways that mental disorder can affect the experience and expression of chronic disease.^{10,20}

The limitations of disease-specific checklists have produced interest in generic or non-categorical approaches. These approaches are predicated on the many similarities in the lived experiences of young people with different chronic conditions, with many of the consequences being independent of a specific disease or disorder.²¹ Stein and colleagues²² proposed a framework based on three definitional concepts that must coexist for a child or adolescent to be classified as having a chronic condition (panel 1).

A similar non-categorical approach has been used to define children and young people with special health-care needs as those who “have or are at increased risk for a chronic physical, developmental, behavioural or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”.²³ This definition identified 12% of people younger than 18 years in the USA with a chronic condition, with an additional 6% having a presumed need for increased services.

Prevalence of special needs increases from childhood through adolescence (figure),^{24,25} but we have remarkably little understanding of how the functional needs of the young change across childhood, through adolescence, and into adulthood, let alone how young people respond to such changes or how they can best be supported. To improve consistency in age criteria and approaches to prevalence estimates, including mental health and behavioural comorbidities, would focus policy efforts on adolescents with chronic disease, and provide a valuable platform from which clinical interventions could be more rigorously tested.

Effect of chronic conditions: disease-specific or generic understandings?

A large amount of disease-specific published work describes the effect of individual diseases and disabilities on adolescents and their families, whether framed in terms of adjustment or coping, comorbid depression and anxiety, or more recently, in terms of health-risk behaviours. Appreciation of the similarities and differences between specific diseases and groups of disorders could inform practice and policy. However, the traditional separation of health-care research, practice, and policy in relation to

Panel 1: Definition of generic or non-categorical chronic health conditions²²

Chronic health conditions are defined as disorders that:

- Have a biological, psychological, or cognitive basis;
- Have lasted or are expected to last for at least 1 year; and
- Produce one or more of the following sequelae:
 - (a) Limitation of function, activities, or social role in comparison with healthy peers in the general areas of physical, cognitive, emotional, and social growth and development
 - (b) Dependency on one of the following to compensate for or minimise limitation of function, activities, or social role:
 - (i) Medications
 - (ii) Special diet
 - (iii) Medical technology
 - (iv) Assistive device
 - (v) Personal assistance
 - (c) Need for medical care or related services, psychological services, or educational services over and above the usual for the child's age, or for special ongoing treatment, interventions, or accommodations at home or in school

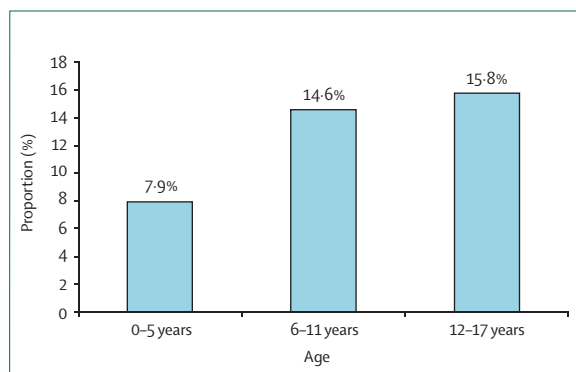


Figure: Prevalence of children with special health-care needs by age²⁵

individual chronic physical diseases, and the common separation of these conditions from mental and behavioural disorders and disability, has effectively downplayed our understanding of young people with such problems. The difficulty of this approach is that the extent of chronic disease in this age group is unclear and underappreciated. More widely, these traditional separations have reduced our appreciation of how different groups of conditions can differentially affect young people. For example, results of a study of the relation between medically attended chronic conditions and functionally defined disability showed that functional disability was most common in children with learning-behavioural conditions (88%), followed by those with neurodevelopmental conditions (61%) and physical conditions (32%).²⁶

