REVIEW

Transition of care from paediatric to adult services in haematology

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The need for adequate preparation for transition for young people with health care needs who require long term follow-up in the adult sector has long been recognised and is a required part of the national service framework for children. The Royal College of Paediatrics and Child Health and the Royal College of Nursing have endorsed this need for improvement in services for adolescents. In 2006 the Department of Health launched guidelines with a wealth of recommendations. Despite these initiatives only slow progress has been made (usually by enthusiasts) and much work is needed to develop good programmes in many specialties, including non-malignant haematology.

> I would there were no age between ten and three-and-twenty, or that youth would sleep out the rest: for there is nothing in the between but getting wenches with child, wronging the ancientry, stealing, fighting (Shakespeare c1611 – The Winter's Tale (act 3, scene 3, line 59) quoted in the Royal College of Paediatrics and Child Health (RCPCH) report[1])

Adolescence is a difficult time. The young person has outgrown the ''fluffy bunny'' paediatric environment, may dispute with his medical staff and parents the constraints caused by his condition, and yet fears the prospect of a move to a new hospital or department (''I worried that the adult hospital would be a place full of dying people with a horrible smell'' – a young patient at a focus group) and has a vision perhaps of authoritarian staff wearing suits who are not interested in any of his interests or concerns (table 1). Young people aged 10–20 make up 13–15% of the population, and although the main causes of mortality are accidents and self-harm, there are many young people with chronic medical conditions. Although usually accompanied by parents in the paediatric setting, by the age of 15 half want to see the doctor or nurse alone, just under a quarter want their parents present and just over a quarter their friend.[1]

Haematological conditions such as haemoglobinopathies, inherited bleeding disorders and other congenital marrow disorders, for example dyserythropoietic anaemia and Diamond-Blackfan syndrome (pure red cell aplasia) together with constitutional and acquired marrow failure syndromes, are among the conditions where care needs to be transferred to adult teams. ''Arranging efficient and caring transfer for adolescents from paediatric to adult care is one of the greatest challenges facing paediatrics and the health services in the coming century''.[2] Transition is defined as ''the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health care systems''.[3] Despite such recognition, arrangements for transfer into the adult sector are very variable, and facilities (particularly inpatient) for adolescents in both the paediatric and adult setting are often unsatisfactory. Whatever the chronic condition, the young person may have reduced independence compared to his/her peers, difficulty with relationships, social isolation, and educational and vocational difficulties. Medical care (both the professionals and their advice) may be rejected during adolescence as part of separation from parental control, and the youngster who loses the benefit of such parental and medical support may be more prone to risk-taking behaviour with sex, drugs and smoking. The transfer of adolescents from their paediatric team to another very different service is ''often a major, often frightening, life event''.[4] Where ''young adult teams'' have been developed research shows that the young people are 2.54 times more likely to participate in society (where participation indicates such things as enjoyment of normal mobility, self-care, work and leisure, getting on with people) than those who used ad hoc services.[5]

The transition from dependent child to independent adult is well recognised to be a gradual process taking several years. Why then should we expect young people with a chronic medical condition to make it in one hop? This is a time of social, emotional and biological change in which the adolescent should consolidate his/her identity, achieve independence from parents, establish adult relationships outside the family and find a vocation.[6] The WHO defines ages 10–20 years as adolescence. Children with chronic medical conditions usually have long-standing relationships with particular individuals in the paediatric setting, for example with specific medical, nursing and other allied professionals who they and their parents have come to trust over several years. Parents may also fear transfer as they need to learn to ''let go'' of some control, which may be particularly difficult with a child with additional medical needs. At worst, the young person defaults from follow-up in the adult sector with potentially disastrous consequences,[7] but at best, well-managed transition results in the development of new

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Table 1 Cultural issues for adolescents

