



Burdens Versus Benefits

When Family Has to Decide How Much Is Too Much

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Advanced directives allow patients to designate an agent to make decisions for them if they become incapacitated and unable to make their own decisions. Unfortunately, designating an agent does not ensure that that person understands the patient's preferences for treatment or has the ability to carry out the patient's wishes. This can leave end-of-life decision making up to individuals who may not be able to understand medically what is happening and may be too emotionally invested to make difficult decisions. Families may request nonbeneficial treatments in these situations that can raise ethical issues such as autonomy and nonmaleficence. Conflict within the family and between the family and health care team regarding the burdens and benefits of further treatment can lead to moral distress. The many dimensions that can influence health care decisions including communication about goals and values, the risks and benefits of proposed treatments, prognostication, and the family's and clinicians' response to the situation will be discussed. The palliative care advanced practice registered nurse can play a key role in providing information and supporting family during this difficult time. However, even with this support, family members may continue to have difficulty making end-of-life decisions for their loved ones.

the patient's preferences for care up for interpretation, which can, in turn, cause ethical and moral issues to arise similar to when patients have not discussed their health care wishes in advance. This has led to many families struggling over the benefits and burdens of treatment and choosing to continue aggressive care despite a very poor prognosis. This article presents one such case and discusses the ethical issues that arose. A recommendation for a new approach to clarifying patient's wishes and completing advanced directives will be provided.

CASE STUDY

C.J. was an 88-year-old man with a history of dementia, congestive heart failure, pulmonary hypertension, end-stage renal disease on hemodialysis, and stage 2 sacral decubitus ulcer. He was admitted for altered mental status from a long-term-care facility where he had lived for 5 years. This was his third hospital admission in the last 3 months. Imaging was consistent with large left middle cerebral artery stroke. C.J. had expressive aphasia, right-sided paresis, and dysphagia, which continued after 1 week of hospitalization. He failed a bedside swallowing examination, and nothing by mouth was recommended by the speech language pathologist. Long-term alternative means of nutrition was suggested if this was in line with the patient's goals of care. Palliative care was consulted to assist with a family meeting to address options for care.

C.J.'s daughter, Mary, and son, Ben, participated in a care conference with the neurologist and palliative care advanced practice registered nurse (APRN). They presented a copy of the patient's Power of Attorney for Health Care listing Mary as the health care agent. Within the document, the patient indicated, "I do not want my life to be prolonged, nor do I want life-sustaining treatment to be provided or continued *if my agent believes* [emphasis added] the burdens of the treatment outweigh the expected benefits. I want my agent to consider the relief of suffering, the expense involved, and the quality, as well as the possible extension of my life, in making decisions concerning life-sustaining treatments." Ben requested discontinuation of life-sustaining treatments including hemodialysis as he believed it was consistent with his father's stated wishes. Mary believed their father was showing some improvement as he would appear to smile intermittently

KEY WORDS

advanced directives, decision making, ethics, palliative care

All 50 states allow individuals to designate an agent to make health care decisions on their behalf should they become incapable of making decisions for themselves because of illness or injury. The names and content of these documents vary from state to state but are commonly referred to as Power of Attorney for Health Care. Some forms offer specific scenarios and allow individuals to choose which treatments they would or would not be willing to undergo. Others are vague and leave

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when his eyes were open. She requested continued aggressive care.

The neurologist discussed that because of the size and location of the stroke, the patient's multiple comorbidities, and poor functional status, the patient had "little chance" of recovery. Despite the grim prognosis, Mary wanted to give the patient every chance to improve and asked for a feeding tube to be placed. She did not think the feeding tube was an unbearable burden and believed it would give her father the benefit of time to "help him recover." Ben was visibly upset by his sister's decision and tried to convince her to let their dad die peacefully. After a heated exchange, Ben said goodbye to his father and returned to his home on the east coast.