Increasing acknowledgment that chronic conditions affect a young person's global developmental processes has led to increased measurement of co-morbid conditions, psychosocial adjustment, and quality of life. However, cross-referencing is strikingly uncommon between studies of different disorders and groups of disorders. For example, remarkably little cross-referencing has taken place between publications on diabetes and cystic fibrosis, even though both are severe, lifelong disorders that necessitate daily medication, regular personal monitoring, and medical review. Although this tendency is consistent with the disease-specific orientation of clinical services, the risk of this approach is that we fail to capitalise on understanding the common challenges for adolescents, parents, and clinicians—and equally fail to capitalise on efficiencies of scale that could facilitate systems and supports that transcend traditional clinical groupings. For example, experience from peer support groups emphasises the extent to which many problems and issues are shared by young people with different chronic diseases.²⁷

Much previous research has emphasised that adolescents with chronic conditions are an at-risk group, although the assumptions underlying the nature of these risks have changed with time.²⁸ Attempts to identify the degree to which physical and psychosocial wellbeing might be compromised fall broadly into two categories:

studies that focus predominantly on risk factors and risk-taking behaviours, and those focusing more broadly on health-related quality of life.

Health-related quality of life

The past 20 years has seen an explosion of studies of health-related quality of life in people with chronic conditions, reflecting a widening of focus from biomedical outcomes to include psychological and social dimensions of health. Measurement of health-related quality of life in young people with chronic conditions is still at an early stage of development^{29,30} with issues relating to proxy reporting by parents and clinicians still unresolved. Parents and their children often differ in their assessments of function, behaviour, and quality of life.^{30,31} In particular, young people report higher rates of physical health and better quality of life than do their parents.³²⁻³⁴ These discrepancies are not consistently accounted for by proxy characteristics such as sex, socioeconomic status, or cognitive ability. Appreciation of age-related understandings about health and illness as well as age-related notions of quality of life are urged.³⁰ Importantly, the mother's health also seems to affect her ratings of her child's health—the worse the mother reports her own health, the lower her assessment of her child's health.^{35,36}

However, whether in relation to decision-making about choice of treatment, measurement of outcomes of clinical trials, or comparison of results across studies, differing assessments of quality of life are problematic. Eiser³⁰ suggests focusing on areas in which parents and young people are likely to make more dependable assessments. For example, whereas parents might be best placed to comment on the effect of illness on family and sibling relationships, adolescents will be better placed to comment on experience of symptoms, peer relations, and worries about the future. Children's perceptions will change with time, emphasising the importance of measures for quality of life that accommodate usual changes that would be expected to occur during childhood and adolescence.^{30,37}

The choice of generic versus disease-specific instruments is as relevant for adolescents with chronic conditions as other populations. Generic measures facilitate comparison between adolescents with different conditions and comparison with population norms. That a study of obese children and adolescents showed lower health-related quality of life than in young people of a similar age who had cancer shows the power of this approach.³⁸ Disease-specific measures can more sensitively measure differential effects of specific aspects of a disease or its treatment which might, for example, facilitate comparison of outcomes between children and adolescents, and between adolescents and adults.

How are these measures being used? In a systematic review of the measurement of health-related quality of life in clinical trials in patients aged up to 20 years, Clarke and Eiser³⁹ found little evidence that these measures are

routinely used in clinical trials, identifying only 18 published trials using standardised instruments. Few studies have compared health-related quality of life across adolescents with different disorders (eg, asthma, epilepsy, attention deficit hyperactive disorder) or groups of disorders (eg, physical, behavioural). Even fewer have determined changes in this factor over time as a function of disease stability (where age and maturational effects could be explored) or instability (where interactions of changing health status and age could be assessed and explanatory mechanisms could be investigated).^{40,41}

Risky behaviours

Poor adherence to treatment is commonly viewed by doctors and parents as risky behaviour in adolescents with chronic illness.⁴² While worse health outcomes can result from poor adherence, the question of how to promote better adherence with treatment is increasingly conceptualised within the notion of self-management, rather than of risk behaviours.⁴³

