Dealing With the End of Life

Dean Schuyler, MD, and John Franklin, MD

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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A case can be made for a team approach to the patient in the final stage of life. While medicine is properly focused on curative intent, some patients benefit from interaction aimed at the issues commonly encountered as life ebbs. For the patient's medical team, the major concern is diagnosis ("What is wrong?") and treatment ("What can we do to rectify it?"). For the palliative care team, the major concern is the patient's comfort. Our palliative care team consists of 2 internists, a social worker, a chaplain, a physical therapist, and a psychiatrist. While there is no established protocol for how to approach the end-of-life stage, it is likely that each team member has his or her own idea of the issues that require attention.

Of course, the individual patient, too, has his or her own awareness of what areas might profit from attention at the end of life. The ticket of admission for a staff person wanting to join the process relates to engagement. It is crucial for one or several staff members to "connect" with the patient. Then, their task is to direct the patient's focus toward the issues to be resolved. This work will be aided by a patient who is bright and thoughtful.

In our experience dealing with end-of-life patients on an inpatient hospice unit, we have observed that, frequently, patients suffer far more from nonphysical than from physical pain. In hospice care, we deal with the concept of total pain: physical, emotional, economic, social, spiritual, and existential. Sometimes, when it is present, existential pain and life regret may cause the greatest suffering and be the most difficult to treat. Kissane[1] discussed 8 major forms of existential challenge: death anxiety, loss and change, freedom with choice or loss of control, dignity of the self, fundamental aloneness, altered quality of relationships, the search for meaning, and mystery about what seems unknowable.

Mr A was admitted to the Veterans Administration hospital after he had several falls and showed signs of debilitating weakness. With a diagnosed chronic illness as well as severe heart disease, his expectation was of a brief inpatient stay terminated by death. A psychiatrist (D.S.) and an internist (J.F.) on the palliative care team rapidly established working relationships with Mr A. The patient's mindset and intellectual ability led to a unique focus on achieving resolution of this final stage of life.

CASE PRESENTATION (Dr Schuyler)

Mr A was a 75-year-old Hispanic man, several times married and divorced. He had fathered 3 children but had not maintained contact with them. Born and raised in New York City by immigrant Puerto Rican parents, Mr A was the youngest of 4 children.

Mr A graduated high school in New York, where he lettered in 3 sports: football, basketball, and baseball. He attended an Ivy League university where he starred on the football team. Having failed college during his third year, Mr A left school, only to return later to complete his degree. This process lengthened his college period to 8 years and was followed by a professional football tryout. His father died during his time out of college, resulting in Mr A's belief that he had disappointed his father.

After college, Mr A had a very successful career in real estate while living in the Midwest. During this time, he married several times and fathered his 3 children. When one child turned to substance abuse, Mr A felt shamed because he had “abandoned” him. When another child received a police charge, Mr A once again felt shamed that he had left his son and the mother. “If I had only stayed with them,” he said, “this might never have happened.” When he was later passed over for a promotion in his chosen field, Mr A was accepting of the verdict. Now, he maintained that he should instead have asserted himself and spoken up on his own behalf.

Later in life, Mr A became a committed golfer after moving to Charleston, South Carolina. In response to the shame and blame he felt about how he had conducted various aspects of his life, Mr A was withdrawn during his 10 years in Charleston. He claimed few friends and contacts, did not work, and lived alone in a basement apartment. He acknowledged chronic low self-esteem.

MEDICAL ASSESSMENT (Dr Franklin)

Mr A had a history of chronic lymphatic leukemia with recent reactivation and poor tolerance of and complications from treatment, including autoimmune hemolytic anemia and severe idiopathic thrombocytopenic purpura. His platelet count at admission was $1{,}000 \times 10^9$/L. He was admitted for weakness and recurrent falls. Because of his poor performance status, severe complications, and intolerance to treatment, systematic therapy would no longer be offered. He made the decision to forgo further transfusion support. When discussing his goals of care, Mr A said, “I just want an easy departure. I am not a big pain person. I want to get this over and done with.” He was most proud of some aspects of his job performance and work accomplishments. His biggest regret was that he “didn’t have a better family life.” He blamed himself for this. His symptom burden included shortness of breath, fatigue, dizziness, depression, and severe existential pain. He had very low self-esteem and felt unworthy of people coming to visit or caring about him. His regrets included 2 divorces, financial and legal problems of one of his sons (for which he blamed himself), and situations at work in which his supervisors took credit for his significant accomplishments. He felt that he had let down his father by leaving college after 3 years and not going back to complete college until after his father died. For the past 10 years he had isolated himself from his large family and lived alone, with only 1 or 2 friends.

