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Getting it right for young people: developing adolescent rheumatology services

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These are exciting times for young people and rheumatology professionals alike, with the advent of major policies, guidance and professional initiatives relating to adolescent health and transition. Furthermore, rheumatology has made a major contribution in the research arena, with the first published trial of transitional care in any chronic illness. However, adolescent rheumatology services encompass more than just transition and form part of holistic, age- and developmentally appropriate healthcare provision for young people with rheumatic conditions. Such services are generally underdeveloped, reflecting, at least in part, the lack of formal adolescent health training opportunities. This paper reviews the available evidence to support the development of adolescent rheumatology services, in order to provide young people with the best care possible.

Keywords: adolescent development, adolescent health, juvenile idiopathic arthritis, transitional care

The age-specific needs of young people with chronic rheumatic conditions are now well recognized [1,2], as is the potential burden of morbidity of childhood-onset rheumatic disease in adulthood [3–8]. A potential time to influence such morbidity with effective interventions is during adolescence, when many health-promoting and self-management behaviors become established. However, dedicated adolescent rheumatology services remain uncommon in the UK [9], as in the rest of the world. Young people themselves have called for adolescent-focused services [2]. Dedicated adolescent rheumatology services will facilitate the delivery of age- and developmentally appropriate care, as advocated by national and international standards [10,101–103], and convey an important message that the young person is growing up and moving out of pediatric and into adult-centered care. Excellent guidance has been provided in the UK with the 'You're Welcome' quality criteria [104] in regards to what constitutes a young-person-friendly service, irrespective of setting (Box 1). The prevalence of rheumatology services that meet such criteria is as yet unknown.

The aim of this perspective is to review the current evidence to support the development of adolescent rheumatology services, using the UK 'You're Welcome' quality criteria [104] as a framework. For the sake of clarity, adolescence will be defined in this paper by the WHO age criteria, for example, 10–19 years [102]. Although this paper specifically addresses adolescent health provision with respect to rheumatology, the discussion has wider relevance to all specialties involved in the care of young people with childhood-onset disease.

Accessibility

Since young people already perceive barriers to accessing healthcare [2,11], it is important to consider how accessible adolescent rheumatology services are to young people as opposed to parents and, indeed, professionals. Young people are, after all, the 'new users' of healthcare services, the latter having been previously accessed by their parents on their behalf.

Independent access to rheumatology services is a challenge to family-centered pediatric care. Only 16% of young people are being seen independently of their parents in rheumatology clinics [12], despite it being reported that young people value such opportunities [2]. Such opportunities are considered key in the demonstration of transition readiness [13], and were considered best practice and feasible in most UK hospitals in a Delphi study involving rheumatology professionals, young people and their parents [14]. Furthermore, such autonomy has been reported to be the key determinant of attendance at one adult cardiology clinic (Grown Up Congenital Heart Disease) appointment [15] and associated with improved health-related quality of life in adolescents with juvenile idiopathic arthritis (JIA) [16].

Accessibility issues have important implications for the whole of the multidisciplinary team. This includes secretarial and reception staff, who should be appropriately trained in terms of attitudes and the rights of young people to confidentiality, particularly as they are a frequent first point of contact. Accessing advice from the rheumatology team via forms of communication familiar to this age group, including text messages and/or emails, can help foster

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Box 1. ‘You’re Welcome’ quality criteria for young-person-friendly health services.

- Accessibility
- Publicity
- Confidentiality and consent
- The environment
- Staff training, skills, attitudes and values
- Joined-up working
- Monitoring, evaluation and involvement of young people
- Health issues for adolescents
- Sexual and reproductive health services

‘You’re Welcome’ Quality Criteria, available from [104].

healthcare utilization skill development and has been proven to be effective in other contexts [17].

An important aspect of accessibility is available time for adolescents. Adolescent clinic appointment times have been advocated to be longer than both pediatric and adult clinic appointments owing to the complexity of adolescent health-service delivery [105]. Pediatric appointments tend to be significantly longer than adult clinic appointments [18], although sometimes adolescent consultations are perceived to take longer than other age groups when this is not true in practice [19].

