Transition: the cancer perspective

There is an ever-increasing number of cancer survivors entering adult life. Health-care professionals in this field must ensure that there is seamless transition through paediatric, teenage and young adult and adult services such that an individual patient is able to achieve his/her maximum potential and enjoy a quality, 'cancer-free' future.

Over the last four decades, the incidence of cancer in children and young people has steadily increased (Steliarova-Foucher et al, 2004). Over the same period, improvements in cancer therapy have resulted in a dramatic increase in overall survival, such that around 75% of all patients are now long-term survivors (Campbell et al, 2003; Steliarova-Foucher et al, 2004). At present, around 1 in 715 of the UK young adult population were treated for a malignancy as a child (Campbell et al, 2003; Kroll et al, 2004). Thus, the long-term medical and psychosocial consequences of cancer therapy in children and young people are becoming increasingly apparent (Skinner et al, 2007) and demand a shift from the historical goal of cure alone to that of cure with the highest quality physical and personal life attainable.

The transition from a dependent child and adolescent into an autonomous adult is complex for any individual, requiring achievement of a number of well-defined goals (*Table 1*) (Freyer and Kibrick-Lazear, 2006). There are many ways in which cancer and its treatment can impact or interrupt this process (*Table 1*), tending to make it more difficult or delayed (Blum et al, 1993; Rosen, 1993). It is essential that the health-care professionals caring for young people are sensitive to these issues and can expertly respond to the evolving developmental maturity of individual patients.

In the UK, cancer care is delivered in paediatric, teenage and young adult and adult services. Children under the age of 16 years are treated within a network of 22 children's cancer and leukaemia group affiliated paediatric oncology centres. Adult service provision is organized into cancer networks, each with a central cancer centre which provides specialized services, e.g. radiotherapy and haemopoietic stem cell transplantation. The first teenage cancer unit was established at the Middlesex Hospital in 1990. There are now eight other units around the UK and several others in development. The specialist units have been developed on a local service need configuration rather than a pre-defined, nationally accepted model of best practice.

Age boundaries for service entry and exit vary between services, directly influencing the professional background of those primarily responsible for delivering care. Teenage

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Table 1. Goals of adolescence, challenges presented by cancer and its treatment and the benefits of transition into age-appropriate services

Goals of adolescence	Challenges presented by cancer and its therapy	Ways in which transition to age-appropriate environment may address these challenges
Gradual separation from parents	Emotional and practical dependency on parents during treatment Awareness of mortality	Graduated information according to maturity, promoting bi-directional communication, decision-making skills and gradual independence
Establishment of financial and emotional independence	Interference of treatment with schooling or employment Financial impact of lost work hours and hospital attendances on patient and family	School on site/liaison with schools or university Peer support
Development of self-confidence, individuality, sexual identity	Physical disability caused by disease or treatment Altered physical appearance (weight gain, hair loss, poor growth) Treatment-induced infertility Separation from peers Isolation from normal social activities	Peer support Patient groups Age-appropriate health education including literature and posters Activity coordinators promoting normal socialization Age-appropriate facilities
Formation of mature relationships and concern for the welfare of others	Awareness of own mortality and impact on friends and family Separation from friends and family	Peer support Specialized psychosocial input Ambulatory care Facilities for friends or family to stay with or close to hospital during inpatient treatment
Acquisition of a future-orientated outlook	Fear of relapse and death Interrupted education and employment	Transition into adult services with an emphasis on personal responsibility and choice

From Freyer and Kibrick-Lazear (2006)

and young adult units caring for 16–24-year-olds are now being developed nationally, with plans for up to 22 units. In 2005 the National Institute for Health and Clinical Excellence recommendations for the delivery of cancer care for children and young people up to the age of 24 years specified that all children and young people under the age of 19 years will be treated in age-appropriate facilities at a children's or young people's principal treatment centre. Young adults, aged 20–24 years, must be given the option to have care at the teenage and young adult principal treatment centre or within an adult service with access to the principal treatment centre multidisciplinary team.

This presents an exciting opportunity for all children and young people to receive their cancer treatment in an age-appropriate environment, delivered by health professionals who have expertise in their specific cancer but who are also sensitive to the holistic needs of each patient according to his/her individual stage of developmental maturity. Effective and timely transition between such services is vital if the full benefits of this strategy are to be realized, particularly as young patients may have to move between health-care providers more than once.

Importance of transition

Initial follow up of young people who have had cancer is essential in order to monitor for relapse but as the risk of recurrence diminishes over time, the emphasis of surveillance is towards detection, monitoring and pre-emptive treatment of late effects of therapy, some of which may arise decades later (Freyer and Kibrick-Lazear, 2006).

