

## HEALTH POLICY



# Artificial Nutrition and Hydration: The Evolution of Ethics, Evidence, and Policy

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**INTRODUCTION:** The debate over use of artificial nutrition and hydration (ANH) in terminal illness, including advanced dementia, remains contentious despite extensive ethical and empirical investigation.

**METHODS:** For this narrative review we undertook a focused, selective review of literature reflecting ethical analysis, empirical assessment of outcomes, legal responses, and thinking within the Roman Catholic religious tradition.

**RESULTS:** The history of the debate over the past 60 years results from a complex interplay of ethical concerns, a growing empirical database, legal changes, public opinion, and financial as well as institutional concerns. Discussions of ANH today are often conducted without any understanding of this historical context.

**DISCUSSION:** Patients' interests could be better protected through remedial action at both the individual and the policy levels.

**KEY WORDS:** artificial nutrition and hydration; ethics; palliative care; terminal care; health policy.

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## CASE EXAMPLE

Mr. Tyler is an 86-year-old white widower who has been confined to a nursing home for the last 5 years with advancing Alzheimer's disease. His family visits regularly, but it has been 2 years since he showed any signs of recognizing any of them. He is verbally noncommunicative and unable to perform any self-care activities.

Over the past 2 months Mr. Tyler has become increasingly uncooperative with oral feedings and has lost 12 pounds. A new nursing home policy requires percutaneous endoscopy-

guided gastrostomy (PEG) tube insertion in patients at risk for malnutrition or aspiration.

The Tyler family tell one of the administrators that while their father has no formal advance directive specifically addressing tube feedings, they feel certain that artificial nutrition and hydration (ANH) would be contrary to his previous wishes. When they visit on weekends (the only time they can get away from work), they can often coax their father to eat an acceptable meal, especially if they bring his favorite foods from home. The administrator counters that she is worried about regulatory agencies issuing penalties if they find patients not being properly fed. She also laments that their staffing level is inadequate to provide time-consuming assisted oral feeding.

## INTRODUCTION

If Mr. Tyler has a PEG tube inserted, he will join the approximately one-third of US nursing home residents with severe cognitive impairment with feeding tubes.<sup>1</sup> Palliative care practitioners have for some time regarded patients with advanced dementia as having a terminal illness, and recent studies of disease trajectory and prognosis confirm the limited life expectancy.<sup>2,3</sup> It is very unlikely that Mr. Tyler's quantity or quality of life would be improved by the feeding tube.<sup>3,4</sup>

The evidence about Mr. Tyler's anticipated outcome was addressed in two recent reviews.<sup>5,6</sup> Both found serious gaps in the existing literature, with an absence of randomized trials and reliance on observational studies. Despite looking at the same body of research, one study, from the Cochrane database, stressed the lack of proven benefit of ANH and the greater likelihood of harm.<sup>5</sup> The other study, in a publication of the National Catholic Bioethics Center, offered a "vigorous defense" of the use of ANH in dementia and argued that the literature was insufficient to overcome the presumption in favor of tube feeding.<sup>6</sup>

The policies of many health care organizations would support the view that Mr. Tyler ought not have a PEG tube placed, in keeping with his prior wishes.<sup>7–11</sup> These policies are based on extensive ethical analysis, as well as the evidence put forth in the Cochrane review and common palliative care practice.<sup>3,5</sup> As the case example indicates, however, there is every likelihood that Mr. Tyler's treatment will be determined by factors other than his and his family's wishes.

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How did we arrive at a point where positions on ANH are so conflicted, despite a substantial body of empirical evidence and ethical analysis? Our thinking about ANH in the US has experienced a tortuous history over the past 60 years. Today's contentious positions on ANH become more understandable when viewed within that historical context.

We limit our discussion in an important way. Much of the ANH debate has focused on patients in permanent vegetative state (PVS).<sup>12,13</sup> The debate over feeding tubes in PVS is generally reducible to the debate over the value of sustaining unconscious human life, and not about ANH *per se*. Here, instead, we discuss a much larger group of patients who are most often affected by ANH laws and policies—patients like Mr. Tyler with advanced dementia or other terminal illness.

Our discussion of religious perspectives focuses upon the Roman Catholic tradition, because its shifts seem to have both echoed and potentially influenced the larger cultural dialogue. Also, Roman Catholic thought, especially the distinction between ordinary (proportionate) and extraordinary (disproportionate) care, has greatly influenced US bioethics.

