

EXTENDED REPORT

Growing up and moving on. A multicentre UK audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care

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Objective: To assess the provisions made for the transfer of adolescents with juvenile idiopathic arthritis to adult rheumatology clinics in the UK and the impact of a transitional care programme.

Methods: An audit of the documentation of the provisions made for transfer in 10 centres participating in a controlled trial of transitional care. Each centre conducted a retrospective case note audit of the recent patients transferred to adult care before and 12–24 months after the start of the trial. Demographic details, age when transition was first discussed, age at transfer, transitional issues, multidisciplinary team involvement, adolescent self advocacy, and readiness were documented.

Results: There were improvements at follow up in documentation of transitional issues, disease specific educational needs, adolescent readiness, and parental needs with the exception of dental care, dietary calcium, and home exercise programmes. The age at which the concept of an independent clinic visit was introduced was lower (mean (SD): 16.8 (1.06) v 15.8 (1.46) years, $p=0.01$) but there were no other changes in age related transitional milestones. Significantly more participants had preparatory visits to the adult clinic, had a transition plan, and had joint injections while awake at follow up.

Conclusions: The improvement in documentation suggests that involvement in the research project increased awareness of transitional issues. The difficulty of changing policy into practice was highlighted, with room for improvement, particularly at the paediatric/adult interface. The reasons for this are likely to be multiple, including resources and lack of specific training.

Adolescents with juvenile idiopathic arthritis (JIA) and their parents have reported that transfer from paediatric to adult services in the United Kingdom is associated with many difficulties. Along with families of children who have other chronic illnesses, they have called for greater preparation and increased professional liaison during this time.^{1,2} Transition is defined as a multifaceted active process that attends to the medical, psychosocial, educational, and vocational needs of adolescents as they move from child to adult centred care. This is in contrast to transfer, which is an event rather than a process. Transition programmes for adolescents with chronic diseases aim to provide coordinated, uninterrupted health care that is age and developmentally appropriate and comprehensive. They promote skills in communication, decision making, and self care and therefore enhance a young person's control and independence.

There are many differences between adult and paediatric care.^{3–4} Young people need to be aware of these differences and to be equipped with knowledge and skills to allow them to interact effectively with their new adult health care providers. Conversely, adult providers need to be aware of the dramatic change that these young people experience at this time. The need for this aspect of care provision has been highlighted by several professional bodies^{5–8} and recently has been recognised as a core standard of care for children with lifelong chronic illness in the UK's National Service Framework of Children, Young People and Maternity Services (NSF).⁹ Preliminary data from the first controlled trial of transitional care in any chronic illness showed significant improvement in health related quality of life, disease related knowledge, satisfaction in health care, and vocational readiness markers^{10–13} Our aims in the

present study were to audit the documentation of the provisions made for the transfer of young people with JIA from the trial centres to adult health services and to assess indirectly the impact of the coordinated transitional care programme¹¹ developed in response to a prior needs assessment^{2, 14–17} on transfer.

METHODS

A retrospective case note audit of recent patients with JIA transferred to adult centred rheumatology care was conducted in 10 participating UK paediatric rheumatology centres before and 12 to 24 months after the implementation of a structured coordinated programme of transitional care.¹¹ All but one of the centres had been identified previously in an audit of adolescent rheumatology care.¹⁸ The controlled trial of the implementation of the transitional care programme enrolled participants at ages 11, 14, and 17 years and therefore represented a minority of the patients audited. Full details of the trial cohort have been described elsewhere.¹⁰ Data collected included demographic details, age when transition was first discussed, when transfer occurred, transitional care components, documentation of transitional issues and needs, multidisciplinary team (MDT) involvement, and details about the adult rheumatology service involved. Comparisons were made between the baseline and follow up data for actual data values where applicable and the documentation of information in the medical notes.

