

Tube feeding patients with advanced dementia: an ethical dilemma

Edel P. McNamara* and Nicholas P. Kennedy

Department of Clinical Medicine, Trinity Centre for Health Sciences, St James's Hospital, Dublin 8, Republic of Ireland

Many patients with dementia lose the ability to feed themselves in the advanced stages of the disease. Tube feeding is sometimes initiated to overcome feeding difficulties. Recent studies have questioned the appropriateness of tube feeding in these patients. There is limited research to support the benefits of enteral nutrition in patients with advanced dementia. Deciding whether to tube feed or to withhold tube feeding from a patient with dementia poses a difficult challenge, and many carers may make decisions without adequate information and with an overly hopeful view of the future clinical course. Numerous studies have examined opinions about life-sustaining treatments; many individuals do not want to be tube fed if they were to develop dementia. Results from studies examining the opinions of physicians and other health professionals regarding the use of tube feeding in these patients are conflicting. A number of factors, such as race and cultural background may affect decisions. Healthcare professionals, relatives and patients must be aware of the realistic expectations of tube feeding in patients with dementia, as it can be difficult to withdraw once it has been initiated.

Dementia: Tube feeding: Ethics

Dementia is defined as an acquired global impairment of intellect, memory and personality without impairment of consciousness (Clare, 1990). The most common causes of dementia are untreatable, although reversible forms of dementia do exist. Reversible forms include the dementias resulting from vitamin B₁₂ deficiency, hypothyroidism, thiamine deficiency, cerebral tumours and sub-dural haematoma.

Five major syndromes cause irreversible dementia, i.e. Alzheimer's disease, dementia associated with stroke, Parkinson's dementia, rapidly-progressive dementia and fronto-temporal dementia (Sheiman & Pomerantz, 1998). Alzheimer's disease is the most common cause of irreversible dementia in old age. The deterioration seen in Alzheimer's dementia results in a median survival of about 8–10 years. The prevalence of dementia rises sharply with increasing age (Gjerdingen *et al.* 1999). One US study showed that the prevalence increased from 3 % in the subjects aged between 65 and 74 years to 47 % among those over 85 years of age (Evans *et al.* 1989). Elderly patients with dementia may also suffer from other diseases associated with aging. Medical advances in the treatment of many of the complications of old age have led to an increasing survival of patients with dementia to more

advanced stages of the disease (Sheiman, 1996). In Ireland over 18 % of patients in nursing homes and extended-care facilities suffer from dementia (Department of Health and Children, 1999). It is estimated that there are approximately 25 000 dementia sufferers in Ireland (Wrigley, 1995). Patients in the advanced stages of dementia present with progressive loss of cortical function, progressive loss of coherent speech, progressive loss of intentional movement and progressive loss of ability to eat by mouth; they are disabled and totally dependent (Sheiman, 1996). About half these patients lose the ability to feed themselves within 8 years of diagnosis (Volicer *et al.* 1987). The eating difficulties experienced by patients with dementia may be due to a reduced ability to feed themselves, an impaired ability to swallow, or a combination of both (Priefer & Robbins, 1997). Some of the reasons why patients with severe dementia may be unable to feed themselves are listed in Table 1. Swallow may be impaired in many patients with advanced dementia due to abnormal or absent chewing movements and abnormal tongue and jaw movements. Patients with advanced dementia also experience coughing, choking and delayed swallow when eating (Priefer & Robbins, 1997).

