

Young Adult Cancer Patients

GEOFF EATON

Each year in Canada, at least 6500 young adults in the age group 15–39 are diagnosed with some form of cancer. The most common malignancies in young females are cancers of the breast, cervix, and ovaries; while in young males testicular cancer is followed by non-Hodgkin’s lymphoma. For unknown reasons, some malignancies are increasing among young adults of both sexes including cancers of the thyroid, lung, brain, and non-Hodgkin’s lymphoma in young women and testicular cancer in young men. Young adults are also affected by the more common cancers.¹

The numbers are relatively small, but do not give a true reflection of the potential years of life lost to society, nor the cost to each individual having to deal with cancer at this young age. The cost can be better estimated in terms of Potential Years of Life Lost or PYLL. This metric evaluates the societal impact of any given disease by calculating the lost potential of those dying between the ages of zero and 70. As shown in Table 1, the incidence of cancer in the age group 15–39 in 2002 was only 10 per cent of that in older age groups² (9.1 per cent versus 89.7 per cent) but the PYLL is 28.3 per cent of the total PYLL from cancer.

For many years the prognosis for adolescents and young adults with cancer compared favourably with

that for both younger and older patients. However, over the period 1975–1997 not only did adolescents and young adults develop more cancer, but improvements in survival in this age group failed to keep pace with improved outcomes seen in children and older adults. The data are shown in Figure 1. There are several reasons for the disparity in survival between this age group and the others.

One factor generally recognized as contributing to the disparity is the paucity of age-specific clinical research. It is well recognized that survival rates among participants of structured clinical trials are uniformly higher than in the general population of cancer patients, and that clinical research in general improves survival. Approximately 30 to 50 per cent of cancer patients under the age of 15 participate in clinical trials, compared to only about one to two per cent of young adults.³

In 2006, the Canadian Institutes of Health Research, the National Cancer Institute of Canada (funded primarily by the Canadian Cancer Society) and the Terry Fox Foundation invested, in the aggregate, \$76-million in newly funded research studies for that year, as documented elsewhere in this Report Card. A search for projects focusing on young adults with cancer identified exactly one grant, approved for \$61,061 (0.08 per cent

TABLE 1 **PYLL* vs. CANCER INCIDENCE FOR VARIOUS AGE GROUPS** – 2002 DATA

AGE RANGE	PYLL	% OF TOTAL PYLL	INCIDENCE	INCIDENCE %
0-14 years	56,000	6.0%	845	1.1%
15-39 years	263,000	28.3%	6,817	9.1%
40-69 years	610,000	65.7%	66,930	89.8%
TOTAL	929,000		74,592	100 %

*PYLL Potential Years of Life Lost

Adolescent and young adult cancer survivors indicate that a defining feature of their illness was a feeling of profound isolation

of the total). The proposal was to study preservation of fertility in female cancer survivors.

Notwithstanding the fact that results from other cancer research will at times benefit young adults, the group under consideration has unique problems that merit special attention. It is possible, for example, that treatments tested in older adults are not as well suited to the biology of the cancers occurring in younger adults. Some as yet unrecognized biological factors may well be operating which disadvantages young adults from the outset, for example, more aggressive tumor biology, different hormonal milieu, different rates of metabolizing drugs, etc.

Furthermore, young adults might benefit from and be able to tolerate more aggressive and more effective treatments than older adults. The therapy they currently receive from oncologists accustomed to treating older patients is generally less aggressive than that administered by pediatric oncologists to children with the same malignancies. International studies indicate that adolescents treated in pediatric centres have much better outcomes than if they are referred to adult treatment centres.⁴ Hopefully, the young adult oncology program pioneered at McGill University Health Centre under the direction of Dr. Petr Kavan will serve as the model for others to follow to see whether advantage can be taken of this aspect.

Thus a combination of factors may be conspiring against this patient group to tip the scales against their odds of survival. Inadequate participation in trials, lack of age-specific protocols, a cancer which may behave more aggressively, a different physiologic milieu, reduced treatment dose intensity, delays in diagnosis, and treatment inappropriate for their particular malignancies may all be operating.

