

CURRENT TOPIC

Transition from paediatric to adult care. Bridging the gaps or passing the buck?

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The fate of older adolescent patients in paediatric clinics is either one of transfer to adult services, long term retention in the paediatric clinic, or discharge from medical supervision, either voluntarily or by neglect. Neither simple transfer to adult doctors nor allowing adolescents to “drop out” of medical care is now acceptable quality care for young people with chronic illness. Arranging efficient and caring transfer for adolescents from paediatric to adult care is one of the great challenges facing paediatrics—and indeed the health services—in the coming century.¹

Many illnesses once considered to be confined to childhood, such as cystic fibrosis and metabolic conditions, must now be thought of as diseases that begin in childhood but continue into adult life. Paediatric and adult medicine differ greatly in their approach to issues of growth, development, patient agency, and involvement of the family—differences that may become more noticeable with the recent separation of paediatricians from the Royal College of Physicians in the UK. Adolescents sit poorly between the family centred, developmentally focused, paediatric paradigm (which frequently ignores their growing independence and increasingly adult behaviour) and the adult medical culture, which acknowledges patient autonomy, reproduction, and employment issues but neglects growth, development, and family concerns.²

The simple matter of transferring care to adult physicians has been challenged in the past decade by the notion of “transition”, emphasising the need for the change to adult care to be a guided educational and therapeutic process, rather than an administrative event.³ To achieve effective transition, it must be recognised that transition in health care is but one part of the wider transition from dependent child to independent adult and that, in moving from child centred to adult health services, young people undergo a change that is systemic and cultural, as well as clinical.²

The most useful definition of transition comes from the American Society for Adolescent Medicine, who call for: “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems.”⁴ Interest in transition has been driven by the remarkable

success of medical science in improving survival in the past 20 years,⁴ together with the rise of “adolescent medicine” as a discipline in America and Australia, where most work in this area has been carried out.³⁻⁶ Little attention has been paid to the concept in the UK and Europe, despite the clear advantages that nationalised health systems hold for transition planning. Although some paediatric services outside North America have established good links with adult centres,⁷ there is a general lack of awareness of the need for transition planning and a lack of guidelines on establishing transition services. The fifth report of the House of Commons Select Committee on Health concluded in 1997 that: “Services for adolescents should be given greater focus and priority. The transfer of young people, particularly those with special health needs, from child to adult services requires specific attention.”⁸ Although British Paediatric Association working parties have flagged up transition as an issue,⁹ it is telling that none of the medical royal colleges in the UK have developed policies on transition.

It is important to note that the change from paediatric to adult health care systems is difficult for normal young people as well as those with chronic illness. Young adults often do not register with a general practitioner,^{10 11} and frequently drop out of the system after they leave home and leave behind childhood surveillance for immunisations, growth, and development.^{4 12 13} These young people often only make contact again with the medical profession in times of emergency—crises that regular contact and health promotion might have avoided.

These dangers are greater for those with chronic illness who require regular medical supervision. The burden of chronic illness in adolescence is increasing in all developed countries as larger numbers of chronically ill children survive into their 2nd and 3rd decades.¹⁴⁻¹⁶ The prevalence of cystic fibrosis over 15 years of age in the UK more than doubled between 1977 and 1985,¹⁷ and currently over 85% of children with chronic illness survive to adult life.¹⁶ The particular dangers of the period of moving from paediatric to adult services is well illustrated by reports of disasters resulting from the treatment of grown up congenital heart patients by adult cardiologists.¹⁸ However, there is evidence (if

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largely anecdotal) that transition programmes in areas such as cystic fibrosis,⁶ diabetes,²⁰ 21 and arthritis²² improve health outcomes and patient quality of life.

For those speciality clinics without transition programmes, transfer of patients often happens in a haphazard and idiosyncratic fashion. Common precipitants for transfer are leaving school, crises such as pregnancy or a suicide attempt,³ patient refusal to attend paediatric clinics any longer, or when young people have used a period of good health to “drop out” of the clinic. Sadly, too often, non-adherence and oppositional behaviour can result in a transfer to adult services out of desperation by paediatric professionals. An abrupt transfer, particularly when precipitated by crises or an inability by paediatric services to deal with adherence problems, may well be interpreted by young people as a punishment and rejection by their previous carers.

