

### LESSONS LEARNED AT THE INTERFACE OF MEDICINE AND PSYCHIATRY

The Psychiatric Consultation Service at Massachusetts General Hospital (MGH) sees medical and surgical inpatients with comorbid psychiatric symptoms and conditions. Such consultations require the integration of medical and psychiatric knowledge. During their thrice-weekly rounds, Dr. Stern and other members of the Consultation Service discuss the diagnosis and management of conditions confronted. These discussions have given rise to rounds reports that will prove useful for clinicians practicing at the interface of medicine and psychiatry.

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## Clinical Challenges to the Delivery of End-of-Life Care

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**E**nd-of-life care presents many challenges (e.g., the management of pain and suffering) for clinicians, as well as for patients and their families. Moreover, the care of the dying patient must be considered within the context of the psychological, physical, and social experiences of a person's life.<sup>1</sup> Foremost among those who require end-of-life care are the elderly, who are prone to loneliness, who frequently underreport pain, and who have a greater sensitivity to drugs and to drug-drug interactions.<sup>2</sup> Unfortunately, clinicians who are responsible for the treatment of patients at the end of life commonly lack adequate training to help guide end-of-life decisions and to deliver bad news to patients and families.<sup>3,4</sup> They must also face their own discomfort with discussions about death and deal with poor compensation for the time spent discussing end-of-life care with patients and families. Given the unique process of each person's death, algorithmic strategies are often inadequate to guide patients, their families, and the clinicians who care for them through this complex and emotionally challenging process.

In the following sections, we will discuss the major challenges faced by dying patients and their families. We will then comment on the difficulties clinicians face in caring for the dying patient. Lastly, we will make several recommendations for improving the care of terminally ill patients and their families.

### CHALLENGES FACED BY PATIENTS AT THE END OF LIFE

The challenges faced by the dying patient are substantial and potentially overwhelming. These challenges include physical pain, depression, a variety of intense emotions, the loss of dignity, hopelessness, and the seemingly mundane tasks that need to be addressed at the end of life. An understanding of the dying patient's experience should help clinicians improve their care of the terminally ill.

#### Pain

Pain, and the fear of pain, often drives the behavior of patients at the end of life. In a survey of 310 patients with life-limiting illness,<sup>5</sup> "freedom from pain" ranked most important in their considerations of the end-of-life process. Pain, especially cancer-related pain, is common; moreover, it is experienced by 50% to 90% of patients with advanced disease.<sup>6</sup> Fortunately, over 90% of those with cancer-related pain respond to basic analgesic measures; however, many patients fear that their suffering will progress unabated.<sup>6,7</sup> Although there is no evidence that the perception of nociceptive pain is altered by advancing age, the elderly are often unwilling to report their pain because they believe it is a normal symptom of aging and that their pain is directly associated with the worsening of their illness.

While nociceptive pain is commonly and successfully treated with nonsteroidal anti-inflammatory drugs and opioids, bodily changes in the elderly demand attention when considering pharmacologic interventions. Declines in renal and hepatic function predispose the elderly to side effects and toxic effects of medications. In addition, pain is a notable risk factor for depression and suicide, particularly in those at the end of life, and it must be carefully assessed and monitored.<sup>8</sup>

### Depression

Studies reveal that more than 60% of patients with cancer report psychological distress, while nearly 50% of patients with varying stages of cancer fulfill diagnostic criteria for psychiatric disorders.<sup>9</sup> Depression, which occurs in up to 45% of terminally ill patients with cancer, has also been positively linked with thoughts of suicide.<sup>7</sup> Patients who are particularly prone to suicidal ideation are older men with a diagnosis of cancer or HIV infection/AIDS and/or a history of hopelessness, delirium, and exhaustion.<sup>7</sup> The presence and severity of clinical depression are both positively correlated with the severity of physical illness, and, in some, a progressive inability to get out of bed and a decreased appetite may also suggest major depression.<sup>8</sup> Anxiety commonly co-exists with depression, and it may be driven by fears of helplessness, a loss of control, abandonment, or pain.<sup>10</sup> When screening for depression in patients with advanced illness, one must consider that anxiety, as well as organic mental disorders, may mimic the features of mood disorders.<sup>7</sup> Furthermore, the physical symptoms of terminal illness and its treatment (e.g., chemotherapy) can generate the neurovegetative symptoms of depression (e.g., fatigue, increased sleep, weight loss). Often the distinguishing factor among clinical depression, demoralization, and organic causes of neurovegetative symptoms is the presence of anhedonia. Treating patients with terminal illnesses who also suffer from clinical depression not only helps improve their mood, but also enhances their coping strategies and promotes their compliance with treatment.<sup>11</sup>