Accessibility is often frustrated by the inherent inflexibility of outpatient scheduling. Late-afternoon and early-evening clinics can enable young people to avoid missing school, college or perhaps the first year in their first job when they are trying to impress. Nonadherence to appointments in late adolescence, particularly during periods of disease remission, may reflect this desire to optimize their vocational potential. Drop-in clinics are one solution to facilitate open access for times of relapse and/or concern, and would also facilitate young people attending without their parents. Acknowledgement of this in the development of services demands a responsive and flexible service, which is often challenging for hospitals with a ‘9- to 5-’ style outpatient care. The potential of emerging information technologies in this area in adult rheumatology remains to be fully recognized [20].

Publicity

The first encounter with the rheumatology service may be the letter informing the patient of their first appointment. However, often this letter is addressed only to the parents and fails to include the young person as an addressee – a missed opportunity for respect. Copy clinic letters sent direct to the young person can help engagement and facilitate disease education and self-management skills training. However, the implications of sending copy clinic letters direct to the young person has not, to date, been specifically addressed in current guidance [106], particularly with respect to confidentiality, comprehension, and adolescent and parental satisfaction [21].

Adolescence is the developmental stage when self-management behaviors become established, and disease-education programs and publicity materials should include advice regarding health-service utilization as well as disease-specific issues.

Confidentiality & consent

Adolescents are more willing to communicate with and seek healthcare from physicians who assure confidentiality [22]. Confidentiality has been reported to be the most important attribute of an adolescent-friendly practice according to adolescents [23], with females and older adolescents expressing most concerns [24]. Provision of confidential services to adolescents has been reported to be less likely in pediatric practices as compared with family or internal medicine in the USA [25]. Confidentiality needs to be routinely explained to every young person, including the limits, and their understanding assessed. Posters detailing the policy should be clear in the waiting room and included in the informational resources of the service.

The environment

Adolescent-focused clinics, wards and waiting areas have been called for by adolescents in rheumatology [2]. Young people with JIA have been reported to find pediatric environments ‘patronizing’, adult environments ‘distressing’, and both isolating [2]. Dedicated adolescent environments were one of three components of care considered by the aforementioned Delphi study to be best practice, but are feasible in only a few UK centers [14]. Clinical areas where young people have their weight and height measured and urine tested also need to be specifically considered. Young people, particularly in early adolescence, may have a heightened sensitivity to their developing bodies, making privacy of major importance. The ongoing controversy about the pros and cons of dedicated adolescent inpatient units is acknowledged [26], but there remains a need for adolescent-friendly ‘areas’ within inpatient and ambulatory-care environments.

Waiting times are a concern for patients of all ages, and prolonged waiting can be perceived as a lack of respect by the patient as a lack of respect [2]. Reduction of both anxiety and boredom are other concerns with this age group [2]. Ensuring that appropriate activities are available within the waiting area can deflect some of the negative outcomes, for example, appropriate reading material. The waiting area is also a missed opportunity for peer support activities [14], which is optimized if there is a separate waiting area for young people that is distinct from their parents'. Scheduling appointments to facilitate peer support has potential but can be challenging to implement. Environmental consideration in meeting parental needs should also be considered, including adequate numbers of clinic rooms to facilitate concurrent visits for their own needs to be met while their child is being seen by another professional [2].

Staff training, skills, attitudes & values

Lack of training in transitional care and/or adolescent health has been reported as a major barrier for service delivery by several authors [27–30], with 43% of rheumatology health professionals in a national survey reporting unmet training needs [29]. These findings echo reports elsewhere that support the need for increased guidance, education and training, both at the practice and policy level. In a US-based survey of physicians, there was a significant gap between their perceived importance of transitional care and their perceived effectiveness in the latter [31]. Telfair *et al.* reported that, although the majority of providers agreed that a transition program was necessary for adolescents with sickle-cell disease, few actually did anything to demonstrate their involvement in the transition process [13]. Healthcare providers have also reported perceived discomfort with transitional-care issues, ambivalence about their role and perceived lack of applicability as potential barriers in delivering adolescent healthcare [32,33]. Professionals which are knowledgeable in transitional care were considered best practice, but only feasible in a few hospitals, in a UK Delphi study [14]. Furthermore, provider characteristics were more important determinants of adolescent satisfaction with transitional care in rheumatology than process and/or environmental characteristics [34].

