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Comments and Critique

Care for the Adolescent with Cancer

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EACH YEAR in the U.K. (population 60 million), 750 adolescents (age 13–19 years) are diagnosed as having cancer. Of these 60% will be cured. In the paediatric (0–12 years) age range there are 1000 new cases. In the adolescent, the main tumour types and incidence are shown in Table 1. Compared with the younger age group there are more sarcomas and germ cell tumours, and fewer brain tumours and leukaemias. Provision for cancer in the very young is well established in most European countries, with the development of paediatric oncology as a well defined specialty. Cancer in adolescence, on the other hand, has received relatively little attention as a separate problem.

Most children aged 13–16 are cared for as in-patients in paediatric units, and those above that age on adult wards. Outpatient treatment is similarly divided. These arrangements may be unsatisfactory. Adolescents have little in common with small children on a paediatric ward, and yet may not have the specialised care and attention they need when treated in an adult cancer unit. The diagnosis of cancer in an adolescent produces stress and anxiety which is different from that engendered when either a small child or an adult is found to have the disease. Adolescents are beginning to move away from the family ties which bound them as young children. They spend more time with their friends, admire and emulate their peers and heros, but at the same time need the sustaining support of family life. At school they are often studying for examinations which will lead to choices at college, work or university. They are usually interested in sport, sex, music, going out, school work and 'hanging out' with friends. Parents, though loving and loved, are often a restraining and irritating force.

Table 1. *Incidence and survival of cancer in adolescence (age* 13–19)

	Incidence /million	Total no./ year in U.K.	% survival	Total no./year surviving in U.K.
Lymphoma	20	170	79	134
Leukaemia	16	96	68	80
Brain	13	77	50	39
Germ cell	13	77	90	69
Bone sarcoma	10	60	50	30
Thyroid	10	60	80	48
Skin	8	48	60	29
Soft tissue sarcoma	6	36	60	22
Others	16	107	50	54
Total	112	731	69	505

Assumptions: population of U.K. 60 million. Birth rate: 800 000/year.

The diagnosis of cancer at this period of change and excitement has an impact which is often different in nature from that which occurs at other times of life. Of course, many of the reactions are the same as in adults—anxiety, fear, depression, and the need for reassurance being chief among these. But at this period of life, the management of cancer requires skills which are supplementary to those which most oncologists or paediatricians have acquired in the course of their training.

Recently, these problems have been recognised more formally, and special units for the care of adolescents with cancer have been established. These are often part of a paediatric oncology department, and many of the working practices derive from paediatric skills, especially the emphasis on a team approach to management. These units have special problems which are now becoming rather more clear. My own unit for adolescent cancer of 10 beds was established at the Middlesex Hospital 3 years ago, being one of the first in the U.K., and others have followed since then. There is a growing body of experience and writing emphasising aspects of cancer care in this age group.

It is obvious that the most important aspect of management is a high degree of technical competence in the management of the tumours concerned. Treatment of bone and soft tissue sarcomas, germ cell tumours, brain tumours and lymphomas demands a high degree of professional expertise. Evidence from paediatric units has indicated that the prognosis for many cancers treated in specialist units is better than for those treated outside, and for other cancers equivalent survival may be achieved with less toxicity in paediatric oncology units. There is now no place, in my opinion, for the treatment of cancers in adolescence in general cancer departments, whose experience of the tumour types is limited to one or two cases a year. Specialised orthopaedic or maxillo-facial surgery, experience in radiation of brain tumours and sarcomas in adolescence, familiarity with the intensive cytotoxic drug regimes which are increasingly employed and knowledge of when to stop treatment, are all essential. Skill is only acquired by constant exposure to the medical problems involved.

The adolescent cancer unit provides a physical structure for this medical expertise [1]. Multidisciplinary meetings are easier, and training of junior staff greatly facilitated. The patients have a location which they can contact easily and know that their problems will be understood and dealt with promptly and expertly. An atmosphere of kindly competence and professionalism goes a long way to developing the confidence and trust which must be established at the time when the diagnosis is made.

