Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care

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Objectives. To determine the perceived education and training needs of health professionals involved in transitional care for adolescents with juvenile idiopathic arthritis (JIA).

Methods. Two distinct questionnaires to identify transitional issues in JIA were distributed to key health professionals (n = 908) and clinical personnel involved in the implementation of a transitional care programme (n = 22).

Results. The first survey was completed by 263 professionals. Education needs were reported by 114 (43%) of health professionals. Transition issues and informational resources were the most frequently reported areas of need. The second survey was completed by 22 clinical personnel who rated ‘lack of training’, ‘lack of teaching materials geared towards adolescents’ and ‘limited clinic time’ as the main barriers to providing developmentally appropriate care to adolescents.

Conclusion. Unmet education and training needs of health care professionals exist in key areas of transitional care and provide useful directions for the development of future training programmes.

KEY WORDS: Juvenile idiopathic arthritis, Adolescence, Transition, Survey, Multidisciplinary, Education, Training.

Methods

This study forms part of a large multicentre research project in transitional care for adolescents with JIA, funded by the Arthritis Research Campaign and conducted on behalf of the British Paediatric Rheumatology Group [11–13]. The data reported here were collected during the initial needs assessment phase of this project prior to the implementation of a structured transitional care programme in 10 paediatric rheumatology centres in the UK. Two sets of data were collected.

National survey of health professionals

A postal questionnaire was developed to identify the transitional needs of adolescents with JIA from the perspectives of professionals involved in their care. Development followed standardized procedures [14] and was guided by an advisory board that included representatives of the target professional groups and young people with JIA. The main results have been reported elsewhere [12]. The data presented in this paper specifically concern the unmet education and training needs reported by health professionals (including members of the British Paediatric Rheumatology Group (BPRG), British Society of Rheumatology (BSR) and British Health Professionals in Rheumatology (BHPR), social workers, clinical psychologists and hospital youth workers in relation to transitional care. The questionnaire was designed for self-completion and distributed to 908 health professionals. Open questions were used to ensure that respondents’ answers were not constrained by the researchers’ assumptions about current education and training needs. To enhance validity, all key terms were explicitly defined. Reminders were sent to non-respondents where possible.

Baseline perceptions of adolescent issues and resources of participating centre research personnel

A modified version of the Perceptions of Adolescent Issues and Resources: Care of Adolescents questionnaire [15, 16] was
administered to the clinical research personnel (n = 22) responsible for implementing the transitional care programme in the 10 rheumatology centres. This included 11 clinical leads (consultant rheumatologists, including paediatric rheumatologists and adult rheumatologists with an interest in paediatric rheumatology) and 11 local programme coordinators (six clinical nurse specialists, three occupational therapists and two physiotherapists). The following sections were included.

(1) Perceived barriers to providing developmentally appropriate care to adolescents. This section includes seven items (see Table 3) and asks respondents to rate each potential barrier on a five-point scale anchored by ‘least significant barrier’ at 1 and ‘most significant barrier’ at 5.

(2) Perceived skill/comfort level in addressing adolescent conditions/concerns/issues.

(3) Perceived knowledge of available information or resources to assist with named conditions/concerns/issues.

(4) Perceived importance of addressing individual conditions/concerns/issues. Sections 2–4 consist of 20 items (see Table 4), each scored between 1 and 5, with higher scores indicating higher levels of skill/comfort, knowledge and importance, respectively.

(5) Perceived confidence of addressing individual conditions/concerns/issues. This section consists of 27 items and includes issues that relate to working with adolescents, their parents/families and other health professionals (see Table 5), using a five-point response format in which higher scores represent higher levels of confidence.

Analyses

Qualitative data collected in the national survey were analysed independently by two researchers using content analysis.

Results

National survey of health professionals

Two hundred and sixty-three (29%) surveys were completed (Table 1). Educational needs were identified by 114 (43%) health professionals (Table 2). Of these, 79 (70%) reported specific areas of need, with transition issues and informational resources most frequently reported. In addition to specifying current needs, 18 (7%) respondents reported no formal training regarding transitional care and 16 (6%) indicated a willingness to attend workshops/study days and/or receive educational packages.

Of the 149 (57%) who did not identify education needs, 13% stated that they had no needs and 12% felt the section was not applicable to them. The majority (70%) however, left this section blank. Amongst rheumatology professionals (BHPR, BPRG, BSR, n = 196), 47% identified themselves as having education needs. Only 18% felt that they had no needs or that it was not applicable.

