Handbook of Supportive Oncology and Palliative Care is a practical guide to providing evidence-based and value-based care to adult and pediatric cancer patients experiencing severe symptoms and stressors due to cancer diagnosis, cancer treatment, and comorbid conditions. This accessible reference provides the art and science behind the whole-person and family approach to care by delivering the best practices to relieving a cancer patient’s symptoms across physical, psychosocial, and spiritual dimensions. Unlike other resources, this book covers all dimensions of palliative care but with a special emphasis on primary palliative care. Part One of the handbook provides the essential background and principles of supportive oncology and palliative care, including chapters on understanding the adult and pediatric patient and family illness experience, the roles and responsibilities of the palliative care team, and the art of the palliative care assessment interview. Part Two covers symptom management and includes ten chapters considering the major physical and psychosocial symptoms a cancer patient may face—neurologic, cardiac, respiratory, gastrointestinal, genitourinary, psychiatric, sleep and fatigue, pain, and psychosocial and spiritual distress. Part Three addresses special considerations and issues that an oncologist, physician, nurse or other healthcare provider often face in these settings, including chapters on intimacy, sexuality, and fertility issues, grief and bereavement, running a family meeting, care for the caregiver, and survivorship.

Written by expert clinicians, this state-of-the-art handbook is a necessary resource for any oncologist, nurse, primary care physician, psychosocial expert, or related practitioner who endeavors to improve quality of life and provide healing to those suffering from cancer and its treatment.

KEY FEATURES:
- Provides the binding principles of palliative care for pediatrics, adults and families from diverse cultures and spiritual beliefs
- Easy-to-read format makes extracting content fast and convenient for both the clinical and educational setting
- Guides the clinician and practitioner through the palliative care assessment process, including the appropriate questions for the palliative care interview
- Interdisciplinary team approach to psychosocial and spiritual care
- Includes access to the fully searchable downloadable eBook

Recommended Shelving Category: Oncology
Handbook of Supportive Oncology and Palliative Care

Whole-Person Adult and Pediatric Care

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To our spouses and children, whose love and support make our work possible.

Carl, Stephen, Rebecca.

Ann M. Berger

With deep and lasting gratitude, I thank each patient, each family, each student, and each colleague for patiently teaching me about the needs of the human spirit while experiencing suffering.

Pamela S. Hinds

To all my patients who have inspired me through their strength and courage in the midst of their suffering; they have taught me the meaning of compassionate presence and love. To my students who continually inspire me with their hopes and determination to bring compassionate, whole-person care to all their patients.

Christina M. Puchalski
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Palliative care begins at the time of diagnosis of any chronic and/or life-threatening disorder. As part of quality patient care, this care must focus on physical, psychological, social, and spiritual dimensions for the patient, caregiver, and family to achieve the best quality of life possible for any patient going through any phase of the oncological journey from diagnosis to cure or to end of life.

Palliative care is healthcare which focuses care on all aspects of the patient—emotional, social, and spiritual as well as physical issues. Thus, palliative care focuses on preventing, assessing, and treating all dimensions of pain and suffering. Palliative care additionally concentrates on accompanying patients and families during their illness journey to help them find healing and peace whether cure of the disease is possible or not. This care focus is done concurrently with the work of the oncologist, who primarily focuses on treatments given to an oncology patient that includes chemotherapy, immunotherapy, surgery, and radiation, all of which are focused on treating the cancer. The primary care doctor, nurse practitioner, and/or physician assistants, who are collaborating to treat the cancer, need to understand the principles of palliative care and, in particular, of primary palliative care. Treating the disease is important, but to achieve health and well-being to the extent possible for the patient and family, clinicians need to treat the whole person, including addressing psychosocial and spiritual suffering with a goal of helping patients find acceptance and healing as they define both. This can be done through the practice of primary palliative care (or basic palliative care) and, often-times, in collaboration with specialty palliative care providers.

