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## Rethinking the Role of Tube Feeding in Patients with Advanced Dementia

A byproduct of the aging of the population has been a dramatic rise in the rate of Alzheimer's disease and other types of dementia. A conservative estimate is that there are currently 4 million people in the United States with dementia.<sup>1</sup> In the final stage of dementia, patients are typically unable to walk or to feed themselves, they are incontinent and aphasic, and they have lost the capacity to have relationships with other people. Family members or other surrogate decision makers must make difficult and often painful decisions about limiting care.<sup>2</sup> Should they authorize surgery, hospitalization, intravenous medication? Is a proposed treatment excessively burdensome to a patient who cannot understand its purpose and who is nearing the end of life?

Of the many decisions that family members and physicians must make about medical care for patients with dementia, none is more heart-wrenching than the decision about artificial nutrition and hydration. Despite an extensive bioethical literature arguing that the use of feeding tubes is not mandatory<sup>3,4</sup> and despite the opinion by a majority of the Supreme Court justices that artificial nutrition and hydration constitute a form of medical care,<sup>5</sup> family members repeatedly state that they cannot let a relative "starve to death." They often feel they have no choice but to authorize the placement of a feeding tube.<sup>6</sup> Furthermore, many physicians are either unfamiliar with or unpersuaded by the bioethical arguments or the law. A study of 1446 physicians and nurses found that 34 percent of the respondents who were medical attending physicians and 45 percent of those who were surgical attending physicians believed that even if all forms of life support, including mechanical ventilation and dialysis, are stopped, nutrition and hydration should always be continued.<sup>7</sup> As a result, when patients with advanced dementia start to have difficulty swallowing or lose interest in eating, as happens frequently in such patients,<sup>8</sup> the decision is often made to insert a feeding tube. Percutaneous endoscopic gastrostomy tubes are being used with increasing frequency. In 1995, gastrostomy tubes were inserted in

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121,000 elderly patients in the United States<sup>9</sup>; approximately 30 percent of these patients had dementia.<sup>10</sup>

How can we help physicians and surrogate decision makers make compassionate, morally sound, and technically reasonable decisions about the treatment of persons with advanced dementia? Ideally, such decisions should reflect the preferences and values of the patient<sup>11</sup> and should arise from a clear determination of the overall goals of care.<sup>12</sup> Unfortunately, the preferences of the patient are seldom known, and the goals of care — such as prolonging life, promoting independence in activities of daily living, or maximizing comfort — cannot readily be translated into practice.<sup>13</sup> For the specific case of artificial nutrition and hydration, perhaps the most emotionally troubling of all the treatment-limitation issues, data accumulated over the past decade can aid in the decision-making process. Surrogate decision makers for demented patients who opt for feeding through a gastrostomy tube usually do so because they hope to extend life and prevent aspiration pneumonia, because they wish to prevent suffering, or because their values, particularly their religious beliefs, dictate that sustenance must never be withheld.<sup>14,15</sup>

Recent information supports the conclusion that tube feeding seldom achieves the intended medical aims and that rather than prevent suffering, it can cause it. Moreover, just as many secular bioethicists have argued that feeding tubes are not required in patients with advanced dementia, in recent years several religious ethicists have come to the same conclusion. Given the weight of the scientific evidence that gastrostomy tubes are not effective and given the lack of a compelling ethical argument for their use, I suggest that physicians, nursing homes, and hospitals adopt a policy of recommending that gastrostomy tubes not be used in patients with advanced dementia.

## **Do Feeding Tubes Work in Patients with Dementia?**

A gastrostomy tube is placed in a patient to provide nutrition and hydration. Although in theory tube feeding can provide adequate nutrition in a patient with dementia, in reality this is often not the case. Because of problems with diarrhea, clogging of the tubes, and the tendency of patients with dementia to pull out the tubes, nutritional status often does not improve with the use of feeding tubes.<sup>16</sup>

Aside from maintaining nutrition, one of the primary reasons to use a feeding tube is to interrupt the cycle of eating, aspiration, and then pneumonia that is so common in patients with advanced dementia. It is now clear from multiple observational studies that feeding tubes do not prevent aspiration in patients with dementia.<sup>17</sup> The continued risk of aspiration appears to result from reflux of gastric contents and aspiration of saliva. I am unaware of any randomized study that has compared the risk of aspiration with and without tube feeding in patients with advanced dementia. Hence, whether feeding tubes reduce the risk of aspiration is unclear. Some studies have found that jejunostomy tubes may be slightly less likely to result in aspiration than gastrostomy tubes, but other studies have not confirmed this finding.<sup>18</sup> Despite the lack of evidence that tube feeding reduces the risk of aspiration in persons with dementia who have difficulty swallowing, the standard of care in many institutions is to withhold oral intake and to insert a gastrostomy tube if there is videofluoroscopic evidence of aspiration.

