Discussing Goals of Care for a Delirious Advanced Cancer Patient in the Hospice Setting

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Abstract

In the United States, patient autonomy is generally considered the most important ethical principle; however, patients sometimes make decisions that are medically futile or in conflict with the principles of beneficence and nonmaleficence. Difficult issues are often compounded if the patient loses capacity and a surrogate must provide substituted judgments. Allowing autonomy free reign can sometimes be detrimental to patient care and contribute to family distress. Here, we describe the case of a terminally ill patient whose conflicting desires were to have “everything” done—including cardiopulmonary resuscitation—and to simultaneously avoid hospitalization and die peacefully at home.

Introduction

IN THE UNITED STATES, patient autonomy is considered the main ethical principle when making important decisions.¹ When considering withholding or withdrawing life-sustaining treatment, American courts have upheld autonomy as the premier ethical principle.^{2,3} In general, physicians may ethically override the patient’s wishes only when the requested intervention is medically futile based on the best available research.¹ Unfortunately, owing to delirium, dementia, coma, or other causes, many patients lack the capacity to make decisions at the end of life.⁴ The patient’s legal surrogate must then exercise substituted judgment to make decisions reflecting the patient’s previously stated preferences, values, and beliefs.⁵ However, in as many as one-third of scenarios, surrogates’ decisions are inaccurate.⁶ Moreover, many patients do not discuss their preferences with their surrogates or physicians prior to losing decision making capacity.⁷

In an end-of-life setting, neglecting to clarify a patient’s preferences can not only cause considerable emotional distress for the patient’s surrogate, family, and medical team, but also result in unnecessary interventions that can exacerbate suffering. We present a case of a hospice patient who, despite multiple statements suggesting that she did not completely endorse the hospice philosophy, never engaged in an in-depth discussion of her goals of care with her medical team. This case highlights the importance of timely discussions of goals of care in preventing potentially devastating end-of-life experiences as well as the detrimental effects of bowing arbitrarily to patient autonomy.

Case Description

Ms. R was an African American woman in her 50s who was diagnosed with poorly differentiated adenocarcinoma after a small bowel resection for obstruction approximately four years prior to her final inpatient hospice admission. She underwent chemotherapy. Regrettably, her disease recurred two years before the final hospice admission and progressed despite multiple chemotherapeutic regimens. Five months before her final admission, Ms. R moved into her daughter’s home in another state. She almost immediately had recurrent small bowel obstruction secondary to extensive peritoneal carcinomatosis and underwent a venting gastrostomy. She became dependent on total parental nutrition (TPN). TPN caused intractable vomiting, necessitating five emergency department visits and three admissions for renal failure and dehydration within a two-month time period. Finally, her condition deteriorated to the extent that her inpatient physicians determined that chemotherapy could not be tolerated. The palliative care service was consulted to manage her pain and nausea and transition to hospice care. However, she initially refused to consider palliative care or hospice and desired aggressive treatment, including the re-initiation of TPN.

Following the administration of TPN, Ms. R again had severe nausea and vomiting. After a discussion involving only her primary caregiver—her daughter—she decided to discontinue TPN and enroll into hospice services. No medical team members were present during the discussion. The oncology team rapidly arranged Ms. R’s transfer to hospice care, and she was discharged from the hospital within a few hours.

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of her decision. This sudden transfer prevented the palliative care team from being able to return to fully discuss goals of care with Ms. R.

During the following two months, Ms. R was admitted multiple times to the inpatient hospice unit for nausea and pain. Initial attempts to discuss code status with her were rebuffed. After one of these admissions, Ms. R moved from her daughter's home to her longtime boyfriend's home and designated her boyfriend as her preferred surrogate, since her daughter disagreed with her full code status.

