How to Live With a Terminal Illness

Dean Schuyler, 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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For the past several years, my clinical focus has involved the application of the cognitive therapy model to patients with severe medical illness. Some people have reached the life stage that encompasses the end of life. Some of these patients have been diagnosed with cancer.

To all I have said, "How you feel at this time will be determined by how you think." In my job as a member of a palliative care team, my approach has been added to that of internal medicine aimed at easing the burden of ill and often dying patients. Established by the chief of the Department of Medicine of the Veterans Administration hospital in Charleston, South Carolina, this job underlines their commitment to providing palliative care to those patients in need.

It came, therefore, as not a great surprise to be invited to join the health care team that works in the amyotrophic lateral sclerosis clinic in Charleston. Amyotrophic lateral sclerosis is a terminal illness that afflicts both young and old and both men and women and progresses through loss of function to death without hope of a cure. The staff recognized that adjustment to the progressive course of the illness would be aided by the addition of an approach to the emotional aspects of adaptation. And, after all, that is what I've been doing, albeit in other settings, for the past 4 years.

Amyotrophic lateral sclerosis typically begins with signs of focal weakness.[1] The disease progresses to involve muscle wasting and stiffness. Common symptoms include difficulty swallowing, difficulty speaking, and, eventually, difficulty breathing. Mobility is also typically affected. There may be physical pain, and pseudobulbar affect often occurs. Fine motor tasks (writing, dressing, personal hygiene) often become difficult.

CASE PRESENTATION

Mr A is a 70-year-old black man who is married and has 5 adult children. He is a college graduate and a life-long teacher. He served in the US Army and was stationed for a time in Vietnam. He was previously diagnosed with diabetes, hypertension, and coronary artery disease.

Mr A's younger sister died of pancreatic cancer at age 65. His father died of emphysema at age 71, and his mother died of heart disease at age 90. Mr A lived much of his life in New York State, where he studied, married, helped raise his children, and eventually became a successful and sought-after college professor. One year ago, he and his wife moved to Charleston.

Mr A was diagnosed with amyotrophic lateral sclerosis shortly after he arrived in Charleston. The disease manifested initially with right leg weakness. It progressed quickly to affect communication, swallowing, and eating. Mr A had a feeding tube inserted surgically. Mobility was difficult, and he became wheelchair-bound. Mr A now communicates by using a computerized board as well as his personal computer.

PSYCHOTHERAPY

A psychological evaluation encompassed activity, relationships, coping mechanisms, and mindset. What is Mr A able to do, and how does he spend his time? His wife is his caretaker. How do they deal with each other, and what is their life like together? When thoughts turn to the future, or consider ongoing behaviors, how does he deal with these thoughts? Has he ever updated his identity to account for his current status, or does he retain a self-view wedded to his past?

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Religion has always been a central aspect of Mr A's life. How does he practice his religion now? Communication has been a hallmark of his work as well as a central feature of his personal life. Does he maintain contact with people, and if so, how? What is his level of acceptance of a feeding tube?

For our interaction, I posed questions, and Mr A typed out answers on his board. After a short while, I moved next to him so that I could read his responses as quickly as he could produce them. He seemed to like that! He described his wife as "devoted to his care" and "able to take some time for herself." He had managed to continue a social existence, he said, by spending time physically with some friends, as well as by communicating with people via e-mail. He had a wide range of contacts, with friends, service people, and church members among them.

Mr A's self-view seemed solidly grounded in the "now," with an excellent adjustment to what he could, and could not, do. We discussed life stages, and he readily acknowledged how he dealt with the changes in his life. He prayed several times a day and continued to attend church weekly. He paid his bills electronically. He "read several books" each month. He did a variety of puzzles to "keep his brain active."

Mr A continued to take good personal care, including showers, mouth care, and bowel movements. He described his mood as "not depressed," got adequate sleep, and, despite having lost some weight, maintained what he considered to be reasonable energy. His memory continued to be sharp.

We have discussed his thoughts in detail. He has refused to dwell on thoughts that arise about the future and functioning. He sees himself as reasonably busy and connected to important aspects of his world. Only occasionally is he aware of being anxious, and a small dose of a minor tranquilizer is infrequently used.

Mr A has made a rather extraordinary adaptation to a difficult illness and life stage. He expressed great appreciation for the addition of a psychiatrist to his "team" and looked forward to more time together in the future. It seemed clear that further progression of his disease was very likely. If his response is anything like it has been to date, the prediction is for further successful adjustment. There will be more trials ahead, and only time will tell how well he might do. It is hoped that the addition of this psychiatric relationship to his clinic team will yield significant benefits.

REFERENCE

1. Bedlack RS, Mitsumoto H. *Amyotrophic Lateral Sclerosis: A Patient Guide for Clinicians*. New York, NY: Demos Medical; 2013.

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