Although experimental behaviours such as sexual activity and substance use can be understood as a normal part of teenage development, they have historically been viewed differently in young people with chronic conditions. Suris and Parera²⁸ stated that for a long time chronic conditions were assumed to serve as a protective factor in young people, restricting opportunities for enacting risky behaviours. A recent summation of published work has changed this understanding, suggesting that “young people with a chronic condition are not less likely to undertake risk behaviours than their healthy peers”.⁵ Others are more emphatic, suggesting that that they are “as likely or more likely to undertake risky behaviours than their healthy peers”.²⁸

Methodological limitations are a feature of many studies of psychosocial outcomes in adolescents with chronic conditions.⁴⁴ In addition to small sample size, absence of appropriate population-based representation, omission of control groups, and lack of standardised measures of severity of illness and outcome are common. With this caveat, Valencia and colleagues⁴⁵ reviewed two decades of publications on risky behaviours in adolescents with chronic conditions. They prioritised studies that took a non-categorical approach to sample inclusion. Focusing on sexual health, higher rates of sexual activity are reported by young people with chronic conditions than healthy peers.⁴⁶⁻⁴⁹ Additionally, lack of knowledge and reduced use of contraception was also described in these young people.⁵⁰ Unsurprisingly, more sexually transmitted infections were reported.^{45,47} The visibility of the condition did not seem to affect rates of sexual activity.⁴⁵

Findings about substance use in young people with chronic conditions are inconsistent. Tobacco use is at least as common in young people with asthma and diabetes as in healthy peers.^{51,52} Alcohol is thought to be the substance most frequently used by young people with chronic conditions, with little variation by diagnosis.^{53,54} Rates of

use of other substances (eg, marijuana) and delinquent behaviour seem to be lower in young people with chronic conditions than in comparison groups^{54,55} although these behaviours have been less frequently studied and data are again inconsistent.^{5,28} One explanation might be that, as in adults, self-reporting of risky behaviours by adolescents is less reliable in clinically recruited samples compared with population-based studies, underscoring the importance of using objective measures (eg, urinary cotinine) in clinical studies when possible.^{56,57}

In summary, growing evidence suggests that adolescents with chronic conditions are likely to engage in risky behaviour to at least similar if not higher rates as healthy peers. However, a worrying feature of such behaviours in chronic illness is the increased potential for adverse health outcomes. For example, adolescents with asthma and cystic fibrosis who are exposed to tobacco are at increased risk of pulmonary deterioration;⁵⁸ those with sickle-cell disease are at increased risk of acute chest syndrome.⁵⁹ Tobacco use accelerates the development of cardiovascular disease in individuals with diabetes and lupus.⁶⁰⁻⁶² Alcohol use potentiates the hepatotoxicity of methotrexate, which is used to treat various autoimmune diseases.⁶³ Many conditions and therapeutic regimens necessitate careful planning to maximise pregnancy outcomes;⁶⁴⁻⁶⁶ unprotected sexual intercourse in adolescents with these conditions thus carries additional risks.

Young people with chronic conditions are thus doubly disadvantaged by an increased prevalence of risky behaviours and increased risk to health from these behaviours. At the very least, a stronger focus on preventive efforts seems to be needed. In a health-care system where health professionals report less confidence and competence in dealing with adolescents than with other age groups,⁶⁻⁹ investment in generic training about adolescent development and health-care needs is clearly necessary. However, competencies related to specific diseases are also needed. For example, young people with spina bifida and cystic fibrosis report inadequate information about general and disease-specific issues of sexual health.^{66,67}

Social and emotional resilience

A chronic health condition in adolescence can represent a major psychosocial burden. Initial stresses associated with diagnosis, ongoing stresses from treatments and social disruption, social stigma and marginalisation, and changes in plans and expectations about the future can be a substantial challenge to social and emotional wellbeing.^{68,69} Although many young people adjust well to the challenge of a chronic condition, psychological comorbidity in US samples is estimated at about 20%, twice that of healthy young people (panel 2).^{71,72}

