EUROPEAN JOURNAL OF CANCER 42 (2006) 280–281

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Editorial Comment

The 'Lost Tribe' and the need for a promised land: The challenge of cancer in teenagers and young adults

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ARTICLE INFO

Article history:
Received 15 November 2005
Received in revised form
15 November 2005
Accepted 15 November 2005
Available online 19 January 2006

The paper by Desandes et al. published in this issue, rehearses a clear message in reporting outcomes for French teenagers with cancer.[1] They remind us that their data and other evidence in the literature show survival rates for this important group to be less satisfactory than might be expected, particularly when compared to the results achieved for children over the same period of time. Definitions used for work in this area are inconsistent and some studies, like theirs, are confined to the more typical 'adolescent' age range (15–19 years), with its upper age limit shaped by the end of secondary education. Others argue that it is important to recognise the continuum of medical and social need from the mid-teens to the mid-twenties and it is certainly the case that most 20-year olds treated, for example, for osteosarcoma would be as uncomfortable in a paediatric oncology environment as they would be in an adult oncology facility. The need for designated 'age appropriate' facilities has been well rehearsed particularly, in a European context, in the United Kingdom, where the work of organisations like the Teenage Cancer Trust[2] has stimulated action to address the needs of the population now more frequently described as Teenagers and Young Adults with cancer, known for brevity as TYA.

The issues confronting these young people were highlighted in a special edition of this journal in 2003 when recognition of the disadvantages they experienced led to the label of the 'Lost Tribe'.[3] TYA are a group of patients whose needs are squeezed between, and insufficiently addressed by, the achievements of the paediatric oncology world on the one hand and the weight of cancer burden on adult cancer services on the other. The incidence of cancer in early life rises from approximately 130 per million in children to the age of 14 years and rises to 150–200 per million in young people by the age of 20 years,[4] yet what Desandes et al., can show is that this group of patients have, overall, very encouraging survival (5-year overall survival of approximately 70–75%) rate.[1,5] As young people with a potential lifetime ahead of them, we can ill afford to ignore their needs and the persistence of cancer as the most important medical cause of death in this age group demands urgent attention. So where do we go from here?

First, service provision for these young people should reflect the evolving epidemiology of cancer type between the patterns described in paediatric and adult practice.[6,7] The TYA period is characterised by the emergence of carcinoma,

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doi:10.1016/j.ejca.2005.11.007

a peak in the incidence of bone sarcoma and in Hodgkin's disease, and the disappearance of the classical 'embryonal' tumours of earlier childhood. Leukaemia, lymphoma, CNS tumours, soft tissue sarcoma and germ-cell tumours all remain important conditions. The skills required for the treatment of this range of diagnoses derive both from paediatric and adult oncology practice: there is no room for territorial dominance by either side and specialists should work together to deliver what is required by the individual young person.

Second, there needs to be a critical evaluation of where things can be done better. Although survival has improved in the most recent era of treatment, specific survival rates for leukaemia, bone and soft tissue sarcoma in the French study were less good than when the same diagnoses occurred in younger teenagers, and the outcome for patients with ALL, NHL, CNS tumours and osteosarcoma was less satisfactory than that reported in the United States in a similar age group over a similar period.[8] Although the French data are consistent with other European countries, there are well-recognised inequalities across Europe, principally in an East-West direction.[9] Amongst the causes postulated by Desandes et al., two factors stand out. First, the remarkably low recruitment of TYA into clinical trials,[10,11] and second the possibility that a lack of appropriate multidisciplinary care may matter in this context. The poor enrolment of TYA into clinical trials contrasts with the high figures for paediatric studies and merits immediate attention – particularly as the survival advantage conferred by recruitment to trials is well recognised.[12] The contribution of age appropriate multidisciplinary care to survival is likely to be harder to establish but, apart from the quality of the treatment experience itself, age appropriate management by staff with skills appreciated by TYA in a suitable physical environment, may have a positive impact on issues such as treatment compliance and follow-up, and on the willingness of this population to support clinical trials.

