

Palliative Care Through Illness Trajectory

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Case scenarios are written to express typical situations that family physicians may encounter; authors remain anonymous. Send scenarios to afpjournal@aafp.org. Materials are edited to retain confidentiality.

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Case Scenario

I am caring for Y.S., a 50-year-old man with multiple health problems, including type 2 diabetes mellitus, depression, hypertension, and advanced scleroderma complicated by severe pulmonary hypertension. He has pain and progressive shortness of breath with declining function, which cause him to be homebound nearly all the time. I am aware of research demonstrating improved quality of life and less health care utilization among patients with advanced illness who receive specialty outpatient palliative care alongside usual, life-prolonging treatment. Some studies have even shown increased lifespan in patients with lung cancer.^{1,2} However, there are no ambulatory palliative care services available in my area. Is it possible to deliver basic palliative care through my practice, and does it make a difference for patients?

Commentary

Persons with multimorbidity often have unmet multidimensional needs related to their health.^{3,4} For example, Y.S. may also be experiencing poorly controlled symptoms, financial distress, and increasing anxiety. His family is likely distressed by his decline in health and unsure about what to expect next. Palliative care specialists employ a systematic approach to evaluating unmet needs across a range of physical, mental, social, and existential and spiritual dimensions, and then develop care plans that explicitly reflect patients' goals for their health. Palliative care delivered by subspecialists is known to have many benefits: enhancing quality of life^{1,5}; improving communication^{6,7}; reducing deaths away from home^{5,8}; reducing depression and other symptoms^{1,2,5,8}; and reducing health care utilization.^{5,6} Palliative care can

begin at any time during illness, or even before illness occurs. Patient and family needs are evident throughout the course of progressive illness, not only near the end stage.

Persons with multimorbidity and advancing illness are treated in primary care practices more commonly than in any other setting.⁹ The Institute of Medicine and the World Health Organization encourage primary care physicians to deliver basic palliative care.^{10,11} Although many primary care physicians respond to identified patient needs as best they can, most physicians do not realize that they can readily incorporate proactive or systematic assessments for multidimensional needs into their practice, thereby facilitating the delivery of basic palliative care. We refer to basic palliative care as supportive care.

The Institute of Medicine recommends addressing pain, depression, and advance care planning as key elements of basic palliative or supportive care. We would add addressing dyspnea,² care management (especially at the end of life), and bereavement as essential elements of palliative care in a primary care setting.¹²⁻¹⁵

In applying these elements to the care of Y.S., we recommend the following approach:

(1) **Ease symptoms.** Opioids should be considered for moderate or severe pain during progressive illness that persists despite nonopioid management. Dyspnea may be experienced independent of oxygen status and can be disabling and anxiety provoking. Initial dyspnea management should include teaching specific breathing techniques and having the patient use a fan aimed at the face.² Low-dose opioids also safely improve dyspnea by augmenting endogenous endorphins. The timely evaluation and

management of depression and anxiety are essential because these conditions can severely impair quality of life and function, and treatment may not become effective for weeks. This time frame is especially relevant in persons with a limited lifespan.

(2) Initiate advance care planning. An advance care plan should identify a proxy medical decision maker and address the kind of care that is most likely to help the patient live and die the way he or she wishes. A facilitated family meeting can help all relevant persons establish a shared understanding of the patient's hopes and goals, and develop an agreement regarding which interventions should be included or excluded to help achieve these goals. For example, Y.S.'s main goals may be to have his dyspnea managed comfortably and to be home with his family as much as possible, including dying at home when that time comes.

Intubation and perhaps bilevel positive airway pressure should likely be avoided in this patient if he develops respiratory failure. Even if he survived the event, he would have a low chance of returning to his identified satisfactory function or quality of life given the severity of his pulmonary hypertension. Because these devices require being in the hospital rather than at home, such treatment also has opportunity costs. Thus, we recommend jointly developing a care plan that allows hospitalization for exacerbations, if needed, but does not include an intensive level of care, such as artificial ventilation. Rather, if Y.S. does not respond to routine hospital care, the plan should allow him to return home with hospice.

Y.S.'s spouse, who may also be his proxy decision maker, should be involved in these discussions and support this plan to the extent possible. The physician should explain that at some point his spouse may be called on to make critical decisions. Involving the proxy decision maker in the development of an advance care plan significantly reduces the risk of depression, anxiety, and posttraumatic stress disorder associated with this role and, therefore, supports the well-being of all those involved in the patient's care.¹⁶

(3) Provide active care management. Managing supportive care needs in a

primary care setting requires consideration of several factors. Practices may designate roles among personnel for optimal coordination. For example, practices can train medical assistants to initiate advance care planning conversations, with physicians completing them, or train psychosocial practitioners to lead such discussions. Advance care planning conversations need to be documented and the resulting forms managed in a standardized approach, with copies sent to other health care professionals, including hospital personnel. Advance care planning is a process designed to reflect how the patients' goals and values inform their choices for medical care. Those choices are often fluid as illness and other circumstances change. Therefore, periodically revisiting the plan is another important effort that should be managed by a designated staff member.

Practices may create and manage registries of patients with multimorbidity and standardize assessment of basic palliative care needs. Coordination of care outside the practice may include setting up home services to assist with safety and functional support, social worker evaluation to ensure that the family has access to the financial resources for which they are eligible, and home nursing to facilitate the plans for symptom management. Also, when appropriate and available, a practice care manager can assist with referrals to specialty palliative care, including hospice and bereavement services, when patient and family needs exceed what the practice can provide.

The development and implementation of a basic palliative care plan for patients with multimorbidity and advancing illness are within reach for primary care practices. Managing this approach proactively and systematically requires effort and organization. Primary care physicians who deliver basic palliative care can help patients and their loved ones traverse some of the most difficult challenges they will experience. Providing this level of support to those with life-limiting illness can be deeply satisfying and meaningful for physicians and entire practices.

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