End-of-Life Care in the Long-Term Cancer Survivor

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Column Editor?s Note: This column presents a problematic case that poses a medical-ethical dilemma for patients, families, and healthcare professionals. As it is based on a real case, some details have been changed in the effort to maintain patient confidentiality. In this case, a patient with a long-term disease experiences a prolonged period of relative ?wellness? and is lost to follow-up until fatal complications evolve. The case is complicated by the lack of adequate surrogacy.

Column Editor: Ferdinand D. Yates, Jr., MD, MA, Acting Consultant in Clinical Ethics, CBHD.

Question:  
How should the family and the medical team proceed with medical care when there is conflict over treatment options in a long-term cancer survivor in the absence of clear surrogacy?

Case Presentation:  
A fifty-three-year-old African-American man, who had been diagnosed with a rare and aggressive type of cancer more than twenty-five years ago, was recently admitted to the hospital for severe hypoglycemia and was unresponsive to stimulation. This was his first admission to this particular hospital, and, most recently, he had been under Hospice services in the community. At the time of his initial diagnosis of cancer, the treatment included a craniectomy for a brain metastasis.
Subsequently, multiple chemotherapeutic regimens, including experimental therapies, were attempted with temporary respites of tumor growth. He returned to his original community after the academic center told him that they had no further curative treatment to offer. Apparently, Hospice and comfort care were not explicitly discussed.

Surprisingly, despite the aggressive nature of the underlying malignancy, the patient was lost to medical follow-up and apparently had minimal complications for many years. At the time of presentation, with hypoglycemia, the workup documented a large metastatic tumor in the liver, and he also had extensive metastatic disease in the lungs, kidneys, and pancreas. In addition, the patient had visible tumor masses throughout much of his subcutaneous tissue. Initially, the patient was conversant for short intervals, but he seemed unwilling to engage in medical decision-making with or without the presence of his family. He expressed no particular religious preference in any of the hospital records.

At times, even after correction of the hypoglycemia, he was confused, unresponsive, or belligerent with caretakers, and after the first week of hospitalization he was no longer communicative. Despite his previous entry into hospice care, the attending physicians were surprised to learn that certain family members wanted further medical treatment other than palliative care. Specifically, the patient had a massive tumor on his upper right arm that was not causing pain or circulatory embarrassment, and the family insisted that it be surgically removed despite the physicians’ opinion that such a course of action would be invasive, burdensome, and futile. A medical consultant agreed with the family, and a meeting was arranged for the family and the medical team.

The patient was not married, but had a “common law?” relationship for more than ten years. However, he had been estranged from his female partner for the past fifteen years. The patient had a son living in the same community, and they saw each other several times each week. The relationship was described as a good one, and the medical team felt that the son was likely the most appropriate member of the family to speak on the patient’s behalf. However, no one had been granted a durable power of attorney, there was no health care agent, and a living will was not available.

The patient’s son had assisted in the prior hospice placement. In addition, the son noted that he and his father had some detailed conversation regarding his father’s upcoming death with recall that his father had repeatedly told him that he wanted to die at home. His common law partner and other relatives ? verbally abusive at times? noted that the patient ?always refused to give up,? and that ?everything? should be continued. The family and the medical team could not reach consensus on either the establishment of a do-not-resuscitate order or the reinstitution of hospice care. The estranged partner perceived that the improvement of the patient’s glucose level was proof that he was responding to treatment and still “fighting.” An Ethics Consultation was requested.

**Denouement**

The ethics consultants sympathized with the son and the healthcare team regarding the appropriateness of comfort care without resuscitation effort and continued hospice enrollment if the patient was discharged. An Oncologist spoke to the family and told them that there were no treatments that could reverse his terminal condition and that every effort would be made to make him comfortable. As the “common-law?” partner no longer asked for surgical intervention, a
temporary agreement to palliate (without a do-not-resuscitate order) was reached. Over the next week, the patient accumulated a large amount of abdominal fluid and developed increasing difficulty with breathing; however, he seemed comfortable with morphine. A few days later, the patient developed signs of pneumonia with fever, and his son asked for another family conference with the medical team. At this meeting, consensus was reached regarding comfort care, and a do-not-resuscitate order was initiated. The patient expired peacefully about two days later.

