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European Journal of Cancer 39 (2003) 2571–2572

European Journal of Cancer

www.ejconline.com

Introduction

Adolescent Oncology—a Homeland for the "Lost Tribe"

In the continual enterprise of trying to guide appropriately, renegotiate with, listen to and just generally coexist with our teenage children, we ourselves are changed. We learn even more clearly what our baseline virtues are. We listen to our teenagers and change our minds about some things, stretching our own limits. We learn our own capacity for flexibility, firmness and endurance. (Jean Jacobs Speizer, *Ourselves and Our Children*, Boston Women's Health Collective 1978 (chapter 4)).

The chief priority of this Special Issue is to increase awareness and stimulate debate amongst both the paediatric and adult oncology communities, of the special needs of adolescents and young adults. The question is—"Should they be treated differently"?

First, there is a 'terminological problem'. The term 'adolescents' is less than ideal because it has implications, for many people, that tend to typecast the patient as potentially immature, rebellious and, as far as treatment is concerned, often non-compliant. Moreover, the problems of the 'young adult'—up to her/his late 20s—are much the same as the adolescent, with an equal need for candour, tact, combined with respect by carers and a particular need for privacy and age-appropriate facilities in the treatment centre. Although this issue is entitled 'Adolescent Cancer' we, the editors, would in a way have preferred to use the title 'Teenage and Young Adult (TYA) Cancer Care', especially as several contributors—though asked to write about 'adolescents' actually provided excellent contributions covering patients in their 20s as well as those in their teens.

It is increasingly clear that the discipline of Adolescent Medicine in general, and of 'Adolescent Cancer Care' in particular, is less a speciality incorporating a particular set of diseases that affect a defined age group but, rather, recognition of the need to address the way in which the service is provided [1]. A series of reports in this Issue advocate on behalf of these patients, the logic underpinning the definition of specific services and the supporting arguments behind future developments.

Are the patient numbers enough to justify "separate" service provision? The epidemiological data presented here is persuasive of a significant 'critical mass', not just reflecting patient numbers but highlighting a huge "unmet" need. Access to cancer care varies from country to country and from region to region—with adolescents receiving cancer care either within a paediatric setting, surrounded by staff, facilities and recreation more suitable for infants and young children, or dispersed across the multiple facets of adult site-specific cancer service provision (at both secondary and tertiary levels), where the average age of patients is often in the 60 to 70 year old range. The argument is that a more specifically planned and cohesive strategy for the adolescent group is more likely to be successful in tackling issues such as 'access', 'survival' and 'compliance'. In addition, these young people are very clear that they *want* such facilities, a view powerfully presented by a teenage cancer survivor who was fortunate to have access to a specific Teenage Cancer Treatment Unit [2].

Who should manage this service? This question is certainly open to debate which will be fuelled, we hope, by some of the papers in this volume. Will the advantages of an adolescent Unit always outweigh the medical advantages of subspecialty Units? Are paediatricians and paediatric nurses the appropriate source of cancer care for the adolescent patient, because of their training emphasis on multidisciplinary care and family health provision? Or is it now possible to define new models of working that have the potential to combine the best of both adult and paediatric subspecialties and thereby meet better both the medical and development needs of these young people?

What other issues are relevant to the provision of adolescent healthcare in oncology? Does medical training encompass health concerns such as teenage access, communication, confidentiality, consent and privacy? The discipline of 'Adolescent Medicine' is not taught uniformly across the world. Should more consideration perhaps be given to training and the inclusion of non-traditional ways of patient-professional communication including web-sites, email and text messaging? Staffing and training for adolescent Units needs to be addressed specifically and with determination if initiatives of this sort are to succeed. The fact that there is still no formal training agenda for Paediatric Oncologists in most Western countries should not deter those devoting

0959-8049/$ - see front matter
doi:10.1016/j.ejca.2003.09.012

themselves to this age group from setting up basic and practical training programmes which embrace relevant facets of paediatric and adult oncology, with a special focus on psychological and social needs.

Clinical trial research is also a major issue. In striking contrast to younger children age <14 years with cancer, up to 90% of whom are entered into at least one clinical trial, the figures for adolescent patients are much lower. In one study of young people aged 14–29 years with acute leukaemia, only 36% of acute lymphoblastic leukaemia (ALL) patients and 46% of acute non-lymphoblastic leukaemia (ANLL) patients entered the relevant national treatment trial [3]. The average figure for adults enrolled on the trials is well under 10%. With proper referral patterns to adolescent Units equipped with data managers and with strong links to national and international collaborative trial groups, the figure for the younger people should rise. We need to keep reminding ourselves that patients treated in trials fare better than those who are not. If we fail in this responsibility, we risk providing those patients with less than the best available treatment advice.

Several cancers of adolescence and young adulthood already have a considerable evidence base—Hodgkin's disease and osteosarcoma, for instance [4,5]. Discussion of the features and treatment of these tumours is already available in textbooks and review articles and we have chosen to commission articles specifically on those cancers, more usually seen in adult practice, for which there is a scant or anecdotal database. We hope, to help others already trying to raise awareness of the need for more international collaboration to address the specific health issues posed by these rare tumours, particularly when the natural history seems to be different from the adults in whom they may more commonly occur. Breast cancer provides a good example. The same 'international planning' logic would apply to the development of multinational consortia that study management of rare cases of 'late onset' of paediatric cancers—neuroblastoma, for example. This Special Issue also gives voice to other recently welcomed 'stakeholders'—the charities and Hospice movement. Their input is already influencing the field and their contributions will be more and more valuable as time goes by.

We and others have termed the TYA (adolescent) group of patients as the 'Lost Tribe'. We hope that soon, with the help of this volume, we will see these needy patients on their way to finding a 'homeland' of their own.

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