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FEEDING TUBES, SLIPPERY SLOPES, AND PHYSICIAN-ASSISTED SUICIDE

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INTRODUCTION

In the past few years, articles in the New England Journal of Medicine, the Journal of the American Medical Association, and the Journal of the American Geriatrics Society have suggested that feeding tubes are substantially overused in patients with advanced dementia or other serious illnesses. Contrary to common understanding, artificial feeding often does not improve the patient’s nutrition or ability to function. The feeding tube, in fact, may not be providing any benefit to the patient in terms of length or quality of life.

Although the overuse of feeding tubes is troubling in some respects, it is reassuring in one important way. It indicates that slippery slope concerns about the “right to die” may be exaggerated. Some commentators resisted on slippery slope grounds the recognition of a right for patients to forgo artificial nutrition and hydration. According to those commentators, laws permitting

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† Director, Indiana University Center for Aging; Scientist, Regenstrief Institute for Health Care, Indiana University School of Medicine.
4 Gillick, supra note 1; Mitchell et al., supra note 2; Finucane et al., supra note 2; Callahan et al., supra note 3.
the discontinuation of artificial feeding could not be enacted without opening up patients to a serious risk of abuse. The legal option to refuse artificial nutrition and hydration would become a duty to refuse them." The overuse of feeding tubes provides important evidence for the view that extensions of the right to refuse life-sustaining treatment can occur without a slide down the slippery slope. Patients, families, and physicians apparently are reluctant to take action they think will hasten a patient’s death, even if the action is permitted by law. This reassuring finding is important for its own sake. Society needs to be alert to the possibility of premature terminations of life-sustaining treatment. Fortunately, it appears that feeding tubes are not being discontinued too soon.

The finding also may be important in terms of its implications for the legalization of physician-assisted suicide. Just as many commentators argued that laws permitting withdrawals and withholdings of feeding tubes would result in abuse, so, too, do many commentators oppose a right to assisted suicide on the ground that it would not be limited to the few compelling cases in which it might be morally acceptable. Yet, if patients, families, and physicians are reluctant to engage in legally permissible withholdings or withdrawals of life-sustaining treatment, we might expect patients and physicians to be even more reluctant to engage in legally permissible physician-assisted suicide.

Before we develop our arguments in more depth, a clarifying point is in order. We are not taking a position on the legalization of physician-assisted suicide. We are, in fact, divided on that question.

I. FEEDING TUBES AND THEIR VALUE FOR PATIENTS

Perhaps because the value of artificial feeding seems intuitively obvious, the empirical literature is relatively sparse on the question of whether feeding tubes are beneficial for seriously and irreversibly ill patients. Most studies have involved retrospective chart reviews, and none of the prospective studies have involved a randomization of patients between tube feeding and oral feeding. At one time, tube feeding was provided exclusively by naso-gastric tubes that were inserted into the stomach by passing them through the nose, throat, and esophagus. While naso-gastric tubes are still used for short-term feeding, they have been replaced for long-term feeding by gastrostomy tubes. Gastrostomy tubes cause less discomfort for the patient, and they entail fewer complications than naso-gastric tubes (such as erosion of the nasal tissue and aspiration pneumonia).

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6 Callahan et al., supra note 3.

7 Finucane et al., supra note 2; Callahan et al., supra note 3.
Originally, gastrostomy tubes were inserted into the stomach during a surgical procedure that required the cutting of an opening into the abdominal wall. Dr. Michael Gauderer and his colleagues then developed the percutaneous endoscopic gastrostomy (PEG) procedure in 1979, which requires only two small incisions into the abdominal wall (much like laparoscopic surgery now has supplanted open abdominal surgery for most gall bladder removals).

Gauderer reported that his experiences with high complication rates among children undergoing surgical gastrostomy motivated his research to find a safer alternative. Over the past 25 years, Gauderer and other scientists have demonstrated clearly that the PEG procedure is safer and associated with fewer complications than open gastrostomies. In reflecting on the success of this procedure, Gauderer notes that “in part because of its simplicity and low complication rate, this minimally invasive procedure also lends itself to over-utilization.” He suggests that “much of our effort in the future needs to be directed toward the ethical aspects associated with long-term enteral feeding [because] . . . we as physicians must continuously strive to demonstrate that our interventions truly benefit the patient.”

One of the difficulties in understanding the benefits of PEG is the implicit assumption that, if the procedure provides nutrition and is safe, then it must be beneficial for those unable to eat because nutrition is so fundamental to health and recovery from illness. Over the past two decades, patients, clinicians, caregivers, and scientists have increasingly challenged this assumption. Most of the early research on PEG focused on short-term operative complication rates. Then, case reports and editorials began to surface about patients or patient groups who were harmed or endured prolonged suffering because of artificial feeding. These reports were followed by retrospective studies examining mortality and longer-term complication rates among older adults receiving PEG. Eventually, long-term prospective studies examining nutritional, functional, and quality of life outcomes were conducted. These studies demonstrated the limited beneficial effects of PEG among some older adults receiving the procedure, and particularly those with dementia. Here, we review the empirical evidence addressing the clinical outcomes of older adults receiving percutaneous endoscopic gastrostomy.

Until the mid-1990s, most studies reporting on the outcomes of PEG focused on the operative and peri-operative complications rates. This was understandable, given the clinical motivation for the early development of the procedure and the focus on decreasing the complication rate associated with

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9 Gauderer, supra note 8, at 882.
10 Id.
open gastrostomies. Most of these studies relied on data from retrospective chart reviews of patients undergoing the procedure at major academic medical centers. In a review of 48 such studies, Wollman and colleagues reported a 95.7% success rate for PEG placement. Major complications occurred in 9.4% of patients, minor complications in 5.9%, and tube-related complications in 16%. Thus, the procedure clearly was safe in terms of peri-operative complications. However, Wollman also reported a 30-day mortality rate of 14.7% across all studies. Although these deaths did not appear to be related to the procedure, this finding provided some early indications about the magnitude of competing morbidities among this patient population.

