

Nalini Vadivelu · Alan David Kaye
Jack M. Berger *Editors*

Essentials of Palliative Care

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I wish to thank my parents, Major General Vadivelu and Gnanambigai Vadivelu, my husband, Thangamuthu Kodumudi, and my sons, Gopal and Vijay, for their steadfast support. I would also wish to thank my brother, Dr. Amarender Vadivelu, and sister, Suguna Vadivelu, for their inspiration, and my innumerable friends, colleagues, and students who encourage me to reach for heights higher than the day before.

–NV

I want to thank my wife, Dr. Kim Kaye, for her dedication and love over many decades; my brother, Dr. Adam Kaye, for a lifetime of friendship and support; and my mother-in-law, Dr. Patricia B. Sutker, for the thousands of loving and helpful things she has done for me over the past 25 years. Finally, I want to thank my mother, Florence Feldman, for inspiring me to be a doctor many years ago and for her love and support during my life.

–AK

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–JB

Foreword

When my mother turned 90 years old, she had moderately advanced Parkinson's disease, but no other major ailments. Her function was declining gradually, and she began to fall and become a bit forgetful. Her ability to live independently was waning. But her need for palliative care was clear and rapidly growing. It began with a general consideration of her medical goals—she did not want any big medical adventures, so resuscitation and intubation were easily taken off the table. But she still had a lot of things to enjoy in life, so she was willing to have her doctors try to fix easily treatable problems as long as she had a good chance of returning to an acceptable level of independence. But the ground rules of this approach were not clear, because her condition was fragile and her ability to live alone in her beloved house was becoming more and more difficult because of the ravages of her Parkinson's disease.

The next big event in her life was a fall where she sustained a broken hip. Surgically repairing the hip made sense given her goals (and the absence of good alternatives), but her recovery was complicated by pain, postoperative delirium, deconditioning, and worsening of her Parkinson's disease. The need for palliative care expertise to address the growing complexity of her symptoms and her condition was clearly growing, as her goals were now shifting more toward purely comfort-oriented approach. She had no definable terminal illness, so she did not qualify for a formal hospice program (even though that was the philosophy of treatment both she and we wanted), and no one could say with honesty that she was more likely than not to die in the next 6 months. With excellent palliation, she eventually made it to a rehabilitation program in a skilled nursing facility. Although her function improved modestly, she did not return to her former baseline. She hated living there, and her inability to safely walk without someone with her at all times was a real challenge to her sense of identity and personhood. Palliation now required multidimensional interventions that included orthopedic guidance, pain management, physical therapy, neurologic management of her Parkinson's disease, and psychological treatment of her grief.

My mother was adamant in her desire to return to her home, yet we as a family knew it was unsafe without 24-hour supervision, which she flatly refused. As we

were struggling with next steps, she suddenly became jaundiced. Her doctor fortunately was skilled in palliative care and knowledgeable about hospice care. He helped us think through her limited options. My mother was painfully aware that her quality of life was waning rapidly, as was her ability to live independently, and that more medical intervention was the last thing she wanted unless it had a high likelihood of returning her to full independence. A biopsy or a biliary drainage procedure would not help her achieve these goals, and therefore would not be in her best interest. It was time to shift gears toward pure, noninvasive palliation, and a hospice referral was made without any biopsies or interventions. With her new found terminal illness, she now qualified for hospice medically as well as philosophically, and we began to think through where she would spend her final time. Although our extended family lived on the North Shore of Boston where my mother was living, she agreed to a move to Rochester to be near us so that we could help care for her over her final weeks or months. She put on my Red Sox cap for her final road trip, and my brother and I brought her to Rochester where she lived in a comfort care home for her final weeks. With the help of a skilled hospice team, we were able to keep her very comfortable. There were symptoms that required intensive management, including pruritis, pain, and delirium, but there were also wonder times of storytelling and family members coming together. She died very peacefully in our presence 3 weeks after her move to Rochester.

