End-of-Life Care in a PACE Program: Respecting the Patient’s Wishes While Supporting the Caregiver

Abisola B. Famakinwa, MD

Family caregivers play a key role at the end of life. They provide high levels of assistance and are often called on to make complex medical decisions. This is a period where there is potential for conflict, particularly when the patient lacks decision-making capacity. This case report describes how an interdisciplinary team helped an end-of-life caregiver to find closure while advocating for the patient’s wishes to be carried out. The intervention of appropriate advanced care planning and frequent communication resulted in a positive outcome. (J Am Med Dir Assoc 2010; 11: 528–530)

Keywords: Family caregivers; end-of-life care

Programs of all-inclusive care (PACE) provide comprehensive community-based care that enables nursing home–eligible elders to live in the community. The participants receive a wide range of services from one interdisciplinary team, which works closely together to develop a care plan for each participant. The long-standing relationship and good communication between the PACE team and the patient and her caregiver, demonstrated in this case, contributed to appropriate decision making at the end of life.

The participant was an 87-year-old widowed white female who enrolled in the program in January 2005. She lived alone in elderly housing and attended the PACE day center twice a week. She had the services of a home health aide twice daily, a homemaker twice weekly, and saw a psychologist weekly. The PACE program provided transportation for all services as well as all medication and durable medical equipment. She was equipped with a personal emergency response system referred to as “Life-line.” Her daughter, who was also her health care proxy, was actively involved in her care and assisted with shopping and managing her finances.

Her past medical history was significant for Alzheimer’s dementia, hypertension, hyperlipedema, depression, spinal stenosis, urge incontinence, recurrent urinary tract infections, recurrent falls, a lung nodule, being followed with computerized axial tomography (CT) scans, chronic constipation, and a long history (>30 pack years) of cigarette smoking.

Her medications included citalopram, 40 mg daily; nitrofurantoin, 50 mg daily; long-acting detrol, 2 mg daily; a multivitamin tablet daily; artovastatin, 10 mg daily; enteric-coated aspirin EC, 81 mg daily; nifedipine extended release, 60 mg daily; calcium carbonate, 500 mg twice daily; vitamin C, 500 mg daily; ferrous sulfate, 325 mg daily; soluble fiber, 1 to 2 tablets daily, each with 40 oz of water; gabapentin, 100 mg daily; and sennokot, 17.2 mg twice a day as needed for constipation.

On July 27, 2006, the patient complained of dizzy spells. Her home health aide reported these symptoms at the daily morning meeting. She was visited at home by the home care nurse who checked her vital signs: her heart rate was 80 beats per minute, temperature was 98°F, systolic blood pressure was 112 mm Hg, and diastolic blood pressure was 64 mm Hg. The findings were reported to the PACE provider who directed the nurse to draw blood for labs and obtain a urine sample. The patient was unable to give any extra history except to confirm the reported symptoms.

Advanced directives had been discussed with the patient upon enrollment and she had made it very clear that she never wanted to be in a hospital for any reason, and if she had cancer, she wanted to die at home. Her wishes were “do not resuscitate or intubate” (DNR/DNI). She declined all screening tests including colonoscopy, which was mentioned in the context of her anemia.

On July 27, 2006, the patient complained of dizzy spells. Her home health aide reported these symptoms at the daily morning meeting. She was visited at home by the home care nurse who checked her vital signs: her heart rate was 80 beats per minute, temperature was 98°F, systolic blood pressure was 112 mm Hg, and diastolic blood pressure was 64 mm Hg. The findings were reported to the PACE provider who directed the nurse to draw blood for labs and obtain a urine sample. The patient was unable to give any extra history except to confirm the reported symptoms.

The patient was then assessed at the PACE center. On examination she was a pleasant female in no distress. Physical examination was significant for an oxygen saturation of 91%, which was her baseline, and the findings that she seemed more forgetful and had word-finding difficulty. It was noted that she had lost 6 pounds since June 5, 2006.
Labs showed mild hypokalemia and a low prealbumin.

Additional history was obtained from her daughter who had noticed that her mother was sleeping more, and seemed withdrawn and depressed. She noted that the patient complained of problems with her dentures and had some difficulty swallowing. Her appetite was poor and it took tremendous effort to coax her to eat. She had also noticed a decline in her mother’s ability to perform her activities of daily living. The patient acknowledged that she was more forgetful but wanted to continue living alone in her apartment with her prior services. She stated she felt safe and knew how to use her lifeline. She also wanted to be able to continue to smoke. The plan was to increase home service and increase frequency of PACE center attendance for closer monitoring. The center nutritionist met with the patient, her daughter, and home health aide to ensure that the patient had adequate nutrition and hydration. Appointments were made for the patient to be seen by the center dentist and the psychiatric advanced practice nurse.