In 1997, Rabeneck and collaborators reported patient outcomes from a retrospective review of patients who received PEG in Veterans Affairs hospitals between 1990 and 1992. The authors identified 7,369 veterans who had received a PEG for cerebrovascular disease, other neurologic disease, or cancer. The complication rate was reported as low (4%), but the scientists reported 23.5% in-hospital mortality. Furthermore, the median survival of the cohort receiving PEG was only 7.5 months. The authors suggested that the high mortality rate was related to the patients' underlying disease rather than the procedure, but raised the question of the utility of the procedure among patients who were terminally ill. In a similar study using claims data from hospitalized Medicare beneficiaries, Grant and colleagues reported mortality rates among 81,105 Medicare beneficiaries receiving gastrostomy in 1991. The authors reported a 30-day mortality rate of 23.9%. Mortality increased to 63% at one year and 81.3% at three years.

In one of the first prospective studies specifically designed to examine nutritional and long-term patient outcomes following PEG, Loser and collaborators completed a four-year study of 210 patients receiving PEG in a German hospital. Body weight among the survivors in this cohort of patients increased a mean of 3.5 kilograms in the first year and almost 20% of

12 Id.
13 Id. at 702.
15 Id. at 288.
16 Id. at 289.
17 Id.
18 Id. at 291-92.
20 Id. at 1974, table 3.
21 Id.
surviving patients returned to oral feeding. These authors also reported that 83% of patients reported excellent acceptability of the procedure. Although this patient cohort was younger than the VA and Medicare cohorts, mortality in the Loser and colleagues study was 27% at 30 days and 66% at one year. Notably, this study did not include older adults with dementing disorders.

Callahan and colleagues conducted the first prospective study among all older adults receiving PEG in a defined community in order to identify a truly representative sample of older adults receiving the procedure. Assembling the patient population in this manner provides greater assurance that all older adults receiving the procedure are included. Studies limited to outcomes among patients who survive the initial hospitalization may miss as many as 30% of the patients undergoing the procedure, because those patients die before they leave the hospital. Studies limited to a single academic medical center or hospital suffer from the selection biases that determine how patients come to receive the procedure at that particular site. For example, some tertiary medical centers may attract the most complicated patients and thus report higher mortality rates. Studies relying on national claims data are able to capture complication rates and mortality for a nationally representative sample, but typically cannot monitor nutritional parameters or functional status.

By monitoring the practice of all gastroenterologists in a small community in Indiana, Callahan and colleagues were able to identify 150 patients age 60 and older who had a PEG tube placed over a 15-month period. The mean age was 78.9 ± 8.1 (range 60-98), 56% were women, and 83.3% were white. The mean Cumulative Illness Rating Scale score for this group of patients was higher than any other group reported in the literature, demonstrating the high burden of chronic illness among this cohort. About half of the PEGs were placed during the course of care for an acute hospitalization and the other half were placed among chronically ill patients receiving care in the community. The most frequent indications for the PEG were stroke (40.7%), neurodegenerative disorders (34.7%), and cancer (13.3%). Among remaining patients (11.3%), the most frequent indication was prevention of aspiration pneumonia.

There were 24 patients among the original 150 who could not undergo the detailed study assessment because they died precipitously following the

23 Id. at 2552-53.
24 Id. at 2554.
25 Id. at 2555.
26 Callahan et al., supra note 3; Christopher M. Callahan et al., Decision-Making for Percutaneous Endoscopic Gastrostomy Among Older Adults in a Community Setting, 47 J. AM. GERIATR. SOC’Y 1105 (1999).
27 Callahan et al., supra note 3, at 1050.
28 Id.
29 Id.
Among the patients surviving long enough to complete the baseline assessment, the majority reported severe impairment in their abilities to perform basic activities of daily living such as toileting, dressing, and bathing. Almost two-thirds of patients could not communicate verbally at the time of PEG. Among those capable of communication, the majority could not provide data for self-reported subjective health status measures because of severe cognitive impairment. Thus, these data had to be collected from their caregivers. This finding highlights the limited capacity of many of these older adults to participate in their medical decision-making, including the decision to proceed with PEG.

The 30-day mortality among all patients undergoing the PEG procedure was 22% and 12-month mortality was 50%. Among the 72 patients surviving at least 60 days, there were no changes in mean values of nutrition, physical function, cognitive function, mood, pain, or quality of life. Only rarely did patients experience improvement in functional or nutritional status. The study also examined the process of care and found, perhaps surprisingly, that more than half of patients receiving PEG continued to receive food, liquids, or medications by mouth. One-third had to have the PEG tube replaced during the follow-up period. Nearly all patients reported PEG-related symptoms, such as vomiting and diarrhea, and many received treatment with sedative-hypnotics and narcotic analgesics. In sum, the study findings depict older adults in the terminal stages of illness receiving the PEG in a perhaps desperate attempt to improve function and longevity or reverse the course of the illness. There clearly were patients in this cohort who did benefit from PEG, but the study was not large enough to begin to identify those patient characteristics that portend a favorable outcome. The definition of a favorable outcome can easily become a mercurial concept and some researchers have argued that PEG simply may provide for a more comfortable death. This does not, however, appear to be the reason that caregivers seek a PEG tube.

