CHAPTER 10

Palliation

From caring to curing and back again
The experience of and response to pain
The moral imperative to relieve pain
Assisted and permitted dying
Pediatric palliative care
Palliative care and hospice
Palliative care: giving up or giving permission

FROM CARING TO CURING AND BACK AGAIN

Providing comfort, especially at the end of life, is neither a new concept nor a departure from the traditional responsibilities of the caring professions. Until the middle of the twentieth century, the cure of disease and the prevention of death were largely beyond the capability of those who ministered to the sick by trying to relieve their pain. With the development of biotechnology, the obligation to provide care became the obligation to provide cure, where cure often meant prolonging life, and a focus on comfort was reserved for those times when “nothing more could be done.” Rather than an inevitability, death was often perceived as a failure of skill and the very notion of dying made professionals feel uncomfortable, even guilty. Increasingly sophisticated science and technology inflated both professional and lay expectations about the power of medicine. The resulting belief that cure is always possible led to a perceived requirement to “do everything” and a sense of defeat whenever patients did not recover or improve.

Beginning in 1974, palliative care was initially delivered in the United States through community-based hospices. As efforts to promote comfort and relieve suffering came to be seen as coexisting with cure-oriented care rather than being reserved for dying patients, palliative care services for inpatients were added to hospitals during the past decade and are now offered in almost two-thirds of U.S. hospitals. In a 138% increase since 2000, consultative palliative care services are provided in 63% of hospitals with more than 50 beds. Palliative care clinics now offer services for outpatients and, more recently, community-based palliative care (CPC) has been proposed to complete the outreach by providing services to patients at home, in residential care-providing facilities, in rehabilitation centers, and in transition across care settings. Regardless of location, these services span the illness trajectory, including management of acute and chronic symptoms (Kamal et al. 2013).
Palliative care as a discipline has successfully reintroduced the notion that relieving pain and suffering is central to the complete and authentic practice of medicine. Its defining philosophy is that cure and comfort are consistent objectives that may assume greater or lesser prominence, depending on the patient’s condition, prognosis, and values. Critical to its full appreciation and optimal application is the recognition that palliative care is not synonymous with end-of-life care or a prelude to hospice, but an essential part of the entire therapeutic continuum. Symptom management is always an integral element of care.

The therapeutic enterprise seeks a balance of curative and palliative care that responds to the patient’s changing condition. When the potential exists for significant improvement, the plan of care emphasizes aggressive curative interventions, supplemented by comfort measures. As the likelihood of remission fades and the patient approaches the end of life, the goal of care shifts and aggressive palliation becomes the primary focus. Perhaps the clearest explanation is the now-iconic diagram (see figure), which illustrates the coexistence of disease-modifying (curative) treatment and palliative care throughout the entire therapeutic continuum, and the gradual shift in emphasis as the clinical condition evolves and the end of life nears.

This transition, which occurs over time rather than at a given moment, depends on attention to the evolving medical status; the clinical effectiveness of specific interventions; and the wishes and values of the patient, family, and others who are authorized to make decisions on the patient’s behalf. Helping patients, families, and professionals to adjust their goals and make decisions in ways that are clinically sound and ethically defensible is an important contribution of the ethics committee.

One effort to clarify the palliative approach suggests changing the terminology from palliative care to palliative treatment as a way to emphasize its importance and efficacy. “Because an intervention with proven benefit is generally referred to as a treatment, and because there is clear evidence that palliative measures are effective in reducing suffering, these interventions qualify as treatments. Labeling evidence-based, goal-directed interventions that ameliorate suffering as treatment is important so that physicians and patients alike may view such treatment as important, effective, and based on good science” (Kon and Ablin 2010, p. 644).
Mrs. Heller has been a resident of a long-term care facility for many years, during which her chronic obstructive pulmonary disease, diabetes, and osteoarthritis have become more severe. She is now confined to a wheelchair because of the intense pain in her back and hips, which she often describes as excruciating. The mild analgesics, including Tylenol, that have been prescribed do not bring relief and she has become increasingly immobilized, withdrawn, and depressed.

When her nephew, Dr. Agin, visited recently, he was alarmed by the deterioration he saw in his aunt. The person he remembered as vibrant and active was now saying, “I have no life. All I have is pain.” When he asked what she would like to be able to do that the pain prevented, he expected her to talk about missing her hiking, gardening, and painting. Instead, she replied, “Sleep. I don’t remember the last time I was able to sleep without being awakened by pain.”

Dr. Agin has requested a meeting to discuss his aunt’s pain management.

THE EXPERIENCE OF AND RESPONSE TO PAIN

Pain

Despite its subjective quality, the experience of pain is very real and can be consuming. As one writer describes it,

Pain is dehumanizing. The severer the pain, the more it overshadows the patient’s intelligence. All she or he can think about is pain: there is no past pain-free memory, no pain-free future, only the pain-filled present. Pain destroys autonomy: the patient is afraid to make the slightest movement. All choices are focused on either relieving the present pain or preventing greater future pain, and for this, one will sell one’s soul. Pain is humiliating; it destroys all sense of self-esteem accompanied by feelings of helplessness in the grip of pain, dependency on drugs, and being a burden to others. In its extreme, pain destroys the soul itself and all will to live. (Lisson 1987, p. 654)

Whatever the clinical setting, medical condition, or technological sophistication, one caregiver mandate remains constant and compelling—the relief of pain. Even when cure is impossible, the duty of care includes palliation. Moreover, this obligation is central to the therapeutic interaction, unquestioned and universal, transcending time and cultural boundaries. Whether the source of the pain is physiological or psychological, its relief is considered a primary moral goal of medicine because of the unique and intimate connection between those who hurt and those who comfort.

