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Bridging the gaps: transition for young people with cancer

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Gaps are an inevitable outcome of the organisation of patient care around age bands, specialities and diseases. One such gap, that between child and adolescent health services and adult medical care, is particularly problematic for those whose medical problems begin in childhood and continue into adult life [1]. These 'transition' issues are beginning to be addressed in classic chronic illnesses, such as asthma [2] and diabetes [3]. They have additionally been given particular emphasis by the survival into adult life of cohorts with conditions once considered confined to childhood, such as cystic fibrosis, congenital heart disease [4] and metabolic conditions. The appropriate management of transition is now recognised as part of high quality care of adolescents with chronic conditions [4].

Cancer in the modern era, where more than 70% of children and adolescents will survive their primary disease [5], while not a chronic *illness*, has many management issues in common with chronic *conditions*. During the so-called 'maintenance' stages of treatment for some cancers, the scenario of a well adolescent taking regular medication and attending regular check-ups to prevent recrudescence of disease is little different to that of any chronic illness clinic. After the end of treatment, as with any chronic condition or disability, potentially life-long medical supervision may be required to deal with the multiple physical and psychosocial 'late effects' of both the original disease and the treatment [6]. The need for long-term follow-up must depend on the type of cancer and treatment, as does the frequency and organisation of follow-up [7,8]. While we must be careful not to 'over-medicalise' well survivors, attention to transition is important to prevent gaps in healthcare, either at the end of treatment or during long-term follow-up.

In any speciality, the fate of elderly adolescent patients in paediatric clinics is either one of transfer to adult services, retention long-term in a paediatric clinic, or discharge from medical supervision altogether, either voluntarily or by neglect. The development of long-term follow-up for cancer patients is still in its early stages, with no settled models. Services may be based around transfer to generic adult cancer services, transfer to dedicated adult follow-up clinics, retention in specialist paediatric clinics, follow-up to primary care or planned discharge [8,9]. In those models of long-term follow-up requiring change to new services, mere transfer to adult services is no longer adequate. Comprehensive transition planning must take its place. The simple matter of transferring care to adult physicians has been challenged in the last 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 merely an administrative event [2]. It must be recognised that transition in healthcare 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 [10]. 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 healthcare systems' [11].

1. The dangers of poor transition

Poor transition results in either gaps in medical supervision, transfer to a new service which is underprepared and ill-informed, or stress and lack of trust in the transferred young person. The change from paediatric/adolescent to adult healthcare systems is difficult for normal young people as well as those with cancer. Young healthy adults often do not register with a GP [12,13] and frequently drop out of the medical system after they leave home and leave behind routine childhood surveillance [11,14,15]. These young people often

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only make contact again with the medical profession in times of emergencies—crises that regular contact and health promotion might have avoided. These dangers are obviously greater for cancer survivors, where a period of lack of supervision may delay recognition of disease recurrence, detection of secondary tumours and treatment for late-effects. In the late adolescent/young adult period, psychosocial, sexual and fertility issues that the subject does not recognise as related to their cancer may be particularly neglected.

Transfer to a new service where either the service or the transferring young person are under-prepared can also be highly problematic. Simple transfer letters may not provide sufficient information for optimum ongoing treatment and the new service may respond to this lack of information by embarking on a distressing and unnecessary series of new investigations. On the other hand, an unprepared young person may not have the necessary skills to protect their best interests in the busy world of adult medicine.

2. Barriers to effective transition

Barriers to effective transition may arise from the transferring child/adolescent service, from the receiving adult service, from young people and their families and from structural or management problems within the health service. Paediatric cancer services may see themselves as the best caregivers long-term for survivors of childhood/adolescent cancer, regardless of the age of the patient, citing their special knowledge of the diseases and treatments involved as a rationale for not transferring to adult services. While there may be much truth in this (see section on models below), there may also be an inability to 'let go' and trust to the independence of the adolescent/young adult or the skills of the adult services. Paediatric staff may find it very difficult to lose the long-term relationship they have developed with a survivor, particularly when they have little confidence in the knowledge, skills or flexibility of the accepting adult service [15]. 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 young people subtle non-verbal cues, implying distrust of the competence or commitment of adult staff, which work unconsciously to undermine a successful transition [16]. Other factors that can undermine the commitment of the paediatric caregivers to transition include the negative research consequences if patients are lost to long-term follow-up [15], which may be particularly important in rare paediatric cancers.

For the young people themselves, transition can be a life event, losing respected and loved carers and being forced to trust new and unknown carers. There may be little incentive for adolescents to abandon a service that has served them very well for a long period and they may not understand the necessity of moving on. The more 'individual' approach of adult staff can also be threatening to young people and their families, who may be more used to the family-centred model of child health services. Indeed, families may sabotage effective transition if they feel excluded from all decision-making in the new setting. The sense of transition as a process rather than a simple transfer is important as young people may take some time to develop confidence in new services, particularly if the style of practice in the new setting is notably different to their previous carers.

