Refusal of Hydration and Nutrition

Irrelevance of the “Artificial” vs “Natural” Distinction

The recent case of Terri Schiavo has reignited a public dispute about certain aspects of the care of patients who are severely cognitively impaired, including those in a persistent vegetative state. Schiavo’s parents repeatedly pointed out that her ability to swallow was never tested and believed that it was possible for her to be safely hand-fed. They also unsuccessfully petitioned the courts to be permitted to attempt hand-feeding if and when her gastrostomy tube was removed. In the United States there is an ethical and legal consensus that a competent adult or surrogate may refuse any unwanted medical intervention. Since hand-feeding is not a medical intervention, this request by Schiavo’s parents may have appeared legitimate. In this article, we argue that a convincing response to their request cannot be made within the framework of the current consensus. Instead, we propose that under certain circumstances surrogates may choose that feeding is administered artificially or naturally (by hand-feeding). More specifically, we argue that the justification for withdrawal of feedings does not hinge on whether feeding is administered artificially or naturally; rather, it is based on the fundamental rights to self-determination and bodily integrity that permit patients to refuse any unwanted intervention.

The current consensus about refusal of hydration and nutrition has evolved through a series of legal cases, beginning with the landmark case of Karen Quinlan in 1976. That case initiated the development of a set of principles that have come to guide decision making in end-of-life care. Perhaps foremost among these principles is that a competent patient may refuse any medical intervention, even when such treatment may be life-saving. When patients are not competent to make these decisions for themselves, surrogates are legally empowered to make these decisions on the patients’ behalf.

The case of Nancy Cruzan in 1989 tested the limits of these principles, by questioning whether nutrition and hydration administered through a feeding tube should be classified as a “medical intervention” that may be refused by a patient or surrogate. In that case, the US Supreme Court affirmed that tube feedings are medical interventions, just like mechanical ventilation or dialysis. The justices did not, however, inquire whether Nancy Cruzan could safely take oral nourishment and did not address the question of what to do when patients for whom the withdrawal of tube feedings is being considered are capable of being hand-fed and of being sustained by oral hydration and nutrition.

To set the stage for considering this question, a review of some of the arguments on each side of the debate about withdrawal of tube feedings is helpful. Those who oppose the refusal of tube feedings on behalf of patients like Terri Schiavo argue that the kinds of medical interventions that may be refused should be limited to those that typically occur in medical settings and that require special medical expertise, such as mechanical ventilation or dialysis. Once a patient has had a feeding tube surgically placed in the stomach, they claim, then feeding the patient requires no special technology or expertise and therefore should not be seen as a medical intervention. As such, they claim that providing food and water to a patient through a feeding tube is not an act that can be refused by surrogates, but rather is an obligatory part of simple humane care.

On the other hand, those who support the rights of surrogates to withdraw tube feedings from these types of patients insist that tube feedings are indeed a medical intervention. Just as mechanical ventilation artificially supports life by breathing for patients who are unable to breathe on their own, feeding tubes artificially support life by providing nutrition and hydration to patients who are unable to eat and drink on their own. On this view, just as patients and surrogates are empowered to refuse mechanical ventilation when the burdens of this treatment are judged to exceed its benefits, so should they be permitted to refuse tube feeding.
posed to the less rigorous requirement of a preponderance of the evidence.\textsuperscript{3,7} While many of the best known cases have involved patients in a persistent vegetative state, no law limits the refusal of treatment to particular diseases or prognoses,\textsuperscript{3} and the right to refuse unwanted medical interventions, including tube feedings, extends to those with severe cognitive impairments.

Without addressing all of these issues, our comments relate to the observation that many patients with severe neurological injury may retain the capacity to be hand-fed and to adequately sustain their own nutrition and hydration. While there is scant literature regarding whether patients in a persistent vegetative state can ever be successfully hand-fed, it is clear that many cognitively devastated patients with traumatic brain injury and advanced dementia can be sustained this way.\textsuperscript{6,8,12} These patients rarely have normal swallowing function, and some require feeding tubes to minimize problems with recurrent aspiration, yet many of these patients can be kept adequately hydrated and nourished if one is willing to spend the time necessary to hand-feed them at regular intervals. This may require, for example, placing small amounts of food at the back of the tongue to stimulate the reflexes that control mastication and swallowing.\textsuperscript{11,12} Even when possible, this may require the undivided attention of a caregiver for up to several hours a day. For practical reasons, therefore, even patients who retain this capacity, or those who could be trained to acquire it over time, typically have a feeding tube placed to facilitate their care, either at home or in a nursing facility.\textsuperscript{9,10}

This may seem like just a small medical curiosity about the retention of certain brainstem reflexes in patients with profound neurological damage, but in fact this observation may have profound ethical and legal significance. Until now, the debate about withdrawal of tube feedings has focused primarily on whether these feedings should be considered “medical interventions.” To our knowledge, however, no one has ever argued that orally feeding a patient is a medical intervention. In all cultures and in all times, healthy newborns and infants have required the help of others to obtain nourishment, and adults with a variety of illnesses and infirmities have required the assistance of others to eat and drink. The withholding of oral feedings from these individuals would never be considered the withholding of a medical intervention.

Even those who support the right to choose withdrawal of tube feedings from some patients with severe neurological damage must therefore agree that the current consensus cannot justify the withdrawal of oral feedings from a patient on the basis that such feedings are a medical intervention. In other words, if the patient is being fed through a feeding tube as a matter of convenience, rather than because of medical necessity, then the current consensus cannot be used to ethically or legally justify withholding feedings.