Baseline perceptions of adolescent issues and resources of participating centre clinical research personnel

Only one statistically significant difference in perceptions of adolescent issues was demonstrated between groups of health
professionals; local programme coordinators felt less comfortable dealing with suicide risk than lead clinicians \((P = 0.002)\). As no other significant differences were detected, respondents were considered as one cohort in further analyses.

The most frequently perceived barriers to providing developmentally appropriate care were insufficient teaching materials geared towards adolescents and limited clinic time (Table 3). Relatively few respondents felt that communication difficulties or discomfort in dealing with adolescents were significant problems.

In terms of perceived skill and comfort, over half of the respondents reported low or very low perceived skill/comfort levels in addressing suicide risk, sexually transmitted infections/HIV/hepatitis and gay/lesbian sexuality (Table 4). In contrast, less than 10% of respondents perceived themselves to have very low/low perceived skill/comfort in dealing with the less age-specific issues of depression, anxiety, education and exercise.

In terms of perceived knowledge, over half of the respondents reported themselves as having very low/low perceived knowledge of information and resources in two-thirds of the items, including suicide risk, sexuality, drug use, eating disorders, dating/vulnerability, body image, parental conflict and peer relations (Table 4).

In terms of perceived confidence (Table 5), over a quarter of respondents lacked confidence in key areas of transitional care, such as fertility, peer support, benefits and available adolescent programmes/agencies/services.

**Discussion**

Transitional care is one of the major subject areas recommended for coverage in future adolescent health training programmes in the UK [2]. The development of transitional care services in adolescent rheumatology, as in many other subspecialties, is still in its relative infancy in the UK [17, 18]. This report highlights that health-care professionals, in both paediatric and adult sectors, perceive the need for additional education and training in transition, extending beyond the medical aspects of JIA and including generic adolescent health issues. This need has not yet been addressed in any formal manner in the UK but has recently been acknowledged by an intercollegiate working party, which recommends that ‘training in adolescent health should be mandatory for both undergraduates and the trainees of all the Royal Colleges whose members may be involved with the care of young people. Multidisciplinary modular training programmes in general and specific aspects of adolescent health should (also) be developed for allied health professionals’ [2].

The need for education and training in adolescent health is peculiar neither to the UK nor to the medical profession [4–6, 9, 19, 20]. Looking at training from the user perspective, 81% of UK teenagers felt that general practitioners (GPs) should know more about their age group in general terms [21].

The number of professionals responding ‘not applicable’ to the request for identification of training needs is surprising in view of...
the fact that over a third of young people with JIA will have significant morbidity in adulthood [22–26].

The main education and training topic specifically identified in the national survey was transitional care itself, in agreement with reports in the US literature [8, 27]. However, of the 114 people who identified education and training needs, only 23 and 3% of respondents did so with respect to transition and transfer respectively. This may indicate a lack of awareness, which is perhaps not surprising in view of the current lack of transitional care provision in the UK [17].

Less than half of the respondents identified further training/information needs in adolescent issues (114 of 263, 43%). Assuming that most respondents did not miss the question unintentionally, it is possible that many felt that they were already appropriately trained. This seems unlikely in view of the lack of training opportunities currently available in the UK [2]. Another explanation is that respondents were unaware that they had training needs. In a US-based study of adolescent transition programs, Scal [8] reported a gap between the importance that the physician respondents attributed to transitional care issues and their perceptions of their own effectiveness in addressing the issues, and postulated that this was suggestive of the need for additional training.

Other factors which may affect the perceived need for further training include insufficient clinician time, reflected in the time constraints in providing developmentally appropriate care for adolescents in the out-patient setting (Table 3). Robertson et al. [28] reported a significant difference between paediatric and adult rheumatology consultation times, the former being longer (33.9 vs 14.66 min, P < 0.001). The need for longer clinic appointments in adolescent care compared with both paediatric and adult clinics has been highlighted [2]. Finally, there is likely to be an additional need for continuing professional development in adolescent medicine, as the majority of respondents (91%) reported direct working experience with adolescents who have a chronic physical condition [12].

The education needs reported in this study may be artificially low, as respondents were more likely to be interested in transitional care/adolescents and more likely to know their limitations and maintain continuing professional development. Some respondents admitted to not knowing what their needs were. This is reinforced by the fact that 31% of respondents reporting needs did not specify what they were (Table 2). The true picture of education and training needs in adolescent rheumatology is therefore probably more pessimistic than the figures in this paper suggest.

