Review

The challenging adolescent

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Adolescents are medically, developmentally and psychologically distinct from children and adults. Although we all have patients in this age group who are communicative, adherent and capable, many of us have been faced with young people who are difficult to work with, for a variety of reasons. The aim of this article is to consider which young people are most challenging to rheumatology professionals, why they appear challenging and to offer some practical solutions to addressing such behaviours in clinical rheumatology practice.

KEY WORDS: Adolescent rheumatology, Chronic illness, Adolescent health, Health services, Adolescent development.

Introduction

Adolescents are medically, developmentally and psychologically distinct from children and from adults [1]. Although we all have patients in this age group who are communicative, adherent and capable, many of us have been faced with young people who are difficult to work with, for a variety of reasons. It is perhaps because of these experiences that only a third of doctors, whether paediatric or adult, are reported to actually like working with adolescents [2]. Young people need health professionals who are equipped with the necessary age-related and developmentally appropriate skills and knowledge to look after them and advocate for them as they grow up and emerge into adulthood. A first step for such skills training is to understand why some young people appear so challenging to professionals. This article examines which young people are most challenging to rheumatology professionals, why they appear challenging and to offer some practical solutions to addressing such behaviours in clinical rheumatology practice. We will discuss both the adolescent rheumatology literature and the literature in other chronic conditions, as many issues are common to this larger group of young people.

Who are the young people we find challenging?

Adolescence is the only time health professionals do not deal directly with adults. In paediatric rheumatology, significant attention is directed to the parents and in adult rheumatology to the adult patient. However, in adolescent rheumatology the centre of attention is not an adult, nor someone who shares an adult view of the world. Examples of behaviours rheumatology health professionals often encounter are listed in Table 1.

Why do we find certain young people challenging?

Being a normal adolescent

To understand adolescent behaviour, a working knowledge of adolescent development is vital [3, 4], much of which is now supported by a growing body of evidence from neuroscience (reviewed in [4]). Throughout adolescence, there is significant growth and change in various regions of the prefrontal cortex especially with respect to processes of myelination and synaptic pruning, both of which increase the efficiency of information processing. These changes are considered integral to regulatory competence and executive functioning (including long-term planning, self-evaluation and self-regulation), characteristic of mature functioning [4]. While the brain develops post-pubertally, there is a long period prior to adulthood when the young person ‘wants to be treated like an adult’ yet has difficulties expressing his/her thoughts and feelings and/or asking for assistance. As they become more independent, young people separate from their parents and may identify health care providers as additional ‘parents’ to separate from. Particularly pertinent to health, adolescents will have difficulties taking another’s point of view and anticipating the consequences of their actions. During adolescence, there is significant restructuring between regions of the prefrontal cortex and areas of the limbic system that affects the ways in which individuals evaluate and respond to risk and reward [4]. Although adolescents may know the risks of certain behaviours, they lack ability to balance risk/reward with future benefits or adverse consequences as a result of their immature brain development.

Mental health issues

Chronic rheumatic disease during adolescence has a psychological as well as physical impact. Adam et al. [5] reported greater effects of arthritis and rheumatism on measures of mental health of affected individuals compared with individuals without chronic disease or indeed with other chronic disease. In a multicentre cohort of 17-year olds with juvenile idiopathic arthritis (JIA), two-thirds expressed depressive symptoms and two-thirds of these identified depression as their ‘biggest problem’ [6]. In a study of adults with JIA, Packham et al. [7] reported that over a third of individuals who reported depression recalled that their first episode was mid/late adolescence and early adulthood (15–25 years). Awareness of such mental health issues is important, not only on an individual basis but also with respect to design of services. Adolescents who report psychological distress are more likely to cite confidentiality concern as a reason for forgone health care [8]. Adolescents report that they are more likely to ask to see a health care provider without their parents when highly stressed [9]. In many rheumatology clinics, there is no provision for young people to be seen alone [10], even though this has been called for by the young people themselves [11] (see below).

