Self-management in adolescents with chronic illness. What does it mean and how can it be achieved?

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Recognition of the growing burden of chronic illness has led to health policy responses, both globally[1-4] and in Australia, increasingly referring to self-management.[5-7] However, the term "self-management" means different things to different people.[8,9] On the one hand, it can mean simply living with a chronic illness in ways that allow a person to "get on with life" as much as possible. On the other, it can refer to a set of medical constructs about what constitutes good disease management from the health professional's perspective, such as adherence with treatment regimens. The concept of self-management is typically based on the notion that it will improve wellbeing and strengthen self-determination and participation in health care, while reducing health care utilisation and health costs.[2-4]

Most of the self-management literature has focused on older populations, in which the burden and costs of chronic illness and disability are increasingly evident. However, chronic illness, disability, developmental delay and behaviour problems are also prevalent in children and adolescents. Although there is no consistent definition of either "chronic illness" or "disability" in paediatrics, existing definitions have included the concepts of (a) having particular service needs; (b) carrying a diagnosis of a specific physical or mental condition; and (c) exhibiting specified functional deficits.[10] Children with "special health care needs" have been defined 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 beyond that required by children generally".[10,11] Using this definition, 15%–20% of children and adolescents have a significant ongoing health care need related to a chronic health condition.[11]

Chronic illness can affect adolescents in myriad ways. In addition to the demands of complex treatment regimens, chronic illness can affect the rate of young people's growth and development, their appearance, identity, mental health, relationships with peers, and engagement with education and employment.[12] Chronic illness in children and adolescents can also profoundly affect family function, sibling experiences and marital relationships. Supporting adolescents with chronic illness can be especially challenging for parents and health professionals alike. In comparison with younger children, who generally acquiesce to parental requests around health, young people no longer automatically do what they are told. As adolescents mature, they learn to become more engaged in self-care. Here we consider the usefulness of the concept of self-management in caring for adolescents with chronic illness and how this might differ from efforts to promote self-management in adults.

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ABSTRACT

- The concept of self-management is based on the notion that it will improve wellbeing and strengthen self-determination and participation in health care, while reducing health care utilisation and health costs.
- Increasing self-management is a desirable goal for the 15%–20% of children and adolescents who have a significant ongoing health care need related to a chronic health condition.
- Promoting self-management in young people with chronic illness can be difficult for parents and health care practitioners.
- Doctors can help parents recognise the potentially competing aspects of the parenting role — protecting young people's health while supporting their growing independence and autonomy. Optimal care may or may not be achievable, depending on a young person's level of development.
- As children mature through adolescence, they increasingly want their own voice to be heard, as well as the right to privacy and confidentiality in health care consultations.
- As well as listening to parents and supporting their roles, doctors should see young people alone for part of the consultation, taking a psychosocial history and carefully maintaining confidentiality.

MJA 2005; 183: 405–409

Adolescent development and self-management

Adolescent development is commonly conceptualised in terms of physical, cognitive and psychosocial maturation. It is not simply chronologically determined: the timing of puberty is a key determinant of the trajectory of physical development, and psychosocial development is strongly influenced by social engagement with families and peers. Passage through adolescence is characterised by increasing capacity for abstract thought, which enables young people to contemplate future possibilities or events not personally experienced and increases their ability to defer immediate gratification for perceived future benefit.

However, as parents of adolescents with chronic illness know only too well, even young people with more advanced cognitive capacities remain primarily oriented to the present. In comparison with adults, young people (including those with chronic illness) are less influenced by longer-term health risks.[13] This can pose difficulties when the aim of much daily treatment is to limit future complications.

Current thinking about self-management of chronic illness assumes that the person with chronic illness is an autonomous adult. But young people do not magically develop the capacity for self-management on their 18th or 21st birthdays. Rather, as children mature, they variably develop the knowledge, attitudes and life skills that underpin engagement with chronic illness self-management practices. How then can health professionals balance supporting parental involvement while promoting the engagement of young people with self-management, and how can parents balance vigilance and monitoring of young people's health-related behaviours while supporting their development of greater autonomy and independence? And what of the attitudes and behaviours of young people themselves?

What we know about young people and chronic illness

Medical perspectives

Three concepts have surfaced within the medical literature in relation to chronic illness and adolescence. The first is the notion of adherence to treatment regimens. Parents are held account-able for the adherence behaviours of their teenagers with chronic illness, yet at the same time, adolescents are expected to take increasing responsibility for their own behaviours, including disease management. This can be a major source of tension between young people and their parents. The adherence literature explicitly views better adherence as a route to better health outcomes,[14] with little appreciation that adolescents with the best disease control can also be those with the poorest psychological adjustment.[15] While there is support for a partnership model between doctor and patient as a route to better adherence in adults,[16] a central partnership for young people with chronic illness is the relationship between them and their parents. However, neither medical nor parental partnerships have been sufficiently explored in relation to how this might promote better adherence with chronic illness management in young people.

The second concept is the notion of transition from paediatric to adult health care settings for young people with special health care needs, especially those with chronic illnesses requiring continuing specialist services. This concept is well developed in terms of advocating for policy shifts to produce closer links between child and adult health care providers and services in order to promote greater continuity of health care.[17-19] The notion of transition is implicitly based on an understanding of adolescent development and the dynamic relationships between young people, parents and health professionals.[20] Engagement with appropriate health professionals or services within the adult sector is viewed as the means of enhancing the capacity of young people to take greater responsibility for managing their health.

The third concept is the practice of developmentally appropriate health care, a key principle underpinning the practice of adolescent medicine. Within this rubric lie a set of clinical practices oriented to concomitantly achieving better developmental and health outcomes for young people.[21] A simple example of these practices is addressing clinical questions to a young adolescent rather than his or her accompanying parent. While this may be misconstrued as ignoring parental roles and responsibilities, the practice of adolescent medicine is one that daily tries to balance the sometimes competing perspectives of both young people and parents. We believe that this need for balance lies at the heart of what constitutes self-management for adolescents with chronic illness.

Parent perspectives

When patients are younger children, the dominant interaction in the clinical setting is between the doctor and the parents. Notwithstanding the validity of the parental role in protection, advocacy and support, there are increasing calls for clinicians to pay more attention to children's voices.[22,23] As children mature through adolescence, there is even greater likelihood of tension about whose voice needs to be heard in the health consultation.

Parents of adolescents continue to be legally responsible for their children, while being expected to promote their independence and autonomy. For parents of young people with chronic illness, the difficulty lies in how to maintain a supervisory role while supporting young people's emerging ability to independently manage their health. There can be tension about how this is played out on a day-to-day basis in the home (Box 1).[15,24] Parents may feel accused of being overprotective when, from their perspective, they are simply fulfilling their parental obligations.

Young people's perspectives

Only recently have young people's views about preferences in health care been sought. For example, health care satisfaction surveys have long used parents as the proxy patient respondent for both children and adolescents.[25] Calls for greater attention to young people's voices coincide with the views of young people themselves, who report they often feel left out of consultations, in which the discussion commonly focuses on parent issues and perspectives.[26,27] From early adolescence, young people with chronic disease report wanting greater engagement with health professionals, which includes wanting to see doctors alone for at least part of the consultation and wanting more confidentiality in health care.[28,29]

Young people report significant psychosocial impacts of chronic illness in adolescence.[30] Olsson et al identified that negotiating relationships with peers is a central aspect of managing chronic illness in adolescence, as are young people's emotional responses to chronic illness, their acceptance of illness and their efforts to find meaning out of having a chronic illness (Box 2).[30]

Towards self-care

The development of self-management practices for adolescents with chronic illness requires active engagement of both young people and their parents, with attention to the psychosocial world of the young person. Poor family relationships and low levels of

1 Different views about medication

Doctor: So how have you found the new asthma preventer, Michelle?

Michelle (a 14-year-old): Well, I suppose it's been OK.

Michelle's mother: But some things haven't changed, doctor. I still have to remind her to take it all the time . . .

Doctor: How often are you reminding her?

Michelle (interjecting): She nags me all the time! "Clean up your room, take your medication . . ."

Michelle's mother (interjecting): But if I didn't remind you, you wouldn't take any . . .

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2 Young people's descriptions of managing chronic medical conditions in adolescence*

"With my diabetes, if I have a healthy diet and do all the right things, I will feel better in myself and make myself better . . . I can help myself along the way." (17-year-old female)

"[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 that I have to do — it also gets boring." (15-year-old male)

"I'm managing well, but I feel that I don't have any social life at all." (17-year-old female)

"I really have only got one friend that I can talk to because he has the same thing as me." (17-year-old female).

"I tell my friends [about my illness] . . . but I don't like to tell everybody because they might want to say 'you can't do this, you'd better do that, or I feel sorry for you' . . . I really hate it when people do that. It is really annoying." (13-year-old female).