When Ms. R suddenly became somnolent with low-grade fevers at home, she was readmitted to the inpatient hospice unit for suspected sepsis. On her arrival, it was immediately clear that she was delirious. Ms. R's boyfriend stated that Ms. R wished to have "everything possible" done, including cardiopulmonary resuscitation (CPR). However, when physicians suggested to him that they revoke hospice care and call an ambulance to transport her to an acute care hospital, he replied that she had previously told him that she wanted to die peacefully at home and did not want to be hospitalized again. Under the current health care system, these desires were mutually exclusive. Ms. R could not receive aggressive treatment without hospital admission; nor could she die peacefully at home while receiving CPR. Because she had not discussed her goals in depth with the medical team, she may not have known that her goals were incompatible. Additionally, although Ms. R had discussed her goals with her surrogate, she had never ranked them according to importance or disclosed her reasoning for each goal. He was therefore unable to rank her wishes and felt unable to make a decision. Hoping to be able to discuss the choices with her, he opted to wait for her to have a lucid interval.

That lucid interval never came. Ms. R rapidly declined; the following morning, she had respiratory distress followed by agonal respirations. As she was still a full code, the hospice staff activated emergency medical services (EMS). While EMS prepared Ms. R for transport to an acute care hospital, her boyfriend remained conflicted and hesitated to revoke hospice care, saying, "We want to go home." EMS returned Ms. R to her bed, and another ambulance was called to transport her home. The hospice staff arranged for Ms. R's inpatient nurse to accompany her home to provide crisis care services and, if needed, pronounce her death en route to prevent the ambulance from rerouting to a hospital for pronouncement. Addressing Ms. R's physical distress, counseling her surrogate through a difficult decision, and arranging her final disposition took several hours.

Ms. R arrived home safely, but never fully emerged from her delirium. She continued to deteriorate and died comfortably in her home two days later. The crisis care nurse reported that her boyfriend simply held her for 10 minutes—and then called EMS. EMS arrived 40 minutes later and performed CPR at her surrogate's request. Ms. R could not be resuscitated and was pronounced dead with the assistance of the crisis care nurse.

Discussion

An in-depth discussion of goals of care while Ms. R had decision making capacity could have prevented the emotional distress experienced by her surrogate and the medical team and allowed for appropriate end-of-life care. The literature on quality of life and satisfaction with care reveals three goal

domains: goals for the disease process, goals for quality of life and suffering, and goals for the circumstances of death.⁸ Some patients continue to desire disease-directed therapy with intent to cure or halt disease progression despite uncertain benefits and significant treatment burdens. Others value quality of life and the alleviation of discomfort more than the overall length of life. Patients with advanced illnesses often prefer to dictate the location and circumstances of their death.⁸

If a patient becomes incapacitated, surrogates must make decisions based on their knowledge of the patient's preferences. If reliable evidence regarding the patient's wishes is unavailable, the surrogate should make decisions in the patient's best interest.^{5,6,9,10} The question then becomes whether a surrogate can accurately make substituted judgments. Reviews indicate that the accuracy of surrogates' decisions is only 68%.^{5,6} Accuracy also appears to depend on the hypothetical scenario: in a systematic review, it was lowest for stroke and dementia (58%) and highest for the patient's current health state (79%).⁶ Accuracy varied less based on the type of intervention proposed, ranging from 60% to 72% across the board for interventions such as CPR, blood transfusions, amputations, and antibiotics.⁶ Various reasons for this low accuracy rate have been proposed. The surrogates may themselves have impaired capacity, or might lack sufficient knowledge of the patient's preferences or the best course of action for the patient's welfare. Surrogates might also fail to follow the patient's preferences to avoid guilt or criticism from family members. One study showed that surrogates' decisions were heavily influenced by their own preferences.¹¹

In another study, only 68% of patients had previously discussed their preferences with their surrogates.⁷ Among patients who had not discussed their preferences with their surrogates, the most common reasons were because the patients did not feel they were ill enough to merit a discussion (31%) and because the patients were uncertain of their preferences (25%). Another study showed that over 90% of patients without advance directives felt that their surrogates understood their preferences at least "pretty well." The accuracy rate of these surrogates' substituted judgments was 94% for the patients' current health state but ranged from 62% to 79% for hypothetical situations such as cancer, stroke, or dementia.¹² Despite these limitations, surrogate judgments have been consistently shown to be more accurate than physician judgments.⁶ In the absence of more accurate methods of preserving patient autonomy when the patient lacks capacity, surrogate judgments remain the best available means.^{6,11}

