

Barriers and good practice in transition from paediatric to adult care

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INTRODUCTION

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 century¹. Many once ‘paediatric’ diseases, such as cystic fibrosis and metabolic conditions, are now increasingly being met by adult doctors, sometimes with poor results². These conditions must now be thought of as diseases that begin in childhood but continue into adult life.

Some ask what the fuss is all about? Transferring patients has been around as long as we have had paediatricians. But the simple transfer has been challenged in the last decade by the notion of ‘transition’, emphasizing the need for the change to adult care to be a guided educational and therapeutic process rather than an administrative event³. Indeed, this health transition is but one part of the wider transition from dependent child to independent adult. The American Society for Adolescent Medicine define good transition 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’⁴.

Despite the well-developed services in some parts of America and Australia, little attention has been paid to the concept of transition in Britain. The House of Commons Select Committee on Health Fifth Report 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’⁵. It is telling that none of the medical Royal Colleges in Britain have developed policies on transition.

Interest in transition has been driven by the increased survival of children with chronic illness into adolescence and adult life. The burden of chronic illness in adolescence is increasing in all developed countries as large numbers of chronically ill children survive into the second and third decades^{6–8}. The prevalence of cystic fibrosis in those over 15 years of age in the UK more than doubled between 1977 and 1985⁹, and currently over 85% of children with chronic illness survive to adult life⁸.

Transfer of patients between paediatric and adult clinics often happens in a haphazard and idiosyncratic fashion. Common reasons to transfer include leaving school, getting too big for the clinic chairs, even pregnancy or a suicide attempt³. Sadly, too often non-adherence or difficult behaviour can result in a transfer to adult services out of desperation. An abrupt transfer, particularly when precipitated by crises or an inability of the paediatric services to deal with adherence problems, may well be interpreted by young people as a punishment and rejection by their previous carers.

The greatest barrier to effective transition arises from the inability of paediatric professionals to ‘let go’ and trust to the independence of the adolescent or the skills of the adult services. We must recognize that the loss of a favourite patient can be a ‘life event’ for paediatric staff. When paediatricians have little confidence in the knowledge, skills or flexibility of the accepting adult physician, it becomes even more difficult to let patients go¹⁰. Other factors that can undermine transition from the paediatric perspective are the loss of long-term patient follow-up and the reduction in clinic critical mass¹⁰. These problems may result in paediatricians continuing to see patients well into adult life, particularly with rare congenital and metabolic disorders, in which paediatricians see themselves as the best caregivers regardless of the age of the patient.

Obstacles to successful transition may also arise from adolescents themselves, their parents, and from the receiving adult services. For young people also, transition can be a life event, as they lose respected and loved carers and are forced to trust new and unknown ones. Moving to adult services may also be seen as a step closer to disease complications and even death, particularly with 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. 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, and parents may sabotage 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

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interest in 'paediatric' diseases in adult life, and frantic clinics full of elderly sick patients are often alienating for young patients. Particularly in diseases such as diabetes, young people with few complications may get short shrift from adult physicians, who may focus their time on older patients with complications. The new adult service may also embark on a complete reassessment at the first meeting, which can be very unsettling for the young person, particularly when previous carers and their treatment were seen by the patient as having been responsible for their survival¹¹.

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 the following key elements¹²:

A policy on timing of transfer

There is no 'right' time for transition and a flexible 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 providers⁴. 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), whereas others use social transitions such as school-leaving.

I believe that, provided that paediatric services make an effort to cater for adolescents, transition should not occur until young people have largely completed the developmental tasks of adolescence—i.e. a transition target such as 18 years, or school-leaving age, is best. Earlier, at 15 or 16 years, many with chronic illness will not have completed their growth or pubertal development, and adult services are unlikely to pay attention to growth and development. Additionally, 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, i.e. until they have the necessary skills and education to manage their illness largely independent 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 their understanding of disease,

the rationale of therapy, the source of symptoms, recognizing deterioration and taking appropriate responses and, most importantly, how to seek help from health professionals and how to operate within the medical system¹³. 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 the age of 13 (with parents invited to join the session later). A schedule of likely timings and events should be given to young people in early adolescence, and they should be involved in developing detailed timings for their own transition. Leaflets and material about the transition programme and details of the adult service should be provided in clinic settings from early adolescence. Additionally, young people should be given information on their healthcare 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. Rather, the initial transfer of young people to a formal 'young adult clinic', 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 may 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 specialty 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 organized with the active participation and interest of the adult staff (which may be the clinical nurse specialists if the doctors remain lukewarm). It is my experience that as large adult clinics rarely provide the family support and rapid staff response characteristic of usually smaller paediatric services, 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 clinics, it will be unacceptable to patients, who may refuse to transfer¹⁵.

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 a 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 easy to set up, are prone to failure¹⁰. Resources such as administrative and secretarial support must be available to ensure the efficient organization of appointments and the transfer of medical records. A formalized transfer checklist should be developed, necessitating the preparation of detailed medical and multi-disciplinary summaries prior to transfer¹⁶.

Primary care involvement

Transition planning must involve primary care physicians, who may provide the only medical continuity for young people and their families during this time of discontinuities. It is a sad fact that many young people with chronic illness have little involvement with their general practitioner^{17,18}.

CONCLUSIONS

The appropriate management of transition is an essential part of best practice in any paediatric clinic. How and when transition occurs will differ between specialties and hospitals, but the essential features (policy, preparation, education, evaluation) remain the same. 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, as geographical closeness often does not translate into a close professional relationship.

Unfortunately, very little evaluation of transfer and transition programmes has yet been published. Studies of patient satisfaction after transition programmes in areas such as cystic fibrosis^{19,20}, diabetes^{21,22} and arthritis²³ show that such programmes improve health outcomes and patient quality of life. However, no formal evaluation of the

effectiveness of different models of transition has been undertaken and is undoubtedly needed.

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