

REVIEW

The adolescent with a chronic condition. Part II: healthcare provision

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The treatment and management of chronic conditions during adolescence pose specific issues that need to be appropriately handled by health professionals. In this paper, questions related to disclosure of the diagnosis, the management of adherence to therapy, the need for an interdisciplinary network approach, lifestyles' anticipatory guidance and prevention, and the transition into an adult healthcare setting are reviewed. Special areas such as the issue of life threatening diseases and the ethical aspects of the treatment of chronic conditions are also discussed.

being recognised by health professionals,^{4–8} but also by young people themselves.⁹ Qualitative research shows that adolescents experience extra effort, restriction, pain, and additional worries because of chronic illness.^{10–11} Qualitative research with young people with a variety of chronic illnesses has also suggested a number of themes for health professionals to address when working with young people (table 1).¹⁰

Children have a right to be involved in decisions about their care, and communication must be appropriate to their stage of development and level of understanding.¹² However, evidence based on qualitative research indicates that in most cases, diagnosis and treatment information is directed to the parents;^{13–14} even young preadolescents complain about the fact that their doctor mainly interacts with his parents.⁹ The wishes, desires, knowledge base, capabilities, and rights of the young person involved must also be taken into account—as must the fact that these are constantly evolving and changing. Different approaches are required to all aspects of the doctor-patient relationship. Specialised clinical communication skills are needed to take an accurate history, bearing in mind new life domains not applicable to children (see part I of the review¹) and adding communication and engagement of the young person to the standard paediatric communication with the family. Physical examinations of adolescents require consideration of privacy and personal integrity as well as additional skills such as pubertal assessment, breast examination, and possibly genital examinations.^{15–17}

This is the second of a two part shorter version of a review and discussion paper on the clinical management of chronic conditions in adolescents requested to the authors by the World Health Organisation (Obligation no. HQ/01/407101). The methods used for the search of the literature have been described in the first part of this review.¹ While the first paper tackles the impact of chronic conditions on the bio-psychosocial processes of adolescence, the purpose of this second paper is to provide suggestions on how to manage young people with chronic conditions in a comprehensive and holistic way and, as far as possible, based on evidence. In the following text, the expression “very strong evidence” will usually refer to level 1 evidence (systematic review; RCT/high quality cohort study), “strong evidence” to level 2 evidence (cohort or case-control studies and longitudinal surveys), “evidence” to level 3 evidence (qualitative research; observational study), while “some evidence” will refer to level 4 evidence (case series; unsystematised review; expert opinion). As in the previous part, we will be using a non-categorical approach of chronic conditions, as defined by Stein and Jessop.^{2–3}

THE TREATMENT AND MANAGEMENT OF CHRONIC CONDITIONS DURING ADOLESCENCE

In working with adolescents with any medical condition, the treatment of disease, the prevention of ill health, and the promotion of healthy behaviours are played out against a background of rapid physical, psychological, and social developmental changes. These developmental changes, which are unique to the adolescent period of life, thereby produce specific disease patterns, unusual symptom presentations, and above all, unique communication and management challenges. These issues are increasingly

A developmental perspective: objectives and approaches

Disclosing and discussing the diagnosis

Breaking bad news and discussing the diagnosis is a difficult task with patients of any age, particularly adolescents.^{18–19} Whether the condition is new or not, it may be appropriate to begin by asking the teenager what he knows about his condition and how he feels about it. Open questions allow the adolescent to express his or her feelings in a free way and also allows the physician to appraise their perceptions about their illness. Language must be adapted to the adolescent's cognitive level and developmental stage. In many cases, the patient will want to tackle the issue of prognosis:²⁰ this constitutes a challenging task, especially when dealing with a potentially lethal condition or with diseases and disabilities which may impede expected professional activities, influence sexual life, or have genetic implications. These issues should

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Table 1 Themes for health professionals to address when working with young people with chronic conditions¹⁰

- (1) Treat me like a person
- (2) Try to understand
- (3) Don't treat me differently
- (4) Give me some encouragement
- (5) Don't force me
- (6) Give me options
- (7) Have a sense of humour
- (8) Know what you are doing

however be addressed honestly. The family should be as much as possible involved in the process,²¹ but the adolescent has a right to full disclosure even though his parents may be reluctant to discuss these matters.^{18 19 22-24}