There is evidence that training in adolescent health is beneficial. Sustainable, large improvements in knowledge, skill and self-perceived competency were reported in a randomized, controlled trial within primary care in Australia, which were sustained at 5 years [35]. In rheumatology, screening for risk behaviors has been reported to improve with training intervention strategies [32]. The potential of using adolescent healthcare as an invaluable model to teach patient- and family-centered care, differences between pediatric and adult care, dyadic versus triadic consultations, cultural competencies and shared decision making should not be underestimated [36]. The inclusion of chronic illness and transition modules in a forthcoming e-learning package in adolescent health, funded by the Department of Health and to be delivered by the Royal College of Pediatrics and Child Health, is to be warmly welcomed in the UK [107]. Examples of other key training resources in other countries are available online [108–110].

Joined-up working

Adolescent healthcare is, by definition, multidisciplinary, and ideally the personnel involved in the service and/or linked to the service should reflect this. In a UK-based Delphi study, consultant rheumatologists (pediatric and adult) considered delivery of transitional care by a multidisciplinary team as less feasible than their allied health-professional counterparts, reflecting the current challenges of commissioning such services [14].

Adolescent rheumatology clinics require a minimum of two trained health professionals to facilitate concurrent visits for parents and young people, in addition to chaperone availability. Continuity of these professionals is also of importance to both young people [2,11,37] and their parents [2] in the building of a therapeutic alliance, which is vital to confidentiality and engagement. Meeting the specific needs of parents of adolescents with JIA was considered to be important by both parents and rheumatology professionals alike in national studies [2,27].

The role of a key worker in chronic conditions is well established in the literature [38], although it is not always translated into practice. In a multicenter study of transitional care in rheumatology, the local coordinator role was considered better than paper-based resources by the adolescents themselves [39]. In the latter study, the role was undertaken by a range of personnel, including occupational therapists, nurses and physiotherapists [39]. Nurses are the profession most frequently advocated for this role in the literature [38], and are supported by guidelines from their professional body [111]. Telfair reported that nurse practitioners were more likely than other providers to demonstrate involvement in transition [13]. However, with the raised awareness of adolescent health and increased opportunities for training, the potential for other professions should not be underestimated and should, instead, be recognized and encouraged.

Effective links with local adult providers is integral to an adolescent service including rheumatology. In several studies of different chronic diseases, young people with a range of chronic conditions have reported a preference in meeting adult doctors prior to transfer [2,40–44], which, in turn, is associated with positive outcomes [42]. In view of the different age ranges of pediatric and adult rheumatology case-loads, a young adult service (i.e., for 16–25 years) is highly appropriate and is advocated by some practitioners in the area [45,46]. In support of such developments, a young-adult team approach for young people with a range of physical disabilities has been shown to be as cost effective as *ad hoc* services, yet associated with better outcomes [46].

An integral aspect of joined-up working is effective communication. Within a hospital specialty team, post-clinic team meetings and effective written documentation is imperative, whilst always respecting confidentiality of the young person. Repeated asking can readily turn into nagging. Unfortunately, in a national audit of case notes of recently transferred young people to adult rheumatology care, there was limited documentation of key developmentally appropriate health issues. However, documentation significantly improved following center participation in a transitional-care research project [47]. Similarly, effective communication with other teams, such as ophthalmology, orthopedic surgery, nephrology and primary care, is important to ensure coordination. Primary care, in particular, represents a vital mainstay of continuity at the time of transfer to adult services, but has to be involved throughout to be effective in this role. Poor intra- and inter-agency coordination was reported by rheumatology professionals in a UK survey of transitional-care needs for young people with JIA [27]. At a minimum, good working relationships with local key personnel listed in Box 2 should be developed and actively supported. In view of the generic nature of issues facing all young people with chronic illnesses, some of these roles can potentially be jointly commissioned by several disciplines. Finally, one team member should be the designated adolescent lead within the pediatric rheumatology team as a whole, with the responsibility of service evaluation and development.

Young people and their parents have expressed specific fears regarding the actual transfer of information at the time of transfer to adult services [2]. Such concerns have some foundation in truth, with reports of no improvement in the number of patients for whom copy letters and/or medical and/or multidisciplinary team summaries were sent to the adult team prior to transfer following the implementation of a transitional-care program [47].