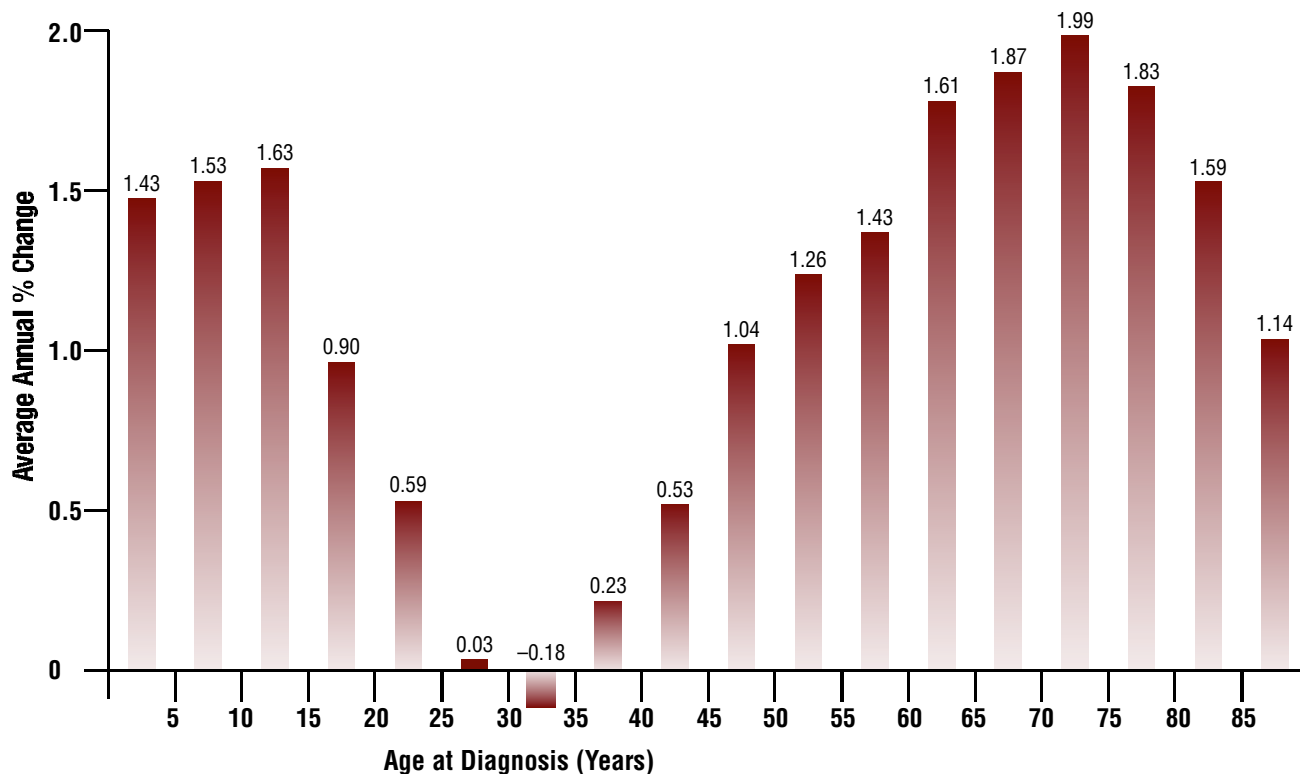
A diagnosis of cancer also has important age-specific psychosocial ramifications for adolescents and young

adults different from those seen in children or older adults. Young adult cancer patients report encountering systems at all levels geared to individuals two or three times their age, producing feelings of profound isolation. Compounding this is the small number of peer-support programs for young adults with cancer. For example, CACC could identify only four major cancer centres (Victoria, Vancouver, Winnipeg, and Ottawa) that had support groups open to young adults which met on at least a monthly basis. Even these were somewhat restricted. In Victoria the support group was for women only, in Vancouver the support group was only for patients with breast cancer while in Ottawa the support group accepted only cancer survivors treated at the Ottawa Regional Cancer Centre.

The survey uncovered three additional support programs: two offered sporadically throughout the year and one, at the Princess Margaret Hospital, offered daily childcare to patients receiving treatment. In contrast, the Princess Margaret Hospital has 23 support programs targeted at various segments of the adult population. The survey also revealed only five additional support groups run by community based organizations in Vancouver, Toronto and Montreal.

The personal challenges faced by young adult cancer survivors are also unique. Looming large, just as adult life supervenes, are issues related to fertility preservation and a struggle for physical and financial independence. Compounding these issues is the isolation of young patients from survivor peers who truly understand the challenges they face. In fact, a recent study revealed that young adults place a higher value on a connection with survivor peers than support from family and friends.⁵ With so little support designed to meet their unique needs, small wonder that adolescent and young adult cancer survivors indicate that a defining feature of their illness was a feeling of profound isolation.

FIGURE 1 **CHANGE IN 5-YEAR RELATIVE SURVIVAL RATE OF ALL INVASIVE CANCER, SEER, 1975–1997**



Source: Cancer in Young Adults, 2006

Recommendations

A shift of at least a subset of young patients to treatment in specialized centres is in order which, as mentioned earlier, is being undertaken at McGill University Health Centre. This would not only reduce delays in diagnosis and treatment, it might also lead to more appropriate treatment, and ultimately better survival if some of the following areas were investigated as they apply to individuals aged 15–39:

- 1 Age-specific differences in the biology of selected malignant diseases,
- 2 Barriers to development of and accrual to clinical trials,
- 3 The impact on survival, quality of life, and delayed side effects of treatment of specially tailored oncology programs, and
- 4 Unique psychosocial issues.

Acknowledgements

The author would like to extend special thanks to Dr. Anthony Miller, a former CACC Board member now chair of the CPAC Quality and Performance Assurance Action Group, Dr. Mark Greenberg at the Pediatric Oncology Group of Ontario, Karen Joblin and the various professionals in cancer centres across the county for the help they graciously extended in the research for this article.

References

1. Cancer Care Ontario: Cancer in Young Adults in Canada, Toronto, Canada, 2006. May 2006, ISBN 0-921325-10-X (print), ISBN 0-921325-11-8 (pdf)
2. Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries, Health Canada: Canadian Cancer Statistics 2002
3. Archie Bleyer, Aaron Viny, Ronald Barr: Cancer in 15 to 29 Year-Olds by Primary Site, *The Oncologist* 2006; 11: pgs 590–601; doi:10.1634/theoncologist.11-6-590
4. Jennifer Couzin: In Their Prime, and Dying of Cancer, *Science*, August 31, 2007; 317: pgs 1160–1162
5. Brad Zebrack, Archie Bleyer, Karen Albritton, Sandra Medearis, Julia Tang: Assessing the Health Care Needs of Adolescent and Young Adult Cancer Patients and Survivors, Wiley InterScience, November 13, 2006, online www.interscience.wiley.com pgs 2915–2923

© 2008, Geoff Eaton. Used with the kind permission of the author.