Different priorities

Although young people are not aware of it, their priorities are formed to meet their developmental needs. They may make decisions that seem bizarre to us, like not taking their steroids

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because of how it will affect their appearance. Their developmental priority here is to identify with their peer group and to incorporate the physical changes they are undergoing into a healthy body image. Future illness, organ damage and even death are abstract concepts to young people, compared with their ‘concrete’ reality of needing to look like their friends to fit in and see themselves as sexually attractive. Persistence of such concrete thinking and reduced ability to plan has been reported in JIA [12] and impacts adherence to therapies. This is of particular relevance to remitting (and relapsing) diseases such as JIA or SLE. It is difficult for concrete thinkers to take medications with unpleasant side effects when they are in remission. A developmentally appropriate approach requires the use of immediate (e.g., ability to play in sports) rather than future motivators (e.g., avoidance of joint replacement surgery in the future). Regression from abstract back to concrete thinking can also be observed during crises. The seriousness of the subsequent non-adherence during adolescence is highlighted by the reported graft loss in adolescent transplant cohorts particularly following transfer to adult services [13].

Denial, avoidance and ambivalence

An important lesson in adolescent health is that adolescent logic is not the same as adult logic. In addition to having different priorities from adults, young people are less likely to be able to understand that actions can have consequences in the future. If they are informed of a risk, but the consequence is not perceivable or immediate, it is unlikely that they will see this as a serious threat. Also, their exploratory and risk taking behaviour meets a number of developmental needs. Nash et al. [14] reported no difference in alcohol use between MTX- and non-MTX-treated adolescents with JIA, despite the risks of combining these. Adolescents with diabetes, knowing the physical risk of substance use, still thought their peers were at higher risk than they [15]. The young person who appears to us during mid-adolescence as ‘bullet proof’ probably feels very vulnerable, but this feeling may not apply to health risks.

Coercion

When seeing adolescents, it is important to remember that they may not actually want to see you, but may have been coerced by parents to attend. Similar coercion can potentially influence consent to therapy and/or adherence to therapy. In a study of adolescent and parent-proxy ratings in JIA, 50% of parents disagreed with their son/daughter rating of physical disability, pain, global well-being and health-related quality of life [16]. Other authors have reported an increasing likelihood of mental health issues the wider the discrepancy between parent and adolescent [17], emphasizing the value of collecting independent information from both parties.

Table 1. Examples of challenging behaviours for rheumatology health professionals

