

Feeding Decisions in Advanced Dementia

Abstract

Feeding problems are common in the advanced stages of dementia. The decision to initiate artificial nutrition is one of the most difficult dilemmas facing families, clinicians, and health care systems caring for these patients. Clinicians play a critical role in this decision-making process. An understanding of and approach to feeding problems in advanced dementia is needed. Clinicians must feel comfortable discussing feeding problems in terms of the overall goals of care of the patient. The clinician should be prepared to communicate to families the options to manage eating difficulties in severely demented patients and present the risks and benefits of each option including the limitations of the data. Moreover, the clinician must have the skills necessary to guide feeding decisions effectively and compassionately and to provide families with the decision support they require. Finally, clinicians must be an advocate for the patient in the face of the many external factors influencing feeding decisions in advanced dementia.

Key words

dementia, feeding problems, nutrition, decision-making, goals of care, tube-feeding, palliative care, outcomes, advance care planning, quality of life

Objectives

The objectives of this module are to:

- develop an approach to feeding problems in advanced dementia
- develop techniques to communicate treatment options for feeding problems and the risks and benefits of each option
- develop compassionate and effective methods to guide families through the steps of decision-making
- be aware of resources for decision support for the family
- recognize the need to periodically revisit feeding decisions
- understand multiple factors that influence feeding decisions

Introduction

Currently, 22 million older persons world-wide are estimated to have Alzheimer's disease or other dementias. Remarkable scientific advances have been made in understanding the molecular genetic basis of dementia and several medications show promise as agents to prevent or slow the progression of this illness. Nonetheless, dementia remains a terminal condition.

With better supportive care, a growing percentage of patients are reaching the stage of advanced dementia in which they are dependent in all their activities of daily living, demonstrate minimal language capacity and have profound memory deficits. Swallowing

and eating problems are hallmarks of this end-stage. Up to one third of US nursing home residents with advanced dementia and feeding problems are tube-fed despite growing empiric data and expert opinion suggesting that tube-feeding may not be beneficial in this population. Nonetheless, the decision to initiate artificial nutrition is one of the most difficult dilemmas facing families, physicians, and health care systems caring for these patients. Contributing factors to this dilemma include: emotional circumstances, a decision that is value-laden, reliance on substitute decision-making and limited outcome data. How to provide the best decision support to families faced with this issue is a challenge facing clinicians.

Effective communication and transfer of knowledge between clinicians and families is a critical factor in promoting ethically sound feeding decisions in advanced dementia. Essential components of counseling include an explanation of what to expect in the final stages of dementia and an understanding of the choices available to manage feeding problems. These issues are best addressed before feeding problems develop. The option of comfort care needs to be carefully explained, such that families do not feel they are doing “nothing” by choosing palliation.

Clinicians must be knowledgeable about evidence regarding the outcomes of this tube-feeding in advanced dementia in order to promote informed decisions. It is the practitioner’s responsibility to communicate this information effectively. Once informed, families will need to weigh the risks and benefits of tube-feeding against the perceived values and preferences of the patients. Clinicians can help families approach this decision-making process by explaining the basic principles of surrogate decision-making. A discussion between families and other team members (e.g. physicians, nurses, dietitians, social workers, clergy, occupational and speech therapists) can be helpful to strive for unified decisions and to avoid conflicting information.

This module will discuss feeding problems of advanced dementia. It will review the current evidence regarding the outcomes of long-term tube-feeding (percutaneous endoscopy tube (PEG) or jejunostomy tube (J-tube)) in this population and present an approach for clinicians to guide families through feeding decisions.

Eating problems in dementia

In order to approach feeding decisions, it is important to understand the nature of eating problems in advanced dementia.

Natural history: Eating problems are expected in advanced dementia. While there may be individual variation, studies have shown that eating is usually the last activity of daily living to be lost during the course of dementia. On average, patients will have a Mini Mental Status Score below 7 when eating problems first present. At this point, in addition to total functional dependence, they often demonstrate minimal verbal communication, profound memory deficits and limited ability to recognize even familiar faces. Therefore, patients with dementia who develop eating problems are in the final stages of their illness. The duration of this final stage is variable, lasting from months up until to several years.

