

Pediatric Psycho-oncology

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Psychosocial Aspects and Clinical Interventions

Second Edition

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*The book is dedicated to all the children and families
we had the honor to take care of in the past
and who will benefit from it in the future.*

Contents

List of Contributors	ix	Chapter 8	Communicating with Children: their Understanding, Information Needs, and Processes	71
Foreword	xiii			
<i>Jimmie Holland</i>				
Introduction: Embedding Psychosocial Care in Medicine: Pediatric Psycho-oncology as a Model	xv	Chapter 9	Psychosocial Interventions: a Cognitive Behavioral Approach	92
<i>Gary M. Kupfer</i>			<i>Bob F. Last, Martha A. Grootenhuis</i>	
Preface	xvii	Chapter 10	Education in Pediatric Oncology: Learning and Reintegration into School	104
Part A Active Treatment	1		<i>Ciporah S. Tadmor, Rivka Rosenkranz, Myriam Weyl Ben-Arush</i>	
Chapter 1 Cancer in Children: an Overview	3	Chapter 11	Psychopharmacology in Pediatric Oncology	118
<i>Shai Izraeli, Gideon Rechavi</i>			<i>Elizabeth G. Pinsky, Annah N. Abrams</i>	
Chapter 2 Comprehensive and Family-Centered Psychosocial Care in Pediatric Oncology: Integration of Clinical Practice and Research	7	Chapter 12	Complementary and Alternative Medicine Use in Children with Cancer	135
<i>Lori Wiener, Maryland Pao</i>			<i>Subhadra Evans, Laura Cousins, Lonnie Zeltzer</i>	
Chapter 3 Quality of Life in Children with Cancer	18	Chapter 13	Fantasy, Art Therapies, and Other Expressive and Creative Psychosocial Interventions	143
<i>Shulamith Kreitler, Michal M. Kreitler</i>			<i>Shulamith Kreitler, Daniel Oppenheim, Elsa Segev-Shoham</i>	
Chapter 4 Pain in Pediatric Oncology	32	Chapter 14	Palliative Care for Children with Advanced Cancer	160
<i>Richard D. W. Hain</i>			<i>Stefan J. Friedrichsdorf, Lonnie Zeltzer</i>	
Chapter 5 Psychiatric Impact of Childhood Cancer	43	Part B Survivorship	175	
<i>Margaret L. Stuber</i>		Chapter 15	Neuropsychological Sequelae of Childhood Cancer	177
Chapter 6 Psychosocial Effects of Hematopoietic Cell Transplantation in Children	52		<i>Matthew C. Hocking, Melissa A. Alderfer</i>	
<i>Ronit Elhasid, Michal M. Kreitler, Shulamith Kreitler, Myriam Weyl Ben-Arush</i>				
Chapter 7 Psychosocial Aspects of Radiotherapy in Pediatric Cancer Patients	62			
<i>Shulamith Kreitler, Elena Krivoy, Amos Toren</i>				

Chapter 16	Survivorship in Childhood Cancer <i>Elena Krivoy, Meriel E.M. Jenney, Amita Mahajan, Monique Peretz Nahum</i>	187	Chapter 21	When a Parent has Cancer: Supporting Healthy Child Development During Challenging Times <i>Susan D. Swick, Andrés S. Martin, Paula Rauch</i>	246
Part C	Death and Bereavement	197			
Chapter 17	Care of a Child Dying of Cancer <i>Sergey Postovsky, Myriam Weyl Ben-Arush</i>	199	Chapter 22	Collaborations in Psychosocial Care in Pediatric Oncology: the Middle East as a Case Example <i>Aziza T. Shad, Maria E. McGee, Matthew G. Biel, Michael Silbermann</i>	260
Chapter 18	Psychological Intervention with the Dying Child <i>Shulamith Kreitler, Elena Krivoy</i>	209			
Chapter 19	Providing Support for Families Experiencing the Death of a Child <i>David J. Schonfeld</i>	223	Part E	Appendix	269
Part D	Additional Considerations	231	Appendix A	Assessment Tools in Pediatric Psycho-oncology <i>Dafna Munitz-Shenkar, Michal M. Kreitler, Shulamith Kreitler</i>	271
Chapter 20	Ethical Considerations in Pediatric Oncology: a Case-Based Psychosocial Overview <i>Ryan W. Blum, Andrés S. Martin</i>	233	Appendix B	Additional Resources	298
			Index		301

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Foreword

It is an honor and pleasure to write the Foreword for the second edition of this important textbook of pediatric psycho-oncology. By identifying the international leaders in the field, the editors present a remarkable view of the state of the art in pediatric psycho-oncology, as we know it today, of the management of symptoms and psychosocial care. I commend them for it and also I commend this book to the reader.