Abbreviations: AHP, allied health professionals; CHAQ, Childhood Health Assessment Questionnaire; CNS, clinical nurse specialists; JIA, juvenile idiopathic arthritis; MDT, multidisciplinary team; NSF, National Service Framework

Table 1 Baseline and follow up participants by centre and project involvement

Centre	Baseline, n=128 (%)	Follow up, n=93 (%)	Number of participants enrolled into transition project*
1	20 (15.6)	39 (42)	18
2	20 (15.6)	4 (4.3)	2
3	18 (14.1)	12 (12.9)	7
4	10 (7.8)	10 (10.8)	2
5	21 (16.4)	15 (16.1)	0
6	20 (15.6)	8 (8.6)	3
7	17 (13.3)	5 (5.4)	3
8	2 (1.6)	0	0

*Missing data for eight patients.

All participants gave written informed assent/consent before assessment, and the project had multicentre (West Midlands) and local research ethics committee approval in each of the participating centres.

Statistical analyses

Non-parametric data was analysed using the Mann–Whitney U test, and nominal data using the Pearson χ^2 test. Patients less than 21 years were compared with those 21 years or older at time of transfer to assess if these older patients were affecting the overall results. Data was also analysed with respect to participation in the transitional care project at follow up. Probability (p) values of 0.05 or less were considered significant. Data was analysed using SPSS software version X (SPSS Ltd, Woking, UK).

RESULTS

Data from the initial audit with the first 110 patients have been published elsewhere.¹⁸ Data from the second round were available for 93 patients. These were compared with the data from the initial audit, which recruited 128 patients. There were proportionally more male subjects in the follow up audit than in the first audit (30% v 43%; p = 0.05) and less co-morbidity (39% v 20%; p = 0.007). Median age at transfer was the same in both groups (18 years (range 12 to 49) v 18 years (range 15 to 40); p = 0.26). If the over 21s were excluded from analyses, median ages at transfer were 17 (12 to 20) years and 18 (15 to 20) years at baseline and follow up, respectively, and not significantly different (p = 0.09). There were no differences in the age at onset of JIA or in the proportions of JIA subtypes. The patient numbers per centre are shown in table 1. Forty one per cent of the follow up group were recruited to the transitional care project (table 1).

Self advocacy skills

There were significant improvements in the documentation of self advocacy skills (table 2).

Comparing the actual age related data between the two groups the only difference was in the age at which the concept of independent clinic visits was introduced. This was

lower at follow up (table 3) and this difference was maintained when patients ≥ 21 years were excluded from the analysis (mean (SD): 16.8 (1.1) v 15.7 (1.39) years, p = 0.006).

Parents

There was improved documentation of the transitional needs of parents at follow up (1.7% v 26.7%, p < 0.001) and also whether concurrent visits for parents were documented when the young person was seen independently (39.7% v 60%, p = 0.003), but there was no difference in the actual proportions of parents seen separately between the baseline and follow up groups (31.3% v 37.0%, p = 0.54).

Involvement of the multidisciplinary team

The majority of discussions about transition occurred as an outpatient (92.2% and 96.8% in baseline and follow up groups, respectively). There were no differences in the proportion of “transition discussions” involving different health care professionals (consultant, specialist registrars, clinical nurse specialist, physiotherapist, occupational therapist, social worker). However, there was significant improvement in the continuity of senior medical staff during the transition process (58.4% v 87.1%, p < 0.001). High proportions of patients had documentation of multidisciplinary team involvement at the time of transfer at baseline (mean 72.1%). This increased to 99.3% in the follow up group (p < 0.001). Fewer patients had contact with a physiotherapist in the follow up group than at baseline (59.1% v 40.7%, p = 0.015), or with clinical nurse specialists (CNS) (61.3% v 19.2%, p < 0.001). There were no differences in the proportions of young people seeing occupational therapists, psychologists, podiatrists, social workers, or dieticians. A few young people in both groups were also in contact with a variety of other health professionals including ophthalmologists, dentists/maxillofacial, dermatologists, orthopaedic surgeons, endocrinologists, gastroenterologists, renal physicians, and youth workers.