Monitoring, evaluation & involvement of young people

Research has identified differences between the views of young people and the view of the adults close to them, suggesting that adults can not be used as reliable proxies for young people's views [48–50]. There have been many national initiatives to involve young people's views in matters that concern them, and these should be incorporated into adolescent rheumatology service provision [9,101,112–114]. Actively involving young people in decision making promotes citizenship and social inclusion, which is important for the health of the community. Moreover, strategies for enhancing participation will develop self-esteem, personal development and a range of skills in young people [51].

Health issues including sexual & reproductive health

The knowledge and skills framework for adolescent rheumatology not only includes the condition-specific framework, but also that of general adolescent health issues that are of relevance to all adolescents irrespective of illness. Such issues include substance use, nutrition, sexual health, mental health and transition. There is no difference in the prevalence of risky behaviors in young people with chronic illnesses compared with healthy controls [52], although sometimes such behaviors can be delayed [53]. Often, young people with chronic conditions face a 'double whammy' of risk [54], owing to the addition of their chronic condition and its therapy. For example, young people with JIA on methotrexate face the risks of alcohol and/or tobacco, plus the increased risk of toxicity of these owing to methotrexate. However, such issues are frequently ignored in rheumatology clinics. A smoking and/or alcohol history was documented in only 4 and 16% of case notes of patients with JIA, respectively [47]. Assessment and intervention strategies in this area also require more attention [55–57]. In one study, 45% of rheumatology professionals failed to assess the adolescent's understanding of 'units of alcohol' [56]. In a study of Australian pediatricians, although 54% asked about smoking, only 16% assisted with quit strategies [57]. It is important to remember that up

Box 2. Key personnel in adolescent rheumatology.

- Consultant rheumatologist with specialist interest in adolescent health*
- Clinical nurse specialist*
- Occupational therapist*
- Physiotherapist*
- Outpatient clinic support staff
- Social worker
- Youth worker
- Adolescent psychologist
- Peer advocates
- Adolescent-team secretary
- Friendly reception staff

Links to:

- Child and adolescent mental health services
- Careers (e.g., Connexions [121,122])
- Sexual health services for young people (e.g., Brook [123] and genitorurinary medicine services)
- Local drug and alcohol services for young people
- Relevant voluntary agencies including those with a specific rheumatic disease remit (e.g., Arthritis Care [124])
- Adult rheumatology services

**All senior permanent staff should have specific adolescent-health training.*

to a third of young people reporting substance use reported no opportunity for private time with a doctor [58]. Furthermore, high-risk behaviors such as substance misuse have been reported to be associated with nonadherence to therapy [59] and hence are of particular relevance to the rheumatologist. Screening tools such as HEADSS [60] and CRAFT [61] are useful in specialty clinics, and assist in both the engagement of young people and the assessment of risk and aid formulation of future interventions. Every clinical encounter with a young person should be considered a potential 'teachable moment', whether it be with respect to the specific rheumatic condition, exercise, nutrition, substance use or sexual health. Adolescent health is about opening doors to advice and support for young people, so they know where such doors are when the need arises.

Considering the evidence regarding the nature of the information that young people want [2], the deficits in knowledge reported [62] and the potential antecedents of the psychosocial morbidities reported in adulthood [3–6,8], addressing the reported unmet informational needs is an integral component of adolescent rheumatology care. Young people have expressed the wish that there should be no gate-keeping of such information [2]. However, facilitating anonymous access to a wide range of information, particularly in pediatric settings, can present practitioners with challenges. Multiple methods need to be developed and the format of these considered carefully to ensure usefulness from the young person's perspective. For example, credit-card-sized paper-based resources that are easily put away in a wallet are often preferred to an A5-sized booklet that does not fit into an adolescent pocket! In multiple-user clinic areas, mobile bookshelves and/or leaflet racks in clinic toilets are useful considerations. Modern technologies, including the internet [115,116] and text messaging [17], have great potential.

Transition has received significant attention in the literature recently [1,63,117]. However, there is a risk for transition to be considered as separate rather than an integral part of the wider concept of adolescent health. Transition has been highlighted with national guidance to 'get it right' for young people with chronic conditions, including rheumatic conditions [117]. Transition is therefore a further health issue listed as a quality criteria in young-person-friendly health services in rheumatology. The author has reported an evidence-based transitional-care program [39], the implementation of which was associated with improvements in health-related quality of life, patient and parent satisfaction, disease knowledge, vocational readiness and documentation of adolescent issues [16,47]. Further research is awaited to determine whether such results can be sustained in the long term.