There is evidence that adolescents who suffer from invisible conditions (for example, epilepsy, cardiac defects) sometimes have more difficulties in accepting and discussing openly their condition.²⁵ In an attempt to look like their peers, they may make every attempt to avoid disclosing their disability. This can place them in difficult situations, such as not participating in peer activities for unusual or odd reasons, or experiencing unexpected medical situations that then place their friends or mentors in a difficult position. The physician should be aware of this difficulty and encourage these young people to disclose their disease or disability to their closest friends as well as to selected representatives in their school or environment.

Improving adherence to therapeutic regimen Assessment of compliance/adherence and its determinants

Adherence to a therapeutic regimen, also often named compliance, is defined as "the extent to which a person's behaviour (in term of taking medication, following diets, or executing lifestyle changes) coincides with medical or health advice".²⁶ Bad compliance is a major cause of treatment failure.²⁷ Such treatment failure may induce unnecessary changes in the medical regimen and even lead to medication overdoses or underdoses. This issue is of utmost importance since it is during this period of their life that adolescents frame the way they behave towards medication and general medical measures. The very first task of the health professional caring for an adolescent with a chronic condition is to assess the young person's adherence to the various parts of the therapeutic regimen. In performing this important task, practitioners should keep in mind several factors. Treatment regimen involves not only the prescription of medication, but also various other measures such as physiotherapy, wearing a orthopaedic device, adopting precise nutritional patterns, avoiding certain situations, or restricting oneself from certain behaviours, etc. Evidence indicates that adherence to one aspect of the treatment does not necessarily mean adherence to all aspects of the regimen.²⁸

There are many ways to measure adherence with medications, such as the concentration of various drugs and metabolites in the serum or saliva, or simply calculating the number of pills that the adolescent has used over time. But the most simple and efficient way is to straightforwardly ask the young persons about how well they managed to adhere to the treatment and how they feel about the issues the treatment raises. Evidence points out that as few human beings are able to achieve one hundred per cent compliance, the question should be formulated in such a way that the adolescent feels free to express himself: instead of asking "Did you take your medication?", the health professional can

ask "When was the last time you were not able to take your medication?", or "How many times this week did you manage to take all your medication?" and "How often does it happen to you?".²⁹⁻³¹ Non-compliance does not mean distrust in the physician and the healthcare team, nor does it equal rejection on the part of the patient. Poor adherence should be regarded as (unfortunately) relatively developmentally appropriate in adolescence. Thus, when faced with a teenager who has been poorly adherent, the physician should not respond in an angry or disappointed manner. On the contrary, the health professional should thank his patient for his confidence and carefully examine with him the reasons why he has not adhered to the prescribed therapeutic measures.²⁸ Evidence based on qualitative research⁹ shows that chronically ill adolescents are very unlikely to raise questions that the health professional might condemn or reprimand. A sympathetic approach is very likely to reduce the chances of the patient lying about treatment adherence.

A lot of research has been devoted to evidence based factors associated with higher or lower adherence (table 2).^{28 29 32-37} Findings from these studies are conflicting, which may reflect the fact that each situation and each treatment is somehow different, and that it is difficult to identify one single or several features which can validly predict adherence in every patient or situation. Most studies have focused on the patient's features such as cognitive factors, perception of the disease, emotional and psychological factors, or characteristics of the adolescent's environment. In fact, the setting and the quality of the physician-patient relationship may be as important and is often neglected as a way to improve adherence to a therapeutic regimen.

A contractual approach to improving adherence

There is strong evidence suggesting clues for improving adherence in general^{29 30 37 38} and the adherence of adolescents with a chronic disorder such as diabetes, asthma, or cancer.^{27 30 39 40} Most well trained professionals adopt a practical tactic that processes through an ongoing assessment and negotiation of the various components of the treatment. This approach should be applied with the adolescent as well as with the parents/guardians, month after month. Adolescents have many personal resources^{41 42} and often prove quite imaginative in suggesting avenues which may not have occurred to their health professionals. The concept of "self-management" has recently gained much attention and is a promising way to help the adolescent in his individuation process,^{43 44} although there is evidence that it is only moderately associated with improvements in outcome measures.⁴⁵ This process can be conducted in close collaboration with the patient himself.⁴⁶

