

Chapter 1

Hospital Care for Seriously Ill Patients and Their Families

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Mrs Morton was an 82-year-old woman with ovarian cancer metastatic to the lung, liver, and peritoneum with massive ascites diagnosed 1 year ago. She had undergone many cycles of chemotherapy but stopped chemo several months ago due to progression of disease and increasing fatigue. Mrs Morton was living at home with her daughter, son-in-law, and three grandchildren. A few days earlier, she had stopped eating and drinking. She became sleepier and spent all of her time in bed. On the morning of admission, Mrs Morton's daughter awoke to find that her mother was not able to speak or even open her eyes and was moaning and breathing fast. Feeling panicked, her daughter called 911. The ambulance arrived within a few minutes. They found Mrs Morton hypotensive, tachypneic, tachycardic, hypoxic, and in respiratory distress. They asked about advance directives, but were told that Mrs Morton had not completed one. They started an IV, gave fluids, administered oxygen, and rushed Mrs Morton to the hospital.

On arrival in the emergency department, the emergency physician and nurse asked the family, "Would you like us to do everything possible?"

Her family responded, "Yes," as virtually anyone would to this question.

The emergency physician called the hospitalist on call STAT to the emergency department to admit Mrs Morton and notified the intensive care unit that she would soon be on her way up.

1.1 EPIDEMIOLOGY OF HOSPITAL CARE FOR THE SERIOUSLY ILL

For hospitalists, intensivists, emergency physicians, advance practice nurses, nurses, and all clinicians who practice in the hospital, the story of Mrs Morton is all too common. Overall, about one-third of Americans die in hospitals; many

more spend some time in a hospital in the last year of life [1]. Among Medicare beneficiaries, nearly 70% are hospitalized in the last 3 months of life, one-third receive ICU care in the last month of life, and over half die in a hospital or nursing home [2].

While it is arguable whether Mrs Morton needed hospital admission to receive quality care at the end of her life, as hospice or palliative care at home would likely have provided the care she needed, the reality is that for many people hospital care provides relief and recovery from exacerbations of chronic illness. People with acute shortness of breath from heart failure or chronic obstructive pulmonary disease (COPD), bowel obstruction from pancreatic cancer, altered mental status from liver failure, and pain from a pathologic fracture often experience rapid and dramatic improvement in symptoms and quality of life from hospital care. Even patients who prefer to avoid hospitalization may find that hospital care provides the quickest and best option for relief of symptoms. For example, Chapter 4 discusses options for treating patients with malignant bowel obstruction. In this clinical setting, hospitalization may offer the best option for relief of nausea, vomiting, and pain. At the same time, for a patient like Mrs Morton, there will likely come a time when hospitalization will not only fail to provide relief but may also impose additional burdens for her and her family. Although it can be difficult to predict which hospitalization will be the last one or whether hospitalization will provide more benefit than harm, each hospitalization for the seriously ill provides an opportunity to clarify goals of care to ensure that care is consistent with patient preferences, promotes benefit, and limits harm.

Studies of patients with serious illness have shown consistently what these patients need and want from the healthcare system: relief from pain and other symptoms; clear communication about their illness, prognosis, and treatment options; and psychosocial, spiritual, and practical support [3, 4]. Addressing these needs is critical for providing high-quality care to patients with serious illness, and as such provides the overarching organizational structure to this book. Further, it requires a team approach as no single clinician has expertise in all these domains. Hospitalists and other hospital-based physicians, nurses, social workers, and chaplains must collaborate to ensure that patient needs are attended to. Such collaboration can happen formally, as with a palliative care consultation team, or more informally through clinicians working together to share insights and develop and implement plans of care.

Increasingly, it is hospitalists and other hospital-based specialists who care for people with serious illness in the hospital like Mrs Morton [5]. Over time, hospitalists have come to care not only for people with classic medical conditions, such as pneumonia and COPD, but also for people with cancer and cardiac, neurologic, and surgical problems either as admitting physicians or through comanagement. The high frequency of hospitalization among the seriously ill and those approaching the end of life places the clinicians who work in these settings in an ideal position to promote optimal quality of life for these patients.

