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Where should teenagers with cancer be treated?

J. Whelan*

The Middlesex Hospital, UCL Hospitals NHS Trust, Mortimer Street, London W1T 3AA, UK

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Abstract

Cancer in teenagers is relatively uncommon. Few health professionals in oncology are familiar with caring for teenagers, although most would acknowledge them as a characterisable clientele with specific needs different to those of others with cancer, whether younger or older. Many of those diagnosed with cancer between 13 and 20 years of age will be cured, often after intensive, toxic and life-changing treatment. The provision of the highly specialised medical and nursing care needed for cancer treatment must go alongside meeting the specific needs associated with this age group, an age of transition from childhood to adulthood. Care provision for teenagers must therefore address the treatment, information, educational, social and other support requirements of teenagers and their families. This must be done through the work of a highly specialised, experienced multidisciplinary team. A dedicated Teenage Cancer Unit (TCU) provides an appropriate environment in which teenagers may feel comfortable and from which such a multidisciplinary team can function. Such units cannot provide every aspect of a teenager's care throughout their cancer journey so must work in harmony with other agencies, particularly those in the community. TCUs are most successful when they are of sufficient size to ensure a critical mass of staff and experience. Not all teenagers with cancer will be treated on a TCU and other models that can meet both medical and age-specific needs are required.

Keywords: Adolescent; Transitional care; Teenage Cancer Unit; Treatment

1. Introduction

In recent years, considerable attention has been focused on the particular needs of teenagers with cancer [1–5]. The nature of these needs and how best they may be provided are continually debated. A particular focus of this debate has been around the concept of the 'Teenage Cancer Unit', in other words a specific environment in which appropriate specialist cancer care can be delivered [6]. This recognises that the treatment of cancers affecting this age group commonly involves highly specialised care, much of which must be delivered to in-patients. In some cases, there has been movement beyond the concept and debate to the establishment of such units. In the United Kingdom (UK), the first such unit opened at the Middlesex Hospital in 1990 and further TCUs will open in the near future in the UK. This trend towards specialist in-patient units has been led by the UK, but it is expected that further developments will take place in other European countries. For example, a specialist unit for teenagers and young adults opened at the Institut Gustav-Roussy, Paris in January 2003.

The development of such units is not yet part of a co-ordinated health policy for teenagers. Instead, they have been predominantly local initiatives developed as the perceived appropriate solution to local needs usually supported by the concern and opinion of health professionals and sometimes families. Despite claims in the press of "15% better recovery rates" for teenagers when treated in dedicated Units (Daily Mirror, 6 December 1999), there is no universally persuasive supporting evidence to demonstrate the benefits of TCUs. As a consequence, no such development has taken place in other locations, leading to considerable variation in the provision of in-patient services for teenagers with cancer.

This paper outlines how such Units can operate, how they fit in to the overall provision for care of teenagers with cancer, outlines their potential advantages and

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* Corresponding author. Tel.: +44-207-380-9346; fax: +44-207-436-0160.

E-mail address: jeremy.whelan@uclh.org (J. Whelan).

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disadvantages and looks forward to ways of achieving more equal access to this provision.

2. Meeting medical and nursing needs

The cancers that most commonly arise in this age group are haematological malignancies (acute leukaemia, Non-Hodgkin's and Hodgkin's lymphomas), brain tumours, sarcomas (especially those arising in bone) and germ cell tumours [7]. At diagnosis, as in the paediatric age group, a curative approach to treatment can be planned for almost all of these patients. To achieve cure, treatment programmes generally involve intensive chemotherapy and often the intercalation of surgery and radiotherapy. Programmes like these are complex, demanding of both the patient and staff and often associated with complications, sometimes fatal, that require highly supportive care management. These treatments are most appropriately delivered within a properly constructed and regulated clinical trial, this being one of the single most important factors associated with the dramatic improvement in survival from childhood cancer over the past 40–50 years.

Meeting these demands requires the full apparatus of a modern cancer centre. Where is such expertise to be found? In the UK and Eire, there is a network of 22 recognised paediatric oncology centres with an overarching professional organisational body, the United Kingdom Children's Cancer Study Group (UKCCSG). In addition, services for adults with cancer are now organised around some 40 regional 'Cancer Networks' covering the UK, each served by a Cancer Centre where specialist cancer resources, such as radiotherapy expertise, are centralised [8]. Together, these facilities provide the necessary expertise for modern cancer treatment across all ages and for all malignancies. However, each Centre may not provide exactly the same services and sub-specialisation within this structure, especially for rare cancers and complex treatments, is well established as is the principle that, whilst a primary goal is to provide care at the nearest Cancer Centre, this is sometimes inappropriate and some patients must travel beyond the boundary of their local Network.

