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ESSAYS/PERSONAL REFLECTIONS

Adolescents and young adults with cancer: The challenge

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Adolescence and young adulthood is a time of enormous change. For many young people, the profound shift from dependence to autonomy that is the hallmark of this period is physically, emotionally, and spiritually demanding. On the other hand, this phase of life is generally marked by an exuberant optimism that is the envy of jaded adulthood. This optimism, when coupled with intelligence, lack of respect for established forms, and iconoclastic energy, may be the source of a lifetime's achievement.

It is a feature of the age between 15 and 25 years that death appears unreal. Many young people in this age group are reckless and, with a sense of immortality, are keen to experience what life has to offer. Not surprisingly the major killer of young people in Western countries is violence and road accidents. Young adulthood is also a time when life is to be conquered, not submitted to. Not for the young, the meek acceptance of what life has to offer! I want a dollar for each time I have heard a young person say: "If I ever get like that [gesturing contemptuously at the decrepitude of old age], put me down." Age habituates one to physical weakness.

So what about cancer? It is not widely appreciated that cancer is the most common nonviolent cause of death in young people in the West. At both a social and an individual level, a diagnosis of cancer in a young person is incongruent: the prospect of death at a time of greatest exuberance and potential. It just doesn't seem right. Enormous time, energy, and money are expended on pediatric cancer. The ratio of oncologist to patient in pediatric cancer is 10 times greater than in adulthood. By unanimous agreement, children are generally cared for at single institutions, where clinical trials, experienced clinicians, and psychosocial resources are concentrated. To their credit, the pediatric community, in the United Kingdom and elsewhere, has moved to develop units specifically caring for young people with cancer. The problem is that the over 90% of 18–25-year-olds with cancer are not treated at pediatric institutions.

In the state of Victoria in Australia, there are 160 new cases of pediatric cancer diagnosed annually, but over 21,000 new cases of adult cancer. Cancer remains a disease of old age, and unsurprisingly, the medical health system is overwhelmingly geared to treating and researching the common cancers of aging: breast, bowel, lung, prostate, and pancreas. These patients are treated at a multitude of centers, and there is often little consistency in patterns of care. For adult cancers that are not common, dilution of expertise and experience may result in poorer survival, because caseload corresponds to outcomes in so many areas of medicine.

Fortunately, adolescent and young adult cancer is not common. There are 360 new cases a year in Victoria. Moreover, the cancer types seen in adolescents and young adults are often distinct from those seen in pediatric settings or adult centers. In some cases these cancers are so rare that useful trials present enormous challenges. For example, pediatric cooperative oncology groups run trials of Ewings sarcoma in the pediatric population, leading to underrepresentation of young adults in these studies. We must be wary of assuming that the results of pediatric studies can be extrapolated to adolescents and young adults, particularly because the clinical results for many cancers in adolescence and in young adults are generally worse than for pediatric patients. We simply do not know why this is

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so, and only increasing the participation of young people in clinical trials will answer such questions.

Psychosocial supports are no less adversely affected, as outlined in the article in this issue by Palmer et al. There is a tendency for adolescents and young adults to be treated as though they were big children. This is why an oncologist would direct her explanations to the mother of a 17-year-old, rather than the 17-year-old himself. Conversely in adult institutions, ward routines frequently fail to recognize the need for the 17-year-old to have his mother near him overnight. In both circumstances, young people may appear "difficult": Or is it that our failure to address the needs of young people leads to perceived problems? There is abundant evidence in other illnesses, such as juvenile diabetes and cystic fibrosis, that adolescence is associated with problems of adhering to treatment. Because levels of awareness in adult cancer centers are not high for issues such as drug use, domestic and sexual abuse, education, peer supports, and sexuality, an adolescent in an adult ward may flounder.

It is interesting and significant that death was not mentioned by the young people who participated in the study by Palmer et al. Perhaps this is because death appears as incongruent to young people with cancer as it does to the rest of us; or perhaps there is a sense of taboo; or maybe the lack of exposure to death of young people today leaves them without sufficient experience to make comment. Whereof we cannot speak, we must be silent. There is no doubt that palliative care is among the most challenging of the many challenging aspects of caring for young people with cancer. How is death to be reconciled with youth? It is very moving to witness young people who, fully aware of death, pack a lifetime's experience into a few short months. It is difficult to describe it, let alone prescribe it, but I have seen that it is possible to achieve a "good" death, even in the young.

The issues in adolescence and young people with cancer run the gauntlet from physical to psychological. Moreover, the age group is not homogeneous. A patient may vary from an immature 15-year-old to a 25-year-old with two children; from a 16-year-old living on his own to a 27-year-old living at home. We must recognize the many areas where more work is needed and then set about that task. We advocate establishment of adolescent and young adult cancer units, particularly within "adult" cancer centers such as now exist at the Peter MacCallum Cancer Centre. Such a unit could concentrate skills necessary to answer questions of host genetic factors, disease biology and pharmacokinetics in puberty, and treatment regimens, provide adequate caseload to ensure optimum outcome, and provide age- and stage-appropriate psychosocial support.

That is the challenge of adolescents and young adults with cancer.