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Reducing Feeding Tube Insertions in Advanced Dementia Patients

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ABSTRACT

Dysphagia is common in advanced dementia patients (ADP) and usually worsens as the disease progresses. It is often complicated by dehydration and malnutrition, and is a common cause of aspiration pneumonia, one of the leading causes of death in these patients. Over the past two decades, numerous studies have discouraged the use of enteral nutrition (EN) in ADP, as there is no evidence that tube feeding improves nutritional status, prolongs survival, or reduces the risk of pressure ulcers. Additionally, weight loss often continues despite EN, and laboratory nutritional markers frequently show no improvement. Moreover, in ADP, the use of a feeding tube clearly leads to a decline in quality of life. Accordingly, the 2024 European guidelines on nutrition and hydration recommend that EN should not be initiated in ADP.

In June 2017, we implemented a clinical pathway to avoid EN in patients with ADP. Initially, we conducted informational sessions with various specialties to introduce the protocol. Subsequently, we reviewed hospital discharges of patients with ADP, analyzing whether EN was initiated during admission, either via nasogastric tube (NGT) or percutaneous endoscopic gastrostomy (PEG). In the second half of 2015, before the protocol was implemented, EN was initiated during admission in 16 patients with ADP. After implementation, EN was initiated in 1 patient in the second half of 2017 and in 2 patients in the second half of 2021. All differences (NGT, PEG, and total) were statistically significant when comparing 2017 and 2021 with 2015.

Numerous studies have shown that enteral feeding in these patients does not increase life expectancy, improve nutritional status, reduce the risk of aspiration, or reduce the prevalence of pressure ulcers, but rather clearly impairs their quality of life. Therefore, feeding tubes in patients with ADP may serve as an indicator of poor-quality healthcare.

Introduction

Dysphagia is common in advanced dementia patients (ADP)[1]; it appears due to damage to neurological structures that control swallowing and usually worsens with disease progression[2]. In addition, there may be an apraxia of swallowing-chewing and a food refusal. In ADP, dysphagia is often complicated by dehydration and malnutrition, and it is a common cause of aspiration pneumonia, one of the most important causes of death in these patients[3]. As a person with Alzheimer's disease or another type of dementia reaches the later stages, there are often multiple treatment decisions that must be made. One that family and healthcare team caring members may face is the use of a feeding tube.

Because of the risk of aspiration pneumonia episodes, as well as malnutrition, some physicians recommend tube feeding to provide this kind of patients with enteral nutrition (EN). Additionally, economic factors can be considered, as preparing meals for these patients is labor intensive, takes longer to administer, and requires more staff. All of this makes institutional care more expensive compared to EN.

There have been many papers published for more than 20 years against EN in ADP. One of these works was the Cochrane systematic review published by Sampson et al[4]. In this review of 452 articles, the authors state that there is no evidence that EN is effective in improving nutritional status, prolonging survival or reduce the risk of pressure ulcers. Like this 2009 review, many other works reach the same conclusion.

Subsequent studies have shown that in these patients, despite EN, weight loss continues and laboratory nutritional markers often do not improve. Research suggests that swallowing difficulties and weight loss are the beginning of the dying process and thus a feeding tube cannot reverse that end-of-life process. The 2024 European Society for Clinical Nutrition and Metabolism (ESPEN) guideline on nutrition and hydration in dementia[2] indicate that “EN shall not be iniciated in patients with severe dementia” with a consensus of 100% of the participants in the development of these recommendations.

On the other hand, studies have found that in ADP, a feeding tube implies a clear deterioration in the quality of life of the patient[5]:

- In the nursing homes residents with tube feeding are often not in the dining room while others are eating, causing an increased chance of social isolation.
- They do not enjoy the taste of food or liquids by mouth, and it is one of the few pleasurable stimuli that ADP have.
- Feeding tube is associated with risk of infections, bleeding, skin irritation, vomiting, diarrhea, a tube displacement, blockage or leakage.
- Enteral tubes do not appear to contribute to comfort at the end of life. Dementia patients are bothered by the tube and try to pull it out. To prevent that, they are often tied down or given sedative drugs.

