

Medical Ethics



By Jonathan Evans, MD, MPH,
CMD

Advance Directives vs. Family Decisions

The Case

An 88-year-old woman with dementia and a history of multiple strokes lived in a nursing facility for 6 years. Impaired in cognition and function, she was deemed mentally incapacitated.

She was a Jehovah's Witness, and prior to her incapacity had exercised an explicit advance directive that she was not to have a feeding tube under any circumstances nor receive intravenous hydration to prolong her life. She named one of her daughters as her durable power of attorney (POA) to make additional decisions on her behalf.

She required assistance with all basic activities of daily living and was fed by facility staff. Over the past 2 years, she lost the ability to communicate with words. She became gradually less alert, and spent more and more time asleep. She became bedbound. Her weight remained stable.

Throughout her nursing facility residence, her family was attentive to her needs and mindful of her advance directive. They attended care conferences and communicated regularly with her attending physician. As her condition declined, her family decided to focus on comfort care and to avoid hospitalization.

On three occasions, she had experienced what appeared to be acute strokes with loss of neurological function, decreased alertness, and reduced oral intake. In each instance, the facility's speech therapist contacted the POA directly and recommended intravenous hydration and possibly a feeding tube. In each instance, however, the patient's condition returned to baseline within a day, without initiation of intravenous fluid.

She subsequently had another neurological event, and on the basis of the speech therapist's recommendation, the family asked that intravenous fluids be started. There were several family birthdays in the coming weeks and family members wanted to avoid having her die on one of those dates.

After more than 2 weeks there was no improvement in her condition. She was unresponsive and profoundly impaired neurologically. A family meeting was held, led by the attending physician. The family decided to forgo feeding tube placement, to consult hospice, and to discontinue the intravenous fluid. The POA indicated that it was "selfish" on their part to keep her alive, acknowledging her advance

directive and adding that "she would never want to live like this."

The patient was enrolled in hospice. The patient's granddaughter (the daughter of the POA and a certified nursing assistant) indicated that she would like to be present at the time of death to provide personal care. For several weeks, the patient continued to decline. Death was considered imminent.

With the POA's permission, the granddaughter arranged for a friend of hers, a reflexologist, to provide treatments for her grandmother at the facility. The practitioner did so without any appreciable improvement in the patient's condition.

The reflexologist indicated to the granddaughter that the treatment could not work as long as the patient was dehydrated, and recommended that intravenous fluid be provided. The POA then contacted the attending physician and asked that intravenous fluids be restarted.

The attending physician and the facility leadership team were uncomfortable restarting intravenous fluid. They felt that doing so would violate the patient's advance directive. They discussed this with the POA, who agreed but felt that it was important to maintain harmony within the family.

Further discussion ensued involving the medical director, the attending physician, the director of nursing, and the hospice's medical director and clinical director. The granddaughter then informed the facility administration that her attorney had reviewed the advance directive (which had been executed in another state) and felt that it was not legally valid. She suggested that legal action might be necessary.

Additional discussion ensued. The facility contacted corporate risk management and considered several options including contacting the long-term care ombudsman, reporting the patient to adult protective services, and sending the patient to the hospital. They wanted to avoid doing anything to inflame the situation, however, and worked with both the attending physician and medical director to try to reach a consensus with the family.

Ultimately, intravenous fluids were restarted and continued for 10 days. Seeing no improvement with reflexology treatments, the POA decided to discontinue the intravenous fluids. The patient died comfortably 7 days later with family in attendance.

Discussion

This case demonstrates, among other things, the challenges and limitations of advance directives and, hence, the limits of autonomy.

The advance directives have long been hailed as a critical tool to promote autonomy for people who can no longer make or communicate choices on their own behalf. This patient made the effort to both implement an explicit instructional directive and name a proxy decision maker, her daughter, who knew her well. There is little more that an individual can do.

In this case however, it appears that on more than one occasion, the patient's wishes were ignored or overruled by her family. In addition, a health care practitioner made explicit recommendations, such as for intravenous hydration, that were contrary to the patient's explicit wishes and plan of care.

► **Autonomy vs. Power:** Autonomy may be a right, but rights require power to be realized. Naming a surrogate decision maker is a way to empower another to act on one's behalf, based on the belief that the surrogate will honor the loved one's beliefs, attitudes, and wishes. The granddaughter's threat to involve her attorney was another way for a family member to exert power.

Surrogate decision making assumes that close family members know what their loved ones would want. Various studies, however, have demonstrated that adult children generally assume that their parents would want more aggressive care than is true.

Another assumption is that surrogates will always put the needs and desires of their loved ones ahead of their own. Trying to keep a mother from dying on family birthdays illustrates a conflict of interest between family members and their mother. It also illustrates ambivalence toward different goals and treatment choices. Patients often change their mind. It is therefore probably not reasonable to expect that family members, including proxies, won't change their minds either.

► **Team, Minus One:** Numerous studies have shown that advance directives are often ignored or overruled by physicians, particularly in hospitals. This case illustrates how other health care professionals may do the same thing, by imposing their own values, beliefs, and fears upon patients and their families.

The right to refuse treatment sometimes comes into conflict with a health care practitioner's own fears of the consequences, which can influence treatment recommendations. This may explain why

someone (the speech therapist in this case) would repeatedly make recommendations contrary to the recommendations of every other member of the interdisciplinary team. Unfortunately, this had a detrimental effect for the rest of the team and contributed to confusion and disagreement within the family.

► **Team, Minus Two:** Neither the facility nor the attending physician had any prior experience with reflexology. All were committed to trying to help the family in any way possible by accommodating their wishes without violating the facility's policies and procedures. However, the reflexologist did not communicate about intravenous fluid therapy with any member of the interdisciplinary team. Many members felt that her recommendation to restart intravenous fluids was detrimental to the team.

► **Desire to Avoid Conflict:** The POA, the attending physician, and the facility administration all wanted to avoid conflict with other stakeholders. For the physician and facility, this was especially acute when the granddaughter threatened legal action. The steps that were necessary to avoid conflict with family members appeared to be in conflict with the wishes of the patient, the person with the least power in this situation.

► **Ethics Committee?** Had the facility had an ethics committee or access to one locally, the interdisciplinary team probably would have consulted it early on to help the family members in their decision regarding intravenous fluid therapy. The facility would probably have appreciated the support that the ethics committee could offer regardless of the ultimate decision that the family made, and the ethics committee might have felt less threatening to family members than, say, adult protective services.

Advance directives, intended to help individuals get their way when they become incapacitated, are not everything their proponents have hoped. The competing interests of others, ambiguity about the meaning of specific instructions, the significance and finality of specific choices, and the intense emotion and family dynamics involved in end-of-life decision making all have the potential to undermine or negate the seemingly dispassionate and logical decisions that individuals make on their own behalf far from the heat of the moment.

DR. EVANS is a full-time long-term care physician in Charlottesville, Va., and medical director of two skilled nursing facilities. He serves on AMDA's board of directors and the CARING FOR THE AGES editorial advisory board.