The case I am presenting is one involving an 83 year old white female with a history of Alzheimer’s disease who presented to the emergency department accompanied by her husband complaining of abdominal pain x 3 days. She had no bowel movement x 3 days and had a decreased appetite over this time period and also some nausea and vomiting. Patient denied fever, body aches, sick contacts, or travel. Vitals signs were stable and the patient was is obvious discomfort. The patient was very agitated and aggressive so she was placed in restraints. MMSE was a 15. Physical exam revealed dry mucous membranes. Abdomen was soft, nondistended with diffuse tenderness to palpation with rebound and guarding. Bowels sounds were faint. Imaging of the abdomen revealed a small bowel obstruction with areas of necrosis.

With this information her condition was explained to the patient’s husband and daughter. The options were to either have surgery to correct the problem with the high possibility that the patient would not survive the surgery due to age and medical history or do not have the surgery and the patient would die from a ruptured bowel. Both options seemed very grim but the husband made the decision to proceed with surgery. The patient survived the surgery but remained on the ventilator afterwards for 6 days. Finally she was weaned off the ventilator on post-operative day 7 and began to come around. Her mental status was the same as before surgery and the wound was healing well. There were problems keeping her blood pressure and heart rate regulated which kept her in ICU but soon they were corrected and the patient was moved to the floor on post-operative day 16. She still progressed for a couple of days but then there was a change in her mental status. She stopped talking and could not focus her eyes. She would lie in bed either sleeping or repeating the same phrase over and over when awake. This would wax and wane over the days. She had been on TPN since the surgery and when introduced to oral feedings again it was discovered that she had forgotten how to swallow. It was clear that the patient was slowly deteriorating. We discussed resuscitation issues with the family and they decided to withdraw all care and not to resuscitate. All they wanted was for the patient to be given pain medication so that she would remain comfortable. All feeding tubes and IV lines were removed. The decision was made by the family to transfer the patient to hospice. After a couple of days the patient began to come around again and wake up. The family began feeding her Ensure and anything else she would take. We discouraged this due to the risk of aspiration but they continued. Eventually she refused any food or drink. She held on for another 8 days until finally after 45 days the patient passed away.

There are many ethical issues I would like to discuss. Did the patient have the right from the beginning to refuse the surgery? With a long history of Alzheimer’s disease, was the patient competent to refuse the surgery? Was the patient competent at all to make any medical decision throughout the entire course? Are restraints considered humane? Was artificial hydration and nutrition the right thing to do in this case? Should the family have been allowed to feed the patient given the patient’s condition and risks associated?
I believe all of these issues lie on ethical principles. Given the patient’s 7 year history of worsening dementia and the evaluation from the physician that the patient lacked decision-making capability, it is clear that the patient’s husband had the legal right to make all medical decisions. Also supporting this was the fact that the couple had been married for 65 years and the husband knew exactly what his wife would want. He was the one to look out for her best interests. “The process of informed consent makes sense only for people who have the ability to make informed decisions. Adults are presumed to have this capacity when they reach the "age of majority" (usually 18 years of age). This does not change unless the individual is determined to be "incompetent or incapacitated" by a court of law. In practical terms, physicians are sometimes asked to evaluate a person’s capacity to make decisions. If a physician believes that a person lacks the ability to make informed decisions about medical care, that person is deemed "incapable." This is significant because it means that decisions will then be made by someone other than the patient.”

“Physicians have the capacity to legally judge the capacity to make decisions. They base their decisions on many issues including the patient’s ability to understand relevant information, understand the consequences of the decision, communicate a decision, care for oneself, accept needed help to keep oneself safe, manage bill payment, appropriately calculate and monitor funds, remember estate plans, and express logic behind choices.”

“The most difficult legal and ethical issues raised by Alzheimer's Disease concern who ought to be making medical and other kinds of decisions for severely demented people. According to Kapp, there are three basic models of surrogate decision-making. In the most traditional model, the decision-maker acts according to her own values in what she believes to be the patient's best interest. The second approach encourages the decision-maker to imagine what the patient's own preferences would be. The third model, known as Advance Planning, goes one important step further, by referring to written preferences articulated by the patient before severe dementia set in. These stated wishes usually take the form of trusts, durable powers of attorney, living wills, etc. They may not completely eliminate the need for the other surrogate decision-making techniques, but they help steer the decision-making process according to the patient's own agenda.”

