



THEME

Adolescence



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Adolescents with chronic disease

The double whammy

BACKGROUND

Approximately one in 10 adolescents have limitations of activity from chronic disease or disability. Self management of chronic disease is increasingly recommended in adults, but there has been remarkably little discussion of its application in adolescents. Evidence suggests better outcomes for patients who are able to self manage their disease.

OBJECTIVE

This article outlines some of the challenges associated with working with adolescents with chronic disease. Self management is discussed, focusing on how it can inform clinical strategies with both the adolescent and their parents.

DISCUSSION

The developmental challenges faced by adolescents with chronic conditions, and their parents, are common across disease categories. Clinicians are required to concurrently support the adolescent's emerging capacity for self management while simultaneously supporting parents to take on a different role in relationship to their child's health care. General practitioners are ideally placed to assist adolescents to engage in developmentally appropriate self management practices.

Approximately one in five children and adolescents have special health care needs, one in 10 have limitation of activity due to chronic illness or disability, and one in 1000 have a life limiting disorder.^{1,2}

Adolescence is now well recognised as a time of risk for the onset of behavioural and mental disorders such as depression and anxiety, eating disorders, and substance use disorders, which are equally well recognised to be experienced at higher rates in contemporary youth than in previous generations.

There has arguably been little appreciation of the growing prevalence of chronic physical disease in childhood and the burden this places on young people during adolescence. A number of chronic conditions are characterised by an increasing incidence in adolescence such as diabetes, cancer, chronic inflammatory bowel disease, allergy, and obesity.² Technical advances over the past few decades have increased survival which further contributes to the growing number of children with

chronic disease and disability who reach adolescence.² Indeed, more adolescents have special health care needs than children.³ Special health care needs has been defined as children who 'have or are at increased risk for a chronic physical, developmental, behavioural or emotional condition and also require health and related services of a type or amount beyond that required by children generally'.¹

Many health professionals report that managing the complexity of health concerns in adolescence, including chronic disease, is more challenging than in other age groups.⁴

Data from our Optimising Pathways research study illustrate some of these challenges. Optimising Pathways is a qualitative study that aims to explore the impact of chronic illness and self management on the lives of adolescents from three perspectives: adolescents with chronic illness (n=60), their parents (n=60) and their clinicians (n=30). Adolescents in this study have one of four disorders: cystic fibrosis, asthma, diabetes and acute

lymphoblastic leukaemia. To date, we have interviewed 18 adolescents (10 with cystic fibrosis and eight with asthma). Selected transcripts from these adolescents, and their parents, are used to illustrate some of the challenges of chronic illness in adolescence.

Self management in chronic illness

Global recognition of the growing burden of chronic illness has focused on the concept of self management; current evidence suggests that patients with effective self management skills have enhanced self care and make better use of health care professionals' time.⁵ In Australia, the National Chronic Disease Strategy focuses on self management as one of four central themes.⁶ Despite some concerns,⁷ the allocation by the Australian Government of \$515 million toward activities that promote self management in patients with chronic illness will ensure continued focus on this concept locally.

However, the overwhelming focus of these developments has been adults. Whether framed in terms of research, policy or programs, the perspective of adolescents with chronic illness has been essentially absent.^{2,8}

Self management in adolescents with chronic illness

The concept of self management is based on the person with chronic illness being an autonomous adult. Despite 18 years being the age of legal maturity, the capacity for self management does not suddenly appear at this, or any other age. Rather, clinicians and parents know that as children mature, they variably develop the knowledge, attitudes and skills that promote more positive, autonomous disease management practices.^{8,9}

'About 10 years old is when I started asking the questions... because before that, I didn't know why I had to [take medication and do physiotherapy]. I just knew I had to do it and yeah, now I know why I have to... So I can breathe and live, and stuff, yeah... If I stop doing physio for like ages, like a year or something like that, my lungs can like clog up and I can like suffocate and not breathe, yeah.'
Male, 13 years of age, with cystic fibrosis.

Clearly, an adolescent's capacity for self management is both age and task dependant. Therefore, while we might expect even young children to name their condition or list the various medications or treatments required of them, many parents continue to be responsible for arranging and paying for repeat prescriptions of medication until their child leaves home (Table 1).

'If [the medication] starts to run out, I just tell mum. I ask her, 'Do you have enough?' Because she keeps a stern

Table 1. Specific knowledge, attitudes and skills that underpin autonomous self management practices
Can name and explain their condition
Can list their medications, treatments or other management practices (eg. special diet)
Can explain why each medication or management practice is necessary
Remembers to take their medication most of the time
Can answer questions asked of them by doctors or other health professional
Can ask questions of their doctor or other health professional
Can arrange (and cancel) appointments
Can consult with a doctor or other health professional without a parent
Has their own Medicare card
Remembers to obtain more medication before it runs out
Can have prescriptions filled at a pharmacy
Develops the desire for their health care to be independent of their parents
Can prioritise their health over (some) other desires

lock on the cupboard – like she's got a medical cupboard, like you know, cold tablets and all that, and she keeps her – the stuff up there and I just check with her that she's got another one, and if she doesn't, I just ask mum, 'Oh can you go get one at the chemist', and that's how I keep up with them.'