Gastroenterology was consulted and presented the risks and benefits of a gastrostomy tube (G-tube) and asked Mary how she wanted to proceed. She chose to pursue the G-tube because she did not want her father to "starve to death." The palliative care APRN discussed the underlying medical problems that could not be resolved and explained artificial nutrition would not help these issues. She also reiterated the associated risks including bleeding, infection, and potential for aspiration pneumonia. Mary remained convinced the patient would improve if just given more time. She insisted on having the G-tube placed, and it was scheduled for the following day. Privately, the gastroenterologist disclosed to other staff he felt his "hands were tied," and he had to perform the procedure because the daughter was insistent. He did not believe he had grounds to refuse to do the procedure and feared legal action. The procedure was completed, and the patient was discharged back to long-term care.

Two days later, C.J. was readmitted with a suspected upper gastrointestinal tract bleed. The admitting nurse contacted the palliative care APRN and commented the patient was "back for more torture." The RN confided to the APRN that she could not bear to watch the patient suffer and would request not to be assigned to him during her upcoming shifts. She was visibly distressed and had a difficult time communicating with C.J.'s daughter without showing her emotions.

Mary met with the palliative care APRN who discussed the options for care including continued aggressive care, no further escalation in care, or comfort-focused care with hospice. She recommended hospice care based on the patient's written directives. Mary continued to request aggressive care. She stated the patient had not had enough time to show improvement after the G-tube was placed and remained hopeful the patient would recover. She consented to endoscopy, and blood transfusions were ordered for anemia. The procedure did not find any source for the bleeding, and the patient was subsequently discharged back to long-term care.

Two days after discharge, the patient was readmitted to the hospital with vomiting and labored breathing. He received a diagnosis of aspiration pneumonia and was administered antibiotics and noninvasive ventilation with bilevel positive airway pressure. The following day, palliative care was reconsulted. After lengthy conversations with Mary, she agreed to comfort-focused care and inpatient hospice. Dialysis was discontinued along with the bilevel positive airway pressure. Morphine and Ativan (lorazepam) were administered as needed for dyspnea, pain, and agitation.

The next day, the patient appeared comfortable with no dyspnea, moaning, or distress. He was becoming hypotensive with cyanotic extremities, and it appeared his death was imminent. Mary stated he appeared "better" and requested a chest radiograph to evaluate the status of the pneumonia. She was hopeful if chest radiograph showed improvement she could revoke hospice and the patient could return to long-term care. The palliative care APRN explained the patient was actively dying and provided emotional support to the daughter. She recommended other family be called in, and Mary tersely replied that her brother had already said goodbye. C.J. died the next day.

ETHICAL AND MORAL DILEMMAS

Many ethical issues arose from this case. There was conflict within the family and between the family and health care team regarding the expected benefits of further treatment. The bedside nurse and specialists were distressed about providing nonbeneficial care. Comments such as "I would never do that to my loved one" and "what is she thinking?" were expressed by members of the health care team.

Autonomy

The cornerstone of medical ethics is autonomy. Patients have the right to accept or reject treatments offered by clinicians. It is important that patients have an understanding of the risks and benefits of proposed treatments so they are able to make informed decisions. Patients may choose aggressive care that appears to offer little benefit to the health care team members. These decisions are highly personal and are often enveloped in a patient's life experiences, culture, and religion.

When a patient lacks decisional capacity, a surrogate decision maker or designated health care agent can make decisions on behalf of the patient. Individuals usually choose an agent with the goals of ensuring that treatment decisions are in line with their preferences and reducing the burden on the family regarding these decisions.¹ However, in practice, some patients will complete advanced care planning documents and fail to take the next step in discussing their wishes with the individual responsible for



decision making. This leaves the person in a position to utilize substituted judgment regarding how to proceed. The family member or agent will also likely bring their own beliefs, values, and emotions into their decision making. Often the decisions made by family members do not correlate with what the patient would decide.² Ensuring patient autonomy when they lack decisional capacity is fraught with difficulties. Despite the problems associated with health care agents utilizing substituted judgment for end-of-life decisions, it is a necessary process in order to protect autonomy.³