As well as unplanned abrupt transfer, problematic transition may arise from the inability of paediatric professionals to “let go” and trust to the independence of the adolescent or the skills of the adult services. The effects on paediatric staff of the life event of the loss of a frequently life long relationship with a young person is underestimated, particularly when paediatricians have little confidence in the knowledge, skills, or flexibility of the accepting adult physician.¹³ This may be true of all members of the paediatric team, especially those who have had no contact with the target adult service. These uncertainties in the paediatric team may result in staff giving adolescents subtle non-verbal cues implying distrust of the competence or commitment of adult staff, which work unconsciously to undermine successful transition.²³ Other factors that can undermine the commitment of the paediatric caregivers to transition include the negative research consequences of a reduction in patient numbers and a loss in long term follow up.¹³ These problems may result in paediatricians continuing to see patients well into adult life, particularly those with rare congenital and metabolic disorders, in which cases the paediatricians see themselves as the best caregiver, regardless of the age of the patient. In addition, in private health care systems, the negative financial consequences of patient loss may lead paediatricians to retain patients long term.⁵

Obstacles to successful transition may also arise from adolescents themselves, their parents, and from the receiving adult services. For young people, transition can be a life event, losing respected and loved carers and being forced to trust new and unknown carers. Moving to adult services may also be seen as a step closer to disease complications and even death, particularly in cystic fibrosis and diabetes. There is often little incentive for adolescents to abandon a service that has served them very well for a long period. The self image of patients with chronic illness is often infantilised and dependent¹³ 23 (a self image frequently encouraged by paediatric services), and the transfer to adult services may represent or require a change in self perception that the

young person is ill prepared to make. The individual rather than family approach of adult physicians can be threatening to young people and their families, and young people frequently take some time to develop confidence in new services, particularly if their style of practice is different from their previous service. Adult services rarely engage with families in the same way as paediatric clinics. However, families often remain the strongest support available to young people with chronic illnesses and may sabotage effective transition if they feel excluded from all decision making in the new setting.

Adult services themselves frequently present obstacles to successful transition. Adult physicians may have little interest in “paediatric” diseases in adult life and additional patients with chronic illness may be a financial liability in health care systems such as are found in Australia³ or the USA.¹³ Busy clinics full of elderly sick patients are often alienating for young patients, and particularly in diseases such as diabetes, young people with few complications may seem to warrant little time from the adult physician who has many older patients with complications. Understandably, when presented with new patients, adult physicians can be tempted to embark upon extensive investigations and management reassessments soon after the first meeting. This can be very unsettling for the young person and their parents, particularly when previous carers and the treatment they administered is seen by the young person as responsible for their survival.²³

Structural hospital problems may be equally important deterrents to transition. Few hospitals even within the NHS have well established and reliable communication channels for transfer of medical records and imaging results. In addition, during the transition period, neither the paediatric nor adult services may feel fully responsible for patient care, resulting in miscommunications, contradictory advice, and potential conflict. If a period of limbo occurs, the young person might take the opportunity to opt out of both systems.

Obstructions to transition are many; however, the development of a clear transition programme for each clinic can overcome many of the problems inherent in moving between two different systems. An effective transition programme requires several key elements.

The key elements for an effective transition programme

A POLICY ON TIMING OF TRANSFER

There is no “right” time for transition and a flexibility of approach is most important. Timing must depend on the developmental readiness and health status of the individual adolescent, as well as the capabilities of the adult providers.⁴ However, a target transfer age is useful for both staff and young people in anticipating and preparing for transition. Some clinics use a chronological cut off (varying from 15 to 20 years in different clinics), others use social transitions such as school leaving.