Pain and Suffering

A related distinction has been made between pain and suffering. Dr. Eric Cassell (1982) has written about pain as a physiological response of the body and suffering as an existential assault on the person. He describes how one can experience pain without suffering when the goal is a noble or joyous one, using as an example the pain of childbirth. Conversely, a person can suffer without physical pain when he feels the disintegration of his personhood and his sense of control. When pain and
suffering are closely related, Cassell claims, it is because the patient perceives the pain as overwhelming, uncontrollable, or unending. Emotional isolation may be added by the suggestion that the pain is only imagined. Pain of this kind represents suffering that is a threat, not only to life but also to the integrity of the patient’s sense of self.

It is impossible to spend any time in a clinical setting without recognizing this distinction. Patients are often asked to endure pain in the pursuit of a cure or remission. In weighing the benefits and burdens of a proposed treatment, current discomfort for clear and likely future relief seems ethically appropriate. The calculus is different when the intervention will impose pain or suffering with no benefit. Likewise, suffering without pain is evident in the patient with aphasia that prevents him from communicating with his family, the trained athlete who can no longer care for her most basic physical needs, the father who must accept that his infant will never develop, and the artist trying to create faster than her eyesight is failing.

Responses to Pain

Mr. Peters is a 27-year-old African American man with sickle cell anemia, admitted to the ED in sickle cell crisis. He is experiencing severe pain in his thighs, arms, hands, and feet. He is also dehydrated and anemic. An emergency medicine resident orders an injection of Demerol for pain and admits him to the hospital.

Following admission, Mr. Peters continues to complain of pain and asks the nurses repeatedly about the medication that has been ordered for him. During morning rounds the following day, the medical team is impressed by how much he knows about his disease and its management. He reports that, most of the time, he is able to manage his pain with an anti-inflammatory drug, such as Motrin. During a sickle cell crisis, however, the only effective pain relief is achieved with intravenous morphine, and he specifies the dosages and schedules that have been successful. He says that, during past hospitalizations, self-administering the morphine with a patient-controlled analgesia (PCA) pump has allowed him to achieve a constant blood level of medication, with supplementary morphine as needed for breakthrough pain.

The attending tells Mr. Peters that Demerol will be available when he requests it to control his pain. She also asks where and from whom he usually receives care, and Mr. Peters names several hospitals where he has been treated during crises. During post-rounds discussion, several residents express concern about the patient’s detailed request for a particular opioid in specific dosages. They suggest that this may be drug-seeking behavior by an addict. One resident recounts a similar case during his internship, concluding, “That patient conned us for two days before we caught on. When we cut off her drugs, she left the hospital.”

Nothing should be more self-evident than the clinical and ethical imperative to relieve pain. Yet, pain is a complex phenomenon for both patients and care providers in several important ways. First, pain is solitary, experienced only by the patient. Unlike other indications of illness or injury, clinicians rely heavily on patients’ first-person descriptions of their pain, although corroborative objective signs accessible to others may also be present. This reliance on patient assessment of
symptoms makes the evaluation and treatment of pain significantly different from other patient-physician interactions.

Second, although universally acknowledged, the experience and understanding of pain is influenced as much by personal values and cultural traditions as by physiological injury and disease. If the perception of and response to pain are to be understood in a useful way, they should be examined in the context of culture, gender, power, morality, and myth. These factors are especially important in the health care setting, where pain becomes an interpersonal encounter between the sufferer and the reliever. How pain is experienced and expressed by the patient and how it is understood and responded to by the provider are influenced by these factors and largely determine how it is valued and, ultimately, how it is treated (Brennan, Carr, and Cousins 2007).

Both patient and clinician attitudes are affected by their respective personal and cultural values. For example, physicians’ clinical judgments about and responses to pain are influenced by group-based factors, including age, gender, race, ethnicity, and physical appearance. The balance of power between provider and patient is yet another theme in the pain management interaction. So long as therapeutic control is vested in the caregiver, the patient remains the passive victim of pain, a supplicant in the standard p.r.n. (as circumstances require) regimen that requires the patient to ask for medication each time it is needed (Post et al. 1996).

Third, both patients and their doctors are influenced by their understanding—often misunderstanding—of pain and the agents for its relief. Studies have shown that physicians are inhibited by their inadequate professional education about analgesia, misconceptions about opioids and addiction, and fears about regulatory and legal liability. Similar misconceptions are shared by the lay public, and Americans have been shown to reject what they believe to be effective medicinal pain relief because they fear over-reliance and addiction. Reluctance to provide sufficient pain medication has also been related to clinician fears that use of opioids will “kill patients” by depressing respirations and hastening death. These fears, plus concerns about legal liability and suspicions that patient requests for pain medication are a cover for drug-seeking behavior, are reflected in the stringent laws regulating drug prescription. The unsurprising and unacceptable result is the routine undermedication of even terminally ill patients (e.g., Fine 2007; Furrow 2001; Post et al. 1996).

Mr. Peters’s case illustrates several of these issues. He comes to the ED requesting morphine, a potent opioid, and specifying the dosages and intervals that he would prefer. The care team has no prior experience with him and no way of confirming his history of sickle cell or its prior management. Mindful that morphine’s effects are euphoric as well as analgesic, and also potentially addictive, the team believes that it must consider the possibility that he is a drug seeker rather than simply a patient in pain. While no explicit mention has been made of his race, it may influence some team members’ perception about the likelihood that he abuses drugs. Even if he had not requested an opioid, by specifying dosages and intervals, Mr. Peters may have seemed “demanding” or “bossy” to some caregivers, who prefer to be in control of the clinical interaction. Individually or in combination, these factors may result in his claims of pain and requests for relief to be discounted.
Patients who appear to exhibit drug-seeking behaviors trigger an intense and, usually, counterproductive dynamic. On one level are the care team's explicit efforts to determine what the patient needs and what therapy will be most effective. On another level, caregivers often react to patient requests for pain medication with resistance, disbelief, and anger. The inchoate reaction is, “This guy’s looking for drugs and he’s trying to scam me. Well, I’m on to him and I’m not going to let him get away with his con on my watch.” Left unacknowledged, the result can be an exercise in power playing, disrespect, and erosion of trust. Your ethics committee can help caregivers recognize the implications of their understandable but unhelpful response, and replace it with a more informed and professional approach.