The use of feeding tubes in persons with dementia is thought to prolong life. In fact, however, it has been remarkably difficult to demonstrate any difference in longevity between patients with feeding tubes and those without tubes. A carefully performed study of the outcomes of nursing home patients with advanced dementia and eating disorders found that the patients who were fed through a gastrostomy tube and those who continued to be fed by hand had the same survival rates.<sup>19</sup> Other studies have confirmed that swallowing or eating problems in patients with dementia are

independently associated with mortality, regardless of whether a gastrostomy tube is in place.<sup>20</sup> These were observational studies, however, not randomized trials. Despite adjustment for coexisting conditions, the patients who were fed through a gastrostomy tube may have been sicker than the patients who were fed by hand, and the equivalent survival rates may indicate that the patients with feeding tubes lived longer than they otherwise would have. It is also possible that there is a subgroup of persons with dementia and feeding problems whose lives are prolonged by the use of feeding tubes — for example, persons with vascular dementia who have difficulty swallowing because of a small brain-stem stroke.

There is a more plausible explanation for the failure to find a survival advantage with the use of gastrostomy tubes — or more generally, the failure to find that such tubes are effective.<sup>21</sup> Difficulty with eating is a marker of severe dementia, which is a uniformly fatal disorder. Since eating is typically among the last activities of daily living to become impaired in persons with dementia,<sup>22</sup> difficulty with eating unfortunately signals that the person has entered the final phase of the illness.

## **Do Feeding Tubes Promote the Comfort of Patients with Advanced Dementia?**

Families and physicians often believe that the use of a feeding tube will promote the comfort of a person with advanced dementia. Someone with inadequate nutrition to maintain his or her weight is widely assumed to suffer from the adverse consequences of dehydration or malnutrition. A gastrostomy tube is therefore used as a means of preventing a protracted and painful death. Is a person with advanced dementia who has difficulty eating actually uncomfortable in the absence of artificial nutrition and hydration?

It is difficult, if not impossible, to obtain data on the subjective experience of patients with advanced dementia who stop eating and drinking. We can, however, try to extrapolate from the experience of patients dying of cancer or stroke who have anorexia or profound dysphagia and who are sufficiently lucid to describe their sensations. A growing literature from the hospice movement indicates that such patients do not experience more than transient hunger and that any thirst they experience can be assuaged with the use of ice chips and mouth swabs.<sup>23</sup> Moreover, many elderly patients do not feel distress from dehydration because they have an impaired thirst mechanism.<sup>24</sup> Whereas in other circumstances the inability to experience thirst is maladaptive, in the terminal phase of Alzheimer's disease, it minimizes discomfort. A few observers have suggested that maintaining hydration promotes comfort by preventing delirium,<sup>25</sup> but most clinicians find that, on balance, hydration without nutrition causes discomfort, because it prolongs the process of dying and increases the production of urine and sputum.<sup>26</sup>

Not only do gastrostomy tubes fail to prevent suffering, they may actually cause it. The percutaneous insertion of a gastrostomy tube, the most common method used, requires upper endoscopy, an incision in the abdominal wall, and intravenous sedation. Once the endoscope is in place, the permanent gastrostomy tube is threaded into the stomach, anchored in place, and pulled through the abdominal wall. Although it is a relatively simple procedure, the long-term rate of complications has been reported to range from 32 percent<sup>27</sup> to 70 percent.<sup>28</sup> The problems, such as superficial skin infections and dislodgment or clogging of the tube, are usually relatively minor.

When tube feeding is used as a permanent alternative to oral feeding, patients are deprived of the enjoyment derived from eating. Patients with dementia who are fed through a tube no longer have the opportunity to taste food or experience the social satisfaction associated with mealtimes. Feeding by hand is an act of nurturing that cannot be

accomplished by hanging a bag of nutrients on a pole for delivery through a tube.<sup>29</sup> These problems might be overcome — but only in some instances and to a limited extent — by supplementing tube feeding with the provision of small amounts of food to persons with dementia who have difficulty swallowing.