The adult rheumatology interface

With respect to the paediatric/adult care interface, similar proportions of young people were offered or actually made a preparatory visit to the adult clinics in each group (21.4% v 34.2%, p = 0.06; 16.7% v 22.9%, p = 0.32, respectively). There was improved documentation of whether an overlap visit to the paediatric clinic was made after the first adult clinic appointment (72.2% v 88.2%, p = 0.004). The proportions of patients actually experiencing this was higher at follow up, but the difference was not significant (26.4% v 39%, p = 0.076). More over 21 year olds were offered preparatory visits to adult clinics (17.9% v 45.5%, p = 0.035), made these visits (13.3% v 40%, p = 0.03), or had an overlap visit at the paediatric clinic (23.1% v 57.1%, p = 0.05) than the under 21s. Following transfer there was improved documentation as to whether there were any problems with respect to the transfer (40.5% v 75.5%, p = 0.001) but no difference in the

Table 2 Comparison of the documentation of self advocacy development

	Baseline, n=128 (% documented)	Follow up, n=93 (% documented)	p Value
Age when independent visit concept introduced	14.1	49.5	<0.001
Age when independent visits began	14.1	52.2	<0.001
Age when self medication discussed	10.9	37.6	<0.001
Age when self medicating	7.8	43	<0.001
Age when making own appointments	11.7	16.9	0.29

Table 3 Comparison of self advocacy age related data: baseline v follow up (Mann-Whitney U test)

	Baseline median years (min, max)	Follow up median years (min, max)	p Value
Age at first discussion of transfer	17 (12, 18.5)	17 (13, 40)	0.5
Age at transfer to adult care	18 (12, 49)	18 (15, 40)	0.26
Age when independent visit concept introduced	17 (15, 18)	16 (13, 19)	0.01
Age when independent visits began	16 (15, 19)	17 (12, 20)	0.98
Age when self medication discussed	14.5 (12, 19)	15 (14, 18)	0.3
Age when self medicating	16.5 (12, 19)	16 (14, 20)	0.77
Age when making own appointments	18 (5, 19)	17 (15, 18)	0.15

proportions of young people experiencing problems (17.6% v 10.8%, $p = 0.48$) or the proportion of cases where a letter was received from the adult rheumatologist (19.2% v 28.8%, $p = 0.14$).

Transition issues and adolescent readiness

There was significant improvement in the documentation of disease specific educational needs being addressed at follow up (26.7% v 87%, respectively; $p < 0.001$). There were improvements in the documentation of discussions regarding specific transitional issues for the follow up data (table 4) and significant improvements in the documentation of all aspects of adolescent readiness comparing baseline with follow up groups: decision making, communication skills, self care, independent visits, phoning with own queries (table 5).

There was increased documentation of preparation for joint injections without sedation in the follow up group (5.4% v 23.8%, $p = 0.008$) and fewer patients were having joint injections under general anaesthesia (60% v 40%, $p = 0.002$) at follow up.

Administrative issues

More of the follow up group's medical notes contained a structured transition plan (3.1% v 35.3%, $p < 0.001$) and more young people were provided with written information detailing the transition process (1.3% v 21.3%, $p < 0.001$).

There was general improvement in documentation about whether summaries from all members of the MDT were sent to the adult clinic (table 6).

The actual proportions of patients having these summaries sent to the adult clinic significantly improved with respect to copies of discharge summaries, DEXA scans, Childhood Health Assessment Questionnaire (CHAQ)¹⁹ results, core outcome variables,²⁰ and future management plans (table 3). Young people themselves were more likely to receive a copy clinic letter in the follow up group (3.9% v 53.6%, $p < 0.001$) and to hold their own monitoring cards (17.9% v 32.3%, $p = 0.04$).

