

# Foreword: Looking Beyond Cure: Pediatric Cancer as a Model

Julia H. Rowland, PhD

Office of Cancer Survivorship, National Cancer Institute, National Institutes of Health, Department of Health and Human Services, Washington, DC

In treating and controlling cancer, the most dramatic evidence of progress is that seen in childhood cancer. Once almost uniformly fatal, pediatric cancer has become a commonly curable illness in the last 30 years. For children diagnosed with cancer, the current 5-year cancer-free survival rate is 79%, and the 10-year survival rate is approaching 75% (Rowland et al., 2004). These figures already surpass the U.S. Department of Health and Human Services (2000) Healthy People 2010 goal (Rowland et al., 2004) of 5-year survival for 70% of those diagnosed with cancer, and they exceed that for the adult population, where 5-year survival currently stands at 64%. Although pediatric cancer survivors currently represent less than 2% of the 9.8 million cancer survivors in the United States, they are in many respects the vanguard of survivorship. [B3] With the growing population of those living years beyond a cancer diagnosis, survivorship has emerged as an important field, leading to the establishment in 1996 of the Office of Cancer Survivorship at the National Cancer Institute, charged with expanding, directing, and championing cancer survivorship research and education.

A number of activities in the national arena have helped fuel interest in survivorship. In 2003, the Institute of Medicine released its report *Childhood Cancer Survivorship: Improving Care and Quality of Life*. In collaboration with the Lance Armstrong Foundation, the Centers for Disease Control and Prevention produced *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* in April 2004. The President's Cancer Panel—after devoting 2 years to collecting testimony from survivors and their family members; health care providers; and payors, advocates, and policymakers—released its report *Living Beyond Cancer: Finding a New Balance* in June 2004. Meanwhile, no fewer than six bills have been advanced in Congress from members of the

House and the Senate that include language calling for increased research and resources to address cancer survivorship.

The fact that so many young patients live long enough to become young, even aging adults is certainly one explanation why pediatric oncology clinicians and researchers are among the leaders in identifying the chronic and late effects of cancer and their treatment. Even when the survival figures were not as favorable as they are now, pediatric oncology practitioners recognized that curing a child was not enough (D'Angio, 1975). They understood that they also had an obligation to ensure that the quality of children's lives were as important as their length. As a consequence, we now have a wealth of information documenting that for this growing population of cancer survivors, being cancer-free does not mean being free of cancer's effects.

As evident in the important collection of papers in this issue, pediatric researchers, including many psychologists, were among the first to identify and characterize the long-term and late-presenting effects of curative therapies on a range of areas affecting survivors' health: neurocognitive status; endocrine, cardiac, and pulmonary function (including reproduction); physical and physiologic growth; psychosocial adjustment; health behavior and lifestyle choices; and risk for second malignancies.

More important, as news of specific complications became available, pediatric cancer teams sought to translate these data into practice. They actively modified protocols to reduce children's exposure to potentially adverse iatrogenic effects of curative attempt by

- reducing the dose of, or exposure to, chemotherapy or radiation when possible;
- modifying drug selection in favor of agents with less long-term toxicity;

All correspondence should be sent to Julia H. Rowland, PhD, Director, Office of Cancer Survivorship, National Cancer Institute, 6130 Executive Blvd, Room 4086, Bethesda, Maryland 20892. E-mail: rowlandj@mail.nih.gov.

*Journal of Pediatric Psychology* 30(1) pp. 1–3, 2005  
doi:10.1093/jpepsy/jsi010

*Journal of Pediatric Psychology* vol. 30 no. 1 © Society of Pediatric Psychology 2005; all rights reserved.

adding protective agents (when available) when prescribing certain drugs, to minimize risk to specific organs; and  
 adopting approaches during radiation, such as moving reproductive organs out of a radiation field, to minimize postradiation risk.

Today, the pediatric oncology community is once again being challenged to look beyond the search for new curative therapies and to serve as champions for quality of life throughout the survivor's lifetime. In response, its members have taken the lead in developing guidelines for the comprehensive follow-up care of their young survivors (Children's Oncology Group, 2004). These recommendations go beyond those typically developed for adult cancer survivors which emphasize surveillance monitoring for recurrence, to stress the importance of screening for and treating chronic and delayed effects of treatment; reducing the risk of second malignancies where feasible; and promoting the adoption of healthy behaviors and lifestyles. As outlined in the following articles, many of the recommendations being advanced draw on the published evidence documenting chronic and late effects as well as their interventions.

Understanding and treating cancer in adults can be informed by the many lessons learned in the pediatric setting. First, the focus of care in pediatrics always includes the family. Most pediatric oncology settings are organized and staffed to address the needs of parents and siblings as well as those of the patient. Although family members and caregivers are playing an increasing role in providing care in the adult setting, they are by contrast rarely afforded assistance in executing these responsibilities. We have seen this burden escalate with the migration of cancer care into the outpatient setting. Despite this, the cost of family/caregiver health and well-being remains largely undocumented. Given that social support is consistently shown to benefit people's health outcomes (Cohen & Syme, 1985), a major gap in our current delivery system appears to be a failure not only to address the needs of these individuals and networks but to leverage them as well.

Second, in caring for children, pediatric clinicians are trained to be attentive to developmental issues that may be affected by illness. When formulating therapy plans, they routinely focus on a given therapy's potential adverse effects on organ growth and function and on the future social and intellectual capacity of the pediatric cancer patient after therapy is completed. In the adult arena, consideration of functional outcomes has been less emphasized. Concern about starting treatment for an adult often takes precedence over what long-term

impact it may have on fertility and sexuality, family, work and social roles, and economic status. As a consequence, late-effect considerations, such as sperm or ovarian tissue banking to preserve the option of parenthood, are addressed later than they should be—too often after the initial decision-making process, when treatment has already commenced.