Obesity/diet/anorexia
Smoking
Alcohol and drugs
Sexuality and fertility
Pregnancy – periods, contraception
Education/employment – exams, work experience, career
Leaving home – relationships, social support
Driving and exercise

and secure relationships for the young person with a new health care team, enhancing his/her self-reliance and esteem at the same time as continuing good professional medical care.[8]

In recognition of these issues, a Royal College of Paediatrics and Child Health (RCPCH) report in 2003[1] identified some of the barriers perceived by adolescents to their use of health care services and made recommendations for improvements to the service. In particular, clinicians need to develop protocols of good practice for transfer. Key elements include a written transition policy between paediatric and adult services, flexible timing of transfer, an education programme for patient and parent which addresses all aspects of care, a written individualised plan for transition for each patient and training of both paediatric and adult team members in adolescent health.[9]

Despite the increasing recognition of the need for better transition, to date there are few centres where such programmes exist in haematology, although a few haemophilia centres are starting to develop programmes. Similar issues exist for young people with haemoglobinopathies where generally there are no formal transition programmes, although recommendations are made in the recent standards for clinical care.[10] In both these groups of inherited conditions, the young person needs both regular medical review, and more inconveniently, often also requires regular therapy. Boys with severe haemophilia are currently advised to use prophylactic intravenous factor treatment two or three times a week (given in the morning) to prevent joint bleeds and therefore protect their joints from arthropathy, and young people with thalassaemia have the burden of several hours' iron chelation therapy (usually overnight). Adolescents may deny or ignore their inconvenient condition, and may default from these nuisance treatments at a time when they are exploring greater freedom and a less regulated lifestyle. A Scandinavian survey of compliance with treatment and understanding of severe haemophilia (in young people aged 13–25 years) was consistent with this, noting that 41% of patients had not followed prescribed treatment. Encouragingly, however, the level of knowledge about their condition was good but with less than expected understanding of the inheritance which is an important consideration at an age when young people are becoming sexually active.[11]

Table 2 Health-related websites for young people*

http://www.youthhealthtalk.org
http://www.teenagehealthfreak.org
http://www.childrenfirst.nhs.uk
http://www.need2know.co.uk
http://www.connexions.gov.uk
http://www.lifebytes.gov.uk
http://www.mindbodysoul.gov.uk
http://www.dreamteam-uk.org (a site developed for rheumatology patients)

*From a resource list given by J McDonagh in March 2006 at the national launch of the Department of Health guidance (all sites accessed on 6 April 2007).

It has been important to find out what will help; focus groups where adolescents are encouraged to talk together about their experiences of hospitals, out-patient clinics and transition have been very helpful in developing models of care in rheumatology.[12] A number of common themes emerged, including the need for a multidisciplinary team, good co-ordination between professionals, a need for clear sources of information and an identified key worker or co-ordinator. Not surprisingly, the young people particularly wanted care that would minimise the impact of their medical problem on their life.[12] Other common themes included the need to make the environment less formal, continuity of health professionals at every clinic visit, noting the difficulty of developing trust in a new environment if strangers (eg, medical students or other doctors) are present in the consultation. The young people suggested that permission to have additional people in the consultation be sought in the waiting room and/or that the additional person was only present for part of the time. Adolescents are likely to be uncertain about their body image and need encouragement to develop their own advocacy skills - ''you don't want some young lad doctor there when you're having a fat day and you've got to get down to your undies, do you?''.[12] Young people need information, and websites are a popular source, perhaps because one can seek answers to questions one dare not ask. In response to these needs, the rheumatology group in Birmingham have developed a web resource and there are other websites devoted to health issues specifically for adolescents (table 2). Cultural issues for adolescents (table 1) include alcohol and drugs, sexuality and pregnancy, areas which adult specialists may not have adequate training in or desire to address. Similar data have been obtained from a survey of young people with sickle cell disease and their providers in the USA.[13 14]