### The 1950s: Early Roman Catholic Thinking

Until the modern phase of bioethics began in the late 1960s and early 1970s, Roman Catholic institutions did more than most others to address medical-ethical questions.

Pope Pius XII, addressing resuscitation at a Congress on Anesthesiology in 1957, summarized long-standing Catholic teaching—while all have the right to medical care, no *extraordinary* burden should be placed on the patient, medical staff, and family. The alleviation of pain and suffering—not mere prolongation of life—should be the ultimate end of medical treatment. “Life, health and all temporal activities are subordinate to spiritual ends.”<sup>14</sup> To value above all the ability of medical technology to extend life indefinitely was interpreted by the Church as idolatry.<sup>15</sup> Before mechanical ventilation became common, Catholic writers on medical ethics routinely used feeding tubes as examples of “extraordinary” treatments that the patient or family might refuse as excessively burdensome.<sup>16</sup> In this era, Mr. Tyler's family would likely refuse the feeding tube because it constituted extraordinary treatment in his situation.

### The 1980s: Active Bioethics Debate

Bioethics in its early period, roughly 1976–1990, focused on patients' rights and a duty to respect patient autonomy. These newly articulated principles implied a right to refuse life-extending medical care.<sup>17</sup> Few empirical data about ANH were then available, so it seemed reasonable to regard ANH as a potentially life-prolonging therapy. The debate took the form: is ANH *simply* medical treatment, so that a competent patient or qualified surrogate may refuse it? Or is ANH morally different from other medical care, so that it must be provided even when other treatments may be refused?<sup>18</sup>

Bioethicists who supported mandatory ANH offered several arguments: terminating food or fluids made the physician causally responsible for death; the burdens of ANH seemed minor compared to the overriding good of life prolongation; food and fluids represented “care” at a basic, symbolic level;

and in an environment dominated by cost containment, forgoing ANH might lead to the selective elimination of vulnerable patients.<sup>19,20</sup> Bioethicists favoring a right of refusal pointed out that none of these arguments distinguished clearly between ANH and other life-prolonging treatment. Breathing air seems as basic as providing food and fluids, and stopping a ventilator seems as direct a cause of death (or not) as discontinuing tube feeding.<sup>21–23</sup> In this climate, while Mr. Tyler's family may still have classified the feeding tube as a life-sustaining intervention that a patient could choose to forgo, they might well have found the decision an agonizing one.

State statutes enacted during this era reflected the ethical debate. Rarely is state law the final arbiter of whether a patient receives ANH; rather, law usually sets ground rules for who may make decisions and under what circumstances. Some states' advance directive statutes considered all life-prolonging therapy, including ANH, together and gave general procedures by which patients and/or surrogates might request or refuse any such treatment. In other states, the law distinguished between ANH and other therapy, such as ventilators, and required additional restrictions or safeguards for ANH. Laws enacted in earlier years were more likely to create a special status for ANH, as permitted in the 1985 and 1989 versions of the Uniform Rights of the Terminally Ill Act (URTIA).<sup>24</sup>

### Early 1990s: Greater Consensus

Legal developments in the early 1990s indirectly signaled that one of the two clashing positions from the previous decade had become the majority view within bioethics. The 1990 US Supreme Court decision in *Cruzan* sided with the view that ANH was indeed life-sustaining medical treatment that could be terminated under appropriate conditions.<sup>25</sup> In 1993, the National Conference of Commissioners of Uniform State Laws adopted the Uniform Health-Care Decisions Act, which superseded URTIA. Statutes enacted on that model have tended to treat ANH as on par with other life-prolonging therapy.<sup>26</sup> Mr. Tyler's family would have received more support in refusing the feeding tube, with the assurance that it was morally no different from other forms of life-prolonging medical care.