Even when preferences for treatment are discussed, the designated agent may not be able to carry out the patient's wishes because of the emotional burden of feeling responsible for the patient's death. These decisions are, at times, inherently more difficult as they frequently involve the past relationship between the patient and decision maker. Emotions including feelings of guilt and grief can play a role in the choices made. The stress of making these decisions takes a toll on family members.^{4,5}

As the designated health care agent, C.J.'s daughter, Mary, was legally able to make decisions for him that she considered were in his best interest and in line with his wishes. However, data show that many caregivers are unable to differentiate patient preferences from their own.⁶ The vague language in the patient's advanced directives did little to assist her and made her feel the decision was hers alone to make because her father had designated her as his agent. The patient's son, Ben, disagreed with her decision to proceed with a G-tube, but deferred to her as the chosen decision maker. He then removed himself from the situation when the stress of seeing his father incapacitated was too much to bear.

When the proposed procedure or treatment is not medically contraindicated, clinicians often have to reconcile their personal feelings regarding the decisions made for their patients. The palliative care APRN struggled with the decisions Mary was making for her father as she believed she was not respecting her father's wishes based on his documented choices. Despite the APRN's distress, she continued to support the daughter as she attempted to come to terms with her father's imminent demise. The APRN reminded herself "it is not my journey" and attempted to meet Mary where she was in order to continue to advocate for the patient while supporting the daughter. Her role was to ensure the daughter had the information needed to make an informed decision, but she could not make the decision for her.

Nonmaleficence and Nonbeneficial Treatments

"First, do no harm" is the guiding principle of non-maleficence. Clinicians may struggle over this principle when procedures such as dialysis, feeding tubes, or mechanical ventilation are requested in patients near the

end of life. Placing a central line, surgically inserting a G-tube, or intubating a patient may cause harm or undue suffering and offer little benefit. Patients and families, though, may see a benefit in delaying death and accept the potential pain and suffering in return for more time.

Families rarely understand the risks associated with insertion of a feeding tube. There is a lack of good quality evidence for the use of artificial nutrition in the palliative care patient.⁷ Enteral nutrition at the end of life has not been shown to prolong life.⁸ The palliative care APRN had a lengthy discussion with C.J.'s daughter and explained the risks and benefits of the procedure including aspiration. She also explained how the treatment would not improve the patient's quality of life. Mary remained insistent on proceeding with G-tube placement.

Requests for nonbeneficial treatment can create conflicts between the family and the treating providers.⁹ Advances in medical technology include procedures and interventions that can prolong the dying process days to weeks and, in some instances, months to years. Medical futility is not easily defined, and laws concerning medical futility differ from state to state. For instance, Texas has a stringent medical futility law, and New York no longer has one. Life-sustaining treatments for a patient in the terminal stage of illness may seem futile to clinicians; however, when patients or families request such care, the benefit of a prolonged life can cloud the discussion about quality of life.

Quality of life is highly subjective. When individuals are healthy, it may be very clear what burdens they are willing or unwilling to bear. However, as death nears, patients sometimes request life-sustaining treatments they previously documented they would not want. Death anxiety, a type of existential distress, can fuel denial of the dying process.¹⁰ Patients may be able to endure suffering they previously thought would be unbearable because of the fear of dying.

When surrogate decision makers have to make decisions whether to allow a natural death or prolong the dying process, they often view the situation through the lens of their experiences and feelings. Clinicians have the advantage of professional distance that allows them more objectivity in these decisions. Sometimes, however, strong personal beliefs or their experiences with a family member may influence their recommendations and how they present information.

The gastroenterologist consulted in C.J.'s case did not think the G-tube would provide any benefit to the patient and discussed with other clinicians that he really did not want to perform the procedure. However, he left the decision to the daughter and then felt obligated to proceed because the daughter had strong feelings about providing nutrition. When clinicians fail to make a recommendation, medical decision making is left in the hands of laypersons



who may not have all the information necessary to make an informed decision or be too emotionally invested to look at the situation objectively.