I believe that as long as paediatric services make an effort to cater for adolescents,

transition should not occur until young people have largely completed the developmental tasks of adolescence; that is, a transition target such as 18 years or school leaving age is best. At an earlier age of 15 or 16 years, many patients with chronic illness will not have completed their growth or pubertal development, and adult services are unlikely to pay attention to growth and development. In addition, many young people will quickly go on to many years of further education, requiring an immediate second transfer to adult services closer to their university or college.

A PREPARATION PERIOD AND EDUCATION PROGRAMME: IDENTIFICATION OF A NECESSARY SKILL SET TO ENABLE THE YOUNG PERSON TO FUNCTION IN THE ADULT CLINIC

Transition should not occur before the young person is able to function in an adult clinic; that is, they should have the necessary skills and education to manage their illness largely independently of parents and staff—skills they are unlikely to be taught in the adult clinic. To achieve this, preparation must begin well before the anticipated transfer time—preferably in early adolescence, when a series of educational interventions should discuss the understanding of the disease, the treatment rationale, the source of symptoms, recognising deterioration and taking appropriate action, and most importantly, how to seek help from health professionals and how to operate within the medical system.²⁴ As part of this programme, young people should be helped to take responsibility for medications from as early an age as possible, and should be seen by themselves in clinic visits from age 13 years (with parents invited to joint the session later). A schedule of likely timings and events should be given to young people in early adolescence, and young people should be involved in developing detailed timings for their own transition.²⁵ Leaflets and material about the transition programme and details of the adult service should be provided in clinic settings from early adolescence. In addition, young people should be given information on their health care rights and effective ways of dealing with medical staff situations including casualty, waiting rooms, etc.

A COORDINATED TRANSFER PROCESS

About a year before the anticipated transfer date, adolescents should receive a detailed outline of the adult programme, and should undertake at least one visit to the adult clinic, preferably with parents and a trusted paediatric carer. A personal introduction to the adult environment and staff should be arranged, and at least one return visit made to the paediatric clinic to discuss any concerns before transfer. A joint paediatric–adult clinic is very useful to introduce adolescents to adult physicians and to hand over clinical issues; however, a single joint clinic must not replace a coordinated transition programme.²⁶ Rather than a single joint clinic, the initial transfer of young people to formal “young adult clinics” staffed by both paediatric and adult physicians may be the best

method, particularly in diseases such as diabetes, where the average age of the adult population might be very high.

A coordinated process requires a coordinator, and busy paediatricians may rarely have time to undertake this role. Clinical nurse specialists, if available, are best suited to run transition programmes in speciality clinics. In larger children’s services, such as at Great Ormond Street Hospital, an adolescent medicine clinical nurse specialist can fulfil this role.

AN INTERESTED AND CAPABLE ADULT SERVICE

A transition programme can only be successful if organised with the active participation and interest of the adult staff (who may be the clinical nurse specialists if the doctors remain lukewarm). It is my experience that because large adult clinics rarely provide the family support and rapid staff response characteristic of paediatric services, which are usually smaller, young people and their families frequently see adult hospitals as “B grade”. Clearly, unless the care in the adult setting is equivalent in quality and intensity to that of the paediatric clinic, it will be unacceptable to patients, who may refuse to transfer.²⁷

Those seeking to set up a transition programme must explore the economic and research consequences of the loss of patients from paediatric follow up and the addition of the burden of patients to the adult service. The development of close and frequent clinical and academic links between the services can ensure that the collaboration is beneficial to both services and that patients are not lost to research follow up.

ADMINISTRATIVE SUPPORT

Institutional and management support must be assured at both ends of the transfer chain. Casual agreements between doctors, although they are the most easy to set up, are prone to failure.¹³ Resources such as administrative and secretarial support must be available to ensure the efficient organisation of appointments and the transfer of medical records. A formalised transfer checklist should be developed, necessitating the preparation of detailed medical and multidisciplinary summaries before transfer.⁵

PRIMARY CARE INVOLVEMENT

Transition planning must involve primary care physicians, who might provide the only medical continuity for young people and their families during this time of discontinuity. It is a sad fact that many young people with chronic illness have little involvement with their general practitioner.^{12 28}