There ought not to be very much special or unique about this story, but in fact in the current environment it is probably the exception rather than the rule. Part of the reason it is exceptional is that many physicians do not have the knowledge and skill about palliative care and hospice that her physician and our family had. Such knowledge, skill, and advice is thoughtfully and accessibly presented in *Essentials of Palliative Care*, co-edited by three highly skilled and respected palliative care physicians, Drs. Vadivelu, Kaye, and Berger. The physicians caring for my mother were not specialists in palliative care or hospice, but they knew enough about palliative treatments to be able to help us think through a broad range of options at each clinical curve in the road. Although they did not always have all the palliative care treatment options at their fingertips, they knew how to find them and how to adapt the treatment plan to my mother's preferences and changing clinical circumstances. Many of the chapters in this book would have been relevant to my mother's care, including the chapters on pain management, on physical and occupational therapy, and psychological distress, as well as the chapter covering the transition to hospice. There are other chapters that provide guidance about vascular access, ostomy care, and palliative use of interventional radiology that might not be within the knowledge base of all clinicians, but would increase awareness of potential palliative options to address difficult symptom-related problems.

Not everyone providing palliative care needs to be a subspecialist (there is far too much work and too few fully trained and certified clinicians), but all clinicians who care for seriously ill patients should have solid basic palliative care skills both in terms of pain and symptom management, and in terms of helping patients negotiate the medical system in light of a full understanding of their patients' goals and clinical options. *Essentials of Palliative Care* should be a part of that toolkit, and we

are indebted to Drs. Vadivelu, Kaye, Berger, and their other chapter authors for providing such an accessible, useful resource.

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Timothy E. Quill Rochester

Preface

Palliative Medicine has become a familiar term in recent years and is becoming established as a key component in modern health care, and many institutions promote Palliative Care teams. Although this is a term relatively new to many practitioners, palliative care was coined several decades ago by Dr. Balfour Mount, a Canadian physician. After training in Dame Cicely Saunders' St. Christopher's Hospice in London, he was so impressed that he was inspired to bring this type of care to mainstream curative medicine. As a result, he founded the Royal Victoria Hospital Palliative Care Service in 1974 and is credited with establishing the first in-patient palliative care unit in North America. Having emerged from the nurse driven hospice movement, the care of the dying has evolved to a formal hospice benefit and development of a recognized subspecialty.

This specialty of Hospice and Palliative Medicine (HPM) is dedicated to promoting quality end of life care to patients and families struggling with advanced disease. In recent years, palliative care has become increasingly common in the medical literature as well as in public media. Although the delivery of palliative care is influenced by the hospice model, the composition of a hospital-based palliative care team varies significantly from one institution to another, but fundamental roles are generally identified as the provision of physical, emotional, social, and spiritual comfort. The requirements for a "home" based palliative care team service is similar to those of the hospital-based service.

In developing an education program for symptom management and palliative care, physicians and other healthcare providers will need to learn how to make the difficult decisions with respect to recommending or initiating therapeutic interventions or recommending and discontinuing interventions. Examples of symptoms which would have to be considered can be grouped as follows:

- Pain of any etiology, tumor metastasis, spinal cord or nerve root compression, lymphedema, bowel obstruction, electrolyte abnormalities.
- Dehydration, malnutrition, anorexia-cachexia syndrome, radiation enteritis, diarrhea, nausea, vomiting.
- Asthenia, fatigue, weakness.

- Dyspnea, respiratory failure, respiratory tract infections, pleural effusions, lymphangitis carcinomatosa.
- Anemia, wound breakdown, ulcerations, decubitus ulcers, ostomies.
- Anxiety, confusion, sleep disorders, depression, sadness, anger.
- Hiccoughs, cough, bloating, belching, mucositis, foul body odors, wheezing.

It is necessary to develop systems for evaluating the necessity or futility of intervening based upon an understanding of the pathophysiology of the above symptoms in the terminally ill patient. The costs both economic and psychosocial of intervening or not intervening or cessation of ongoing interventions must be better defined. Only through facing these difficult problems critically can we learn how best to deal with them.

