



Cancer in adolescents and young adults

ADOLESCENT ONCOLOGY: ORPHANED IN THE SYSTEM

Marianne B Phillips ■ Princess Margaret Hospital for Children, Roberts Road, Perth, Western Australia.
Email: marianne.phillips@health.wa.gov.au

Snow and Adolescence are the only problems that disappear if you ignore them long enough
(Earl Wilson 1907).

Adolescents and young adults (AYA) are increasingly recognised as a specific, separate population group, deserving of specialised health care provision. Adolescents aged 10-19 years comprise approximately 8% of the population in Australia and have an incidence of malignancy of approximately 150 per million per annum, with cancer proving to be the fourth leading cause of all deaths in the age group.

The aim of this volume of *Cancer Forum* is to increase awareness of the special needs of adolescents and young adults and to identify some of the many reasons why they should receive specific management appropriate to their age and psychological development, in addition to their specific underlying oncological diagnosis, with the aims of benefiting treatment tolerance, compliance and importantly, disease outcomes.

The population addressed in this volume is identified as complex for many reasons. There is a significant lack of an agreed single definition of the age referred to, which renders the provision of single uniform national service planning recommendations difficult. Best is the recognition that adolescents and young adults aged 13-29 years encompass all those making the transition from childhood to adulthood, physically and psychologically, educationally and financially. There are also, not insignificant terminological challenges. The term 'adolescent' is less than ideal, as it has implications for many that tend to typecast the patient as potentially immature, rebellious and often non-compliant. The problems of the 'young adult' are similar, with an equal need for candour, tact, respect and privacy, and with their care provided by choice in age-appropriate facilities within the treatment centre. Appropriate psychological and social support is a very important aspect for these patients, as there are specific recognised psychosocial needs existing within the group and adolescents with cancer.¹ Adolescents then not only have to cope with the recognised physiological and psychological challenges of their age, but also concomitant to their diagnosis, with treatment adverse effects, relationship isolation, educational disruption and employment issues.

The spectrum of tumours seen in adolescents and young adults is different from that of childhood, young adults or elderly people. In addition, more young people aged between 15 and 25 years are diagnosed with cancer than all children aged less than 15 years. During the past 25 years, the incidence of cancer in 15 to 29 year-olds has increased, while the reduction in cancer mortality has been lower than in younger or older patients. Certainly the improvement in the five year cancer survival rate from the mid 1970s to the early 1990s was significantly lower for adolescents and young adults than the improvements noted in either younger or older age groups.² Whereas it was once a relative advantage to have cancer during the adolescent and young adult years, patients in this age group now lag behind patients in all other age groups with regard to services, outcomes and trial enrolments.³ Currently, access to age-appropriate cancer care varies from region to region across Australia. Adolescents may receive cancer care either within a paediatric setting surrounded by staff, facilities and recreation more suitable for infants and young children. Alternatively, it is dispersed across the multiple facets of adult site-specific cancer service provision, where the average age of patients is nearer the 60 to 70 year-old range.

The series of reports in this issue advocate on behalf of all adolescent patients diagnosed with a malignancy, identify the logic underpinning the definition of specific services and address some of the supporting arguments for potential future service and management developments.

Currently, fewer patients in the 15 to 29 year age group are referred to dedicated, comprehensive cancer centres than patients in any other age group and almost 80% of adolescent patients are not enrolled in clinical trials. It appears that the significant difference in outcomes for this patient group are influenced in part by their lack of clinical trial participation, with published data highlighting older adolescent cancer patients having significantly less access to clinical trials than younger patients; a recent report from Australia identified a sharp fall-off in cancer patients above the age of 15 years entered on to clinical trials.⁴ This is despite clinical trials for most of the paediatric type malignancies being open to patients from adolescent and young adult age-groups and the increasing development and availability of national disease-specific collaborative group trials within the adult sectors, for which patients

aged 15 years and over are often eligible. This is particularly relevant when the natural history for some disease entities in the adolescent group seems to be different to that observed in children or adults for the same specific tumour types. The current lack of clinical trial enrolment risks the provision of best available treatment advice for adolescent patients. The development of national trial collaborative groups will go some way to better address outcomes and the understanding of biological characteristics, differences and prognostic markers for adolescent malignancies. With proper referral patterns to adolescent units equipped with data managers and strong links to national and international collaborative trial groups, the figures for the younger people enrolled on to clinical, biological and therapeutic collaborative trials should rise.

It is, therefore, increasingly clear that the discipline of adolescent cancer care is the recognition of the way in which the service should be provided, rather than a speciality incorporating a particular set of diseases that affect a defined age group. Adolescents and young adults with cancer should have their care provided by an age-appropriate adolescent cancer service with access to and treatment within therapeutic and biological protocols to ensure improved quality of life and survival outcomes.⁵ Cancer care for this age-group should include appropriate transition programs for young adults moving from a paediatric facility to an adult oncology facility. It must also include age-appropriate palliative care to ensure best quality of life for all patients, regardless of outcomes. Due to the fortunate relative rarity of malignancy in this age group, it is unlikely patient numbers alone justify 'separate' specific service provision, but the epidemiological data presented is persuasive of a significant 'critical mass', reflecting not only patient numbers but highlighting a huge, as yet, unmet need. A specific cohesive national strategy for the adolescent group is more likely to be

successful in addressing access, survival and compliance issues. Young people are clear that they want specific age-appropriate facilities and support groups, but how this service should be configured will be state and territory dependent and must vary according to the diverse population and geographical needs across the continent. Some of the benefits of specific adolescent oncology units are clear, however staffing and training for adolescent units must be specifically addressed if initiatives of this sort are to succeed. Who should manage this service is open to debate and whether the advantages of a specific adolescent unit always outweigh the medical advantages of sub-specialty units has not been confirmed.

It is however, possible to define new models of care that have the potential to combine the best of adult and paediatric multi-disciplinary sub-specialty teams in order to meet the unique medical and development needs of these young people. The urgent need to address the appropriate care and management of the adolescent cancer cannot afford to be ignored. The current gaps in services, management and outcomes must be addressed in order for the current problems of their care to disappear....as will snow over time.

References

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