

Initiating Tube Feeding in the Demented Elderly: Motivation for Change

Marc Freiman, Joshua Minsky* and Michael A Grodin

Department of Health Law, Bioethics & Human Rights, Boston University School of Public Health, Boston Medical Center, USA

Abstract

While the medical literature does not support the placement of feeding tubes in the demented elderly it remains a very common practice. Through an analysis of medical evidence as well as the decision-making processes surrounding the placement of feeding tubes we hope to further clarify the complexity involved in the decision to perform this procedure and why, despite the evidence, it still happens on a regular basis. Furthermore, through an analysis of theories of change we will analyze how frame-shifts in medicine occur and put forward suggestions so that feeding tube placement is not performed unnecessarily in patients with severe dementia.

Keywords: Feeding-tubes; Advanced enteral nutrition; Dementia; Severe-dementia; Frame-shift; Bioethics

Introduction

A sixty-three year old woman with advanced fronto-temporal dementia was transferred from a nursing home to hospital with a request for feeding tube placement. The patient had end-stage dementia and would not eat of her own volition. The medical team in the hospital felt that the procedure was not clinically indicated but they felt they had to follow the family's wishes. A percutaneous gastric tube was placed in the operating room. The patient subsequently pulled out the feeding tube, developed peritonitis and required emergent open laparotomy with partial gastric resection. A percutaneous jejunostomy tube was placed at this surgery, which the patient also subsequently removed. The patient died with hospice care approximately one week later.

While the medical literature does not support the placement of feeding tubes in the demented elderly it remains a very common practice, with some hospitals performing the procedure on approximately 40% of their patients admitted with severe cognitive impairment [1]. Through an analysis of medical evidence as well as the decision-making processes surrounding the placement of feeding tubes we hope to further clarify the complexity involved in the decision to perform this procedure and why, despite the evidence, it still happens on a regular basis. Furthermore, through an analysis of theories of change we will analyze how frame-shifts in medicine occur and put forward suggestions so that feeding tube placement is not performed unnecessarily in patients with severe dementia.

What is the Clinical Evidence for Advanced Enteral Feeding in Patients that also have Advanced Dementia?

A seminal Cochrane review performed in 2008 found that there was *insufficient evidence* of effectiveness of enteral feeding tubes for people with advanced dementia for multiple outcomes. Their primary outcome was mortality; there were no randomized trials identified. Of the six studies that examined mortality only one study initially reported a significant survival advantage of nasogastric feeding vs. oral feeding, but the statistical significance disappeared when the authors corrected for co-morbidities. All of the remaining studies either showed *no difference* in mortality (3 studies) or an *increased* risk of mortality (2 studies). Other parameters investigated included quality of life, nutrition, pressure ulcers, and psychiatric symptoms of dementia; none of the studies showed an advantage to advanced enteral nutrition in these situations [2]. A comprehensive meta-analysis performed a decade earlier found similar results [3]. There were significant shortcomings of the studies examined in the Cochrane review: none of the studies reported comparisons of key characteristics between the

intervention and control groups. For example, in two studies it was not clear if any patients in the control group actually had dementia. There was also significant under-reporting of key methodological components, such as the degree of dementia, the indications for feeding tube placement, as well as a high risk of bias in the studies due to the open study design [2].

A more recent prospective cohort study examined Medicare data from all US nursing homes (over 36,000 patients in total) and looked at patients with advanced dementia and new onset eating problems and the association of feeding tube placement with mortality. The clinical co-morbidities, age and type of eating difficulties (dehydration, inability to consume fluids and/or solids, chewing/swallowing problems, etc) were similar between the two groups. They found that the one-year survival rate was no different with or without a feeding tube. Dr. Teno's group also examined the timing of feeding tube placement at 1 through 4 months from the onset of diagnosis of eating difficulties to determine whether the timing of feeding tube insertion would play a part in the patients' overall clinical status; the thought being that if the feeding tube was placed earlier in the clinical course it may have a more substantial effect on outcomes. They found that there was no significant difference in mortality between the groups [4].