1.2 PALLIATIVE CARE

Palliative care is the field of medicine focused on providing the best possible quality of life to people with serious illness and those near the end of life. Palliative care is defined as follows:

...specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment. [6]

There are several important parts of this definition that bear highlighting. First, palliative care is for people with *serious illnesses*. While palliative care is also about caring for people near and at the end of life such as Mrs Morton, fundamentally, palliative care is for people with serious illnesses such as heart disease, COPD, cirrhosis, cancer, and dementia and would have been appropriate for Mrs Morton from the time of diagnosis. The term *serious illness* is also helpful when talking with patients about the need for palliative care or the decision to involve palliative care specialists. Patients can easily relate to and understand that they have a serious illness and that additional care will be helpful to them. In the hospital, palliative care will also be appropriate for patients with fulminant acute illness such as massive intracranial hemorrhage and trauma. The important point for hospitalists to remember is that palliative care is not only for the terminally ill and also for those at the very end of life.

Palliative care is also *appropriate at any stage in a serious illness*, and patients can receive palliative care *while still pursuing curative intent treatment* such as chemotherapy, radiation therapy, percutaneous coronary interventions, surgery, and hemodialysis. Many patients and physicians harbor the misconception that receiving palliative care means that patients must forsake curative intent treatment. This misunderstanding is a common barrier that unnecessarily precludes patients from receiving palliative care. Patients admitted with exacerbations of heart failure or COPD, with complications of cancer or its treatment, and those with dementia all may benefit from symptom management, clarification of goals of care, and psychosocial support. One helpful question to ask for determining whether a patient would benefit from palliative care is, “Would I be surprised if this patient died in the next year?” This “surprise” question helps clinicians identify patients appropriate for palliative care [7]. If the question is difficult to apply to every patient, clinicians can also consider the types of patients who would be appropriate for palliative care (Table 1.1).

Consistent with what patients say they need from the healthcare system, palliative care seeks to *relieve the symptoms, pain, and stress of a serious illness*.

Table 1.1 Types of Patients Appropriate for Palliative Care

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- Advanced heart failure, second readmission in a year
 - Breast cancer and malignant pleural effusion
 - Brain metastases
 - Dementia and aspiration pneumonia
 - New diagnosis of idiopathic pulmonary fibrosis
 - Cirrhosis, second admission for altered mental status
 - Awaiting solid organ transplant
 - “Would I be surprised if this patient died in the next year?”
 - If the answer is “No,” provide and/or refer for palliative care.
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Relief of symptoms and pain is the first priority as patients can only focus on what is important to them and on having meaningful time when their symptoms are controlled. Control of symptoms allows patients to consider the issue that is at the heart and the ultimate goal of palliative care: *improving quality of life*. In fact, one helpful way to explain palliative care to patients and families is to state that the goal is to help patients “achieve the best possible quality of life for as long as possible.” This focus on promoting quality of life and understanding that it is defined uniquely by each patient is at the crux of what palliative care is about. It is also helpful to explain to patients that palliative care provides an *extra layer of support*. Few hospitalized patients would decline extra support, and the more seriously ill the patient, the more attractive and necessary the extra support becomes.

Hospitalized patients fall along a continuum of an illness trajectory, and palliative care plays a significant role in the care of patients throughout this continuum. The needs of these patients with serious illness will vary over the course of illness, and as shown in Figure 1.1, the relative focus on palliative care and curative intent treatment may change. Similarly, the depth and intensity of involvement with palliative care concerns will change over time, but from diagnosis to death, patients with serious illness will encounter situations where they will need and benefit from palliative care.

