

## CONTENTS

<b>Preface</b>	xv
Tammy I. Kang, David Munson, and Jeffrey C. Klick	

<b>Collaborative Communication in Pediatric Palliative Care: A Foundation for Problem-Solving and Decision-Making</b>	583
Chris Feudtner	

In an ideal world, all of us—patients, parents, family members, nurses, physicians, social workers, therapists, pastoral care workers, and others—would always work together in a collaborative manner to provide the best care possible. This article bases the framework for pursuing this ideal upon studies of communication between patients, families, and clinicians, as well as more general works on communication, collaboration, decision making, mediation, and ethics, and is comprised of four parts: (1) what is meant by collaborative communication; (2) key concepts that influence how we frame the situations that children with life-threatening conditions confront and how these frameworks shape the care we provide; (3) general topics that are important to the task of collaborative communication, specifically how we use heuristics when we set about to solve complicated problems; and (4) three common tasks of collaborative communication, offering practical advice for patient care.

<b>Psychosocial and Spiritual Needs of Children Living with a Life-Limiting Illness</b>	609
Mary McSherry, Kathy Kehoe, Jean M. Carroll, Tammy I. Kang, and Mary T. Rourke	

Quality end-of-life care includes the management of distressing symptoms; provisions of care, including the assessment and management of psychosocial and spiritual needs; and respite

from diagnosis through death and bereavement. Meeting the palliative care goal of improved quality of life depends on medical and nursing practitioners understanding and effectively assessing psychosocial symptoms.

### **Compassion Fatigue in Pediatric Palliative Care Providers**

631

Mary T. Rourke

The experience of compassion fatigue is an expected and common response to the professional task of routinely caring for children at the end of life. Symptoms of compassion fatigue often mimic trauma reactions. Implementing strategies that span personal, professional, and organizational domains can help protect health care providers from the damaging effects of compassion fatigue. Providing pediatric palliative care within a constructive and supportive team can help caregivers deal with the relational challenges of compassion fatigue. Finally, any consideration of the toll of providing pediatric palliative care must be balanced with a consideration of the parallel experience of compassion satisfaction.

### **The Management of Pain in Children with Life-limiting Illnesses**

645

Stefan J. Friedrichsdorf and Tammy I. Kang

The management of pain in children with life-limiting illnesses is complex and unfortunately not often done effectively. Pain is a multidimensional symptom that can overshadow all other experiences of both the child and family. This article focuses on topics common to practitioners caring for children with lifelimiting illnesses, including a review of myths and obstacles to achieving adequate pain control, a review of the pathophysiology of pain, an overview of the use of opioids in children, an approach to the management of neuropathic pain, and a brief discussion of nonpharmacologic pain management strategies.

### **Common Gastrointestinal Symptoms in Pediatric Palliative Care: Nausea, Vomiting, Constipation, Anorexia, Cachexia**

673

Gina Santucci and Jennifer W. Mack

Gastrointestinal symptoms are suffered commonly by children at the end of life. Diagnosis and management of these common symptoms include careful history and physical examination to assess for possible causes; treatment—pharmacologic and non-pharmacologic; and a discussion with patients and families of care goals. Aggressive management of these symptoms is essential to improving the quality of life for these children.

## **Depression and Anxiety in Children at the End of Life**

691

Leslie S. Kersun and Eyal Shemesh

A significant component of palliative care is the prompt diagnosis and management of distress, anxiety, and depression. This article reviews the symptoms and treatment of anxiety and depressive disorders in children at the end of life. Distinguishing between symptoms and disorders, the importance of open communication, consideration of the child's understanding of death, diagnostic challenges in chronically ill children, and suicidality are discussed. Because treatment options are available, it is imperative that symptoms are recognized and addressed. Understanding the issues involved in screening and diagnosis and the risks and benefits of available treatments can lead to an informed approach to the management of these disorders in the palliative care setting.

