Introduction to the Special Issue: Surviving Pediatric Cancer: Research Gains and Goals

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Nearly every review of the research literature in pediatric oncology describes the significant progress of medical treatment over the past 30 years resulting in the increased survival rate for children and adolescents with cancer. Concurrent with these medical advances, a vast amount of research has emerged in an area that has come to be known as “pediatric psycho-oncology.” From these studies we have learned a great deal about the neurocognitive and psychosocial functioning of children, adolescents, and young adults with cancer and their families. The field has progressed from strictly descriptive studies of adjustment to more explanatory research and to development of interventions to improve functioning. It is an apt time for an overview of the progress made, the current state of the science, and the perspectives on future directions. We believe that such a review can offer lessons that will benefit not only the researchers who work in pediatric oncology but also those who work with children coping with other life-threatening and chronic diseases.

The impetus for this special issue began with the merger of the two largest cooperative clinical trials groups in pediatric oncology—the Pediatric Oncology Group and the Children’s Cancer Group—as well as two disease-focused groups: the National Wilms Tumor Study Group and the International Rhabdomyosarcoma Study Group. Many psychologists have been actively involved in these groups’ research studies and have come together to form the psychology discipline of the new group, the Childhood Cancer Group (COG). As coprincipal investigators, we were pleased to receive funding from the COG and the National Cancer Institute to develop a research summit on the state of the science in pediatric psycho-oncology, which was held in San Antonio, Texas, October 2001. As a result of the summit and with encouragement from Ron Brown, the editor of this journal, we called for papers that reviewed current literature and that incorporated discussions from the summit. Following peer review, we invited commentaries on the submitted papers—hence, this special issue.

As colleagues who have been working in this field over the past 30 years, we have been pleased to edit this special issue and to work with such productive and thoughtful senior and junior investigators to provide a critical overview of the field. Because we wanted to include viewpoints spanning this 30-year period, we invited papers from senior researchers, who began their careers when survival rates were lower and when little was known about coping, adaptation, and neuropsychological functioning; and from junior investigators, whose careers started on the foundation of recent treatment and research advances and who may therefore have different views on current findings and future directions. We believe that the perspectives of these researchers are generally representative of the field at large, but we also encourage readers to review the articles by the many pediatric psycho-oncology authors who are listed in the authors’ extensive bibliographies.

The neurocognitive and psychosocial sections are separated in this issue, but their subjects should always be considered intertwining aspects of the child’s total functioning. Although neurocognitive functioning can be considered an endpoint, as it defines the capacities and limitations placed on the child as a result of disease and treatment, it is also an intermediate endpoint. Research often necessitates separating neurocognitive or specific psychosocial variables such as depression; however, it is important to remember that in the lives of cancer survivors, neurocognitive and psychosocial variables are interdependent and that our goal as researchers is to optimize each survivor’s overarching quality of life.

In the neurocognitive and psychosocial sections of this issue, the first paper is devoted to an overview of the state of the science and the second paper to current intervention research. The section entitled “Enhancing the Research Environment for the Future” begins with a paper about psychological research in the clinical trials
groups, as this is where most of the medical treatment and research occur in pediatric oncology. Given that global collaboration is increasingly important, the second paper in this section focuses on a view of the international research in pediatric psycho-oncology. Following these papers in each section are two commentaries, one by a senior researcher and one by a relatively new investigator.

In her forward “Looking Beyond Cure: Pediatric Cancer as a Model,” Julia Rowland, director of the Office of Cancer Survivorship at the National Cancer Institute, has written an inspiring summary of progress in pediatric psycho-oncology research. Dr. Rowland is a highly respected researcher in pediatric and adult psycho-oncology and a valued author and editor of the *Handbook of Psychooncology* (1989). She notes as exemplary several aspects of the way research in pediatric psycho-oncology is conducted, and she endorses tailoring the communication between pediatric providers and patients/patients’ families. Dr. Rowland encourages researchers to appreciate and translate the “valuable lessons” that pediatric psycho-oncology research has provided, and she suggests that progress in pediatric psycho-oncology could well serve as a model for similar advances in the psychosocial treatment of adult cancer patients.

