Taking Care of the Caretakers

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Working with cancer patients for a number of years, I have met many caretakers. They have been husbands and wives, daughters and sons, neighbors and friends. Although it is not original with me, the concept that people are made patients by the disease of others is worthy of our attention as therapists.

My cancer work served to acquaint me with the long hours, the often unacknowledged duties, the multiple stresses, and the frequently unrecognized burdens that came with the role of caretaker. A society, I thought, should make some provision to support the needs and sacrifices of this critical segment of the population.

In the 3-plus years I have worked in an outpatient psychiatric office, there have been few referrals of caretakers. Brief cognitive therapy, including an opportunity to ventilate and to achieve some perspective, would seem ideally suited to this population. With the clinical focus firmly fixed on the index patient, providers would be unlikely to readily recognize this need.

It came as somewhat of a surprise, therefore, to receive a call from one of my favorite primary care doctors, asking me to meet with the caretaker for one of his severely ill patients.

CASE PRESENTATION

Jack described himself as a 55-year-old man who had never suffered from depression or clinical anxiety. He was college educated and had worked most of his adult life as a social worker. He met his wife Mary 35 years ago. They had lived together for 7 years, then married, and had raised 4 grown children, 2 daughters and 2 sons.

Aside from hypertension, for which Jack took medication, his health had been excellent. Mary, too, was well until 5 years ago when, at age 48, she developed some cervical spine problems. They consulted several physicians and specialists, without establishing a clear diagnosis. However, she became progressively unable to work as a clinical psychologist and finally was confined to their home. One year ago, she experienced the onset of periodic seizures, visual hallucinations, and, finally, bizarre evening and nighttime behavior.

With the diagnosis now determined to be a neurological degenerative disease, Jack initially tried to handle everything himself. Progressively, he noted increasing exhaustion, irritability, and preoccupation with all the ways in which their lives had changed. He now focused on trying to assemble a team of caregivers to “guard” Mary at night so that he could sleep and continue to work. He hired additional personnel to stay with Mary and help her with activities during the day.

Despite the helpers, he became noticeably more tense and ruminative and no longer seemed to have time for a social network of friends that had been important to the couple over the years. My diagnosis for Jack was adjustment disorder with anxiety (309.24, DSM-IV).

I spoke with the referring physician and then with Jack by telephone. We decided that antianxiety medication was not indicated at this time.
The prescription agreed upon was for a course of brief cognitive therapy for Jack.

PSYCHOTHERAPY

Jack began our first therapy session talking about Mary and her changes in functioning, especially over the past 6 months. Then, he focused on his decision to obtain help in caring for Mary at home. Finally, he discussed his investigation of nursing homes, acknowledging that a time would come when Mary could no longer be cared for at home.

He felt guilty about “abandoning” his wife and sad about the “loss of the life” they had built together. He listed the practical management problems he had confronted in dealing with Mary’s care. Bringing caregivers into their home had violated the sense of privacy he and Mary had shared together since their last child had moved on in life. They had previously “done everything together” and were each other’s “best friend.” Watching Mary’s deterioration had been “painful in the extreme” for Jack.

Over 3 working sessions, I listened to and encouraged Jack to talk about Mary. After he had taken the opportunity to express how he felt and what he thought, I gently shifted the focus from Mary to Jack. We defined this time as a new stage in his life and considered his needs as well as hers. How could he be responsive to Mary and manage to maintain himself at the same time? How did he view their life as a couple, from the time they met until Mary became ill? What was the feedback and communication like between Jack and the 4 children?

During the month we worked together, Jack learned to apply the cognitive therapy model. When he felt distressed, he learned to identify the “issue” and then examine his thoughts about it. He found strategic alternative ways to think and adopted some of them. He gained perspective about the Herculean caretaking task he had undertaken and became more accepting of the wisdom of seeking help. He learned to feel okay about periodically doing something for himself, so that he could retain the capacity to care for Mary. He considered the future, from a viewpoint of Mary’s likely needs and his own.

It was a total of only 4 hours of work, but Jack said afterward that he felt “recharged” and “optimistic” about life’s direction. It was a thoughtful, insightful physician who had considered the burdens on Jack as a caretaker and referred him for help.