When the data were reanalysed excluding centre 1, which was over-represented at follow up (42% of case notes reviewed) (table 1), there was no change in the results except that a significant improvement in the age when self medication was discussed was now observed (excluding centre 1: age at baseline = 14.5 (12 to 17) years; age at follow up = 14 (14 to 20) years, $p = 0.028$; compare table 3), although documentation of this information was incomplete from centre 1 (data available for eight of 39 at follow up; median age when self medication was discussed 17 years). There was also an improvement in the frequency of involvement of the consultant ($p = 0.021$), CNS ($p = 0.001$), and physiotherapist ($p = 0.002$) in transition discussions. The male sex bias and the improvements in the documentation of provision of transition information leaflets, patient held

Table 4 Documentation of transitional issues

Transitional issue (HEADS)	1st round audit, n = 128 (% documented)	2nd round audit, n = 93 (% documented)	p Value
Home - relationships/social support	24.8	69.9	<0.001
Education - school	57.3	89.3	<0.001
Work experience	30.8	63.2	<0.001
Career plans	43.4	78.4	<0.001
Statement re transition plan	2.4	16.7	<0.001
Exercise - general	36.6	80.6	<0.001
Exercise - home programme	40.3	46.2	0.38
Activities - peers/social life	21.3	60.4	<0.001
Alcohol	15.6	58.7	<0.001
Driving	14.6	41.1	<0.001
Drugs	4.1	36.6	<0.001
Diet - general	9.8	35.5	<0.001
Diet - calcium, vitamin D	15.4	21.7	0.24
Dental care	2.5	6.5	0.15
Sexual health - general	9.8	33	<0.001
Sexual health - periods	16.9	32.5	0.017
Sexual health - contraception	10.7	36.6	<0.001
Sleep	8.2	29	<0.001
Future independent utilisation of health service	8.3	51.6	<0.001

Table 5 Documentation of adolescent readiness

Aspect of adolescent readiness	Baseline, n = 128 (% documented)	Follow up, n = 93 (% documented)	p Value
Decision making	7.9	63.6	<0.001
Communication skills	10.4	75	<0.001
Self care	12.8	80.7	<0.001
Independent visits	13.5	66.3	<0.001
Phoning with own queries	6.3	26.5	<0.001

monitoring cards, and offers of preparatory visits to the adult clinic were, however, lost.

When the follow up data were reanalysed comparing the results for those enrolled in the transitional care project, the populations were comparable in terms of sex, age at disease onset, co-morbidities, and disease subtypes. There was no significant difference in the actual ages of self advocacy development (as in table 2). Multidisciplinary involvement and the practice of sending copy letters to the young person were also better in the project patients (72.2% v 46%, $p = 0.016$). Documentation of transitional care components, discussion of transitional issues, features of adolescent readiness, and parental needs were generally significantly better with a few interesting exceptions. No difference was observed between project participants and others in the following:

- transitional care components: preparatory visits to adult clinics, addressing disease specific educational needs;
- discussion of certain specific transitional issues as detailed in table 4: education – school, career plans, exercise (general/home), driving, diet, dental care, sleep;
- preparation for intra-articular injections done while awake;
- documentation of patients phoning with own queries;
- the majority of the paper based items transferred to the adult service (detailed in table 6) except for the medical summaries and core outcome variables.

DISCUSSION

The improved documentation of transitional issues in addition to some aspects of practice reported here highlights the immediate impact of research on clinical practice in terms of raising awareness beyond research participants in addition to the challenges of translating policy into practice. Process issues such as documentation are integral to transitional care, particularly in view of the multidimensional and

multidisciplinary nature of care provision, the latter requiring effective communication (including written) between professionals. Unfortunately the administrative workload of these process issues has currently not been adequately recognised to date. In view of the generic nature of the main findings reported here this study has potential wider relevance to all young people with chronic illnesses requiring transitional care.

Timing

Early introduction of the concept of transition is viewed as advantageous in preparing young people and their families for the move to adult care.^{2 21 22} Although this age criteria did improve at follow up, the median age was still 15.8 years, with no significant difference between the project participants and the rest. Preliminary results from the outcome data reveal significant benefits to starting transition at age 11 years,^{12 13} earlier than that advocated by both the Royal College of Nursing (13 years⁸ and the American Academy of Pediatrics (“by age 14 years”⁶).