Third, in the pediatric setting, treatments are tailored to take into account the patient's age and functional status (current and future). Further, when new information on adverse treatment effects becomes available, the pediatric oncology community is generally quick to translate it into modifications of standard therapy. By contrast, adult oncologists may recommend treatments based on inadequate knowledge or faulty assumptions about a patient's potential life span, preferences, or likelihood of an active lifestyle. With a healthier aging population, knowing that a person is 75 years old tells us little about his or her health. The expectation is that those treated today will live years after their diagnosis. It is therefore becoming more important—and increasingly demanded by patients themselves—that therapies enable people to pursue life goals and meaningful activities. To be responsive to this demand, adult practitioners need to emulate their pediatric colleagues: they need to draw on the new body of research regarding adult survivors' health-related quality-of-life outcomes to inform current decision making and the development of future treatment protocols.

Fourth, pediatric oncologists are attentive to the language they use when talking about cancer and its treatment, being aware of the different levels of understanding regarding illness and death that children and adolescents bring to their care. Oncologists routinely modify their communication so that it can be understood by, and be appropriate for, each patient's chronological age and emotional maturity. Adult oncologists rarely receive specialized training in how to communicate with their patients (Simpson et al., 1991). This oversight continues despite the increasingly complicated decision-making process, consequent to the growth of available treatment options and to the indisputable evidence that effective communication is imperative to optimal patient outcomes (Arora, 2003).

Fifth, pediatric oncologists are aware that treatment can create ongoing challenges to patients and families, even years after treatment has finished. More than two dozen programs and clinics have already been established that offer an array of medical and nonmedical services to meet these needs. As part of this effort, the pediatric community is actively exploring the issue of which physicians should follow treated patients. Health

care insurers often require that ongoing surveillance and posttreatment follow-up be reverted to patients' primary care physicians after a specific period. These subsequent physicians may be less familiar than the oncologists are with how to follow patients for late effects, such as risks based on psychosocial issues, genetics, and applied therapies (including surgery, radiation, and chemotherapy). Non-oncology specialists who care for adult survivors of pediatric cancer may not consider how treatments given years ago may put patients at increased risk for diagnostic and therapeutic procedures delivered later in the patients' lives. For their part, many survivors are unaware of the different treatments they received and their associated risks for future health conditions (Kadan-Lottick et al., 2002). Currently, the Children's Oncology Group is working to refine and promote the use of a standardized treatment summary form, to be provided to patients and their families at the end of therapy. If broadly adopted, this practice model could help ensure that survivors of all ages and their future health care providers are given the information necessary to discuss, design, and receive/deliver optimal ongoing care.

In the adult arena, many survivors need to be followed for life after treatment ends. We are only beginning to recognize that need, much less worry about who should meet it or how it should be done. This need is particularly acute for those treated below the age of 65, for whom the effects of surviving cancer may represent a major source of morbidity. To date, only a handful of programs across the country have been specifically designed to meet the follow-up needs of adult survivors posttreatment, although this situation is slowly changing (Tesauro, Rowland, & Lustig, 2002).

If applied, these valuable lessons hold the promise of advancing the science and art of adult cancer care. They might also help adult cancer survivors achieve the same dramatic improvements in length and quality of life now possible for pediatric cancer survivors.

*Received May 5, 2004; revisions received May 5, 2004; accepted June 8, 2004*

## References

- Arora, N. K. (2003). Interacting with cancer patients: The significance of physicians' communication behavior. *Social Science and Medicine*, *57*, 791–806.
- Children's Oncology Group. (2004, March). *Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers* (version 1.2). Retrieved September 16, 2004, from <http://www.curesearch.org/pdf/LTFUGuidelines.pdf>
- Cohen, S., & Syme, S. L. (Eds.). (1985). *Social support and health*. Orlando, FL: Academic Press.
- D'Angio, G. J. (1975). Pediatric cancer in perspective: Cure is not enough. *Cancer*, *35*, 866–870.
- Kadan-Lottick, N. S., Robison, L. L., Gurney, J. G., Neglia, J. P., Yasui, Y., Hiyashi, R., et al. (2002). Childhood cancer survivors' knowledge about their past diagnosis and treatment. *Journal of the American Medical Association*, *287*, 1832–1839.
- Rowland, J. H., Mariotto, A., Aziz, N. A., Tesauro, G., Feuer, R., Blackman, D., et al. (2004). Cancer survivorship—United States, 1971–2001. *Morbidity and Mortality Weekly Report*. Vol. 53, No 24, 526–530.
- Simpson, M., Buckman, R., Stewart, M., Maguire, P., Lipkin, M., Novack, D., et al. (1991). Doctor-patient communication: The Toronto consensus statement. *British Medical Journal*, *303*, 1385–1387.
- Tesauro, G. M., Rowland, J. H., & Lustig, C. (2002). Survivorship resources for post-treatment cancer survivors. *Cancer Practice*, *10*, 277–283.
- U.S. Department of Health and Human Services. (2000, November). *Healthy people 2010: Understanding and improving health* (2nd ed.). Washington, DC: U.S. Government Printing Office.
- U.S. Department of Health and Human Services. (2000, November). *Healthy people 2010*, 2nd ed.: *With understanding and improving health* (2nd ed.). 2 vols. Washington, DC: U.S. Government Printing Office.

