Commentary: Psychosocial Functioning of Children and Adolescents
Surviving Cancer: The Junior Investigators’ Perspective

Eugene A. Meyer,1 PsyD, and Bernard F. Fuemmeler,2 PhD, MPH
1Department of Pediatric Oncology, Dana-Farber Cancer Institute and Children’s Hospital, Boston, and 2National Cancer Institute, Health Promotion Research Branch

In their articles, Patenaude and Kupst (2005) and Kazak (2005) have aptly provided the next generation of pediatric psycho-oncologists with not only a thorough review of how far we have come but also a direction for future research in the field of pediatric psycho-oncology. Patenaude and Kupst highlight that although substantial progress has been made in a relatively short period, we are only beginning to understand what the psychosocial needs of patients and their families are and how to address them. In both articles, the authors comment that as methods of treatment for cancer have improved and as length of survival has increased, the needs of children and families have changed. For instance, Kazak points out that advances in pharmacological treatments for pain management have decreased the need among some patients for traditional cognitive behavioral therapy for pain management. Patenaude and Kupst point out that as length of survival increases, the need for management of late effects—for example, neurocognitive deficits, infertility, cardiotoxicity—is quickly becoming a burgeoning area of study. Other pertinent issues for children with cancer and their families are decision making regarding treatment options, patient-provider communication, end-of-life care, genetic counseling, and the need to reach out to racial and ethnic minority groups. There is also a need to develop innovative psychosocial interventions that can be feasibly disseminated in practice.

An area of research that has yet to be explored in psycho-oncology is the concept of “burden” related to treatment and survivorship. As trends in pediatric oncology continue to emphasize outpatient care over inpatient care, home-based support services over clinic support services, and the growing potential for oral versus intravenous chemotherapy, patients and families are likely to experience an increase in their amount of burden, including that of care, psychological well-being, financial management, and compliance and adherence. Additionally, as the survivors of today transition through the stages of life, there will be a need to understand the extent and type of burden subsequent to disease and medical treatment that is placed on the survivors and their family members in regard to securing health insurance, education, employment, and social relationships. Such research has potential for informing health care (acute and follow-up) and for guiding survivors’ long-term planning. Attention to the transition into adulthood will likely need to include a focus on how best to promote optimal health and avert health behaviors that compromise the quality of survival—namely, smoking, poor diet, and physical inactivity. There may be “teachable” moments (e.g., as children end treatment) when the delivery of such health messages may have a more robust effect. Strategies to reach and communicate such messages with this growing cohort of survivors will need to be better developed and implemented.

To address these emerging issues, young investigators will need to build on the foundation of extant research in pediatric psycho-oncology and develop new theories, improve methodology to obtain meaningful data, and continue efforts to develop evidence-based interventions. Young investigators in pediatric psycho-oncology will need to ask whether current theoretical frameworks are sufficient to guide research questions and hypotheses. For example, areas of research emphasis in long-term cancer survivorship are shifting to include long-term psychosocial effects, health behaviors, posttreatment surveillance, and health care utilization (Aziz & Rowland, 2003). What are needed are theoretical frameworks that address the trajectory from illness, to treatment, to long-term survivorship. Frameworks that address posttraumatic growth or maintenance of health behavior change may
need to be studied, as well as their utility to research in pediatric psycho-oncology.

With regard to methodology, there is a need for continued improvement and advancement in the ways that we gather data. Traditional measures of psychopathology are not adequate in capturing the experiences of children with cancer and their families. To better capture the adjustment and resiliency of children and families to the cancer experience, young investigators in pediatric psycho-oncology will need to become proficient at developing, validating, and evaluating measures relating to quality-of-life issues and adaptive functioning in the context of survivorship and acute treatment. Becoming involved in organizations such as the International Society for Quality of Life Research or developing working relationships with established leaders in the field will ensure the attainment of such goals. Finding new ways to use such technology as the Internet and personal digital assistants to our advantage in research may become critical as the practice of oncology continues the shift from inpatient care and frequent, lengthy clinic visits to brief outpatient appointments and home treatment protocols.

