

# Pediatric Psychosocial Oncology: Textbook for Multidisciplinary Care

Annah N. Abrams  
Anna C. Muriel  
Lori Wiener  
*Editors*

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 Springer

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*To our mentors and colleagues who have taught us invaluable lessons about being present with and caring for patients and families.*

*To the children living with cancer and their family members who have allowed us to share in their journey. You inspire us with your strength, courage, and resilience.*

*To those who have not survived. We carry your stories with us.*

*To Marty, Lulu, Rachel, and Charlie whose love and support keep me grounded  
For my parents who inspire me by the lives they lead*

*Annah Abrams*

*To Theo, Sam, and Karen who remind me of what is most important  
Nina Muriel*

*With love and gratitude to Marilyn and Walter Wiener who provided me with deep roots and flexible wings  
To Sylvan who provides loving arms to come home to  
For Marisa and Brett whose gifts of spirit, wisdom, and resilience have nourished my soul*

*Lori Wiener*

*In Memoriam*

*Robert Arceci, MD, PhD*

*1950–2015*

*Scientist, physician, colleague, patient advocate, friend and champion for children and adolescents with cancer and the field of pediatric psycho-social oncology. You will be missed.*



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## Foreword

Many of us who work in the field of pediatric psychosocial oncology have had the experience of meeting someone for the first time at a cocktail party or other social gathering and being asked what we do for a living. Disclosing that we work with children who have cancer and their families in order to help them manage the stresses and challenges of this illness may bring a number of common responses: often an awkward pause; sometimes an expression of admiration suggesting that we must be saintlike to do such work; and not infrequently a question – “Isn’t that depressing?” We each must develop our own response to that question, and while mine varies depending on the circumstances, it always includes a definitive statement, “No, it’s not depressing, it’s actually quite rewarding.” And because most of us are not saints (not even close in my case), it behooves us to reflect on why it is that this work is, in fact, so rewarding. From whence comes the uplift?

My introduction to work with the childhood cancer population began during my postdoctoral fellowship training nearly 30 years ago. At that time, great strides had already been made in the treatment of pediatric cancer and survival rates were improving rapidly, while the areas of supportive and psychosocial care were earlier in development and just beginning to catch up. I remember vividly one of my first patient care experiences. An 11-year-old boy with relapsed lymphoma was having a bone marrow transplant. He had had his first dose of total body irradiation (TBI) that morning and suffered a panic attack during the procedure. This was a major concern for his treatment team, not only for his distress but because he needed to maintain some degree of self-control for the treatment to be administered properly. His second dose of TBI was scheduled for later that afternoon, and we were consulted urgently to help him get through the process. I felt ill-prepared for this challenge and rather apprehensive with the enormity of this responsibility. Then I met him. He was a pleasant young man who appeared to be developing normally and adjusting well in most spheres of his life, although he was notably and understandably anxious about his current predicament. Given his level of anxiety, we agreed to postpone the discussion of his upcoming procedure while we talked about more pleasant things. I learned that he loved baseball, and gathered quite a bit of information about the exploits of his little league team. Talking about this appeared to be a good distraction and he became less anxious. Thus, we hatched our initial treatment plan to get him through that afternoon’s procedure. Using the intercom system in the radiation suite to continue our baseball dialogue, I suggested he could close his eyes and picture himself



back on the baseball field, so that he could describe the game to me. He was able to engage in this imagery, and before we knew it, the procedure was over. My own relief was palpable. Then, the radiation doors opened and he walked out slowly, dressed in the full “space suit” in use at that time. He came directly to me and gave me a hug saying, “Thanks for helping me.” Although I honestly wasn’t sure that anything I had done had contributed to this improved outcome, the experience of his gratitude was something I will never forget. It engendered a lot of feelings, but depression was not one of them.

Now I will not pretend that all my subsequent clinical experiences have been as successful or rewarding as that one. But they need not be. To have just the occasional satisfaction of knowing that something we have done may have helped to reduce the distress of a child or ease the worry of an anxious parent is sufficient to remind us of why we do this work and maintain our commitment to it. I have experienced more than my share of failures and frustrations along the way, as most of us do, but the positive experiences keep us going, even if occurring infrequently. Of course, our goal is to have all of our clinical encounters result in positive outcomes, and to move toward that goal we want to ensure that our work is guided by the most up to date and comprehensive information available, as developed by the leading experts in this field. To make that knowledge available in a single volume has been the ambitious goal of the editors of this book, an aim that I am pleased to say has been admirably achieved.