Chochinov and colleagues<sup>12</sup> found that assessment and diagnosis of depression in the terminally ill can be effectively addressed with the single question, "Are you depressed?" Also, the Hospital Anxiety and Depression Scale<sup>13</sup> (a psychological instrument developed to probe for depression in medically ill patients) can be used to assess for depression in the dying patient. However, several studies have confirmed that the clinical interview remains the best tool for the diagnosis of depression in the medically ill or the dying patient.<sup>7,10</sup>

### Coping

Patients with advanced illness face the challenge of coping with their disease on a daily basis. While some

patients (known as "good copers") demonstrate optimism, practicality, resourcefulness, awareness, and flexibility, others (known as "bad copers") present with a variety of defensive styles in response to their diagnosis.<sup>14</sup> These more "primitive" defenses include suppression or isolation of affect, projection, noncompliance, avoidance, and denial, which may be manifest as a deliberate delay in treatment or as a disagreement between the patient and the physician about the presence, implications, or likely outcome of disease.<sup>15</sup> A study of 189 individuals with cancer linked cognitive avoidance with poor psychological adjustment (to living with cancer) and suggested that the degree of deterioration in one's physical impairment correlates directly with one's levels of psychological distress.<sup>16</sup> When associated with noncompliance, incidents of avoidance and denial become dangerous; noncompliance remains the number one modifiable risk factor for unfavorable outcomes in psychopharmacology.<sup>17</sup>

### Dignity

For dying patients, a primary illness-related concern is the preservation of dignity, broadly defined in terms of being worthy of honor, respect, and esteem. For many patients, dignity is directly related to the level of independence and autonomy retained through the course of illness. In a case series of 50 patients in an urban hospital diagnosed with advanced-stage cancers, Chochinov and colleagues<sup>18</sup> found that a variety of factors were necessary for preserving dignity in the terminally ill. These factors included functional capacity, cognitive acuity, symptom management, and alleviation of psychological distress.<sup>18</sup> Furthermore, anguish about medical uncertainty (i.e., not knowing, or being unaware of, aspects of one's health status or treatment) and anxiety specifically associated with the process or anticipation of death and dying worsened a patient's sense of dignity. Another study involving 213 terminally ill patients from 2 palliative care units<sup>19</sup> suggested that loss of dignity is closely associated with certain types of distress (such as the loss of independence for inpatients confined to the hospital, deterioration of physical appearance, and a sense of being burdensome to others) common among the terminally ill. When coupled with heightened depression and a sense of hopelessness, the loss of dignity may lessen a patient's desire to continue living in the face of imminent death.<sup>19</sup>

### The Need for Control

For a subset of terminally ill patients, maintaining a sense of control is a central task of the dying process. This need for control is prominent among patients who request physician-assisted suicide (PAS) in Oregon (where the practice has been legal since 1997).<sup>20</sup> In a survey of 2649 Oregon physicians, Ganzini and colleagues<sup>21</sup> studied the epidemiology of PAS in Oregon as well as the characteris-

tics of patients and physicians surrounding the request. The most common reasons for patients to request PAS were a loss of independence, a desire to control the circumstances of death, readiness to die, and poor quality of life. Other symptoms associated with the request for PAS were pain, dyspnea, and fatigue; in addition, wanting to maintain control and not wanting to be a burden on others is important for many dying patients.<sup>22</sup> Ganzini and coworkers<sup>23</sup> further refined this concept by interviewing Oregon physicians about their patients who had undergone PAS. These patients were universally described as having had strong personalities; they were determined and inflexible, and they wanted to control both the timing and the manner of their deaths. For most of these patients, the request was persistent, forceful, and often accompanied by refusal of palliative treatments. Regardless of the legality of PAS or a caregiver's particular opinion of it, physicians and nurses should strive to give such individuals as much control over their care as possible (to support their coping style and help them maintain their dignity).