Therefore, tube feeding, whether nasogastric tube (NGT) or percutaneous endoscopic gastrostomy (PEG), in ADP can be considered an indicator of poor quality of healthcare[6]. It is essential to inform family members about this situation and have a nutrition protocol in this clinical setting.

It is still surprising that despite the lack of evidence on its benefit, the number of ADP with feeding tubes is very high. Advanced dementia is sometimes not valued as a terminal disease, but is considered a long-term disease, and it is difficult to assume that it has reached a final stage. Furthermore, training in non-cancer palliative care is scarce. These facts favor that the final phase in dementia is not easily recognized, and this causes ambivalence in decision-making among family members. It is much more difficult to make the decision to remove a tube than to implant it.

In our hospital's Internal Medicine Department, in 2017, we created a protocol for nutritional decision-making in ADP. The main objective of this protocol is to guide care toward patient comfort, avoiding tube feeding.

Create a Nutrition Protocol for feeding ADP

To ensure the protocol reached the largest possible number of professionals, we held clinical sessions in the different specialties (Internal Medicine, Geriatrics, Neurology, Digestive Medicine, etc.) and prepared an informational brochure for families, in which we explained that EN in ADP does not improve nutritional status or reduce the risk of aspiration or the prevalence of pressure ulcers, and also significantly impairs the patient's quality of life.

It is important to provide families with clear and comprehensive information so that difficult decisions are as consistent as possible with the patient's wishes. We should explain some tips for feeding ADP instead of EN:
1) Hand-feed with tasty, easy-to-digest foods.
2) Elevating the head of the bed after meals can help prevent aspiration pneumonia.
3) Offer a soft or pureed diet and liquids with the addition of commercial thickeners.
4) Discontinue sedatives that interfere with swallowing.

Following protocol implementation, we reviewed the impact of the recommendations on the professionals. To do so, we conducted a descriptive study analyzing the number of hospital discharge reports of ADP who initiated EN during their admission, over a period of 6 months, before and after protocol implementation (June 2016).

	RESULST BEFORE THE INTERVENTION Second semester of 2015	RESULTS AFTER THE INTERVENTION Second semester of 2017 (*)	RESULTS AFTER THE INTERVENTION Second semester of 2021 (**)
NGT feeding initiated/ Total admissions of dementia patients	6/472	0/452	2/410
PEG feeding initiated /Total admissions of dementia patients	10/472	1/452	0/410
Total NE initiated/Total admissions of dementia patients	16/472	1/452	2/410

* $p < 0,05$ 2015 versus 2017
** $p < 0,05$ 2021 versus 2015

In the second half of 2015, 472 ADP were discharged: 16 of them initiated EN during admission: 6 with a NGT and 10 with PEG. In the same period in 2017, after protocol implementation, among the 452 discharges, EN was initiated in only one case (with PEG); and in the second half of 2021, 410 patients were discharged and two of them received EN (both with a NGT). All differences (NGT, PEG, and total) when analyzing 2017 versus 2015 and 2021 versus 2015 reached statistical significance ($p < 0.05$, Fisher´s exact test). Therefore, we were able to change the goals of care for these patients, avoiding tube feeding and keeping them comfortable. This change persists over the years.

Conclusion

Dysphagia is an indicator of the final stage of dementia. Numerous studies have shown that enteral feeding in ADP does not increase life expectancy, improve nutritional status, or reduce the risk of aspiration or the prevalence of pressure ulcers, but rather clearly impairs the patient's quality of life.

Therefore, feeding tubes (NGT or PEG) in ADP can be considered an indicator of poor quality of healthcare. It is essential to properly communicate this information to family members and to have a nutrition protocol for these patients.

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