As will be highlighted throughout this book, there is considerable evidence for the efficacy and effectiveness of palliative care. A review of the evidence shows that palliative care relieves symptoms such as pain and depression, improves quality of life, increases satisfaction with care, and reduces resource utilization including ICU length of stay and costs of care [8–11]. Such an impact is easy to imagine when thinking about Mrs Morton. In addition, palliative care and conversations between patients and physicians about goals and preferences for care not only improve quality of care and life for patients but also improve outcomes for loved ones of patients who die [12, 13]. Those loved ones are less likely to experience complicated grief and depression 6 months after their loved one died.

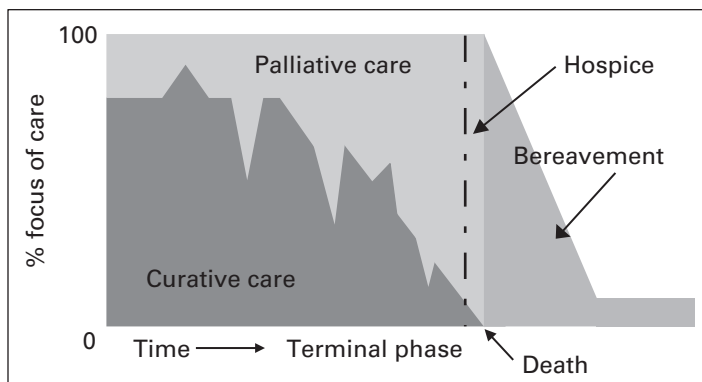


Figure 1.1 Concurrent model of palliative care. *Source:* © Steven Pantilat, MD and Regents of the University of California.

1.3 THE ROLE OF THE HOSPITAL-BASED CLINICIAN IN PALLIATIVE CARE

Hospitalists, intensivists, and other hospital-based clinicians frequently care for patients with serious illness and those approaching at the end of life like Mrs Morton. Hospitalists recognize the importance of palliative care to their practice and acknowledge a relative lack of education in pain management and palliative care during training [14]. Hospital-based clinicians can interact with palliative care in following four ways.

Refer to a Palliative Care Team: At a basic level, these clinicians need to identify patients who need palliative care and make appropriate referrals. Mrs Morton would be just such a patient. Many patients, like her, who need palliative care have complex symptom management and communication needs that require an interdisciplinary team of palliative care experts. In addition, when hospitalists are too busy with other patients to have extended goals of care conversations and family meetings, palliative care teams can assist to ensure that patient needs are met.

Work as a Member of a Palliative Care Team: Many hospitalists and other hospital-based clinicians will have extensive experience with palliative care and develop a strong interest in it. While currently the only path physicians in the US have to board certification in palliative medicine is through a 1-year clinical fellowship, many palliative care teams are challenged to find qualified physicians and advance practice nurses and would likely welcome experienced hospitalists dedicated to gaining continued education and experience in palliative care. Hospitalists, intensivists, and others can split their time between their primary specialty and working with a palliative care team, diversifying their professional responsibilities and income streams.

Become Board Certified in Palliative Care: Hospital-based clinicians who find palliative care compelling can pursue fellowship training in palliative care. The 1-year clinical fellowship is open to physicians from nearly all hospital-based disciplines. Understandably, taking a year away from practice to be a clinical fellow may be difficult financially. Some hospitals that have had difficulty hiring a board-certified palliative care physician have offered to supplement the salary of a hospital-based physician during fellowship in exchange for a guarantee of a certain number of years of work on the palliative care team. Given the shortage of palliative medicine-trained physicians, this arrangement can be a win–win for the hospital and the clinician and is often the fastest way of recruiting a board-certified palliative medicine physician. Nurses can also pursue board certification in palliative care. In addition, there are excellent educational courses for nurses in palliative care (End-of-Life Nursing Education Consortium (ELNEC) <http://www.aacn.nche.edu/elnec>), although there are few fellowships in palliative care for nurses.