Although patient autonomy is highly valued, patients' or surrogates' decisions sometimes conflict with two other ethical principles: beneficence and nonmaleficence. U.S. courts have supported medical teams' decisions to decline patients' desires when they have no physiological benefit.^{1,10,13} For example, physicians are not obligated to treat viruses with antibacterial agents. Medical futility, however, is more of a gray area: keeping a patient in a persistent vegetative state alive with mechanical ventilation may be considered medically futile by many physicians, but patients and families may greatly value being kept alive. In cases of medical futility, the U.S. precedent has been that patient autonomy trumps beneficence in court.^{2,14,15} Fortunately for medical professionals, however, the courts are also reluctant to punish physicians who—acting on the principles of beneficence and

nonmaleficence—have refused to provide treatments that they consider inappropriate, futile, or not in keeping with the standard of care.^{1,9,10,13}

In the case we presented, Ms. R's previously stated desire for CPR became a source of great distress for both her surrogate and the medical team. The surrogate's decision to wait 10 minutes after Ms. R stopped breathing to call EMS may represent an attempt to fulfill her incompatible wishes. Fear of legal repercussions may prevent physicians from overruling a desire for CPR even when CPR is not indicated. Historically, CPR was designed to be used in sudden, unexpected death. The 1986 CPR guidelines state that it was never meant to be utilized for the "terminally ill patient for whom no further therapy for the underlying disease process remains available and for whom death appears imminent."¹⁶

Reviews suggest that approximately 39% of patients initially survive after CPR, but only 15% survive to be discharged. The prognosis appears to be fairly good for discharged survivors: one study demonstrated that 93% of discharged patients were alert and oriented at discharge,¹⁷ and another showed that 75% of them were still alive a year later.¹⁸ Unfortunately, although patients with metastatic malignancies, neurologic diseases, renal failure, respiratory diseases, and sepsis have a similar chance of initially surviving after CPR, studies have shown they have virtually no chance of survival to discharge.^{19–21}

Although CPR was clearly not indicated for our terminally ill patient, Ms. R's medical team felt compelled to discuss it as an option because it is the default code status. Consequently, her surrogate found himself deliberating painfully between two mutually exclusive choices. During the hours that he spent agonizing over how best to avoid breaking any of his promises to Ms. R, there was significant inefficiency in the use of health care resources: time physicians spent counseling him on medical options and prognosis, time multiple nurses spent away from their own patients to assist with her care as her condition deteriorated, and time spent by case managers and social workers to arrange for her transition home or to the hospital. In addition, EMS was activated twice, possibly diverting EMS workers from other patients in need—once for a call that was ultimately canceled, and once to perform CPR, which was futile from the outset.

Much of the distress and inefficiency associated with Ms. R's end-of-life care could have been avoided by a detailed discussion of her goals of care earlier in her disease trajectory. An early referral to palliative care for psychosocial support and symptom management when Ms. R's functional status was still good could have helped to build a relationship that may have proved invaluable later in the trajectory, when she was forced to face difficult end-of-life decisions.²² Furthermore, Ms. R's initial transfer to hospice care could have been delayed until the palliative care consultants were able to fully discuss the hospice philosophy with her and her family and reconcile her goals of care. In both the acute care and hospice settings, organizing a family conference—including the medical team, Ms. R, her daughter, and her boyfriend—early in the course of care would have facilitated communication, helped clarify her goals of care for both the medical team and her surrogates, and dispelled any misconceptions regarding her prognosis or CPR.²³ Additionally, establishing the legal surrogate early in the course of care—especially in patients at high risk of losing capacity—is

imperative, and the designation of a different surrogate should be documented promptly.

One must also consider whether a physician's duty is to facilitate autonomy even if the gains are minimal or nonexistent—as the current cultural atmosphere in the United States often demands—or to provide care that is appropriate, effective, and equitable. For now, it seems patient autonomy is still the victor^{2,14,15}—but it has not remained unchallenged.^{10,13,24} We hope that, in time, it will become culturally acceptable to refrain from offering medically inappropriate—and potentially harmful—treatments without fear of social or legal repercussions.

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