### Other Aspects of the Dying Process

Patients who reach the end stage of advanced illness may also suffer from a variety of complications, including anorexia, weakness, and sexual dysfunction. Multiple interacting symptoms contribute to suffering (which is manifested by depression, cognitive disturbance, and interpersonal and spiritual crises) at the end of life. Furthermore, dying patients and their families often have to deal with complicated "practical" issues, such as financial problems (e.g., paying for home care) and legal issues (e.g., organizing wills or health care proxies). These seemingly mundane concerns can cause a great deal of distress for dying patients and their families. Physicians should be aware of the possibility that these problems may contribute to patient distress and should be mindful of asking about them. Lastly, in those who are actively dying (i.e., the rapidly evolving process immediately preceding death, which can be recognized hours to days before death), discomfort may be heralded by shortness of breath (a result of an accumulation of respiratory secretions).<sup>5</sup>

## CHALLENGES FACED BY CLINICIANS INVOLVED WITH END-OF-LIFE CARE

Clinicians who oversee the treatment of patients at the end of life often face obstacles to providing optimal care. Among these obstacles are inadequate preparation for facilitating difficult conversations, insufficient compensation for the relational aspects of end-of-life care work (as compared to invasive procedures), and personal discomfort with dying and death. These challenges must be considered alongside those faced by patients and families in the process of formulating improvements in end-of-life care.

### Inadequate Training

The management of end-of-life care and the process of engaging in difficult conversations are topics that are frequently neglected in medical education. The conventional pedagogic method of "see one, do one, teach one" applied in medical instruction is typically absent when related to end-of-life care. Many medical and surgical residents (who are often the physicians responsible for eliciting a patient's treatment preferences at the end of life and for facilitating difficult conversations with families) receive inadequate preparation for these tasks. A survey of 1455 medical students, 296 residents (in internal medicine, general surgery, and family medicine programs), and 287 faculty affiliated with 62 accredited U.S. medical schools revealed that only 18% of medical students and residents received formal training in end-of-life care, and over 40% of residents felt unprepared to teach end-of-life care to younger clinicians in training.<sup>24</sup> A subsequent survey of 282 internal medicine residents in 1 community-based program and 2 university-based programs revealed that only 4% ever received useful feedback on conversations with patients and families from a senior resident, and only 7% had received useful feedback from an attending physician.<sup>25</sup>

These statistics are particularly distressing when compared with similar studies conducted on medical instruction of invasive procedures (e.g., arterial puncture, central venous line placement, and thoracocentesis). Conventional teaching methods for invasive procedural skills involve planning ahead, demonstrating the procedure, observing the learner in action, providing feedback, and encouraging the learner's self-assessment. An informal study of 161 internal medicine residents in a university-based program revealed that only 6% of all conversations with patients and families facing end-of-life issues were observed or supervised by senior residents or faculty, compared with the 90% of invasive procedure training sessions that were reportedly supervised by faculty members.<sup>26</sup>

However, certain medical specialties (e.g., geriatrics, oncology, and intensive care) seem to offer stronger preparatory programs for end-of-life care and encourage the recognition of death as part of the life cycle. A study of 230 geriatric medicine fellows revealed that 97% of physicians trained in geriatrics felt either moderately prepared or well prepared to care for a dying patient.<sup>27</sup> The majority of respondents had rotations in end-of-life care, palliative care, or hospice care and maintained positive attitudes about caring for very ill and dying patients; moreover, they were explicitly instructed in the key concepts involved in end-of-life care.<sup>27</sup>