*Corresponding author: Edel McNamara, fax +353 1 4542043, email mcnamarae@tcd.ie

Table 1. Factors affecting food intake in patients with dementia

Reduced food intake
1. Patient may be distracted from eating
2. Patient may refuse to eat
3. Agnosia
4. Decreased olfactory function
5. Apraxia of eating
6. Patient may not want to eat due to depression (this is reversible)
7. Patient may have a reduced appetite
Impaired swallow
1. Abnormal chewing movements
2. Absent chewing movements
3. Abnormal tongue and jaw movements
4. Coughing
5. Choking
6. Delayed swallow when eating

Tube feeding patients with dementia

When feeding becomes difficult in the patient with dementia, tube feeding is sometimes initiated to overcome these difficulties. In the USA a retrospective cohort study of over 7000 patients found that approximately 30 % of gastrostomy tubes inserted in older patients were inserted in those with dementia (Rabeneck *et al.* 1996). In the UK about 3 % of the patients registered as receiving home tube feeding over the age of 65 years were categorised as having dementia. However, about 58 % of this group required tube feeding following stroke; but the presence or absence of dementia in stroke patients is not reported (Elia *et al.* 1999). In Ireland the absence of a register of patients on tube feeding makes it difficult to ascertain the percentage of patients who are tube fed as a result of dementia, but a single-unit study found that 10 % of patients discharged on tube feeding had a tube inserted as a result of diminished eating capacity due to dementia, and a further 36 % required tube feeding following stroke (E McNamara, P Flood and NP Kennedy, unpublished results).

Clinical evidence

Tube feeding became widely used as the treatment for the weight loss that occurs in ageing and dementia due to its simplicity and convenience and to the fear of allegations of neglect if tube feeding is not employed (Sheiman & Pomerantz, 1998). We expect that by providing tube feeds to patients with dementia and swallowing difficulties we will prevent and reverse malnutrition, in turn preventing skin breakdown and pressure ulcer development, and improving the patient's functional status. We expect tube feeding to prevent dehydration, thus improving the patient's overall level of comfort. We expect that tube feeding will reduce feelings of hunger and thirst, and prevent aspiration and aspiration pneumonia, which in turn should lead to a prolongation of the patient's life, and an improvement in the quality of that life. Recently, however, the clinical evidence for tube feeding patients with severe dementia has been challenged. In their review of the clinical evidence for tube feeding patients with advanced dementia, Finucane *et al.*

(1999) found no data to suggest that tube feeding reduces the risk of pressure sores or infection, improves functional status, improves comfort, prevents aspiration pneumonia or improves survival. They conclude that tube feeding patients with severe dementia should be discouraged on purely clinical grounds. An extensive review of the use of tube feeding to prevent aspiration pneumonia concluded that there are no data showing conclusively that it reduces the risk of aspiration pneumonia in neurogenic dysphagia, but rather that data exists which shows the opposite (Finucane & Bynum, 1996). Peck *et al.* (1990) found the incidence of aspiration pneumonia and decubitus ulcers to be greater in tube-fed patients compared with non-tube-fed elderly patients with dementia. Furthermore, physical restraints were used more frequently in the tube-fed group. Other studies report the use of restraints on patients to keep nasogastric tubes *in situ*; ironically, where the feeding tube was often used to improve patient comfort (Quill, 1989). Three review papers have found no evidence to suggest that tube feeding can improve pressure-sore outcome in these patients (Finucane, 1995; Berlowitz *et al.* 1996, 1997). Kaw & Sekas (1994) found no improvement in either functional status or nutritional status after a long-term follow-up of a group of nursing home patients, the majority of whom had a feeding tube placed as a result of dementia.

Prospective randomised controlled trials to examine whether there are any differences in life expectancy between tube-fed and non-tube-fed patients with dementia are difficult to conduct from an ethical and practical point of view, but one study on the risk factors and impact on survival of tube feeding in nursing home residents with severe cognitive impairment found that even after adjusting for independent risk factors, the presence of a feeding tube conferred no survival benefit (Mitchell *et al.* 1997). More recently, however, Rudberg *et al.* (2000) have shown that patients with feeding tubes are less likely to die than comparable residents of nursing homes without feeding tubes, even if the gain in life is not substantial (the estimated survival at 1 year was 39 % for those without feeding tubes and 50 % for those with feeding tubes). Rudberg *et al.* (2000) concluded that the difference between their findings and those of Mitchell *et al.* (1997) were due to the fact that Mitchell *et al.* (1997) did not include as a condition for their sample selection whether or not a patient had total eating dependence and a swallowing disorder (but just a swallow disorder). Many of those patients without feeding tubes had milder eating disorders and hence better health.

