

# How we can improve end-of-life care

**M**y mother and I were in the hospital lobby waiting for my father. My normally upbeat, sharp, energetic mom looked sick, weak, and confused. She had just been discharged from the hospital after experiencing a seizure caused by brain metastasis from long-standing breast cancer. Although we had discussed hospice care during my mother's admission, we left the hospital without setting up the service because we wanted more time to see if she could recover. Two days later, we arranged hospice because of my mother's rapidly deteriorating condition and our inability to manage her illness on our own. Five days later, she passed away at home surrounded by loved ones.

I am bewildered that my family did not transition my mother to end-of-life care earlier. Several family members and I work in the medical field. Being resourceful, we chose treatment at a large medical center that was a 3-hour drive from our home. Also, we were familiar with palliative care because other family members had died with hospice. Yet, in those last precious moments, we did not initiate end-of-life care for my mother until it became an emergency. This experience cultivated my interest in palliative care and hospice, specifically, in barriers to access and better ways to transition from life-saving treatment to end-of-life care. As a psychiatry resident, I feel it is important to expand opportunities for psychiatrists to participate in palliative care teams.

## Barriers to end-of-life care

**Poor physician-patient communication** near the end of life can be a major barrier to care. Studies suggest that patients and

physicians are ambivalent about end-of-life discussions and tend to avoid them.<sup>1</sup> Communication is crucial to helping patients prepare to die well. Researchers have found that end-of-life discussions between patients and physicians can result in fewer aggressive interventions and better quality of life near death.<sup>2</sup> These discussions did not increase emotional distress and were associated with lower rates of ventilation, resuscitation, and intensive care unit admissions.<sup>2</sup> End-of-life discussions between physicians and patients also lead to earlier hospice enrollment and improve the quality of end-of-life care.<sup>2</sup>

Approximately one-third of patients spend <1 week in hospice.<sup>3</sup> Studies have suggested that patients who receive >1 week of hospice care have improved quality of life compared with patients who do not receive hospice care.<sup>1</sup> Addressing end-of-life issues early in treatment of terminally ill patients allows them to become familiar with their options as their disease progresses.

**Lack of integration** between hospice and the medical community is another barrier. According to Medicare guidelines,<sup>4</sup> to be eligible for hospice a patient must have a terminal illness with a prognosis of ≤6 months. The patient must agree to give up curative treatment. If a patient lives >6 months, hospice benefits can be re-



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## Clinical Point

End-of-life discussions with patients can result in fewer aggressive interventions and better quality of life near death



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### Box

## Psychotherapy for terminally ill patients: 3 modalities

**D**ignity therapy is a form of brief individual therapy developed by Chochinov et al<sup>14</sup> that focuses on existential distress to help patients feel that their lives have been worthwhile. The goal is to have patients describe what they are most proud of, what they want to be remembered for, and what is most meaningful to them.

Viederman et al<sup>15</sup> characterized a type of therapy known as the psychodynamic life narrative. Palliative care psychiatrists use this technique to examine patients' lives and take stock of successes and failures. The narrative attempts to create a new perspective within terminally ill patients that increases self-esteem by emphasizing past strengths and coping mechanisms that have been successful.

Meaning-centered group therapy, developed by Breitbart,<sup>16</sup> emphasizes group didactics, discussion, and experiential exercises, with a focus on themes related to advanced cancer.

newed as long as the patient has shown a persistent decline. Patients must desire and accept a palliative approach rather than a curative focus and agree to have all care provided by Medicare-certified hospices.<sup>5</sup> These eligibility requirements may give patients and their families a sense that they are losing the forms of health care they had been using, physicians they know, and treatments they had become accustomed to, and are transferring their medical care to a unknown entity. This transition occurs when diseases are progressing and patients may feel vulnerable. In this way, end-of-life care is segregated from the rest of the medical system and can feel foreign and frightening to patients.<sup>6</sup>

**Lack of palliative care specialists.** The U.S. population is aging, and more people are living longer with chronic illness. Although the palliative care field is growing, only 60% of U.S. hospitals have palliative care programs and there is a shortage of palliative care clinicians.<sup>7</sup>

## Psychiatry and end-of-life care

Psychiatry and psycho-oncology can help address these barriers by providing resources and expertise to palliative care teams. Psychiatrists can facilitate communication between families and primary clinicians and help patients mentally prepare for end-of-life options.

The dying process may uncover psychological, psychosocial, and existential suffering in patients and their families that often is underdiagnosed and undertreated.<sup>8</sup> Psychiatrists can:

- diagnose and treat psychiatric disorders that surface under the stress of a new diagnosis
- aid in the psychodynamics of coping with terminal illness
- assess decision-making capacity
- recognize and treat staff stress
- provide bereavement care.