There was a significant improvement at follow up in the time period between first discussion of transition and age at transfer of the patients studied (median gap = 0 (0–4) years at baseline compared with 1 (0–4) years at follow up, $p < 0.001$) which persisted even when the over 21-year-olds were excluded. The timing of transfer from paediatric to adult services is influenced by many factors, chronological age being only one. Therefore it is generally agreed that, although it is useful to have a target age, flexibility regarding this is necessary⁹ and this should be applied to all stages of the transitional process.

Self advocacy skills

There was little change in the documented clinical practice of self advocacy skills training after the introduction of the transition project, or in the proportions of parents being seen alone, although there were improvements in the documentation. The project participants included in this audit, however, were primarily the 17 year old “control group”, in that they were receiving transitional care relatively late in adolescence, the project being primarily aimed at early adolescence. The age when independent visits began was actually slightly older at follow up, though not significantly so, and relatively old when compared to the age proposed by the young people themselves (13–16 years)²³ and by health care providers in other studies (12 years).²⁴ Giving adolescents the option of being seen by professionals without their parents was one of six items identified in a Delphi study of users and providers as constituting best practice and being highly feasible.¹⁶ In a retrospective study of young adults with congenital heart disease, clinic visits without parents or siblings were associated with successful transfer.²⁵ Promoting this can pose difficulties for health care professionals because of concern about negative responses or attitudes of parents and young people. However, when surveyed, professionals, patients and parents all agree that the option of being seen by professionals alone is an important aspect of transition but

Table 6 Transfer process issues

Item sent to adult service	Baseline group (%)	Follow up group (%)	p Value
Copy clinic letters	50.8	59.3	0.21
Copy discharge summaries	1.8	20.3	<0.001
Medical summary	77.1	77.9	0.708
Plan for future management	23	65.8	<0.001
Ophthalmology summary	18.8	20.8	0.826
Nursing summary	8.5	8.4	0.984
Physiotherapy summary	13.2	17.8	0.46
OT summary	9.1	2.9	0.13
DEXA scan results	2.8	15.4	0.014
CHAQ scores	13.8	63.5	<0.001
Core outcome variables	1.2	62.2	<0.001
Growth charts	23.6	26.3	0.75

CHAQ, Childhood Health Assessment Questionnaire; DEXA, dual energy x ray absorptiometry; OT, occupational therapy.

they have been shown to prioritise it differently.^{2 16 24} Young people also need assurances of confidentiality if seeing health workers alone. This has been shown to increase the willingness to disclose sensitive information and to seek future care.^{26–28} Such assurance is important for young people with chronic disease as they may not be aware of this change as they grow up,¹³ having always been used to parents or carers being involved in the consultation.

Multidisciplinary team involvement

Multidisciplinary involvement was prevalent in the baseline and follow up groups, physiotherapist and occupational therapists being most commonly involved, with the exception of nurse specialists at baseline. However, nurse specialist involvement fell sharply in the follow up group. This could be explained by, first, other allied health professionals or medical staff, or both, undertaking primary roles in transition, including the impact of the local programme coordinator (LPC) role in the project^{10 11}; second, local resources, as exemplified by the improved results following the exclusion of centre 1, where there was no nurse specialist available in the adolescent clinic at the time of the study; and third, the bias of only medical notes being audited. This finding is, however, of interest as the coordinating role has primarily been identified as nursing in policies to date^{8 9} and supports the generic nature of this role, which can be undertaken by other allied health professionals.²

The adult rheumatology interface

Contact between paediatric and adult providers remained relatively low after the introduction of the transition project, as illustrated by the proportions of patients having overlap visits and the correspondence received from the adult providers. In view of this, the proportions of young people reported to have experienced problems after transfer may be artificially low as problems simply did not get communicated back to the paediatric teams. The increased frequency of preparatory visits to the adult service observed in the over-21-year-olds raises interesting questions: does their maturity or experience allow them to communicate this need, or do they or their paediatric team have more problems letting go? The latter has been reported in other studies of childhood onset disease²⁹ and has been highlighted as a potential barrier to transfer.³⁰