Callahan and colleagues reported patients’ and caregivers’ expectations for benefits from PEG tube feeding among the same cohort of patients described above. Either patients or their surrogate decision-makers completed a semi-structured, face-to-face interview to map out the information-gathering process, expectations, and discussants involved in the decision to proceed with gastrostomy feeding. Physicians completed a written questionnaire to determine their likelihood of recommending PEG tube placement,

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30 Id.
31 Id.
32 Id.
33 Id. at 1050 & 1052, table 2.
34 Id. at 1050 & 1053, table 3.
35 Callahan et al., supra note 26.
36 Id. at 1106.
their involvement in the decision-making and recommendation process, and sources of perceived pressure in the decision-making. Patients or their surrogate decision-makers reported that they discussed the decision to proceed with PEG with multiple people prior to accepting the procedure. Often, these decision-makers sought the advice of family or friends who had a health care background. Decision-makers complained that they had to make their decisions based on incomplete information and reported considerable distress in arriving at the decision to proceed with artificial feeding. The decision for gastrostomy often appeared to be a "non-decision" in the sense that decision-makers perceived few, if any, alternatives. Physicians also reported considerable distress in arriving at recommendations to proceed with PEG, including perceived pressures from families or other health care professionals. Providers whom the patient or caregiver identified as the primary care physician often reported that they were not intimately involved in the decision-making process. These physicians had definable patterns of triage for PEG, but the assumptions underlying these patterns are not well supported by the medical literature (for instance, prevention of aspiration pneumonia).

Decision-makers listed improved nutrition as the goal of PEG tube feeding in 70% of the cases. Other reasons included a desire to increase patient comfort (22%), extend life (18%), increase strength (14%), and help overcome an acute illness (10%). Because data on these patients' long-term functional outcomes were lacking, decision-makers appeared to focus primarily on the short-term safety of the procedure and the potential for improved nutrition. Callahan and colleagues suggested that the interviews with decision-makers belied "a pervasive climate of 'inevitability' in the judgment to proceed with the artificial feeding." Decision-makers simply saw no other reasonable alternatives.

Economic incentives also may play a role in medical decision-making about PEG tubes. Again using the cohort of older adults receiving PEG from the defined community, Callahan and colleagues estimated the economic costs of PEG tube feeding over one year. Patients were interviewed at baseline and every two months for one year to obtain information on the use of enteral formula, complication rates, and health services. Inpatient charge data for all hospitalizations and PEG-related procedures for one year were obtained from the health care systems serving the defined community. Outpatient costs were
estimated using volume data and customary charges for Medicare ambulatory visits.\textsuperscript{45} Data collection was concluded at the time of the patient’s death or one year post-PEG. The mean number of days of PEG tube feeding was 180 (range 5 to 365).\textsuperscript{46} The average annual cost for PEG tube feeding for this cohort of patients was $7,488 (median $3,691) in 1997 dollars. The average daily cost of PEG tube feeding was $87.21 (median $33.50). The estimated cost of providing one year of feeding via PEG is $31,832 (median $12,227).\textsuperscript{47}

The main components of these costs included the initial PEG procedure (accounting for 29.4\% of total costs), enteral formula (24.9\% of total costs), and hospital charges for major complications (33.4\% of total costs). There was considerable variation in charges among patients due to the cost of rare but expensive major complications. Using cost estimates from the literature, the authors then compared the cost of PEG tube feeding to hand feeding and found little evidence that PEG tube feeding accounted for lower total costs. However, feeding patients via PEG resulted in cost shifts affecting the interests of the primary payer. Because PEG costs are primarily borne by third party payers such as Medicare and hand feeding is reimbursed only through the daily charges allowed for skilled facility care (or is provided by informal caregivers among those living in the community), there may be financial incentives for skilled facilities to favor PEG tube feeding.

In 2001, Dharmarajan and colleagues conducted a systematic review of the literature to summarize research on the outcomes of PEG in older patients with dementia.\textsuperscript{48} They noted the absence of randomized trials of PEG tube feeding as compared to alternative methods such as hand feeding. Among 19 studies reporting patient outcomes, 11 studies had been published in the prior three years.\textsuperscript{49} The Dharmarajan and colleagues review described the low rate of serious short-term complications, but a high 30-day mortality (\textasciitilde 25\%).\textsuperscript{50} None of the reviewed studies demonstrated significant improvement in nutritional parameters, prevention of aspiration pneumonia, pressure sores, or infections, and some studies found the PEG tubes actually could increase the likelihood of these complications.\textsuperscript{51} None of the reviewed studies demonstrated improvement in functional status, comfort, or quality of life.\textsuperscript{52} Again, some studies suggested a decline in comfort with the use of PEG tubes. The authors concluded: “Although tube feeding may not be totally futile in all

\begin{footnotesize}
\begin{itemize}
\item[45] Id. at 1526-27.
\item[46] Id. at 1527.
\item[47] Id. at 1528, table 1.
\item[48] Thiruvinvamalai S. Dharmarajan et al., Percutaneous Endoscopic Gastrostomy and Outcome in Dementia, 96 AM. J. GASTROENTEROLOGY 2556 (2001).
\item[49] Id. at 2557.
\item[50] Id. at 2557-58.
\item[51] Id. at 2559-60.
\item[52] Id. at 2560.
\end{itemize}
\end{footnotesize}
cases, an analysis of the benefits and risks seldom leads to a definite positive result in cognitively impaired individuals."

In sum, the studies generally suggest that patients, families, and physicians misjudge the benefits derived from tube feeding. Recall, for example, the prospective PEG study in a small community. Researchers found that, of the patients who survived at least 60 days, more than two-thirds had no significant improvement in functional, nutritional, or subjective health status. Other studies also have failed to detect improvements in functional or nutritional status, and they have not found any improvement in survival for patients with advanced dementia. In the SUPPORT study, artificial feeding was associated with increased survival in coma patients but decreased survival in patients with acute kidney failure, multiple organ system failure, cirrhosis of the liver, or COPD.

Tube feeding often is advocated to reduce the risk of aspiration pneumonia, but studies in patients with advanced dementia have not shown that it reduces that risk. Indeed, gastrostomy tube placement may increase the risk that the stomach contents will reflux into the esophagus, and some studies have found that tube feeding increases the risk of aspiration pneumonia. Other purported benefits from artificial nutrition also have not materialized. Tube feeding has neither enhanced the healing of existing pressure sores nor prevented the formation of new sores. It also has not reduced the overall risk of infection.