### Insufficient Compensation

An issue that receives little formal attention among clinicians who care for dying patients is the way they are

compensated for their work. Physicians who care for terminally ill patients and their families are often driven by an altruistic need to ease suffering. However, for many, altruism eventually confronts financial realities. It is reasonable to assume that continuing disparities in compensation between physicians who spend much of their time talking to patients and families and those who spend much of their time performing procedures may lead physicians who currently care for dying patients to grow resentful and keep talented individuals from entering the field. It is well known that the Medicare resource-based relative value scale compensates physicians more for invasive procedures (per minute of work) than for evaluation and management procedures.<sup>28</sup> Evaluation and management procedures include the extensive discussions with patients and families that are frequently demanded of clinicians who provide end-of-life care. For example, a 2004 model of work value for cognitive work versus procedures<sup>29</sup> revealed that a brain magnetic resonance image with and without contrast carries more than twice the number of relative value units as that carried by 25 minutes of counseling and discussion, and a diagnostic colonoscopy carries more than triple the number of relative value units as that carried by cognitive-based visits.<sup>29</sup> More research is needed to examine whether these disparities in compensation actually lead to lower job satisfaction among physicians in the field or whether this system has detrimental effects on patient care.

### Personal Discomfort With Death

Many physicians, after 7 to 14 years of intensive training that focused heavily on science and technology, feel uncomfortable when directly addressing issues (particularly those concerning spiritual and emotional needs) faced by patients and families at the end of life. Attention to dying (especially elderly) patients tends to focus on tangible questions directed toward a nurse such as "Are they eating?" or "How are they sleeping?" rather than on questions directed toward the patient like "How are you doing?" and "What would you like to do?"<sup>30</sup> Clinicians frequently feel uncomfortable confronting death because they relate to and identify with terminally ill patients and their families and resist doing so in the name of professionalism. Death also means the loss of the patient; this may be interpreted by medical caregivers as that they have somehow failed in their work.<sup>31</sup>

Additionally, a clinician's personal anxiety about death and disease may be further incited by interactions with a dying patient. In particular, doctors often think of death as a sign of failure or as an enemy rather than as a natural and universal part of the life process. Furthermore, a patient's dying process may remind the clinician of similar losses suffered in his or her own personal life, leading the physician to have surprisingly

strong feelings toward this particular patient (i.e., countertransference).<sup>32</sup>

### RECOMMENDATIONS FOR CLINICIANS

There are many clinical challenges inherent in the care of the dying patient. Nonetheless, there are many interventions that clinicians are able to perform to treat the emotional and physical symptoms of the patient at the end of life. Although a comprehensive discussion of these treatments is beyond the scope of this article, we will discuss a clinical approach to the dying patient as well as the major interventions that clinicians should be aware of.

The first step in caring for dying patients is to avoid clinical nihilism: that is, to avoid thinking that there is nothing left to be done. Often patients and families appreciate a doctor for simply listening to their concerns far more than any specific physical intervention. Additionally, such an approach will allow the doctor to provide care that is better tailored to individual patient needs and concerns.<sup>33</sup> Many patients are most afraid of not knowing what the process of dying is like, of pain, and of being left alone at the end of their lives. The engaged clinician can offer a great deal of reassurance simply by telling patients what to expect from the dying process, by treating their pain, and by promising not to abandon them at the end (and by following through with this promise).

The second issue for physicians treating dying patients is to recall that, even at the end of life, there are many conditions that can and should be treated to improve a patient's quality of life. In fact, among patients requesting PAS in Oregon, those for whom physicians made "substantive" interventions were more likely to change their minds about wanting a prescription for a lethal medication.<sup>21</sup>

In defining its clinical practice guidelines, the National Consensus Project for Quality Palliative Care (a consensus project of 5 national palliative care organizations) outlined 8 domains that should be addressed (Table 1).<sup>34</sup> Primary care physicians who care for patients with terminal illness should ensure that they address each of these domains (either directly or through referrals). The first is the structure and process of care. The work of caring for dying patients is best performed by a multidisciplinary team to help distribute the multiple tasks of this work so that staff can support each other during difficult times. The plan of care for the palliative care patient should be a product of an interdisciplinary assessment that includes both the patient and his or her family. Furthermore, this interdisciplinary structure recognizes that the care of the dying patient is associated with significant personal burdens for caregivers. Even the most experienced clinician should rely on colleagues for help in facing the difficult emotions of patients and their families, as well as his or her own memories and feelings.<sup>34</sup>