Physicians sometimes feel compelled to offer interventions because of concerns of litigation by family.¹¹ While clinicians are not ethically obligated to provide care that will not benefit the patient, many do not understand the avenues that exist to support them if they decline to offer such interventions. The hospital ethics committee, futility policy, and/or legal counsel and risk management departments can help support clinicians with conflicts that arise in medical decision making.

Moral Distress and Compassion Fatigue

Nurses and physicians have increased feelings of moral distress when they believe they are incapable of effecting change, sense tension in family dynamics, or witness unrelieved distress.¹² Nurses derive a sense of satisfaction when providing routine bedside care when they know their actions are helping a patient heal. When patients are in the terminal phase of their life, simple actions such as turning the patient can cause pain or distress. Job satisfaction is decreased when nurses believe their care is no longer helpful.

The primary RN experienced significant emotional distress when caring for C.J. She believed she was torturing the patient with every dressing change and thought there was little she could do to influence the patient's care. Her interactions with the daughter became terse. She had difficulty finding compassion for her and was not able to attend to her grief. She believed she could not continue to care for C.J. because of the emotional burden it placed on her and distanced herself by asking for a different assignment. The APRN listened to the RN's concerns and validated her feelings, as well as offered suggestions for self-care.

Caring for patients with advanced illness and multiple comorbidities can take a toll on nurses and other caregivers. Witnessing unrelieved suffering on a daily basis places nurses at risk of moral distress and compassion fatigue.¹³ Nurses and employers need to be aware of the warning signs and take action or offer intervention when needed. Resources are available to assist clinicians in dealing with difficult and distressing patient encounters. An employee assistance program can offer counseling and referrals to support caregivers during times of conflict. The institution's spiritual care department is often available to provide a caring presence and prayers to employees if they find comfort in those practices.

Prognostication

Discussions about prognosis can further complicate decision making. Vague predictions or euphemisms such as "no one has a crystal ball" or "only God knows" do not

help family members when life and death decisions need to be made. Although it may be difficult to speak in absolutes and say the patient has no chance of meaningful recovery, clinicians can use patients' comorbidities and previous functional status to guide their predictions about the future. Even when complete explanations of the patient's condition are given and recommendations are made, decision makers sometimes continue to have poor insight into the patient's prognosis.¹⁴

In further discussions with C.J.'s daughter, she disclosed that although she was made the health care agent, she and her father never talked about his end-of-life wishes. Mary discussed how her father was a decorated war hero and a fighter. He had chosen to start dialysis when his kidneys failed, even though his overall health was not good at the time. She felt he would want to do everything possible to live if there was a chance of recovery. She stated the neurologist had offered a glimmer of hope, and she wanted to make sure her father had every opportunity to improve.

In instances such as this, it can be helpful to discuss chances of meaningful recovery. Eliciting from family activities the patient used to find enjoyable and then discussing their ability or inability to participate in those activities in the future may assist families in understanding how the illness will affect quality of life. It is also important to discuss overall goals. If a family members state their overall goal is for the patient to get stronger and walk again, the clinician can discuss how the patient's prior debility and a new devastating neurological injury will prevent that goal from being attained.

ADVANCED DIRECTIVES

Physician decision making used to be the norm, then patient autonomy developed as a concept; now the pendulum has swung to the extreme, and patients/families are essentially dictating medical decisions. The Patient Self-determination Act of 1991 requires all hospitals to ask patients if they have an advanced directive. The spirit of the act was to promote conversations about end-of-life care and increase completion rates of advanced directions. In reality, though, this is how the conversation often goes:

Nurse: "Do you have an advanced directive?"

Patient (who does not know what that means): "No."

Nurse: "Would you like information about an advanced directive?"

Patient (who still does not know what that means): "No."
End of conversation.

The nurse has satisfied her legal obligation to ask. However, the patient still remains uninformed about the importance of completing an advanced directive, and the health care system still remains unaware of the patient's preferences for care.