## **Management of Common Neurologic Symptoms in Pediatric Palliative Care: Seizures, Agitation, and Spasticity**

709

Courtney J. Wusthoff, Renée A. Shellhaas, and Daniel J. Licht

Palliative care for children is complex and focuses on patients' comfort. Some of the most troublesome symptoms as patients approach the end of life are seizures, agitation, and spasticity. Many doctors caring for children at the end of life are uncomfortable or untrained in managing these symptoms in children. Our goal is to help physicians recognize and treat these neurologic symptoms optimally.

## **Assessment and Management of Fatigue and Dyspnea in Pediatric Palliative Care**

735

Christina K. Ullrich and Oscar H. Mayer

Fatigue is one of the most prevalent symptoms in patients with a life-threatening illness. Untreated, fatigue can impair quality of life and prohibit addressing practical needs, psychosocial and spiritual distress, and opportunities for growth and closure at life's end. To this end addressing fatigue is a crucial component of the provision of effective palliative care. Dyspnea is the sensation of breathlessness. The challenge in treating it, however, is that it can come from various different abnormalities so understanding the underlying disorder and the acute abnormality are critical. With that understanding several different treatments can be offered to treat the cause of the dyspnea or palliate the symptom itself.

## **Do Not Attempt Resuscitation Orders in Pediatrics**

757

Ivor Berkowitz and Wynne Morrison

Do-not-attempt resuscitation orders are becoming more common in pediatrics, particularly as programs for hospice and palliative

care in children develop. Concomitantly, there arises the need to decide when it is appropriate to use these technologies. It is at this point that the skills of relationship building, listening, and empathic concern become indispensable.

### **Withdrawal of Mechanical Ventilation in Pediatric and Neonatal Intensive Care Units**

773

David Munson

Withdrawing life-sustaining technologies requires all of the resources and concepts that the field of palliative care has to offer. By learning some fundamental principles of medical management at the time of withdrawal and by mastering a few communication techniques, pediatricians, neonatologists, and pediatric intensivists can dramatically improve the care provided to their patients at the end of life. Although we may argue in pediatrics if there is ever such a thing as a good death, we should all strive to ensure one that is free of suffering, and one that supports the family in moving down a path of healthy grief and recovery.

### **Palliative Care for the Family Carrying a Fetus with a Life-Limiting Diagnosis**

787

David Munson and Steven R. Leuthner

Prenatal diagnosis of a lethal anomaly is a monumental moment in a family's life. It requires extensive team counseling and planning about complex neonatal and obstetric medical management. The construct of palliative care with its focus on emotional, spiritual, social, and symptom support can provide a model for caring for these families.

### **Providing Care in Chronic Disease: The Ever-Changing Balance of Integrating Palliative and Restorative Medicine**

799

Jeffrey C. Klick and Allison Ballantine

Caring for children who have a chronic life-limiting illness can be emotionally and physically challenging. Just as families may struggle with whether they are making the right decisions, care providers struggle with whether they are giving the right advice, predicting the medical course correctly, and making the correct medical decisions. Uncertainty is a constant for the family and the care provider. The willingness of the care provider to develop a relationship with the family that involves continuing communication and re-evaluation of the child's condition and the family's perspective can relieve some of the emotional and physical suffering associated with a chronic disease and support the family in times of hope and grief.

**Issues Related to Providing Quality Pediatric Palliative Care in the Community**

813

Jean M. Carroll, Christy Torkildson, and Jeannine S. Winsness

The medical practitioner in the community is in a unique position to assist children and their families from the time of diagnosis with a life-threatening condition through to the end of life. The purpose of this article is to inform medical practitioners who care for children with complex, chronic, and life-limiting conditions about pediatric palliative care in the community. It is intended as a guide to improve understanding about (1) the misconceptions and barriers surrounding the provision of care in the community for children with chronic, complex, and life-limiting conditions; (2) the availability of services for care in the community; (3) challenges concerning out-of hospital do-not-attempt-resuscitation orders for children; and (4) reimbursement issues that impact the provision of care.

**Index**

829