Accompanying the family

Adequate family functioning tends to improve both emotional wellbeing and psychosocial and medical outcomes for adolescents,^{21 47 48} and there is evidence that this is especially true for those who suffer from chronic conditions.⁴⁹ Evidence based studies indicate that the arousal of feelings such as guilt, anger, a feeling of injustice, depression, or despair are also part of the normal reaction of parents⁵⁰⁻⁵² to their progeny's chronic condition, and these feelings should be investigated. With the onset of adolescence, these feelings are often reactivated by the questions that the teenagers may raise themselves and by complications that might occur as a result of the difficulty some adolescents have in accepting their condition. The healthcare team should be trained and willing to deal with the parents' emotional and psychological responses to the situation.^{53 54} Under severe circumstances it may be appropriate to use the skills of family therapists. Parents should not be viewed as a supplementary source of burden, but above all as a resource:^{48 55} they have known their

Table 2 Main areas which have been identified as potentially interfering with adherence^{29-31 34 35 40} and strategies to improve compliance/adherence^{27 30 32 38 39}

Identified areas	Strategies
Factors related to the adolescent	
Cognitive factors	Provide information meeting the adolescent's maturational stage
Perception of the disease	Take into account underlying psychological factors
Emotional/psychological factors	Tailor the treatment to the patient's individuation process and stage
Patient education	Communicate information in a straightforward way, trust the adolescent, do not hesitate to correct wrong ideas
	Tailor the doses of the medication to the patient's physiological status (puberty/growth)
	Adapt the therapy to the adolescent's lifestyles
	Ask for proposals from the patient
Factors related to the teenager's environment	
Family functioning	If needed, suggest the support of siblings, peers
Peer influence	
Factors related to the setting and communication	
Setting	In each setting (<i>paediatric</i> or adult) keep the same professionals in charge of the same patients over time
Relationship with the healthcare team, communication style	Assess adherence regularly and in a non-threatening manner, check for side effects
Complexity of the therapeutic regimen	Simplify the therapeutic regimen as much as possible, negotiate
Interference of the treatment with the adolescent's needs and lifestyles	

child since birth and they observe the way he/she feels and behaves in everyday life. This precious information should not be discarded under the reason that the adolescent should become autonomous. Thus, the physician and the professionals involved in the care of the adolescent should organise areas and moments when they meet with the adolescent alone, and, depending on the state of affairs, other opportunities to meet with the parents alone, the parents with the adolescent, or the whole family. Many parents benefit from linking with support groups.⁵⁶ The treatment team should not only support psychologically the parents and the family but also provide them with precise, continuous, and up to date information on the course of the therapy or specific outcomes. For instance, parents or children with cancer rate very high their needs of information⁵⁷ and may in certain instance give more importance to concrete information (treatment, tests, cure) than to issues of emotional or family impact.⁵⁸ Similarly, mothers of adolescent females with cystic fibrosis want more specific information on the disease, such as sexual health, to be able to discuss it with their daughters.⁵⁹

Siblings should not be forgotten in this process, as they too may have important questions as well as experience psychological reactions to their brother's or sister's disease, especially when faced with new events or a crisis situation.⁶⁰⁻⁶² They can act as "co-therapists" as well as their parents (even sometimes better) and provide support to the teenager facing a critical stage of his illness or a psychological crisis. On the other hand, they may themselves need psychological support on certain occasions:^{53 63} there is evidence that more than 50% of well siblings of children who have chronic illness exhibit psychological or behavioural problems.⁶⁴