When dealing with patients in pain, especially pain that is chronic or intermittently intense, it is important for caregivers to understand the nature of the discomfort, its effects, and useful ways to respond to it. Assuming that Mr. Peters suffers from periodic sickle cell crises, it is reasonable that he is very familiar with the medications, dosages, and schedules that most effectively treat his pain. Unless and until he demonstrates that his description of symptoms is inaccurate or that he has another motive for his requests, the primary clinical goal should be to relieve his pain as quickly and completely as possible. Collaborating with him in this endeavor has the added benefit of helping him to regain some control over a situation that may well make him feel repeatedly helpless.

Mr. Charles is a 32-year-old man with end-stage AIDS. He is wasted and noncommunicative, but responsive to painful stimuli. His rapid breathing, sweating, and restlessness indicate that he is experiencing considerable discomfort. His attending, Dr. Fellows, has written a standing order for Tylenol to be given every four hours, with Demerol to be given “if the patient appears especially uncomfortable.”

When Mr. Charles’s sister, a nurse, arrives from another state, she is appalled by her brother’s condition. She discusses his pain management with Dr. Fellows and asks why he is not receiving constant intravenous morphine. Dr. Fellows replies, “Morphine will depress his respirations and may speed up his dying. I will not be responsible for contributing to his death. We can keep him comfortable by increasing his other medication.” She responds, “He’s dying now and nothing will change that! Why should he have to die this horribly?”

A critical distinction supporting adequate palliation, especially at the end of life, is the doctrine of double effect, which responds to the ethical tension between the obligations to promote patient well-being and to avoid inflicting harm. The doctrine holds that a single act having two foreseen effects, one good and one bad, is not morally or legally prohibited if the harmful effect is not intended. The doctrine requires that three conditions be met: the act itself is not wrong; the good effect is the direct result of the intentional act, not the result of the bad or harmful effect; and the benefits of the good effect outweigh the foreseen but unintended bad effect. All three conditions are essential to prevent the doctrine from being abused or perverted in an effort to justify actions intended to cause harm.

The doctrine of double effect recognizes that, while the administration of sufficient opioids to manage pain at the end of life risks depressing respirations enough...
to hasten death—although the risk is generally small with careful management of the administration of pain medication—the clinical and ethical mandate to relieve suffering is paramount. Mr. Charles may not be verbally asking for analgesia, but he gives every clinical indication (rapid shallow breathing, rapid pulse, elevated blood pressure, perspiration, grimacing) that he is in terrible pain. As his sister points out, he is actively and irreversibly dying, so the question is not whether he will die, but how. His death is not preventable, but dying in pain is. Under these circumstances, the only thing that can be done to benefit him is to relieve his suffering and make his remaining time more bearable. Using the rationale of the doctrine of double effect, the palliative intervention is both justified and protected. Helping physicians appreciate this distinction so that they can confidently and comfortably provide adequate palliation at the end of life is often an important part of ethics committee involvement.

THE MORAL IMPERATIVE TO RELIEVE PAIN

Carla is a 9-year-old girl who was diagnosed several months ago with Ewing’s sarcoma. She has received radiation and chemotherapy, and was recently hospitalized for amputation of her entire left leg. Following surgery, Carla’s pain was being successfully managed with a continuous IV morphine drip supplemented by patient-controlled IV morphine to be used when she felt she needed additional pain control. On the third postoperative day, one of her physical therapists told her that she should not activate the patient-controlled morphine until the pain became unbearable because, if she overused narcotics, she would become addicted. An intern who overheard this statement corrected the physical therapist, explaining that addiction is not associated with use of opioids in the immediate postoperative period and is rarely the result of even chronic use to control severe pain. He emphasized using the term opioids rather than narcotics, and reassured Carla, telling her that she should activate the morphine as often as she needed it and that she would not be risking addiction.

Carla’s parents, however, became very concerned about the potential danger of addiction and tried to discourage her from using the patient-controlled morphine. When she continued to use the medication, they insisted that her oncologist, Dr. Brader, stop both the continuous IV drip and the patient-controlled morphine. Dr. Brader replaced the morphine with non-opioid analgesia, which was much less effective, and Carla began to experience severe pain. Dr. Brader has recommended restarting the morphine to relieve Carla’s pain, but her parents are adamant that she not receive any opioid medication, which they insist on referring to as “narcotics.”

Do the obligations of care professionals include the relief of pain? Does pain management require the informed consent of a capable patient or an authorized surrogate? Can the conflict between Carla’s doctor and her parents be resolved in a way that prevents her from suffering?

More than a professional obligation, the relief of pain has traditionally been considered a moral imperative. It is also an endeavor that reflects the tension between
the two fundamental ethical principles of autonomy and beneficence. As discussed in chapter 3, the notion of autonomy is expressed in the health care setting in the doctrine of informed consent. Under this doctrine, capable, knowledgeable, and voluntary consent, either by or for the patient, is required for legally and ethically valid authorization for most diagnostic and therapeutic interventions.

Yet, the requirement of informed consent is conspicuously absent from the relief of pain. The reason goes to the very core of the caring interaction and invokes the mandate to relieve pain and suffering. This imperative is so powerful that it gives rise to the presumption that, unless patients explicitly object, they would want their pain relieved. In that circumstance, respect for autonomy requires that a capable patient’s decision to refuse analgesia—either because she finds the experience of pain meaningful or she does not want to chemically compromise her awareness—must be honored.

As discussed in chapters 2 and 3, however, beneficence is elevated over autonomy in protecting and benefiting patients who are vulnerable because they cannot make decisions or advocate for themselves. Thus, an incapacitated patient who is clearly in pain must not be deprived of relief because she is unable to provide informed consent. While honoring the wishes of a capable individual shows respect for the person, withholding relief from one who cannot decide or communicate would be an indefensible abandonment. It would also be indefensible not to provide pain relief simply because a family member finds it objectionable. Rather, principled and compassionate caring embraces both the respect for and the protection of persons. No explicit informed consent is required precisely because relieving pain is central to the very notion of healing and, for that reason alone, it requires no additional justifications.

