Palliative Care at the End of Life

Dean Schuyler, MD, and Sophie Fowler, FNP-BC

EDITOR'S NOTE

Through this column, we hope that practitioners in general medical settings will gain a more complete knowledge of the many patients who are likely to benefit from brief psychotherapeutic interventions. A close working relationship between primary care and psychiatry can serve to enhance patient outcome.

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Palliative care is an approach to medical care that can improve the quality of life of patients and their families facing the problems associated with life-threatening illnesses. Our team members get involved in interactions with seriously medically ill men and women at the end of life. In South Carolina, some patients live hours away from the hospital, so we speak with them by telephone. Some of these interactions take place by videophone. Mostly, these patients visit the hospital as outpatients. In addition, some are seen as inpatients while they are here for another reason. We walk beside them to assess their physical, psychosocial, and spiritual needs, sometimes at the beginning of their journey and sometimes toward the end.

We speak with them about pain, loss of appetite, inadequate sleep, diminished activity, anxiety, relationships, and anger, among other issues. Sometimes, we address shortness of breath, bowel habits, fatigue, and depression. We always try to reduce pain and suffering. The family nurse practitioner focuses on pain relief. The psychiatrist emphasizes living life, activity, and anxiety. The purpose of this article is to share with the reader some of the stories we encounter at the end of the lives of our patients.

CASE PRESENTATIONS (DR SCHUYLER)

Case 1

Mr A is a 68-year-old black married man with a diagnosis of multiple myeloma. Born in Chicago, Illinois, he is the youngest of 3 children in his family. Throughout much of his adult life he has been medically well, until the multiple myeloma diagnosis was made 1 year ago. Now, in this stage of his life, he says that he stays home and "does nothing."

I spoke with Mr A in detail about activity and stages of life. In this life stage, if he does nothing he is likely to be alone with his thoughts. Some of these thoughts relate to multiple myeloma. As such, it becomes important that he involve himself in activity (engage). So, I urged him to live his life during this stage and clearly expressed to him what the consequences of doing nothing were likely to be.

When we met again, Mr A stressed how much more active he had become. There were projects he used to complete that he had resumed. He was now walking outside each day and meeting people at a coffee shop to talk.

Case 2

Mr B is a 65-year-old white man married for the fourth time. His current wife has 4 children, who he has raised. He has worked for much of his adult life in engineering. When he was younger, his health was good. Esophageal cancer was diagnosed 2 years ago. He had serious reminders of posttraumatic stress that traced to his military combat experience. He tells me that he thinks often of his cancer and has the consequential anxiety as a result. A prescription of clonazepam 0.5 mg twice daily was made.

Mr B returned far less anxious 2 weeks later but mostly inactive. I made the case that he needed to find some things to do. When he returned 1 month later, he reported being active, involved, and busy with movies, television shows, and grandchildren. He felt markedly better.

Case 3

Mr C is a 65-year-old divorced white man who lives with a roommate. He is passive and anxious, having worked in the military service in an intelligence capacity. His health had been good until cancer was diagnosed 10 years ago. He had always been active: hunting, fishing, and riding a motorcycle. He was being treated for a cancer recurrence with a new drug and swiftly developed an inability to walk. True to his personality style, he kept all of his appointments but made few demands on his providers.

I implored one of the oncologists to evaluate Mr C despite the fact that he had no appointment to see a medical specialist. The physician was agreeable. This examination resulted in a plan of treatment, both for the side effect and for the cancer recurrence. When he returned to the clinic, Mr C noted progress. We discussed the benefits of assertiveness in his case.

Case 4

Mr D is an 80-year-old white married man who has lived an independent life. His wife raised their 3 children while he was often away at work. She died suddenly 6 weeks ago. He spoke with me in detail about her last days. He reviewed his life and his accomplishments. Mr D spoke about his children and then noted that he had shared with me aspects of his life that he had told to no one.