The emotional and psychological support of patients and their families requires experience, stamina and organisation. Teenagers enjoy the company of other patients of their own age

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with whom they can share their experience and anxieties. They learn from each other about the technical aspects of their treatment, and feel more in control of the treatment timetable. Many adolescents feel alienated both on paediatric oncology and adult cancer wards. Nursing and other medical staff on adult wards may have no special training in the needs of patients of this age. Issues such as hair loss, infertility, sperm banking and genetic causes of cancer, need careful and sensitive advice from medical staff who must themselves be fully conversant with the facts.

At diagnosis the parents and patients need to spend time with the medical team so that they can partly recover from the feelings of anxiety, fear and disbelief. At this stage the team must be able to speak with one voice—conflicting emphases are a further source of anxiety. Here again an adolescent unit comes into its own, since staff can discuss, among themselves, the attitudes of individual patients and their families. They can inform each other of advice and conversations they have had [2]. We have found it helpful to have a weekly multi-disciplinary meeting at which doctors, nurses, teachers, counsellors and social workers all meet to go through the events of the week and the problems which have emerged. At such meetings it is important that no single group or individual dominates the discussion, and that everyone's opinion is carefully considered.

Concentration of expertise in a teenage cancer unit, therefore, brings many advantages. There are difficulties of course, and these become apparent with experience. Because the patients come to know each other, they also know when adverse events, such as distant metastasis or local recurrence, occur to other teenagers undergoing treatment. These are traumatic outcomes not just for the patient but for other patients on the unit and their families. Staff must be aware of the anxiety that these events cause. For the same reason, when a teenager develops a metastasis, his or her reaction will be coloured by knowledge of what has happened to other patients.

The junior medical staff and nurses are often only a few years older than the patients. They frequently develop strong feelings about the teenagers, and may find it difficult to detach themselves from the patient's illness, especially when there are major setbacks such as relapse. All teenage units, therefore, need to establish support mechanisms for the staff. The role of the counsellors is important for both staff and patients [3]. The training and background of counselling staff is of less importance, in my view, than the person concerned and the experience he or she has acquired on the unit.

If untreatable relapse occurs, the responsibilities do not end with the conclusion of active treatment. The care of the adolescent continues at home, and it is essential both for the patient, and all those responsible for his or her care, that contact is maintained, and advice and support continued. Even after the death of a child, parents may wish to return to the unit to talk about the illness and to try to put it into context. Mourning and bereavement may continue for a long time [4], and staff need to be aware of the signs which indicate that parents or siblings need help. Parents self-help groups are being established which may be helpful both during treatment and after bereavement [5,6].

The late effects of cancer treatment in childhood and adolescence are assuming increasing importance. In the U.K. and other Western countries, approximately 1 in 1000 adults now have a history of cancer in childhood. Long-term organ toxicity of chemotherapy—cardiac, neurological, renal and haematological—are increasingly described as treatment regimens are intensified [7]. The consequences of cure of inherited cancers such as retinoblastoma [8] and Li–Fraumeni syndrome are emerging more clearly. Follow-up of adolescents (as for paediatric cases) should continue throughout life, and expert advice will be needed at times of major life decisions—marriage, planning a family, buying a house or working overseas. It seems that late psychological adaptation is, perhaps surprisingly, very good [9].

As in paediatric cancers, concern over long-term toxicity is leading to the development of prognostic indices in order to identify those patients where there is a high risk of death and treatment needs to be identified, and, on the other hand, those patients where cure is probable and the aim should be to reduce treatment toxicity without compromising long-term survival. In Ewing's tumour, for example, the presence of pulmonary metastases at presentation and large volume tumours are both very adverse prognostic factors [10]. The increasing complexity of management of the physical and psychological aspects of cancer in adolescents are the major reasons for the development of special facilities for care.

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