The most serious potential adverse consequence of tube feeding is the need to restrain the patient. A patient with advanced dementia does not have the cognitive capacity to understand why a tube is protruding from the abdominal wall and often pulls it out. To prevent the patient from removing the tube, the physician frequently orders the use of restraints. In one study, 71 percent of patients with dementia who had feeding tubes were restrained, regardless of the type of tube used.<sup>30</sup> Even with educational programs designed to reduce the use of restraints in nursing homes, the presence of a "treatment device" such as a gastrostomy tube was associated with the use of restraints.<sup>31</sup> The experience of being tied down is distressing, even to persons with severe dementia, and it often results in agitation, which in turn may lead to the use of pharmacologic sedation.<sup>32</sup> In summary, data collected over the past decade suggest that gastrostomy tubes are not necessary to prevent suffering and may actually cause suffering.

## **Is Withholding Artificial Nutrition Morally Wrong?**

Some believe that failing to provide nutrition and hydration for patients with dementia is morally wrong. Geriatricians and ethicists have argued that artificial nutrition and hydration are forms of medical therapy that can legitimately be withheld if their risks, judged according to the patient's values, outweigh their benefits.<sup>33</sup> Patients or their surrogates who choose tube feeding are most often influenced by the inestimable value of life itself,<sup>34</sup> and this value is frequently based on a set of religious beliefs.

Although religious values may prompt some persons to favor any intervention that offers a chance, however small, of prolonging life, even these values are not absolute. The Roman Catholic position on the use of artificial nutrition and hydration near the end of life is that although "there should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration," this approach is warranted only as long as it "is of sufficient benefit to outweigh the burdens involved to the patient."<sup>35</sup> The Orthodox Jewish tradition, also commonly assumed to advocate any intervention that might prolong life, in fact rejects interventions that cause or prolong suffering.<sup>36</sup> Equally important, many Orthodox Jewish thinkers regard the dying person in a special light and argue against "impediments to dying" in the final year of life.<sup>37</sup> For surrogate decision makers who evaluate the decision on religious grounds, the ethical question is to determine whether the use of a feeding tube may have disadvantages and, if so, whether they outweigh the possible benefits.

## **A New Standard of Care**

Making decisions about artificial feeding in patients with advanced dementia has been difficult because it has hinged on assessing the quality of life. Advocates for withholding gastrostomy tubes have based their argument principally on their beliefs about patients' comfort, not on data about outcomes.<sup>38,39</sup> I have argued, in contrast, that recommendations about tube feeding should be based on its effectiveness. Gastrostomy tubes have not been shown to prolong life, ensure adequate nutrition, or prevent aspiration, and there is neither a secular nor a religious ethical imperative to use them. In addition, they are not necessary to prevent suffering. Since there are few if any benefits and there is considerable potential for harm, the routine use of gastrostomy tubes in patients with severe dementia is not warranted. Physicians, professional organizations, hospitals, and nursing homes should recommend to patients and their families that nutrition

be provided orally, not through a feeding tube, during the final stage of dementia. This approach is distinct from the broader recommendation that patients with advanced dementia receive exclusively palliative care.<sup>40,41</sup> Decisions about hospice care as opposed to curative care are typically based on an assessment of the quality of life. Decisions about hand feeding versus tube feeding can be made by weighing the pros and cons of gastrostomy tubes.

There is just enough uncertainty associated with tube feeding, just enough chance that a tube might, in some unanticipated situations, prolong life or provide comfort in patients with dementia, that family members should be able to request a feeding tube if they believe it is truly what the patient would have wanted. However, if family members are unable to make a decision and if there are no extenuating circumstances, the physician should assume that a person with advanced dementia would not want a gastrostomy tube. An analogous default position forms the basis of the do-not-resuscitate policy of some nursing homes. These facilities advise that cardiopulmonary resuscitation not be attempted, and in cases in which the resident or a surrogate cannot decide, a do-not-resuscitate order is written.<sup>42</sup>