By way of example, two important initiatives have recently emerged in the United Kingdom which will begin to address the TYA issue. First, there has been recent guidance from the National Institute for Health and Clinical Excellence (NICE) on 'Improving outcomes in children and young people with cancer'.[13] Interestingly, this important publication, which will shape future service delivery for all young people with cancer, defines no upper age limit but advises that all care for children and young people under 19 years old must be provided in age-appropriate facilities and that young people aged 19 years or older should have unhindered access to age-appropriate facilities and support when needed. It is likely that this will be a driver for the development of an increasing number of specialist TYA cancer units, offering multidisciplinary care from teams derived both from adult and from paediatric oncology.

The second initiative has come from the National Cancer Research Institute with an announcement of their intention to form a clinical studies development group for teenagers and young adults.[14] One specific remit of this group is to ensure that TYA are considered for, and have opportunities to enter, disease-specific clinical trials and other research protocols.

Similar initiatives will emerge elsewhere in Europe and what will be required is a framework within which work needed to improve outcomes for TYA can be coordinated. Collaborative clinical trials will be essential in this age group, just as they have been seen to underpin the progress seen in paediatric oncology over the past 30 years. But where will the resources come from? How will progress seen in Western European countries be translated across to the new countries of the European Union? And can we afford to ignore the investment in infrastructure that is needed to improve cure rates for all young people with cancer across Europe?

Conflict of interest statement

None declared.

REFERENCES

1. Desandes E, Lacour B, Sommelet D, et al. Cancer survival among adolescents in France. *Eur J Cancer* vol. etc., to be provided by editorial team.
2. Whiteson M. The Teenage Cancer Trust – advocating a model of teenage cancer service. *Eur J Cancer* 2003;**39**:2688–93.
3. Michelagnoli MP, Pritchard J, Phillips MB. Adolescent oncology – a homeland for the "Lost tribe". *Eur J Cancer* 2003; **39**:2571–2.
4. Stiller C. Epidemiology of cancer in adolescents. *Med Pediatr Oncol* 2002;**39**:149–55.
5. Cotterill SJ, Parker L, Malcolm AJ, et al. Incidence and survival for cancer in children and young adults in the North of England, 1968–1995: a report from the Northern Region Young Persons' Malignant Disease Registry. *Br J Cancer* 2000;**83**:397–403.
6. Birch JM, Alston RD, Kesley AM, et al. Classification and incidence of cancers in adolescents and young adults. *Br J Cancer* 2002;**87**:1267–74.
7. Wu XC, Chen VW, Steel B, et al. Cancer incidence in adolescents and young adults in the United states, 1992–1997. *J Adolesc Health* 2003;**32**:405–15.
8. Ries LAG, Eisner MP, Kosary CL, et al. SEER Cancer Statistics Review, 1975–2000. National Cancer Institute, Bethesda, MD. Available from: <http://seer.cancer.gov/csr/1975_2000>.
9. Gatta G, Capoccacia R, De Angelis R, et althe EUROCARE Working group. Cancer survival in European adolescents and young adults. *Eur J Cancer* 2003;**39**:2600–10.
10. Bleyer WA, Tejeda H, Murphy SB, et al. National cancer clinical trials. Children have equal access; adolescents do not. *J Adolesc Health* 1997;**21**:366–73.
11. Newburger PE, Elfenbein DS, Boxer DA. Adolescents with cancer: access to clinical trials and age appropriate care. *Curr Opin Pediatr* 2002;**14**:1–4.
12. Stiller CA. Centralised treatment, entry to trials and survival. *Br J Cancer* 1994;**70**:352–62.
13. National Institute for Health and Clinical Excellence. *Improving outcomes in children and young people with cancer*. London: NICE; 2005. Available from: <http://www.nice.org.uk>.
14. National Cancer Research Institute. *Remit of NCRI Teenage and Young Adults Clinical Studies Development Group*. London: NCRN; 2005. Available from: <http://www.ncrn.org.uk/csg/remit.htm>.