**Discussion**

It was apparent that the patient defied all odds and survived much longer than anyone expected. However, his prolonged survival may have given everyone, including himself, his partner, and his son unrealistic expectations. Earlier in the course of the illness, surgery and chemotherapy affected long periods without the obvious progression of an incurable malignancy. Medical situations such as this are not only rare, but also are difficult to employ in the typical cancer milieu. Nonetheless, physicians should be hopeful and yet remarkably circumspect when making any predictions regarding progression of disease and prognosis. A recent study revealed that women who were presumably cured from breast cancer who in fact demonstrated manifestation of early as well as late stage disease at the time of the initial diagnosis had died from complications of breast cancer (not complications of treatment) twenty-three years after the initial diagnosis. The results of this study have led others to observe that physicians should be cautious in ascribing a complete cure to any cancer. Similar late recurrences have been documented with other tumors including testicular and rectal cancers. In our case, during the course of his illness, the patient may have sincerely believed that he was cured despite mounting (and undiagnosed) evidence to the contrary. While he seemed to accept his prognosis, distant relations seemed to grasp at early respites from active disease, and any continuity of medical care relationships was hampered by interrupted geographic contingencies. The patient's health care may have been compromised by the lack of a primary care physician who typically would have established a longstanding relationship with the patient and family and who would also facilitate appropriate end-of-life care plans. In this specific situation, the healthcare team, the patient, and the patient's family were thrust into a chaotic situation without any background preparation or relationship and with limited medical information.

The other prominent issue arising in this case is the notion of surrogacy. Although surrogates do sometimes make decisions for loved ones that are contrary to the wishes of the patient, the primary intent is for the surrogate to act on the patient's prior statements. In this scenario, most people would recognize that the patient's son should have the authority for healthcare decision-making. He had the most intimate contact with his father, had conversation with his father regarding the terminal illness, and seemed to be in the best position to understand the limits of medicine in dealing with his father's malignancy.

Being hopeful and yet circumspect in prognosis, identifying appropriate surrogate decision makers, and developing trust through years of compassionate care are still the best ways to realize a dignified death with cancer. These interrelated activities are really the basis for appropriate healthcare and should be safeguarded in our sometimes fragmented system of providing health.
Editor's Comment
The primary concern of surrogacy should be that of enacting the medical decisions that represent the medical preferences expressed by the patient. Surrogacy may become a complicated problem because of a number of reasons: 1) there is no directly appointed surrogate (our case), 2) the surrogate may not be willing or able to act as such, 3) the surrogate may not know the patient's medical preferences, 4) the surrogate's decisions may be in direct contradiction to the known choices and preferences of the patient, and 5) the physicians may not be willing to employ the decisions made by the surrogate. Whereas each of the above reasons?and perhaps others?has its own peculiarities, we will focus on the first one, because, in our case, the patient apparently had not selected a surrogate, and there were several family members who wished to speak for the patient.

When there is no official surrogate speaking on the behalf of the patient, the medical team necessarily must go to extra effort to learn what, if anything, the patient had said in prior discussion that may give some direction to the decision-making process. Many states have a family medical decisions act (of some sort) that allows other members of the family to express what they know about the patient's medical preferences and empowers the physicians to proceed with end-of-life care even if there is no surrogate. In addition, many states endorse a rank-order of family and friends whom the physicians may enlist in the decision-making process. In my state of New York, the following is the authoritative order: patient's spouse, adult children of the patient, surviving parents of the patient, and siblings of the patient. In certain situations, where a very close friend or neighbor or a religious person has had intimate dealings with the patient, this information may be instrumental. Conflict among family members occurs occasionally in these situations, and the main hope of resolution typically lies in repeated conversations. Sometimes the physicians may enable the family to agree to a time-limited trial of a particular treatment to see the effect on the patient's medical condition, and the physician may also enlist the family's help in setting particular therapeutic goals. This type of reasoning often helps the family jointly approach a more definitive end-of-life decision.

Suggested Reading
Fins, Joseph J. A Palliative Ethic of Care (Sudbury, Mass.: Jones and Bartlett, 2006).