Provide Primary Palliative Care: This option is the one that applies to all clinicians and could have the greatest impact on ensuring that all patients who need palliative care receive it [15]. For example, regardless of whether a hospital had a palliative care team, and many still do not [16], Mrs Morton needed to receive palliative care. All hospital-based clinicians should have a basic knowledge and facility with palliative care issues including pain and symptom management, discussing prognosis and goals of care, ensuring psychosocial and spiritual support to patients and families, and providing care that is culturally aware and sensitive. The tools, knowledge, and skills associated with palliative care—such as pain management and good communication—apply to the care of many, if not all, hospitalized patients. In addition to being able to address pain, hospital-based physicians should have facility with management of dyspnea, nausea, vomiting, bowel obstruction, depression, and anxiety. A thorough knowledge of good communication techniques including sharing bad news, running a family meeting, and discussing goals of care are critical activities for all hospital-based clinicians. Finally, addressing and attending to patients' psychological, social, emotional, and spiritual needs is important not only for patients nearing the end of life but also for many seriously and acutely ill patients. The fundamental goal of this book is to provide hospital-based clinicians with that knowledge base in an easy-to-use, evidence-based way with sufficient specificity and direction that will help guide care at the bedside.

Fortunately, there is large overlap in the knowledge, skills, and practice of hospital medicine, other hospital-based specialties, and palliative care. Clinical care in each realm includes interdisciplinary collaboration, seriously ill patients and those near the end of life, a wide range of clinical conditions, and a focus on improving quality of life and quality of care. This synergy across specialties can reinforce practice in each setting and help clinicians improve care overall.

1.4 THE STRUCTURE OF THIS BOOK

This book is divided into three parts that map the issues most important to seriously ill patients and their families and the major focus of palliative care: symptom management, clear communication, and psychosocial–spiritual support. The goal is to provide useful, practical, evidence-based information for busy hospital-based clinicians that forms the foundation of care for seriously ill patients and those near the end of life. This book also provides the science and the art of medicine and the science behind the art. In addition to evidence-based medicine, the authors share their clinical expertise and pearls of wisdom to put the evidence in context and offer guidance where evidence is lacking; akin to what they would impart in a consultation.

1.5 REWARDING PRACTICE

The care of seriously ill patients and those approaching the end of life can be challenging and richly rewarding [17]. Working with Mrs Morton and her family to help ease her respiratory distress; pausing the resuscitation long enough to understand her preferences for care; providing support, compassion, and empathy to her family; and implementing a plan consistent with her wishes allow the clinicians to use their heart as well as their head to provide the best possible care to patients and their families. In our technological age, it is easy to think that the only important aspects of medical care and the ones that patients value the most are the things we do to them. Such thinking grossly underestimates the importance that patients place in the human side of medicine and the caring that clinicians demonstrate by relieving symptoms and eliciting patient preferences carefully enough to really understand their goals and values and develop a plan to make those happen. In these cases, hospitalists and other hospital-based specialists can bring their humanism to bear on the care of the patient and can provide healing even, and especially, if cure is not possible.

1.6 CARING FOR MRS MORTON

A hospitalist or other hospital-based clinician well versed in palliative care can see the case of Mrs Morton as an opportunity to stop the onslaught of medical intervention for a patient who is dying and understand what her preferences would be to ensure she receives the care she and her family want. The hospitalist might start by asking, “How were you hoping we could help?” That question, much better in this situation than the one asked, could begin to elicit Mrs Morton’s preferences as expressed by her family [18]. The hospitalist could order opioids for the tachypnea and respiratory distress. If the family expresses understanding that Mrs Morton is dying and states that her wish in this setting is to have her care focused on comfort and dignity, the hospitalist might recommend admission or explore the possibility of Mrs Morton returning home with hospice services. The hospitalist might also ask about spiritual and religious issues to ensure that these are addressed in case

Mrs Morton dies soon. The hospitalist could provide a best estimate of prognosis and explain about the dying process. Finally, the hospitalist could provide guidance to the family about what they can say and do at the bedside to promote comfort, dignity, and healing. The skills and knowledge essential for providing this type of care are the essence of this book.

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