The nature of the relation between chronic illness and mental health conditions remains unclear. Vessey⁷² suggests that the disruption of social roles by chronic

disease is especially important, rather than particular aspects of individual disorders. This idea is consistent with those of social capital theorists, who increasingly stress the value of social connectedness and support on health and wellbeing.^{73,74}

Beyond consideration of risk factors, more recent work has focused on the emerging notion of social and emotional resilience in young people with chronic conditions to explain why many negotiate adolescence in productive and effective ways, despite the risks they face.⁷⁵⁻⁷⁷ However, many important questions are unanswered. Does having a chronic illness affect the social and emotional resilience of young people? Might some protective factors (eg, family, peers) have a different capacity to influence young people with chronic conditions than in healthy adolescents? And how might educational and health systems facilitate greater social support for these young people?

Quality health care

Despite having more frequent contact with health-care services than do healthy young people,⁷⁸ adolescents with chronic conditions receive suboptimal general and preventive care. In the USA, the National Ambulatory Medical Care Survey queries doctors about their counselling of adolescents about tobacco use. Asthma is the only chronic condition with adequate sample size to analyse the effect of the condition on counselling rates. In the 1991 and 1996 surveys, notwithstanding the greater risk of smoking in young people with asthma, counselling took place in only 4.2% of visits.⁷⁹ In this survey, primary-care providers were more likely to report counselling than specialists.

As early as the 1970s, youth with chronic conditions were found to receive suboptimum preventive care.^{79,80} Reports of preventive service delivery in adolescents with chronic conditions are sparse, with data derived mainly from clinical samples. Apart from within specialised adolescent health units, broader screening of health-risk behaviours and mental health in adolescent inpatients is uncommon.⁸¹ Immunisation rates of children with spina bifida are worse than in the general population.⁸² Findings of a population-based study of adolescents with cystic fibrosis and sickle-cell disease showed that despite the

greater attributable risk of tobacco smoking in both these groups, only 27% of those with cystic fibrosis and 37% of those with sickle-cell disease reported discussion of tobacco use.⁸³ Similarly, despite greater sexual and reproductive health complications in adolescents with spina bifida, only 39% of youth with spina bifida and 30% of their parents reported they had ever discussed aspects of sexuality with a doctor.⁶⁶ Perhaps not surprisingly, 95% of these young people and 59% of their parents reported inadequate knowledge about sexual and reproductive health.

How can the health-care system best serve the needs of adolescents with chronic conditions? Defining and measuring quality of care for adolescents is more complex than for adults for several reasons. The most prevalent chronic conditions in childhood tend to be mild, whereas more severe diseases tend to be rare. This small segment of the population is most likely to be affected by variations in quality of care, yet most sampling strategies are unlikely to capture them well.^{79,84} Mangione-Smith and McGlynn⁸⁴ provide a framework for addressing quality of care in children and adolescents. First, developmental considerations must be taken into account in determining outcomes of care for adolescents. Extensive variation exists in normal adolescent development, and to ascertain when development has been adversely affected by disease is difficult. Second, developmental outcomes of care received earlier in childhood may not manifest themselves until adolescence. Third, many adolescents receive care outside of traditional health-care systems, such as schools and family planning centres. These services will not be represented in payor or institutional record systems. Finally, as described, many studies of health-related quality of life or other family-based outcomes have relied on proxy reporting. Developing measures of quality of care for adolescents with chronic conditions is a challenging but critical undertaking for this burgeoning area of measurement.