Transition to teenage and young adult and then adult services are valuable steps in enabling an individual to develop through adolescence into a well-adjusted, autonomous adult (Rosen, 1993) (*Table 1*). Age-appropriate facilities provide environments more akin to teenage and young adult lifestyles, reducing the sense of being different to their peers. Information, given according to the individual's evolving maturity, allows the patient to increasingly make informed decisions, promoting independence, responsibility and an ability to separate from his/her parents. Risk-taking behaviour and unhealthy life choices can be addressed more easily using posters, literature and patient groups than would be possible in a paediatric environment (Oeffinger et al, 2004; Freyer and Brugieres, 2008). Support for educational and financial issues can be provided by professionals experienced in dealing with the specific problems faced by young people. Very (possibly most) importantly, co-location of these patients provides an opportunity for peer support which can dramatically reduce the sense of isolation and of 'being different' felt by many. Finally, the transition to adult services can signal to the patient that his/her team expects him/her to survive and that it is appropriate for that patient to own a sense of the future (Blum et al, 1993; Rosen, 1993).

Table 2. Potential barriers to transition

	Barriers
Patient	Lack of knowledge of initial diagnosis and the potential for long-term effects of treatment
	Lack of understanding of need for follow up
	Lack of personal responsibility
	Trust in paediatric service
	Fear and distrust of adult services
	Adult clinics and wards busy with many elderly patients
	Desire to move on and not to think about the past
Family	Fear of loss of control
	Trust in paediatric service
	Perception that adult services are inferior
Paediatricians	Emotional bonds with patient – difficulty in 'letting go'
	Desire to study the long-term effects of paediatric cancer therapy
	Perception that adult services are inferior
Adult physicians	Uncomfortable with psychosocial needs of patient and their family
	Unfamiliarity with rare paediatric cancers and treatment protocols
Organizational	Lack of agreed patient pathways
	Lack of agreed evidence-based policy regarding late effect surveillance
	Service configuration with paediatric and adult services often in different geographical locations
	Lack of consistency of age boundaries for exit and entry to different services

Resistance to transition

Resistance to transition may come from the patient, his/her family, clinicians or health-care organizations (*Table 2*) and has been well described (Schidlow and Fiel, 1990; Mertens et al, 2004; Freyer and Kibrick-Lazear, 2006).

The prospect of moving from the familiar, nuturing environment of a paediatric service into the unknown territory of adult medicine can be an understandable source of anxiety for patients and families. Compounding this are the emotional bonds which often exist between them and their health professional team, making it difficult for all concerned to 'let go'. Some young people, particularly if they were uninvolved in their diagnosis and treatment discussions because of their young age at presentation, have very limited knowledge about their cancer or long-term consequences of therapy (Kadan-Lottick et al, 2002). As a result, they have little appreciation of the importance of ongoing follow up and the need for transition. It is not uncommon for young people to want to 'move on' and live life as if they had never had cancer. Regular visits to hospital serve as an unwelcome reminder of the past and may lead to avoidance behaviour and non-attendance (Hobbie et al, 2000). Parents may fear loss of control with a shift from the parent-directed medical discussions and consent of paediatrics to the patient-focussed approach of the adult world.

Barriers to effective transition may also exist within health-care structures. Paediatricians may have emotional ties with the patient and his/her family, may be the expert in their patient's rare paediatric cancer and may perceive adult teams as being less able to cater for their patient group. These beliefs may be unwittingly revealed in non-verbal or even verbal cues, further exacerbating patient and parent anxiety. Transition to other services has the potential to impair or prevent clinical study of the long-term outcome in specific diseases or treatments. The receiving adult physician may be ambivalent about transition, possibly as a result of lack of familiarity with certain paediatric cancers or protocols or lack of confidence in addressing the psychosocial needs of young people. There is also often considerable organizational inertia in respect to transition, with lack of agreed patient pathways, paediatric and adult services existing in different geographical locations, different units having different age restraints and a lack of regular contact between paediatricians and adult physicians.

Effective transition

Transition between paediatric, teenage and young adult and adult cancer services in the UK is, for most networks, in its infancy. Too often it is presented as a choice, approached with ambivalence by patients, parents, health-care professionals and organizations. It is interesting to consider the analogy of education. From the day a child starts school, both child and parents know that transition to senior school will happen at 11 years of age. After GCSEs, the young person may leave school, stay on to take A levels or go to college. A further transition may occur at 18 years of age, either into employment or to university.

Many children and their parents are anxious at the time of leaving the perceived safety and familiarity of primary school to move to the great unknown of senior school. However, it is accepted that should the child remain in primary school, he or she would be disadvantaged developmentally, educationally and psychologically. Moving to senior school is seen as a new opportunity and a natural progression with subsequent transitions signalling ongoing maturity and achievement. The steps are generally fully endorsed by teachers, tutors and parents. Winnie the Pooh murals and soft toys are gradually replaced by information about smoking, bullying, sex, drugs and careers. Children are gradually expected to take on more personal responsibility, are given information appropriate for their age and are gradually prepared and empowered for their next step towards adulthood. This analogy raises some important issues which are useful to consider as we strive to develop effective health-care transition.

