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Dementia and the Loss of Descartes's Attributes of the Soul

One of the many disease processes physicians witness is what becomes of the body of someone with advanced dementia. Over time, there is a loss of many of the "attributes of the soul" René Descartes lists in his second meditation on philosophy: nutrition, walking, and eventually, thought. In other words, with the natural progression of dementia, in addition to becoming "non-verbal and bedbound" (in medical terms), the individual also stops eating.

Descartes ponders the question of: "But what am I? A thing which thinks" (Descartes 1641, pp 13-23). If the converse were true – that an individual with advanced dementia stops thinking, or is sufficiently impaired that the electrical impulses between the neurons are stymied from producing a coherent message – does the individual cease to exist? Descartes states that "the human body may indeed easily enough perish, but the mind or soul of man…is owing to its nature immortal" (Descartes 1641, pp 13-23). At what point does the soul of a patient with progressive dementia abandon its body? Is it before or after the body betrays itself by refusing to take in nutrition and hydration to sustain itself?

Feeding Tubes in Patients with Advanced Dementia

One of the big dilemmas in the care of a patient with dementia at the point of refusal of food and/or drink by mouth is what to do about the lack of nutrition and hydration. The decreased appetite doesn't bother the patient as much as it bothers their loved ones, many of whom will request placement of a feeding tube, known clinically as a percutaneous endoscopic gastrostomy (PEG) tube. As internists, starting early in our medical education and career, looking to society guidelines from the American Board of Internal Medicine for counsel on what to advise our patients and their families, we are taught that "slow hand feeding" of the patient by the familiar faces of loved ones is superior to placing a feeding tube.

Beginning in 2012, the boards of national medical subspecialty organizations asked their members to identify tests and procedures that should be questioned or discussed. This led to specialty-specific lists of "Things Providers and Patients Should Question." The Choosing Wisely campaign was the American Board of Internal Medicine's initiative aimed at helping patients choose care that is evidence-based, not duplicative, free from harm, and truly necessary (ABIM Foundation). Feeding tubes in Alzheimer's dementia were identified as one such procedure to question or

discuss. The Choosing Wisely Campaign noted that there is “no good evidence that tube feeding helps [Alzheimer’s dementia] patients live longer” (ABIM Foundation, American Geriatrics Society, and the American Academy of Hospice and Palliative Care Medicine).

When a family member asks us about a feeding tube, clinicians present the lack of evidence in favor of feeding tubes – specifically preventing aspiration pneumonias or improving nutrition to help decubitus ulcers heal – as some of the major arguments against feeding tube placement. The Choosing Wisely Campaign finds there are many other reasons not to place a feeding tube, the most valid of which include the risks of infection and irritation around the site, and that the patient may find the tube bothersome, leading them to attempt to pull it out. In turn, the patient may then require chemical sedation or mechanical restraints for the sole purpose of preventing them from pulling out the feeding tube. In a consensus among three key subspecialty organizations expert in the matter, the campaign does not list any benefits to feeding tube placement in Alzheimer’s dementia (ABIM Foundation, American Geriatrics Society, and the American Academy of Hospice and Palliative Care Medicine).

Quality vs Quantity of Life

As an experienced clinical ethicist may opine, while there is no good evidence that feeding tubes help in these cases, there is also no good evidence that feeding tubes don’t help in these patients, especially in cases where the patient has stopped taking any food or hydration by mouth. In those cases, death becomes imminent absent a means to provide artificial nutrition and hydration, most often through a feeding tube. We are unlikely to have good evidence either way because patients and their families often have strong feelings regarding feeding tube placement and they are unlikely to relinquish control in that decision by participating in a randomized controlled trial to assess clinical outcomes with and without feeding tube placement. While physicians may see the placement of feeding tubes as being futile, an acceptable quality of life is determined not by the healthcare team, but rather, by the patient, or by the family if the patient is unable to make the decision.

Physicians are often focused on quality of life, and rightly so, but the goal of the family is often simply more days of life, regardless of quality. With the absence of evidence that feeding tubes don’t work, and the differing goals of the family vs the physician of a patient (quantity vs quality, respectively), physicians’ weighing of the pros and cons of feeding tubes may be colored by their own values prioritizing quality over quantity of life. As Descartes wrote, doubt “delivers us from every kind of prejudice” (Descartes 1641, pp 13-16). This is the primary power of doubt, to make us question what we thought we knew, and to think about alternate perspectives. Going forward, while feeding tubes would not be beneficial in all patients with advanced dementia, physicians might at least be more open to discussing such requests, to help determine the care plan that best aligns with the patient or family’s wishes rather than their own.

Heidegger on Technology

In *The Question Concerning Technology*, Martin Heidegger wrote of the danger of the "stultified compulsion to push on blindly with technology" versus the similar risk at the opposite end of the spectrum, "to rebel helplessly against it and curse it as the work of the devil." Instead of taking either extreme, he encourages us to free ourselves by opening our minds "expressly to the essence of technology" (Heidegger 1977, pp 3-35). In the case of feeding tubes, there is an impulse to condemn them by applying them to a scenario that many physicians would not choose of their own accord, namely to prolong a life that we perceive as being of poor quality. However, when we embrace their essence – that of providing nutrition and hydration to a person incapable of oral intake at a sufficient level to maintain themselves – we might see that cases where prolonging life could be worth the risk of the procedure for a given patient and family. Specifically, a feeding tube could be beneficial for a patient who has significantly decreased what they're taking by mouth, but still expresses enjoyment for living, has a life event they're looking forward to attending, or has family who meaningfully interacts with them.

Speaking more generally, in situations where there is no obvious right answer, and there is time to weigh the next best step, a healthcare professional may find it helpful to envision themselves as a well-informed life guide, presenting the pros and cons of a particular test, procedure, surgery, or treatment. They can answer any related questions in order to assist the patient and/or family member in making the best medical decision they can for themselves. This participatory form of medicine is one of the less touted advancements of modern medicine, and it represents progress from its original paternalistic form.

A Word of Warning Against Casuistry

In clinical ethics and the practice of medicine, there often is not only one right answer. Applying theoretical rules to specific scenarios, or casuistry, may not give a clinician the perfect one-size-fits-all answer to apply to a group of similar scenarios across the board. Albert Jonsen and Stephen Toulmin wrote the following in the chapter "The Revival of Casuistry" in their larger book *The Abuse of Casuistry*:

> *The heart of moral experience does not lie in a mastery of general rules and theoretical principles, however sound and well-reasoned those principles may appear. It is located, rather, in the wisdom that comes from seeing how the ideas behind those rules work out in the course of people's lives: in particular, seeing more exactly what is involved in insisting on (or waiving) this or that rule in one or another set of circumstances. Only experience of this kind will give agents the practical priorities that they need in weighing moral considerations of different kinds and resolving conflicts between those different considerations (Jonsen and Toulmin 1988, p 314).*

There are many good reasons to not place feeding tubes in all patients with advanced dementia. However, rather than blindly applying the recommendations of the Choosing Wisely campaign to deny all requests for feeding tube placement in patients with dementia, we can apply Jonsen and Toulmin's principles against abusing casuistry: We can acknowledge that there are a few scenarios,

when taken on a case-by-case basis, and following a thorough informed consent process, that proceeding with feeding tube placement in a patient with dementia may be reasonable in accommodating the wishes of the patient and/or family.

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