On August 3, 2006, the patient was seen in follow-up. Her chief complaint was that of dizziness in the preceding few days. This was further characterized as lasting for a few seconds and occurring only when standing. It was noted that the outside temperature was over 90°F and the patient admitted to poor oral intake. Physical examination revealed an elderly female who was alert and at her baseline cognition. She had great difficulty arising from a seated position but was able to ambulate slowly with her walker.

Her buccal mucosa was dry and she was markedly icteric. Vital signs showed orthostatic hypotension, a normal temperature, and oxygen saturation on room air was 94%. The patient’s lungs were clear to auscultation and her abdomen was soft with normal bowel sounds; her extremities showed no edema. She refused to go to the hospital as was her usual pattern but was persuaded to be admitted to a nursing home for further management. In PACE, patients can be admitted directly to a skilled nursing facility without prior hospitalization. The social worker made the referral and the patient was subsequently transferred to the nursing home.

The patient was admitted to the nursing home by the PACE physician who saw her daily thereafter and gave progress reports to the team. The initial diagnosis was hepatic encephalopathy and the plan was to identify and treat the precipitating cause. Laboratory tests were ordered that showed marked elevations in hepatic enzymes, hyperbilirubinemia, and leukocytosis. The patient was treated with intravenous fluids containing potassium and oral lactulose. A chest x-ray showed a slight left upper lobe infiltrate. Antibiotics were added. The patient became more alert after she had a bowel movement but remained lethargic and disoriented and her mental status continued to deteriorate.

On account of this decline, the health care proxy was activated.

The patient’s daughter understood the severity of her mother’s condition and was aware of her prior advanced directive decision including her desire not to go to the hospital and die peacefully at home. However, she stated that she could not let her mother go without knowing to some degree the underlying pathology. She said she had to be sure her mother did not have a potentially reversible condition. She felt conflicted with her desire to find closure and her mother’s stated wishes. Several meetings were conducted by the PACE physician at the bedside with the patient’s daughter and other siblings, as well as at the PACE site with the interdisciplinary team. The family finally agreed to noninvasive testing in the nursing home. Hepatitis serology was negative and tumor markers (carcinoembryonic antigen and alpha-fetoprotein) were noncontributory. An abdominal ultrasound revealed at least one cystic lesion in the left kidney and a second questionable lesion in both left and right kidneys. The radiologist felt that further evaluation, in view of the patient’s age, would depend on the overall clinical situation.

With the available investigation results, the patient’s children understood that their mother might be dying from a possible form of cancer and not from a potentially reversible condition. They did not insist on a tissue diagnosis and were now ready to take the next step of ensuring their mother had a peaceful death at home. Arrangements were made to transport the patient home the following morning. However, the patient died peacefully in the early hours of the morning with her children at her bedside. The family was very appreciative of the efforts of the PACE team to ensure her wishes were met while respecting their need to be able to find meaningful closure. Further bereavement counseling was offered but they felt it was not required.

**DISCUSSION**

Family caregivers play an integral role at the end of life. This is a period where the family is dealing with the emotional stress from losing a loved one while having to make complex medical decisions. End-of-life caregivers also provide higher levels of assistance and report more challenges than other informal caregivers of chronically disabled community dwelling older adults. At this time there is potential for conflict particularly when the patient is no longer able to make decisions. Family members may struggle with letting go even if it would have been the elder’s wish to die peacefully without aggressive care. Further conflict may be generated if family members have different philosophical or religious views relating to end-of-life care.

Physicians and other members of the health care team have an important role to play supporting these caregivers and intervening to resolve conflict. This is of particular importance as studies have shown that family involvement is crucial in ensuring a good death for the patient. **Rabow et al** identified areas important for caring for family caregivers at the end of life including communication, appropriate advanced care planning and decision making, supporting home care, demonstrating empathy for family emotions and relationships, and attending to grief and bereavement.

In this case, the family was represented by one daughter who was the health care proxy. She wanted to respect her mother’s wishes but also needed to feel that she had carried out her duties and considered nontreatment of a potentially reversible illness a failure on her part. The concerns of this caregiver were addressed largely by providing regular updates...
and education about the patient’s clinical condition while involving her in the decision-making process. By using a nursing home to provide limited noninvasive clinical and lab investigations, it was possible to infer that the patient’s demise may have been attributable to malignancy. This intervention was sufficient to help the caregiver find closure, thus decreasing her stress and assisting with the grieving process. Although the patient did not die at home, the family was satisfied that the patient’s preferences had been followed: she was not admitted to the hospital and the PACE team had made significant effort to ensure a peaceful death at home. This is in keeping with literature that suggests end-of-life caregivers are more likely to be satisfied if the patient’s preferences are followed.6

Positive outcomes can be achieved at the end of life when the health care team simultaneously respects the patient’s autonomy while supporting the caregivers and helping them to find closure. It is essential that the treatment team addresses the needs of the patient and his or her family members at this pivotal time.

REFERENCES