Accordingly, adequate relief of Carla’s pain may not be impeded by her parents’ well-meaning but misguided rejection of morphine, including the repeated use of the term narcotic to equate the medication with illicit drug use. Every effort should be made to help them understand the considerable benefits and minimal risks of opioid use in managing her severe pain, and the distinction between increasing tolerance and addiction. Including the palliative care service in this discussion would be helpful in educating and reassuring her parents about the care plan. The care team should be supportive of their desire to be responsible guardians and the focus should be on the shared goal of promoting Carla’s best interest and protecting her from harm. Ultimately, however, her parents must know that, with or without their consent, Carla’s pain will be managed according to the standard of care and the ethical requirements of professional practice.

Here too, language matters. While opioids and narcotics are often used interchangeably, their impact is powerful, which is why the terms should be distinguished. Both opioids and narcotics are a class of drugs derived from opium that have potent analgesic and mood-altering effects. Narcotics, however, are persistently associated, especially in the lay community, with illicit, recreational, and risky drug use. This negative association has been reported as a barrier to patient and family acceptance of appropriate analgesia. In contrast, the connotation of the term opioids is that of therapeutic, safe medication approved by the medical community and included in standard of care. Pain specialists are increasingly encouraging all caregivers, as well as professional journals and lay media, to use the more accurate and
neutral term *opioids* when referring to this class of medication (Wallace et al. 2012; Quinn and Miller 2008).

An important contribution of your ethics committee is ensuring that the care team appreciates that symptom management does not require surrogate consent. Rather than requesting permission, the approach should be, “Let me assure you that everything possible will be done to promote Carla’s comfort. We will begin with a low dose of medication and increase it only until it is effective.”

Mrs. Heller, the nursing home resident with multiple medical problems, is experiencing pain severe and persistent enough to interfere with her activities and her sleep. Despite her best efforts, pain has become the focus of her attention and has profoundly impaired her quality of life. Far from rejecting pain medication, she is clearly asking for relief. Her care team has both a clinical and an ethical mandate to assess her pain carefully; discuss with her the benefits, burdens, and risks of the analgesic options; and provide her with sufficient medication to relieve her suffering. The team should also identify and address the barriers to adequate pain relief that have prevented her symptoms from being recognized and managed appropriately.

If, as appears happened here, the care plan is still not adequately managing Mrs. Heller’s pain, additional resources should be involved. The nursing staff should ensure that her primary care physician (PCP) is aware of her continuing discomfort. If the PCP appears reluctant to modify the analgesic regimen, the nursing home medical director should be enlisted to speak with him. In addition, an ethics consultation requested by the care team or, as here, the family, can be critical in highlighting Mrs. Heller’s needs and goals, emphasizing the moral and legal imperative of pain relief, and reassuring the care team, including the treating physicians, that the benefits of palliation outweigh any possible risks.

**ASSISTED AND PERMITTED DYING**

The lab results of Diane’s blood tests confirmed Dr. Timothy Quill’s worst fears—she did have leukemia. His distress reflected the disappointment common to physicians whose patients contract life-threatening illnesses, as well as the special concern he had for someone who had been his patient for many years and with whom he had developed a close and trusting relationship. In addition, he greatly admired the resilience and determination with which she had overcome significant physical and emotional difficulties. In the process, she had strengthened her relationships with her husband, son, and friends, and reinvigorated her business and artistic work.

Now they faced this devastating news together, going through the confirmatory tests and discussing with her husband the various options, including chemotherapy, followed by radiation and possible bone marrow transplants. Even with the most aggressive treatment regimen, the chances for long-term survival were 25%; the certain outcome of no treatment was death within a few months. After considerable discussion, Diane decided not to undergo chemotherapy because she was convinced that the quality of whatever time she had left was more important than the unlikely benefits of treatment. Despite Dr. Quill’s misgivings and her family’s attempts to persuade her to change her mind, she remained steadfast in her determination to make
the most of her time at home. Ultimately, her family and physician reluctantly supported her decision.

Dr. Quill had known throughout their relationship that, for Diane, regaining and maintaining control of her life was a central value. Now he realized that being in control of her dying was just as important to her as she faced the end of her life. She became preoccupied with deteriorating, lingering, being helpless and in pain. Her anxiety about the prospect of a protracted death became so severe that it threatened to undermine the quality end of life she had as her goal. She asked Dr. Quill to help her avoid the painful, debilitating, and dehumanizing ravages in store by providing drugs that she could take to end her life when she chose. She was convinced that having the ability to control her death would give her the dignity and peace of mind that she needed.

After extensive discussion and psychiatric consultation, Dr. Quill acceded to Diane's unwavering determination, prescribed the barbiturates, and provided the information necessary for her to take her own life. She was able to spend the next several months focusing on the people, relationships, and activities that were most important to her. She received aggressive palliative treatment but, eventually, she determined that the benefits of life no longer outweighed its burdens. Her death was on her own terms, at the time and in the manner of her choosing. Yet, concerns about potential legal liability prevented her from having her family or physician with her at the end, and she died alone. When Dr. Quill writes or speaks about this episode, he invariably says that not being with his patient as she died is his only regret (Quill 1991).

Distinguishing Forgoing Life-Sustaining Treatment, Euthanasia, and Assisted Dying

Discussions about end-of-life issues inevitably refer to behaviors that promote, permit, or hasten death. Because these concepts are highly charged with medical, legal, ethical, and emotional significance, it is critical that we begin by distinguishing their definitions.