Table 3 summarizes the key elements of effective transition for children and young people with cancer.

Table 3. Key elements of effective transition
Agreed, formalized patient pathways
Transition expected
Patient and family gradually prepared for transition
Verbally and non-verbally supported by staff currently caring for the patient
Tailored for the individual and at an appropriate time in his/her care
Accompanied by formal transition plan and good communication between health-care teams
Support available for patient and family including key workers and the multidisciplinary team

Agreed, formalized patient pathways

Formalized patient pathways according to a patient's disease and age, which are agreed by physicians, institutions, networks and commissioners, provide the cornerstone for effective transition. A number of models have been used in the UK and internationally including:

1. Long-term follow up provided by the paediatrician treating the patient from diagnosis and/or in the same facility
2. Discharge to the GP
3. Transfer from site-specific paediatrician to site-specific adult physician
4. Transfer into an adult late effects programme (Freyer and Kibrick-Lazear, 2006; Ginsberg et al, 2006; Freyer and Brugieres, 2008).

There are relative merits and limitations of these different models and it is unlikely that any single model would be optimal for all situations. Individual networks and institutions need to develop pathways which consider: local service configuration and resource; patient factors including the duration of time since completion of treatment (and thus risk of relapse), presence of chronic complications of disease or treatment and risk of late effects of therapy; and the importance of delivery of care in an age-appropriate environment and manner. Irrespective of the model chosen, an established policy agreed by all of those involved allows transparency, allocation of resource and a timeline by which the patient and his/her family can prepare for change.

Transition expected, as a planned event for which the patient and family are prepared

Transition is facilitated if it is presented as an expected, desirable event rather than an unanticipated choice. The earlier the transition pathway is introduced, the longer the patient and the family have to become accustomed to the concept. Preparation for the change should be gradual, as in education, such that the young person feels ready to move on when the time comes.

Verbally and non-verbally supported by staff currently caring for the patient

It is crucial that the health-care professionals caring for the patient endorse both the need for transition and also the team to which the patient will be transferred. A greater understanding of care provided by the future team and collaboration between referring and receiving clinicians will increase the credibility of this endorsement. Teenage and young adult and adult service providers have a reciprocal obligation to ensure that the health care offered to young people is equivalent in quality to that provided in paediatric centres (Rosen, 1993).

Tailored for the individual and at an appropriate time in his/her care

Any policy must be flexible and able to accommodate the specific needs of an individual patient with transition ideally taking place at a stable time in the disease course (i.e. not at diagnosis or in the middle of complex treatment). In this way a patient who is developmentally and emotionally mature for his/her age could benefit from early transition. Equally, a patient who is in the middle of intensive chemotherapy when the agreed age for transition is reached would usually be best served by transition being delayed.

Accompanied by formal transition plan and good communication between teams

A formal transition plan is an essential component of the process (Rosen, 1993; Rosen et al, 2003). This should include summaries of the cancer diagnosis, including important prognostic information, the treatment given and any early complications, the awareness of the patient and the family about the diagnosis, prognosis and likelihood of late effects, any significant family, social, educational or financial issues and clear identification of the individual responsible for and coordinating ongoing follow up. Good bi-directional communication and collaboration between teams at the time of transition is essential.

Support for patient and family including key workers and the multidisciplinary team

However well prepared a patient and his/her family are for transition, the process will usually be a time of vulnerability. Support should be readily available from the multidisciplinary teams of both referring and receiving services (Harvey et al, 1999; Hinkle et al, 2004). Many anxieties may be alleviated by a member or members of the new team meeting the patient and the family before the transfer of care in the environment they have become used to. This role is generally best fulfilled by the future ‘key-worker’ such as a clinical nurse specialist (Viner, 1999).

Conclusions

Advances in the treatment of childhood and adolescent cancer have resulted in an increasing number of young people entering adulthood. The challenge to health-care providers now extends from cure alone to also providing the environment in which patients can navigate their way through adolescence to enjoy an empowered and future-orientated adult life. Effective transition through paediatric, teenage and young adult and adult services are crucial if this aspiration is to be realized. **BJHM**

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KEY POINTS

- Increasing cancer incidence and more effective treatment of children and young people is resulting in a growing proportion of survivors of cancer in the general population.
- Many children and young people treated for cancer will experience a move between providers of care, especially shifting from childrens’ to adult services. These transitions are frequently episodes of tension and destabilization.
- Developing effective transition pathways which are understood by patients and families from the time of diagnosis is a priority for cancer service improvement. Successful transition requires coordination between professionals coupled with effective communication and support for patients and families.
- Further research is required to define models of care in adult services which are appropriate for individual patients’ needs.