Since the first edition was published, several important studies have been carried out and the importance of the care of the total child, not just the tumor, has become more widely recognized. An acknowledgement of this is the fact that in 2010 the International Pediatric Oncology Society (SIOP) endorsed the statement of the International Psycho-Oncology Society and the International Union Against Cancer (UICC) that a new standard of quality cancer care has been established: quality cancer care today must integrate the psychosocial domain into routine cancer care. The SIOP Board, at its meeting in Boston, MA, in September, 2010, endorsed this statement as it applies to the care of children with cancer. These are landmark statements which will encourage the field to move forward more rapidly with this policy support from the major oncology international societies.

I dedicated the first edition to my grandson, Gabriel, who had just died of hepatoblastoma, aged 3. I continue to honor his memory, like other professionals in the field, who have shared a similar loss, to carry the work forward as a memorial to him and to the children whom many pediatric oncologists remember with equal love, sadness and yet joy for their short lives and the pleasure they brought us. The struggle goes on to reduce the numbers of children who do not survive, and also to continue making our own contribution to improve the quality of life of those children during their illness to be the best possible. This dedication of purpose is the least that we can do to remember those whom we have loved and lost. I am grateful to be a part of this important effort to make the most up-to-date research results available to pediatric oncology teams around the world.

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Introduction: Embedding Psychosocial Care in Medicine: Pediatric Psycho-oncology as a Model

The history of pediatric oncology is a transcendent one. Until 1948, a patient with leukemia simply was provided with supportive care, itself most meager, and family and medical caregivers awaited the patient's death. Through the vision of many, including in no small part the pioneering Sidney Farber, clinical remissions were first achieved, and the modern age of chemotherapeutics in oncology began.

Concomitant with the provision of chemotherapeutics was the emergence of the modern age of supportive care. Blood-banking, so crucial to counteract the deleterious effects of chemotherapy, became more scientific in screening for antibodies and infection. Penicillin and the elaboration of multiple categories of antibiotics allowed aggressive infection-fighting efforts to combat rampant fever and neutropenia. A greater realization of the importance of treating pain allowed rational use of narcotics to combat the inevitable mucositis that accompanied dose intensification efforts that clearly resulted in improvements in overall survival.

In essence, knowledge culminating in the rise of rational cancer therapeutics was accompanied by the advancement of medical knowledge in the areas of hematological support and infectious diseases. The consistent rise in survival rates, as exemplified by steadily improving Kaplan-Meier curves in repeated acute lymphoblastic leukemia clinical trials, could never have occurred without the remarkable progress in each of these areas.

The past 60 years also saw growing social awareness of mental health disorders and the (gradual) removal of the stigma of such disorders. Increasing acceptance of the importance of addressing mental health has led to present-day efforts to openly lead patients to mental health resources and to legally encode in practical terms access to such services.

Coincidentally, these efforts have strongly paralleled the diminishing negative connotations associated with those afflicted with cancer. Not so much time has elapsed since the diagnosis of cancer was sometimes hidden from the patient and certainly hidden from those around the patient, such as co-workers, for fear of ostracism or unemployment. The Western media today abounds with bold depictions of currently treated patients and survivors and with pink-shrouded football players raising cancer awareness.

The confluence of these factors makes it even starker that psychosocial challenges still abound for patients with cancer. First, there is a greater incidence of diagnosis of mental health disorders in cancer patients, whereby underlying or latent issues are enhanced or exposed by the anxieties of diagnosis, therapy, and disruption of activities of everyday living. Second, the stress of caring for and enduring the treatment of a child with cancer confers similarly increased risk of psychosocial disturbances upon both parents and siblings. Third, side effects of the therapy itself (chemotherapy, surgery, and radiation), especially in the developing child, can result in loss of cognition and coping skills, which imposes increased risk of disordered behavior. Of course, the challenges to our patients do not end with the final dose of chemotherapy, the pronouncement of cure, or a contrived 5-year window, but rather follow them through a lifetime as they grow, mature, go to school, and become job holders, spouses, and parents themselves.

In spite of the vast advantages of resources available in the developed countries, the provision of resources necessary for psychosocial care of patients and their families remains uneven. While more and more insurance plans cover some modicum of psychosocial services, reimbursements are often inadequate for the task. Even insurance that

may be available does not guarantee that a given provider will accept that particular insurance, and examples abound of the most august institutions insisting that patients self-pay. In addition, when such services are obtained in the community and out of contiguity with the clinic experience, a disconnect occurs for both caregiver and patient.

We and others have found that the model of embedded psychosocial care, on an equal footing and integrated with chemotherapy, antibiotics, and blood products, has proved to be an especially effective manner of intervention. The typical pediatric oncology clinic has some combination of exam rooms and infusion space, often with therapy administered “in the round” with common areas for play for patient and siblings alike. A sense of community is created, as patients typically have recurring and regular days of the week for their visits, whereby patients and their families interact in an ongoing way with their caregivers: nurses, nursing assistants, nurse practitioners, and oncologists. It is within that community that the psychosocial team is able to introduce itself, becoming a seamless part of the caregiving team that encounters that particular patient and family during each visit.

The concept of the psychosocial team is one that can vary from program to program, depending on local custom and state regulatory agencies. A collaborative psychosocial team such as that we have constructed at Yale consists of such people as psychiatrists, psychologists, social workers, special education teachers, child life specialists, and volunteers. While very often overlapping in certain skill sets and abilities, each of these specialists brings a unique perspective that rounds out the entire team.

Ultimately, the greatest challenge in the embedded model is one of provision of resources. Hospitals and medical schools are under financial pressure due to decreasing reimbursements, increasing unfunded care, and increased regulatory environment. Psychosocial care, even in this age of enlightenment, in many circles is still viewed as a superfluous or unnecessary frill. The acquisition of resources to fund a full staff in order to run such a team requires the infusion of philanthropy and grant support in most centers. The challenge of funding is magnified by the fact that provision of services is never-ending; personnel are a constant cost center on the ledger sheet.

Fortunately, pediatric oncology is a specialty that attracts attention: bald-headed children on chemotherapy are head-turners on billboards, television, print media, and, of course, social media. Pediatric oncology also benefits from infrastructure in general pediatrics, in which focus on growth and development, school, and behavior figures prominently. Yet chronic disease or disease that requires long-term care abounds in pediatrics. Thus, the relationship between pediatrics and pediatric oncology has the chance to become symbiotic: pediatric oncology can gather resources and test the embedded model. Departments of Pediatrics, and as a result other subspecialties within it, can benefit from the ingathering of talent that is nucleated by such a paradigm.

The greatest barriers toward establishment of psychosocial services remain recognition and commitment at every level of a particular program from caregiver to hospital administrator. Pediatric oncology programs that understand that the concept of mental health care is as important as the chemotherapy and the antibiotics are well on their way to successful implementation and sustenance of a truly well-rounded program.

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Part A

Active Treatment

Cancer in Children: an Overview

Shai Izraeli, Gideon Rechavi

Introduction

Approximately one in every 350 children will develop cancer by adulthood, and despite the remarkable cure rate, cancer is still the leading cause of non-accidental death in children in affluent countries after the neonatal period. In this Introduction we shall highlight some unique medical aspects of childhood cancer that are especially pertinent to pediatric psycho-oncology. For more details about specific diseases, the reader is referred to the available textbooks in pediatric oncology.

The characteristic cancers of children are different from those encountered in adults. Typically they arise in tissues and organs that develop most rapidly during embryogenesis and the postnatal period. Indeed, it is likely that most cancers in children result from unfortunate developmental “accidents,” often occurring *in utero*. In contrast, the typical “adult” malignancies arise in epithelial cells covering the surface of ducts and body cavities that are exposed for prolonged periods of time to a large variety of environmental carcinogens. Colon cancer, for example, is the end stage of a slow multistep transition from normal tissue through benign polyps to malignant invasive carcinomas. Colon cancer may be prevented by either modifying diet or by treatment with drugs such as aspirin, which affects the tumorigenic response of the colonic mucosa to carcinogens, or by removal of benign polyps. Unlike cancers in adults, most cancers in children cannot be prevented, are not preceded by obvious pre-malignant lesions and are not amenable to early diagnosis. Indeed, several international trials of massive screening for pre-malignant lesions or early stages of neuroblastoma, a childhood cancer of the sympathetic nervous system, have proved futile. These issues are relevant when dealing with the parents of a child with cancer, who are, naturally, overwhelmed by guilt and self-blame. It is important to explain to parents that to the best of our knowledge cancers in children are not

caused by any wrongdoing of the child or his/her parents, nor could they have been diagnosed earlier (except, of course, in cases of clear medical neglect).