Despite this convergence of ethics and law, the default position in any individual case was generally dictated by the assumption that ANH was effective in extending life. Positive evidence, such as a competent patient's statement or an advance directive, was required to establish that it was ethical to forgo ANH.<sup>27</sup>

### Late 1990s: Empirical Data

As ethicists viewed the decision-making around ANH as largely resolved, attention shifted to empirical studies in palliative care, geriatrics, and gastrointestinal medicine. Evidence from observational studies showed that in general, ANH was futile for terminally ill patients, including those with advanced dementia.<sup>28–35</sup> No evidence showed extension of life or improved quality of life with ANH, but considerable evidence indicated a high risk of bothersome complications—aspiration pneumonia, need for physical restraints, nausea, increased

respiratory secretions, diarrhea, edema, and need for burdensome laboratory monitoring.<sup>36</sup>

For the populations that concern us—terminal illness, including advanced dementia—the new data hinted that the default position of providing ANH when oral intake declined should shift. The assumption that the typical patient would want ANH no longer seemed plausible if the burdens associated with therapy were significant and the benefits either minimal or absent. A few analyses attempted to integrate these new data with the accepted ethics teachings about ANH.<sup>37</sup> These developments would have provided further support for Mr. Tyler's family's decision to refuse tube feeding.

The field of palliative care reflects the newer literature. State-of-the-art palliative medicine seldom utilizes ANH, stresses the avoidance of ANH, and has evolved other effective means of relieving the few symptoms attributable to dehydration or lack of nutrition.<sup>38</sup> Palliative strategies are based on the understanding that as the patient approaches the end of life, bodily functions slow. For many terminal patients, including those with advanced dementia, loss of appetite and thirst, often complicated by difficulty in swallowing, parallels the dying body's inability to utilize nutrients.<sup>39–43</sup> Moreover, biochemical and metabolic changes decrease appetite, decrease awareness, and have other salutary effects on symptoms.<sup>44</sup> Under these circumstances, Ganzini has argued that the effects of ANH are “counterpalliative.”<sup>32</sup>

**A Growing Disconnect Between Evidence and Practice.** The evolving views of the bioethics and palliative care communities, however, largely escaped public attention. Yarborough objected to the image of ANH as feeding the hungry and giving water to the thirsty, preferring the metaphor of *force feeding*.<sup>45</sup> This metaphor reflects the palliative-care concept that nutrients are being pushed into a body that cannot assimilate them. But the “force feeding” metaphor never took hold amongst the general public, and the image of ANH as assuaging hunger and thirst persisted. One study of all feeding tube placements in an Indiana community over a 16-month period revealed families who felt unable to alter the decision because “common sense” dictated that “you could not just let him starve to death,” while physicians perceived that they had been pressured into inserting feeding tubes by families.<sup>46</sup> When individuals are asked their own preferences (as opposed to what they would want for a family member), sizeable majorities would refuse feeding tubes at the end of life.<sup>47,48</sup> Yet many physicians believe that the feeding tube represents the standard of care and are unaware of data showing its lack of benefit.<sup>49</sup>

Aided by market forces, public opinion created an institutional environment in which it was nearly impossible to implement the lessons of ethics and palliative care. The factors making ANH the default practice within institutions such as nursing homes are summarized in the Table 1.

These factors are mutually reinforcing. For example, if physicians helped families work through their anticipatory grief and guilt, and recommended against ANH because of its lack of benefit and excessive burdens, family resistance might be dramatically reduced. But busy physicians who are unaware of this evidence and unfamiliar with palliative techniques lack the time and ability to educate families. Thus, they are unlikely to adopt this helpful role.<sup>46,50</sup> The results reflect a health system that generously reimburses for procedures and reimburses very poorly for taking the time to explain complex concepts to families.

**Table 1. Factors Encouraging the Use of ANH in Practice**

Involved party	Factors favoring ANH
Family members	Unwillingness to accept terminal prognosis Belief in cruelty of dying process if ANH not administered Need to demand interventions to avoid guilt
Physicians	Lack of familiarity with palliative care techniques and evidence Length of time required to educate families on true facts of ANH Reimbursement for insertion of PEG tube, etc. Desire to avoid controversial discussions Fears of litigation
Administrators	Reimbursement for tube feedings, etc. Fear of regulatory sanctions if ANH not administered (nursing homes) Extra time and staff needed to assist with oral feedings in weakened or demented patients Fears of litigation

While some educational interventions have reduced the number of terminally ill patients subjected to ANH,<sup>32,51</sup> the factors listed in Table 1 are deeply entrenched.

## 2003 and After: Post-Schiavo Era

By 2003, therefore, ethical, geriatric, and palliative care considerations opposed routine use of ANH in terminal illness, including advanced dementia, whereas institutional practice and much popular opinion still favored ANH as the default option. Into that standoff came the Theresa Schiavo case.<sup>12,13</sup> What would have been a comfortable decision about Mr. Tyler's feeding tube a decade earlier now turned again into one fraught with second guessing, as it was in the 1980s.

