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Commentary

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Barr states correctly that “Much remains to be done to better meet the needs of adolescents with cancer”, and the new focus on adolescent care in paediatric oncology is welcome and timely.

In all areas of healthcare, there is an increasing recognition of the special needs and problems of ado-

lescents internationally [1]. Adolescents are the one age group in which mortality and morbidity has not decreased in the last three decades [2]. Diseases with social origins such as suicide, accidents and drug-related illnesses, have replaced communicable and congenital diseases as the largest source of mortality for those aged 12 to 17 years [2].

While cancer remains relatively rare in adolescents, the need for better services for teenagers with cancer is clear, particularly given Barr's observation that incidence rates for cancer in young people in the USA have

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increased by 30% from 1973 to 1995, three times the increase in children during the same period.

What is unique and different about cancer in adolescents? The answer is 3-fold. The first element is a unique epidemiology of disease in adolescence. In terms of cancer, this includes 'late' presentations of paediatric type cancers, e.g. rhabdomyosarcoma, medulloblastoma, 'age-specific' cancers of adolescence, e.g. bone tumours and testicular cancer and early onset of 'adult-type' carcinomas. Additionally, the prognosis of different tumour groups may be affected by age, e.g. the accumulation of poor risk features with ascending age in acute lymphoblastic leukaemia.

Secondly, there are the unique developmental tasks of adolescence related to biological and psychological maturation, and their impact upon social development. These include the completion of growth and pubertal development, together with the completion of identity formation, the development of abstract thinking, plus the challenges of achieving educational success, personal and financial independence from parents, and beginning intimate relationships with others. Clearly none of these tasks is unique to young people with cancer. It is the interplay between the developmental tasks of adolescence and the demands of cancer and its treatment that require special skills from all those treating young people with cancer.

The third element that is different about working with young people are the issues concerning healthcare delivery that are unique to adolescence. These include issues of transition from paediatric to adult care, issues regarding confidentiality and consent for young people who are not yet adults, but no longer children, and issues of access to healthcare (traditional clinics and hospitals are difficult for young people to access and alternatives are often necessary). Again, these are not specific to patients with cancer, but require careful consideration when attempting to treat young people with cancer within traditional paediatric or adult cancer services.

Because young people have specific developmental needs that are poorly served by the healthcare professions, and because they often respond poorly to traditional health care interactions, young people are generally perceived as a 'difficult' group, who are often demanding, non-compliant with treatment and poor attenders of outpatient services. American studies suggest that only around a third of physicians and paediatricians actually like working with adolescents [3] and that around another third have very little interest in adolescent care [4].

Deficits in the care of young people are not limited to the field of cancer. Adolescents have long been poorly served by the medical community in general [5,6] and the deficiencies in the provision of health services for adolescents in Britain have been recognised repeatedly since the Platt Report of 1959 [7].

Barr's article in this issue of *EJC* addresses many of these issues from a North American perspective. It is important to place his comments within a European context and within the contexts of adolescent health more generally.

1. European perspective on cancer in adolescents

In the UK, approximately 600 cases of cancer will occur each year in the age group 13–20 years [8]. The need for dedicated hospital facilities for adolescent patients in the UK has been stressed repeatedly since 1959 [9]; however, review of evidence concerning the development of adolescent services found that the rate of commissioning healthcare facilities for adolescents remains low [9]. In the framework for the development of cancer services launched by the Expert Advisory group for Cancer Services [10], it was recommended that adolescent services should become a feature of most cancer centres. Apart from the establishment of a small number of specialist teenage cancer units in recent years, adolescents have been and often still are, cared for by disease or age-group specialists on adult or paediatric cancer units. Identification of appropriate levels of care for teenagers and young adults with cancer and improving access to specialist care and clinical trial entry are the current foci of the United Kingdom Childhood Cancer Study Group (UKCCSG) adolescent group.