Since those early days of my postdoctoral experience, the progress across multiple areas of supportive and psychosocial care of the child with cancer has been remarkable, and exciting developments and new approaches are currently being studied, as described in many of the following chapters. Looking back, it is impressive to reflect on how far we’ve come. It is hard for me to believe it has been two decades since the publication of an earlier volume on pediatric psychooncology, edited by my close colleague and longtime Division Chief, the late Raymond Mulhern, along with David Bearison, summarizing progress in the field up to that date. A decade later, a special issue of the *Journal of Pediatric Psychology* focused on childhood cancer (Mulhern and Bearison 1994), and the editors of that special issue, Andrea Patenaude and Mary Jo Kupst, along with Anne Kazak, provided comprehensive reviews of recent progress in the field (Patenaude and Kupst 2005; Kazak 2005). Notably, the focus had changed somewhat over that decade, with a much greater emphasis on survivorship, as mortality continued to decline and pediatric cancer was becoming conceptualized as a chronic illness. Thus, much research addressed the recognition of late effects of cancer and anticancer therapy – psychosocial, physical, functional, and neuropsychological – and interventions to prevent or ameliorate them. In the past decade, there has been increased emphasis on the development of evidence-based treatment and empirically supported interventions, again focused largely on survivorship issues but with continued attention to acute care issues and end-of-life care as well. With all this emphasis on intervention, I would be remiss if I didn’t also mention research pointing to the resilience demonstrated by so many children and families facing this challenge, which has been the focus of my own recent work (Phipps et al. 2014). The positive adjustment observed in this setting

provides another example of the remarkable human capacity to adjust, and even thrive in the face of adversity, and provides another source of inspiration for many working in the field.

The great progress that we have seen over the past decades is the result of the dedication, creativity, and perseverance of many individual investigators and clinicians across multiple disciplines. One of the many strengths of this volume is the multidisciplinary nature of the authors, which includes contributions not only from leaders in pediatric psychology and psychiatry but also oncology, behavioral pediatrics, nursing, child life, social work, and pastoral care, along with the consumer view of both patients and parents. The challenge of providing effective and comprehensive psychosocial care to children with cancer and their families requires a multidisciplinary team effort, which is illustrated so persuasively in the following chapters. Progress in psychosocial care has also been augmented by the support of the Children's Oncology Group (COG), the national cooperative group for clinical trials in childhood cancer (Noll et al. 2013). The COG has provided a forum for investigators from multiple disciplines to develop research and translate empirically supported interventions from research to practice. Thus, for a young person entering the field today, there is a much broader knowledge base and wider repertoire of empirically supported techniques and treatments available than when I began my training years ago. This volume provides a comprehensive compendium of that progress and a manual for the current state of the art in supportive and psychosocial care in pediatric oncology. I am very grateful to the editors for the opportunity to provide this foreword and hope that this volume will serve as a reference for all working in this field and as a guide to promote future research that will maintain and accelerate our progress in the future.

Memphis, TN, USA

Sean Phipps, PhD

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## Preface

We are pleased to offer the first edition of *Pediatric Psychosocial Oncology: Textbook for Multidisciplinary Care*. It has been written to provide up-to-date clinical information and resources addressing the many aspects of exemplary psychosocial care for children, adolescents, and young adults living with cancer and their family members.

We have assembled this textbook into practical readable chapters covering the breadth of psychosocial care in pediatric oncology. Sixty four authors, from 37 centers, share their expertise to help clinicians assess, anticipate, and respond to the emotional issues that arise in the context of treating children and adolescents with cancer. We are hopeful that the chapters will be useful for new clinicians in the field of pediatric oncology as well as for those who are more experienced. We anticipate the chapters will be used in the classroom, as reference material, and in inpatient and outpatient clinical settings.

Each chapter includes case material that brings the clinical challenges and opportunities to life. Clinical pearls are also provided at the end of each chapter to highlight the key points for each topic covered. The last chapter in the textbook includes a comprehensive resource guide that can be copied and shared with colleagues.

All cases described in this textbook are a compilation of patient experiences, and names have been changed to protect the identities of children and families. You will note that we use he or she interchangeably throughout the book and the material applies to either gender. We use parents as a general term as opposed to caregivers while recognizing that many children receive primary care from other family members.

We acknowledge that not every child and family will have access to the full range of psychosocial services described here. This book highlights the ideal psychosocial care that oncology programs can provide and how to access resources online or through cancer networks when comprehensive psychosocial care is not available locally.

We hope the textbook conveys the warm spirit of collegiality and mutual respect that exists among pediatric oncology care providers including, but not limited to, psychologists, social workers, psychiatrists, chaplains, child life specialists, nurses, and oncologists. We also value the chapter contributions from parents, advocates, and survivors, who help us better understand and appreciate the patient and family experience.

Pharmacological dosage information provided in this textbook is a guideline, and prior to prescribing medications, one should consult drug

manufacturers' current indications, dosage recommendations, and drug interactions as well as warnings.

We extend wholehearted thanks to our chapter authors who not only share their expertise in this textbook but who also provide thoughtful clinical care to children with cancer and their families in pediatric oncology settings. We greatly appreciate the support of our respective pediatric oncology programs which value the role of psychosocial care. And most of all, we are grateful to our patients and their families who teach and inspire us every day.