The expectations of a patient in adult settings are different and much less orientated towards the family. Young people need help learning to speak for themselves. Transfer can also be difficult for the staff at the adult centre, who often know no more than the diagnosis and some issues relating to the medical management – transfer information has been less likely to include information about the career interests and prospects of the young person, or any information about their major interests, or family support. The young person is suddenly cut off from his trusted team and this can feel like being ''dumped'' or ''abandoned'',[12] while the adult team have to build a relationship without adequate insight into the previous 16 or so years. Preparation for transfer is essential, for clinical staff, the young person and parents. Where there has been a lack of planning for the transfer, there may be failure of successful transition into adult care[3] or serious medical problems.[7 15]

Additional studies confirm that training and awareness of the major issues in adolescent medicine are insufficient. Sixty per cent of hospital respondents in a paediatric hospital had received no prior specific training in adolescent health,[16] although the recent RCPCH report considers it mandatory for both paediatricians and adult physicians who are managing young people.[1] Written resources are also poor, with only 2% of paediatric textbook pages on adolescent issues, and no coverage in six adult textbooks examined.[16] Adolescents themselves report difficulties in consultations with doctors (53% in one survey of more than 4000 people aged 15–16 years)[17] and particularly wish to see someone with an interest in teenage problems.[18]

Within haematology it has been common practice for the paediatric team to write a referral letter to the adult team with transfer taking place at a single clinic visit usually to the adult centre, with or without representatives from the paediatric

Table 3 Topics for transition guidelines in haemophilia*

Topics for transition	Headings	Age groups (years)
Social support Health and lifestyle Educational/vocational/ financial planning Sexual health Independent health care behaviours	Goals and objectives for each topic Strategies for achieving them	Birth to 4 5–8 9–12 13–15 16–18

*With permission from the National Hemophilia Foundation of the USA (NHF).[28]

team. Sometimes the young people have been on a preliminary visit to learn the new geography and to meet the adult team informally. Abrupt transfer can be precipitated by events such as leaving school, pregnancy, refusal to attend the paediatric clinic or because the paediatrician is desperate to get rid of an non-adherent oppositional young person.[2] Additional obstacles to good transition include the paediatric team giving subtle non-verbal cues about their non-trust or sense of lack of commitment of the adult team to whom the young person is being transferred, the paediatric team being unwilling to ''let go''. Transfer is a major life event for the young person with loss of the known and caring team coinciding with changes in self-perception, possibly a feeling of being nearer to complications of the disease as he/she moves into adulthood. Parents may sabotage the transition if they feel excluded from all decision making in the new setting.[2] They may be over-protective and reluctant to let the young person attend appointments alone.[19 20] Evidence from studies in diabetes,[21] cystic fibrosis[22] and juvenile arthritis[19] all show that young people generally prefer to meet the doctor from the adult centre prior to transfer, and when this occurs there are higher rates of adherence to clinic appointments in the adult sector. It is important to spend adequate time with the young person, to listen to his/her perspectives.[1]

SOLUTIONS

In recognition of these difficulties, the Department of Health launched a new best practice guideline in March 2006 – ''Transition: getting it right for young people''.[23] The principle is ''that the handover from children's to adult services should be planned and managed as a process''. In Manchester a programme of research looking at transition in various specialties is underway entitled ''From bare feet to six feet''. A seminar for patients, parents and professionals (renal and non-malignant haematological conditions) in April 2006 produced many of the same themes as have emerged elsewhere. The adult hospital is a daunting place. Families were delighted to be consulted. Involvement of the young people themselves in planning transfer is essential but rarely occurs.[24] The Manchester survey identified a very strong desire for an adolescent centre. Many participants commented on the great difference between the childish environment of the paediatric centre and the absence of any suitable facilities for young people in adult hospitals. National data on the use of hospitals over a 12 month period by young people demonstrate that an average district general hospital has enough adolescent activity to support an adolescent ward of 12–15 beds.[25] The associated editorial notes that this is not a new suggestion and that at the very least ''we need to ensure that all health care professionals… have the training they need to provide optimal care for this age group''.[26]

Good transitional care models are available (particularly in rheumatology) which can be applied in haematology. Despite increased recognition of the need for a planned process, even where templates exist there has been slow progress. Audit of 10 paediatric rheumatology centres demonstrated that 2/10 had a written policy at the start, but 3 years later none of the rest had developed a policy despite provision of a template.[27] There are also generic hospital transitional policies, but only five of 38 specialities had taken this up 2 years after development.