Young investigators will need to sharpen their skills in intervention development, evaluation, and dissemination. To accomplish this, they will need to be proficient at conducting efficacy and effectiveness trials. That is, not only will they need to evaluate whether a treatment or service is effective, but they will also need to conduct “practice research,” which is the process of investigating how treatments or services can be delivered to large cohorts of patients and how the delivery can be improved or enhanced (Roberts, 2003). An example might be evaluating the usability and diffusion of brief evidence-based psychosocial interventions or health promotion programs that could be delivered by non–mental health care professionals.

Although psychologists have successfully negotiated the initial integration into medical settings, an additional step is required by the next generation of researchers and clinicians to advance the field of psycho-oncology. For junior investigators who are beginning their careers in psycho-oncology, it has become apparent that specialized training and education is needed. While maintaining a solid grounding in child clinical psychology, additional education and training in fields such as public health, prevention science, and quality-of-life research have the potential to enhance the developmental, behavioral, and systems perspectives obtained through doctoral training as psychologists. This additional training could occur through course work, certification programs, or specialty rotations in internship or fellowship programs. Further, seeking senior mentors from within the pediatric psycho-oncology discipline as well as from different fields of study could be helpful in maximizing didactic postdoctoral training and education. Mentoring programs such as the one recently established by the psychology committee of the Children’s Oncology Group provide an excellent opportunity for junior investigators to receive guidance from established senior psycho-oncologists. Funding mechanisms also exist through the American Cancer Society’s Research Scholar Grants and the National Cancer Institute’s Mentored Research Training Program (i.e., K-07 and K-22) to help junior investigators become independent investigators in the field.

Creating a career that is entirely centered on pediatric psycho-oncology is extremely challenging. Entrance into this field most often occurs through general clinical pediatric psychology positions that include oncology as only a small part of the job responsibility. Such division of responsibilities makes it difficult to devote full-time effort to building a program of research in pediatric psycho-oncology. Additionally, if the pediatric psychology position is in a small hospital, it may be difficult to secure an adequate sample size of participants for most research projects. Another challenge of being in a small or rural hospital is that the junior investigators might find it difficult to identify experienced mentors or collaborators on-site or may find themselves in the position of “breaking ground” for psycho-oncology research at that hospital. For example, in some settings, there may be a need to work on integrating psycho-oncology research within a treatment-oriented clinic that has thus far not had the opportunity to experience the potential benefits of such research and collaboration. Young investigators who find themselves in these positions will need to build collaborative relationships with pediatric psycho-oncologist from other hospitals.

Although a career including psycho-oncology research may be challenging to develop for the reasons discussed, none of the existing barriers are insurmountable. Being cognizant of the changing needs of patients, using theoretical frameworks to guide research, improving measurement and research methodology, finding ways to translate and disseminate efficacy research, and gaining additional expertise beyond the doctoral degree are some strategies that may be helpful in addressing these barriers. There is still much to learn in the field of pediatric psycho-oncology. As the provision of services in pediatric oncology change and as the needs of patients and families change, a host of new and exciting research directions and questions are emerging. Attaining a fruitful
career and solid program of research in the dynamic field of pediatric psycho-oncology is possible with a flexible, creative, and innovative approach to training, collaboration, and research.

Received February 15, 2004; revisions received April 6, 2004; accepted June 8, 2004

References


Note

1 Bernard F. Fuemmeler is a fellow in the Cancer Prevention Fellowship Program, Division of Cancer Prevention, National Cancer Institute, National Institutes of Health. The views expressed in this article are those of the authors and do not necessarily reflect the official policy of the National Institutes of Health, the National Cancer Institute, or any other component of the United States Department of Health and Human Services.