In this case, I feel like the patient’s husband used a combination of all three of these models. It was obvious he loved her and wanted the best for her. I completely agree with the physician’s assessment of the patient’s inability to make medical decisions and the reliance on the husband for decision-making. I would have done the same thing.

Regarding restraints, it is clear that they had to be used in order to ensure the patient’s and others’ safety. Although they are often considered inhumane, removing what little dignity and independence these people have left, in some situations they allow the patient to get the medical care they need. In this case, the restraints allowed the patient to get the fluid, nutrition, and medication she needed for that period of time.
When physicians are considering artificial hydration and nutrition, there are many guidelines they go by that assist in decision making.

“Indications to consider starting artificial hydration or nutrition:

The patient or decision maker, after being provided appropriate counseling and options, chooses this intervention to reflect personal values.

When the primary goal of the patient is to maximize the quantity of life.

When the patient is stable or improving, and the intervention has a reasonable chance of reaching the patient's goals.

When the risk/benefit ratio is unclear, or the evolution of the disease is uncertain. In this case, consider a trial of the intervention with withdrawal if little or no benefit accrues.

As short-term interventions in healthy patients or those with mild or moderately severe illness (e.g., acute infections, perioperative use, acute stroke).

In selected chronic conditions (e.g., patients with esophageal obstruction or massive bowel resection, where oral intake is not possible or inadequate).

When a patient is unable to swallow and remains hungry or thirsty.

When delirium may be due to dehydration.

To maintain life for a period, while the decision maker/family struggles with end-of-life decisions.

When there is no clear decision maker, and the family cannot reach a consensus.

When the quality of life is good, as defined by the patient.

Potential reasons to withhold or withdraw artificial hydration or nutrition:

The patient or decision maker, after being provided appropriate counseling and options, decides against this intervention to reflect personal values.

When the primary goal of the patient is palliation of symptoms.

When the intervention is bound to fail (e.g., in patients with a disease that is uniformly fatal).

When the patient is dying, and the intervention is merely prolonging the dying process or causing suffering.

When a patient has moderate or severe, irreversible cognitive impairment (e.g., Alzheimer's dementia or vascular dementia).

When the intervention causes complications (e.g., agitation requiring sedation or physical restraints, infection, multiple tube obstructions or withdrawal, aspiration pneumonia).
To help relieve symptoms of fluid overload (e.g., dyspnea, diarrhea, urinary frequency or bowel obstruction) in terminally ill patients.

When the patient has end-stage organ failure (e.g., respiratory, cardiac, renal).

When other end-stage diseases, such as metastatic cancer or advanced acquired immunodeficiency syndrome, are present.¹

In this case, artificial hydration and nutrition were completely legitimate in the beginning when the patient first came out of surgery and was doing well. However, the point of concern is whether it should have been removed earlier in the course when the patient began to decline. Ultimately it was removed when the family decided to transfer the patient to hospice. I think the physician did a good job explaining the options to the family and therefore the decision was in the husband’s hands. I believe the time course of artificial hydration and nutrition was adequate; it did not seem to harm the patient and it gave the family time to make their decision. The real issue was whether or not the family should have been feeding the patient in her final days.

“Near the end of life, patients and families may naturally be concerned that the lack of fluids and food will cause suffering. We now know that gradual dehydration is not painful; rather, it brings a lessening of awareness about discomfort, so that the person slides naturally toward death. At the end of life, IV hydration can prolong dying rather than prolong living.”³

It seemed as though the food was increasing the patient’s quantity of life but not the quality. At first I did not agree with the family’s attempts at all. It seemed to be prolonging the dying process. In addition, the patient could have easily aspirated which would have complicated everything further. Clearly, the risks seemed to outweigh the benefits. However, I then began to accept that the patient would refuse the food when she was ready to go. And that is exactly what happened. Soon the sweet woman decided it was her time and ultimately made the decision herself.

Throughout my limited medical experience, I have been faced with many ethical dilemmas that have really forced me to think. I have found that ultimately it comes down to doing what it right, always having the patient’s best interest in mind, treating every patient equally, and treating every patient like a member of one’s own family. Any problem that arises after all that is done requires some research I guess.
References:


