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CORE TRAINING FOR DOCTORS

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Artificial feeding in patients with advanced dementia

Introduction

Patients with advanced dementia commonly experience swallowing and feeding difficulties that predispose to weight loss, malnutrition and aspiration pneumonia. Artificial feeding using nasogastric and percutaneous endoscopic gastrostomy tubes has been used to combat these problems. There is often uncertainty among clinicians as to whether the use of artificial feeding is appropriate in patients with advanced dementia. As the number of patients with dementia in the UK continues to rise decisions about artificial feeding will become increasingly common. This article summarizes evidence around the use of artificial feeding and highlights key issues when making decisions about treatment for patients with advanced dementia.

Why do dementia patients have feeding difficulties?

It has been estimated that up to 86% of patients with advanced dementia experience eating difficulties (Mitchell et al, 2009). The process of swallowing is complex, requiring effective interplay between skeletal and smooth muscles, neuromuscular fibres, the brainstem and cerebral cortex to allow passage of food through the oral, pharyngeal and oesophageal phases of swallowing.

With advancing age, loss of muscle mass and connective tissue elasticity results in a reduction in the strength and range of oral motion. There is also delayed onset of airway protection and upper oesophageal sphincter opening. This leads to difficulties with chewing and a general slowing of the swallowing process, predisposing to aspiration of food into the upper airways. Slow swallowing also increases the time taken to finish a meal, resulting in poor calorific intake.

Dementia patients also commonly lose the ability to feed themselves. This can be a result of weakness or apraxia, or because they cannot plan tasks such as using cutlery or preparing a food bolus. Furthermore some patients lose the ability to recognize food and may even develop a disinclination to eat (Sura et al, 2012).

Current evidence: risks *vs* benefits

A systematic review in 1999 (Finucane et al, 1999) first highlighted that there was little evidence to support commonly held beliefs at that time that artificial feeding in dementia patients lowers the risk of aspiration, malnutrition and pressure ulcers, and improves functional status, survival and patient comfort.

It is ethically challenging to justify controlled studies with randomization of dementia patients to artificial feeding or oral feeding. Consequently the number of high quality studies examining the benefits of artificial feeding in dementia patients has remained low. A Cochrane review in 2009 (Sampson et al, 2009) was unable to find sufficient evidence to determine whether tube feeding provides any benefit to a dementia patient.

Mortality and survival

Percutaneous endoscopic gastrostomy tube placement is an endoscopic procedure which is associated with several complications; aspiration, haemorrhage, perforation and peritonitis. The rate of procedure-related complications is approximately 0–2% (Dharmarajan et al, 2001). Additionally problems can occur weeks later; diarrhoea, buried bumper syndrome, wound infection or fistula formation and inadvertent removal, blockage

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and leakage of the percutaneous endoscopic gastrostomy tube. These risks are not insignificant but several studies have found that the presence of dementia does not increase the 30-day mortality following percutaneous endoscopic gastrostomy tube insertion (Gaines et al, 2009). Median survival following percutaneous endoscopic gastrostomy tube placement is similar for patients who have dementia and patients who do not have dementia (Higaki et al, 2008).

While the timing of percutaneous endoscopic gastrostomy tube insertion does not affect survival (Teno et al, 2012b), there is some evidence to suggest that patients with low biochemical markers of nutritional status, such as albumin, at the time of per-cutaneous endoscopic gastrostomy insertion have greater mortality (Nair et al, 2000). In addition the presence of comorbidities, especially congestive cardiac failure, predicts poor survival.

Currently there is insufficient evidence to suggest that percutaneous endoscopic gastrostomy feeding prolongs survival in dementia patients. Several prospective and retrospective observational studies have failed to demonstrate any survival benefit for percutaneous endoscopic gastrostomy tube placement in patients with dementia (Mitchell et al, 1997; Murphy and Lipman, 2003). With or without artificial feeding, patients hospitalized with advanced dementia have a 6-month median mortality of approximately 25–50% (Meier et al, 2001).

Aspiration

Contrary to popular assumptions there is also insufficient evidence to suggest that artificial feeding prevents aspiration. Some studies have shown that percutaneous endoscopic gastrostomy feeding may increase risk of aspiration by lowering gastro-oesophageal sphincter pressure and worsening reflux (Finucane et al, 1999).

Nutrition and healing

Some studies have found that artificial feeding can provide modest short-term gains in biochemical markers of nutritional status, such as serum albumin (Dwolatzky et al, 2001). However, this benefit has not been found to persist and does not translate into gains in functional status (Sanders et al, 2008). Similarly artificial feeding has not been found to improve healing in patients with pressure ulcers and may even be associated with a higher rate of pressure ulcer development (Teno et al, 2012a).

Quality of life

Quantifying quality of life in patients with advanced dementia who are commonly unable to communicate can be challenging. A recent systematic review has found that concepts of quality of life in patients without capacity are wide-ranging across different cultures and contexts (Clarke et al, 2013). Percutaneous endoscopic gastrostomy feeding can allow easier administration of medications and nutrition but can also be perceived to result in prolongation of the dying process and thus a prolongation of pain and suffering.