Most of the tumors arise spontaneously, although there are rare familial hereditary cancer syndromes. For example, retinoblastoma, a malignant tumor of the retina, is often hereditary. A child with hereditary retinoblastoma is likely to develop tumors in the other eye and later may also be diagnosed with osteosarcoma, a malignant bone tumor. Most of these children are cured and their chances of passing the hereditary trait are 50%. Families with hereditary cancer syndromes require therefore special lifelong attention and present the health care community with new challenges. One of these challenges is caused by modern genetic diagnostic techniques that enable identification of individuals carrying a cancer-predisposing mutation while they are still healthy. This medically helpful knowledge may also add a significant psychosocial burden to the patients and their families.

Another high-risk group is identical twins. An identical twin of a child with leukemia has a 25% risk of developing the same leukemia before the age of 10. This high risk of a non-genetic disease among identical twins has been puzzling. The mystery has been solved recently. As leukemia is commonly an “accident” during embryonic development, pre-leukemic cells can circulate from one embryonic twin to the other through their common vascular channels. Other than these examples, in most instances there is no substantial basis for the fear that other young members of the family will develop cancer as well. Moreover, the rate of cancer in offsprings of childhood cancer survivors is not significantly higher than in the normal population. Thus, in the majority of instances we can safely reassure the families that the cancer will not spread in the family.

The most common malignancy in children involves the lymphoid system, especially acute lymphoblastic

leukemia (ALL). During embryonic development and early childhood the normal lymphoid system has to develop rapidly and acquire the capabilities to mount specific immune responses against an enormous variety of foreign antigens. For efficient diversification of the various immune receptors, lymphoid cells possess an unusual type of genetic instability that predisposes them to rare genetic accidents leading to acute leukemia. ALL is most common in young children but occurs throughout childhood.

The nervous system is another rapidly developing organ that also involves substantial fine-tuned diversification and differentiation during embryogenesis and early childhood. The frequency of tumors of the nervous system is almost equal to ALL and together these malignancies are responsible for more than half of the cancers in children. Many of these tumors are relatively slow-growing gliomas, often implying living through childhood with slowly progressing brain tumors. A large fraction of childhood brain tumors have an embryonic and more aggressive phenotype. These include medulloblastoma, a cancer of the cerebellum, retinoblastoma, and neuroblastoma, a malignant tumor of the peripheral sympathetic nervous system. Embryonic tumors outside the nervous system such as Wilm's tumor of the kidney, hepatoblastoma and various tumors of the gonads are also typical of children.

The third most common type of malignancy of children is a diverse group of tumors of the musculoskeletal and the soft tissues. These sarcomas can arise at any age and have specific molecular, pathological and clinical characteristics. Many of those occur more frequently during adolescence, a period of robust musculoskeletal development.

Pediatric oncology is one of the greatest medical success stories of the past four decades. The cure rate of childhood cancer has increased from about 25% in the 1960s to more than 75% in the 1990s. This remarkable progress has occurred in almost all types of childhood malignancies and is due to the exquisite sensitivity of these malignancies to chemotherapy and to the series of carefully conducted collaborative empirical clinical trials in Europe and the USA.

The paradigm to this success is childhood ALL, a uniformly fatal disease in the 1960s that has become curable in almost 80% of children today. The treatment "protocol" of childhood ALL consists of 2–3 years of therapy utilizing up to ten chemotherapeutic drugs given in various combinations. Intensive remission induction and consolidation therapies, lasting up to half a year, are followed by prolonged and less intensive maintenance therapy. During the first half year,

the child requires frequent hospitalizations for administration of drugs or for combating infectious complications of chemotherapy. The child can attend kindergarten or school and function almost normally during the rest of the therapy.

A specific problem associated with ALL and relevant to the topic of this textbook is the need for prevention therapy to the central nervous system (CNS). Early trials with chemotherapy have failed because of the recurrence of the leukemia in the CNS. Apparently due to the poor penetration of most chemotherapeutic drugs into the CNS it serves as a "sanctuary" haven for leukemic cells. Cure of ALL became a reality only when routine irradiation of the brain was added to systemic chemotherapy. This success has proven to be a mixed blessing as the exposure of the brain of young children to a hefty dose of radiation resulted in severe long-term intellectual, behavioral and other neurological impairments. In most modern treatment protocols of ALL, cranial irradiation has been replaced by a combination of systemic high dose methotrexate and intrathecal chemotherapy. While this approach has been proven to be less toxic than irradiation, its long-term neurological implications still need to be studied.