The Physician

The American Board of Medical Specialties is a self-policing organization that sets standards and grants certification for medical practice beyond the minimum requirements for licensure. In a given field of medical practice, a physician seeks recognition for expertise. When Palliative Medicine became part of modern medical practice, the logical result was the pursuit of formal certification. As a result, the American Board of Hospice and Palliative Medicine was formed, an independent certifying organization.

From 1996 to 2006, the available certification for physicians practicing palliative medicine was through the independent American Board of Hospice and Palliative Medicine. This entity provided recognition of expertise for practitioners caring for the dying, while promoting the importance of the specialty and working toward transition to formal recognition by the American Board of Medical Specialties, the official body that is recognized by healthcare systems as the stamp of approval of medical specialties. Currently, there are ten co-sponsoring boards that offer subspecialty certification in Hospice and Palliative Medicine (HPM), including the American Boards of Anesthesiology, Emergency Medicine, Family Medicine, Internal Medicine, Obstetrics and Gynecology, Pediatrics, Physical Medicine and Rehabilitation, Psychiatry and Neurology, Radiology, and Surgery.

Competencies of subspecialist-level hospice and palliative medicine include skills in symptom management, relief of suffering and improving the quality of life for patients and families living with life-threatening illness, provision of assistance for patients and families coping with loss, and management of challenging problems associated with end-of-life care.

Nursing

The nursing profession has been in the forefront of the hospice movement and plays a pivotal role in modern palliative medicine. The National Board for Certification of Hospice and Palliative Nurses (NBCHPN), established in 1993, provides nursing

certification for hospice and palliative medicine for several categories of nursing positions. The classifications of expertise include Advanced Certified Hospice and Palliative Nurse (ACHPN), Certified Hospice and Palliative Nurse (CHPN), Certified Hospice and Palliative Pediatric Nurse (CHPPN), Certified Hospice and Palliative Licensed Nurse (CHPLN), Certified Hospice and Palliative Nursing Assistant (CHPNA), Certified Hospice and Palliative Care Administrator (CHPCA). Each certification period is valid for 4 years and is renewable.

Advanced practice nursing certification is granted for nursing professionals who either hold a Clinical Nurse Specialist or Nurse Practitioner license, and have graduated from an accredited education program specializing in palliative care that includes a minimum of 500 hours of palliative care training, or have post master's graduate practice experience of 500 hours in providing palliative care in the year prior to examination. Successful completion of the examination establishes excellence in the area of clinical judgment, advocacy and ethics and systems thinking, professionalism and research, collaboration, facilitation of learning and communication, and cultural and spiritual competence.

For a registered nurse to test for CHPN status, the candidate must hold a valid registered nurse license. It is recommended that the individual also have at least 2 years of practice in end-of-life care prior to testing. Successful completion of the examination demonstrates ability in recognition of life-limiting conditions in adult patients, pain and symptom management, care of patient and family, education and advocacy, interdisciplinary/collaborative practice, and professional issues.

A nursing professional seeking certification for NBCHPN is required to hold a valid registered nurse license and is encouraged to have a minimum of 2 years experience in the care of terminally ill children. This encompasses the care of patients ranging in age from perinatal to young adulthood. As a result of certification, the pediatric nurse establishes competencies in recognition of life-threatening conditions in children, pain and symptom management, treatments and procedures, family centered care, education and advocacy, care at end of life, grief and bereavement, and professional issues.

The certification exam for licensed practical nurses (LPN) and licensed vocational nurses (LVN) has been offered since 2004. Successful candidates achieve the CHPLN credential, which is valid for 4 years. Candidates holding a valid LPN or LVN are eligible to take the exam. Two years experience in the hospice or palliative care setting is recommended. Clinical areas of expertise include various aspects of patient care such as end-stage disease process in adult patients, pain, symptom, and comfort management, treatments and procedures, care of patient, family, and other caregivers, patient and family education and advocacy, and interdisciplinary and collaborative practice issues.

Nursing assistants are eligible to test for the CHPNA credential if the candidate can provide documentation of 2000 practice hours under the supervision of a registered nurse in the previous 2 years. It is also recommended that the candidates have 2 years of experience specifically in the field of hospice or palliative care.