If transfer is to be to adult cancer services, the existence, quality, capability and geographical location of adult services affect the quality of transition. Adult cancer doctors may have little interest in 'paediatric' diseases and their consequences in adult life and additional patients may be a financial liability in over-stretched public clinics. Busy general cancer clinics, full of elderly sick patients, are alienating for young patients, and young survivors with few complications may seem to warrant little time compared with sick older patients. If the information that accompanies the transferring patient is deficient, adult physicians may embark upon extensive and possibly unncessary investigations and reassessments at the first meeting. This can be very unsettling for the young person and their parents, particularly when previous carers and their treatment was seen by the young person as having been responsible for their survival [16].

Structural health service issues may be equally important deterrents to transition. Communication channels may not be entirely reliable for transfer of medical records and imaging results. Additionally, during the transition period, neither the paediatric nor adult services may feel fully responsible for patient care, resulting in miscommunication, contradictory advice and potential conflict. If, as a consequence, there is a period of limbo, the young person may take the opportunity to opt out of both systems.

3. Good transition practice

To provide quality transition and overcome these obstacles, each paediatric/adolescent cancer centre should have a transition programme with clear policies for different diseases or circumstances.

3.1. 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 [11]. Time since end of treatment is clearly also an issue. 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), whilst others use social transitions, such as school-leaving.

I believe that, provided 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, say at 15 or 16 years, many will not have completed their growth or pubertal development, which may be delayed following treatment [17]. Adult services are unlikely to pay sufficient attention to growth and development. Additionally, many young people will quickly go on to many years of further education, often away from home, requiring an immediate second transfer to adult services closer to their university or college.

3.2. 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. before they have the necessary skills and education to function 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 mid-adolescence when discussions with the young person themselves should re-address their understanding of their disease, the type of treatment they had and possible side-effects, and, most importantly, how to seek help from health professionals and how to operate within the medical system [18]. As part of this programme, young people should be seen by themselves in clinic visits from the age of 13 years, with parents invited to join the session later. A schedule of likely timings and events should be discussed with young people in early adolescence, and they should be involved in developing detailed timings for their own transition. Leaflets and material about 'moving on' and details of the adult service should also 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 situations including casualty, waiting rooms, etc.

3.3. A co-ordinated transfer process

The way transfer is organised depends on the 'model of care' in use locally. If transfer is to be to a distant clinic, adolescents should receive a detailed outline of the adult programme around a year before the anticipated transfer date, 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 a return visit to the paediatric clinic organised to discuss any concerns before formal transfer. Importantly, a co-ordinated process requires a co-ordinator. This role can be undertaken by any member of the multidisciplinary team. In speciality clinics, however, clinical nurse specialists may be best suited to run transition programmes.

3.4. An interested and capable adult service

A transition programme can only be successful if organised with the *active* participation and interest of the receiving adult service. 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.

3.5. Administrative support

Institutional and management support must be assured at both ends of the transfer chain. Casual agreements between doctors, while easy to set up, are prone to failure [15]. Resources such as administrative and secretarial support must be available to ensure the efficient organisations of appointments and the transfer of medical records. A formalised transfer checklist should be developed, and detailed medical and multidisciplinary summaries prepared prior to transfer [19].

3.6. Primary care involvement

Transition planning must involve primary care physicians, who may provide the only medical continuity for young people and their families during times of 'discontinuities' such as these.

4. Potential transition models

Most of the work on models of transition has been undertaken with chronic illnesses in mind and is not necessarily applicable to cancer [6]. There are many possible models for quality transition in cancer. The model chosen in each locality will depend on the resources available and the quality, interest and geographical location of both paediatric/adolescent and adult services.

The 'gold-standard model' for long-term follow-up is a 'seamless' clinic which begins in childhood or adolescence and continues into adulthood, with both paediatric and adult professionals providing ongoing life-long care as appropriate. This joint approach allows patients to benefit both from experts in paediatric diseases and the appropriate management of fertility, cardiovascular health and other 'adult' problems. This service is undoubtedly best provided within the adult setting, with a reduced 'transition programme' as these young people will continue to be looked after in part by their paediatric professionals long-term.

Alternatively, dedicated long-term follow-up services may be set up within the adult setting, but without input or continuity from paediatric services. In this situation, more detailed attention to transition planning is required. Young people from a paediatric/adolescent service may be transferred to a number of such services, with consequent resource implications for those coordinating transition from the paediatric end. Where care for adolescents has begun in an adolescent service staffed by adult oncologists or haematologists, life-time follow-up may be possible within that service. However, this follow-up is best organised as a formal Late-effects clinic in order to ensure that relevant issues are addressed and that long-term follow-up is not swamped by the demands of the average, busy, acute, general cancer clinics.

Alternative models which place life-long follow-up within the paediatric setting, while ensuring continuity of care, run the risk of a lack of access to knowledge of fertility issues and diseases of aging. Additionally, such clinics may not provide sufficient vocational and financial/benefits advice.

Perhaps the least preferable model, but one that is seen all too commonly, is transfer of young people to their local general adult cancer service with no dedicated Late-effects service. Despite goodwill on all sides, long-term follow-up may be a very low priority in this situation, and expertise on the late effects of childhood cancer may be lacking.

5. Conclusions

Transfer to adult care is a major life event for young people who survive cancer in childhood or adolescence, and the appropriate management of this transition is an essential part of best practice in any paediatric cancer centre. All paediatric cancer centres should have formal policies and programmes for transition to long-term follow-up and adult care.

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