The treatment of solid tumors combines usually at least two modalities. Local control is achieved through surgery or radiotherapy. Because of the severe long-term toxicities of radiating growing tissues, surgery is preferred when possible. Modern pediatric surgical oncology has become much less mutilating. Thus, in most instances, bone and soft tissue sarcomas can be removed by limb-sparing surgery. Still, in many instances, such as brain tumors, Hodgkin's disease and inoperable sarcomas, radiation is unavoidable. It is critically important that radiation will be delivered in centers specializing in treatment of children because of many specific considerations unique to these patients that are required to minimize the long-term side effects and encourage conservation of symmetric growth and development.

The most significant progress in the treatment of childhood solid tumors occurred when the concept of "adjuvant chemotherapy" was introduced, initially for treatment of Wilm's tumor and osteosarcoma. In the case of osteosarcoma, even when the tumor was localized to the limb, and the limb was amputated, the long-term survival was no more than 20%. Since all deaths were caused by distant metastases, the unavoidable conclusion was that micro-metastases were present in most of the patients with localized tumors at the time of diagnosis. The administration of "adjuvant chemotherapy"—chemotherapy that is delivered with the intention to destroy those unseen micro-metastases, has

led to the current 70% survival rates. Typically these patients today are treated first with chemotherapy, followed by surgical removal of the tumor with sparing of the limb, and another period of intensive chemotherapy. The concept of adjuvant chemotherapy has been also adopted by the adult oncologists for chemotherapy-sensitive tumors such as breast cancer.

The recent decade has witnessed remarkable development in molecular biology and diagnostics. Techniques allowing the visualization and quantifications of genes and gene products have enabled molecular classification of tumors and personalized adjustment of therapy to the biological tumor subtype. Again, pediatric oncology has shown the way. Thus, for example, the identification of the BCR-ABL fusion gene in a child with leukemia or the detection of multiple copies of the NMYC oncogene in a child with neuroblastoma led to their classification as high risk patients and to assignment to especially intensive treatments that included bone marrow transplantation. The molecular determination of minimal residual disease has allowed tailoring of therapy to the molecular response to therapy. The identification of specific molecular abnormalities has also raised hopes for development of cancer-specific, less toxic therapies. In the recent years since the first edition of this book, several novel targeted therapies have been finally introduced for children with cancer, and others are in clinical trials. For example, the addition of inhibitors of BCR-ABL to chemotherapy has caused such a dramatic improvement to survival that the presence of this abnormality no longer constitutes an automatic indicator of stem cell transplantation. These novel therapies are not “magic bullets” free of side effects. Indeed, many of these novel drugs target pathways important for childhood growth and development and hence have a multitude of newer side effects different from those caused by chemotherapy.

While childhood cancer is a relatively rare disease, its high cure rate is having a significant impact in developed societies. Currently, one in every 900 young (less than 45-year-old) Americans has been cured of childhood cancer. It is estimated that within 20 years this rate will increase to more than one in every 400. Unlike adult cancer, occurring mostly in the post-retirement age, children cured from cancer are expected to live many more productive years. Thus the quality of life of childhood cancer survivors and late effects of the cancer and its treatment have become a major focus of modern pediatric oncology and are particularly relevant for the field of psycho-oncology.

Although children tolerate the acute toxicities of chemotherapy better than adults, growing children are

more vulnerable to the delayed effects of cancer therapy such as effects on growth, the endocrine system, fertility, the myocardium, neuropsychological function, and the occurrence of secondary cancers. Moreover, because children tolerate chemotherapy better than adults, they often receive far greater dose-intensity and are therefore more likely to develop late sequelae. Of the different therapeutic modalities, radiation is associated with the highest rates of late effects in children.

Most relevant for this textbook are the late neuropsychological sequelae of childhood cancer therapy. Long-term neurological impairments are associated with leukemia and brain tumors, the two most common malignancies of children. Learning difficulties have been most commonly attributed to cranial irradiation and are related to the dose and the age at the time of irradiation. For example, cranial irradiation with 3,600 cGy of children with brain tumors who are younger than 36m is universally associated with marked decreases in I.Q. Newer therapeutic protocols are attempting to delay radiation and lower the dose in young children.