Patient preferences for tube feeding

By the time tube feeding becomes an option for the patient with dementia and feeding difficulties, the patient will clearly be unable to express their wishes concerning the use of the treatment. A number of studies have examined opinions about life-sustaining treatments. Gjerdingen *et al.* (1999) surveyed eighty-four cognitively-normal American men and women over 65 years and found that most subjects did not desire life-sustaining treatment if they were to suffer any degree of dementia. The proportion of those subjects not wanting such treatments increased with the progressing severity of the dementia. Only 4 % said that they would

desire tube feeding if they could not communicate and care for themselves. Only 22 % of an Israeli population group would choose tube feeding with an irreversible condition of severe mental impairment (Carmel, 1999). O'Brien *et al.* (1995) interviewed 379 American nursing home residents about their preferences for tube feeding if they were unable to eat due to permanent brain damage. One-third of those subjects surveyed said they would want tube feeding in such a scenario. The authors conclude that the relatively high percentage in favour of tube feeding may be due to the fact that residents of nursing homes are accustomed to seeing patients on tube feeding, and they may expect that this is a natural course of their treatment. A postal questionnaire survey of 218 community-living Americans by Reilly *et al.* (1994) found that 43 % of subjects aged between 60 and 87 years of age would want to be tube fed if in a state of moderately-advanced Alzheimer's disease. The authors conclude that the results of this particular survey of attitudes are not relevant to the general population, as respondents were generally better educated than most elderly Americans. A lower preference for tube feeding in Alzheimer's disease was found by Emanuel *et al.* (1991), who studied the treatment preferences of patients of all ages in the Boston area. Only 11 % wanted tube feeding in the case of dementia, and 82 % said they did not want to be tube fed if they were in a state of dementia with a terminal illness. A predominantly male American nursing home population studied by Gerety *et al.* (1993) found that 38 % would accept tube feeding in a state of severe physical disability and 25 % would accept tube feeding in a persistent vegetative state. This group was interesting in that they were nursing home residents and included subjects with moderate cognitive impairment. The research found that patients with mild to moderate dementia may not differ greatly from less-impaired patients with respect to treatment selection.

The preferences for treatment appear conflicting according to the studies outlined earlier. However, comparisons between studies are difficult, as the populations studied differed in terms of age, gender, race, cultural factors, education status, health status and functional status, all of which are factors which may influence their decisions about life-sustaining treatments (Garrett *et al.* 1993). Possibly more importantly, the questions and scenarios posed to participants differed. The use of a scenario to examine preference for treatment may be limited to the precise scenario described (Reilly *et al.* 1994). In addition, the patient's knowledge about tube feeding will affect their preference for it under particular circumstances (Krynski *et al.* 1994). Evidence regarding the consistency of life-sustaining opinions of elderly subjects is conflicting; Kellogg *et al.* (1992) found that opinions of older subjects on the use of life-sustaining treatments (including tube feeding) are not always consistent when re-assessed at a later date. Conversely, Carmel & Mutran (1999) found preferences of older subjects for the prolongation of life were stable after 1- and 2-year intervals. The disparity in results is again probably due to differences in the populations studied and experimental protocols used.