Palliative care focuses on value-based care. Care is provided by a large interdisciplinary team, essentially an entire community of providers who treat the whole person and family. Doctors and nurses work with a larger interdisciplinary team with staff from multiple departments, including social work, chaplaincy, psychiatry, nutrition, recreation therapy, and pharmacy. The services offered are anything that needs to be done to relieve total pain and suffering and help quality of life. This includes pharmacologic management, emotional and spiritual counseling, and complementary modalities, such as acupuncture, massage therapy, art therapy, reiki, hypnosis, biofeedback, labyrinth, mandala, and pet therapy.

To achieve whole-person care, the oncologist, oncology nurse practitioner, and physician assistant must understand how to support an integrated care team. The provider needs to start by getting a patient story that includes all physical–medical, psychological, social, and spiritual
dimensions. The provider needs to learn how to coordinate a single longitudinal care plan that is fluid and changes throughout the disease process but can also be delivered by all members of the interdisciplinary team. In addition, the provider needs to learn humanistic integrative care and how to communicate with a community of healthcare providers.

This book is meant to be a practical handbook for oncologists, residents, fellows, nurse practitioners, nurses, psychosocial providers, and physician assistants so that they understand and will be able to provide primary palliative care to patients and families who live with cancer. What is additionally emphasized is how to support an integrated team. Because medical care and oncologic care can be fragmented, we felt an urgent need to put this resource together for anyone entering oncology, nursing, primary care, or palliative care specialties. With this book, we hope to help the reader understand practical ways of integrating curing and healing and improve the quality of life for all patients and their families enduring disease-related and treatment-related symptoms.

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INTRODUCTION
Palliative care principles transcend all ages and cultures. By recognizing the shared values of quality of care, symptom management, family-centered care, compassionate communication, and interdisciplinary service, the field of palliative care reaches across life stages and care locations. This chapter depicts the intergenerational nature of palliative care work with the goal of care phrased in developmentally informed steps. Healthcare providers foster dignity when adapting universal palliative care principles to a local community in a participatory and culturally, spiritually, and developmentally informed way.

THE CROSS-CULTURAL VALUES OF PALLIATIVE CARE
The World Health Organization (WHO) and member states were called upon by the World Health Assembly resolution WHA67.19 to improve access to palliative care as a fundamental and core component of community health systems (1).

The Center to Advance Palliative Care defines palliative care as:

• “Palliative care is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family” (2).

Both of these definitions can be applied to any infant, child, adolescent, young adult, or an adult advanced in age, regardless of geography, ethnicity, and religion. The adaptation of models of care specific to children and adolescents has been recognized as a research and clinical priority in spirituality and palliative care (3).

PRIMARY AND SECONDARY PEDIATRIC PALLIATIVE CARE
Primary palliative care refers to the fundamental competencies and basic skills required of all healthcare professionals striving to provide quality of life and comfort. Eliciting goals of care and documenting quality of life goals in the patient’s medical record represents a primary palliative care competency as a universal skill relevant for all healthcare providers.

Secondary palliative care refers to the subspecialist clinicians, who provide specialty complex care specific to palliative care principles (4). Referrals to subspecialist palliative care providers may occur because of complex symptom management, existential distress, or complex care coordination.
FRAMING PEDIATRIC PALLIATIVE CARE ACROSS SETTINGS

Because of the high remission rates for many childhood cancers and the challenge of prognostic certainty in pediatric illnesses (involving vital organs in young children and advancing medical technologies), many pediatric palliative care teams ground their introduction to families and children as "supportive care" and "symptom management" and "psychosocial support" teams upfront at the time of early integration diagnosis. Goals of care for a child are best determined through longitudinal care of a family across care settings.

Emphasis in pediatric palliative care is on quality of life and optimal living: “How can today be a good day for this dearly loved child?” is a common pediatric palliative care inquiry.