- **Aid in dying (AID) or assisted dying** is clinician facilitation of a patient’s death by providing the means and information (prescription, medication, instructions) that enable the patient to perform an act that results in self-inflicted death. The clinician’s actions are taken with the knowledge that the patient

*Until recently and in the first edition of *Handbook for Health Care Ethics Committees*, the practice of a terminally ill patient self-administering physician-prescribed medication to achieve a peaceful death was referred to as “physician-assisted suicide (PAS)” or “assisted suicide (AS).” Language matters, however, and the highly charged and pejorative connotations of “suicide” have increasingly been distinguished from and replaced by the more neutral and accurate “dying,” based on the following reasoning: “Terminology is evolving because of an understanding in both the mental health field and in the legislation and case law of many states that a mentally competent, terminally ill patient bases a decision to end his or her life for fundamentally different reasons than a clinically depressed person uses to justify suicide” (personal letter from Kathryn L. Tucker, director of Legal Affairs, Compassion & Choices). Accordingly, this edition of the handbook adopts the more accurate terms “aid in dying (AID)” or “assisted dying.”
intends to use the provided drugs and information to end her life, but the agent of death is the patient. Aid in dying is legal in five states (Oregon, Washington, Montana, Vermont, and New Mexico), which have adopted formal, multi-step protocols with safeguards for its limited use. The legal climate appears to be changing, however, as more states are considering legalizing AID (Orentlicher, Pope, and Rich 2014).

- **Euthanasia** is clinician administration of a lethal agent with the intent of relieving the patient’s untreatable suffering or pain. Whether the act is performed at the request of the patient (voluntary euthanasia) or without the patient’s request (nonvoluntary or passive euthanasia), the agent of death is the clinician. Euthanasia of either kind is illegal in all 50 states and the District of Columbia and all other countries, except the Netherlands, Belgium, and Luxembourg (Siegel, Sisti, and Caplan 2014; Menzel, Steinbock, and Summer 2013).

- **Forgoing life-sustaining treatment** is the withholding or withdrawing of interventions that maintain one or more organ system functions necessary to keep the patient alive. When these interventions are discontinued, the patient’s death is considered to be the result of the underlying disease(s). Patients with decisional capacity, health care proxy agents, and, in some states, other surrogates acting on behalf of patients without capacity have the well-settled legal and moral right to refuse unwanted life-sustaining treatments. Even when that refusal leads to or hastens death, the action is not considered suicide, assisted dying, or euthanasia.

- **Aggressive palliation** is the provision of therapeutic interventions, including opioid medications, to relieve pain and manage other symptoms effectively, throughout the therapeutic continuum and, especially, at the end of life. While these interventions may have two possible effects, one positive (e.g., pain relief) and one negative (e.g., depression of respirations), when the intent is palliation, the action is considered medically, ethically, and legally justified under the doctrine of double effect. Therefore, although aggressive palliation at the end of life may hasten the patient’s death, the action is not considered suicide, assisted dying, or euthanasia.

It is worth noting that even the U.S. Supreme Court went out of its way in 1997 to articulate that patients at the end of life have a protected liberty interest in pain relief and are entitled to sufficient analgesia even if it hastens death. In June 1997, the Court ruled in two cases, *Washington v. Glucksberg* and *Vacco v. Quill*, which sought to turn the right to refuse treatment into a constitutionally protected right to assisted death. (The cases are discussed in part IV.) These two rulings are more significant for what they say about palliative care than about assisted death. Repeatedly, the Court reaffirms the doctrine of double effect, saying that it is both legally and ethically appropriate to give terminally ill patients as much medication as necessary to relieve pain, recognizes the unintended potential for hastened death, and explicitly distinguishes between forgoing life-sustaining treatment and assisted dying. The critical take-away message is that providing sufficient medication to manage pain effectively at the end of life is a clinical and ethical imperative, not to be confused with assisted death or euthanasia. The importance of these rulings to compassionate end-of-life care cannot be overstated.
Ethical Issues

It is beyond the scope of this handbook to discuss adequately the multiple and complex aspects of aid in dying. For our purposes, it is enough to raise some of the ethical issues, including caregiver obligations, individual autonomy, public policy, and the moral imperative to relieve suffering. Some argue that respecting patient autonomy includes respecting the wish of the terminally ill to control when and how death occurs. Consistent with the principle of nonmaleficence, however, the concept of facilitating patient death is counterintuitive to those who devote themselves to promoting and protecting life. Yet, many have come to see assisting the rational decision of a capable person to effect a peaceful death as the last act in a compassionate continuum of care and forcing the patient to take that final step alone as abandonment. Some suggest, in vulnerable and disempowered populations, such as the poor and elderly, the right to die may become the obligation to die as a way of relieving family or society of the unwanted burden of their care (e.g., Hardwig 1997). Yet these and similar worries about permitting withdrawal of life-sustaining measures have not been borne out by experience. Moreover, others argue that these same marginalized populations, which often lack access to health care and providers, may be deprived of the opportunity to end their suffering under physician care. Ultimately, there is concern that the individual, morally justified act of aid in dying could become the generalized policy of euthanasia (e.g., Emanuel 2012; Prokopetz and Lehmann 2012; Shalowitz and Emanuel 2004; Bascom and Tolle 2002; Emanuel, Fairclough, and Emanuel 2000; Salem 1999; Thomasma 1996).

While assisted death is not a legal option in 45 states and the District of Columbia, it highlights issues that demand attention in all care settings. Both the public and professionals are troubled by the reality of overtreated disease and undertreated pain, especially at the end of life. Considerable research demonstrates that the medical profession does an inadequate job of pain management and that many people who request assistance in ending their lives are actually asking for the assurance of pain relief. It is a matter of concern when the debate centers on the alleged moral right of terminally ill patients to receive physician assistance in ending rather than easing their lives.

Among health care’s most pressing challenges, then, is introducing and improving palliation along the entire therapeutic continuum, especially as death approaches. Encouraging clinicians to collaborate with palliative care specialists can be a valuable contribution of clinical ethics consultation. In particular, your ethics service can help care teams to distinguish cases that are appropriate for ethics consultation, those that require palliative care expertise, and those that will benefit from involvement of both services. Consider, for example, the following requests for clinical ethics consultation:

- Mr. Cowan, a 78-year-old man, is admitted with altered mental status and delirium, which are considered potentially reversible with psychotropic medication. His son has agreed to the care plan but his daughter has been refusing medications and a recommended peripherally inserted central catheter (PICC) line, and threatening to sign the patient out against medical advice (AMA).
Mrs. Epstein is an 84-year-old woman admitted with fever, hepatic abscesses, and advanced acute myelogenous leukemia (AML). According to the treating oncologists, she is no longer a candidate for chemotherapy. Her husband and daughter are unable to appreciate the gravity and irreversibility of her condition, and are insisting on continued aggressive, cure-oriented measures that are increasing her suffering.

Samuel is a neonate, born at 30 weeks’ gestation with a rare, lethal syndrome that includes skin blistering, skin absence, and pyloric atresia. Life expectancy for afflicted children is typically five to six months. The parents are struggling with a decision about surgically repairing the intestinal atresia and taking Samuel home for whatever time remains or instituting a comfort care plan and allowing him to die.

The case of Mr. Cowan is appropriate for a clinical ethics consult because it raises ethical issues related to identifying the most appropriate surrogate decision maker and setting boundaries for family members to prevent interference with the delivery of care and protect a vulnerable patient from harm. Mrs. Epstein’s case is appropriately referred to the palliative care service because it requires the assessment of medical needs, symptom management, and goals and plan of care. Samuel’s case can benefit from both ethics and palliative care consultation to help the parents and care team sort out the medical, surgical, and palliative options, and analyze the ethical imperatives of the options. Although there is often no sharp distinction between when ethics intervention and when palliative care involvement are appropriate, assisting care teams in identifying and requesting consults that will be most effective in each case is one of your ethics service’s most valuable contributions.

**PEDIATRIC PALLIATIVE CARE**

Eric is a 16-year-old boy who has undergone a second bone marrow transplant for sickle cell disease, after rejecting his first transplant. His second post-transplant course has been complicated by septic shock and coding, post-transplant lymphoproliferative disorder (a type of secondary cancer), prolonged intubation requiring tracheostomy and a gastrostomy tube, amputation of several fingers, peripheral neuropathy, pain, and depression/anxiety. On this admission, Eric’s pulmonary status is deteriorating, despite aggressive antimicrobials and extensive respiratory support.

These complications, as well as the very poor prognosis, have been discussed at length with Eric’s mother. Because the treating doctors concur that, if Eric were intubated, it would not be possible to subsequently extubate him, the decision has been made not to intubate him if he goes into respiratory failure. This difficult decision has not been explained to Eric because of the concern shared by his mother and the treating team that it may exacerbate his anxiety. The goals of the comfort care plan are to manage Eric’s pain with continuous opioids, which may also help his breathing and manage the attendant anxiety.

Eric’s case illustrates several factors unique to pediatric palliative care. Most adults who receive palliative care have typical and predictable trajectories that allow for
more realistic goal setting. In contrast, because of their resilience combined with the rarity of their diseases, children frequently have very unpredictable medical courses. A child may be, literally, “one in a million,” leaving care teams and families without similar cases as precedents or FDA-recommended medications known to have been effective. This prognostic uncertainty may be among the most difficult challenges with which practitioners and parents grapple as they try to chart a therapeutic course that neither overlooks potentially effective therapies nor subjects the patient to unnecessary, nonbeneficial treatment in an effort to “do everything” or, at least, “do something.” Here, pediatric palliative care can play an invaluable role in guiding parents and, in many cases, patients in focusing on quality of life and revising their goals to those that are achievable.

Children are not small adults. Capable adults are routinely engaged in determining the goals and plan of care, following disclosure of the diagnosis and likely prognosis, the benefits, burdens, and risks of the treatment options, and the alternatives. As a result, patients are accorded not simply the courtesy of involvement, but the basic dignity and control that accompanies self-determination about what happens to one’s body and one’s future. As noted in chapter 5, children are presumed to lack the capacity to make autonomous decisions because they have not yet developed the maturity, judgment, and ability to take a long view and recognize that the unexpected may still be manageable. With parents/guardians as primary decision makers for minors, care planning is a delicate balance of parental hopes, fears and anticipatory grief, and the wisdom of involving the patient to the extent possible, while considering the effect of decisions on the patient’s siblings and extended family.

As discussed in chapter 4, withholding information is an imperfect enterprise at best. Even when families insist that the patient does not know, does not want to know, or would be harmed by the information, there is no guarantee that the information can be successfully withheld. The greater likelihood is that patients sense when things are being kept from them and inevitably imagine something far worse than the actual situation. The erosion of trust, the anxiety, insecurity, and isolation are as true and damaging for children as for adults. “If my parents and caregivers can’t even talk to me about whatever’s going on, it must be really awful and I have no one to tell how scared I am.” While not every minor is eager to or capable of receiving certain information, the ethical imperative is to determine what each patient knows and wants to know. Because minors’ cognitive and emotional capacities are so variable, this ongoing assessment is especially important. Whenever possible, children deserve to know what to expect in terms they can handle. Eric, at 16 and having had more than his share of experience with illness, is likely wondering about his future and how his care will be managed. His mother, in collaboration with the pediatric palliative care service, can help him know that he is not alone with his concerns.

Finally, in addition to caring for sick children, pediatric palliative care cares for parents during some of the worst times of their lives. When, because of illness or injury, parents are unable to meet their most central responsibility of protecting their children from harm, it can be unbearable for them and painful for those around them. Their anguish can be lessened by reframing their decision making in terms of protecting their child. Discussions with the parents of a dying child about forgoing curative treatment, especially at the end of life—surely the most
counterintuitive interactions imaginable—can be made tolerable by helping parents see themselves as protecting their child from the burden of interventions that cause suffering or prolong dying without compensating benefit. Helping parents regain their role as protectors is among the most important things that pediatric palliative care offers, especially as the end of life nears.