Conclusion

There is now a useful evidence base to support further development of adolescent rheumatology. However, in these times of financial restraint, developments will also require professionals to be as imaginative and creative as the young people in their care, and to start looking beyond the limits of rheumatology to areas of potential sharing in adolescent health, both interspecialty and interagency. First and foremost they are, after all, young people who happen to be living in the 21st century with a chronic condition.

Future perspective

In the next 5–10 years, adolescent rheumatology will hopefully become recognized as a distinct area within all pediatric and adult rheumatology services, with adolescent-health-trained staff in both settings to facilitate transitional care. Recognizing the noncategorical nature of chronic illness, some of these posts could be shared with other chronic illness specialties to ensure efficiencies of scale. Such staff could then ensure services would become health-led rather than disease-led – a major diversion away from the traditional medical model of rheumatology practice.

Such developments in the UK will be supported by the following initiatives aiming to become established in 2008:

- National e-learning package in adolescent health, including chronic illness and transition modules, using rheumatic disease as exemplars [107];
- Multidisciplinary national association for young people's health [118], reflecting other such organizations in the world [119,120], in which rheumatology should seek a major profile;
- Special interest group in young people's health within the Royal College of Pediatrics and Child Health.

Effective interventional strategies delivered by rheumatology services will need to be developed to address the increasingly recognized adolescent antecedents of adult rheumatic disease (e.g., osteoporosis and cardiovascular morbidities). This will require rheumatology professionals to look out beyond the 'rheumatology box' and learn from colleagues in adolescent health.

Executive summary

Are young people welcome in rheumatology services?

- All adolescents with and without chronic conditions require age- and developmentally appropriate healthcare. Adolescents do not readily fit into traditional pediatric or adult rheumatology services, which, according to published evidence, do not yet satisfy the UK 'You're Welcome' quality criteria for young-person-friendly health services.

Accessibility

- Young people are the new users of health services and yet perceive barriers to healthcare. Accessibility is therefore important to consider, including access for advice, clinic times and opportunities to be seen independently of their parents.

Publicity

- Important messages of how young-person-friendly a service is can be readily conveyed to the young people themselves in introductory clinic letters and/or literature provided by the service.

Confidentiality

- Confidentiality is of major importance to adolescents and particularly with respect to their willingness to disclose information and seek future healthcare. Challenging shifts from the family-centric pediatric rheumatology towards the patient-centric adult rheumatology need to be made with respect to the provision of confidential services for adolescents with rheumatic conditions.

The environment

- Dedicated areas for young people in pediatric and adult settings are called for by young people and those professionals involved in their care, but remain uncommon in the UK.

Staff training, skills, attitudes & values

- Lack of adolescent-health training has obvious impacts on the delivery of developmentally appropriate adolescent-rheumatology and transitional-care services. Incorporation of generic adolescent-health training into specialty training for both pediatric and adult rheumatology professionals is imperative to raise standards of care for this age group.

Joined-up working

- Adolescent rheumatology is multidisciplinary and mulitagency, reflecting the reciprocal influences between the physical, psychosocial, cognitive and educational/vocational aspects of adolescent development and health/illness. Joined-up working between such personnel is vital for success, and effective communication (including written) is key to this.

Monitoring, evaluation & involvement of young people

- Too often, when young people are consulted regarding service developments, adults ask the questions but also decide which answer to accept. Young people have the right to be heard and their opinion respected. Young people should be involved not only in consultation, but should participate in the monitoring and evaluation of future rheumatology services.

Health issues including sexual & reproductive health for adolescents

- Rheumatic conditions can not be considered in isolation of the rest of adolescent health – a young person with a chronic rheumatic disease is a young person first and foremost.
- The knowledge and skills framework for adolescent rheumatology includes both condition-specific issues and the general adolescent health issues that are of relevance to all adolescents irrespective of illness. Such issues include substance use, nutrition, sexual health, mental health and transition.
- A rheumatology-based transitional-care program that addressed such issues in an age- and developmentally appropriate manner from the age of 11 years has been reported to be associated with significant improvements in health-related quality of life, patient satisfaction, disease knowledge and vocational readiness.

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