Although radiation doses in children with ALL are significantly lower than those used for children with brain tumors, they are still likely to have long-term neuropsychological sequelae. These effects are mainly in attention capacities and other nonverbal cognitive processing skills and not in the global IQ. These deficits correlate with focal findings in magnetic resonance imaging (MRI) of the brain and neurophysiological studies. As with brain tumors, the extent and timing of the deficits are related to the radiation dose and the age at the time of radiation. Girls less than 5 years old are most vulnerable. At the extreme end of the spectrum of neurological toxicity is progressive necrotizing leukoencephalopathy, a rare and devastating complication, occurring mainly in patients who have received a combination of higher dose radiotherapy and intrathecal methotrexate. Although significantly less neurological impairment is seen in children with ALL treated with intrathecal therapy only, it is premature to conclude that no neuropsychological deficits are expected. Indeed, minor abnormalities in brain imaging are commonly detected and the long-term significance of these changes is presently unknown.

It is impossible to write an introduction to a book on psychology of children without relating to adolescence. Surviving normal adolescence is a challenge to children, their parents and educators and provides the livelihood of pediatric psychologists. Cancer in this life period is extraordinarily more challenging. Adolescents tend to delay bringing medical problems to

attention and are less compliant with therapy. For example, it has been clearly shown that adolescents with ALL tend to be less adherent to the oral chemotherapy regimen during the maintenance period and that their prognosis directly correlates with their degree of compliance. There are also some unique medical issues such as preservation of fertility, and a large list of psychosocial issues. Because of these issues, the need of a specific discipline for adolescent and young adults oncology is being considered now in the USA and Europe.

The final issue relates to the topic we all try to avoid. Despite the enormous success, one in every five children with cancer will die from the disease. The grim outlook of a particular child is often known soon after diagnosis. Yet studies have repeatedly shown that the prospect of dying is usually, if at all, addressed only very shortly before death. Even in the most hopeless cases, treatment is usually characterized by intensive attempts to cure and by ignoring the option of palliative care. This is one area where we, who deal with

childhood cancer, can learn from our colleagues in the adult oncology field. Hospice and palliative care are new and much needed concepts in pediatric oncology that, naturally, combine medical and psychosocial approaches. And after the death, there are bereaved parents, siblings, and friends. They often cling to the pediatric oncology department and look for comfort and help. The "end of life" issue is a chapter in pediatric oncology waiting to be defined and written.

Pediatric oncology meets childhood psychology at the time of the diagnosis of these devastating diseases, during the difficulties associated with the toxicities of intensive chemotherapy, the rehabilitation period, during the follow-up of the majority who are long-term survivors, and the bereavement of those who lost the most precious of all. Although the child is the one with the cancer, the pediatric oncology team interacts intensively with the siblings, parents, grandparents, friends, schoolteachers and more. It becomes a community affair in which the pediatric oncology team is at the center.

Comprehensive and Family-Centered Psychosocial Care in Pediatric Oncology: Integration of Clinical Practice and Research

Lori Wiener, Maryland Pao

Introduction

Pediatric oncology programs aspire to provide comprehensive clinical care to patients and their family members. Patient and family-centered care is an approach to health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families, and where the vital role that families play in ensuring the health and well-being of infants, children, and adolescents is recognized [1]. Within a family-centered care environment, emotional, social, and developmental support is an integral component of health care. Attending to the child's and family's emotional distress and psychosocial needs due to a cancer diagnosis requires many experts, in addition to the oncologist, such as social workers, psychologists, child life workers, rehabilitation therapists, child psychiatrists and many others. To incorporate this practice of psychosocial care within a pediatric oncology setting means that the health care providers listen to and honor patient and family perspectives, choices, values, beliefs and cultural differences. Providers also shape policies, programs and facility design, and facilitate day-to-day staff interactions through ongoing discussions and feedback with patients and families. In addition to seeking patient's and family's points of view, conducting clinical research is another excellent mechanism to assure that the developed programs and provided interventions are based on what patients and families experience and need and in fact are improving outcomes.