Although participation in the project improved the frequency of preparatory visits actually made, the administrative transfer process was not significantly influenced by the project except for an increase in medical summaries, a template for which had been part of the project resource pack.¹¹ Finding an interested and capable adult service has been highlighted as a major difficulty for young people, their families, and the paediatric services.^{21 31} Collaboration with adult services has been cited as critical for the success of a transition programme³² and an essential component of it.^{9 33} In a survey of transfer methods for diabetic services it was found that higher rates of clinic attendance two years post-transfer were seen where young people had the opportunity to meet the adult diabetes consultant before transfer.³⁴ Young people themselves are keen advocates of this practice in several studies.^{35–37}

Administrative issues

Copies of clinic letters were more commonly sent to young people in the follow up group and particularly those in the research project, which included a template for such letters in the project resource pack. As from April 2004 this has been a standard for adult services in the United Kingdom.³⁸ The acceptability of such practices for young people has not, however, been wholly determined.³⁹ Ali and Charlton

reported 69% of a small cohort of children over 11 years read and valued such letters highly.³⁹ Therefore it is likely to be helpful to introduce this practice to transitioning adolescents before transfer, giving them the opportunity to become familiar with the general style of such letters; it may also identify unmet disease education needs which can then be addressed before transfer. Patient-held transfer summaries are also advocated in the Children's NSF for young people with special health care needs.⁹ Although the latter were not specifically addressed in this study, copy letters would obviously contribute to such practice.

The amount of information available to the adult teams remained limited although did improve at follow up for some aspects (table 3). However, approximately one third to a quarter of adult rheumatologists were not receiving copy clinic letters, a medical summary, CHAQ scores, or core outcome variables sent. Furthermore there was no change in the limited numbers with AHP (allied health professionals) summaries sent, which could be viewed as particularly important for the multidisciplinary nature of rheumatology, and for the potential differences in AHP service provision in the adult sector compared with the paediatric sector. Young people attending their first few adult clinic appointments may be very aware of this, noticing that the new adult clinic notes are much thinner than the thicker volumes they were familiar with in the paediatric clinic. This has potential psychological implications for the young person, reducing confidence in the adult team and exacerbating shyness, as they feel that they and their past and present problems are not known or appreciated. This could lead to the view that continuing to attend appointments in the adult clinic is a waste of their time. The ability to transfer appropriate information at the right time to the right people requires adequate administrative back up and this needs to be taken into account when planning transitional services.⁹

Process

Transition plans were significantly more prevalent in the medical notes following the introduction of the transitional project. This was largely due to the participants in the project in which such plans were integral. The use of such plans has been acknowledged as important in a national survey of professionals¹⁵ and recommended in national guidelines for transitional services,^{6–9} yet reported to be similarly deficient in a recent Australian study.⁴⁰ The recent publication of generic transition plan proforma by the Royal College of Nursing will hopefully further support this area of practice development in the UK.⁸

The documentation of discussions regarding transitional issues generally improved with three exceptions. Dental care was seldom addressed and this is supported by two studies that found very poor dental health⁴¹ and increased periodontal disease⁴² in children and adolescents with JIA. Home exercise also remained poorly documented but perhaps this was included in the discussions around exercise in general, which did improve. The lack of both documentation and improvement in provision of dietary advice regarding calcium and vitamin D is concerning in view of the increasing awareness of osteoporosis risk in JIA⁴³ and known prevalence of suboptimal intake in healthy adolescents⁴⁴ although the precise role of supplementation in primary osteoporosis prevention in children remains unclear.