FRAMING PALLIATIVE CARE ACROSS AGES

Even while considering how parents grieve the loss of a child (unique parental bereavement needs), palliative care providers are compelled to also consider how an adult child grieves the loss of his or her aged parents (unique adult child bereavement needs), and how a young child grieves the loss of his or her parents (unique developmental bereavement needs). Palliative providers caring for children and adults recognize a remarkable mutualism that speaks to the beauty of our development, our complex relationships, and the arch of the human trajectory that spans ages. Consider how children develop many of their remarkable milestones (head control, babbling vocalizations, trunk control, ambulation, fine motor skills) in a pattern that is the reverse of how aging adults with advanced dementia lose many of their milestones. This circle-of-life recognition reminds palliative providers that there is no dichotomy between pediatric endings and adult beginnings; this field acknowledges a shared journey with symbiotic knowledge across ages. Adult and pediatric palliative providers can and should learn from each other. For example, in pediatric palliative care, one of the quality of life metrics is “minutes able to engage in meaningful play”—that could and should be a lifelong quality of life metric! Some of what medicine tries to silo is actually shared experiences across developmental and chronological ages.

THE INTERGENERATIONAL NATURE OF PEDIATRIC PALLIATIVE CARE

Consider the following case examples representing one palliative care provider’s case list that depicts the vast age array of patients cared for by palliative care teams (Table 3.1).

DEVELOPMENTAL RELEVANCE OF PEDIATRIC PALLIATIVE CARE

Care providers would be wise to familiarize themselves with the cognitive and spiritual developmental stages of childhood, as this empowers a palliative team’s interaction with a child so as to be most meaningful for that child’s understanding of illness, life, and even death (Table 3.2).
<table>
<thead>
<tr>
<th>Age</th>
<th>Patient example</th>
<th>Consult goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fetal</td>
<td>An yet-to-be-born infant carrying a diagnosis of hypoplastic left heart diagnosed</td>
<td>Help pregnant mom and her partner consolidate complex medical information prenatally; focus on surgical decision making and</td>
</tr>
<tr>
<td></td>
<td>on the echocardiogram in the second trimester of pregnancy</td>
<td>goals of care; establish pregnancy legacy</td>
</tr>
<tr>
<td>Neonatal</td>
<td>Peri-viable 25-week infant born with congenital diaphragmatic hernia</td>
<td>Pain management; coordination of communication among multiple subspecialty teams; sibling support from 7-year-old big brother</td>
</tr>
<tr>
<td>Infant</td>
<td>3-month-old male with Trisomy 18</td>
<td>Determine goals of care in context of life-limiting illness; hear parental perspectives and narratives on evolving view of</td>
</tr>
<tr>
<td></td>
<td></td>
<td>medical interventions for children with Trisomy 18</td>
</tr>
<tr>
<td>Toddler</td>
<td>18-month-old female from rural community with tracheostomy and G-tube</td>
<td>Discuss transition from extended inpatient stay to home setting; coordination of care for rural community to include training</td>
</tr>
<tr>
<td></td>
<td></td>
<td>of rural paramedics; engage in ongoing psychosocial support for complex, chronic condition; secretion and spasticity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>management</td>
</tr>
<tr>
<td>Preschool</td>
<td>3-year-old male with hypoxic brain injury from drowning accident</td>
<td>Parental resilience at bedside; spiritual support</td>
</tr>
<tr>
<td>Elementary</td>
<td>8-year-old female with cystic fibrosis</td>
<td>Coordination of school support services during recent increase in admissions; pulmonary symptom management</td>
</tr>
</tbody>
</table>