Within this system of provision, dependent on whether one is regarded as a 'child' or an 'adult', it might be imagined that there is a watershed, an expectation that, after a certain point, care for younger patients will be provided on the 'adult' side. In fact, no such critical point of transfer exists, reflecting such issues as long-established referral practices, the gradual evolution of services, an absence of consensus about the 'who, when, where and how' of it, and the rarity of cases. Implicit in this state of affairs is the wider acknowledgement of teenagers not 'fitting' because they have particular needs that fall outside of the day-to-day provision.

Co-existence of the paediatric oncology centre at the same location as the adult cancer centre is by no means the rule, children's services often being delivered from separate hospitals. Under such circumstances, and in the absence of clearly agreed referral pathways, teenagers over 16 years of age may be referred for treatment in either a child or adult environment, a decision often taken without consideration of which may be most suitable for their age-dependent needs. Furthermore, a choice must be made as to where a TCU might be sited—in the children's hospital where expertise and enthusiasm to manage older teenagers may be limited or in the adult hospital, where Unit admissions policies tend to be restricted to those aged over 16 years? The model of a TCU that can serve the full age range of adolescence with a coming together of paediatric and adult skills requires specific and favourable local circumstances. However, such Units may be ideal for the development and preservation of expertise of members of all the disciplines necessary to look after teenagers, may facilitate recruitment of staff with a particular interest in this age group, especially nurses, and may be of sufficient size to provide a sustainable critical mass for practice development and research.

Thus, teenagers with cancer must have access to skilled medical care appropriate for them and for that cancer. The medical needs are not unique to teenagers, but draw on generic skills of both adult and paediatric oncological medicine and nursing. Bringing these together is a key component of meeting the needs of teenagers and can be logically focused around a dedicated, recognised in-patient unit which has input and support from both paediatric and adult oncology.

Does treatment on a TCU lead to improved survival rates for teenagers with cancer? It is unnecessarily narrow to consider this as an exclusive justification for Units as survival from some of the relevant cancers, such as Hodgkin's disease, are excellent already and unlikely to be improved solely by shifting care to a teenage unit. However, other cancers such as brain tumours and some sarcomas still have a relatively poor survival compared with younger children's cancers. Focusing the care of patients with bone sarcomas in specialist units may be associated with improved survival (C.H. Stiller, Childhood Cancer Registry, Oxford), but such units are not necessarily the same thing as TCUs and any such improvement may relate more to the concept of a comprehensive Cancer Centre described above. Treatment in a specialist unit may be of significant benefit and associated with an improved survival because of the greater likelihood of inclusion in a clinical trial [9]. It has been clearly demonstrated in the United States that older adolescents have much lower rates of inclusion in trials than younger children and appear to be disadvantaged in overall survival by this [10].

In a study involving interviews and focus groups of healthy teenagers, teenagers with cancer and health professionals, there was a strong preference for management in a specialist centre over other issues such as the proximity of the hospital to home [11]. In a detailed ethnographic study of one such specialist TCU, parents and teenagers repeatedly placed similar emphasis on the importance of applying the combination of medical and nursing skills with a special sensitivity for teenagers [12]. Furthermore, teenagers themselves have reported differences in approach to them depending on whether they were seen in a paediatric or an adult clinic, highlighting the negative aspects they experienced in each setting [13]. The principle of access to oncological services appropriate to a patient's cancer type is now widely accepted and established, particularly in adult oncology. For children, it is accepted that this is combined with the additional qualifications and skills appropriate to this age group. Despite the endorsement by teenagers and their families of an identical principle of access to expertise that combines optimal medical care with age-specific care, wider implementation of properly supported multidisciplinary care in regional TCUs is still far from being a reality.

3. Meeting the needs of teenagers with cancer

Starting from the time of diagnosis, all cancer patients must be provided with appropriate information about their disease, must receive the best available treatment programme and should receive the support necessary to allow them to successfully proceed through the obstacles and traumas always associated with a cancer diagnosis. For teenagers with cancer, the role of dedicated units has already been discussed. But what are the specific support needs that are best delivered through such units?