Male, 16 years of age, with asthma.

Clinicians are encouraged to educate and empower adolescents to manage as much of their chronic condition as they are personally capable of doing. At the same time, clinicians are also encouraged to work closely with parents to empower them to gradually hand over the responsibility for self management to their child. This can be a difficult task for parents, who must balance continued vigilance and monitoring of their adolescent's health related behaviours (or lack of) while supporting greater autonomy and independence in self care by their children.

This process could be viewed as analogous to a dance, with the two partners (the adolescents and their parents) moving together. While parents may believe that they are leading the dance, adolescents may take the lead position (either gently or more overtly), and parents are required to follow. It is surprising how little we know about the affect on the development of appropriate self management practices in adolescents. We know even less about how things go wrong when one partner gets out of step. From clinical experience, we know that some parents do not sufficiently encourage their teenager to take on an appropriate level of responsibility, while others can hand over too much responsibility too soon.

'It would be nice to think that she would take that responsibility and look after herself but at the same time it's hard to let go. It's hard because while you think you've got control, it's your mistakes... Say she was 18, and she lived somewhere else, I would not feel confident. She would do it, but she would be haphazard, I reckon she'd think, 'I'll have a night off tonight', like I reckon she'd have a few nights... She's admitted to me she hates taking [her medication] in front of people. She hates people seeing her. She doesn't want to be seen as different. I don't think she wants people to know she has a problem.'

Mother of a female, 14 years of age, with asthma.

The double whammy

Contemporary adolescents with chronic illness have to negotiate an increasingly complex social world. At the same time, greater availability of health technologies means that increasingly complex health care demands are placed upon them. For example, 50 years ago, approximately 85% of infants with extreme prematurity or congenital heart disease would have died. Now, 85% survive through childhood to adolescence but commonly carry a much heavier burden on health practices than in previous generations. In addition, we now manage cohorts of adolescents with previously uncommon disorders such as HIV and other sexually transmitted infections, and obesity. Adolescents may experience health risks and social burdens of these illnesses differently to other generations.

The distinct absence of research in this area suggests that, at least until recently, health professionals may have assumed that adolescents with chronic disease were less likely to participate in health risk behaviours such as drug use or unsafe sexual activity. Instead, there is now evidence that adolescents with chronic disease participate in health risk behaviours at a greater rate than in healthy adolescents.^{2,10}

However, adolescents with chronic disease can be viewed as experiencing a 'double whammy'. In addition to the higher prevalence of health risk behaviours and mental health states, they are 'doubly disadvantaged' by the higher attributable risk from these behaviours in the context of their underlying chronic disease or its treatment.² For example, the attributable risk from smoking is higher in adolescents with diabetes, asthma and cystic fibrosis than in otherwise healthy adolescents. Therefore, in addition to aspects of disease management, efforts to limit the onset of health risk behaviours should be a major component of self management education.

Adolescent development

Management approaches are more likely to be successful when they are underpinned by knowledge of

the developmental challenges facing adolescents, the individual behavioural and emotional issues experienced by adolescents, and the social context of these issues. It is important to appreciate the many ways in which the presence of a chronic disease (and its management) can conflict with these developmental challenges. For example:

- adolescents with external markers of illness (eg. body scars, deformity) may feel less attractive. This can affect their capacity to form healthy peer friendships and intimate relationships
- the developmental desire to belong to a peer group and feel 'normal' can reduce adherence with medication because of embarrassment taking medication publicly
- aspects of experimentation which could be considered normal in healthy adolescents may have severe consequences for health
- educational opportunities may be subtly affected by reduced parental and school staff expectations
- limited role modelling of successful life transitions may affect identity formation
- over protection by parents may hinder the development of independence.

'We pack her lunch still. At the same age her sister started packing her own lunch, but I guess we're more obsessive... We make sure she's got her [pancreatic enzymes]. When she comes home, we get her to unpack her bag. We then check and know that [it] hasn't been taken and we've given up nagging about that ... We've decided not to battle about it too much. I really think that if we battled she'd do less. One of the issues for these kids is that they are asked to do things that are really age inappropriate. Five year olds should not be managing their medication really, neither should 12 year olds really, I think... A lot of the parenting of a child with CF for us is more about how we're going to manage our worry... I mean, my understanding is that teenagers go out and they live a life and they lose their lung function and the difficult thing is that they can't get it back, whereas normal teenagers, it doesn't impact in that way and that as a parent, you really just have to watch it happen, really.'

Mother of a female, 12 years of age, with cystic fibrosis.