In our “Psychosocial Functioning in Pediatric Cancer,” we trace the historical roots of psychosocial research in pediatric oncology from a period when honest communication with children about their illness was discouraged to the active involvement of patients and parents today. We discuss the need for research that addresses the quality-of-life impact that late effects of cancer treatment have on the lives of survivors, such as infertility. We consider the benefits of and hurdles to longitudinal research, and we discuss various methodological challenges in pediatric psycho-oncology. Despite the hurdles, we conclude with assurances that there remain many important and interesting areas of study in this field.

That a review of intervention studies exists is an indicator of how far the field of pediatric psychosocial oncology has come, from its nearly exclusive early focus on treating physical symptoms and supporting the terminally ill child. Kazak’s “Evidence-Based Interventions for Survivors of Childhood Cancer and Their Families” is a sensitive and comprehensive overview of recent and current social–behavioral interventions. It describes the growth of the field to a point where focused interventions can provide empirically supported treatments to improve specific aspects of pediatric cancer survivors’ quality of life, as well as that of their families.

The commentaries for the psychosocial section raise several fascinating issues. Phipps’s “Contexts and Challenge in Pediatric Psychosocial Oncology Research: Chasing Moving Targets and Embracing ‘Good News’ Outcomes” offers an honest and thoughtful discussion of the challenge for psycho-oncologists to keep up with research questions that change as medical treatment for children with cancer changes. He champions the advancement beyond earlier research that focused on treatment-associated symptoms, which now leaves room for the important study of the factors underlying the successful adaptation of many pediatric survivors. Meyer and Fuemmeler’s “Psychosocial Functioning of Children and Adolescents Surviving Cancer: The Junior Investigators’ Perspective” describes new approaches to studying the “burden” related to childhood cancer treatment and its sequelae, which persist despite markedly improved survival. The authors suggest the need for a broad theoretical framework, one that can encompass the several outcomes of interest in longitudinal studies of survivors and they discuss the need for research on health care utilization and adaptation for patients coping with continuing health risks. The authors suggest reaching out to researchers in related fields who may have useful methodologies that can be applied to studying the impact of pediatric cancer treatment. They also speak about the need for mentoring young investigators.

The markedly increased survival of pediatric oncology patients has unfortunately been accompanied by significant neurocognitive late effects. Neuropsychological research has detailed the resulting deficits and has led to the immediate translation of psychological findings into pediatric oncology treatment. Based on these findings, medical treatments have been changed to lessen the adverse central nervous system effects of earlier modalities. Many patients, however, still experience neurocognitive losses, especially in the areas of attention and working memory. Butler and Mulhern’s “Neurocognitive Interventions for Children and Adolescents Surviving Cancer” describes psychopharmacologic cognitive remediation and ecological interventions to improve attention and neurocognitive functioning. Findings from ongoing research are promising and may significantly reduce the burden of treatment-induced and disease-related cognitive deficits on survivors of pediatric cancer.

Moore’s “Neurocognitive Outcomes in Survivors of Childhood Cancer” reviews the state of the science of neurocognitive research in pediatric oncology. It provides an excellent description of the effects of central nervous system disease and its treatment on the young brain. As well, it interprets the meaning of such developmental
trauma in terms of long- and short-term functioning. Furthermore, the author summarizes research into the risk variables for neuropsychological deficits, including type and intensity of treatment, tumor location, age, and time since diagnosis. He describes medical advances in diagnosis and treatment for children with cancer and points to new directions for neurocognitive research in pediatric oncology.

