My 12-year-old daughter recently visited Children’s Hospital on a school field trip for science class. Although the purpose of the visit was to peer into the microscopes in the hospital laboratory, my daughter and her classmates saw several children in the waiting areas and hallways. Many were presumably being treated for cancer, which prompted the class’s collective response of “it’s so sad, seeing all those bald kids who are going to die.”

Happily, I could tell my daughter and her classmates that not all children with cancer die these days. In the United States, the five-year survival rate is now about 78%, and the number of childhood cancer survivors alive today is estimated to be at least 270,000 (Reis et al., 2002). Similar childhood cancer survival rates have been reported in Canada and Europe (Population and Public Health Branch, Health Canada, 2003).

Although most children survive cancer, it doesn’t mean easy sailing. A report from the National Cancer Policy Board of the Institute of Medicine (IOM), Childhood Cancer Survivorship: Improving Care and Quality of Life, indicated that about two-thirds of all childhood cancer survivors experience one or more late effects of treatment, such as second cancers, endocrine disorders (including infertility), and cardiopulmonary, renal, or other organ system impairment. One-fourth experience late effects that are severe or life threatening (IOM National Research Council, 2003).

Research study findings on long-term survivorship are increasingly being reported in the literature. Hudson et al. (2003) assessed the health of 9,535 survivors of childhood cancer who were diagnosed from 1970–1986 and compared them with 2,916 survivors’ siblings. Survivors of childhood cancer reported poorer general health, activity limitations, functional impairment, and worse mental health when compared to the siblings, and 44% of the survivors reported at least one adversely affected health domain (Hudson et al.). Post-traumatic stress disorder also has been noted when compared to the siblings, and 44% of the survivors reported at least one adversely affected health domain (Hudson et al.). Post-traumatic stress disorder also has been noted when compared to the siblings, and 44% of the survivors reported at least one adversely affected health domain (Hudson et al.).

Late effects of childhood cancer treatment arise years after treatment, becoming symptomatic with disease progression. These late effects are sometimes treated by childhood cancer specialists; however, many of these late effects, such as osteoporosis, renal dysfunction, or psychosocial distress, are treated by primary care physicians and specialists in fields other than oncology. The care of childhood cancer survivors is consequently fragmented in many cases and information about long-term survivorship is often not available to be collectively analyzed. IOM recommended the following seven strategies for improving long-term follow-up of childhood cancer survivors.

- Develop evidence-based practice guidelines for the care of childhood cancer survivors.
- Define standards for comprehensive follow-up care that link primary care providers with childhood cancer specialists.
- Increase the awareness of late effects of childhood cancer treatment.
- Improve healthcare providers’ knowledge of late effects and their management.
- Enhance childhood cancer survivors’ access to resources.
- Increase research funding support aimed at preventing or managing long-term treatment effects.
- Support the Maternal and Child Health Bureau of the Federal Health Resources and Services Administration in implementing the Healthy People 2010 goals for children with special healthcare needs.

Healthcare providers caring for childhood cancer survivors need to be informed about the late side effects of treatment and remain vigilant in detecting them. However, as childhood cancer survival rates increase, so does the need to monitor adults for late physical and psychosocial treatment side effects.

References