(continued)
<table>
<thead>
<tr>
<th>Age</th>
<th>Patient example</th>
<th>Consult goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Junior high</td>
<td>14-year-old female with vertically transmitted HIV and sickle cell disease</td>
<td>Maximize medication adherence during adolescent years; foster peer connectedness via adolescent support group; focus on life goals</td>
</tr>
<tr>
<td>High school</td>
<td>17-year-old male with chronic headaches with negative biomedical work-up—currently on opiates</td>
<td>Establish opiate contract with goal to wean off of all opiates; work on functional goals such as returning to school and sports; introduce integrative therapies such as hydrotherapy and acupressure; foster pain diary accountability</td>
</tr>
<tr>
<td>Graduated</td>
<td>20-year-old female with osteosarcoma who has had limb salvage surgery and completed radiation/chemotherapy</td>
<td>Transition to adult care team with empowerment of young adult; longitudinal psychosocial needs assessment; employment connectedness; adaptation to new identity as cancer survivor</td>
</tr>
<tr>
<td>Young adult</td>
<td>30-year-old male with a toddler and a pregnant spouse newly diagnosed with Huntington’s disease</td>
<td>Engage in goals of care conversation; discuss location preferences of care; focus on symptom management; consider legacy opportunities for family and practical realities of advanced care planning</td>
</tr>
<tr>
<td>Adult</td>
<td>65-year-old retired, widowed mail clerk diagnosed with advanced pancreatic cancer</td>
<td>Determine goals of care; address symptom management; review social and spiritual support resources; consider practicalities of access to health services; discuss life goals and preferences for family inclusion</td>
</tr>
<tr>
<td>Age</td>
<td>Stage of cognitive development</td>
<td>Concept of death</td>
</tr>
<tr>
<td>--------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Infancy: 0–2 years</td>
<td>• Sensorimotor: learning to trust the world</td>
<td>• Death is perceived as separation or abandonment</td>
</tr>
<tr>
<td></td>
<td>• Experience of the world through sensory information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Limited conscious thinking</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Limited language</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Reality that is based on physical needs being met</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Death is perceived as separation or abandonment</td>
<td></td>
</tr>
<tr>
<td>Early childhood: 2–6 years</td>
<td>• Stage of preoperational thought; imaginative and egocentric</td>
<td>• Death is reversible or temporary</td>
</tr>
<tr>
<td></td>
<td>• Prelogical</td>
<td>• May equate death with sleep</td>
</tr>
<tr>
<td></td>
<td>• Development of representational or symbolic language</td>
<td>• May believe they can cause death by their thoughts (e.g., wishing someone would go away and thus cause the death of the person)</td>
</tr>
<tr>
<td></td>
<td>• Egocentric orientation</td>
<td>• May not express personal emotion, but may associate death with the sorrow of others</td>
</tr>
<tr>
<td></td>
<td>• Magical thinking</td>
<td>• May see death as a punishment</td>
</tr>
</tbody>
</table>
(continued)
### Table 3.2 Stages of Development and Supportive Interventions (continued)

<table>
<thead>
<tr>
<th>Age</th>
<th>Stage of cognitive development</th>
<th>Concept of death</th>
<th>Spirituality</th>
<th>Supportive interventions</th>
</tr>
</thead>
</table>
| Middle childhood: 7–12 years | • Stage of concrete operations  
• Logical  
• No abstract reasoning  
• Orientation is egocentric | • Death is irreversible but is unpredictable  
• Aware that death is personal and can happen to them  
• May have great interest in details  
• May be interested in what happens after death  
• Can understand the biologic essentials of death | • Mythic: Takes on stories and beliefs of community  
• Faith is literal and concerns right and wrong  
• Connects ritual with personal identity | • Don’t assume, exercise curiosity. Listen actively. Evaluate for fears of abandonment, destruction, or body mutilation  
• May benefit from specifics about the illness and treatments and reassurance that treatments are not punishments  
• Maintain the child’s access to peers and spiritual support persons  
• Foster the child’s sense of mastery and sense of control |
Table 3.2 Stages of Development and Supportive Interventions (continued)

<table>
<thead>
<tr>
<th>Age</th>
<th>Stage of cognitive development</th>
<th>Concept of death</th>
<th>Spirituality</th>
<th>Supportive interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescence and adulthood:</td>
<td>• Stage of formal operations; adopting new ideas; working out identity</td>
<td>• Death is irreversible, universal, personal, but distant</td>
<td>• Approaches synthesis: more conventional</td>
<td>• Reinforce comfortable body image, self-esteem</td>
</tr>
<tr>
<td>Older than 12 years</td>
<td>• Development of abstract thought and advanced logical functions (e.g., complex analogy, deduction)</td>
<td>• Has the ability to develop natural, physiological, and theological explanations of death</td>
<td>• Formulation of a personal faith, incorporating environment and experience</td>
<td>• Allow expressions of anger</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Evolution of relationship with God or higher power</td>
<td>• Provide privacy for the child</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Searches for meaning, purpose, hope, and value of life</td>
<td>• Support reasonable measures for the child to achieve independence</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td>• Maintain the child's access to peers</td>
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<td></td>
<td></td>
<td></td>
<td>• Explore spiritual meaning</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Consider peer support groups</td>
</tr>
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THE SPIRITUAL NATURE OF PALLIATIVE CARE