Feeding tube insertion is not a benign procedure. It has been associated with operative complications, erosions of the tube into the pleural cavity, gastric reflux, peritonitis and sepsis, bowel obstruction, among others [3]. An editorial in the New England Journal of Medicine regarding feeding tube placement noted that, while the data is not conclusive, it has consistently failed to show benefit for patients with dementia. Furthermore, dementia is a uniformly fatal disease, and eating is one of the last activities of daily living to erode. Finally, despite the lack of evidence for the prevention of aspiration, impaired swallowing is often an *indication* for feeding tube placement. The author goes on to note "I suggest that physicians, nursing homes, and hospitals adopt a policy of recommending that gastrostomy tubes not be used in patients with advanced dementia." The most striking feature

*Corresponding author: Joshua Minsky, Department of Health Law, Bioethics & Human Rights, Boston University School of Public Health, Boston Medical Center, USA, E-mail: jminsky@bu.edu

Received June 24, 2013; Accepted July 26, 2013; Published July 31, 2013

Citation: Freiman M, Minsky J, Grodin MA (2013) Initiating Tube Feeding in the Demented Elderly: Motivation for Change. J Palliative Care Med 3: 153. doi:10.4172/2165-7386.1000153

Copyright: © 2013 Freiman M, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

of this editorial is that it was written 13 years ago [5].

Evidence from the past decade has consistently failed to demonstrate that placement of feeding tubes improves quality of life or mortality, yet it remains a common procedure. When dealing with the complexity of feeding at the end of life it is necessary to examine the decision-making process involved in placing a feeding tube, namely the use of surrogates and the effects of physician framing on the decision-making process.

The principle of autonomy allows for a patient to make informed medical decisions for him or herself [6]. However, if a patient lacks capacity (the ability to understand the nature and consequences of their actions including the risks/benefits of treatment as well as the alternatives) we must rely on the patient's prior wishes, which are commonly either a living will (describing what the patient would want in certain situations) or a health care proxy/surrogate [7]. A surrogate is a person chosen by the patient or the state (if the patient has no advanced directive and has not identified a surrogate themselves) to make decisions on behalf of the patient. There are two principles that govern surrogate decision-making: the first is *substituted judgment*. Substituted judgment asks 'what would the patient have wanted if he or she were able to make decisions'. Substituted judgment is the preferred method of surrogate decision-making, but often it is not known what a patient would have wanted in a particular situation. The second principle is the *best interest standard*, used only if substituted judgment is not possible, which asks 'what would be best for the patient'; different people may interpret what is 'best for the patient' to be significantly different actions or treatments.

The accuracy of surrogate decision makers has been reviewed in the literature – one meta-analysis examined 16 studies that involved hypothetical scenarios to determine how congruent the answers were between surrogate and patient. Surrogates accurately predicted what the patient actually wanted only 68% of the time, they were the least accurate with scenarios involving dementia [8]. Researchers did not find relationship between who the surrogate was (spouse, child, relative etc.) and the prediction of accuracy, nor was there a clear trend towards providing unwanted treatment or withholding desired treatment. Interestingly, there was no difference in prediction of accuracy whether the surrogate was chosen by the patient or legally assigned. Whether or not a surrogate had a discussion with the patient regarding his or her preferences did not have a significant difference in terms of prediction of accuracy [9,10].

Yet as bad as surrogate decision makers were in predicting what patients want for their care, they were consistently more accurate than the physicians caring for the patients in all 4 studies that were examined the physicians were approximately 10-20% less accurate than the surrogate in predicting what type of care their patient would want at the end of life [11-14].

How well do the patients themselves know what they want? It turns out that what patients want from their care is dependent on their perceptions of what medical treatment can actually offer. In one unique study, Diem et al. "watched all the episodes of the TV programs ER and Chicago Hope during the 1994-1995 viewing season and 50 consecutive episodes of Rescue 911" to compare CPR outcomes within the shows to those reported scientifically [15]. The results showed survival rates higher than the highest statistics reported in the literature, as well as a much younger and healthier demographic than those actually experiencing cardiac arrest. Yet this portrayal is important because it has been noted that upwards of 80% of patients over the age of 62 reported that they learned about CPR from viewing

television [16]. Medicine and patient values are not occurring in a vacuum; there is a profound effect of culture (and popular-culture) on what patients expect from the medical field. There is some evidence to suggest that the incidence of feeding tube placement varies depending on the patients' race [4,17]; it is likely that ethnic, racial, and religious considerations also play a role in patients' understanding of feeding tubes.