"I'd probably like to be an astronomer or an archaeologist. But you have to get really good [marks] with them and I don't think that I would cope in the VCE year and all that. I don't think I would get to school enough to do all that." (16-year-old male).

"It is different now, because I am not as anxious, because I am starting to get used to having [asthma]. If I have an asthma attack I know what to do. I am not as anxious as I was." (15-year-old male).

". . . whenever I had [epileptic fits], I would get angry all the time, frustrated."(16-year-old male).

"I feel depressed at times, just about the condition. That causes other feelings like relationships . . . not having a girlfriend, which is probably because of my height." (25-year-old male).

"I feel confident that I can do what I want to do." (15-year-old female).

"I think it might come down to accepting [chronic illness], accepting that you have got it and dealing with it when it comes up and trying to work your way around it." (25-year-old female).

"I feel that now I am here, regardless of how I got here, I feel I can make myself have a purpose. I can create a purpose." (21-year-old female).

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* From Olson et al.[30]

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parental support are associated with poorer adherence with treatment regimens,[31] while high levels of family functioning and family support are associated with better treatment adherence, even in the 18–22-years age bracket.[15] While engagement in self-management will not necessarily result in good adherence (which is known to reflect many different variables), it is a good start, as poor understanding and poor commitment to treatment regimens are known barriers to adherence.

There are, however, several areas that require further exploration. Firstly, we know surprisingly little about what constitutes self-management in adolescents with chronic illness. For example, we do not know at what age young people generally take on more responsibility for the different components of self-management, such as taking medication, booking appointments or seeking health care when they become acutely unwell. Furthermore, we do not know how the type or severity of the chronic illness or the nature of the treatment regimen alter the age of acquisition of various self-management practices. Little is known about rates of participation in health-risk behaviours in this group. While we might intuitively believe that young people will be less likely to engage in behaviours that have a greater attributable risk (eg, smoking in young people who have diabetes), there is little evidence that this is so, and there are few models about how best to intervene.

We also need more information to guide parents. Some styles of parental interaction are perceived as unhelpful by adolescents with chronic illness (such as parents being overly strict or controlling or giving a lot of negative feedback), while others (such as parents trying to work in partnership with their child and giving positive feedback)[24] are viewed more positively. However, there is little research about how parent behaviour can either facilitate or hinder the emerging capacity for self-care in adolescents with chronic illness, and thus, whether more effective parenting styles can be learnt.

We do know that styles of doctor–patient interaction can influence how adults engage with medical knowledge.[32] Recognising this fact has made doctors more aware of the effectiveness of patient-centred practice as a means of improving health outcomes for patients with chronic illness.[33] A critical tenet of such patient-centred practice is the partnering between doctors and patients. However, a key question for adolescent health is how partnerships are formed between adolescents with chronic illness, parents and doctors and whether these partnerships can improve health outcomes by improving self-management practices in adolescents with chronic illness.

Consistent with the principles of adolescent medicine, we suggest an important method to achieve this is by using clinical approaches that build on an understanding of adolescent development. In addition to listening to parents and supporting their roles, this would also mean seeing young people alone for part of the consultation, taking a psychosocial history, and carefully maintaining confidentiality (Box 3).[21]

Implementing these evidence-based approaches is possible,[35] but there are no formulas for how best to achieve this in practice. Rather, this approach provides a framework for practice in which doctors attempt to balance the needs of both young people and their parents in working towards adolescent self-management. At times, immediate health priorities will need to be balanced against the need to support young people's emerging autonomy and growing capacity to manage their chronic illness.

An obvious example is the arena of adherence with treatment regimens. Understandable concerns about poor adherence in adolescents often result in protective parent behaviours, such as constant reminders to young people to take their medication. While parents hope the reminders will promote better adherence, their prompts are often interpreted by young people as unwarranted "nagging" (Boxes 1,3). The developmental approach to these competing views provides an understanding that young people learn by doing, which at times means learning from their mistakes. Doctors can help parents recognise the potentially competing aspects of the parenting role — namely, protecting young people's health while supporting their growing independence and autonomy. The developmental approach provides a potential framework for doctors to contend with such issues by ensuring that both young people's and parents' voices are heard, and heard by each other.

