Attending to the “Mental Suffering” of Patients With Progressive Medical Illness

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Psychiatrists have found ways to bring their expert skills and knowledge to the care of medically ill patients who are nearing the final phase of life.

*It was true, as the doctor said, that Ivan Ilych’s physical sufferings were terrible, but worse than the physical sufferings were his mental sufferings, which were his chief torture.*

—Leo Tolstoy,
The Death of Ivan Ilych, 1886

Since people with progressive, life-limiting illnesses experience distress in many domains, effective care in this context often requires a comprehensive and interdisciplinary approach. Palliative care is now broadly recognized as an essential treatment model in this scenario. As exemplified by the case vignette, as well as by the description in the epigraph of Ivan Ilych’s “mental sufferings,” serious psychiatric and psychological symptoms frequently accompany a life-threatening illness, and psychiatric expertise is often an important component of the care plan. In fact, as the field of palliative care has matured over the past decade, there has also been significant growth in the development of palliative care psychiatry as a sub-field bridging these two disciplines. As a result, psychiatrists have found ways to bring their expert skills and knowledge to the care of medically ill patients who are nearing the final phase of life.

**CASE VIGNETTE**

Several years ago, in your first contact with Carla, you diagnosed MDD. Her treatment included sertraline and weekly psychotherapy with a psychologist colleague. She eventually achieved a full remission. By mutual agreement, the medication was tapered off, and she stopped seeing you but continued with the therapist, with an understanding that you would be available to reconsider medication if her depression recurred.

Carla returns to your clinic after an absence of more than a year. Her psychologist and primary care physician both spoke to you briefly before the visit; they shared concerns that Carla’s depression has returned, noting that Carla recently received some bad news.

Carla seems relieved to see you, although you sense that she is preoccupied. Through tears, she shares the bad news your colleagues had alluded to: she has metastatic lung cancer, which, her oncologist says, is likely to take her life within a year.

Most of the encounter is focused on making sense of the new uncertainty about her future: Why me? Why now? What’s going to happen to me? Naturally, she acknowledges feeling distressed and depressed, but she asks angrily, “Isn’t it normal for me to feel this way?”

You do your best with her questions, mostly providing a supportive presence and the reassurance that you will help as much as possible. You are glad to have been consulted again, but you have questions of your own. You wonder: Is this a normal response? How can I distinguish between clinical depression and the grief that accompanies a frightening diagnosis with a devastating prognosis? If she is clinically depressed, will treatment be helpful this time? What should I anticipate as the cancer progresses in terms of psychiatric distress? Will there be a role for me in her care, and how will I interface with her cancer care team? How will I be affected as she nears the end of her life?

**What is palliative care and what’s it good for?**

Despite recent advances in the field of palliative care, including the formalization of an accredited medical subspecialty and broad expansion of services in both hospice and palliative care consultation, there remains a low level of understanding about what palliative care is.¹ For readers unfamiliar with hospice and palliative care, a brief review will help to contextualize the roles that psychiatrists can play within this larger field. The definition recently put forward by the Center to Advance Palliative Care is a great place to start.²
Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient’s other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

The most noteworthy elements of this definition include the focus on preserving quality of life, attention to suffering by the patient and his or her caregivers, care that is provided by an interdisciplinary team, and treatment that complements disease-modifying therapies throughout the course of an illness. Hospice care is best understood as a model of enhanced palliative care, provided to patients wherever they live, when the focus has shifted to quality of life, preservation of function, and symptom relief during the last few months of life.

A number of studies, using a wide variety of methods, have examined the benefits of palliative care. In general, these have shown advantages in terms of improved quality of care and reduced costs. Recent data from well-designed trials suggest that palliative care interventions may lengthen survival in some conditions. For example, in a 2010 study of adults with metastatic lung cancer, patients were randomized to two treatment arms: standard cancer care alone, or standard cancer care plus palliative care. In the palliative care arm, patients experienced fewer symptoms of depression, higher quality of life, reduced exposure to “aggressive” care, and improved survival—living on average more than 2.5 months longer than patients who received standard cancer care alone. These data have lent support to practice guidelines, quality measures, and accreditation standards that emphasize the benefits of palliative care as an important component of treatment in patients with a variety of illnesses. They also highlight the importance of addressing nonphysical sources of suffering.