How physicians present information will also affect how patients make decisions. Murphy et al. asked patients at a geriatric outpatient practice whether they wanted CPR before and after discussing the probability of survival; they found that when faced with a scenario involving an acute illness, 41% of the patients wanted CPR, but when they were educated by physicians that their probability of survival was approximately 10-17%, the number of people desiring CPR dropped to 22% [18].

Why is it so Hard to Change Medical Practice?

Health care professionals working with patients at the end of their lives have all been faced with this question: "Isn't my family member going to starve if we don't give them this feeding tube?" This leads to the fundamental question: is artificial feeding a right or a medical therapy? A broad consensus of bioethicists view artificial feeding as a medical therapy [19], as does the law [20]. It is not enough to quote this data to families – physicians must understand that providing nutrition is a symbol of support, nurturing and care. Taking nutrition away is extremely distressing to people – in one national survey in Japan, 70% of family members experienced a *high degree of emotional distress*, including helplessness and guilt in particular. Furthermore, poor patients and those with disabilities may have the fear that they will be denied lifesaving treatments because of their status in society [21].

Withholding or withdrawing care is also a distressing situation for patients and families to be in. Families often have concern that the healthcare team will be 'killing' the patient if they do not provide what is seen as life-sustaining treatment. Withdrawing care tends to be even more distressing to family members than withholding care, as there is the general feeling that the doctors and nurses will be taking away therapy that is keeping the patient alive. So why is this not the case when physicians withhold care? If the doctor denies a treatment, it is because the risks outweigh the benefits, the underlying disease causes the death of the patient, not the withholding of treatment. Dementia is often under-recognized as a progressive and fatal disorder [5]. Likewise, when care is withdrawn it is because *the goals of treatment were not met*. This is why it is absolutely essential to discuss the goals of care prior to initiating a treatment; it is also at this point that health-care professionals can elicit what the family's expectations regarding treatment are. Physicians rarely know for sure what the outcome of medical care will be. Often it may be more reasonable to offer a time-limited trial of a particular therapy and then reassess depending on what the goals of care are.

There are significant systematic factors that encourage the use of feeding tube placement in patients with advanced dementia: in one study up to 37% of demented patients that underwent feeding tube placement were mandated for transfer to a nursing home [22]. There has been mention in both the scientific and public literature that nursing homes may be using feeding tube placement as a cost-saving measure – the time required to feed a resident by hand by a trained staff member is much more expensive than simply adjusting a continuous tube feed. Furthermore, in many states Medicaid reimburses more money for a patient with a feeding tube than one without, and weight loss is a quality measure that needs to be reported to Medicare and

Medicaid for all long-term nursing home residents. One study observed an increased use of feeding tubes among patients living in for-profit nursing homes; but while the financial incentive exists, the association is not yet proven [23]. Misalignment of financial incentives is one of the primary reasons cited for recommending a treatment that is proven to be less efficacious [24].

The medical community is often eager to perform an intervention than to withhold one and tends to be pro-technology even when the evidence does not fully support it. The desire for new technology may undermine long-term comparative trials; one example of this can be seen with the COURAGE study, which was critiqued for only studying bare-metal stents as opposed to the new drug-eluting stents that emerged while the trial was ongoing [24]. Seen in this context, it is very difficult for a physician to recommend doing nothing when there may be a slim chance that doing 'something' (in this case, placing a feeding tube) could help the patient or the family. While we have the technology, this does not mean that we should always use it.

Meta-theory of Frame Shifts and How to Bring about Change

The sociologists Benne and Chin identify 3 different strategies of change – the rational-empirical, normative-reductive, and power coercive models [25]. All three models have played a role in causing frame shifts in medicine.