As adolescence progresses, teenagers experience an evolution of their need for information and of the processing skills which accompany the shift to the independent decision-making of adulthood. When cancer is diagnosed, information-giving about the illness presents specific challenges which arise for several reasons. Depending on their age and maturity, the degree to which teenagers are used to having an independent voice within the family will vary. Parents will rightly see themselves as having a key role in supporting their child and this begins with an understanding of the cancer, a plan of treatment and its implications, and knowledge of the prognosis. This is always difficult, as distressing information which often includes unfamiliar terms and concepts. A common parental reaction is to try to protect their child from distress and withholding particular information, for instance regarding prognosis or infertility or even the use of the word 'cancer' is often seen as appropriate. However, most teenagers, even those who are relatively young, will expect to be involved in the discussions about their disease and will demand information, including 'to be told the truth' [3]. As one 17 year old stated, "I am not a kid anymore. I want to know what is going on here." While such situations may be successfully negotiated early in the course of disease, the tensions between parental and teenagers' needs for information can be extremely difficult to deal with when treatment fails and death is the most likely outcome.

How should the responsible professionals approach such challenging situations? Teenagers will expect information and may be disarmingly frank in their questioning. Deceit and evasion are quickly detected, whether from parents or professionals. Because establishing the trust of every teenager is an early and essential goal, truth-telling from the start is vital and is most appropriately accompanied by an explanation of the uncertainty and unpredictability of cancer. Such an honest and direct approach, centred on the teenager and addressing their questions and concerns, can be very difficult for parents to hear. They, too, must therefore be included and supported, with an explanation about why such an approach is necessary. Even those parents who, from the beginning, can acknowledge that the focus of information-giving is the teenager will still find it hard to be witnesses to the distress and anger of their child and are no less in need of support.

Dealing with such situations, and particularly rapidly reading the dynamics within families, requires skills and sensitivities that may not be regularly employed in other branches of oncology. Communication between professionals, especially medical staff, specialist nurses and ward staff, must be practised and clear. It should co-exist with mutual trust and confidence within the team. Furthermore, the teams of professionals must be themselves well supported and also be sufficiently experienced to be aware that 'success' in this field is often hard to achieve, that such complex and sensitive situations often seem to go wrong or that one may only achieve a 'less bad' outcome. However, the consequences of inexperience or lack of good teamwork can be a loss of confidence and trust in the professionals by the teenager and family, associated with increased anxiety and reduced coping. Unequal knowledge or sustained, inappropriate understanding and expectations become even greater consequences if progress on treatment is unsatisfactory or if treatment has failed to control the cancer. A team needs a critical mass of experience to be able to have some chance of brokering such situations successfully. Experience like this only develops through the regular care of teenagers with cancer.

The issues surrounding information and communication with, and within, a family are central to meeting the needs of teenagers with cancer, but their overall care requires more than this. A TCU can be the focus for a multidisciplinary team that addresses this aspect but, at the same time, there must be provision to meet the other needs of teenagers. This must be seen to be linked and motivated by the desire to preserve the strands of normal adolescent life, so acutely threatened by the cancer diagnosis and treatment (Table 1).

The first area is that of environment. Teenagers characteristically create an individual, 'secret' environment for themselves. Independence within a private space to listen to music, play computer games and so on is highly valued and we all recognise a stereotypical image of the teenager's bedroom. Such space gains its value in part because it excludes younger children and, perhaps even more importantly, adults. While an adolescent environment was not the highest priority in Wilkinson's study, it was certainly important. Teenagers are particularly vocal about their discomfort and sense of alienation when placed on both paediatric or adult wards [11–13]. Thus, an age-appropriate ward can be a vital tool in assisting teenagers to cope with repeated admissions to hospital to receive unpleasant treatment. A TCU should therefore provide a familiar and comfortable surrounding in which teenagers may be able to congregate together, to share activities, to listen to music, watch TV and films and to use computers.

As well as recognising leisure needs, the TCU must also provide continuity of support for educational needs. Teenagers feel very acutely the threat to achievement of educational goals. Teachers are therefore essential members of the multidisciplinary team. Their role must include providing formal lessons, facilitating examinations and working in close liaison with local schools and home tutors, to 'fill in the gaps' caused by school absences. Support for those in higher education is equally important, as is providing vocational guidance, particularly when employment plans must be adjusted to account for consequences of cancer, such as amputation.