These observations are a serious but previously unrecognized challenge to the status quo. If the current ethical and legal consensus permits withdrawal of artificially administered nutrition but prohibits the withdrawal of nutrition provided naturally, then all patients should be required to have an evaluation before the withdrawal of tube feedings, and if they are found to be capable of oral sustenance, then there would be an obligation to provide it. This would certainly represent a radical change in current practice.

As an alternative, we question whether the current consensus really depends on a distinction between “artificial” and “natural.” In other words, is there an ethical and legal foundation for withholding oral nutrition and hydration, even in patients who are capable of swallowing and sustaining themselves? Herein we consider the most important objections to this view and explore considerations that could justify the withholding of oral nourishment from some patients who retain the capacity to swallow.

Some have argued that oral food and fluid should never be withdrawn because this is tantamount to starving the patient to death and starvation is generally seen as cruel and painful. This view is flawed. First, whether tube feedings or oral feedings are withdrawn, death occurs as a result of progressive dehydration, not starvation. Second, observations of patients who have refused nutrition and hydration have consistently shown that they die peacefully and without suffering.\textsuperscript{13-15} Several physiologic mechanisms have been invoked to explain the sedative effects of dehydration, including the accumulation of ketones and a variety of other metabolites known to decrease consciousness.\textsuperscript{15} Far from being a painful way to die, this mode of death appears to be a tolerable and natural form of the dying process.\textsuperscript{16}

Even if these intrinsic physiologic mechanisms are insufficient to guarantee patient comfort, widely accepted ethical and legal standards permit, and even require, that dying patients who show signs of discomfort or suffering be treated with sedatives and analgescs. By analogy, withdrawal of mechanical ventilation may lead to the sudden sensation of severe dyspnea, perhaps one of the most intense forms of suffering. This does not imply that mechanical ventilation must therefore be continued to avoid this suffering, but rather that the onset of dyspnea be anticipated by pre-treating the patient with sedatives and analgescs, with administration of additional medications afterward as required. Similarly, current ethical and legal guidelines support the pharmacologic treatment of pain and suffering in patients who have stopped eating and drinking, if these symptoms should occur.\textsuperscript{17}

Most important, a small but well-established literature documents the course of patients who have voluntarily chosen to stop eating and drinking. A survey\textsuperscript{18} of hospice nurses in Oregon found that 33% of the respondents “had cared for someone who deliberately hastened death by voluntary refusal of food and fluids.” The nurses rated the overall quality of the death with a median score of 8 on a scale from 0 (bad) to 9 (very good).\textsuperscript{18} Eddy\textsuperscript{19} has provided a moving account of the death of his mother, who died following a decision to stop eating and drinking. The great logician Kurt Godel is said to have died this way at Princeton in 1978,\textsuperscript{20} and other anecdotal accounts exist. Some have suggested that the gradual cessation of eating and drinking may be a common mode of death for those who simply die of “old age” without the failure of any particular organ or system.\textsuperscript{16} This literature suggests that, for some patients, voluntary refusal of nourishment represents a rational
choice at the end of life, and some palliative care experts have recommended that physicians explore this option with patients during advance planning for end-of-life care.13,14

There is a big difference, of course, between patients who have voluntarily decided to forgo eating and drinking and those for whom this decision has been made by a surrogate. The former have made this choice for themselves, while the latter have had it made for them. In some cases, it may be possible to discern a patient’s wishes, even when the patient may not be capable of autonomous choice, as when a patient with advanced dementia may turn away from food that is offered orally. Even when it is impossible to know a patient’s wishes, however, there is a well-accepted process for making these decisions. This process is based on ethical and legal standards affirming that incompetent patients cannot be denied rights that belong to those who can choose for themselves.3 In other words, all medical choices that are available to competent patients must also be available to incompetent patients, and the mechanism for exercising these rights is through the authority of surrogate decision makers.7,21,22 In these cases, surrogates are asked to use the ethical principle of proportionality and to make decisions based on how they think the patient would have weighed the burdens of an intervention against its benefits. As noted already, different jurisdictions may apply certain evidentiary thresholds for these decisions, but in principle the withdrawal of oral nutrition and hydration from patients who are capable of eating and drinking has a firm ethical and legal basis. Our analysis, therefore, provides a coherent response to the request from Schiavo’s parents that she receive oral feedings and justifies the decision to withhold them from her. Specifically, the reason patients have a right to refuse nutrition and hydration is not because they are provided medically or artifically. Rather, the right to refuse stems from a right to refuse any unwanted intervention, medical or otherwise, and is grounded in the fundamental rights to self-determination and bodily integrity that are deeply rooted in the American legal tradition, which prohibits any unwanted touching as battery. Aside from the cases of adults with severe cognitive impairment, these insights might also be relevant to the difficult ethical dilemmas that arise in the newborn nursery when infants with global severe neurological damage retain brainstem reflexes that enable them to suck and swallow. Although these reflexes often diminish after the newborn period, many clinicians and ethicists have claimed that these babies must always be offered a bottle as long as they are capable of drinking from it.23 The ethical justification is based on the belief that oral feedings are always obligatory. Our view questions this and could provide a basis for withholding oral feedings from such infants—even while they retain reflexes that enable them to suck and swallow—while treating any perceived suffering or discomfort with standard palliative measures.

In conclusion, we argue that oral feedings are not always ethically obligatory, and that in appropriate circumstances patients and surrogates may authorize the withdrawal of all forms of nutrition and hydration, whether administered orally or by tube. Our view also answers the objections of those who insist that tube feedings are not a medical intervention, because if patients and surrogates may refuse all types of nourishment, the question of whether tube feedings are a medical intervention is moot. In addition to resolving 1 aspect of the controversy surrounding the withdrawal of tube feedings, our analysis furthers a comprehensive view of end-of-life care that is consistent with contemporary ethics and American law.

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REFERENCES