Although artificial feeding may be desired to ensure the comfort of a patient, that goal often is beyond the reach of feeding tubes. Patients often are restrained, either physically or with sedating drugs, to prevent them from pulling their tubes out, and this can be distressing to them. Artificial feeding also can deprive patients of the pleasure they experience from eating. In short, it appears that feeding tubes are being used in many patients without any real benefit to them.

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53 Id. at 2561.
54 Callahan et al., supra note 3, at 1052, table 2.
55 Finucane et al., supra note 2.
56 Marie L. Borum et al., The Effect of Nutritional Supplementation on Survival in Seriously Ill Hospitalized Adults: An Evaluation of the SUPPORT Data, 48 J. AM. GERIAT. SOC'Y S33 (2000). COPD stands for chronic obstructive pulmonary (or lung) disease. Emphysema is a well-known type of COPD.
57 In aspiration pneumonia, the food and digestive secretions in the stomach are regurgitated up the esophagus and down the respiratory tract into the lungs.
58 Gillick, supra note 1, at 206-07; Finucane et al., supra note 2, at 1365-66.
59 Finucane et al., supra note 2, at 1365-66.
60 Id. at 1367.
61 Gillick, supra note 1, at 207-08.
62 Id. at 207; Finucane et al., supra note 2, at 1368.
II. THE ABSENCE OF A SLIPPERY SLOPE

Despite the questionable efficacy of artificial feeding, the use of feeding tubes is common. In 1995 alone, more than 120,000 PEG tubes were inserted into patients age 65 or older. A study based on 1999 nationwide data found that more than a third of nursing home patients with advanced cognitive impairment had feeding tubes. Concern with overuse of artificial feeding has spurred two recent, prominent discussions, with both authors concluding that tube feeding generally should not be used for patients with advanced dementia. As one of the authors observed, difficulty with eating often is a sign of end-stage disease and tube feeding cannot stem the progression of illness at that point. Hand feeding should be attempted, but artificial feeding generally cannot accomplish anything more for the patient than can hand feeding.

What is striking about the apparent overuse of feeding tubes is the extent to which it suggests that patients, families, and physicians have not succumbed to their freedom to withhold or withdraw artificial nutrition from irreversibly ill patients. In the 1980s, before courts clearly recognized a patient’s right to forgo artificial feeding, ethicists, physicians, and other commentators engaged in a major debate about the morality of discontinuing nutrition and hydration in accordance with the patient’s wishes. Many opponents of such a right warned that it would have serious consequences.

Daniel Callahan, for example, wrote that society can easily move from permitting the withdrawal of artificial nutrition to requiring its withdrawal. If patients never will regain their mental faculties, and medical care is very expensive, it is easy for society to conclude that there is no point in trying to prolong life with a feeding tube. Mark Siegler, Alan Weisbard, and others also expressed concern that cost constraints would transform a right to die by withdrawal of artificial feeding into a duty to die that way.

Yet, feeding tubes remain a mainstay of the care of patients whose ability to eat is compromised. The fundamental social ethic in favor of feeding those who are starving has not been eroded as feared. As discussed above, feeding tubes are used even when they do not benefit the patients who receive them. In addition, other studies regularly show that physicians find it more difficult to stop feeding and hydration than to discontinue ventilators, dialysis, or other

63 Callahan et al., supra note 3, at 1048.
64 Mitchell et al., supra note 2.
65 Gillick, supra note 1; Finucane et al., supra note 2.
66 Gillick, supra note 1, at 207.
67 Callahan, supra note 5.
68 Siegler & Weisbard, supra note 5; William E. May et al., Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons, 3 ISSUES L. & MED. 203 (1987).
life-sustaining treatments\textsuperscript{70} and also that physicians often are uncomfortable withholding or withdrawing nutrition, even when doing so is consistent with the patient's wishes.\textsuperscript{71}

To be sure, a few commentators have been arguing for a number of years that some patients ought not be artificially fed or hydrated regardless of the wishes of the patient or family. According to Schneiderman and Jecker, it is futile to provide a feeding tube or intravenous line to permanently unconscious patients, and artificial feeding and hydration should be withheld from such patients unilaterally.\textsuperscript{72} If views like this prevailed, the vision of Callahan, Siegler, and Wiesbard might be fulfilled. The right to refuse artificial nutrition and hydration could become a duty to do so. However, the Schneiderman and Jecker view is a minority position.

The reluctance of physicians and families to discontinue feeding tubes parallels judicial behavior. Courts also have hesitated to authorize withdrawals of feeding tubes. Although judges have concluded that artificial nutrition and hydration are medical treatments in the same way as ventilators or dialysis and, therefore, have recognized an unqualified right of patients to have artificial nutrition discontinued, courts also have erected strict procedural rules to protect incompetent patients from premature withdrawals. When courts are asked whether feeding can be stopped for a patient who is neither terminally ill nor permanently unconscious, they consistently respond that feeding must be given in the absence of very clear evidence that the patient previously expressed a preference against tube feeding.