Recent developments in dissemination of empirically supported interventions [2] and evidence-based

assessments [3] suggest that pediatric oncology programs need to continue to integrate psychosocial practice with research in order to maximize successful psychosocial and physical outcomes for children with cancer. Critical areas of clinical practice and research under exploration include distress assessments [4, 5], screening of psychosocial risk factors after cancer diagnosis [6, 7] and survivorship, particularly studies of the late effects of those who are cured. These questions highlight the need for ongoing concomitant psychosocial practice and research within pediatric oncology settings. In this chapter, we describe the necessary components to be incorporated into an ideal (or model) comprehensive family-centered psychosocial support program and propose that the integration of clinical research can enhance clinical services while reducing the research–practice gap.

Psychosocial Care

Diagnosis

Excellent psychosocial care begins at the time of diagnosis, incorporates early assessment, continuing and consistent care, a range of therapeutic interventions, and utilizes interdisciplinary resources for all family members [8]. A diagnosis of childhood cancer is an acute, often traumatic event for a family. The way in which the diagnosis of cancer is presented significantly influences the family's initial reactions and sets the stage for collaboration with the medical team. The initial meeting with the family, which should be held as

quickly as possible once a cancer diagnosis is reached, is an opportunity to establish a trusting physician–patient–family relationship. The psycho-oncologist has a fundamental role in determining whether the medical information is clearly communicated and understood by the family. Assessing each family member’s coping and learning styles is a key component of helping a family at this critical time. For example, some caregivers might search for and request detailed information on their child’s cancer and treatments (“monitors”), while others may feel overwhelmed by all the new information and only want what they absolutely need to know (“blunters”) [9, 10]. “Monitors” may be quite distressed by all that they read and require considerable support with what they learn, but it is equally important to make sure that “blunters,” while wishing to avoid detailed medical information, have sufficient information to make informed decisions.

The days and weeks following a new cancer diagnosis are an important time to be available and to offer support and guidance to the child and family. Nearly all caregivers report significant psychological distress in the form of anxiety. With the demand for frequent medical tests and treatment, lives are disrupted, roles and responsibilities within the family need to be renegotiated to ensure that basic needs of the family continue to be met (e.g., working to retain medical insurance and pay bills, care of healthy siblings), and highly technical medical information has to be understood. Having a roadmap of treatment can help the family focus on what needs to be done and provide some sense of relief, optimism, and improved mood. Families also benefit from knowing what “normal” emotional responses are and how to answer questions from family and friends.

Initiation of Treatment

For the child, psychosocial care at diagnosis and initiation of treatment includes offering age-appropriate interventions such as positive incentives for cooperation with procedures, breathing exercises and developmentally appropriate distraction techniques during procedures. Storytelling, fantasy play and puzzles are often useful for the preschool child whereas the school-age child may benefit from engaging in medical play. For those undergoing surgery, short preparatory visits to the operating and recovery rooms can help children to become familiar with surroundings and reduce anxiety. Working with families and the medical team to allow and encourage adolescents to participate in medical decisions (i.e., signing consents; when appropriate, control with scheduling; viewing and explaining the

results of laboratory tests; involving them in discussions of treatments) helps establish a strong working relationship with the medical team from the outset.

Ongoing Psychosocial Care

Psychological and developmental problems in the patient or any family member can add significantly to the caregiver burden of dealing with cancer and can exhaust a family’s emotional resources (and staff time). The early assessment of the family’s strengths and vulnerabilities, psychosocial resources, and preexisting problems can help the team anticipate the psychological adjustment of families to cancer and allow for quick and efficient provision of psychosocial care based on their needs [8, 11]. As treatment progresses and families establish a “new normal,” the availability of group support, and individual and family counseling for caregivers can be useful in order to address feelings of anxiety, sibling adaptation, the marital (or significant) relationship (divergent coping styles, intimacy and communication patterns under chronic stress), concerns associated with the child’s prognosis or late effects, or simply for reassurance that they are coping adequately. Good psychosocial care does not encourage dependence on the medical team, but rather encourages development of effective coping strategies, the child’s integration back to school and with peers as soon as possible and supports the family for maximal functioning. The longer the child is away from his or her pre-cancer activities, the harder the adjustment can be to re-establish friendships and to feel comfortable back at school following the completion of therapy.