Pediatric palliative care serves to balance many of the core ethical issues—relief of suffering, best interest, quality of life, truth telling and disclosure, parental autonomy and permission, pediatric assent, futility and hope, access to care and resource allocation—in the setting of non-autonomous patients and the people who care for and about them.

PALLIATIVE CARE AND HOSPICE

Mr. Choi is an 82-year-old man with end-stage colon cancer. According to his son and daughter, he had not disclosed his symptoms to avoid being a burden to his family. By the time his illness was recognized, the cancer was widely metastasized and the consulting physicians agreed that he was not a candidate for surgery, radiation, or chemotherapy. After several meetings, during which the son and daughter translated for their Korean-speaking father, the family, the care team, and, presumably, the patient agreed on a care plan that focuses exclusively on comfort. Given Mr. Choi’s repeated request to return home, a meeting was scheduled with the hospice coordinator and a Korean interpreter to discuss home hospice.

Just before the meeting began, the patient’s children took the coordinator aside to say, “Our father does not know that his cancer is untreatable or that he will be receiving hospice care. He thinks he is going home to get stronger so he can have treatment. All he knows about hospice is that it is for dying people. If he knew he were on hospice, if he even heard the word ‘hospice,’ he would give up all hope and just stop living. We want to make whatever time he has left comfortable and meaningful, and we need your help to make that happen.”

Hospice, either at home or in a dedicated inpatient facility, remains the model for providing palliative services to patients approaching the end of life. While symptom management and palliative care services can and should be integrated into the entire illness trajectory, hospice services are focused exclusively on a subset of terminally ill patients† for whom the goal of cure has been replaced with the goal of maximizing comfort, minimizing suffering, and preventing prolongation of the dying process. There is a common misconception that invasive treatments, such as various types of surgery, are precluded by hospice. As long as these procedures are designed to keep patients comfortable and relieve pain and suffering, they promote and do not frustrate the aim of hospice.

Although the moral imperative to provide comfort has always been central to caregiving, a constellation of developments over the past several decades has brought

† The criterion most often referenced is the Medicare hospice benefit, which reserves eligibility for terminally ill patients expected to live six months or less “if the disease runs its normal course” (Kamal et al. 2013, p. 255).
to public attention the need for and benefits of high-quality, specialized, interdisciplinary care for terminally ill patients and their families. The result is that providers of inpatient or home hospice services have become a ubiquitous and essential health care resource. Yet, for many this is an emotionally charged concept and, often, patients or their families respond to the suggestion of hospice with, “Is it really that hopeless?” Mr. Choi is a good example of a patient whose family wants to protect him by not disclosing the truth about his condition or the care he will be receiving. This well-intended but unsustainable deception is one of the issues that frequently comes before hospice ethics committees.

As noted in chapter 1, hospices often have their own ethics committee or share access to a regional ethics committee. In addition to the issues typically addressed by all health care ethics committees, hospice ethics committees have special strengths and face unique challenges. The strengths include the self-selected membership, which includes clinicians and other members of the interdisciplinary team who are experienced and skilled in the care of dying patients. Likewise, the bedside caregiving team tends to have a more intimate relationship with patients and families than in the acute care setting. Hospice patients are cared for either in their own homes or in an inpatient unit devoted to end-of-life care.

Challenges for hospice ethics committees include geography-related issues for home hospice staff, such as finding a mutually convenient meeting time and place or the awkwardness of asking family to leave the room to protect patient confidentiality. The rather brief length of stay for hospice patients (median 18.7 days nationally) (National Hospice and Palliative Care Organization 2013) means that ethical issues that might benefit from clinical consultation may not be recognized in time to be addressed. While there is a growing body of literature on hospital ethics committees and the dilemmas they routinely address, there has been far less written on the ethical issues confronting hospice patients, families, and clinicians, and virtually nothing specifically for hospice ethics committees. This dearth of material for reference and guidance will begin to be filled by Hospice Ethics (Kirk and Jennings 2014), but the field deserves more educational and practice resources (private correspondence with Timothy Kirk, co-chair Visiting Nurse Service of New York Hospice Ethics Committee).

When she founded St. Christopher’s Hospice in London in 1967, Dame Cicely Saunders identified three core elements in end-of-life care—pain and symptom relief, preservation of patient dignity, and attention to psychological and spiritual suffering as death approaches—which remain the bedrock of hospice care. On Death and Dying, a groundbreaking book by Dr. Elisabeth Kübler-Ross (1969), described the five emotional stages experienced by dying patients. A series of legislative provisions by the U.S. Congress, especially the creation of the Medicare hospice benefit in 1982, reflected the growing societal consensus that the hospice resource was a necessary part of comprehensive health care. The 1995 SUPPORT (Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment) concluded that 50% of dying patients had unrelieved severe pain; 20% of family members experienced financial devastation when they left their jobs to care for a dying relative; and 30–40% of family caregivers lost most of their savings. A 2004 study of end-of-life care in home and institutional settings as assessed by bereaved family members revealed a significant deficit of attention to pain management, physician-patient communication, and respect for patients (National Hospice Foundation 2011; Cassin 2007).
Joyce died in her apartment, two months after she voluntarily stopped eating and drinking. She was 31 at the time of her death and had been quadriplegic since breaking her neck in a diving accident 6 years previously. Initially after the accident, Joyce tried to resume her life, continuing her career as a musician by learning to use mouth-operated electronic equipment and advocating for stem cell research and the needs of the paralyzed. She was convinced that her strong will would sustain her until she was cured.

Gradually, however, Joyce began to realize that a cure for her paralysis was not on the horizon and that her increasing physical and psychological suffering was not temporary. She developed decubiti and autonomic dysreflexia, which caused her body to overreact to pain she could not consciously feel. Even more difficult was the loss of independence and privacy, especially the embarrassment of having others manage her personal needs. She spoke of “living in a body that is no longer mine.”