The Michigan Supreme Court's decision in \textit{In re Martin}\textsuperscript{73} is a good example. Michael Martin was injured in an automobile accident, leaving him with severe impairment of his intellectual and physical abilities. He could no longer walk or talk, and was dependent on a PEG tube for his nutrition. Although there was some disagreement among the medical experts who evaluated Mr. Martin, they generally concluded that he could understand some simple questions but he lacked an understanding of more complex matters like his physical capabilities and medical condition. They all agreed that his impairments were permanent.\textsuperscript{74}

Mr. Martin's wife requested that the feeding tube be removed. In her opinion, he would not have wanted life-sustaining treatment given the severity of his injuries. In reaching her opinion, Ms. Martin drew on conversations that she had had with her husband. She testified:

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\item{70} David A. Asch \textit{et al.}, \textit{The Sequence of Withdrawing Life-Sustaining Treatments from Patients}, 107 \textit{Am. J. Med.} 153 (1999).
\item{72} LAWRENCE J. SCHNEIDERMAN \& NANCY S. JECKER, \textit{Wrong Medicine: Doctors, Patients, and Futile Treatment} 12 (1995).
\item{73} 538 N.W.2d 399 (Mich. 1995).
\item{74} \textit{Id.} at 402-04.
\end{footnotes}
Discussions between Mike and me regarding what our wishes would be if either of us was ever involved in a serious accident, had a disabling or terminal illness or was dying of old age, began approximately eight years ago. These discussions occurred on many different occasions. As I indicate below, several were triggered by movies which we saw together. Mike's position was always the same: he did not want to be kept alive on machines and he made me promise that I would never permit it.

Some of the conversations that we had about medical care in this context occurred after we watched movies about people who no longer were mentally competent either due to illness, accident, or old age; others involved people who could no longer do anything for themselves, such as persons who lived in a nursing home and could no longer feed or dress themselves and needed to wear diapers or have other measures taken to continue existing. Mike stated to me on several occasions: "That's bullshit, I would never want to live like that." He also said to me, "Please don't ever let me exist that way because those people don't even have their dignity."...

Some movies that triggered our discussions were about accidents—car accidents, hunting accidents or other accidents near home or in water. Mike was an avid hunter and frequently expressed concerned [sic] about a hunting accident. Mike frequently told me that if he ever had an accident from which he would "not recover" and "could not be the same person," he did "not want to live that way." He would say, "Mary, promise me you wouldn't let me live like that if I can't be the person I am right now, because if you do, believe me I'll haunt you every day of your life." I stated my promise to him and made him promise me the same.75

The court held that the feeding tube could not be removed from Mr. Martin. According to the court, prior oral statements by the patient will be sufficient to justify withdrawal of treatment “[o]nly when the patient’s prior statements clearly illustrate a serious, well thought out, consistent decision to refuse treatment under these exact circumstances or circumstances highly similar to the current situation.”76 Under this approach, a general refusal of artificial measures is not sufficient. Rather, patients must have spoken to the particular medical problem they have and possibly even to the specifics of artificial feeding. The California, New Jersey, and Wisconsin Supreme Courts also have adopted strict standards for withdrawing feeding tubes from incompetent patients who are neither terminally ill nor permanently unconscious.77

In the California case of Wendland v. Wendland,78 Rose Wendland asked that a feeding tube be withdrawn from her husband, Michael Wendland, two years after an automobile accident left Mr. Wendland with severe and permanent brain damage.79 He retained some ability to interact with others. As the court reported:

75 Id. at 411-12.
76 Id. at 411.
77 Spahn V. Eisenberg, 563 N.W.2d 485 (Wis. 1997); Wendland v. Wendland, 28 P.3d 151 (Cal. 2001); In re Conroy, 486 A.2d 1209 (N.J. 1985).
78 28 P.3d 151 (Cal. 2001).
79 Id. at 154.
At his highest level of function between February and July, 1995, Robert was able to do such things as throw and catch a ball, operate an electric wheelchair with assistance, turn pages, draw circles, draw an 'R' and perform two-step commands. For example, "[h]e was able to respond appropriately to the command 'close your eyes and open them when I say the number 3.' . . . He could choose a requested color block out of four color blocks. He could set the right peg in a pegboard. . . . He remained unable to vocalize. Eye blinking was successfully used as a communication mode for a while, however no consistent method of communication was developed.*"

Despite this residual capacity to interact with people and his environment, Mr. Wendland's impairments were quite severe. The court also observed:

The same medical report summarized his continuing impairments as follows: "severe cognitive impairment that is not possible to fully appreciate due to the concurrent motor and communication impairments . . ."; "maladaptive behavior characterized by agitation, aggressiveness and non-compliance"; "severe paralysis on the right and moderate paralysis on the left"; "severely impaired communication, without compensatory augmentative communication system"; "severe swallowing dysfunction, dependent upon non-oral enteric tube feeding for nutrition and hydration"; "incontinence of bowel and bladder"; "moderate spasticity"; "mild to moderate contractures"; "general dysphoria"; "recurrent medical illnesses, including pneumonia, bladder infections, sinusitis"; and "dental issues."*'

In rejecting the spouse's request that Mr. Wendland's feeding tube be discontinued, the court emphasized the need for clear and convincing evidence that Mr. Wendland "would have refused treatment under the circumstances of this case."* Although Mr. Wendland had spoken about his desire not to live as a "vegetable," he had not disclosed his preferences for treatment when his medical condition would be superior to the condition of someone in a persistent vegetative state.* The New York Court of Appeals has adopted similarly strict standards for discontinuing feeding tubes, as well as ventilators and other treatments, from incompetent patients who are neither terminally ill nor permanently unconscious (or any incompetent patient).*

In sum, although the slippery slope was a real risk once courts recognized a right for patients to have artificial nutrition withheld or withdrawn, the evidence seems to suggest that, if anything, physicians, families, and judges have been too unwilling to discontinue the artificial feeding of patients. Indeed,

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* Id. at 154-55 (quoting from a medical evaluation submitted to the court).
* Id. at 155 (quoting from a medical evaluation submitted to the court).
* Id. at 173 (emphasis added).
* Id.
* In re Westchester County Med. Ctr., 531 N.E.2d 607, 613 (N.Y. 1988). When the patient is terminally ill or permanently unconscious, the standards typically are more relaxed. In re Jobes, 529 A.2d 434 (N.J. 1987); Mark A. Hall et al., Health Care Law and Ethics 544-46 (6th ed. 2003).
one thing is clear—the freedom to refuse a feeding tube has not become a duty to do so.