Special issues

Life threatening diseases

The occurrence of a life threatening condition before or during adolescence constitutes a real challenge for the patient, the family, and the healthcare team.⁶⁵⁻⁶⁷ One difficult issue is the situation of an adolescent who has end stage disease despite all possible treatment options. The approach to a dying adolescent must be multidisciplinary. The amount and nature of the information given to the patient should be discussed with the parents, especially for younger teenagers. Some patients may respond to the pending issue of their

death by denying their situation, a well known defence mechanism that should be respected.⁶⁸ On the other hand, other teenagers may recognise the imminence of their death and want to share their feelings openly, while their parents may not necessarily be ready to face this cruel event.⁶⁸ The staff should be ready to support both the family and the patient, taking into account in a respectful way their values and emotions.⁶⁸ The management of the situation often raises ethical dilemmas; for example, if a teenager decides to discontinue treatment while the parents don't want to, or if an adolescent asks for information that the parents feel not ready to deliver.²² Similarly, the members of the healthcare team, especially those who have managed the treatment of the adolescent over many months or years, should also be offered the opportunity for debriefing, expressing their sadness and, for some of them, their feelings of helplessness.⁶⁸

Ethical aspects

The United Nations Convention on the Rights of Children says that "State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child" (article 12). It is very important to take into account the stage of cognitive and affective development when making any decision. There are two main areas in which these ethical aspects play an essential role:

- Privacy and confidentiality: adolescents should be offered all healthcare interactions in a private and confidential manner,⁶⁹⁻⁷² since confidentiality is considered by many teenagers as a prerequisite for any trustful relationship with a health professional.⁷³⁻⁷⁵
- The same principles apply to the issue of information and informed consent. The more mature the adolescent is, the more freedom he should enjoy as far as the choices regarding his treatment are concerned. It has to be stressed however that such a decision making autonomy is submitted to one condition—that is, that the healthcare professional provides the adolescent patient with detailed and individualised information which gives him or her the opportunity to soundly reflect on the various options he has to make up his mind.^{73 74}

GLOBAL CARE OF THE ADOLESCENT WITH A CHRONIC CONDITION

An interdisciplinary network approach

While the bio-psychosocial adolescent process may interfere with the progress of chronic disease, the reverse holds true, and any chronic condition can potentially affect the development of the teenager. The aim of the healthcare team will be to reduce the impact of the disease and allow the adolescent to run a life as similar as possible to his friends' ones and to encourage them to engage in a fruitful professional career as well as in meaningful affective and social relationships.

It is difficult for a single physician to tackle all the aspects of his young patient's health, especially if the treatment needs the intervention of highly sophisticated therapeutic tools and interventions. Moreover, some treatments require the intervention of several healthcare professionals, including physicians from several specialties, psychologists or psychiatrists, physiotherapists, dieticians, etc. It is thus important to provide the patient with an integrated and coordinated approach to all these aspects. A reference professional, usually a primary care physician⁷⁶ or a nurse, should be responsible for the coordination of the various aspects of the follow up. Ideally, meetings gathering the professionals in charge should be set up on a regular basis to make decisions. There is evidence that identifying a reference person (social worker, member of the health staff) who maintains the connections with the school nurse or the teacher is helpful.^{6 77-80} The contacts should be established with the approval of the patient and his or her family, and all important information should be shared openly with them. Some of the network meetings can be held in the presence of the patient, especially as he gets older.

Primary care needs and general guidance

General health needs

Firstly there are issues related to growth and puberty: mild to severe acne, whose presence may contribute to further deteriorating self-image, questions related to the development of one's breast and genitals, or concerns about actual and future growth.⁸¹ Along the same line, these adolescents, because they are known to be already followed up by physicians, may escape the customary vaccination plan and general screening process that their friends undergo within the school or the healthcare system. Functional symptoms are common among teenagers with chronic conditions, and they should be adequately addressed: one problem which arises frequently is that some of these complaints can mimic complications of the basic disease itself and may thus lead to unnecessary worry and avoidable investigation. It is thus important to investigate simultaneously the physical as well as the psychological aspects of these symptoms.

The adolescent's mental health and psychosocial concerns, such as anxieties or depressive mood, should be taken into account: the patient should be offered the opportunity to express the distresses related to his or her psychological development tasks and family/social relationships.^{82 83} There is evidence showing that educational and psychotherapeutic assistance can greatly improve the adaptation of the adolescent to his or her condition and situation.^{84 85}

Lifestyles: anticipatory guidance and prevention

Adolescents with a chronic condition have the same needs, and physical and psychosocial burden as their peers. Several studies have addressed this issue and provided evidence that these needs are often not adequately met or even ignored.^{86 87} Moreover, other studies have shown strong evidence that a comprehensive holistic approach improves the outcome of the chronic condition itself.^{84 88}