Comprehensive system-based models, such as the chronic care model developed by Wagner and colleagues,⁸⁵ have shown value in improving outcomes for children and adults with various chronic conditions. The key elements of the model include the community (including resources and policies), the health-care system and its design, support for family and self-management, decision support, and clinical information systems. The model is postulated to improve outcomes by improving interactions between a “prepared proactive practice team” and an “informed, activated patient.”⁸⁵ Analyses of elements of the chronic care model and of disease management programmes in general reveal that strong institutional leadership, support for quality improvement, presence of adequate information technology, and external incentives are important at the organisational level.⁸⁶⁻⁸⁸ A meta-analysis that investigated specific aspects of the chronic care model showed that interventions related to self-management support and delivery system

Panel 2: Young people's descriptions of the effect of a chronic condition in adolescence^{43,70}

- “Whenever I had epileptic fits, I would get angry all the time, frustrated” (16-year-old boy)
- “My management is probably medium right now. Not the best it could be, but not the lowest either. I get sick of doing all the things I have to do” (15-year-old boy)
- “I really only have one friend that I can talk to as he has the same thing as me” (17-year-old girl)
- “I’m managing well, but I feel that I don’t have a social life at all” (17-year-old girl)
- “I feel confident I can do what I want” (15-year-old girl)

design were the most powerful in improving quality of life and clinical outcomes.⁸⁹

To date, interventions have tended to focus on one or a few conditions, usually those that require day-to-day management by patients, such as diabetes or depression. System-based interventions in paediatrics have shown improvements in process and outcomes of care for asthma⁹⁰ and some process outcomes for attention deficit hyperactivity disorder.⁹¹ While some studies included adolescents, the unit of analysis was typically the practice, so it is not possible to examine differential effects among adolescents.

Self-management

For adolescents with disorders that need daily attention (ie, adherence with recommended treatments), the individual's and family's ability to manage the condition is crucial. The notion of transition to adult health care is implicitly based on the need to help actualise young people's emerging capacity for self-management. However, rather than self-management, much of the focus of work on this transition has been to explicitly support young people in the physical transfer from paediatric to adult-oriented health-care services.⁹² The shortage of adult expertise in caring for survivors of childhood conditions (eg, congenital heart disease) is now being recognised and rectified in the developed world, but will increasingly affect the developing world as they too experience improved survival of young people with chronic conditions. In the absence of appropriate primary care or specialised adult services, adolescents with complex chronic conditions risk dropping out of health care altogether, with dire health consequences.

A key tenant of self-management support is education and coaching in problem-solving, in addition to more traditional information-giving and technical skills training.⁹³ The ability to self-manage, at least among adults and parents of children with chronic conditions, is correlated with self-efficacy, that is, confidence in one's ability to implement the necessary behavioural changes. Unfortunately, although adolescents have been participants in many of the paediatric and adult trials of self-management support, age-specific analyses have not been done. Developmental considerations in adolescence, including the transition from the parent having primary responsibility for care to the adolescent assuming that responsibility, are likely to require modification of approaches to achieve the best results.⁴³

The largest numbers of studies of self-management support have focused on patients with asthma and diabetes. A systematic review of 36 randomised controlled trials for asthma that included some combination of knowledge provision, self-monitoring, regular practice review, and a written action plan, determined that these interventions reduced unscheduled health-care use (including hospital admission), enhanced quality of life, and reduced numbers of missed school or work days.

Most patients in these trials were adults; a hand review of abstracts from that review revealed no stratification of outcomes by age.⁹⁴ Similarly, a meta-analysis assessed 32 randomised controlled trials that enrolled only children and adolescents with asthma and used interventions designed to enhance knowledge, skills, and feelings of self-control. The pooled effect of the interventions was increased lung function and self-efficacy and decreased school absences, days with restricted activity, and unscheduled use of health-care services.⁹⁵ 15 trials enrolled adolescents, but none stratified by age. By contrast with the efficacy of self-management support interventions, studies that included only knowledge-based education,⁹⁶ written management plans,⁹⁷ or psychological treatment⁹⁸ generally showed no significant effect.

In epilepsy, self-management has been conceptualised as medication management (behaviours to manage medications), strategies to control seizures and their consequences (behaviours to manage seizures), and techniques to manage situations arising from having epilepsy (behaviours to manage life).⁹⁹ A systematic review of self-management interventions is underway within the Cochrane Collaboration¹⁰⁰ and might provide the opportunity to investigate outcomes for children and adolescents separately.