### Specific areas of training need

A range of unmet education and training needs in adolescent health and transitional care was identified during the course of this study. Adolescents often have more diverse and serious health concerns than expected by health care providers [29, 30]. Of some concern, there was frequent discrepancy between the importance of addressing specific adolescent issues in clinic and the perceived skill/comfort of health professionals and their knowledge of information/resources of the respective issues (Table 4).

Adolescent concerns may be missed by the disease-specific approach of adult health care. Paediatric clinical training includes adolescent psychosocial and behavioural issues, which may not be addressed in adult physician training [31]. Chronic illness may also delay the onset of risk-taking behaviour and the latter may present in the adult rather than the paediatric clinic [32], thus necessitating appropriate adolescent training for the adult providers. Conversely, paediatricians who usually see younger patients may not appreciate that young adolescents have specific health concerns and are already involved in risky behaviours [33, 34].

### Mental health issues

Although the majority of research personnel felt that dealing with mental health issues was important in a rheumatology clinic setting (Table 6), most respondents also reported that they felt less skilled and less comfortable addressing suicide risk, particularly in the allied health professionals. There is a large variability in the reported incidence of psychiatric morbidity in chronic rheumatic disease [23, 35–38], although the importance of psychological assessment, however informal, is not in doubt [39]. The national recommendation that specialist paediatric rheumatology clinics should have ready access to a mental health liaison service is to be welcomed [1].

### Sexual health issues

Chronic illnesses like JIA and their therapy may influence puberty and sexual health. Furthermore, discovering sexual identity is a key developmental task integral to adolescence. Of young adults with JIA, 37.6% reported that they were sexually active prior to transfer to adult rheumatology care by age 18 yr [40]. Suris et al. [41] reported that young people with chronic illnesses are as sexually active as their healthy peers but are more at risk of negative outcomes, including sexually transmitted infections and sexual abuse. For example, pelvic inflammatory disease has been reported to be more prevalent in young adults with JIA [42]; this supports the need for opportunistic health promotion within rheumatology clinics regarding safe sex practices. Respondents acknowledged the importance of this area, but recognized that their own competence was limited. This suggests an area to be addressed in future adolescent rheumatology training programmes.

### TABLE 5. Respondents’ perceived confidence in dealing with adolescent issues (n = 22)

<table>
<thead>
<tr>
<th>Adolescent issues</th>
<th>Very unconfident to unconfident n (%)</th>
</tr>
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<tbody>
<tr>
<td>Dealing with fertility/genetic counselling</td>
<td>13 (59)</td>
</tr>
<tr>
<td>Facilitating peer social support</td>
<td>8 (36)</td>
</tr>
<tr>
<td>Dealing with social skills/social concerns (peers and dating)</td>
<td>6 (27)</td>
</tr>
<tr>
<td>Dealing with pregnancy/impact on condition</td>
<td>6 (27)</td>
</tr>
<tr>
<td>Dealing with contraception/impact on condition</td>
<td>5 (24)</td>
</tr>
<tr>
<td>Dealing with legal rights for information/consent</td>
<td>5 (24)</td>
</tr>
<tr>
<td>Dealing with puberty and sexual development</td>
<td>4 (18)</td>
</tr>
<tr>
<td>Encouraging vocational planning</td>
<td>4 (18)</td>
</tr>
<tr>
<td>Discussing school issues/education</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Providing adolescents with the opportunity for independent visits</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Providing developmentally appropriate teaching on disease and treatments</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Dealing with compliance/adherence issues to treatment plans</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Communicating with adolescents</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Encouraging independent health care skills</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Dealing with complications/long-term effects of chronic illness</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Dealing with adolescent growth and development</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Maintaining adolescent confidentiality</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Family issues</td>
<td></td>
</tr>
<tr>
<td>Integrating ethnocultural issues into care</td>
<td>6 (27)</td>
</tr>
<tr>
<td>Dealing with family conflicts/concerns</td>
<td>4 (18)</td>
</tr>
<tr>
<td>Facilitating parent support groups</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Dealing with parental concerns</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Providing parental support</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Healthcare issues</td>
<td></td>
</tr>
<tr>
<td>Dealing with benefits/programmes available for adolescents</td>
<td>8 (36)</td>
</tr>
<tr>
<td>Dealing with community agencies and services for adolescents</td>
<td>7 (32)</td>
</tr>
<tr>
<td>Dealing with community resources/clinics for adolescents</td>
<td>4 (18)</td>
</tr>
<tr>
<td>Coordinating care with other agencies</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Working with adult health care providers</td>
<td>1 (1.5)</td>
</tr>
</tbody>
</table>
Generic health issues were not frequently specifically identified in the national professional survey (Table 2). This may once again reflect lack of perceived applicability as well as the ambivalence of rheumatology professionals with respect to this role and their discomfort with the subject area [43]. One of the requirements considered necessary for successful transition is that the young person has an understanding of the implications of the condition and treatments for their sexual and reproductive health [8]. This has been highlighted as a specific area for training initiatives by surveyed physicians [6] and in other chronic illnesses, such as cystic fibrosis [44, 45]. It is also an area in which the greatest gap between perceived importance and physician effectiveness in adolescent transitional care provision has been identified [8]. Finally, it is important that sexual health be considered in the context of interpersonal relationships in general. Developing intimate relationships is a key component of adolescent development, but several studies of young adults with JIA have identified difficulties in this area, particularly for males [40, 42, 46–47].