PALLIATIVE CARE (Dr Franklin)

After transfusion therapy was discontinued, Mr A maintained a platelet count of $1{,}000 \times 10^9$/L, with hemoglobin in the range of 5–6 g per deciliter. He was transferred from the general medicine service to the end-of-life service. His brother came to town to handle final details, and he notified the rest of the family, many of whom came from out of state to visit Mr A and to offer reconciliation. Mr A commented that he was not deserving of all that love and concern. “The mourners are coming early,” he said.

In the final 10 days of his life, he questioned on a daily basis how he was supposed to feel and what he was supposed to do. He continued to complain of fatigue and depression. When asked if he would like medication for these symptoms, he responded, “Aren’t I supposed to feel tired and depressed when I’m dying?” He declined the prescription of methylphenidate.

Over most of the remaining days of his life, Mr A continued to question how he should feel and what he should do until he died. He became progressively weaker and developed delirium. On the final day of his hospital stay, Mr A was noted to be unresponsive. His eyes were deviated to the left, with nystagmus. He was thought to have had an intracranial hemorrhage. He received comfort medication for end-of-life symptoms and died that evening.

Mr A had no complaints of physical pain during the end-of-life stage. However, his case illustrates severe suffering due to existential pain. Although his symptom burden was similar to that of many dying patients, what was unusual about Mr A was how articulate he was in verbalizing his thoughts and existential issues. Death anxiety and mystery about what seems unknowable were shown by his comments, “I don’t know what is supposed to happen. What am I supposed to feel? When is this going to be over?” He struggled to maintain a sense of control and freedom of personal choice. “Should I go back to my apartment? Should I live with my brother? Should I stay in the hospital? What should I do?”

Over time, he came to accept that he was too weak and debilitated to care for himself or to make the long journey to his brother’s house. Throughout his life, Mr A had struggled with low self-esteem, shame, and the minimization of his accomplishments. In fact, he had been very successful in business as well as athletics. He had difficulty maintaining his dignity and his sense of self. His existential suffering from aloneness was exacerbated during the end-of-life stage, despite family support and visits, due to his feelings of unworthiness. During this hospitalization, Mr A was finally able to accept the visits from family and to begin to mend old relationships.

One important goal of palliative care is to help the patient achieve the best quality of life possible until death occurs. Simply sitting with the patient and listening with compassion can be of great value. As stated by Borneman and Brown-Saltzman, “Presence may, in fact, be our greatest gift to these patients and their families.”[2(p680)]

PSYCHOTHERAPY (Dr Schuyler)

Both an internist (J.F.) and a psychiatrist (D.S.) on the palliative care team did an evaluation of Mr A. He came across as depressed and fatigued while facing a hospital stay of unknown duration, during which he was prepared to die. He described himself as “over-analyzing” and said that he was “preoccupied with what I am supposed to be doing at the end of my life.” He focused on his regrets. Distant from his extended family, he anticipated with dread their plan to travel east and be with him over the weekend: siblings, children, and grandchildren.

Speaking with one of his brothers, a very different picture of Mr A emerged. “He was a big man on campus in high school,” the brother said. “He completed college and actually had a pro football tryout. He later became a superb golfer. He was always a problem-solver, a bright and thoughtful man whom everybody looked up to. He made a real impact in real estate. He always treated people well."

The disparity between how Mr A was seen by his brother and his view of himself was evident. He had lived the last 10 years of his life dominated by his self-view and withdrawn from others. What was a reasonable task for the palliative care team that would manage this final stage of his life?

Mr A was primarily concerned with "face," his term for what others thought of him. His preoccupation was with what he needed to focus on during this time of his life. He mentioned on more than one occasion that he could no longer play golf, could no longer drive a car, and could no longer live alone. A task for the team was to gently challenge his beliefs about how he had lived his life. What was reasonable for him to take responsibility for and what should be left to others? What had he accomplished—in sports, at work, with people—and was he deserving of credit for his successes?

The blitz of family traveling to be with him was difficult for Mr A, both in anticipation and when it occurred. One focus of our visits with Mr A addressed the issue of how he was seen by significant others. We gently brought up the issue of responsibility. Mr A acknowledged that this issue could be seen in a variety of ways by different people. Freed from some of his self-blame, Mr A was more accepting of a positive self-view. We asked Mr A to account for why we had sought him out to speak with him. He could finally acknowledge his attractiveness regarding how he dealt with words, ideas, and concepts. During one of his visits, Dr Franklin noticed a neighbor who had come to visit Mr A, belying the patient's statement that he "had no relationships."

In fact, Mr A wound up spending a busy 2 weeks in the hospital. He had many visitors, along with the continuing presence of a brother and a family friend from the past. Mr A worked openly and publicly at dealing with issues that were salient to him—more than anyone we had seen at this life stage. He involved both of us (as well as several medical residents and nurses) in his search for resolution in his final days.

Mr A died peacefully one night as a massive hemorrhage related to his primary illness predictably took his life. He had negotiated his end-of-life stage effectively, and, in the process, had left an indelible mark on his provider team.

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