Clinical strategies

The usual clinical approaches to consulting with young people are equally important in adolescents with chronic illness, such as seeing the young person alone for at least part of the consultation, providing confidential health care, and taking a detailed psychosocial history.¹¹

A particular focus of the psychosocial history should be to identify adherence 'hooks', namely, patient centred

reasons why the adolescent might benefit from particular health outcomes. For example, in an adolescent with severe exercise induced asthma who plays competitive sport, emphasising the importance of better asthma control in order to improve sporting success (patient centred goal) will be more influential than efforts to improve asthma

management *per se* (health goal). Targeting positive developmental goals (eg. sporting participation, attendance at school camps) promotes better adherence and reduces perceptions of parental 'nagging'.

Efforts to develop treatment routines can be especially helpful in adolescents with chronic disease. Identify what

Table 2. Key issues in promoting self management in adolescents with chronic illness

Adolescent development

Adolescents

Adolescents need to feel that managing their health care need not be at the expense of personal priorities and social roles. They have a life as teenagers beyond a medical diagnosis of a chronic condition and they want to live it!

Parents

Parents can be challenged by simultaneous desires to promote independent self management in their child while 'making things easier' for them

Clinicians

Clinicians can be challenged by simultaneous desires to respect parent preferences around communication styles while wanting to foster developmentally appropriate health care in the adolescent

Level of understanding

Adolescents

What is the adolescent's level of understanding about their condition and their prognosis? Is this sufficient for them to understand why they need to do the health care activities they have been advised to do?

Parents

Are parents trying to 'protect' their child from challenging aspects of their condition or prognosis? Is this appropriate? Can the adolescent adequately understand the significance of necessary health care activities with the level of knowledge that the parent/s is comfortable for them to have?

Clinicians

Is the clinician trying to 'protect' the adolescent from challenging aspects of their condition or prognosis? Is this appropriate? Can the adolescent adequately understand the significance of necessary health care activities with their level of knowledge?

Self management capacity

Adolescents

Is the adolescent equipped with sufficient physical skills and social and emotional resources to embrace a greater level of self management? Do the adolescent's goals and capacities match the self management goals and expectations of the parent/s and health care practitioner/s?

Parents

Parents often express a desire to feel 'in control' of their child's health care routines. Is the parent adequately prepared to take on more of a 'mentor' role and begin to relinquish more of the 'doer' role? What fears and/or hopes does the parent have about the child's increasing responsibility for self care?

Clinicians

Promoting self management is as much about preparing and empowering parents to embrace a loss of control over their child's health care routines as it is about empowering the adolescent to take on greater responsibility as they mature into an adult

Transition to adult health care

Adolescents

If speciality adult health care services will be required, is the adolescent appropriately prepared for transfer to a new specialist and/or team? Do they know at what age this is likely to happen?

Parents

Are the parents prepared for the transfer of specialty care from the paediatric to adult health care sector? Has timing been discussed? What needs to be in place to make this transition as smooth as possible? Even if it hasn't been brought up, these issues will be on parents' minds

Clinicians

If required, when will the adolescent's care be transferred from specialty paediatric to adult health care services? Who is responsible for arranging this? Is the adolescent and their family sufficiently prepared?

Access to resources

Adolescents

Does the adolescent have access to appropriate information, resources and social and emotional support to foster successful development of self management skills? Are financial concerns complicating these issues? Do they have their own Medicare card?

Parents

Does the parent/s have access to appropriate information, resources and social and emotional support for them to foster successful development of self management skills in their child? Are financial concerns complicating these issues for parents?

Clinicians

Does the clinician have access to adequate knowledge, resources, workplace supports and skills to foster successful self management practices in adolescents with chronic illness? Have you promoted the adolescent getting an individual Medicare card?

dose timings are more easily remembered and why. Like adults, adolescents remember to take medications because of routines; and adolescents may need help from their parents to develop routines.

'In the morning, I've got like a schedule kind of thing. I wake up, do my physio, eat breakfast, get dressed, and take some [medication] and then go. But on the holidays, I can just like you know, sleep in whenever I want and eat whenever I want and play.'

Male, 13 years of age, with cystic fibrosis.

It can be challenging for clinicians to concurrently support the adolescent's emerging capacity for self management while supporting parents to take on a different role in relationship to their child's health care. Some of these issues, including a number of tensions, are outlined in *Table 2*.

Tasks for GPs

- Educate adolescents about their illness
- Identify patient focused adherence 'hooks'
- Assist developing treatment routines
- Ensure access to appropriate supports
- Consider the developmental challenges and individual behavioural and emotional issues the adolescent is experiencing – as well as the social context of these issues.

Conclusion

While most of the research literature is disease specific, the developmental challenges faced by adolescents with chronic conditions, and their parents, are common across disease categories. General practitioners, as part of the health care team, have an important role to play in educating and empowering adolescents to manage as much of their chronic disease as they are capable of doing, and empowering parents to gradually hand over the responsibility for management to their child.

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