There are 3 levels of palliative care (Table). All physicians provide primary palliative care, by attending to the whole person and the family; grounding treatment in a personalized understanding of the illness experience; clarifying basic goals of therapy; giving due weight to symptom relief and quality of life; and structuring interventions in time-limited trials. A subset of physicians, with further experience or fellowship training, provide secondary palliative care, often as part of an interdisciplinary consultation team.

Finally, tertiary palliative care is the domain of experts who provide clinical care in the most challenging cases, conduct research to expand the field, and educate colleagues and new trainees in the subspecialty.

A role for psychiatry

Even at the inception of the modern hospice movement, psychological distress was acknowledged as a significant component of suffering in dying patients. In the early 1960s, Cicely Saunders, the British physician (and nurse and social worker) widely credited as the founder of the modern hospice movement, observed that “mental distress may be perhaps the most intractable pain of all.” Saunders argued that terminally ill patients experience distress in multiple domains, summarized as “total pain” from physical, emotional, social, and spiritual dimensions. Effective end-of-life care requires the relief of suffering in each of these domains.

Similar to Ferris and colleagues, expand this concept and identify 8 domains of distress, using a particularly useful model that identifies opportunities for psychiatrists to be involved in palliative care (Figure 1).

Nearly all the domains in the Ferris model include important areas in which a psychiatrist can provide valuable expertise. Alleviating distress in one area often assists treatment in other domains as evidenced, for example, by the reduction in physical pain that frequently follows effective treatment of depression.

Palliative care psychiatry has grown out of psycho-oncology, which, in turn, emerged from psychosomatic medicine (formerly consult-liaison psychiatry). This pattern mirrors the way that palliative care evolved from hospice care, which grew out of oncology (Figure 2).

Palliative care psychiatry, which still shares some overlap with psychosomatic medicine and psycho-oncology, may be thought of as a subspecialty at the intersection of palliative medicine and psychiatry. Much of the field’s content has been distilled in the text *Handbook of Psychiatry in Palliative Medicine*. This body of knowledge has been enlarged and refined by important new data from clinical research in different domains. Some academic medical centers now include psychiatrists in their palliative care teams, often in leadership roles.
Trainees in psychiatry report a high degree of interest in educational experiences focused on palliative care. One such program for psychiatry residents was associated with improvements in palliative care skills and knowledge, and increased confidence in psychiatric practice in palliative care settings.\(^\text{17}\)

Taken together, these developments reflect an increasing recognition that palliative care psychiatry can play a role across the full continuum of care in serious advanced illnesses, bringing expertise in understanding and treating the psychosocial dimensions of human experience to the care of medically ill patients and the support of their families.

**Attending to “mental sufferings”**

But what about the outpatient psychiatrist? What basic competencies in palliative care psychiatry can the outpatient psychiatrist provide? What role will Carla’s psychiatrist play in the management of her “total pain”?

First and foremost, the clinic psychiatrist's diagnostic expertise is essential in beginning to address psychiatric symptoms. In the setting of an advancing, life-limiting illness, distinguishing between normal sadness, grief, adjustment disorder, and major depression, for example, can be quite challenging and may require the expertise of an experienced psychiatrist.\(^\text{18}\) Anxiety, delirium, and other psychiatric symptoms may also emerge, and these may result from the natural progression of disease, adverse effects of treatment, problems coping with stressors, or any number of other causes. Characterizing and addressing these symptoms could very well fall within the scope of the outpatient psychiatrist.

Expertise in psychopharmacology facilitates improved patient care and unburdens nonpsychiatric providers from practicing beyond their comfort level. Treating depression near the end of life, for example, frequently involves the use of psychostimulants, a strategy that often is outside the experience of generalist providers. Similarly, because the management of anxiety and agitation—both highly prevalent in palliative care settings—often involves off-label use of psychotropic agents, expertise in psychopharmacology is vitally important.

Psychotherapies and other nonpharmacological strategies are essential, and the outpatient psychiatrist’s expertise can help ensure that these approaches are optimized. Beyond the general use of supportive-expressive therapies, several psychotherapy approaches aimed specifically at seriously ill patients have recently been developed and assessed. For example, dignity therapy and meaning-centered psychotherapy are aimed at bolstering the patient’s sense of dignity, meaning, and spiritual well-being.\(^\text{19,20}\) Both have shown promise in randomized controlled trials, with positive outcomes including improvements in quality of life and sense of well-being in patients with advanced illnesses.\(^\text{21-23}\)

Other opportunities for psychiatrists may include:

- Attending to the needs of the family during illness and bereavement
- Assisting with the assessment of capacity, especially if depression is felt to cloud the judgment of a patient making complex medical decisions
- Educating front-line clinicians about psychiatric distress and symptoms in seriously ill patients
- Helping teams debrief complex outcomes or deal with “difficult” patients or families

**CASE VIGNETTE (cont’d)**

Carla’s treatment began with the reassurance that her initial difficulty with the new cancer diagnosis did not necessarily signal a return of depression. Over time, though, a true depression did emerge, marked by significant anhedonia and hopelessness. On your recommendation, she resumed treatment with sertraline. Because of her low energy, amotivation, and indecisiveness, methylphenidate was chosen to augment her therapy.

A few months later, Carla sits in your office during an early morning appointment. Despite aggressive treatment, the cancer has continued to spread. She’s been hospitalized several times. She confides to you: “I know I’m near the end. I don’t think I can go through this anymore.” She acknowledges thinking about dying, but she does not want her life to end. Her partner joins the discussion, and they share that they’ve considered enrolling in a local hospice program. You reassure them that you can continue to treat her so long as she remains able to get to the office, and that you’ll continue to be available to consult with her oncologist and a new hospice team. That afternoon you talk briefly with her oncologist, who has been struggling with how to facilitate this transition; you provide some coaching on how to have the conversation and enlist the help of a hospice program.

Two months later, the hospice physician calls you for advice. Lately Carla has had periods of confusion and agitation, and the physician suspects the cancer has spread to the brain. You provide guidance about using antipsychotics to address these distressing symptoms.
The following week, you learn from the hospice social worker that Carla has died, peacefully and at home, with her partner and children nearby—much as she had hoped. Carla’s family wanted you to know of her death, and they’ve invited you to attend her memorial service. You decide to hold space in your calendar to be there.

Table: The 3 levels of palliative care

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<th>Primary</th>
<th>Secondary</th>
<th>Tertiary</th>
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<tr>
<td>All clinicians</td>
<td>Subspeciality clinicians</td>
<td>Subspeciality clinicians</td>
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<tr>
<td>Attention to whole person/family concerns</td>
<td>Attention to the most challenging cases</td>
<td>Care for the most challenging cases</td>
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<tr>
<td>Treatment rooted in understanding of individual's illness experience</td>
<td>Leadership in research and education</td>
<td>Leadership in research and education</td>
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<td>Clarifying basic goals of therapy</td>
<td>Teaching of others in primary and secondary palliative care</td>
<td>Teaching of others in primary and secondary palliative care</td>
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<td>Attention to symptom burden and quality of life</td>
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Figure 1. Dimensions of distress in advanced, life-limiting illness

Figure 2. Evolution of palliative care and palliative care psychiatry

Disclosures:
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2. Center to Advance Palliative Care: 2011 Public Opinion Research on Palliative Care.


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