Eventually, Joyce began researching her options for legally ending a life she considered intolerable. She consulted attorneys and physicians, read articles in journals and online, and had two psychological evaluations. When she asked the opinion of her home hospice nurse, Geri gently reminded her that assistance in dying was not something that hospice could provide.

Joyce finally decided to stop eating and drinking. Recognizing the extent of her physical and psychological suffering, her mother and her close friends understood and supported her decision (case adapted from Braun 2012). Geri, however, was deeply conflicted about her role. Her empathy for her patient and her obligation to provide comfort seemed to conflict with her obligation to protect her patient and the prohibition against assisted dying. Geri requested a consultation with the hospice ethics committee.

Voluntarily stopping eating and drinking (VSED) is a situation in which “a patient who is otherwise physically capable of taking nourishment makes an active decision to discontinue all oral intake and then is ‘allowed to die’ gradually, primarily of dehydration or some intervening complication” (Quill, Lo, and Brock 1997, p. 2099). Because this action is considered to fall within the well-settled right of capable patients to refuse any unwanted interventions, including life-sustaining measures, VSED is a legal option in all states and the District of Columbia. The ethics are somewhat more complicated because of the competing moral imperatives. The care professional’s obligation to respect the autonomy of a capable patient by honoring decisions based on personal values and preferences is in tension with the obligation to protect the patient from harm. Refusing to provide supportive care to a patient who has decided on VSED, however, would violate a fundamental moral obligation not to abandon a suffering patient.

The hospice ethics committee had addressed these issues one year earlier after learning about a hospice patient in another state who elected to forgo nutrition and hydration. “How would we manage that situation if one of our patients chose that course?” the committee chair asked. “Shouldn’t we think this through and have an agreed-to policy and procedure ready?” Over the next several months, the ethics committee deliberated about VSED and the unique role of hospice in caring for patients considering that option. Discussions included patient rights, caregiver respon-
sibilities, determination of patient best interest and harm, the potential abuses inherent in VSED, and the unique role of hospice. The consensus of the committee, reflected in the policy and procedure it drafted, addressed the following:

- The core ethical principle of respect for autonomy that grounds the right of capable patients to accept or refuse any treatment is as central to hospice care as any other health care setting. Accordingly, decision making in hospice defers to the capable patient’s assessment of the benefit-risk-burden ratio when considering therapies. When a capable patient has determined that the harm is continued suffering and the benefit is release from suffering through death, VSED is an ethically and legally acceptable option. The only risk is that, if not managed carefully, the dying process may be unnecessarily burdensome if it is protracted and uncomfortable.
- Because VSED is legal, unregulated, and able to be accomplished without the involvement of care professionals, the following potential abuses may go unrecognized: uninformed or coerced decisions to VSED, especially if the patient is concerned about being a continued burden; coercion to continue the process even if the patient requests nourishment and fluid; without professional support, inadequate palliation of symptoms; unrecognized treatable depression; and lack of support if “starving” is considered morally repugnant.
- The mission of hospice is to maximize the quality of life for patients with life-limiting illnesses by maximizing physical and emotional comfort, minimizing suffering by omitting measures that have no palliative value, and enhancing the dignity and self-determination of patients by honoring their preferences whenever possible.

When Geri requested an ethics consultation to address Joyce's decision and her own concerns, the committee was well prepared to consider the issues. The consensus was that, with appropriate safeguards against potential abuses, Joyce's right to refuse nutrition and hydration should be honored and that the moral obligation of hospice to comfort and not abandon a patient justified Geri providing supportive measures during Joyce's dying. The distinction between providing comfort and support, on the one hand, and actively assisting in a patient's death on the other, was crucial in reframing Geri's perspective and helping her to see her services as an extension of the traditional hospice role. A sample hospice policy, Responding to a Patient's Desire to Voluntarily Stop Eating and Drinking, appears in part IV.

PALLIATIVE CARE: GIVING UP OR GIVING PERMISSION

While the shift in goals from cure to comfort is a process rather than a sudden decision, there comes a time when the care team, family, and often the patient need to acknowledge that palliation is now the focus of care. Recognizing and accepting this reality is unlike other care decisions because of the profound implications for everything that follows. For many people, reliance on palliative care is accompanied by a sense of loss and defeat. The expectation of cure, sometimes even the goal of improvement, must be relinquished. Belief in the power of medicine is exchanged
for frustration and lingering doubts about whether all possible options have been explored. The common but unfortunate distinction between “aggressive” and “comfort” care reinforces the notion that palliation represents a lesser level of attention and commitment while waiting for death. The unintended but clear message is, “We have given up and you should too.”

The perception can and should be reframed, and this can be one of your ethics consultation service’s most important contributions. Rather than abandoning hope, the focus on palliative care can be seen as liberating the patient, family, and care team from increasingly counterproductive efforts to reverse the inexorably deteriorating clinical course. With the investment of time and skill, those who care for and about the patient can give themselves permission to focus on an aggressive palliative care plan that will enhance the quality of the life that remains. Indeed, as recognized by many hospice programs, the therapeutic options can be expanded. Precisely because palliation remains on the care continuum after cure is no longer the goal, it may encompass particular comfort measures posing risks to life, including higher doses of more potent medication that might not have been acceptable when cure was still the goal of care. Rather than “Death is approaching and it must be resisted as long as possible,” the message becomes “Life is continuing and its quality must be enhanced as much as possible” (Post 2007, p. 221). Hope is never extinguished; rather, the objects of hope can change and revised goals can be achievable. Among the unique skills that characterize palliative care practitioners and the ethics committees that support them is the ability to help patients, families, and clinicians envision a different, more comfortable, more hopeful ending to their story.

REFERENCES


Braun B. 2012. For Freehold woman, paralyzed life became too much to bear. The Star Ledger, February 14.


Palliation
183