Peer support is also a potentially valuable benefit of a TCU. Sentiments such as "You don't feel like an outcast, the only one with cancer and all the other people are normal" [12] will ring true with those working in this field. Although teenagers who spend time on a TCU are likely to experience the death of some who have become friends, this is rarely reported as a negative factor of a Unit, but more as an accepted part of cancer of which all are aware and which contributes much to the often-reported accompaniment of the disease in young people—'it makes you grow up fast'. At the same time, a diagnosis of cancer and its subsequent treatment threatens normal friendships, sometimes leading to considerable social isolation outside of the hospital. A 16 year old with lymphoma diagnosed 2 years previously described how he had become a different person: 'More serious, more mature. He has recovered his optimism, sorted things out with God, and says he sometimes feels older than his years. Many of the things he used to be interested in seem trivial now. "When I go out with my friends they just talk about....stuff. It doesn't mean anything to me. They just, like, get drunk. Everyone does that, but I'm not bothered."' (T. Bidwell, quoted in The Guardian, 27 September 2000). Explanation and support for changed attitudes like this are a vital part of the work of the multidisciplinary team.

Table 1
How Teenage Cancer Units meet the needs of teenagers with cancer

- Provide expert cancer site-specific medical and nursing treatment
- Support appropriate information-giving to teenagers and their families
- Provide an adolescent-friendly environment
- Provide educational and vocational support
- Address psychological needs of teenagers and families
- Acknowledge and support social, educational, sexual and family transitions

Other key members of the multidisciplinary team are listed in Table 2. All must have an understanding of the interaction between adolescence and cancer, be familiar with the experience and implications of treatment, for instance with regard to fertility and other treatment 'costs', and work closely together, joined by an agreed philosophy of care alongside ward nurses and medical staff.

4. Meeting the needs of families

Families of teenagers are thrown into turmoil by the diagnosis of cancer. The interruption of a process of developing autonomy with reversion to greater dependency is unsettling and confusing for both teenager and parents. Each may be troubled by a desire to protect the other party, this being a characteristic feature of teenagers with cancer—"it's hardest for the mums", as one 15 year old stated. Respecting the autonomy of a teenager in dealing with their disease is painful and sometimes lonely. Many families will benefit from assistance to recognise the 'normality' of ways in which their child responds to the challenges set by the cancer. Opportunities to talk to experienced staff who can recognise the emotional turmoil are valuable, but may be unavailable outside of a specialist Unit. Siblings, who often find themselves relatively marginalised within the family, as all attention seems to be given to their brother or sister, must be acknowledged and included. Such help will come from both the multidisciplinary team, but also from parents of other teenagers in the TCU.

5. The needs of staff—and staff needed

Those engaged in the care of teenagers will be familiar with responses from their colleagues and peers in other branches of oncology or paediatrics—'how do you do

Table 2
Members of a multi-disciplinary team

Team member	Role
Liaison nurse	Communication with patient and families; link with community team
Activities coordinator	Play therapy background; facilitate age-appropriate activities; ward and individual-focused; support and information resource, especially for teenager.
Social worker	Advice on benefits and other resources; community liaison; support and information resource, especially for family
Psychotherapist	Meets all patients; psychological support for individuals and group work
Dietician	Nutritional evaluation and monitoring appropriate to the age group
Teachers	Work both in hospital and through liaison with local schools; facilitate careers advice and access to other educational resources
Physiotherapist	Experienced in rehabilitation of teenagers undergoing major reconstructive orthopaedic surgery or after neurosurgery
Occupational therapist	Assesses rehabilitation needs especially at home; contributes to ward activities programme
Youth worker	Encourages and aids activities, especially for older teenagers; additional support and information resource
Palliative care team	Liase closely with nursing and medical staff; experienced in needs of teenagers with advanced disease

it?' Regularly caring for teenagers is demanding, stressful and unattractive to many professionals. Teenagers are sometimes difficult to communicate with and staff will often find themselves not far removed in age from those for whom they are caring. Staff must be able to respond effectively without bearing the emotional burden of teenager and family themselves. Professional boundaries can easily be threatened in such an environment where the energy and liveliness of adolescence is tightly intermingled with pain, sadness and bereavement. Again, the value of an experienced multidisciplinary team includes the skills to recognise these challenges and conflicts and to provide support for staff. Managers of TCUs have an explicit responsibility to ensure that an effective programme of staff supervision is in place.