The commentators in this issue raise important topics for discussion. Brouwers’s “The Study of Neurobehavioral Consequences of Childhood Cancer: Entering the Genomic Era?” talks of the critical issue of being able to differentiate the mediators and the moderators of the impact of cancer on pediatric survivors. He briefly discusses the tremendous improvements that the dawn of the genomic era may bring in our ability to understand variation in response to the treatment of children with cancer and to target treatments based on knowledge of genetically determined responsivity and sensitivity. Such targeted treatments promise to significantly reduce the guesswork of treating diverse patients. Ideally, they will likewise significantly reduce the burden on patients at the time of treatment and throughout their lifespan in terms of reduced late effects. Patel and Carlson-Green’s “Toward Greater Integration and Specificity in Conceptual Models of Neurocognitive Functioning in Childhood Cancer Survivors” acknowledges the advancement of our understanding of risk factors in neurocognitive functioning over the past two decades. The authors anticipate increased efforts to predict risk based on the inclusion of ecological factors as well as medical factors. Similarly, they advocate for targeted clinical interventions that involve the family, school, and community. Given the barriers of professional availability and funding sources, they address the significant issue of access to psychological resources, and they provide an optimistic yet realistic perspective on future directions in neurocognitive research and intervention.

In the third section of the issue, Armstrong and Reaman’s “Psychological Research in Childhood Cancer: The COG Perspective” discusses the influence that improvements in cancer treatment have on psychosocial research in pediatric oncology and the influence that psychosocial research has on the treatment environment for children with cancer and on our understanding of the late effects of treatment. The authors discuss opportunities for psychological studies of many aspects of survivorship and the benefits and challenges of working in multidisciplinary teams united by the COG network to pursue important questions of mutual interest. The very existence of this paper is an example of the many valued partnerships that have developed between pediatric oncologists and pediatric psychologists, both at their home institutions and within the clinical trials groups.

Last, Grootenhuis and Eiser’s “International Comparison of Psychosocial Research on Survivors of Childhood Cancer: Past and Future Considerations” provides a fascinating analysis of the history and nature of the publication of research in pediatric psychosocial oncology, comparing publications from North America (United States and Canada) with that of Europe, Australia, and Israel. Their data show a 45% increase in published psycho-oncology papers during the 1996–2000 period compared to the previous 4-year period. Especially prominent was the increase in publications from outside North America, mirroring a trend in scientific publication in general (Broad, 2004). Rather than assume a competitive stance, the authors suggest means to enhance international cooperation, while remaining mindful of the challenge cross-cultural research presents.

The commentaries offer insightful views on the papers in this section and on the field at large. Walco’s “Psychologists in Pediatric Oncology: Kudos, Criticism, and Courses for the Future” frankly and realistically addresses the logistical, fiscal, and other challenges of doing collaborative research in pediatric oncology, which is focused on quality of life rather than on a cure. The author highlights the achievements of pediatric psycho-oncologists in the United States and abroad and offers a challenging view of the road ahead. Briery’s “Traversing Hurdles with an Eye to the Future: The Future of Collaborative Pediatric Oncology Research” describes the balancing of national and international collaborative opportunities with very real “hurdles,” such as competition for authorship, competition among oncology-related organizations, rigid adherence to traditional research paradigms, and difficulty in obtaining research funding and in dissemination of results. Despite these barriers, Briery is optimistic that increased partnerships and advocacy will lead to improved research collaborations.

We are grateful to Dr. Rowland for her inspiring forward and to the authors of the core papers for their devotion to the scholarly task of reviewing the field of pediatric psycho-oncology with such clarity and enthusiasm. While it is with pride that we can look back on growth in this field, the growing literature makes it increasingly formidable to write a comprehensive review. We wish to thank the issue’s many peer reviewers, who offered their time and their suggestions to make good papers even better. We are also grateful to the commentators for their fresh look at where we stand and
for their bravery in suggesting not only revisions to old ways but also the adoption of new paths and methods. We hope that this issue will be a touchstone to all of the pediatric psycho-oncology community for a continuing dialogue about the directions for future research that can most effectively improve the lives of survivors of cancer in childhood.

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References