Opinions of health professionals

As they are frequently the primary decision-makers in the matter of feeding-tube insertion in elderly patients with dementia, the opinions of physicians and other health professionals are important regarding the use of tube feeding in these patients. In a study of 339 doctors in Israel, physicians were found to use more life-sustaining treatments more frequently than an elderly population had reported they would want (e.g. in a condition of irreversible mental illness, 22 % of the elderly population studied said they would want to be tube fed, but 74.6 % of the doctors said they would provide tube feeding in such a scenario; Carmel, 1999). A study of the attitudes of American internists to tube feeding showed that 84 % were generally opposed to tube feeding a nursing home resident with irreversible dementia who had lost interest in eating. Approximately all internists (98 %) were generally in favour of feeding an acutely-ill 75-year-old woman with aspiration pneumonia and delirium (previously cognitively normal; Hodges *et al.* 1994). A Welsh study found that about half (47 %) the geriatricians surveyed felt that percutaneous endoscopic gastrostomy feeding was indicated in dementia with rejection of food. Speech therapists and dietitians held similar views (Hasan *et al.* 1995). A survey of 141 American physicians found that cognition and life expectancy were relatively minor influences on the physician's decisions regarding tube feeding of nursing home residents (Von Preyss-Friedman *et al.* 1992). Conversely, Watts *et al.* (1986) found that the mental status of the patient significantly influenced physicians' (*n* 124) preferences for tube feeding patients. Younger patients tended to be given higher preferences for tube feeding, and the happiness of the patient was the strongest and most significant influence on the physician's preference.

Hasan *et al.* (1995) found that 57 % of nurses were in favour of tube feeding a patient with dementia who had rejected food. An international study of nurses' attitudes to tube feeding patients with severe dementia found clear differences between nurses in different countries. Australian, Canadian and Swedish nurses most often chose not to tube feed a patient with severe dementia, whereas all the Chinese nurses (*n* 10) and 90 % of the Israeli nurses chose to feed such a patient. Nurses choosing not to feed the patient tended to stress the ethical principle of beneficence; the most common justification for those choosing to feed the patient were related to the ethical principles of sanctity of life and beneficence (Norberg *et al.* 1994). Clearly, racial influences play a part in the decision-making process regarding the use of life-sustaining treatments. Mebane *et al.* (1999) found that a physician's race influenced their preferences for end-of-life treatment, with black physicians favouring the use of life-sustaining treatments more frequently than white doctors for themselves and for patients.

Decision-making

Patients with severe dementia are unable to take part in the decision-making process regarding the use of tube feeding.

The physician and family members often make the decision in the absence of an advanced-care directive by the patient, although medical decision-making in general may be dominated by physicians (Van Rosendaal *et al.* 1999). Advanced directives are decisions about how the individual will be cared for in the future when he or she may be incapable of making an informed decision. There are two types of advanced directive; first, the living will, a signed statement of medical treatment preferences and second, the appointment of a durable power of attorney, a trusted individual who will make decisions based on knowledge of the individual's wishes. Both directives have their limitations; for example, the appointment of a durable power of attorney does not guarantee that the wishes of the patient will be carried out, it merely means that he or she will be represented, and living wills apply only to terminal illness (Reilly *et al.* 1994). One study found medical treatment to be consistent with advanced directives in 75 % of cases; however, inconsistencies occurred more frequently in nursing homes where the patients were incompetent, while delivery of the advanced directive to the hospital setting was achieved in only 35 % of cases (Danis *et al.* 1991). In a study of the decision-makers for cognitively-impaired older patients who were tube fed, less than half felt confident that their patients would have chosen to have a feeding tube inserted if they were capable of expressing themselves. Only one decision-maker (of ninety-four) was aware of previously-expressed wishes regarding tube feeding ('the patient didn't want it'; Mitchell *et al.* 2000). Other researchers have concluded that while proxy decision-makers may make incorrect judgments, they tend to not methodically err in either withholding or providing treatment (Gerety *et al.* 1993).

Advanced directives are not common practice in either Ireland or the UK. Their use in the USA is increasing, but still only 9.8 % of patients near the end of their life have completed a living will (Hanson & Rodgman, 1996), although a survey of physicians found that 51 % of older physicians had a living will or an advanced-care directive (Mebane *et al.* 1999). The goal of decision-making is to make the choice that the patient would have made if they had been in a position to make an informed decision (Meyers & Grodin, 1991). Not surprisingly, the time at which a decision to insert a feeding tube must be made can be emotional and difficult, and many carers may make decisions without adequate information and with an overly hopeful view of the future clinical course (Van Rosendaal *et al.* 1999). Physicians (*n* 82) responding to a postal questionnaire survey reported a significant amount of conflict between healthcare staff and family members regarding the decision-making process to proceed or defer gastrostomy. The perception amongst responders was that the decision to have a tube inserted was sometimes driven by concern for the burden to caregivers of providing oral feeding to the patient (Callahan *et al.* 1999).