<table>
<thead>
<tr>
<th>Young people who...</th>
<th>Us—the professionals!</th>
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<tbody>
<tr>
<td>are late for or miss appointments</td>
<td>On many occasions, the problem may not actually be with the young person but with us as professionals. For example, presence of students/trainees can be perceived as supportive or inhibitive by young people [18] who need to be proactively informed of their right to privacy, confidentiality and their right to choose who is in the consultation with them (see below). Although we cannot change our gender to suit our patient’s needs, some young people also report that they feel more comfortable with a provider of one or the other gender [18]. This is not true of all adolescents, and some also surprise themselves by developing a trusting relationship with someone of the gender they would not have chosen. Gender may be particularly important within a cultural context in which being examined by someone of the opposite gender is seen as being inappropriate in adolescence or adulthood.</td>
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<td>fail to attend and then demand to be seen ‘right now!’</td>
<td>If the young person perceives that the provider has a negative attitude towards young people in general, if the consultation is focused on the parent, or if terminology is not explained adequately, adolescents are likely to feel excluded. An approach that is condition-centred rather than person-centred may similarly lead to young people feeling isolated and disempowered, as will a perceived lack of interest in the impact of chronic illness on the adolescent’s life [11, 18].</td>
</tr>
<tr>
<td>refuse to talk or just grunt</td>
<td>Finding solutions</td>
</tr>
<tr>
<td>start yawning and/or fiddling midway through the consultation</td>
<td>Consideration of why we as health professionals find certain young people to be challenging is the first step to finding solutions to ensuring effective health care provision for them within the rheumatology clinic setting. Examples of such solutions are as follows.</td>
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<tr>
<td>answer their cell phones (and chat or text) during appointments</td>
<td>(i) Respect: unlike studies in adults [19–21], respect is specifically reported by young people to be an important quality criterion for adolescent health care [22]. Perceived lack of respect can start with the very first contact with the clinic if appointment letters are written only to the parent/caregivers. Honesty is a further important quality criteria reported by adolescents [23, 24] and considered to be the most essential aspect of best transitional care practice by adolescents with JIA [24]. The key determinant of adolescent satisfaction with transitional care in rheumatology has been reported to be provider characteristics [23]. Adolescent satisfaction in turn has been associated with positive outcomes including adherence to appointments [25, 26].</td>
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<td>do not do as they are told</td>
<td>(ii) Confidentiality: patients are unlikely to open up if they think professionals are going to tell their parents what they have said [27]. Assurance of confidentiality is a major quality criterion of young person friendly health services [28]. However, young people need to know of their rights to confidentiality. Prior to implementation of a transitional care programme in 10 UK rheumatology centres [29], 83% of adolescents did not know what age they could be seen alone at (McDonagh, unpublished data).</td>
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<td>are rude, defiant</td>
<td>(iii) Bracketing: bracketing (a term arising from qualitative research) means setting aside our usual, ‘natural’ assumptions, biases and prejudices when examining phenomena. In the case of adolescent health, professionals need to separate their assumptions that are based on their own teenage years and those of their children and/or relatives in addition to their socio-cultural and religious backgrounds. As an example of lack of bracketing, alcohol screening of adolescents with JIA has been shown to be related to the race of the individual young person [30]. Judgements and pre-conceptions are rarely helpful for our patients.</td>
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<td>have ventriloquist parents (who answer any question asked of the adolescent)</td>
<td>Related to this is the idea of transference. Transference is when our patients redirect a feeling towards us that was</td>
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<td>have parents who will not leave the room</td>
<td>Us—the professionals!</td>
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originally directed towards someone else, often a parent. So sometimes an adolescent’s anger towards a provider is much more about their anger towards a parent than anything we have done. Counter-transference is the feelings that we have that are engendered by the patient, often by their transference. If we find ourselves feeling angry at a patient, we need to notice what is going on and wonder if the feeling is related to their emotions. It is important to remember that these problems cannot always be solved. Sometimes the solution (to this and other challenges) is a change in the health professional and handover of care to another team member.

(iv) Continuity and consistency: Beresford and Sloper [18] identified duration and frequency of contact as a factor influencing communication between young people with chronic illness and their doctors. Young people with chronic illness have reported that it takes at least four to five visits before they trust a doctor [22]. Young people with JIA, their parents and professionals identified having continuity in health personnel to be both best practice and feasible in the majority of UK hospitals in a Delphi study [24]. Parents of young people with JIA report that such continuity is also important for them in the process of ‘letting go’ and enabling interdependence for their son/daughter in the healthcare setting [11, 24].

Continuity also facilitates consistency of approach, another potential challenge for multidisciplinary team working. Mixed messages can threaten the development of trust in the patient–professional relationship, identified as very important by young people as described above [22].

(v) Space and time: young people, as they grow up, gradually need their own space, whether it is at home or in the clinic. Young people with JIA have been reported to value the opportunity to be seen independently of their parents [11] and when such opportunities are provided, they are associated with improved health-related quality of life [29].

In other chronic childhood onset conditions, independent visits have been reported to be a determinant of successful transfer to adult care [31], and is one of the five main methods of demonstrating readiness for successful transition [32]. Such opportunity is often not available to young people with chronic rheumatic disease. Over half of the 17-year olds with JIA in a multicentre UK study were not seeing doctors independently of their parents [33]. However, after the implementation of a transitional care programme in one of the participating centres, 80% of 11-year olds were choosing to be seen alone [34].

Feeling rushed increases anxiety and may lead to the patient feeling abandoned. It may take longer to communicate with an adolescent who is developing their verbal abilities. Providing opportunity for young people to be seen independently requires more time, as it may be important to speak with parents also. Time is also needed to increase feelings of familiarity and trust that is important to young people (see below) [28]. The Royal College of Paediatrics and Child Health has developed this further and proposed that adolescent clinic appointment times need to be longer than either children’s or adult clinic appointments [35].