In the 'Rational-Empirical' model, it is generally thought that people are rational beings, and once they determine that a certain change is worthwhile they will implement the change. In the 'Rational-empirical' model it was thought that research would be performed, the research would be published, and physicians would see the published research and change their behavior. When evidence was *not* brought into practice, rather than abandon the framework altogether people blamed each part of the process individually-- the initial thought was that there was simply a lack of research or high quality evidence, when the evidence was robust it was thought to be a knowledge gap (i.e. the physician simply was not aware of the new research), and finally a behavior gap (researchers at the time would often refer to 'susceptibility of the physician to a new idea'). The transfer of information in this system was one way: it flowed from the experts to the disciples [26]. It seems that the evidence has had *some* effect on the placement of feeding tubes, one estimate notes that the mean rate of feeding tube placement per 100 admissions is down from 7.9 in 2000 to 6.2 in 2007, yet this is only a minor decrease compared to the amount of evidence collected [1]. Yet clearly there is more work to be done in disseminating the research already performed: in one study up to 82% of physicians referred a demented patient for the placement of a feeding tube in order to prevent aspiration pneumonia, despite the fact that feeding tube placement has not been shown to reduce the risk of this disease [27].

In the normative-reeducative model change is largely 'value based' as opposed to rational. Change is motivated by dissatisfaction with the values of the status quo and is changed through the discussion and exploration of many different stakeholders in order to clearly define new values. Information in this system is free flowing and multidisciplinary and is in direct contrast to the 'Rational-empirical' model where the data determines the 'right' way of how the system should operate. In this system, the overall change that occurs is a change in norms or context; therefore it has the potential to have the most longstanding effects. One way to change norms is to have leaders set the standard for practice; in this way guidelines from societies can be helpful to

communicate what the norm of practice is or should be. For example, the American Geriatric Society recently released a guideline in association with the American Board of Internal Medicine Foundation for the 'Choosing Wisely campaign,' which delineates several items that physicians and patients should question, as they are not supported by clinical evidence. The use of percutaneous feeding tubes is the first item on this list [28]. However, more guidelines and policies are needed to help guide physicians. Despite the fact that surrogates tend to not be accurate decision makers, their major concerns are the patient's quality of life and prolonging life, which are topics that physicians can help to explore in conjunction with known clinical data and emotional support [29]. Here, a simple change in language could help family members cope-rather than focusing on what will not be done physicians should communicate what will be done for the patient. Rather than focusing on not placing a feeding tube the focus should be on keeping the patient comfortable, and in particular mention the use of comfort feeding. Although the physician may not place a feeding tube, this does not mean that he or she will let the patient starve or suffer [30].

In the 'power-coercive' approach to change, those that deviate from the organizational vision are punished. The power used may be political or positional, and often involves economic sanctions. This model works best when utilized in conjunction with the 'rational-empiric' and 'normative-reeducative' models of change; isolated punishment tends to not be effective if there are no cultural norms or data to support it. As has been stated, the incentives currently *favor* placing a feeding tube. Change in this sphere needs to occur at the policy level and there should be financial disincentives for performing unnecessary procedures, or at the very least financial and systemic incentives (such as the pressure for feeding tubes to be placed prior to transfer to a nursing home facility) should be eliminated. There should also be more education for nursing home administration and staff regarding current reporting measures: while weight loss is a quality measure reported to Medicare and Medicaid for all long term nursing home residents, as long as there is documentation that the weight loss is expected from an end-stage disease (such as dementia) or that the nursing home has an active plan they are carrying out (including comfort feeding and nutritional supplements) the nursing home will not be penalized.

What Happens when we Disagree?