Studies support that completion rates of advanced directives remain low and even when completed are not always available to health care providers.^{15,16} Another study showed a marked increase of advanced directive completion of the last decade, from 47% to 72%; however, these efforts did little to change the number of hospitalizations in the last 2 years of life or the number of hospital deaths.¹⁷ Completing an advanced directive increases the chances your preferences for treatment will be respected but does not guarantee it.¹⁸

Fortunately, in Illinois, the Power of Attorney for Health Care was recently modified, and the statement “I do not want my life to be prolonged, nor do I want life-sustaining treatment to be provided or continued if my agent believes the burdens of the treatment outweigh the expected benefits” has been eliminated. This language placed the burden on the health care agent to decide how much is too much instead of having the patient indicate what he/she willing or unwilling to bear. Unfortunately, many of the old forms remain in circulation, so similar issues can continue to arise in the future. The new form offers individuals 2 choices (Table) that can assist decision makers and health care providers clarify preferences for treatment, but checking one of the choices is labeled optional.¹⁹ In C.J.’s case, this new language may not have helped as he was awake and appeared to be intermittently smiling, which his daughter viewed as a positive sign.

A New Approach

Most palliative care clinicians agree that advanced care planning should be moved upstream to the primary care clinician’s or specialist’s office when patients receive a diagnosis of a life-limiting or life-threatening illness. Newly enacted coverage by Medicare will reimburse clinicians for their time when having these discussions. However, many clinicians lack the expertise, communication skills, and time to navigate the complexities of these difficult conversations. Health care systems would need to invest in the training of personnel and modify expectations of productivity in order for this model to be effective.

Another approach is to take these conversations out of the clinic or hospital and bring them directly to the

community through church groups, community organizations such as women’s clubs or Rotary, or sponsored community education events. Advanced care planning does not have to be provided by a physician or advanced practice provider. Social workers, chaplains, or trained laypersons can also assist patients and families with completing advanced directives. It is important to not only present the information needed to understand advanced directives, but also offer an opportunity to complete the documents either at that time or through a follow-up appointment with a qualified individual.

The first step can include completing a Power of Attorney for Health Care to designate an agent to make health care decisions if the patient loses decisional capacity. However, as the case illustrated, having this document in place does not ensure your wishes are known or followed. Patients must first understand the importance of choosing a health care agent who not only knows their wishes, but also is able to follow through in difficult and often emotionally charged situations. Ongoing discussions with patients and families are necessary in order for patient preferences to be understood and respected.

SUMMARY

Advanced care planning is necessary in order for preferences for treatment to be known and followed. Unfortunately, some documents have vague language that leaves the decisions in the hands of the designated agent who may or may not know the patient’s wishes. In these situations, there are many dimensions that can influence health care decisions including communication about goals and values, the burdens and benefits of proposed treatments, prognostication, and the family’s and clinicians’ response to the situation. Giving the most complete information and making recommendations on how to proceed can assist families in coming to a rational and sound decision based on the patient’s goals and values. However, clinicians need to remember that it can be difficult for families to be rational and sound when someone they love is dying.

Even if clinicians believe they are doing their best work, decisions will be made that they have no control over.

TABLE Illinois Power of Attorney for Health Care: Choices for Life-Sustaining Treatments

Select only one statement below that best expresses your wishes (optional):

The quality of my life is more important than the length of my life. If I am unconscious and my attending physician believes, in accordance with reasonable medical standards, that I will not wake up or recover my ability to think, communicate with my family and friends, and experience my surroundings, I do not want treatments to prolong my life or delay my death, but I do want treatment or care to make me comfortable and to relieve me of pain.

Staying alive is more important to me, no matter how sick I am, how much I am suffering, the cost of the procedures, or how unlikely my chances for recovery are. I want my life to be prolonged to the greatest extent possible in accordance with reasonable medical standards.



When all is said and done, family members will have to go on being family members and be able to live with the decisions they have made. It is important for clinicians to understand it is the patient's and family's journey, not their own. Navigation can be offered, but the specific route is theirs to choose.

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