Diabetes is perhaps the most obvious model of a common condition that requires daily medication and lifestyle (diet and exercise) management, with evidence that intensive treatment reduces complications in adolescents.¹⁰¹ A Cochrane review of self-management education for adults showed sustained, clinically important improvements in metabolic control and complication rates.¹⁰² Gage and colleagues systematically reviewed studies of education, psychological, self-management, or combined interventions in adolescents with type 1 diabetes.¹⁰³ Although these studies typically did not include sufficient follow-up to ascertain the effect of specific interventions on physical complications, almost all 62 studies reported at least one positive outcome. Incorporating parents into interventions generally had a positive effect. The authors noted, however, that none of the studies directly addressed the transition from parentally-controlled diabetes management to independent management by the adolescent.

Implications and future directions

Despite these developments, more consistent and rigorous monitoring of health status, including quality of life, mental health, and risk-taking behaviours, would provide stronger evidence for clinical and preventive efforts that aim to mediate the effect of chronic conditions on the lives of young people, and their families. We were unable to identify any longitudinal generic cohorts that had tried to identify the effect of social, economic, educational, and pubertal transitions on health outcomes and risk behaviours—and vice versa—in young people

with major chronic disease or disability. Clarification about the distinct and common features of adolescents with specific disorders and groups of disorders would inform clinicians and health-care planners about models of adolescent-friendly health-care services.

The importance of understanding and facilitating the transition of responsibility for self-care during adolescence cannot be overstated. Well-designed theoretical and empirical studies are needed to understand the timing, speed, and nature of the shift in responsibilities.⁴³ In addition to age effects, other critical developmental variables such as the timing of puberty, which can be greatly affected by chronic disease, are important.¹⁰⁴ Again, models that transcend specific conditions would be especially valuable, as is understanding how structural elements of paediatric and adult health-care systems can both facilitate and hinder transitions.^{43,97}

More broadly, deeper understanding of the social aspects of growing up and becoming an adult with a chronic condition is needed, as well as the role of peers, both healthy and ill, in supporting adolescents' self care.^{105–108} How does the experience of adolescence with a chronic condition affect young peoples' capacity to engage in age-appropriate social activities? How are efforts to develop a robust personal identity affected by such conditions, and how in turn, do efforts at developing a satisfactory identity and self-story affect health-related behaviours of young people with chronic conditions? Innovative approaches to qualitative data collection are providing valuable insights into some of these important questions.^{109–111}

Although most chronic conditions of adolescence are not preventable by lifestyle changes, many comorbidities should be highly modifiable. Engaging peer support and positive social interactions can be challenging, especially for adolescents in less populated areas or with rare conditions. However, an evidence base is emerging about the value of face-to-face peer support, whether school-based and disease-specific (eg, Triple A [Adolescent Asthma Action], a peer-led asthma health promotion programme for secondary schools)¹¹² or community-based and generic (eg, ChIPS, the Chronic Illness Peer Support programme, a model of peer support and leadership training for young people with different chronic diseases).²⁷ Evidence is also growing that internet-based support and self-management programmes and other technologically-mediated methods can improve outcomes for people with chronic conditions.¹¹³ In view of young people's enjoyment of communication technologies, these methods seem especially promising for assisting adolescents with varying developmental and disease-related needs without the constraints of geography.

Growing investment in cancer services for young people is an example of how identification of differentially worse survival data can affect various structural elements of the health-care system.^{114–116} However, beyond survival data,

increasingly focused assessment of health, developmental, and psychosocial outcomes in adolescents with chronic conditions will broaden our understanding of the complex issues experienced by so many of them. This knowledge in turn will provide a platform to both challenge the orientation and nature of existing services, and to strengthen the response from health-care systems to better support young peoples' progress towards adult life.

Conflict of interest statement

We declare that we have no conflict of interest.

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