Etiology: The etiology of the patients' eating problems has important implications with respect to management. Some patients primarily have trouble chewing and swallowing due to neuromuscular dyscoordination. These patients may have particular difficulties with aspiration of food, oral secretions and regurgitated stomach contents. Some patients pocket or spit food. Others simply lose the ability to perform the task of eating or to interpret the sensation of hunger. These patients need to be hand-fed by a caregiver. Depression in advanced dementia may also present as a lack of interest in food. Finally, a new acute medical problem (e.g., infection, metabolic disturbance, constipation) or medication side effect may present as a decline in oral intake.

General approach to new onset of eating problems in advance dementia: When eating problems first present, simple steps should be taken to rule out acute medical causes that may be contributing to reduced oral intake such as: infections, acute stroke, depression or medication side effects. Within the context of the patients' goals of care, easily reversible causes should be addressed.

In the absence of an acute illness, simple measures may improve the oral intake of a person with advanced dementia. Patients with dementia may be overwhelmed by a plate of food with many items. Presenting them with various foods sequentially may help. Individuals who have lost the capacity to use silverware may do better with finger foods. Family members may be aware of the patients' favorite foods that they are more apt to eat. Nutritionists often recommend commercially prepared nutritional supplements. A swallowing evaluation by speech or occupational therapist may be useful to identify food consistencies that are easier to swallow and positions that reduce the risk of aspiration. Videofluoroscopy is not well-tolerated in the advanced stages of dementia and there is little evidence that the test is useful in this setting. Therefore, swallowing evaluations are best limited to bedside examinations for severely demented patients.

If there is no easily reversible cause of the eating problem, and if intake is still limited despite the implementation of simple feeding techniques, then clinicians together with family members will need to decide about an approach to the patients' nutrition.

Treatment options

There are two basic options to address ongoing eating problems in advanced dementia. The first option is to continue to feed by mouth. The second option is to place a long-term feeding tube (PEG or J-tube).

i. Continue to feed orally: The main goal of oral feeding in the advanced stages of dementia is to provide food and drink to the extent that eating is enjoyable and comfortable for the patient.

The aforementioned strategies to maximize oral intake should be employed (i.e. nutritional supplements, adjusting textures and portions, techniques to minimize aspiration). Most severely demented patients will require conscientious hand-feeding which takes time and patience. In outlining this option to family members, it is important to point out that their own involvement in hand-feeding provides a meaningful opportunity for them to interact with their loved one.

In choosing oral feeding, the inclination to provide a prescribed daily caloric intake will need to be abandoned. Studies have shown that patients with advanced dementia may live long periods of time with sub-optimal nutrition. Most often, the patients will not ingest enough calories to maintain their nutritional status. However, because patients are in the final stages of their illness and death is inevitable in the near future, a focus on providing comfort rather than prolonging life is appropriate.

Family members must be reassured that the choice to continue oral feeding does not imply that they have chosen to discontinue medical care. Palliation involves a host of treatments that need to be outlined to the family. The type of treatments the patient will receive rather than what they will not receive must be emphasized.

ii. Tube-feeding: The placement of a feeding tube is another approach to eating problems in advanced dementia.

Epidemiology: In US nursing homes, the diagnoses of tube-fed residents are as follows: dementia (52%), CVA (24%), Parkinson's disease (9%), malignancy (7%), other (8%). Among these residents, 70% have advanced cognitive impairment. Up to one third of US nursing home residents with advanced cognitive impairment and feeding problems are tube-fed. Patient characteristics consistently associated with a higher likelihood of being tube-fed in the setting of severe cognitive impairment include: younger age, non-white race, lack of advance directives to limit aggressive care, and no diagnosis of Alzheimer's disease.

There is a ten-fold variation in the use of feeding tubes among nursing homes residents with severe cognitive impairment across the US. Even within the same state, there is tremendous variability in the use of tube-feeding in different nursing facilities. Therefore, there is complex interaction of patient, facility and regional factors influencing this practice.

Tube-feeding decisions are complex: The decision whether or not to initiate tube-feeding in advanced dementia should follow an ethical framework, reflecting a balance of benefits and burdens and respect for autonomy. Nonetheless the decision is complicated for several reasons. Observing patients reduce their food intake at the end-of-life can be very emotional for families and caregivers. Feeding decisions are value-laden and most often made by a surrogate decision-maker rather than the patient. Despite recent research advances, the evidence regarding the outcomes of tube-feeding in advanced dementia are limited. Surrogates may be faced with conflicting information, attitudes and opinions from friends, family and health care providers and may experience feelings of guilt and pressure. Finally, multiple factors influence tube-feeding decisions including the quality of counseling families by health care providers, culture attitudes towards death and dying, regional laws, and fiscal constraints of the health care environment.

Outcomes of tube-feeding: In order to counsel families regarding feeding options, health care providers must understand the best available evidence regarding the risks and benefits of tube-feeding in advanced dementia. They also must be able to transfer that knowledge in an effective and compassionate manner.

There are no randomized trials to provide definitive data regarding the effects of tube-feeding in advanced dementia or to prove it futile. There are only a few cohort studies comparing patients with and without feeding tubes, the majority of which are retrospective and therefore subject to selection bias. There are many case series describing the course of severely demented patients with feeding tubes. While these descriptive studies provide some valuable prognostic information, there are no control groups to assess what would have happened to subjects without tube-feeding.

Potential “benefits” of tube-feeding:

Survival: Intuitively it would seem that providing nutrition with tube-feeding would prolong life. However the best available evidence does not indicate a survival benefit among severely demented older persons with eating problems. A retrospective cohort studies involving 1341 severely demented nursing homes residents with recent onset of feeding problems, found no difference in survival between patients who did and did not get tube-fed. A prospective study of hospitalized older persons with end-stage dementia reported no improvement in survival among patients who received a feeding tube during their hospital admission compared to those who did not. A meta-analysis examining survival in person over age 65 years found the following mortality rates after PEG placement: 1 month – 20%, 6 months - 40%; 12 months - 60%. Risk factors for poorer survival included advanced age (>85 years), malignancy, and albumin < 3.0 g/l.

Aspiration: Individuals with advanced dementia commonly aspirate not only food but also oropharyngeal secretions and gastric contents. Many individual studies and a meta-analysis clearly show that tube-feeding does not prevent aspiration or aspiration pneumonia. Individuals that aspirate prior to tube placement are at the greatest risk of aspirating after the initiation of tube-feeding.

Nutrition and pressure ulcers: Case series have not found a significant improvement in nutritional indices or weight gain after the initiation of tube-feeding among persons with advanced dementia. It has been suggested that the metabolism of patients in the advanced dementia is akin to end-stage cancer or AIDS, such that meaningful weight gain is not achievable regardless of caloric intake. Furthermore, there are no data demonstrating a reduction of pressure sores as a result of tube-feeding. Due to increased immobility, diarrhea and restraint use, it is conceivable that tube feeding may actually lead to pressure ulcer development.

Comfort and quality of life: Families are commonly concerned that their loved ones with advanced dementia and eating problems may be hungry or thirsty. Their hope is that tube-feeding will make them more comfortable. It is not known to what degree, if at all, persons with advanced dementia feel hunger or thirst. However, extrapolating from the cancer literature, persons with other terminal conditions experience little hunger or thirst near the end of their lives. The symptoms that they do have can be alleviated with good mouth care and ice chips.

In a survey substitute decision-makers for tube-fed nursing home residents with advanced dementia, 60% felt that tube-feeding did not improve the patients' quality of life. Another longitudinal study found no improvement in functional status following the initiation of tube-feeding in this population.

Potential "risks" of tube-feeding

Feeding-tube placement: The placement of long-term feeding tubes is relatively safe procedure although complications do occur. The prevalence of complications in the period immediately following PEG tube placement based on a meta-analysis of case series reporting these problems are presented below.

Infections	
minor (skin)	4%
major (life-threatening)	1%
Bleeding	
minor (no transfusion)	< 1%
major (transfusion)	nearly 0%
Tube problems	
minor (dislodgment, leakage)	4%
major (bowel perforation)	< 1%

Restraint use: Demented patients are easily agitated. Agitation is reported as a problem in up to 20% of tube-fed patients with advanced dementia. Physical or chemical restraints may be used to prevent patients from dislodging the tube. Studies have shown that trunk or limb restraints are more common among severely demented residents who are tube-fed compared to those without feeding tubes. Both chemical and physical restraints are associated with adverse outcomes in the frail elderly.

Gastrointestinal problems: Approximately 12% of patients experience diarrhea and 4% have nausea or vomiting around the time that tube-feeding is initiated. These problems may result in electrolyte disorders and discomfort. The gastrointestinal side effects are generally transient and often resolve with change in the nutritional supplement or feeding schedule.

Hospitalizations: Complications from tube-feeding may necessitate management in an acute care facility. Research has shown that tube-feeding is risk factor for hospitalization among nursing home residents. Transfers to the hospital may be burdensome in the frail elderly person with advanced dementia.

Aspiration: Many persons with advanced dementia aspirate. Tube-feeding does not prevent aspiration. However, there are data to suggest that tube-feeding may lead to an even higher rate of aspiration pneumonia presumably due to the aspiration of regurgitated stomach contents.

Disposition: Families should be advised that not all nursing facilities or units within a facility provide care for tube-fed patients. Some special dementia care units in nursing homes have an explicit policy of comfort care from the time the patient is admitted and do not manage tube-fed patients. Moreover, home care services and health care reimbursement for community-dwelling tube-fed patients may be limited. These issues should be explored as part of the decision-making process.

Summary of empiric data and expert opinion of tube-feeding in advanced dementia.

Data are limited due to lack of a randomized trial of tube-feeding. Nonetheless the best available evidence has failed to demonstrate any significant health benefits of tube-feeding in advanced dementia. Moreover, there are risks associated with the procedure. Given that feeding problems occur at the terminal stage of this illness, there is growing expert opinion that conscientious hand-feeding is the most appropriate approach to feeding problems in advanced dementia.

Decision-making for feeding problems

The role of advance care planning: Eating problems are a predictable milestone in the course of advanced dementia. Therefore, health care providers have an opportunity to prepare families and patients to expect feeding problems in the final stages of their illness and to elicit their wishes regarding management. These preparatory discussions should

take place within the context of broader advance care planning by a primary health provider who has an established relationship with the patient and family. While many decision-makers may defer these decisions until feeding problems actually present, counseling beforehand helps families understand what to expect in the final stages of the illness, provides a scaffold for future discussions and prepares them for decision-making. On the other hand, families and patients who are clearly in favor of comfort care have an opportunity to indicate their preference to avoid tube-feeding in the future. Research has shown that the lack of advance directives is one of the strongest risk factors associated with the use of feeding tubes among nursing home residents with advanced dementia.

Steps to decision-making: The following are suggested steps for clinicians to guide decision-making discussions about feeding problems with designated substitute decision-maker for patients with advanced dementia. The “steps” are merely guidelines and the approach presented will vary depending on individual circumstances.

Step 1: Clarify the clinical situation. Explain feeding problems in advanced dementia. It is important to discuss this in terms of the terminal nature of the patients’ underlying illness, the fact that the dementia is not curable and that the patient is nearing the end of his/her life. Any compounding acute conditions should also be discussed. The clinician should assess the family’s understanding of these issues and readdress the points that were not understood.

Step 2: Establish the goals of care. Ask the family what they feel is the most important goal for the patient’s health care at this point in their illness. It is best to ask this in an open-ended fashion early on in the discussion. Many families may equivocally state comfort as the primary goal of care. Others may feel the prolongation of life as the main objective, while many people will opt for something in between or be unsure of their wishes.

Step 3: Present options to manage feeding problems: The clinician should present the two options to manage the feeding problem to those families who truly feel that the patient would have considered tube-feeding as at this stage of their illness. The clinician should clearly present the risks and benefits of tube-feeding in this population as well as the limitations of the data. The approach to continue hand-feeding should be outlined and a detailed description of the option for comfort care should be described.

Step 4: Weighing risks and benefits against values and preferences: Once the family is aware of the options, they must weigh their choices against the perceived values and preferences of the patient. It should be stressed that they are trying to make a decision based on what they feel the patient would want. This is a good time to review the principles of substitute decision-making (see related module): 1. consideration any *advance directives*, 2. making a *substituted judgment*, and 3. consideration of what is in the patients’ *best interests*.

Clinicians must respect differing cultural views regarding death and dying. It has been consistently shown that severely demented patients who are non-white are more likely to

have feeding tubes compared to those who are white. Possible explanations for this observation include: different cultural attitudes towards death and dying, apprehension of non-whites toward the medical system, and poor communication of advance directives to minorities by health care providers. Some families need reassurance from the clergy that their decisions are in agreement with the patients' religion regarding the provision of nutrition and hydration at the end-of-life. It is also the responsibility of the clinician to ensure non-English speaking minorities have access to translators during discussions of advance care planning such that their decisions are informed.

Step 5: How is the decision affecting the family member? Feeding decisions can be very emotional for the family. They may experience feelings of guilt, pressure and conflict between their personal wishes and what they think the patient may want. It is important for the clinicians to try to elicit from the family how the decision is affecting them in order to provide reassurance and support.

Step 6: Offer additional resources for decision support: The family should be made aware of supports available to them to help with this decision. Other members of the interdisciplinary health care team are resources for the family including: nurses, social workers, dietitians, speech therapists, occupational therapists and members of the clergy. If possible, it is best to include these team members in a family meeting to ensure that the family receives a consistent message. Moreover, the clinician should offer in-services and printed materials to the allied health team regarding feeding problems in advanced dementia to ensure they are aware of the available information. Families may also wish to discuss the decision with friends or other family members who know the patient well.

There are several sources of printed materials that may be useful **adjuncts** to counseling by a clinician for family members who are struggling with feeding decisions:

1. The Alzheimer's Association has a fact sheet on feeding decisions:
<http://www.alz.org/ResourceCenter/ByTopic/Diagnosis.htm#ethical>
2. An article written for family members regarding feeding decisions:

Gillick MR, Mitchell SL. Facing eating difficulties in end-stage dementia. *Alzheimer's Care Quarterly*. 2002; 3(3):227-232.
3. A decision aid designed to help families with feeding decisions has been evaluated and shown to improve knowledge, decrease decisional conflict and help those who are unsure what to do to reach a decision.

Mitchell SL, O'Connor A, Tetroe J. Making choices: long-term feeding tube placement in elderly patients. A book and audiotape for substitute decision-makers. Ottawa, Ontario: March, 2000. The decision aid can be ordered by calling 1-617-363-8626, or an online version is available at www.ohri.ca/programs/clinical_epidemiology/OHDEC/decision_aids.asp

4. A review published in the scientific literature that may be useful for some families:

Gillick M. Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* 2000;342:206-10.

Step 7: Who should decide? The decision-making process for feeding problems in advanced dementia should be shared between the clinician and the surrogate. Clinicians should respect the wishes of patients or their surrogates after proper counseling. Some surrogates may feel excessively burdened by the decision and prefer the clinician to choose what he/she feels is appropriate. In this case, the clinician should assume the person with advanced dementia would not want a feeding tube. On very rare occasions, consultation by an ethics committee may be indicated to help resolve a conflict between decision-makers.

Step 8: Provide on-going support and recognize the need to revisit the decision. Families may need time and several discussions to reach a decision regarding feeding problems for their loved one with advanced dementia. This is rarely an urgent decision. Moreover, their views may change as the medical status of the patient evolves.

It is important to explain at the time of decision-making that tube-feeding can be discontinued at a later time. Discontinuation of tube-feeding should be considered if the patient improves to the point that oral feeding can be resumed. Alternatively, as time passes, the family may feel that tube-feeding no longer meets the goals of care. Clinicians should provide ongoing support to the family and recognize the need to revisit feeding decisions and broader advance care planning over time.

External factors influencing feeding decisions

Individual decision-making for feeding problems in advanced dementia may be influenced by external factors of which the clinician should be aware.

Regional laws: Individual states may have specific laws governing the provision of artificial nutrition and hydration. A small number of states, such as New York and Michigan, require clear and convincing evidence that an incompetent patient would forego artificial nutrition and hydration in order for a surrogate to opt to withhold tube-feeding. Clinicians should be aware of relevant laws in the states where they practice.

Nursing home regulations and quality indicators: Recently, quality indicators have been introduced to evaluate the care provided by licensed US nursing homes. Quality indicators are derived from the federally mandated Minimum DataSet. “Weight loss” is considered an indicator of poor quality of care. Therefore, in order to avoid a negative profile, nursing homes may feel pressure to place feeding tubes in residents with weight loss. However, the intention of the quality indicator is to ensure that facilities address the issue of weight loss, not dictate management. In the setting of advanced dementia, where

weight loss is expected in the terminal stages, it is entirely appropriate to address weight loss by discussing goals of care with the family and establishing efforts to hand-feed the patient. The placement of a feeding tube as an automatic response to a quality indicator of weight loss does not make sense for patient with advanced dementia.

Acute hospitalizations: Older persons with advanced dementia are often transferred to the hospital where decision-making is rushed, care is fragmented, and technology is readily available. As such, feeding tubes may be placed without adequate counseling with the family by clinicians. One study from New York reported as many as 51% of patients with advanced dementia underwent feeding tube placement during a hospital admission. This situation may be minimized by the following measures: 1. having established advanced directives prior to transfer to an acute care facility that are clearly indicated in their medical record and communicated to the hospital staff, 2. involving primary care clinicians in decision-making during an acute hospital stay, and 3. avoiding hospital admissions for severely demented patients except when there is little alternative to acute medical care (i.e., repair of a hip fracture).

Fiscal considerations: Several fiscal incentives appear to further the use of tube-feeding in advanced dementia. Medicare pays for the insertion of feeding tubes and for the hospitalizations or emergency room visits to manage complications of tube-feeding. In addition, Medicare pays for 100 days of skilled nursing for institutionalized persons with a new feeding tube. Since the Medicare per diem rate is substantially higher than the Medicaid rate, there is a potential fiscal incentive to advocate insertion of a gastrostomy tube in a Medicaid patient to temporarily shift the patient from Medicaid to Medicare reimbursement. Finally, in many states, Medicaid reimburses nursing homes at a higher rate for tube-fed than for hand-fed residents. Paradoxically, tube-fed residents require less daily nursing care than do patients with comparable cognitive dysfunction who are hand-fed. For-profit nursing homes have been shown to have a higher prevalence of tube-fed residents with advanced dementia compared to not-for-profit homes.

Summary

In summary, feeding problems are expected in the final stages of dementia. When feeding problems present, the clinician should treat any easily reversible contributing acute medical problems. Simple steps should be taken to maximize the patients' oral intake. On-going eating problems should be approached by engaging families early on in discussions of advance care planning in order to establish goals of care. There are two basic options to address feeding problems in advanced dementia. The first is to continue oral feeding as tolerated by the patient. The second is to insert a feeding tube. A growing body of empiric data suggests that tube-feeding in advanced dementia has limited health benefits and some risks. In view of the terminal nature of this illness, experts feel that conscientious hand-feeding is the most appropriate approach to eating problems in the severely demented patients. A step-wise approach is offered to help clinicians guide family members through feeding decisions for patients with advanced dementia. Sources of printed materials that may be useful adjuncts to counseling are described. Finally, the clinician should be aware of external factors influencing individual feeding decisions.

Key Take Home Points

Eating problems in dementia

1. Eating problems are the last ADL to be lost in the course of dementia. Therefore, these problems occur in the terminal stages of the illness.

Treatment options

2. The two main options include the continuation of oral feeding or feeding tube placement.
3. The main goal of oral feeding is to provide food and drink to the extent that eating is enjoyable and comfortable for the patient.
4. Hand-feeding can be a very rewarding social experience for patients and their families.

Epidemiology

5. Up to one third of nursing home residents in the US with advanced dementia and feeding problems are tube-fed.
6. Certain individual clinical characteristics and factors external to the patient are associated with the greater use of tube-feeding in advanced dementia.

Risks and benefits tube-feeding in advanced dementia

7. There are no randomized trials of tube-feeding in patients with advanced dementia
8. Observational data suggest that survival is not prolonged with tube-feeding.
9. Tube-feeding does not prevent aspiration.
10. Tube-feeding does not improve the functional status or quality of life of severely demented patients.
11. There are risks associated with tube-feeding.
12. There is growing expert that hand-feeding is the most appropriate approach to feeding problems in advanced dementia.

Decision-making

13. Establish overall goals of care.
14. Discuss care preferences with families before feeding problems arise.
15. Stress that families are trying to make a decision based on what they feel the patient would want.
16. For families who cannot decide, the clinician should assume the patient would not want tube-feeding.
17. Respect the families' decision.
18. Provide families with access to additional sources of decision support.
19. Revisit decisions as needed and provide on-going support.

Other influences

20. Be aware of external factors influencing feeding decisions.

Pearls

- i. Dementia is terminal condition.
- ii. Feeding problems typically occur in the very end-stages of dementia.
- iii. Simple steps should be taken to address reversible factors contributing to feeding problems.
- iv. Whenever possible, wishes for or against tube-feeding should be discussed with the patients or their surrogates before feeding problems arise.
- v. Most empiric data and expert opinion do not support the use of tube-feeding in advance dementia.
- vi. Feeding decisions should follow an ethical framework, reflecting a balance of benefits and burdens and respect for autonomy.

Potential pitfalls

1. Care preferences discussed with the family before feeding problems arise.
2. Clinician does not effectively communicate with the family.
3. Clinician does not explain feeding problems to family in the context of a terminal condition.
4. Clinician is not aware of the best available evidence regarding the risks and benefits of tube-feeding.
5. Clinician does not explain the components of comfort care to the family.
6. Clinicians fails to coordinate a consistent message from other team members.
7. Clinician feels pressured about feeding decisions by other consultants, team members or administrators.
8. Feeding decisions are made in a rushed hospital setting.
9. Clinician fails to address the emotional concerns of family regarding fears of starvation or discomfort.
10. Clinician fails to establish a trusting relationship with family.

Resources

General

Gillick M. Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* 2000; 342: 206-10.

Volicer L. Management of severe Alzheimer's disease and end-of-life issues. *Clin Geriatr Med* 2001;17(2):377-391.

Epidemiology and Outcomes

Finucane T, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* 1999; 282: 1365-70.

Mitchell SL, Teno JM, Roy J, Kabumoto G, Mor V. A national study of the clinical and organizational determinants of tube-feeding among nursing home residents with advanced cognitive impairment. *JAMA* 2003;290:73-80.

Mitchell S, Kiely D, Lipsitz L. The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Arch Int Med* 1997; 157: 327-32.

Teno JM, Mor V, DeSilva D, et al. Use of feeding tubes in nursing home residents with severe cognitive impairment. *JAMA* 2002;287:3211-3212

Kaw M and Sekas G. Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home patients. *Dig Dis and Sci* 1994; 39: 738-43.

Callahan CM, Haag KM, Weinberger M, Tierney WM, Buchanan NN, Stump TE, Nisi R. Outcomes of percutaneous gastrostomy among older adults in a community setting. *J Am Ger Soc* 2000;48:1048-1054.

Meier DE, Ahronheim JC, Morris J, Baskin-Lyons S, Morrison RS. High short-term mortality in hospitalized patients with advanced dementia. *Arch Intern Med* 2001;161:594-599.

McCann R, Hall W, Groth-Juncker A. Comfort care for terminally ill patients: the appropriate use of nutrition and hydration. *JAMA* 1994; 274: 1236-46.

Decision-making

Gillick MR, Mitchell SL. Facing eating difficulties in end-stage dementia. *Alzheimer's Care Quarterly*. 2002; 3(3):227-232.

Callahan CM, Haag KM, Buchanan NN, Nisi R. Decision-making for percutaneous endoscopic gastrostomy among older adults in a community setting. *J Am Geriatr Soc* 1999;46:1105-1109.

Mitchell SL, O'Connor A, Tetroe J. Making choices: long-term feeding tube placement in elderly patients. A book and audiotape for substitute decision-makers. Ottawa, Ontario: March, 2000. The decision aid can be ordered by calling 1-617-363-8626, or an online version is available at www.ohri.ca/programs/clinical_epidemiology/OHDEC/decision_aids.asp

Mitchell S, Tetroe J, O'Connor A. A decision aid for long-term tube-feeding in cognitively impaired older persons. *J Am Geriatr Soc* 2001; 49: 313-16.

The AM, Pasman R, Onwuteaka-Philipsen B, Ribbe M, van der Wal G. Withholding the artificial administration of fluids and food from elderly patients with dementia. *BMJ*. 2002;325:1-5.

Resource Utilization

Callahan CM, Buchanan NN, Stump TE. Healthcare costs associated with percutaneous endoscopic gastrostomy among older adults in a defined community. *J Am Ger Soc* 2001;49:1525-1529.

Mitchell SL Financial incentives to place feeding tubes in nursing home residents with advanced dementia. *J Am Geriatr Soc* 2003;51:129-131.