Living With a Chronic Illness

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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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As our country ages (and as we get older), it seems that there are more and more people living with a chronic illness. An effective strategy for thinking about life events would allow the chronically ill patient to focus on his or her disease and its treatment only just prior to a medical appointment. It would be reasonable also for him or her to consider the illness whenever symptoms appear that require interpretation or action. It would be ideal, however, for the patient to "forget about the illness" for the remainder of his/her time.

Unfortunately, a more usual approach is for the patient to think about the illness on multiple occasions and to spend time asking a number of "what-ifs" related to its course and effects. In addition, whenever there is a distressing symptom, the patient will typically try to attribute the symptom to the chronic illness. This approach can lead to a disrupted life experience in which the illness is the patient's constant focus. It can interrupt sleep, diminish the pursuit of usual interests, and lead to weight changes, energy changes, and memory loss as well as severely affect mood. Clinical depression can result.

A critical turning point in adaptation would have the patient focus on his or her role in this process. "It isn't happening to me, rather I am making it happen," would illustrate the hoped-for transition. This problem captures the essence of the psychological challenge (alongside the physical challenge) offered by the subject of our case presentation. As is often the case, the patient's spouse was a partner in the enterprise and benefited from being engaged with him in the solution.

CASE PRESENTATION (DR SCHUYLER)

Mr A is a 50-year-old man, married for 30 years, with 2 adult married daughters. There is no history of hypertension, heart attack, or emphysema. He smoked cigarettes briefly but stopped entirely 20 years ago. Alcohol (wine) is an occasional indulgence, but there have been no alcohol problems or intoxication.

A diagnosis of amyotrophic lateral sclerosis (ALS) was first made 2 years ago when Mr A noticed bilateral weakness in his arms and then atrophy. Shaving became a problem, and he couldn't manage to button his collar. Muscle cramps and fasciculations followed. Next, Mr A experienced bilateral hand tremors along with muscle spasms. He had experienced no breathing, swallowing, eating, or speech concerns. The diagnosis was confirmed with electroencephalographic studies.

Throughout his adult life, Mr A was very active physically. He participated in sports, did regular exercise in a gym, went camping, and now continued to be motivated to stay involved in physical sporting activity with his 2 grandsons.

MEDICAL CLINIC VISIT (DR COURTNEY)

Mr A was diagnosed with ALS (also known as Lou Gehrig's disease) 26 months prior to this visit. The disease is characterized by progressive weakness, with predictable complications that affect muscles. Falls with injury, loss of ability to attend to hygiene and other activities of daily living, problems with speech, problems with swallowing, and weakness of the respiratory muscles causing respiratory failure and death are all common concerns as the disease progresses. The frequency of ALS appears to be increasing in the United

States, with about 1 in 140,000 to 1 in 200,000 people developing the disease, usually in middle-age. There is no cure. Management of the disease is based on preventing complications and assisting patients and family to maximize independence as the disease progresses.

Palliative care is an important part of managing this disease. Patients are usually competent and able to express their wishes and direct their care through all stages of the disease. Death from respiratory failure is thought to be particularly stressful for patients and caregivers, and counseling to plan for respiratory weakness as well as patient preferences for management can be discussed at several points in the course of the disease.

For the past 2 years, Mr A had been experiencing slow progression of the disease, with muscle atrophy and weakness of the shoulders and right arm as his principal difficulties. He was disabled to the point of being unable to work but remained active in selected activities. Mr A was pleased that he was still able to play golf but frustrated by the worsening of his game.

This visit was a follow-up to his treatment for pneumonia. Four weeks earlier, Mr A had developed a nonproductive cough with fever and shortness of breath. At that time, he was seen at an outside facility, and a left lower lobe infiltrate was found on chest x-ray.

At the current clinic visit, Mr A related a recent history of 3 episodes of choking when drinking water or thin liquids. He reported noticing a wheeze when he fell asleep on his back but never when he slept on his side. Mr A had, during the previous 4 weeks, several occasions of "really bad coughing" without producing sputum. There had been no fevers, no episodes of shortness of breath, and no awakenings short of breath.

Mr A's physical examination was remarkable for the new finding of an absent gag reflex. When the tongue blade was placed against the back of the throat, there was no tongue lift or withdrawal. The soft palate moved incompletely, with the uvula staying midline, when he said "ah." Speech had normal volume and inflection. There were no other cranial nerve abnormalities. The lung examination was normal. The muscle atrophy of the shoulder girdle was unchanged.

The tone of the visit changed significantly at the discovery of the absent gag reflex. What had started as a positive "everything is getting better after the recent pneumonia" visit now featured the discovery of a finding that predicted recurrent problems, increasing complications, and a significant change in lifestyle. At this visit, Mr A was not prepared to make decisions about advanced directives related to tube feedings or limits on care. Mr A acknowledged that he wanted to be kept comfortable at the end but needed to talk further with his wife. He promised to be prepared to make these decisions at the next visit.

I spent several minutes discussing swallowing techniques, with feedback about when he had trouble swallowing, and he provided insights into his difficulties. We agreed that the wheezing that he experienced while sleeping on his back might represent silent aspiration of his saliva, and we discussed ways to stay off his back during sleep and brought up the future use of treatments to reduce saliva.

Mr A, like many patients with ALS, was well read on the disease. It was clear to me that during the medical counseling, he was processing the increased complexity of managing his disease. Mr A agreed to obtain a swallowing study and was committed to pursuing the techniques for safety that we discussed as well as others that the speech therapist might teach. Mr A had been getting routine pulmonary function studies. We discussed the results of the most recent study and scheduled another to determine the strength of his respiratory muscles. We agreed to talk about advanced directives at Mr A's next visit.

PSYCHOTHERAPY (DR SCHUYLER)

While Mr A was being examined by Veterans Administration hospital medical staff, I spoke at length with his wife. I asked how she had adapted to her husband's slowly developing disease. She told me about considering a large number of what-ifs. She was, she said, attempting to "predict the future" and planning for how she would deal with it. I pointed out that this strategy had a number of negative consequences. An alternative approach was to trust that she would be able to deal with problems once they arose. We considered together what the benefits of this approach might be. I suggested that she "stay on the page you're on." She commented that the couple's major focus was to "enjoy the now," and she gave several examples of how they went about this.

At our second visit (paired with his monthly surveillance appointment), I met with both Mr A and his wife. He noted a nervous stomach along with signs of diminished arm strength. Mr A related his anxiety to his perception of loss of function. We spoke of a new life stage, and I asked him what his plan was for it. What might capture his interest, not be deterred by restriction, and be stimulating for him? Mr A promised to think about this as a challenge and enlisted the aid of his wife in the process.

One month later, the couple emphasized their long activity list: camping, travel, and golf. Mr A's strength level seemed to him to be unchanged. His mood was stable, without undue depression or anxiety. The couple seemed to have made a successful adaptation to a demanding illness, being careful to react to, but not anticipate, whatever would be their future course.

It seemed to be a good example of how a brief intervention could support a healthy reaction to living with a chronic illness.