III. ALTERNATIVE PERSPECTIVES ABOUT THE ABSENCE OF A SLIPPERY SLOPE

To be sure, there are alternative theories about the appropriateness of decisions to stop artificial feeding. The literature reports data on the number of feeding tubes inserted, but we do not have data on the number of patients for whom feeding was discontinued or never started. We know that 120,000 PEG tubes were inserted in 1995, but it may be that 820,000 were forgone. Perhaps physicians and families often are too quick to withhold or withdraw feeding tubes, and efforts have not been made to document such alacrity.

This alternative explanation probably is not correct. The lack of meaningful benefit from feeding tubes in many patients who receive them is good evidence that artificial feeding is overused. Moreover, the strict legal rules for withholding or withdrawing feeding tubes indicate that courts have not made it too easy for patients to be deprived of nutrition and hydration. Indeed, nursing homes often are reluctant to discontinue tube feeding for another legal reason—concern that state regulators will cite them for undernourishing their patients.\(^\text{85}\)

It also may be the case that physicians, patients, and families mistakenly believe that artificial nutrition and hydration provide more benefit than they actually do provide and that they overuse feeding tubes for that reason. In this view, as people come to recognize that feeding tubes are less helpful than expected, they will use them less frequently.

There are a couple of reasons why we cannot attribute the lack of a slippery slope to misunderstandings about the value of feeding tubes. First, even if the empirical data on the actual use of feeding tubes are skewed by misunderstandings, we still have the fact that courts have adopted strict legal rules for the withdrawal of feeding tubes. More than a decade after the United States Supreme Court recognized a constitutional right to have feeding tubes withdrawn, the California Supreme Court imposed strict procedural rules for withdrawing feeding tubes from patients who are neither terminally ill nor permanently unconscious (in the \textit{Wendland} case). Second, if families, doctors, and judges become more willing to stop artificial feeding after learning that feeding tubes are not beneficial, their willingness would not amount to a slide down the slippery slope of abuse. Withholding feeding tubes when they would constitute futile treatment would reflect appropriate medical practice.

\(^{85}\) Alan Meisel, \textit{Barriers to Forgoing Nutrition and Hydration in Nursing Homes}, 21 \textit{AM. J.L. \& MED.} 335 (1995).
Note, too, that the existence of misunderstanding about the value of feeding tubes is itself evidence against the existence of a slippery slope with respect to the withdrawal of feeding tubes. On some matters, people’s perspectives coincide well with reality, and on other matters they do not. Some new information is rapidly assimilated. With other new information, the assimilation is very slow. We therefore need to consider why understanding lags behind reality with respect to the value of feeding tubes. For feeding tubes, we might explain the gap between use and benefit in terms of what has been called the “tomato effect.” The tomato effect refers to a phenomenon that is the reverse of what we see with feeding tubes. With feeding tubes, a medical device is used despite a lack of benefit. With the tomato effect, a medical intervention is not used despite the likelihood of benefit. The tomato effect takes its name from the reluctance at one time of Americans to eat tomatoes. Because tomatoes come from a plant family with poisonous species, Americans assumed that tomatoes were poisonous, in the face of evidence from Italy that large consumption of tomatoes was not harmful to one’s health. The tomato effect occurs because empirical evidence is inconsistent with strongly held, preexisting beliefs, and the preexisting beliefs trump the empirical evidence. The overuse of feeding tubes also is an example of strongly held beliefs trumping empirical data. People believe that feeding tubes are beneficial, and they cling to their beliefs in the face of contradictory evidence.

Why do people cling to a belief in the value of feeding tubes? Providing artificial nutrition and hydration to seriously impaired patients ties into social beliefs about the sanctity of life and the symbolic value of nourishment. Because the latter belief is fundamentally important, it is not easily disregarded, even when empirical evidence contradicts it.

For purposes of this article, an important point is that a change in the law also is not sufficient to shake these important beliefs. Even though the courts have opened the door to the discontinuation of tube feeding slightly, the door has not swung open widely.

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86 For example, surgeons were quick to adopt the endoscopic method of gall bladder removal. Within five years of its introduction, more than 80% of gall bladder removals were performed endoscopically. NIH Consensus Development Panel on Gallstones and Laparoscopic Cholecystectomy, Gallstones and Laparoscopic Cholecystectomy, 269 J.A.M.A. 1018, 1018 (1993).


88 An example of the tomato effect in medicine includes the reluctance of physicians to use gold in treating rheumatoid arthritis, even as empirical data reflected gold’s effectiveness. It did not make sense to doctors that a metallic substance would relieve arthritic symptoms. Id. at 2388-89.
IV. IMPLICATIONS FOR THE ASSISTED SUICIDE DEBATE

The apparent overuse of feeding tubes also has important implications for the debate about legalizing physician-assisted suicide. With that debate, too, slippery slope concerns are common, and legitimately so.

While many people oppose physician-assisted suicide under all circumstances, a number of commentators observe that there might be some justifiable cases of assisted suicide. For example, if a patient clearly is close to death from widely metastatic cancer and is suffering severe, unrelenting pain, assisted suicide might be acceptable. Such a patient could refuse life-sustaining medical treatment, and the right to do so reflects respect for both patient autonomy and the desire to spare people intolerable suffering. Both values also could justify a right to assisted suicide for the patient with widely metastatic cancer.

In this view, a limited right to assisted suicide might be permissible. A broad right to assisted suicide could lead to untimely and inappropriate deaths of depressed persons, but a highly restricted right would allow physicians to have all necessary options to protect people from intolerable suffering. Thus, for example, in Oregon the legal right to assisted suicide is a right only for terminally ill persons. In Oregon, assisted suicide is permitted only for patients with “an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months.” By permitting assisted suicide for terminally ill patients and no one else, Oregon limits the right to the class of persons for whom intolerable suffering is a real possibility and who do not enjoy the prospect of a medical cure for their illness.