Palliative care providers benefit from familiarity with what brings patients meaning, joy, strength, and hope. A spiritual assessment tool well-investigated and applicable to palliative practice includes the F-I-C-A scale (Copyright, Christina M. Puchalski, MD, 1996), a scale that reminds us of the need to allow patients of varying ages and walks of life and religious or nonreligious traditions to define their spirituality.

F - Faith and Belief
I - Importance
C - Community
A - Address in Care

THE FAMILIAL AND COMMUNITY NATURE OF PALLIATIVE CARE

Pediatric palliative teams recognize that while the patient is the unit of treatment and care, the family is the unit of understanding and extended care. A patient’s wellness affects the family unit. The patient and family define the members of their family unit and the roles of those members.

• Parents—Children are held within the context of a parental unit, whether co-parents, single parent, or married parental units. Each parent brings a "lens" of insight into the child’s needs and their hopes for the child. Pediatric palliative care teams are privileged to assess each parent’s individual perspective in addition to a coupled unit perspective. Pediatric palliative care providers often have an opportunity to recognize parents, where each parent may hold shared values in addition to nuanced differences in view/role, and to engage in support for parents not just as individuals but as co-providers for a loved child. When illness impacts adult children, parents often resume the parental role or face the impact of witnessing someone they have attempted to protect from suffering now face frailty sooner than seems biologically acceptable (adult parents expect to experience personal illness/death sooner than their adult children).

• Grandparents—Grandparents are known to be “double grievers” as they feel the impact of illness to their own child (as parent) and they feel the impact of illness to their own grandchild (as grandparent). Thus, many palliative care teams recognize the double-duty to support grandparents through listening to grandparent narrative and attending to grandparent bereavement. This must be balanced by a professional commitment to not reveal confidential medical information to grandparents and to allow the child/child’s parents to define grandparent inclusion.

• Siblings—Siblings of patients with chronic medical conditions feel the impact not only in terms of sensing the absence of their playmate, if this is a pediatric-age patient, but also in feeling their parents’ “torn” wish to be present at home with the sibling and present at the hospital with the ill child. Young siblings sometimes act out in response or sometimes become “the perfect child”—both are a form of attention gathering. Older siblings may now be carrying additional duties.
as “aunty” stepping into a maternal role for the children of an adult patient or “uncle” stepping forward to provide guidance even if there is geographic or relational distance historically. Siblings warrant specific attentiveness for child life specialists and palliative care teams for psychosocial needs assessment, developmentally appropriate support, honest presence, and special recognition.

- **Peers**—Peers, known to the pediatric patient, are often forming their view of illness, and even death, through the pediatric patient’s medical experiences. Peers note physical changes in an ill child and disabilities; this can be an opportunity for mentored adaptability in accepting to avoid bullying or alienating an ill child. Many pediatric palliative care programs offer Internet or in-person outreach to schools or community groups to foster education and peer adaptation. Adult peers of older patients often struggle with not knowing what to say or how best to direct support; palliative care teams can help adult patients consider how they may wish to protect their privacy or communicate their needs with neighbors/colleagues/friends.

**THE RICH DIVERSITY OF PALLIATIVE CARE**

Palliative care brings humanistic principles that transcend into all cultures and settings. The basic principles of palliative care include:

- **An attentiveness to family function**
- **A stance of loving kindness and positive regard for the patient**
- **A listening presence that prioritizes patient voice/patient perspective**
- **A maximization of symptom management**
- **A commitment to quality of life**
- **A coordination of communication**
- **A desire to alleviate suffering**
- **A recognition of the dignity and worth of each patient**

These principles are relevant for all patients and their families.

**REFERENCES**


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