What are the key features of a good transition programme? Transition is an active process and not a single event. Planning must begin early (generally not later than 12 years of age), be regularly reviewed, and be age and developmentally appropriate.[23] One suggested model (but perhaps impractical in the current resource-limited NHS) is to have dedicated adolescent clinics for up to 3 years (ie, with both paediatric and adult staff) ideally occurring in the late afternoon or early evening to avoid disruption of the young person's education. The time of transfer into the adult sector can be tailored to the individual to some extent. Definitely the paediatric and adult teams should develop a ''key elements for effective transition'' shared written policy with input from both groups. A preparation period is followed by a coordinated transfer process with identified key individuals. It is easy in specialist medicine to forget the role of the general practitioner. The young person and his/her family need an individualised ''preparation period'' education programme which takes into account both psychosocial and educational/vocational needs. It is essential that the young person has opportunities to express his/her own views. The young person needs to be encouraged to be seen without parents prior to transfer, and given assurance of confidentiality in those consultations – this was identified as a very important factor.[12] In relation to this, careful consideration needs to be given about what is recorded in case notes and correspondence, particularly what it might be appropriate for parents to see if they ask for the case notes or letters. This is an area which perhaps has not been thought through in many transition arrangements.

The written plan will have goals to be reached by specific dates and is regularly revisited and documented, so that at transfer either to an adolescent service if there is one, or to the adult service, it is clear what has been achieved in terms of self-management and autonomy. For example, boys with severe haemophilia generally learn to administer their own intravenous factor, often starting at less than 10 years of age, but the acquisition of skills is very variable, and some young men are still not doing their own infusions by the age of 16–18. It is important to establish whether the young person has taken on for themselves sufficient knowledge of their condition, its inheritance and its complications. Details of the medication and side effects can be written into this document as the young person takes on his/her own knowledge. The National Foundation for Hemophilia in the USA has published a useful model for transition[28] in bleeding disorders. This details the steps in transition with goals to be achieved by various ages, recognising that ''the transition process should start at diagnosis and continue throughout life''. Each age range has goals and objectives together with the strategies for achieving them, and tick boxes to indicate the age at which these are achieved, recognising that there will be individual variation. The principles are illustrated in tables 3–5. A completed proforma of this kind would be very useful for the adult team taking on the care.

Transition will be considerably assisted by a good written description of the adult service, visits beforehand, and joint clinics on ''home ground'' where the young person can meet key members of the adult team well in advance of transfer. Ideally a key worker, probably a nurse specialist, will be identified who can develop a good relationship prior to transfer. The transition plan also needs to take into account the views

Table 4 Topics for transition guidelines in haemophilia*

Goals and objectives	Strategies for achieving them – subjects to discuss
Social support	Identify relevant sources of support; recommend haemophilia camps or other group activities
Health and lifestyle	
Healthy lifestyle, diet and problem solving	Physical fitness Conflict resolution
Adaptations for bleeding disorder	Appropriate sport/protective equipment; choices of sports Consequences of joint, muscle and major bleeds
Understanding of alcohol, tobacco and drugs	Consequences of impaired judgement
Educational/vocational/financial planning	Explore ideas for further education and college
Youth exposed to a variety of career choices, need to define aspirations and describe a realistic plan	Career choices, interests, employment opportunities Encourage youth to identify mentor
Self-advocacy and self-esteem	Ensure youth can describe condition, physical abilities and can name/describe the role of those involved in his/her health care. Discuss role of family doctor
Youth expresses medical and physical needs to others, youth understands rights and responsibilities for health care	Youth is involved in decision making. Continued discussion of information sources
Youth seeks information/services to ensure ongoing health	Questions, concerns and fears re: changes occurring
Sexual health	
Parents demonstrate understanding of child's bleeding disorder and its relation to sexuality.	Offer support to parents in starting discussions about sexual health. Discussion of puberty changes and possible impact on bleeding disorder (as applicable)
Youth seeks to answers to questions about sexual health	Sources of information
Independent health care behaviour	
Youth demonstrates by participation in treatment and decision making	Assess/reinforce youth's understanding of treatment regimen and when to seek medical advice