However, it is argued, even with a limited right to assisted suicide, there is too great a risk that patients will end their lives non-voluntarily. Patients desiring assisted suicide may have impaired competence from a treatable depression, and physicians responding to requests for suicide assistance often are inadequately trained to distinguish rational requests from those driven by depression. It is all too easy for a physician to assume that a patient is very sad because the patient is very sick, that the patient’s mood is an appropriate response to the patient’s condition, and that the desire for suicide

is understandable. However, for many such patients, psychiatric counseling and/or drug treatment will dissipate the desire to end life.

There are other reasons why a limited right to assisted suicide may expand. Patients may feel that they have a duty to die to spare their families the financial and emotional burden of their continued life. The cost of medical care can readily consume hundreds of thousands of dollars for dying patients, and it can be draining psychologically to care for people in their final months.

Patients also may choose to die because they have not received the kinds of support services that would make them willing to stay alive. Funding for care of the disabled always has been precarious. As states and the federal government face growing budget constraints, it is increasingly likely that services for people with serious illnesses will be underfunded. Indeed, it is common for members of the public to complain that too much money is spent on patients in the final year of life. In short, while a limited right to assisted suicide may make sense in principle, in practice it easily could be extended beyond the justifiable cases.

There is no way to know in advance whether legalization of assisted suicide will take us down the slippery slope of abuse. Nevertheless, this country's experience with the right to refuse artificial nutrition suggests that people in the United States would not abuse a freedom to end their lives through assisted suicide. The pressures for assisted suicide also act on patients, families, and physicians regarding decisions to discontinue life-sustaining treatment. Depression, for example, may lead a permanently disabled patient to conclude that staying alive is meaningless and further treatment is useless. Similarly, just as inadequate palliative or other care might lead a patient to commit suicide, it might lead a patient to request the discontinuation of a ventilator, dialysis, or a feeding tube. Critics of a right to refuse life-sustaining treatment specifically invoke concerns about the influence of inadequate care on patient decision-making.

Economic and emotional burdens on the family are a third kind of pressure that present concerns for the discontinuation of life-sustaining treatment, as well as for assisted suicide. In some ways, they are a more serious pressure on life-sustaining treatment decisions. The right to assisted suicide typically is seen as appropriate only for terminally ill patients, while life-sustaining treatment can be needed for many years. Accordingly, the economic and emotional burdens that can be relieved by stopping a ventilator, dialysis, or a feeding tube can be much greater than the burdens relieved by assisting the suicide of someone with a life expectancy of only a few weeks or months.


95 Steven H. Miles, *Informed Demand for “Non-Beneficial” Medical Treatment*, 325 NEW ENG. J. MED. 512, 513 (1991) (reporting one hospital's bill for more than $700,000 for less than a year's care of a patient in a persistent vegetative state).
In addition, just as the law has developed strict safeguards that have to be satisfied before a feeding tube can be withdrawn from incompetent patients who are neither terminally ill nor permanently unconscious, so, too, is the law likely to require strict safeguards before assisted suicide will be permitted. Under Oregon’s Death with Dignity Act, for example, patients cannot engage in physician-assisted suicide unless they are mentally competent and terminally ill, have expressed their choice of suicide orally and in writing, and have satisfied a 15-day waiting period. The fact that the law has carefully cabin the right to have feeding tubes withdrawn suggests that it also will carefully cabin a right to assisted suicide.

In fact, if there are any differences in the law or practice between a right to refuse treatment and a right to assisted suicide, one would expect a more restrictive policy with respect to assisted suicide. The participation of patients and physicians in assisted suicide deaths is viewed as being active, in contrast to the passive participation that takes place when patients, families, and physicians decide to discontinue artificial feeding. If people are hesitant to employ passive measures that lead to a patient’s death, they are likely to be more hesitant to employ active measures that cause death.

The ethical standards of physicians also are an important consideration. Experience with artificial feeding suggests that physicians are restrained in their use of life-ending practices by their moral scruples as much as by the requirements of the law. The studies on tube feeding indicate that physicians are providing artificial nutrition despite the absence of medical benefit. If the feeding is not supplying medical benefit, physicians must be relying on the existence of other benefit. This suggests that physicians are driven substantially by the symbolic importance of always feeding those who are starving. The law may no longer recognize that value, but physicians still do. If physicians approach legalized physician-assisted suicide with a similar attitude, we can predict that the removal of legal obstacles would not overcome the reluctance of physicians to help their patients die by suicide. In other words, the professional ethic in favor of end-of-life care carries great weight independent of the law.

Data from Oregon support the suggestion that many physicians will hesitate to assist a patient’s suicide even if permitted to do so by the law. In a study of physicians’ responses to requests for assisted suicide in Oregon, patients received a prescription in only 18% of the cases, and for 29% of the requests physicians indicated that they were not willing to provide a prescription for assisted suicide under any circumstances.

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97 Linda Ganzini et al., Physicians’ Experiences with the Oregon Death with Dignity Act, 342 New Eng. J. Med. 557 (2000). Note that the 29% figure is probably an underestimate of the percentage of physicians who would never assist a patient’s suicide. Patients often will have a sense of their physicians’
Although there is reason to be reassured about the slippery slope in assisted suicide, risks still remain. Important distinctions between withdrawing a feeding tube and assisting a suicide may make the latter more prone to abuse. For example, commentators have argued that it is more difficult to detect abuses with physician-assisted suicide than with treatment withdrawal. Treatment withdrawals typically take place in hospitals, where many people who would notice irregularities in treatment are involved in the care of the patient. Physician-assisted suicide, on the other hand, often would occur in the privacy of the patient's home. In addition, families often will play a smaller role in decisions about physician-assisted suicide than about treatment withdrawal, leaving them less able to protect patients from overreaching physicians.