There are generally two reasons why disagreement arises between the health care team and the family unit: poor communication (which is common) or true disagreements regarding value (less common). It is ethically problematic for the physician to simply acquiesce to what a family wants if it is outside the scope of normal medical practice, but it is also ethically problematic if the physician unilaterally refuses the family request. The physician has no ethical obligation to provide care that is not consistent with the patient's goals of care; this again demonstrates the need to *elicit* the goals of care *prior* to initiating treatment [31]. Often providers will use the concept of 'medical futility,' though this concept has been very difficult to actually define in a meaningful way [32]. It may often be helpful to enlist a palliative care or ethics consult to help determine the nature of the disagreement and to act as a third party in mediation [30].

In the rare scenario where there is true disagreement between the family unit and health-care team regarding value (disagreement on the appropriate goals of care) there needs to be an explicit system of dispute resolution within the institution. This will often involve patient advocates, social workers, an ethics consult team, and if necessary legal counsel. If, after involving the above parties, a resolution is still not able to be reached the health-care team should initiate a search to transfer

the patient to another provider or facility that is willing to provide the disputed care, though often this is technically difficult to accomplish. Finally, if transfer of the patient is not possible it may be reasonable, with notice, to discontinue the disputed treatment, provided the hospital review committee is in agreement with the health-care team [33].

Conclusion

Despite the clinical evidence to the contrary, feeding tube placement in the demented elderly remains a common procedure. The reasons for this are complex and include surrogate decision makers, physician framing, emotional stress regarding end of life decision-making, and economic and cultural incentives. To truly change practice will involve complex action at many different levels.

The scientific community must improve the dissemination of clinical research to physicians to allow them to be familiar with the data surrounding clinical outcomes with feeding tubes. It is also important to change cultural norms surrounding feeding tube placement through the use of vocal opinion leaders as well as through practice guidelines from major specialty societies. Although a significant association has been found between the type of nursing home facility and the number of feeding tubes placed, causation has not yet been proven and further study needs to be performed in this area [1]. Regardless, financial and systemic incentives for placement of feeding tubes in the demented elderly should be eliminated.

Health care professionals also must be aware of the emotional stress that is involved with end of life decision-making, both on the side of the surrogates/families as well as the healthcare teams. Simply changing our language to focus on what *will* be done rather than what *won't*, *may* improve patient satisfaction and we encourage utilizing palliative care and other similar service consults to help delineate goals of care and mediate conflict; further study should be done regarding patient and caregiver satisfaction with these interventions.

Institutions should have a standardized system of dispute resolution when goals of care cannot be agreed upon. This process should involve a multidisciplinary committee that focuses on dispute mediation and eliciting the issues at hand. In order to truly change the practice of feeding tube placement in advanced dementia the medical community must apply all of the above models for change.

Acknowledgments

The authors would like to thank Dr. Sharon Levine from the Department of Geriatrics at Boston Medical Center for her review and commentary on this manuscript.

