

Artificial nutrition and hydration in advanced dementia

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Mrs N. is an 80-year-old woman with Alzheimer dementia first diagnosed 7 years ago. Her disease has progressed and she is now bed-bound and dependent in all her activities of daily living. She is largely unaware of her surroundings and at times she does not recognize her daughter or son-in-law, with whom she lives. Fortunately, agitation and other behavioural concerns have been minimal. Her daughter has been able to stay at home to be Mrs N.'s primary caregiver.

You have been Mrs N. and her daughter's family physician for many years. During a checkup, Mrs N.'s daughter asks if a feeding tube for her mother would be beneficial, as Mrs N. is having increasing difficulty eating and often chokes when being fed.

Risks of artificial nutrition and hydration in advanced dementia

It is estimated that up to one-third of nursing home patients with severe cognitive impairment in the United States have feeding tubes.¹ A systematic review of treatment decisions around artificial nutrition and hydration (ANH) in patients at risk of diminished mental capacity revealed that the primary reason for initiating ANH, including in patients with dementia, was to prolong life.² However, evidence indicates that ANH in advanced dementia does not prolong survival or improve quality of life.^{3,4} In fact, enteral feeding puts patients at higher risk of several complications and indignities (**Box 1**). Studies have shown, despite the conventional wisdom that artificial nutrition would mitigate the risks of aspiration and help with wound healing, that the opposite is true: risk of aspiration^{5,6} and the development of pressure ulcers in fact increase with the initiation of tube feeding.^{7,8} In the latter case, it is postulated that by increasing the amount of stool output, oftentimes as diarrhea, we thereby provide a moist environment conducive to skin breakdown.

In 1989, bioethicist Dr Mark Yarborough questioned the growing use of tube feeding.⁹ Yarborough drew parallels to

Box 1. Risks and harms associated with feeding tubes in those with advanced dementia

The following are among the risks and harms of tube feeding:

- Pain and other complications (eg, infection, bleeding) directly associated with placement of tube
- Increased risk of aspiration
- Increased risk of pressure ulcers
- Gastrointestinal symptoms from feeding (eg, diarrhea, constipation, reflux)
- Physical and chemical restraints to prevent patient from pulling out feeding tube
- Fluid overload leading to increased pulmonary or peripheral edema, upper airway secretions
- Can increase the perception of hunger

the idea of enteral feeding as a form of “force-feeding” in certain populations. Although unrestrained in its imagery, it is nonetheless an apt comparison in the context of patients with advanced dementia, as it introduces the concept that with enteral feeding we are likely providing the body with a load greater than it is able to tolerate. Even so, we continue to use ANH in patients with advanced dementia at alarming rates.

Social, cultural, and ethical considerations

Despite the known and mounting evidence that artificial nutrition in persons with advanced dementia is harmful, it continues to be an intervention that is frequently used in this patient population. It would be unfair to point to any one particular group as the cause of this phenomenon, when in fact the cause is likely multifactorial (**Box 2**).

For patients and families, food and water can have important meaning for religious, cultural, or personal reasons. Those who have experienced starvation, for example, whether through persecution or poverty, might view the lack of provision of nutrition in any situation as an indignity that exceeds the potential harms that tube feeding might hold. It is particularly important to be mindful of this consideration in our multicultural population; many Canadian residents have come from places—both abroad and within our own country—where living situations might have been quite dire.

Physicians and other clinicians also play a role in perpetuating the overuse of feeding tubes in patients with advanced dementia. There is evidence of a



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Box 2. Factors that might influence the use of feeding tubes in advanced dementia

Patient and family factors

- Unawareness of or difficulty coping with the terminal prognosis of dementia
- Unawareness of the lack of benefit and increased harm of feeding tubes in advanced dementia
- Perception of "starvation" without artificial nutrition and hydration that might be influenced by cultural or religious factors
- Extra time required to provide oral feeding
- Complicated social dynamics (eg, viewing interventions as a representation of high-quality care)
- Lack of advance directives specifically addressing artificial nutrition and hydration

Clinician factors

- Unawareness of the lack of benefit and increased harm of feeding tubes in advanced dementia
- Lack of familiarity with techniques to address thirst and hunger
- Avoidance of difficult discussions or belief that the discussion will be held by a different clinician (eg, family physician, geriatrician, interventional radiologist)
- Fear of litigation

Administrative and systemic factors

- Extra time and staff needed to assist with oral feeding in patients with advanced dementia
- Financial incentives (eg, institutions might benefit financially from caring for patients with feeding tubes)

considerable knowledge gap among physicians who, for example, often incorrectly cite aspiration pneumonia as being an important indication for feeding tube insertion in patients with dementia.¹⁰ Likewise, many speech-language pathologists erroneously believe that tube feeding in advanced dementia and dysphagia improves nutritional status and prolongs survival.¹¹

Patients under the care of subspecialists are also more likely to receive feeding tubes compared with those cared for by generalists.¹² The reasons for this are unclear but might relate to generalists' propensity to take a more wide-angled view of patient care.

Guidelines put forth by the American Geriatrics Society¹³ discourage the use of feeding tubes in patients with advanced dementia and promote instead the use of careful hand feeding. Certainly in circumstances where careful hand feeding is available, it is a preferred alternative. However, the reality is that many patients with severe cognitive impairment often find themselves cared for by overwhelmed "sandwich generation" children or in institutional settings where one-on-one time can be limited. An American study demonstrated that day-to-day costs for residents with feeding tubes were lower than costs for residents without. However, when

looking at Medicare billings, patients with feeding tubes necessitated much higher reimbursement costs associated with tube insertion and hospitalizations for management of subsequent complications.¹⁴ This puts nursing homes in a difficult situation as they are challenged to balance their own books while considering the well-being of the patient and costs to the health care system as a whole.

Risks and benefits of parenteral hydration

Although some of the risks and harms conferred by tube feeding are also relevant in the case of parenteral hydration (eg, pulmonary or peripheral edema, increased secretions), there might be circumstances in which a limited and focused trial of parenteral hydration might have some benefit. For example, hydration could help to mitigate some causes of delirium such as opioid toxicity or hypercalcemia.

Despite your explanation that a gastrostomy tube insertion in Mrs N.'s situation would, on balance, be more harmful and cause more discomfort, Mrs N.'s daughter cannot shake the belief that her mother is going to starve to death.

Approach to a family requesting ANH

The decision to initiate ANH should ideally be a collaborative one among the physician, the patient, and the family, weighing the benefits (both physical and psychological) against the harms. From a legal perspective, decision making should be undertaken by the designated person according to each province's hierarchy of substitute decision makers (SDMs). In general, such decisions should be based first and foremost on the previously expressed wishes of the patient—which can only be known by asking patients before the onset of dementia or early in the dementia trajectory. In the absence of such knowledge, the decisions should be based on the best interests of the patient.

Most feeding tube insertions occur during acute hospital admissions,¹⁵ when specialists and clinicians who do not have ongoing relationships with patients and families are providing medical care, and often pressure on families to make decisions seems heightened.¹⁶ Therefore, as family physicians, again it is important to have a discussion with the patient and family early on in the dementia trajectory around the lack of evidence supporting artificial nutrition in the advanced stages of disease.

Elicit understanding. Before engaging in a discussion around the harms and benefits of ANH, it is imperative to first understand the particular concerns of the friends and family of the patient. Are the concerns centred on beliefs that their loved one is "thirsty or starving to death"? Or is there a perception that more technologically advanced interventions equate to better-quality care? Or are


decisions being driven by other complex family dynamics? Without this knowledge, it will be extremely challenging to support the family and patient effectively.

Educate. In addition to the aforementioned myths surrounding ANH, concerns around hunger and thirst are commonly at the forefront of caregivers' minds. Although thirst and dry mouth are common at the end of life, intravenous fluids do not seem to ameliorate these symptoms.¹⁷ In patients with advanced disease, enteral feeding might even worsen the sensation of hunger.¹⁸ Both hunger and thirst are effectively treated near the end of life with small amounts of food, fluids, artificial saliva, and good mouth care.^{19,20}

Support. The role of the SDM can be fraught with uncertainty and anxiety, and SDMs should be made aware of potential supports, such as social work or spiritual care, that are available to them. In situations where cultural or religious beliefs are the basis for the family's objection, it might be helpful to offer to speak with the patient's cultural or spiritual leader to understand the nuances of the beliefs and to ensure that information is being communicated clearly. For example, suffering in some cultures is considered an important aspect of the human experience, and so the risk of discomfort might not be a deterrent from pursuing a certain intervention. However, this is different from the risk of harm or altering the dying process in the last days of life, which is explicitly prohibited in some cultures and religions. Continuous communication is important to delineate these often blurry lines.

Set expectations and parameters, but be flexible. In instances where ANH has been initiated, it is often useful to give guidelines to loved ones on signs and symptoms that would indicate that the intervention should be altered or withdrawn. Pre-emptively discussing events

that would necessitate a reevaluation of the harms of ANH, such as signs of shortness of breath from pulmonary edema, diarrhea and the development of pressure ulcers, or patients pulling out feeding tubes or intravenous lines, can help to prepare the family for the withdrawal of ANH. In situations where friends and family still seem torn between the symbolic nature of providing "sustenance" and the apparent harms it is causing, a more flexible approach might be warranted, in which feeding and fluid rates are brought down to levels low enough to avoid symptoms. This sometimes might involve negligible rates. Such a symbolic gesture might buy enough time for loved ones to emotionally come to terms with their loss and ease the grieving process.

You understand that Mrs N.'s daughter is concerned about her mother "starving to death," and you have reviewed the limitations and harms of ANH with her. Mrs N.'s daughter decides to continue with careful hand feeding. Over the next 6 months Mrs N. becomes increasingly somnolent and her daughter requests a trial of hydration. You agree to a trial of hypodermoclysis (subcutaneous fluid infusion) at levels that do not cause additional symptoms. Her daughter is ultimately able to come to terms with Mrs N.'s advanced disease, and eventually the infusion is withdrawn. 

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Competing interests

None declared

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BOTTOM LINE

- There is no evidence that artificial nutrition prolongs life in advanced dementia, or that artificial nutrition and hydration (ANH) improves hunger or thirst symptoms. Parenteral hydration can be considered on a case-by-case basis as it might, in some circumstances, improve symptoms.
- Eating and drinking have strong symbolic connotations that cannot be discounted when weighing the harms and benefits of ANH. Family physicians and generalists play an important role in counseling families on the risks and benefits of ANH in advanced dementia, as they have a holistic perspective that might be lacking during encounters with subspecialists.
- Discussions should take place in a preventive fashion, before complications and hospitalizations arise from swallowing difficulties and ideally when patients are still able to express their wishes.

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