(vi) The importance of effective communication: developmentally, appropriate communication skills—verbal and non-verbal—are integral to adolescent health, and rheumatology is no exception. Adolescents are reported to be worse at reading facial expressions and body language than either children or adults [36]. The young person may think that the health professional is angry when they are concentrating on a physical exam, or thinking about a differential diagnosis. The use of questions such as ‘How are you doing at school?’ during early adolescence is guaranteed to get a single-word response such as ‘OK… fine’ or the much reported ‘grunt’ phenomenon. Open questions such as ‘What has happened to you since we last met?… Which school are you at?… Which subjects do you prefer – science or arts?’, open up discussion instead.

Clinical encounters with adolescents are ideal opportunities to nurture their communication, negotiation, problem solving, decision making, information seeking and disclosure skills. Such skills are readily incorporated into bidirectional communication strategies but not in unidirectional communication strategies, the latter more frequently adopted by doctors [37]. Motivational interviewing techniques are ideal for use with adolescents as they address resistance and/or ambivalence as well as emphasizing self-responsibility in changing or modifying one’s behaviour. Developmental mismatches can lead young people finding it difficult to express themselves and even to ask for assistance. A proactive, anticipatory approach to adolescents is supported by evidence that young people will often disclose health risk behaviours if asked [38]. Young people have been reported to have more positive perceptions of the health professional and are more likely to take an active role in treatment when there has been discussion of a sensitive health topic [39]. Robertson et al. [10] reported that documentation of discussion of a range of adolescent health issues was evident in only 3–57% of case notes of young people about to transfer to adult rheumatology care. Screening tools like HEADSS [40] are useful strategies to engage young people as well as identify their level of health risk as well as assist in formulation of interventions.

(vii) Assist as well as ask: brief intervention strategies are useful in time-constrained clinics and remind us that screening is not enough. The five A’s of brief intervention strategies are Ask, Assess, Advise, Assist and Arrange [41]. However, in a study of rheumatology professionals, 45% did not assess the young person’s understanding of units of alcohol when discussing the risks of alcohol and MTX use [42]. In a study of paediatricians, Milne and Towns [41] reported that although over half of doctors asked adolescents if they smoked and/or advised them to quit, only 44% assessed their readiness to quit and only 16% assisted them in quitting strategies. Adolescent expertise may not be always available in rheumatology teams. Very low or low perceived skill in addressing sexual health, drugs, smoking and alcohol issues was reported by 27, 45 and 18% of rheumatology professionals respectively in 10 UK centres [43]. Training opportunities such as the national, free, e-learning training package in adolescent health in UK will hopefully improve such statistics (http://www.e-lfh.org.uk/Projects/AHP.aspx).

(viii) Making young people welcome: making rheumatology services more adolescent friendly requires different initiatives and interventions compared with making them welcoming to younger children and/or their parents. Quality criteria for young person friendly health services are available [28] and provide a useful benchmark to audit current services against (Table 2).

Conclusions

Adolescence is an exciting time and adolescents are fascinating to work with as they are often different at every clinic visit. Embracing their unique and ever-changing developmental status will assist in exposing them to high-quality care. Training opportunities in adolescent health, although not universal, are increasingly becoming available. Interested professionals should be encouraged to avail themselves of such training to enable them to become the adolescent clinical lead in the paediatric or indeed adult rheumatology team. The evidence is that once
Accessibility
Including accessibility out-of-school/college hours and to be seen independently.

Publicity
Including adolescent-specific information of what the service offers young people and their rights to confidentiality and to be seen independently. Confidentiality and consent.

Staff training, skills, attitudes and values with respect to adolescent health. ‘Joined-up’ or seamless interdisciplinary and interagency working.

Monitoring and evaluation and involvement of young people. Age and developmentally appropriate environment.

Addresses health issues for adolescents including substance use, emotional and mental health and transition. Addresses sexual and reproductive health issues (including access and signposting).

trained, such individuals seek further training [44] and encourage higher rates of desired clinical practices such as confidentiality, health risk screening, etc. [44–46]. If this happens, paediatric and adult rheumatology will be richer for it and the young people in our care will undoubtedly benefit.

Rheumatology key messages

- Some adolescents can be challenging for many reasons—including our behaviour as professionals!
- Adolescent development is a key to understanding adolescent behaviour.
- Provider behaviour is a major determinant of adolescent satisfaction.

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References