Examination for the CHPCA credential is offered for any individual with 2 years experience in an administrative role, verified by a supervisor, that involves hospice or palliative care. The NBCHPN administrator examination tests for competency in leadership, planning, operations, fiscal and human resource management, quality management, marketing, public relations, and ethics.

Social Work

The advanced certified hospice and palliative social worker (ACHP-SW) credential was added in 2009, adapted for the specialized skills and expertise of social work professionals who provide care in the hospice and palliative care setting . The eligibility requirements include a master's degree in social work from an accredited university, 20 or more continuing education credits specific to hospice and palliative care, documentation of at least 2 years of supervised social work experience in hospice or palliative care setting, and a current license to practice as a professional social worker.

Program Certification

With the ambitious credentialing process for all members of the palliative care team, it is logical to expect progression to program certification. The Joint Commission on Accreditation of Healthcare Organizations has developed an Advanced Certification Program for Palliative Care. Expertise and commitment of dedicated individuals representing the credentialed disciplines is greatly enhanced in the setting of institutional support. Standards set forth by the Joint Commission certification program emphasize this need to consign resources and support for palliative care teams. Eligibility requirements for palliative care program certification include: be a joint commission accredited hospital or facility, have full time coverage for palliative care services, have served a minimum of ten patients and have at least one active patient at the time of the initial joint commission review, provide care based on clinical practice guidelines and/or evidence-based practice, have control in the clinical management of patients and coordination of care, follow an organized approach supported by an interdisciplinary team of health professionals, and use performance measurement to improve its performance over time.

These standards are based on The National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care and the National Quality Forum's National Framework and Preferred Practices for Palliative and Hospice Care Quality.

The common goals and standards of all the credentialing disciplines and organizations reflect the scope and complexity of palliative care. All entities strive for complete care of the dying patient and family, including the physical, spiritual, emotional, cultural, legal, and ethical components treatments. Features that are

shared by all programs stress the importance of the interdisciplinary approach for alleviation of suffering, care in multiple settings, education, quality improvement, and attention to family and caregivers.

The monumental efforts that have led to the entry of palliative care into the mainstream of medical practice provide a sound foundation for individual institutions to incorporate this practice into the network of customary hospital services. Although the number of institutions that provide a palliative care team continues to grow, there is a lack of standardization regarding the composition and role of such a team. There is opportunity for institutions to support the excellence and standards of specialized professionals, and offer customized service that is focused on the unique patient populations that they serve. Each hospital has tools available developing its own unique approach for delivery of palliative care.

Education, of course, should be a major component of any symptom management and palliative care program. Mark Lema, MD, PhD commented in the ASA Newsletter, July 1998, that “The AMA is concerned that physician assisted suicide is a symptom of a much bigger problem, that physicians are not prepared to properly care for dying patients” [6]. Changing one’s focus from cure to comfort care is not in the traditional medical curriculum or philosophy. Attendings, fellows, residents, interns, and medical students as well as nursing staff and all other ancillary personnel of the team have to be taught this reorientated mind-set. How to approach the patient and/or significant others with the diagnosis of terminal illness, the presentation of options for end-of-life care, the emphasis that palliative care does not mean “nothing else can be done,” or that no care will be offered, but rather that the goal of therapy will be comfort and dignity is something that must be taught and practiced. How one obtains a “true informed consent” for do not resuscitate (DNR), and how one approaches the completion of an advanced directive needs to be taught and needs to be learned.

In summary, true palliative care involves a paradigm shift. A patient used to receive a diagnosis of a life-threatening disease and a treatment plan was laid out with little attention paid to the consequences of the treatment or what will be done if the treatment fails to arrest the disease. And it was only in the last few days or weeks of life that a patient was offered comfort care measures. Today, as compassionate healthcare providers it is incumbent upon us to introduce comfort care early in the process. Comfort measures (palliative care) will intensify as curative measures are exhausted. Thus, the needs of the patient and his/her family can be met at all stages of the disease process. We hope that our book, *Essentials of Palliative Care*, is useful for clinicians of all disciplines as we move forward in this ever changing and complex world.

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