When indicated, age-appropriate psychiatric interventions for our pediatric patients are equally helpful. Somatic symptoms of depression, such as difficulty sleeping or fatigue, are common symptoms of both depression and cancer, and therefore can be difficult to differentiate. Careful psychiatric assessment of severe distress or prolonged symptoms is important [12]. Regardless of whether these symptoms are normal rather than pathological in nature, the symptoms should be documented and addressed. Assessment of mental health and coping based on the child’s age, development, and personality may be obtained in many ways. Therapeutic interventions are designed to reduce distress and to help the child integrate the facets of his or her illness and life into expression [13]. A therapeutic game has been created for children aged 7–16 that assesses coping skills, family relationships, stressful issues, adjustment/adaptation, self-esteem, peer relationships, depression/sadness, and a view of prognosis [14]. For others, talk therapy can provide a vehicle for

communication. Different forms of self-expression are equally powerful and effective, including behavioral and cognitive techniques, play, the use of workbooks [15], bibliotherapy, storytelling, writing, art, music, humor, and animal-assisted therapy [12]. Most often, however, a combination of approaches is most effective and will change based on the child's current emotional needs and medical circumstances.

Non-adherence can be a significant and often overlooked issue in pediatric oncology. Anticipating, assessing, monitoring, and, when necessary, emphasizing adherence to the treatment regimen are critical components of comprehensive psychosocial care [16]. Additionally, continuous assessment of physical as well as emotional pain is critical. An ideal program documents quality of life from the time of diagnosis throughout survivorship and provides each family access to pharmacologic and nonpharmacologic approaches, including complementary and alternative interventions. This includes energy therapies (e.g., therapeutic massage, energy healing, REIKI), manipulative and body-based methods (e.g., chiropractic, massage) and body-based mind-body interventions (e.g., mindfulness, meditation, prayer, guided imagery, and hypnosis) and thoughtful counsel pertaining to homeopathic approaches taking into account potential drug interactions [17]. Other interventions that aid healing include art therapy [18], music therapy [19, 20], aroma therapy [21] and animal-assisted therapy [22].

Siblings

Paying attention to the siblings in the family is a critical element of psychosocial care. It is only in recent years that the needs of siblings have been identified as being met inadequately compared to other members of the family. Comprehensive care considers the needs of siblings from the time of diagnosis and continues throughout the course of illness, including bereavement and survivorship. Siblings often feel that their needs pale in comparison to those of their sick brother or sister and yet they experience the same emotional reactions to the diagnosis of cancer (shock, disbelief, helplessness, sadness, guilt) plus jealousy without the luxury of doctors and staff who are worried about their emotional needs. Throughout treatment, the healthy sibling may feel a sense of isolation as the family travels out of town to a new treatment facility or as he or she spends time at home with extended family or at a friend's home. Disruptions in daily routine and prognostic uncertainty can lead to difficulties in school, acting out behaviors at home and school, anger or withdrawal. Siblings respond well to support and

consistency and many siblings thrive with the additional responsibility thrust upon them. While most cancer centers do not spend time evaluating the psychosocial needs of pediatric cancer patient's siblings, it is the authors' hope that this practice will change in the near future. Hospital programs that include siblings in their child and teen programming and those that have specific programs for siblings (such as a hospital-wide Sibling Day) are increasingly recognized for their importance. National organizations such as SuperSibs. are working hard to ensure that children whose brothers and sisters have cancer are "supported, honored and recognized to help them face the future with strength, courage and hope" (www.supersibs.org).

Creating an Optimal Healing Environment

Integrated cancer care incorporates the use of complementary and alternative medicine (CAM) techniques, as well as insights from research in medicine, nutrition, interior design, architecture, exercise, and psychoncology [23]. This includes creating a physical space using principles that have been shown to promote health, healing and quality of life and incorporating evidence-based health care environment research findings into hospital design. Healing principles take into consideration the use of color, light, shapes, noise, music, and natural elements. For example, the use of color in a children's hospital has been shown to create a more cheerful environment [24] whereas exposure to art reduces stress [25]. Bright light has been shown to reduce depression and those in sunny rooms have shorter periods of stay compared to those in dull rooms [26]. In a group of parents of children with severely developmentally disabled children, a correlation has been found between their satisfaction with the building environment and their satisfaction with health care services [27]. In another study that focused on the interior of a hematology-oncology unit, patients, their parents, and hospital staff participated in objective ratings of the physical environment along with other measures to elucidate the network of relationships between physical design elements in children's hospital rooms, environmental satisfaction, and outcome measures including psychosocial functioning, parental health care satisfaction, staff co-worker satisfaction, and staff fatigue. Pediatric hematology-oncology patients, their parents, and hospital staff were more satisfied in environments with better physical amenities. For parents, significant relationships between environmental satisfaction, health care satisfaction, and psychosocial functioning emerged. Likewise, environmental satisfaction was associated with co-worker satisfaction, psychosocial