Differences among patients also exist between physician-assisted suicide and treatment withdrawal. However, it is not clear which way those differences cut. For example, the fact that patients need be competent for assisted suicide makes that practice less susceptible to abuse than the withholding or withdrawing of nutrition and hydration. Commonly, patients who are candidates for feeding tubes are mentally incapacitated. Still, the important point is that we cannot simply generalize from treatment withdrawal to assisted suicide.

Some commentators cite data from the Netherlands as evidence of the slippery slope when physicians take death-hastening action. According to studies of euthanasia in the Netherlands, physicians often do not observe the country's strict procedural safeguards. In about 25% to 30% of cases involving euthanasia or assisted suicide, for example, patients had not made the required explicit and contemporaneous request to have their lives ended. However, other commentators respond that the slippage in the Netherlands occurs with respect to the letter of the law rather than its spirit. For example, some patients may not satisfy the requirement of contemporaneous and persistent requests to die, but those patients may have given clear evidence of their wishes before becoming incompetent. Moreover, alleged abuses in the Netherlands involve euthanasia rather than assisted suicide, and euthanasia is more subject to abuse. This difference may explain why Oregon's experience with legalized assisted suicide does not appear to have

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led to the kinds of abuses claimed with regard to euthanasia in the Netherlands.\footnote{Amy D. Sullivan et al., Legalized Physician-Assisted Suicide in Oregon—The Second Year, 342 New Eng. J. Med. 598 (2000); Amy D. Sullivan et al., Legalized Physician-Assisted Suicide in Oregon, 344 New Eng. J. Med. 605 (2001).}

Indeed, data from Oregon are quite reassuring on the question of abuse. For example, despite fears that there would be a high rate of assisted suicide as a result of the law, it apparently is used infrequently, with fewer than 0.1% of deaths in Oregon taking place by assisted suicide in the first four years after the law took effect and 0.13% and 0.14% of deaths taking place by assisted suicide in 2002 and 2003, the fifth and sixth years of the law, respectively.\footnote{Katrina Hedberg et al., Five Years of Legal Physician-Assisted Suicide in Oregon, 348 New Eng. J. Med. 961 (2003); Oregon Department of Human Services, Sixth Annual Report on Oregon’s Death with Dignity Act 11 (2004).} By any measure, these are low rates, and they are especially low in comparison with data from the Netherlands. In that country, assisted suicide occurs more than three times more frequently and euthanasia roughly 20 times more frequently than does assisted suicide in Oregon.\footnote{van der Maas et al., supra note 99, at 1701 (reporting that 0.4% of all deaths occurred by assisted suicide and 2.3% of all deaths by euthanasia in the Netherlands in 1995).} In addition to being used sparingly in Oregon, the right to a legalized form of suicide has not encouraged suicide among young people in the state.\footnote{Barbara Coombs-Lee & James L. Werth, Jr., Observations on the First Year of Oregon’s Death with Dignity Act, 6 Psych. Pub. Pol’y & L. 268 (2000).}

It also is reassuring that physicians appear to be complying with the requirements of the Oregon law\footnote{Sullivan et al., supra note 101, at 602; Oregon Department of Human Services, supra note 102, at 12.} and that decisions to die by assisted suicide apparently are not being driven by poor education, lack of insurance, or inadequate palliative care.\footnote{Ganzini et al., supra note 97, at 561.} Physicians also have not been quick to assist a patient’s suicide, granting only 18% of patients’ requests for assisted suicide.\footnote{Coombs-Lee & Werth, supra note 104; Herbert Hendin et al., Physician-Assisted Suicide: Reflections on Oregon’s First Case, 14 Issues L. & Med. 243, 251-54 (1998). In this regard, assisted suicide patients in Oregon are much less likely to receive a psychological evaluation now than when assisted suicide was first legalized. In 1998, 31% of patients had received a psychological evaluation, compared with 5% in 2003. Oregon Department of Human Services, supra note 102, at 11. Moreover, questions have been raised about a patient with a long history of depression who received a prescription for a life-ending dose of barbiturates under Oregon’s law, but who died of lung cancer without using the barbiturates. John Schwartz, Questions on Safeguards in Suicide Law, N.Y. Times, May 7, 2004, at A1.} Still, as critics of assisted suicide have observed, there may be abuses lurking in the Oregon data. We do not know whether patients in Oregon undergo an adequate psychiatric evaluation,\footnote{Wesley J. Smith, Dependency or Death? Oregonians Make a Chilling Choice, Wall St. J., Feb. 25, 1999, at A18.} whether physicians know their patients well enough to judge the voluntariness of their decisions,\footnote{Ganzini et al., supra note 97, at 561.} or how careful Oregon physicians are in adhering to the law’s requirement that the

\footnote{Sullivan et al., supra note 101, at 602; Oregon Department of Human Services, supra note 102, at 12.}
patient be terminally ill to qualify for assisted suicide. We also do not know whether abuses will become more common over time. We need more data from Oregon to fill out the picture.

In the end, our discussion cannot provide a complete response to the slippery slope concern. Only more experience with legalized assisted suicide can answer the question about slippery slope abuses. Nevertheless, our discussion adds important considerations to the slippery slope analysis.

CONCLUSION

Commentators have rightly expressed concern about the apparent overuse of feeding tubes. Artificial nutrition is not without side effects, and it appears that many patients suffer the complications of tube feeding without realizing any countervailing benefit. At the same time, it is important to recognize the positive message from the data. When cost pressures can make it too easy to devalue the life of a dying patient, society may benefit from an ethic that errs on the side of using life-preserving practices beyond their life-preserving function. In addition, the tendency of patients, families, and physicians to resist the withholding of artificial nutrition suggests that patients and physicians also may resist the use of assisted suicide, even if that practice is legalized.