Vocational issues. Vocational issues were identified as an important but unmet training need in both the national survey (Table 2) and the survey of clinical research personnel, in contrast to their perceived importance of this area (Table 4). Increased unemployment has been reported in young adults with JIA [22, 23, 48]. Several papers have suggested that further training in vocational issues for paediatricians and adult rheumatologists is a high priority [49, 50]. The advent of Connexions in England and Wales will hopefully provide vital support and expertise that rheumatology teams will be able to access in the future (www.connexions.gov.uk).

Exercise. All the research personnel felt comfortable, skilful and knowledgeable in addressing exercise-related issues for adolescents with JIA (Table 4), and this has been borne out in a recent audit [13]. This is particularly pertinent in view of the reports of reduced fitness in children and young adults with JIA [51, 52], in addition to the importance of exercise during adolescence as a predictor of bone density in adulthood [53].

Multidisciplinary and inter-agency working. Training needs with respect to the interagency network integral to transitional care were identified in both surveys (Tables 2 and 4), echoing similar findings in the US literature [8]. Transitional care, like adolescent health in general, is by definition a multidisciplinary activity and therefore training programmes will need to reflect this [2].

Communication skills. A surprisingly low proportion of respondents identified communication skills as a training need in the national survey. This may be due to selection bias but also to lack of awareness of the skills specific to dealing with adolescents. Appropriate communication skills vary with the age and developmental stage of a child and are not the same as those used with adults [54–56]. Jacobson et al. were surprised to report that GPs spent 20% less time with teenagers compared with other patients, despite perceiving that the converse was true [57]. From the user perspective, 24% of 14–to 15-yr-old girls felt uneasy during consultations with their GP [58]. In another study, parents of adolescents felt that doctors lacked communication skills with teenagers and appeared uncomfortable when discussing personal topics such as sexual behaviour [59].

Finally, it is important to remember that the data in this study may be an underestimate of education needs as it relied upon respondents’ perceptions and self-reporting, which may not necessarily reflect actual behaviour. It is individuals’ interpretations of their world that constitute their reality, guide their actions and influence their attitudes, which in turn have been recognized as potential barriers to successful transitional care [8, 60, 61].

In summary, a variety of unmet education and training needs of health care professionals has been identified in this study of transitional care. There is now a need for a systematic educational programme aimed at imparting the core knowledge and skills required by health professionals to provide developmentally appropriate rheumatology and transitional services for adolescents. Innovative programmes are already readily available for subspecialties such as rheumatology to access, such as the European Teaching Effective Adolescent Care and Health initiative (www.euteach.com). Appropriate training provision will not only benefit individual patients but will also enhance further service developments [62]. As the first director of adolescent medicine in the UK said, ‘The solution for the UK must be the development of adolescent expertise and adolescent medicine thinking at ALL levels of health care delivery’ [63], including rheumatology.

<table>
<thead>
<tr>
<th><strong>Rheumatology</strong></th>
<th>Key messages</th>
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<tr>
<td>• Rheumatology health professionals have unmet education and training needs in adolescent health and transitional care. These key areas require inclusion in current curricula and rheumatology training programmes of relevant professionals.</td>
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</table>

Acknowledgements

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