Because many clinicians believe that mood or anxiety symptoms are "normal reactions" in individuals struggling with end-of-life issues, these patients may not receive psychiatric treatment. However, treating mood and anxiety disorders can improve quality of life in palliative care patients.<sup>9</sup>

In terminally ill patients, psychological pain often manifests as symptoms of depression and anxiety. Diagnostic criteria for depression may need to be reconsidered because in patients with terminal illness depressive symptoms commonly are associated with functional decline. For example, restrictions on a patient's ability to participate in activities and disengagement from some areas of interest are common among individuals facing the end of life, but if a patient is unable to find pleasure in any event or activity, he or she may meet criteria for depression. Endicott<sup>10</sup> proposed a list of substitute symptoms of depression in terminally ill patients:

- weight loss or gain is substituted with depressed appearance
- loss of energy is substituted with brooding and self-pity
- insomnia or hypersomnia is substituted with social withdrawal

- loss of concentration is substituted with lack of reactivity or inability to be cheered up.

These substitutions are not in DSM-IV-TR but should be considered when assessing a terminally ill patient.

Most recommendations for pharmacologic treatment of depression in terminally ill patients are based on depression treatments for the general population. Selective serotonin reuptake inhibitors are commonly prescribed for terminally ill patients. Mirtazapine, a noradrenergic and serotonergic antidepressant, has been shown to effectively treat adjustment, mood, and anxiety disorders in patients with breast or gynecological cancer.<sup>11</sup> Its major side effects—sedation and weight gain—might be beneficial in patients with terminal illness. Psychostimulants also have been shown to elevate mood in patients with advanced malignancies.<sup>12</sup>

Potential triggers for anxiety in terminally ill patients include chemotherapy, radiation therapy, or acute pain. Also consider anxiety related to death and dying. Certain drugs commonly used in palliative care—such as corticosteroids and psychostimulants—may contribute to anxiety and restlessness. Cancer patients may develop posttraumatic stress disorder symptoms, including re-experiencing frightening aspects of their diagnosis and treatment, nightmares, hypervigilance, and autonomic hyperactivity.<sup>13</sup> Pharmacologic treatment of anxiety in dying patients is similar to that in the general population; benzodiazepines and antidepressants are first-line agents.

Several forms of psychotherapy can help terminally ill patients address existential issues (*Box*).<sup>14-16</sup>

## A need for training

In a survey of psychiatry residents, 97% of respondents believed psychiatrists should be trained in end-of-life care and 94% felt there should be formal education on palliative care during residency.<sup>17</sup> A study evaluating psychiatry residents' attitudes,

## Related Resources

- Chochinov H, Breitbart W. Handbook of psychiatry in palliative medicine. New York, NY: Oxford University Press; 2009.
- Harvard Medical School Center for Palliative Care. [www.hms.harvard.edu/pallcare](http://www.hms.harvard.edu/pallcare).

### Drug Brand Name

Mirtazapine • Remeron

### Disclosure

Dr. Kester reports no financial relationship with any company whose products are mentioned in this article or with manufacturers of competing products.

perceived preparedness, experiences, and needs in end-of-life care education found that residents felt least prepared when dealing with cultural and spiritual aspects of dying and helping patients with reconciliation and saying goodbye.<sup>18</sup> These residents also expressed a desire for more longitudinal exposure to palliative care.

A dedicated palliative care rotation during psychiatry residency training would help build a foundation of knowledge in this field. Residency programs should make a greater effort to incorporate end-of-life issues into consultation-liaison and geriatric rotations. Education on psychosocial, existential, and spiritual distress should be highlighted, with an emphasis on integrating specific psychotherapy techniques into training. These opportunities would provide residents with necessary skills to help patients cope with end-of-life issues.

As a psychiatry resident, I believe training in this field is one way to decrease barriers for patients to access end-of-life care. End-of-life psychiatric training could help build a culture where end-of-life care is integrated into the medical care system, with the goal of helping terminally ill patients die well.

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## Clinical Point

Residents may feel underprepared to deal with cultural and spiritual aspects of dying and helping patients with reconciliation

### Clinical Point

Residency programs should make a greater effort to incorporate training and education on end-of-life issues

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## Bottom Line

Barriers to patient access to end-of-life care include poor physician-patient communication, a lack of integration between hospice and the medical community, and a lack of qualified providers. Increasing psychiatry residents' training in end-of-life issues could help overcome these barriers.