Surrogate decision-makers have reported that they had been told that 'improved nutritional status' was the most common benefit to be expected from feeding-tube insertion, and early complications post-insertion were the most frequently quoted negative expectations (Callahan *et al.* 1999). In contrast, a Canadian study of surrogate decision-

makers found that prevention of aspiration and the maintenance of life were the medical benefits most often cited as indications for tube feeding. Just over half the surrogate decision-makers in this study felt that they had received adequate support from the healthcare professionals in making their decision regarding tube feeding (Mitchell & Lawson, 1999). In addition, a further study found that of seventy-three surrogates and patients undergoing percutaneous endoscopic gastrostomy found that 24 % of patients and 61 % of surrogates said that they had not been asked their opinions about percutaneous endoscopic gastrostomy insertion and 26 % of surrogates said that they felt their opinions were not respected. In 22 % of the patients with poor prognosis (including patients with severe dementia), conflicting messages regarding the anticipated outcome were given by different healthcare professionals on the medical team (Van Rosendaal *et al.* 1999). Having made the decision to have a feeding tube inserted into a family member, 33 % of surrogates are reported to have felt unsure that proceeding to nutrition support was the right decision (Van Rosendaal *et al.* 1997). A survey of family members of nursing home patients with severe dementia who were not tube fed examined the surrogate decision-makers' preferences for life-sustaining treatment. Tube feeding was the second least accepted life-sustaining therapy, with only 36.4 % accepting it for their family member (Cogen *et al.* 1992). In conclusion, it appears that the decision-making process is difficult for both doctors and surrogate decision-makers. Meyers & Grodin (1991) advise that 'the challenge for the decision-making process is to facilitate communication, respect the ethical principles of respect for autonomy and beneficence, tolerate a plurality of belief systems, and yet safeguard vulnerable patients'. Within this framework, physicians and other health professionals must preserve their own professional and personal ethic.

Ethics of tube feeding patients with dementia

Deciding how to care for a patient with dementia who is not dying, but has stopped eating, poses a difficult challenge for everyone involved in his or her care. The process of deciding whether to tube feed or to withhold tube feeding from a patient with dementia is extremely emotionally charged and poses enormous moral dilemmas. The primary ethical issue in the case of the patient with dementia is the loss of autonomy, which is an inevitable consequence of the decline in the cognitive abilities of the patient (Watson, 1994). Fundamentally, autonomy means that an individual has the right to determine his or her own destiny, and has the right to choose, the right to know and the right not to be harmed (MacFie, 1996). Since the preservation of autonomy is impossible in patients with advanced dementia, the use of advanced directives may be used in an effort to help maintain autonomy. In Ireland, the question of how enforceable an advanced directive would be if it contravened the ethical principles of an institution or healthcare provider is an issue of serious doubt (Cusack, 2000). Patients with mild dementia may often answer rationally to questions relating to their wishes regarding life-sustaining treatments. Thus before autonomy is lost permanently, early and ongoing communication with patients and families can

help to prevent conflict, disagreement and distress later on (Post & Whitehouse, 1995).