Participation in community-based support groups is a common strategy for promoting self-management in adults with chronic illness.[3,36] Peer support groups are also highly rated by young people with chronic illness, who particularly value the social support of other young people in the group and the opportunities

3 Working towards self-management

Mark is a 16-year-old boy who was recently diagnosed with epilepsy. His mother is concerned that he is increasingly moody, as well as physically aggressive with his younger sister. She reports that he has become uninterested in school work and no longer wants to play football, which he'd previously loved. Mark has been told that he can't attend school camp in a few months' time because of the school's concern about poor seizure control (a concern shared by his mother). From her perspective, the main problem is Mark's "refusal to look after himself". She says she's always reminding him to take his medication, and believes Mark is old enough to look after his medication himself. Previous medical visits were with Mark and his mother together, with the primary focus being fine-tuning his medication dose in response to seizure control and side effects. He has recently started a new anti-convulsive.

The doctor suggests it would be useful to see Mark alone to hear his view of how things are going, and describes the confidential nature of medical consultations to Mark and his mother. Specific questioning confirms that Mark's seizures have been much better controlled recently, with no side effects from the new medication. However, using the HEADSS* mnemonic, the doctor identifies that, since having a seizure at school, Mark has been mercilessly teased. He has not told his parents about this, but is happy for the doctor to share this with his mother. He says that because of school absence at the time of poor seizure control, he was "dumped" from the football team, which he is angry about. He also reports that things have "just changed" with his friends, whom he no longer spends time with at weekends, apart from going to the occasional party "just to get pissed". He agrees he is feeling sad, and also reports he is angry about having epilepsy. He acknowledges he is "pretty useless" at remembering to take his medication. Despite knowing that careful adherence will reduce the likelihood of seizures, he reports he "can't get his act together".

The doctor suggests that Mark try to identify some daily routines that would make it easier for him to remember to take his medication. He agrees to keep a medication diary for the next week, and agrees that his mother will remind him to take his medication if, by the time he goes to bed, there is no record that it's been taken. Regarding the school camp, the doctor establishes that if Mark didn't have epilepsy he would love to go to camp, but he is very fearful about having a seizure while away.

The doctor then sees Mark and his mother together and describes the plan to keep a medication diary. Mark's mother is reminded that many 16-year-olds find it hard to remember to take their medication, and that most young people need help from their parents to develop treatment routines. With Mark's permission, the doctor encourages Mark's mother to speak with his student coordinator at school about both the bullying and sporting concerns.

Mark agrees to more frequent medical review in the lead up to the camp to help decide whether he feels safe enough to attend. At each visit, he is seen by himself and then with his mother, who confirms that his adherence is much better since establishing regular medication routines (linked to cleaning his teeth). Despite continued good seizure control, both Mark and his mother remain ambivalent about the camp. His mother gradually becomes more confident as his seizures remain well controlled, and finally discusses her support for Mark to attend the camp with his school. With some encouragement, Mark agrees to attend the camp, which turns out to be medically uneventful and socially enjoyable.

Over the next few months, his social confidence gradually improves and, by the following year, he has returned to his usual sporting activities. While his mother is pleased that Mark is "back to his usual self again", Mark says that "things will never be quite the same".

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* HEADSS = Home, Education/employment, Activities, Drugs, Sexuality, Suicide/depression screen.[34]

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for wider participation.[36] Despite the prevalence of chronic illness and disability in young people, relatively few peer support groups have been specifically developed for them. In some instances, such as when the number of young people with certain chronic diseases is relatively small, it would be beneficial to promote peer support groups that are not "disease specific". Rather, the core premise underpinning such peer support groups is that young people with chronic illnesses share many problems in common. Models for such groups have been developed and successfully put into practice.[37] In addition to face-to-face support, young people can also benefit from "virtual" groups, such as online chat rooms or more formal programs for young people with chronic illness. Schools are a suitable site for health promotion around self-management practices, and school-based programs have been shown to improve health and life outcomes in young people with chronic illness.[38] As with clinical interventions, successful programs are based on a strong understanding of adolescent development, youth participation and promotion of self-management practices.

Conclusion

Although there has been little research on self-management practices in young people with chronic illness and disability, we believe the concept is salient for this group and builds on existing frameworks of adherence, transition to adult health care and developmentally appropriate health care. There is no set recipe for practice. Rather, doctors who manage young people with chronic illness are urged to consider how they can promote better self-management practices. Doctors need to work towards effective partnerships with adolescents as well as parents. Like parents, we need to temper our frustration with adolescents who do not practise effective self-management with the understanding that optimal self-care (as defined by the doctor or parent) may or may not be achievable given a young person's level of development.

The challenge for doctors is to maintain awareness of adolescent development in our interactions with young people with chronic illness and their parents so that, in time, these young people become their own best advocates.

Competing interests

None identified.

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(Received 29 Jun 2005, accepted 9 Sep 2005) ❑