References

1. Teno JM, Mitchell SL, Gozalo PL, Dosa D, Hsu A, et al. (2010) Hospital characteristics associated with feeding tube placement in nursing home residents with advanced cognitive impairment. *JAMA* 303: 544-550.
2. Sampson EL, Candy B, Jones L (2009) Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev*: CD007209.
3. Finucane TE, Christmas C, Travis K (1999) Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* 282: 1365-1370.
4. Teno JM, Gozalo PL, Mitchell SL, Kuo S, Rhodes RL, et al. (2012) Does feeding tube insertion and its timing improve survival? *J Am Geriatr Soc* 60: 1918-1921.
5. Gillick MR (2000) Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* 342: 206-210.
6. Beauchamp TL, Childress JF (2009) Principles of biomedical ethics. (6th Edn.), Oxford University Press, New York.
7. Meisel A, Cerminara KL (2004) The right to die: the law of end-of-life decision making. (3rd Edn.), Aspen, New York.
8. Shalowitz DI, Garrett-Mayer E, Wendler D (2006) The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med* 166: 493-497.
9. Ditto PH, Danks JH, Smucker WD, Bookwala J, Coppola KM, et al. (2001) Advance directives as acts of communication: a randomized controlled trial. *Arch Intern Med* 161: 421-430.
10. Matheis-Kraft C, Roberto KA (1997) Influence of a values discussion on congruence between elderly women and their families on critical health care decisions. *J Women Aging* 9: 5-22.
11. Ouslander JG, Tymchuk AJ, Rahbar B (1989) Health care decisions among elderly long-term care residents and their potential proxies. *Arch Intern Med* 149: 1367-1372.
12. Principe-Rodríguez K, Rodríguez-Cintrón W, Torres-Palacios A, Casal-Hidalgo J (1999) Substituted judgement: should life-support decisions be made by a surrogate? *P R Health Sci J* 18: 405-409.
13. Seckler AB, Meier DE, Mulvihill M, Paris BE (1991) Substituted judgment: how accurate are proxy predictions? *Ann Intern Med* 115: 92-98.
14. Uhlmann RF, Pearlman RA, Cain KC (1988) Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *J Gerontol* 43: M115-121.
15. Diem SJ, Lantos JD, Tulsky JA (1996) Cardiopulmonary resuscitation on television. Miracles and misinformation. *N Engl J Med* 334: 1578-1582.
16. Schonwetter RS, Walker RM, Kramer DR, Robinson BE (1993) Resuscitation decision making in the elderly: the value of outcome data. *J Gen Intern Med* 8: 295-300.
17. Braun UK, Rabeneck L, McCullough LB, Urbauer DL, Wray NP, et al. (2005) Decreasing use of percutaneous endoscopic gastrostomy tube feeding for veterans with dementia-racial differences remain. *J Am Geriatr Soc* 53: 242-248.
18. Murphy DJ, Burrows D, Santilli S, Kemp AW, Tenner S, et al. (1994) The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *N Engl J Med* 330: 545-549.
19. United States (1982) President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. U S Code Annot U S.
20. Gostin LO (2005) Ethics, the constitution, and the dying process: the case of Theresa Marie Schiavo. *JAMA* 293: 2403-2407.
21. Yamagishi A, Morita T, Miyashita M, Sato K, Tsuneto S, et al. (2010) The care strategy for families of terminally ill cancer patients who become unable to take nourishment orally: recommendations from a nationwide survey of bereaved family members' experiences. *J Pain Symptom Manage* 40: 671-683.
22. Van Rosendaal GM, Verhoef MJ, Kinsella TD (1999) How are decisions made about the use of percutaneous endoscopic gastrostomy for long-term nutritional support? *Am J Gastroenterol* 94: 3225-3228.
23. Mitchell SL, Teno JM, Roy J, Kabumoto G, Mor V (2003) Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *JAMA* 290: 73-80.
24. Timbie JW, Fox DS, Van Busum K, Schneider EC (2012) Five reasons that many comparative effectiveness studies fail to change patient care and clinical practice. *Health Aff (Millwood)* 31: 2168-2175.
25. Bennis WG, Benne KD, Chin R (1985) The Planning of change. (4th Edn.), Holt, Rinehart, and Winston, New York.
26. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O, et al. (2005) Storylines of research in diffusion of innovation: a meta-narrative approach to systematic review. *Soc Sci Med* 61: 417-430.
27. Golan I, Ligumsky M, Brezis M (2007) Percutaneous endoscopic gastrostomy in hospitalized incompetent geriatric patients: poorly informed, constrained and paradoxical decisions. *Isr Med Assoc J* 9: 839-842.
28. Cassel CK, Guest JA (2012) Choosing wisely: helping physicians and patients make smart decisions about their care. *JAMA* 307: 1801-1802.
29. Clarke G, Harrison K, Holland A, Kuhn I, Barclay S (2013) How are treatment decisions made about artificial nutrition for individuals at risk of lacking capacity? A systematic literature review. *PLoS One* 8: e61475.
30. Wright AA, Zhang B, Ray A, Mack JW, Trice E, et al. (2008) Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 300: 1665-1673.
31. [No authors listed] (1999) Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs. *JAMA* 281: 937-941.

32. Truog RD, Brett AS, Frader J (1992) The problem with futility. *N Engl J Med* 326: 1560-1564.

33. American Thoracic Society (1991) Withholding and withdrawing life-sustaining therapy. *Ann Intern Med* 115: 478-485.