The question of whether tube feeding is ordinary treatment (i.e. the simple provision of food and water, albeit in an alternative fashion) or a medical treatment is also central to the debate regarding tube feeding in the non-autonomous patient. Fluids and nutrition, in whatever form, have a symbolic significance, in that they represent the core of life, nurturing and care-giving (Cranford & Ashley, 1986), and are thus often set apart from other forms of life-sustaining treatments such as ventilators, antibiotics etc. However, the prevailing consensus amongst medical ethicists is that tube feeding is a medical intervention, and as such is subject to the same considerations of risk *v.* benefit that preside over other medical decisions (Goldstein & Fuller, 1994). A useful distinction between oral and tube feeding is in the concept of 'volitional' *v.* 'non-volitional' feeding. Volitional feeding is eating 'normally', i.e. placing food in our mouths, chewing and swallowing, deriving in the process the pleasure and sensations that go along with that process. Normal subjects would never forcibly prevent volitional feeding. Non-volitional feeding, such as the provision of food and fluids via a feeding tube, does not provide the pleasure and sensations associated with volitional feeding; so withdrawing or withholding it is not as peculiar a concept for us (Lipman, 1996).

Guidelines exist to support the complicated decision-making process. Rabeneck *et al.* (1997) have given guidance to physicians treating patients for whom feeding-tube placement may have uncertain clinical benefits (e.g. a bedridden patient with Alzheimer's disease). In such patients the aspects of quality of life that are affected, or are likely to be affected due to the progression of the disease, should be identified. The alternatives to tube feeding should be sought, and the potential short- and long-term effects of each alternative should be identified. If it is to be utilised, tube feeding should be presented as a trial of management, with its appropriateness being re-evaluated periodically, particularly if it has unfavourable effects on quality of life. The goals of therapy should be set out in advance of tube placement, as withdrawing tube feeding once it has been initiated is difficult.

The weight of evidence seems to suggest that tube feeding is unwarranted in most patients with eating difficulties caused by dementia. However, if tube feeding is not used in a patient with severe dementia and eating difficulties, then how can their nutritional status be maintained? One physician has described several experiences involving withholding tube feeding from elderly patients with dementia and inadequate oral intake despite efforts at hand feeding. He described how withholding nutrition led to a slow death with development of decubitus ulcers, and that this factor has led him to have a substantially more aggressive approach to nutritional support for these patients (Mehr, 1984). On the other hand, a longitudinal cohort study of weight changes, length of survival and energy requirements of long-term-care residents with dementia found that dementia is not necessarily associated with chronic weight loss during institutional care, and that without the use of

tube feeding nursing staff are able to sustain the weight and survival of patients for long periods, even in patients with more advanced dementia (Wang *et al.* 1997). Oral intake can be maintained by numerous practices, such as skillful feeding techniques, altered consistency in dysphagic patients, providing enough time for feeding, and taking advantage of the midday meal when cognitive abilities are at their peak (Suski & Neilsen, 1989). Treatment of depression, providing access to favourite foods, finger foods, strong flavours, energy- and protein-enriched foods and reminding patients with apraxia of swallow to swallow after taking a mouthful can also help (Morley, 1996), as well as altering the feeding environment (Finucane *et al.* 1999). Inevitably, tube feeding will be necessary for a small minority of patients with dementia.

Conclusion

The issue of tube feeding the elderly patient with dementia is becoming increasingly important, given our increasing longevity. There does not appear to be consensus on the criteria for, and the ethics of, nutritional support of the patient with dementia, however. Thus the time is ripe for debate and development of guidelines on these issues. Tube feeding should only be initiated when it is clear that all efforts at hand feeding have been exhausted and are not working. Careful consideration needs to be given before tube feeding is initiated, as once started it can be difficult to withdraw (Volicer *et al.* 1986; O'Mahoney & McIntyre, 1995). When used, the goals of treatment must be first determined, and the potential benefits and burden of tube feeding must be weighed up in each case. The patient must be continually re-evaluated to ensure that the initial goals of treatment are still being met. Early communication is essential to understand the patient's views, which should be respected when known. Healthcare professionals, relatives and patients must be informed of the realistic expectations of tube feeding in this group of patients. Finally, if tube feeding is used to prolong life, but is found to be reducing the quality of the life it is maintaining, then its use must be seriously questioned.

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