There is evidence that adolescents with chronic disorders engage in experimental behaviours and place themselves in risky situations as often or even more often than their peers of the same age.^{42 89-94} Thus, while one may think that these teenagers are less involved in social activities or inhibited in their individuation process because of their disease and the fact their parents overprotect them, this in fact may not be the case. It may well be that their tendency towards placing themselves in risky situations such as not wearing helmets and other protection devices, abusing substances, or engaging in unprotected intercourse is linked with an unconscious desire to "be alike".⁹⁴

As a result of these findings, the healthcare team in charge of the follow up should include in the adolescent's regular assessment a global check up surveying their health habits and lifestyles. This activity of anticipatory guidance requires specific knowledge and skills and may rather be devoted to a trained nurse or a general practitioner. The team should be able to manage the current situation and provide the adolescent with adequate counselling in all these domains. They should also have identified appropriate professionals and institutions where to refer the adolescent if needed.⁶ Some countries have set up multidisciplinary clinics specialised in the care of adolescents with special needs: this "user friendly" approach⁹⁵ may be particularly appropriate for teenagers with chronic conditions.

Transition into adult life, moving into other healthcare settings

As more and more adolescents with potentially lethal condition (for example, cystic fibrosis, cancer, renal disease, HIV infection) survive longer and enter adulthood with good life prospects, the issue of the transition from the paediatric setting to the adult setting has become an important topic and has led to numerous recommendations.⁹⁶⁻¹¹¹

There are several avenues to meeting the objective of an integrative transition. We have evidence that it is not so much the "resistance" of the patient and his family to give up a setting they have been accustomed to for years which constitutes an obstacle, but instead the lack of a structured transition programme.^{110 112} In other terms, the so called resistance of adolescents and parents to move in the adult field is often more derived from the professionals' attitudes than the one of the patient and his family. Thus, the paediatric teams should reflect on issues such as their own grieving processes and they should develop specific strategies to overcome barriers to adequate transition. Research within focus groups with young people has suggested a number of strategies (table 3):^{109-111 113 114}

- The patient and his or her family should be brought face to face with the issues at an early stage, before the procedure will actually take place, as a long term perspective
- The team should identify as early as possible professionals who are aware of the challenges which such a situation represents and who are in a position to actively cooperate
- One or two adults, well aware of the situation, should accompany the adolescent and his or her family in the process, exploring the two settings, attending the consultation in both locations, and assisting the patient in expressing the main concerns they have and the main challenges they face
- Supporting individuals, adults, peers, or professionals outside the team should be identified, who will assist the patient in the transition and provide him or her with resources and encouragement.^{41 88}

Table 3 Ingredients of a good transition programme^{96-104 106 108 111 122}

- (1) Discuss the matter during childhood and as the young person grows up
- (2) Acknowledge issues facing both the patient and his/her parents
- (3) Identify colleagues who have an interest in young adults
- (4) Select a health worker (family practitioner, nurse, etc) who may supervise the transfer
- (5) Organise common meetings with the new team
- (6) Secure some follow up phone calls
- (7) Identify individuals (adults, peers) who can give support

Such programmes have been evaluated, and there is evidence proving that they are effective over time, both in terms of medical outcome and quality of life.¹¹²

CONCLUSIONS

Over the past years an important body of literature devoted to adolescents with chronic conditions has been published and as a result, the healthcare of this population with specific needs has witnessed substantial improvement. Much remains to be done however. Many specialists around the world still do not adequately address the numerous challenges that the global care of young people with chronic conditions pose, as well as the necessity of a comprehensive support of their families.^{115 116} The creation of adolescent medicine as a subspecialty is still relatively new,^{117 118} and only a few countries have set up specific clinics and healthcare teams⁹⁵ who adequately meet the standards that these patients deserve.¹¹⁵ Finally, although the recently published literature gives evidence as to how to improve adherence or adequately address the general health of these adolescents, we still lack evidence on the effectiveness of the curative and preventive approaches suggested by some authors.^{7 119-121} In the future, researchers should engage in clinical studies comparing various healthcare approaches and thus be able to indicate which evidence based strategies are the most effective in improving the medical and psychosocial outcome of chronic conditions during this crucial period of life.

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