People who had not previously attended to the debate heard claims that Ms. Schiavo was being forced to die despite signs that she might recover from her vegetative state, and that the manner of death, starvation and dehydration was inhumane. Some were persuaded that if bioethics and the law approved of these measures, then law and bioethics had indeed become a “culture of death.”<sup>52</sup> Nor were these onlookers inclined to make fine distinctions between PVS and terminal illness or to ask whether different ethical and empirical considerations might apply to the use of ANH in each setting.

*Schiavo* especially affected two areas—law and Roman Catholic doctrine.

**Post-Schiavo Legal Developments.** Laws, or amendments to existing laws, were introduced in a number of states to restrict the rights of patients and surrogates to withdraw or withhold ANH. While inspired by *Schiavo*, these laws generally were not restricted to PVS patients and would have applied equally to terminal illness, including advanced dementia. Changes were enacted in several states.<sup>53–62</sup> Less action is occurring today as memory of *Schiavo* fades.<sup>63</sup> Nevertheless, some states were actively considering legislation as recently as 2008.<sup>64–69</sup>

A further impetus for legislative action in the post-Schiavo period is increased interest in “conscience clause” legislation.<sup>70</sup> States with advance directive statutes based on the Uniform Health-Care Decisions Act often contain conscience clauses that permit a health care provider to refuse to follow a patient's

advance directive or other legally valid request where the provider objects on moral or religious grounds.<sup>71</sup> The objecting provider usually must inform the responsible party and continue status-quo care until (and if) the surrogate can find a compliant provider.

Federal law generally protects the right of providers to refrain from performing services that are contrary to their religious beliefs, where the service is funded through the Department of Health and Human Services.<sup>72</sup> and requires employers to make reasonable accommodation for those beliefs, to the extent that accommodation does not cause the employer undue hardship.<sup>73</sup> A handful of states also permit health care providers to refuse to participate in a broad range of activities if participation would cause the provider moral distress.<sup>74,75</sup> Patients' options to refuse ANH may, in sum, be restricted by laws either directly prohibiting such refusals or allowing health care facilities to refuse to honor the refusals.

**Recent Roman Catholic Teaching.** Since *Schiavo*, the Catholic position on ANH has become difficult for outsiders clearly to discern. In the late 1980s, the family of Nancy Cruzan received the support of a number of Catholic ethicists to have her feeding tube discontinued because of her PVS. As time passed, however, the church hierarchy appeared increasingly concerned that Catholics might use claims of "extraordinary care" inappropriately to choose death over the extension of life. The church's reaction to *Schiavo* threatened to remove ANH from the proportionate/disproportionate calculus by designating ANH "in principle" always as ordinary care. However, the hierarchy's official position is that no shift in thinking has occurred, and that today's teachings are the same as those in force in the 1950s and 1980s.<sup>15,76</sup> Adding to outsiders' confusion is the fact that two statements from the same person within the hierarchy, made in two different contexts, may carry different levels of authority and precedent; where subtleties and nuances exist, local authorities may interpret Catholic policy differently.

The position currently endorsed by the Church hierarchy stresses life prolongation based on fundamental human dignity. The two most recent Popes have each stated that administration of food and water, artificially or not, constitutes ordinary care "in principle;" ANH is to be considered not a medical technology, but rather a "natural means of preserving life."<sup>77</sup> Removing ANH is "euthanasia by omission" because the cause of death would be lack of sustenance rather than the underlying disease.<sup>78</sup> These comments were apparently aimed especially at PVS, so the extent to which they were intended to apply to terminal illness, including advanced dementia, is unclear.

A dissenting position, offered by some Catholic theologians and groups who lack power to speak for the church, argues for continuing to assess ANH within the proportionate/disproportionate framework. Regarding ANH always as proportionate or ordinary care, according to the dissenters, seriously underestimates the burdens that ANH can impose on the groups we focus on—terminally ill patients, including those with advanced dementia.<sup>15,63,79</sup>

In saying that ANH is ordinary care "in principle," the hierarchy's position retains some discretion—permitting, for example, forgoing ANH in patients unable to assimilate food and liquids, or when complications of ANH cause significant

physical discomfort.<sup>80</sup> At precisely what level of burden to the patient, family, or community ANH will be judged to become disproportionate by today's Catholic authorities is as yet undefined.