There is little published data specifically relating to incidence and survival in adolescent cancer [11,12]. The Northern Region Young Persons Malignant Disease Registry (NRYPMRD) was one of the first population-based registries for childhood cancer and is the only registry in the UK having specialist information on the 15–24 year age group [13]. It represents the only recent European published data for comparison with the SEER monograph [14]. The incidence of cancer appears less than the SEER experience, with 144 cases per million per year compared with approximately 200 per million. The incidence of ALL, AML, Hodgkin's and CNS tumours was similar, but there were striking increases amongst the SEER dataset for germ-cell gonadal tumours (31 versus 13), thyroid cancer (14 versus 4), soft-tissue sarcoma (16 versus 9), melanoma (14 versus 7) and NHL (15 versus 10). In common with the SEER data, the North of England data also recognises an increasing trend in incidence of cancers in 15–19 year olds. However, those cancers with the most obvious incidence rate discrepancies are also those which have been reported as increasing in incidence generally (testicular cancer, melanoma and NHL) [15–17]. Additionally, population racial mix may explain some of the differences, e.g. only 5% of the NRYPMRD data set were classified as from ethnic minorities.

The survival rates reported for the 15–24 year cohort in Northern England demonstrate a considerable improvement over a 28 year study period. Data was not teased out specifically for the 15–19 year age group to directly compare with the SEER data, but the perspective was one of matching improvement comparable with the outlook for children.

2. Adolescent health

As noted above, most of the problems faced by teenagers with cancer and those who treat them are not unique to malignant disease. Psychosocial issues regarding mortality and morbidity, palliative care, adherence to treatment regimens, consent and confidentiality and biological problems such as pubertal delay, are common to all chronic illnesses during adolescence.

The burden of all chronic illness in adolescence is increasing as larger numbers of chronically-ill children survive into their second and third decades [18]. Over 85% of young people with a chronic illness now survive into adolescence [19]. The very nature of adolescent psychosocial development (e.g. progression from concrete to abstract thinking, desire for separation from parents, identification with peer group, etc.) can make management of treatment regimens very difficult regardless of the disease or the regimen. Poor adherence and poor clinic attendance are extremely common and have an adverse impact on disease control.

Conversely, having a chronic illness of any type may retard normal adolescent development, producing pubertal and growth delay, delayed social independence, poor body and sexual self-image and educational and vocational failure. The importance of monitoring growth and pubertal development in young people with chronic illness well into their late teens and early twenties has been starkly illustrated in recent papers [20]. Similarly, the importance of thinking proactively about helping young people with chronic illness and/or disability develop independent adult living and vocational skills has been shown in longitudinal follow-up studies [21].

The effective management of transition of paediatric to adult care is particularly important for chronic illness in adolescence [22] but cannot be forgotten in cancer [23]. Many young people with chronic disease use the transfer from paediatric to adult care to ‘drop out’ of medical supervision. While this is rarely a problem for young people on active treatment, it remains an extremely difficult issue for long-term follow-up of cancer survivors. Paediatric services are not an appropriate place for long-term follow-up of cancer, and all paediatric cancer services require policies on transition of patients to appropriate adult services (ideally run conjointly with the paediatric service) [22].

Developmental imperatives to explore ‘risky’ behaviours as part of establishing a secure personal identity is common to all young people whether ill or well, and it is important to remember that our adolescent patients will have exactly the same issues regarding smoking, drug and alcohol use, contraception and safe sex as healthy teenagers. Because of interactions with active treatment, side-effects of treatment and the long-term risks of secondary malignancy, health promotion about the risks of smoking, alcohol, sexually transmitted diseases (STDs) and ultraviolet (UV) exposure are perhaps more important with teenagers with cancer than for the general adolescent population.

3. What action is needed

Greater attention to the psychosocial elements of the acute treatment of young people with cancer is urgently needed. In addition to this, long-term follow-up that includes effective transition planning and targeted health promotion is required if we are to provide the best health outcomes for teenagers with cancer.

Teenage cancer units are well established in the United Kingdom, with seven units now distributed throughout the UK through the pioneering efforts of the Teenage Cancer Trust.

It is unclear whether there is a survival advantage gained by the provision of specific services for adolescents [24]. Extrapolation from adult data which shows that treatment according to a recognised protocol and treatment at a regional specialist oncology centre were each associated with significantly higher survival rates [25] would suggest that specialist adolescent services may provide a survival advantage.

One argument for specific units is data indicating improved outcome for a range of cancers when patients are treated in clinical trials [26]. Adolescents are not represented well within clinical trial registrations [27] and specific adolescent focused units would encourage central registration and specific adolescent trials. Additionally, attention can then be given to psychosocial sequelae and late effects of therapy.

Regardless of the arguments for and against dedicated teenage cancer units, many young people will continue to be cared for in either paediatric or adult services. Therefore, it is the responsibility of all services caring for young people to improve these services to meet the specific needs of adolescents.

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