*An example for 13–16 year olds (third column not included but would be tick boxes for each year in the age group as in table 5). Modified from MASAC document #147[28] with permission from the NHF.

and needs of the parents or carers in order to help them ''let go''. Transition may be easier in hospitals where the paediatric and adult service are under the same roof, but the process still needs to be observed.

Probably the worst model is the joint clinic in the strange environment of the adult centre as the first transfer experience. The young person is confronted with several people from the new team at once, and he/she can feel completely overwhelmed. He/she could then discover that the adult team have divergent views on some issues of his/her management. All this can be avoided by a good transition plan. Most haemophilia centres in the UK have not yet developed transition programmes, but Bristol has a programme pioneered by the nurse specialists.[29] A booklet, ''Getting independent'' is introduced at the age of 11, and the staff run formal group education sessions for patients to attend without their parents to enable them to share learning about self-management of their condition. Social events are arranged for patients to attend, with or without their parents, to encourage them to talk freely about their condition and to promote independence. The transition booklet is owned by the patient and is used as an assessment tool to monitor progress with specific goals. Similarly, the template developed in Birmingham for rheumatology is being adapted for haemophilia care in the haemophilia centres there.

What outcomes might be measured to see if transition programmes work? Records of clinic attendance after transfer, joint function, use of prophylaxis and factor product consumption should be routinely monitored in boys with haemophilia

Table 5 Transition guidelines*

Goals and objectives	Strategies	Achieved by age			
		9	10	11	12
Youth demonstrates understanding of his/her healthcare needs by participating in treatments and decision making	Continue to discuss signs and symptoms of bleeding/pain/poor response to treatment that require medical attention Discuss home exercise programme Discuss who to call for what	☐	☐	☐	☐
Youth participates in health care management by keeping records and communicating with healthcare providers	Increase youth's involvement with record keeping/communication with HTC providers Youth starts to track home therapy supplies Discuss developmental tasks of adolescence as they relate to family (disclosure, etc) Discuss feelings on progressing to independence	☐	☐	☐	☐
Parents/youth understand the genetic component of youth's disorder	Educate parents/youth re: inheritance of bleeding disorder (genetic variables, pregnancy risks, etc) Provide written materials re: inheritance patterns, family tree Educate at risk family members re: carrier testing	☐	☐	☐	☐

*An example for 9–12 year olds from the section relating to independent health care behaviours. Modified from MASAC document #147[28] with permission from the NHF.
HTC, haemophilia treatment centre.

both before and after transfer. Comparisons can be made. Adherence to chelation therapy and measurements of iron loading can be monitored in thalassaemia, and admissions for sickle crisis monitored in the sickling disorders. Young people who have experienced transition programmes have better follow-up, and improved quality of life has been demonstrated for juvenile arthritis,[30 31] patient satisfaction is better in cystic fibrosis patients,[22 32] improved disease control has been demonstrated for diabetes, and appointments are adhered to post transfer.[21]

The need is clear, what is now required is a concerted effort to translate the recommendations into practice. The paediatric working party of the UK Haemophilia Centre Doctors' Organisation is in an ideal position to discuss and recommend a national model for transition in haemophilia and other bleeding disorders, and similar action is required for haemoglobinopathies. Then young people with the less common haematological disorders can probably use a programme adapted from one or other of these. Commissioning bodies need to consider the resource implications for development of transition policies in line with the government recommendations.

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