It is important that generic health issues are covered during transition, as they are often important concerns for adolescents with chronic illness. Adolescents with chronic illness are reported to have more age related health concerns than their healthy peers.⁴⁵ These often have direct or indirect impact on the chronic disease—for example, alcohol consumption and sexual activity with respect to methotrexate

Table 7 Priority areas in transitional care for further research and development**Self advocacy skills**

Young people making own clinic appointments, ringing with own queries

Process

Starting transition early

Preparation for joint injections under local anaesthetic

Provision and/or addressing the following areas: dietary calcium/vitamin D, dental health, sleep

Availability of concurrent visits for parents if young person seen alone

Informational resources

Availability of patient and parent information detailing the transition process

Adult rheumatology interface

Availability of preparatory visits to the adult clinic

Administrative transfer with the adult rheumatology team

Provision of non-medical transfer summaries for the adult team

treatment.⁴⁶⁻⁴⁷ Problems with conceiving and having miscarriages, menorrhagia, and pelvic inflammatory disease have been reported with increased frequency in young women with JIA.⁴⁸ Health professionals have reported difficulty addressing these issues, citing embarrassment, insufficient time, difficulty in finding the "right time", and insufficient training as the main barriers.⁴⁶ The modified HEADS acronym is a useful aide memoire for this in clinical practice (see table 4).

In our comparison of consultation times within paediatric and adult rheumatology clinics, paediatric (including adolescent) consultations were on average twice as long as adult consultations.³ Timing of appointments and the availability of adequate staff, particularly if parents are going to be seen alone concurrently, need to be taken into consideration. The improvement of continuity of senior medical staff for consultations in the follow up group suggests that medical staff were indeed taking more of a lead in the transitional process and possibly freeing up specialist nurse time. Continuity of professionals has been highlighted as an important aspect of the transitional process for patients and their families.²⁻¹⁶⁻⁴⁹ However, this needs to be balanced with the preparation for the adult clinic, where often seeing the same doctor is not possible.

Differences in procedural pain management (for example, being unable to have joint injections with general anaesthesia) can be a major shock to young people with chronic illnesses moving on to adult clinics. This may influence their attendance at adult clinics and ultimately the potential for disease control. Preparation for this is required. The smaller proportion of young people having joint injections without a general anaesthetic in the follow up group indicates increased awareness of this difference between paediatric and adult practice. Apart from the age when the concept of an independent visit is introduced, there were no significant changes in the other age related transition process issues.

Limitations of the study

One of the main limitations of this study is that the lack of, or indeed the presence of, documentation does not necessarily reflect actual clinical practice. However, documentation of relevant information is important in view of the multi-dimensional and multidisciplinary nature of transitional care and therefore an audit of this aspect alone is of value. Another explanation of the discrepancies between documentation and change in practice reported here is the challenge of translating policy into practice. The reasons for this are likely to be multiple, including lack of training in this area for health professionals, inadequate numbers of health

professional staff, and lack of administrative support.¹⁵⁻¹⁷ However, increased awareness—as exemplified by improved documentation—is an important first step in this process and further research into the implementation of transitional care is ongoing. Table 7 details particular priority areas in which there was the least improvement at follow up and which need further investigation.

Another limitation of the study is that notes held by allied health professionals were not examined, only the medical notes. Once again, effective communication within the multidisciplinary team is vital in transitional care and may be enhanced in the future by increased use of individualised transition plans developed with the young person and available to all team members.⁸⁻¹¹⁻¹⁵

Conclusion

Before the transitional care project, the documentation of the transitional process in paediatric rheumatology medical notes in participating centres was limited. The improvement in this documentation suggests an increased awareness of transitional issues and needs of young people with chronic arthritis beyond those who were actually recruited into the project. The transitional care project had some impact in improving practice but this study suggests that the well defined principles underpinning transition⁴⁻⁹⁻³³ are yet to be fully translated into systematic approaches (including administrative infrastructure) that support transition to adult health care. Data analysis relating to the outcomes of the transitional care programme in terms of quality of life, satisfaction, and knowledge is ongoing.¹⁰⁻¹²⁻¹³

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