**Table 1. Domains of Quality Palliative Care<sup>a</sup>**

Structure and process of care
Physical aspects of care
Psychological and psychiatric aspects of care
Social aspects of care
Spiritual, religious, and existential aspects of care
Cultural aspects of care
Care of the imminently dying patient
Ethical and legal aspects of care

<sup>a</sup>Adapted with permission from the National Consensus Project for Quality Palliative Care.<sup>34</sup>

The second domain outlined by the National Consensus Project involves the physical aspects of care.<sup>34</sup> Pain, respiratory symptoms, and gastrointestinal symptoms in particular should be managed aggressively, while employing the best-available evidence. Physicians should assess their patient's pain regularly, preferably with validated instruments (e.g., analogue scale), and treat it promptly. Respiratory symptoms can lead to significant anxiety and fear,<sup>35</sup> while gastrointestinal symptoms (e.g., opiate-induced constipation) can lead to significant discomfort.<sup>36</sup> In general, physical symptoms are best treated assertively, and clinicians should be vigilant for signs of delirium or drug toxicity, particularly in the elderly.

Psychological and psychiatric aspects of care are the third domain.<sup>34</sup> Depression is encountered frequently in patients with terminal illness. It can be primary (caused by preexisting psychiatric illness), medication-induced (e.g., from corticosteroids or chemotherapy), or organic (e.g., from metastases or paraneoplastic syndromes). In patients with terminal illness, physical symptoms can be confused with neurovegetative symptoms of depression; this makes depression difficult to diagnose. Therefore, psychological symptoms (e.g., anhedonia and hopelessness) may be better indicators of depression in this population. Regardless of cause, depression is treated in a similar fashion (with judicious use of pharmacologic [e.g., selective serotonin reuptake inhibitors and psychostimulants] and nonpharmacologic [e.g., psychotherapy] treatments).<sup>37</sup> Physicians should consider referral to a psychiatrist for further evaluation as necessary.

Other psychiatric issues include anxiety and cognitive impairment. If recognized, many of these conditions can be reversed or at least substantially ameliorated.

Other domains important for the treatment of the patient with terminal illness include tending to the social, cultural, and spiritual aspects of care.<sup>34</sup> Often interconnected, these 3 areas refer to successively larger spheres of connection—from the interpersonal (i.e., family and friends), to the cultural (i.e., connecting to a larger set of customs, traditions, and modes of communication), and to the existential (i.e., the way in which people understand their lives and deaths in view of ultimate meaning and value). Ensuring that the needs of patients in these spheres

are attended to is a meaningful task of those who care for the terminally ill.

Clinicians should feel comfortable engaging patients around their concerns in these areas. However, they should feel equally comfortable consulting or referring patients to social workers, chaplains, or psychologists. Only by paying attention to one's own limitations can the physician caring for a dying patient best serve the patient.

The last 2 domains outlined by the National Consensus Project are caring for the imminently dying patient and ethical/legal concerns. These 2 domains are often interrelated, as significant ethical and legal issues often surface around the latter part of the dying process. Primary care physicians should do their utmost to recognize when the patient transitions to the active dying phase and should communicate effectively with the patient and his or her family about their wishes regarding the dying process (e.g., the setting of death and the intensity of symptom management). If not discussed previously, making a referral to a hospice is also an effective way to help care for the imminently dying patient and his or her family. Lastly, working with the patient and family to clarify issues of decision making at the end of life (e.g., What are the patient's wishes, and who will be the patient's surrogate when he or she is no longer able to make decisions?) allows patients and their caregivers to work and communicate better and helps them avoid or ameliorate ethical issues about decision making that can arise at the end of life.

## CONCLUSION

The care of dying patients is fraught with challenges for patients, their loved ones, and their physicians. Clinicians must keep in mind the difficulties a patient faces in this process as well as their own professional and personal obstacles to performing this work to the best of their ability. Therefore, end-of-life care is optimized when approached as a thoughtful collaboration between patients, their loved ones, and their treatment teams. While many Americans remain uncomfortable with thinking about and discussing end-of-life options, armed with this knowledge, clinicians are given a remarkable opportunity to help ease the physical and emotional suffering of patients and families confronting terminal illness and death.

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