A November 2009 pronouncement from the US Conference of Catholic Bishops fails to offer much clarification. It states that Catholic health facilities have an obligation to offer food and water, including ANH, to all patients, even those with chronic and irreversible conditions. On the one hand, the Bishops' list of exceptions includes cases where ANH fails to prolong life, is excessively burdensome, or causes marked physical discomfort. The list suggests that the Bishops, in the end, continue to regard ANH as falling within the scope of the proportionate/disproportionate test. On the other hand, the insistence that Catholic facilities may refuse to accommodate patient requests that are "contrary to Catholic moral teaching" could raise fears that facilities would administer ANH even over patient and family objections—especially in states with broad conscience clause provisions.<sup>81</sup>

Initially the shift in Catholic teaching seemed to ignore the evolving literature in geriatrics and palliative care. More recently, articles referring to that literature have appeared in Catholic bioethics publications. Some dissenting authors cite the low-benefit, high-burden nature of ANH in terminally ill patients.<sup>82</sup> Others, as we noted, challenge the adequacy of the research methods and argue that despite this literature, ANH should be mandatory in most cases of advanced dementia.<sup>6</sup>

## CONCLUSION

When some first suggested that cardiopulmonary resuscitation is futile for some patients, a senior clinician put the matter in a nutshell by observing, "It seems we have lost sight of the difference between patients who die because their hearts stop unexpectedly and patients whose hearts stop because they are dying."<sup>83</sup> Much the same might be said today of ANH. We seem to have forgotten the difference between people who die because they stop taking in food and water, and people who stop taking in food and water because of the natural dying process.

An ironic feature of the current clash of positions is that advocates of each often agree that the most compassionate and humane option for patients near the end of life is hospice and/or palliative care. Yet many who view ANH *a priori* as the more compassionate and humane option seem not to appreciate the fact that standard palliative practice is to avoid the use of ANH in almost all instances. When ANH is used in palliative settings, it is generally employed as a time-limited trial to achieve a specific goal, and the patient is regularly monitored to see if the goal is met.

How can we better assure that patients like Mr. Tyler receive truly beneficial care in accord with their own values? Individual providers should resist the temptation to confuse the decision to employ or to forgo ANH with the consent for a technical procedure. A thorough exploration with the patient or family ought not be led by a busy hospitalist who has only just met the patient and family, or a gastroenterologist consulted solely to address the gastrointestinal tract. Ideally the family would be informed and guided by an attending



physician who has previous knowledge of the patient. Institutional ethics committees can help assure that providers have available effective and accessible educational materials about ANH. A discussion of ANH might also be a suitable trigger for a palliative care consultation.<sup>50</sup> An emerging concept in palliative care is “comfort feeding only,” a specific application of “comfort care only” to providing nutrition and hydration near the end of life.<sup>84</sup>

Changes in policy can also facilitate the provision of medically indicated care at the end of life while respecting the wishes and beliefs of patients and their families. First—as at least one professional association has already requested—legislatures should not enact laws mandating the provision of ANH or presuming that incompetent patients would want ANH unless they expressly directed its non-provision.<sup>85</sup> Going farther, states ought not to prevent statutory surrogates—those appointed by statute for incompetent patients, rather than through a health care power of attorney—from opting to forego ANH.<sup>86,87</sup> Patient preferences are not safeguarded through blanket statutory mandates and exceptions, but rather are best protected by those who know and, ideally, care about the now-incompetent patient. Yet the mere absence of restraints on surrogate decision-making will not protect all patients from care they would not desire. In nursing homes, substantial changes would need to be made at the intersection of palliative care, federal and state regulations intended to safeguard vulnerable residents, and differentials in reimbursement for different Medicare and Medicaid services. Finally, space must be made for conversations between patients, providers, and their families regarding end-of-life care. Medicare reimbursement for such discussions, as proposed but ultimately scuttled in the health reform law, would have been a start.<sup>88</sup> ANH would be an appropriate topic for the Presidential Commission for the Study of Bioethical Issues to review.

Understanding the historical evolution of the ANH debate helps us see the information and counsel that we can offer Mr. Tyler's family. We must now help individual providers to better employ that counsel and minimize institutional barriers to sound decisions.

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