I encouraged him to grieve for his loss. He told me about the many things that his wife had taken care of, about which he knew very little. Now, he would have to manage all of these things for himself (preparing food, shopping, and activities). It would be, he said, a major shift for him, from near total independence to near total dependency. He would have to learn to ask others for help.

I emphasized to Mr D the continuity of life stages. This would be a stage he would need to design for himself. There were no right or wrong answers. I promised to be a part of his deliberations in this regard.

CASE PRESENTATIONS (MS FOWLER)

Case 1

Mr E is a 42-year-old man diagnosed with renal cell carcinoma 2 years ago. He was born in New Orleans, Louisiana, and divorced 10 years ago. He has no children. He had accepted his prognosis despite his young age. His primary care and oncology teams referred him for palliative care.

His symptom burden consisted of fatigue, pain, and loss of appetite. His pain level was denoted 7 out of 10 despite taking oxycodone/acetaminophen 5/325 mg every 6 hours. Our team stopped the combination and prescribed only oxycodone so that it could be taken more frequently. We gave him a flow sheet to chart his pain level before and 1 hour after taking the medication. We started him on a laxative/stool softener, 2 tablets twice daily, to prevent constipation.

One week later, Mr E's pain level was 3 out of 10. Oxycodone 40 mg is the equivalent of 60 mg of oral morphine. We substituted long-acting morphine sulfate sustained release 30 mg twice daily in the hope that he would have more constant pain relief. Our plan was to prevent the “roller-coaster” cycle of experiencing pain, taking a pain pill, its effects wearing off, and then starting all over again. At a 1-month follow-up visit, he reported that his moods had improved because he no longer had to endure the on-and-off pain cycle. He reported having little energy for months. With no contraindications, he was started on methylphenidate 5 mg in the morning and early afternoon. We continue to follow Mr E in our outpatient clinic, addressing any needs that arise.

Case 2

Mr F was a 54-year-old man raised in Minneapolis, Minnesota. He was twice married, now divorced, and had 4 children. He had been unable to work for the past 2 years due to illness. Because of his heavy alcohol consumption, he developed cirrhosis of the liver. He presented to our emergency department with hypotension and jaundice. His laboratory values were a platelet count of 74×10^9/L, international normalized ratio of 1.6, albumin of 1.8 g/L, and total bilirubin of 25 µmol/L. As his laboratory values continued to worsen, and with an overall prognosis that was poor, the palliative care team was consulted.

When I met Mr F, he was oriented to person and place only. He was not aware of his prognosis or why he was hospitalized. He rated his pain as 7 out of 10. He had been receiving tramadol, which he reported had not alleviated his pain. His 2 biggest symptom burdens were pain and nausea. Given his renal insufficiency, the medical doctor on our team started hydromorphone 2.5 mg to be taken orally every 3 hours as needed for pain and haloperidol 1 mg every 8 hours as needed for nausea. I called his family to discuss goals of care with them.

I attended the family meeting 2 days later with the team social worker and Mr F’s mother and sister. His mother told us that her son wanted a “peaceful, natural death, without machines.” We told his hospitalist team to write a do not resuscitate order. His mother told us that her husband had recently had surgery and that she was her son’s full-time caretaker. She would like him to remain at home but felt that it might not be possible. I told her about our end of life nursing home unit at the veterans administration hospital. Since Mr F had 2 weeks or less to live, we could admit him to this service. Our team would make rounds on this patient daily and make sure that we were doing everything necessary to make him comfortable. The family decided to accept this option.

Mr F continued to decline and was admitted to our service. Since the family lived quite a distance away and could not visit each day, I called his mother to give her a daily status report. When he began to have periods of apnea, I informed the family that time was short, and they traveled to Charleston to be with him. They were present at the time of his passing and expressed gratitude about his care.

Palliative care is meant to be prescribed at the time of diagnosis. Unfortunately, it is more usual for a referral from medicine to palliative care to be made nearer to the end of life. Often, when the focus remains curative intent, some of the typical comfort issues are ignored. A referral to palliative care makes it more likely that this oversight does not happen.