Boston, MA, USA

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# Contents

<b>1 Pediatric Oncology: Psychosocial Care in Context . . . . .</b>	<b>1</b>
Robert J. Arceci	
<b>2 Communication in the Pediatric Oncology Setting . . . . .</b>	<b>7</b>
Sarah R. Brand, Sarah Tarquini, and Jennifer W. Mack	
<b>3 Physical Impact of Pediatric Cancer and Its Treatment . . . . .</b>	<b>25</b>
Cheryl Rodgers, Janice Withycombe, and Marilyn Hockenberry	
<b>4 Assessing Family Psychosocial Risks in Pediatric Cancer . . . . .</b>	<b>51</b>
Anne E. Kazak, Stephen DiDonato, Stephanie J. Schneider, and Ahna L.H. Pai	
<b>5 Coping and Adaptation in Pediatric Cancer: Current Perspectives. . . . .</b>	<b>67</b>
Mary Jo Kupst and Andrea Farkas Patenaude	
<b>6 Psychotherapeutic Modalities for Children with Cancer and Their Families . . . . .</b>	<b>81</b>
Larry L. Mullins, Alayna P. Tackett, and Kristina I. Suorsa	
<b>7 Preparation, Education, and Procedural Support in Pediatric Cancer . . . . .</b>	<b>107</b>
Caroline H. Armington, Heather E. Peach, and Stephanie Hopkinson	
<b>8 Psychiatric Issues in Pediatric Oncology: Diagnosis and Management . . . . .</b>	<b>119</b>
Julia Kearney, Abraham S. Bartell, and Maryland Pao	
<b>9 The Impact of Pediatric Cancer on the Family . . . . .</b>	<b>143</b>
Cynthia A. Gerhardt, Christina G. Salley, and Vicky Lehmann	
<b>10 Neurocognitive Late Effects in Children with Cancer. . . . .</b>	<b>157</b>
Sunita K. Patel, Fiona Schulte, Natalie C. Kelly, and Amii C. Steele	
<b>11 Educational Issues: The Impact of Cancer in the Classroom. . . . .</b>	<b>175</b>
Christine L. Trask and Catherine C. Peterson	

<b>12</b>	<b>Adolescents and Young Adults with Cancer: A Biopsychosocial Approach</b> . . . . .	199
	Brad Zebrack, Sheila Judge Santacrose, Pandora Patterson, and Alexandra Gubin	
<b>13</b>	<b>Pediatric Hematopoietic Stem Cell Transplantation: Psychosocial Assessment and Care</b> . . . . .	219
	Kristin Bingen and Jennifer A. Hoag	
<b>14</b>	<b>Palliative Care for Children with Cancer and Their Families</b> . . . . .	243
	Abby R. Rosenberg, Joanne Wolfe, and Barbara L. Jones	
<b>15</b>	<b>Psychosocial Care for Pediatric Cancer Survivors</b> . . . . .	265
	Cori C. Liptak, Candice Chow, Eric S. Zhou, and Christopher J. Recklitis	
<b>16</b>	<b>Integrative Care in Pediatric Oncology</b> . . . . .	291
	Olle Jane Z. Sahler, Hilary McClafferty, and Marilyn A. Rosen	
<b>17</b>	<b>Ethics in Pediatric Oncology</b> . . . . .	307
	Daniel Benedetti and Jennifer C. Kesselheim	
<b>18</b>	<b>Spiritual Care in Pediatric Oncology</b> . . . . .	327
	Reverend Kathleen Ennis-Durstine and Reverend Mark Brown	
<b>19</b>	<b>Social Media Use in Pediatric Oncology: Tweets, Blogs, and Boundaries</b> . . . . .	339
	Sima Zadeh and Rachel Tunick	
<b>20</b>	<b>eHealth and mHealth in Pediatric Oncology</b> . . . . .	351
	Cynthia W. Karlson and Tonya M. Palermo	
<b>21</b>	<b>Self-Care and Sustainability for Pediatric Oncology Providers</b> . . . . .	367
	Barbara L. Jones and Stacy S. Remke	
<b>22</b>	<b>Parents' Perspective on the Role of Psychosocial Care in Pediatric Oncology</b> . . . . .	379
	Victoria A. Sardi-Brown and Peter J. Brown	
<b>23</b>	<b>In Their Own Voices: Experiences of Children and Adolescents with Cancer</b> . . . . .	387
	Michael H. Tang	
<b>24</b>	<b>Advocacy: Helping Others Understand What Children with Cancer Need</b> . . . . .	391
	Sandra E. Smith and Ruth I. Hoffman	
<b>25</b>	<b>Resources Chapter</b> . . . . .	397
	Sima Zadeh, Mitch Golant, Farya Phillips, and Barbara L. Jones	