The assumption that a patient would not want a gastrostomy tube reflects the empirical data. A study of 421 randomly selected, competent persons living in 49 nursing homes found that only one third would favor a feeding tube if they were unable to eat because of permanent brain damage.<sup>43</sup> Moreover, 25 percent of the respondents who initially favored tube feeding changed their minds about its acceptability when they learned that they might have to be physically restrained to facilitate use of the tube.<sup>44</sup> The proportion of respondents who favored feeding tubes might have been even smaller if they had been informed about the lack of efficacy of gastrostomy tubes in patients with dementia, just as in another study many elderly patients who initially said they would want cardiopulmonary resuscitation if they had a cardiac arrest changed their minds when they learned about the poor outcome of attempted resuscitation.<sup>45</sup>

## **Obstacles to a New Standard of Care**

There will undoubtedly be resistance to attempts to alter the standard approach to difficulties with eating in patients with dementia. There may also be legal and regulatory barriers. However, in the one case dealing with artificial nutrition and hydration that has reached the U.S. Supreme Court, that of Nancy Cruzan, the majority of justices equated artificial nutrition and hydration with medical therapy. At the same time, the Court upheld the right of state legislatures to require that a surrogate decision maker for a patient provide evidence that a decision reflects the patient's previously stated preferences. Two states, Missouri and New York, have adopted such a policy for decisions about artificial nutrition and hydration. They have statutes requiring "clear and convincing" evidence that an incompetent patient would not have wanted tube feeding in order for a surrogate decision maker to authorize the withholding of tube feeding. The assumptions underlying such laws are that tube feeding is a life-sustaining treatment and that the state has an interest in protecting life.

Such laws are clearly applicable to patients like Cruzan, who was in a persistent vegetative state, and who could be maintained by a feeding tube indefinitely. The relevance of the laws to patients with advanced dementia, a condition in which medical intervention offers little chance of prolonging life, is highly questionable. As Lo and Steinbrook have pointed out, "It would be irrational to interpret the Cruzan ruling as requiring that futile treatment be administered to incompetent patients merely because they had not given clear and convincing evidence of refusal."<sup>46</sup> In subsequent Supreme Court cases,<sup>47,48</sup> which may be more germane to patients with advanced dementia (even though the cases were prompted by a question about the constitutionality of bans on assisted suicide), the majority of justices stressed

that dying patients have a right to palliative care. By implication, states should remove existing barriers to palliative care for patients near the end of life, including restrictions on the right to withhold artificial nutrition and hydration.<sup>49</sup>

Regulations governing nursing homes are another potential barrier to the implementation of a new standard of care. Federal regulations require nursing homes to ensure that their residents have "acceptable parameters of nutritional status, such as body weight and protein levels, unless the resident's clinical condition demonstrates that this is not possible."<sup>50</sup> A specific example of a clinical condition in which maintenance of nutrition may be impossible is advanced disease, according to the regulations. Adherence to federal guidelines, which are intended to promote high-quality care and to prevent abuse, should focus on ensuring that nursing home residents with eating problems are adequately assessed, perhaps by a trained therapist. Nursing homes will need to supply evidence that the cause of the feeding problem has been established and that appropriate efforts are being made to hand-feed the resident. Given the data on the lack of efficacy of tube feeding and the risk of adverse effects, routine insertion of a gastrostomy tube as a strategy for complying with government regulations makes no more sense than the use of restraints for nursing home residents who fall.

There is a pervasive failure — by both physicians and the public — to view advanced dementia as a terminal illness,<sup>2</sup> and there is a strong conviction that technology can be used to delay death.<sup>51</sup> The first step in changing these attitudes is for physicians to acknowledge that feeding tubes are generally ineffective in prolonging life, preventing aspiration, and even providing adequate nourishment in patients with advanced dementia and that they can have adverse consequences — principally the need for restraints. Although the use of feeding tubes is not unequivocally futile in all cases,<sup>52</sup> balancing the risks and benefits leads to the conclusion that they are seldom warranted for patients in the final stage of dementia. Once physicians are aware of the data on tube feeding, they can move from a position of discussing the issue in a nondirective manner, as is currently advocated by some authors,<sup>53</sup> to recommending that artificial nutrition not be provided. There will always be exceptions and unusual circumstances. However, patients with dementia who have feeding difficulties and their families deserve the guidance of physicians in this highly charged area. Physicians should take the initiative in promoting hand feeding and allow state legislatures and nursing home regulators to follow their lead.

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