Models for transition programmes

A number of different models for transition programmes have been suggested, including disease based programmes and other more generic programmes, where transition is coordinated by generalists such as adolescent physicians or general practitioners.³ Despite 10 years of interest in this area in the USA and Australia, little information is available on the

Table 1 Recommendations for best practice

- Transition preparation must be seen as an essential component of high quality health care in adolescence
- Every paediatric general and specialty clinic should have a specific transition policy. More formal transition programmes are necessary where large numbers of young people are being transferred to adult care
- Young people should not be transferred to adult services until they have the necessary skills to function in an adult service and have finished growth and puberty
- An identified person within the paediatric and adult teams must be responsible for transition arrangements. The most suitable persons are nurse specialists
- Management links must be developed between the two hospitals.¹³ Within the new NHS, contracting and financing issues must be worked out in detail. Local commissioners must be consulted when patients are transferred from one tertiary centre to another
- Large children's services should develop a "transition map" detailing where and how transfer occurs specialty by specialty
- Evaluation of transition arrangements must be undertaken

value of different programmes and their suitability for different patient and disease groups.⁴

DISEASE BASED PROGRAMMES

The greatest experience with transition comes from specific disease programmes, which have been developed where strong adult services have existed, most notably in diabetes²⁶ and renal disease.²⁹⁻³⁰ More recently, the increasing survival of childhood chronic illnesses has led to the growth of adult services in cystic fibrosis⁶ and congenital heart disease,¹⁸ and the consequent development of new transition programmes. Similar programmes are now being set up to monitor the long term effects of cancer treatment. Transition programmes are poorest where no specific adult services exist, for example in metabolic diseases.

Almost all existing programmes are disease based and offer advantages in being able to tailor transition to the particular needs of specialty patients and clinics. For example, the transfer of adolescents to general diabetes clinics is undesirable because of the large numbers of obese, elderly, sick patients populating these clinics. In this situation, transfer of adolescents to young adult clinics is an ideal preliminary to the full adult clinic.²⁶ In contrast, adult cystic fibrosis clinics consist largely of younger adults and intermediary clinics are not useful.

Differing programmes might be necessary for different groups of patients within specialty clinics. Transition programmes for asthma will differ from those for cystic fibrosis within the same paediatric respiratory service, and in renal medicine, those young people requiring chronic dialysis present very different transition problems to those who simply require the adult follow up of childhood kidney problems, such as vesicoureteric reflux.²⁹

GENERIC TRANSITION PROGRAMMES

It has been suggested that adolescent medicine services could develop generic transition programmes offering transition resources to other specialties, with adolescent medicine doctors and nurses coordinating transfer arrangements and ensuring that young people have the necessary skills to function in the adult environment.³⁻³¹ Stand alone transition services are unnecessary where good disease based services have been developed and are highly unlikely to be economically practical. However, work at Great Ormond Street Hospital has shown that the support of an adolescent medi-

cine service can be useful in developing good transition practices in specialty clinics.¹

Suggestions that general practitioners might coordinate transition programmes are also unfeasible. Although data from the USA showing that up to 40% of young people attending specialist clinics for chronic illness have no regular general practitioner¹² are unlikely to reflect the UK situation, British general practitioners presently lack both the resources and training to undertake such a role.

Conclusions

Transfer to adult care is a major life event for young people with chronic illness, and the appropriate management of this transition is an essential part of best practice in any paediatric clinic. Ages and modes of transfer will differ according to locality and history; however, transition in mid-adolescence should be avoided. Services for adolescents should be developed in all paediatric services, and paediatricians should be prepared to care for young people up to school leaving age if appropriate. Transition programmes are necessary even when paediatric and adult services are in the same hospital because geographical proximity frequently does not translate into a close professional relationship.

Table 1 gives recommendations for best practice. However, it must be noted that these guidelines are based largely upon anecdote and experience, and that the literature largely reflects the American and Australian experience, where private medicine is common and subspecialism more widespread among paediatricians. Further developments in transition await comparative studies that evaluate transition models and health and economic outcomes.

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