Percutaneous endoscopic gastrostomy feeding is less time-consuming for carers than hand feeding but in some cases results in reduced interaction with carers or family who would normally hand feed the patient. Our understanding of the perception of hunger in patients with dementia is very limited and difficult to quantify. Subtle agitation or restlessness may be the only indicator of hunger in some patients. Freedom from hunger or suffering and the freedom to enjoy life's pleasures, such as eating and drinking orally, are difficult to balance against the risks associated with unsafe swallowing in patients with dysphagia. In addition deprivation of liberty, through physical or pharmacological restraint, is at times required to prevent dementia patients from pulling out their percutaneous endoscopic gastrostomy or nasogastric tubes (Teno et al, 2011).

Initiating or withholding feeding

Before making decisions about artificial feeding it is essential to ascertain if the patient had expressed any views about the type of treatment he or she would wish to receive should a state of incompetence occur. Advance directives remain underused in clinical practice and their promotion early after a diagnosis of dementia has been made should be encouraged in all clinical settings. However, enteral tube feeding is considered in the UK to be a medical treatment in law, therefore decisions regarding starting, stopping or withholding treatment ultimately lie with the responsible clinician (General Medical Council, 2010).

Current National Institute for Health and Care Excellence (2006) guidance suggests that artificial feeding and hydration may be considered for dementia patients in whom dysphagia is a transient phenomenon, for example dysphagia as a result of cerebral infarction. In these circumstances it is essential to involve dieticians and speech and language therapists to help assess and manage dysphagia. Nurses can also provide valuable information and opinions about factors affecting a patient's feeding. Compensatory strategies (see *Top Tips*) such as postural adjustments, environmental modification, training of carers in hand feeding, modified foods or fluids, sensory techniques and swallowing manoeuvres can often be sufficient to maintain adequate oral intake (Royal College of Physicians, 2010).

If disinclination to eat or inability to swallow is thought to be a manifestation of disease severity in advanced dementia rather than a transient phenomenon then artificial feeding is currently not recommended (National Institute for Health and Care Excellence, 2006). It is essential that there is open and honest discussion between medical professionals and family, friends and carers when decisions about withholding or withdrawing artificial feeding are being made.

TOP TIPS

- When managing patients with an unsafe swallow, make sure that patients are oriented to meals.
- Provide a pleasant environment for eating with limited distractors.
- Provide verbal cues.
- Ensure the patient has adapted eating utensils.
- Help the patient to adopt an appropriate head posture.
- Adapt the food consistency, and provide preferred foods.
- Ensure the patient is reminded to swallow.
- Limit the bolus size with multiple swallows per bolus.
- Encourage gentle coughing.

Individualized feeding strategies should be agreed based upon multidisciplinary recommendations with the quality of life of the patient at the heart of decision making. Plans should be documented clearly to help future management of the patient's nutrition and hydration. This helps to decrease clinical risk and avoid crisis management and unnecessary hospital admission. It is important to establish short- and long-term goals when devising feeding strategies, especially if artificial feeding using a nasogastric or percutaneous endoscopic gastrostomy tube is being considered. Decisions to withdraw feeding once it has been established can be difficult to make but at times entirely appropriate. This can be made easier if specific time periods have been agreed upon to reassess the suitability of artificial feeding in the context of a patient's best interests.

Cultural and religious values

Patients with advanced dementia often rely upon surrogate decision-makers, most commonly relatives, to help make decisions about their care. This can be a stressful and burdensome process. Some who opt for artificial feeding do so because their cultural or religious beliefs dictate that sustenance must never be withheld. For example in Judaism nutrition is held in most texts as a basic human need that must never be withheld because human life at all stages and at any quality is of supreme value (Jotkowitz et al, 2005).

Some may feel that discontinuation of feeding is equivalent to withdrawal of care or that a decision not to feed is equivalent to 'starving a loved one to death'. While the decision to institute or withhold artificial feeding ultimately lies with the physician it is important to be vigilant about cultural and religious beliefs.

Effective communication is essential to enable the family's perception of dysphagia in dementia to be viewed as a natural process that is being allowed to progress rather than an unnatural process that must be halted. Alternative strategies, such as finger feeding or moistening of the lips, can be suggested if nutrition and hydration are withdrawn. Involving palliative care specialists is essential when decisions to withhold feeding are made. The quality of life and comfort of those with end stage dementia is paramount.

Conclusions

Dysphagia remains a common problem in patients with advanced dementia. A stronger evidence base is required to provide clinicians with sufficient data to make well-informed decisions about the risks and benefits of artificial feeding in dementia. Current guidance suggests that artificial feeding should only be considered for dementia patients whose dysphagia is likely to be a transient phenomenon. As with any medical treatment all decisions surrounding artificial feeding should be made in the patient's best interests. BJHM

Conflict of interest: none.

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KEY POINTS

- Artificial hydration and feeding are considered to be medical treatments by law and therefore responsibility for instituting such treatment lies with the physician acting in the patient's best interests.
- Artificial feeding and hydration are currently not recommended if disinclination to eat or inability to swallow are considered to be a manifestation of disease severity in advanced dementia.
- Artificial feeding should only be used after highly individualized case discussions weighing up risks *vs* benefits. Specific short- and long-term goals should be agreed before commencing feeding.
- Honest and open discussion between multidisciplinary medical professionals, patients, family and carers is essential.
- The quality of life and comfort of the patient is paramount.