Recruitment of staff to a TCU may be difficult because of the specialised nature of the work. Fragmented development of services for teenagers, particularly if this involves small units close to each other, may inhibit the creation of sustainable multidisciplinary teams and further impede recruitment.

6. What is an adolescent cancer unit?

A dedicated environment, ideally encompassing both in-patient and out-patient care provides an invaluable, indeed essential, focus for expert, specialised multidisciplinary care for teenagers with cancer. Although there are only 6–8 TCUs in the UK, designated in-patient beds for adolescents exist in as many as 27 hospitals, serving both highly specialised populations, e.g. cystic fibrosis, and as part of general paediatric provision including mental health problems (M. de Souza, University College London Hospitals, London). Most of these facilities are not located in Cancer Centres and there is some debate about the role of 'generic' adolescent units such as these in the provision of care of teenagers with cancer. The twin demands to be met are the expert medical and nursing care required to give the best quality of care for the underlying cancer and the age-specific needs. A cancer diagnosis continues to carry a unique encumbrance of fear and stigma. Aspects of its treatment and the wider impact of the diagnosis contrast starkly with other medical conditions affecting this age group, particularly those chronic diseases carried forward from childhood, through adolescence and into adult life. The special skills developed by oncology-trained staff must be available to teenagers, just as to children and adults. To give the teenage environment a greater weighting in decisions about where patients are to be treated than the requirements of best practice for cancer care is counter to a philosophy, now universally accepted, that recognises the central importance of access for all patients to nursing and medical care which is specifically trained and organised for the treatment of cancer. This imperative underlies the organisation of cancer services, not just in the UK, as described in this article, but also in most other European countries.

Thus, it is expert oncological care that must be the primary defining feature of a TCU and the management of complex diseases, including intensive treatments, should only take place in environments where standards of medical and nursing care appropriate for children and adults with cancer are reproduced. Above all, any Unit providing care for teenagers with cancer must do so united by an appropriate philosophy of care recognising the primacy of the cancer diagnosis as well as its impact on normal adolescent development.

7. Outstanding problems

Many problems remain to be addressed in determining the best structure of care for teenagers with cancer and TCUs should be seen as only one part of the solution. First, data about numbers of patients, current care patterns and ways to improve accessibility, to underpin the development of services are limited. It seems reasonable to propose that TCUs should be developed only as a component of a broader structure of care that includes recognition of local providers, the resources available in the community and an awareness of the factors that can ensure a sustainable, experienced multidisciplinary team. However, in recognition of the importance of specialist Cancer Centre care in the management of cancer in teenagers, TCUs should be regarded as a sensible starting and focal point for such a comprehensive structure.

Next, there are specific areas that require more investigation to identify paths to improvement. These include (a) the transition from paediatric care into adolescent care and on into adult services; (b) training and development for multidisciplinary team members of all professions, including recognition of the very stressful nature of their work and how it can be ameliorated; (c) the evaluation of TCUs; (d) models of care which might be suitable for sparsely populated areas with considerable distances between hospitals; and (e) whether the needs of 'young adults' with cancer are appropriately bracketed with those of teenagers and, if so, determining the upper age limit.

Thus, further debate must encompass all TCUs, accepting their 'permanence', and address how they can continue to meet the needs of teenagers with cancer and those of their families most effectively, but now also more clearly setting them in the context of a wider service.

8. Conclusions

Currently, there is a lack of appropriately resourced services as well as insufficient recognition, especially by doctors, of the special needs of teenagers with cancer and how these may be best addressed. Although much attention has been focused on TCUs, their limitations must be acknowledged. They will only be successful if supported by a skilled multidisciplinary team. This kind of expertise is not widely available and will not be sustainable in most Cancer Centres. In particular, TCUs must work in close co-operation with local care providers, including general practitioners, community nurses and palliative care services and with secondary care providers such as local oncologists and paediatricians.

As a focus for expert medical and nursing management and expert multidisciplinary care, special environments for teenagers, which are separate from those for children or adults, are invaluable and might be regarded as the core component of a 'gold standard of care'. Access to this quality of care is currently far from universal. An appropriate medium term goal is for all teenagers with cancer to have access to a TCU. Different national organisations and healthcare systems, especially those in Europe and North America, should share their experiences in this field so that optimum facilities, accessible to all adolescents and young adults, can be developed over the next 5–10 years.

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