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ENTERAL NUTRITION IN PERSON WITH DEMENTIA: INDICATION, EFFECTS AND BENEFITS

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ABSTRACT

Objective: This systematic literature review aims to clarify indications for the use of enteral feeding in patients with dementia. Difficulties in feeding patients with dementia may arise at any stage of the disease and may include malnutrition, weight loss, decreased quality of life, among others. Enteral tube feeding by tube may be a way of mitigating the effects, but its benefits are under discussion. **Methods**: Eight qualitative studies were included: 5 primary sources, 3 systematic literature reviews, published in the 2008-2013 period. **Results**: Enteral tube feeding in patients with dementia may affect survival/mortality rate (no evidence of benefit), nutritional status (no improvement), functional status and cognitive development (no improvement), aspiration (does not reduce the risk of aspiration), pressure ulcers (no evidence of benefit in ulcers incidence and progression), and quality of life (without hard data in most studies). **Conclusion**: Evidence on benefits of enteral tube feeding in patients with dementia was not conclusive and may even have the opposite effect. We lack data on the adverse effects of these interventions.

Keywords: Palliative care; Dementia; Enteral feeding; Therapeutic use.

INTRODUCTION

The Portuguese Law No. 52/2012 on palliative care defines it as "active, coordinated and global care, provided by specific units and teams in the hospital or patient's home, when patients suffer from advanced and progressive incurable or severe illness, as well as to their families, with the main objective to promote their welfare and their quality of life through prevention and relief of physical, psychological, social and spiritual suffering, based on early identification and rigorous treatment of pain and other physical, but also psychosocial and spiritual issues." Dementia is one of many incurable and progressive diseases that affects patients and their family/close friends.

Today it is estimated that 7.3 million European citizens have dementia and these numbers will double by 2040. In Portugal, it is estimated that about 153,000 people have dementia, almost 1.5% of the Portuguese population. Every year 1.4 million Europeans develop dementia, which means one new diagnosed case every 24 seconds[2].

Dementia is a progressive disease causing cognitive and intellectual deterioration, which then persists, leading to progressive functional decline and in patient's autonomy, with clear implications on survival, since eventually the patient will die because of the same pathology or its limitations (immobility, swallowing changes and associated infections)[3].

It is classified according to the presumed etiology[4]:

- Dementia of the Alzheimer's type;
- Vascular dementia;
- Dementia due to other clinical conditions, e.g., the human immunodeficiency virus, traumatic brain injury, Parkinson's disease, Huntington's disease;
- Substance-induced persisting dementia, e.g., caused by prolonged abuse of drugs, medication or by exposure to toxins;
- Dementia due to multiple etiologies or unspecified dementia (if etiology is undetermined).

Its duration cannot be estimated and a much-debated issue these days, with survival rates between 3 and 16 years. During the evolution of dementia, the patient progressively loses autonomy and functionality until complete dependency and cognitive impairment. This gradual process and its evolution depend on the type of dementia, age, comorbidities, treatment, health care and support network[5].

What makes early diagnosis difficult is age at onset, level of education and sociocultural status, as well as changes in behavior and/or fundamental repercussions[6].

Main characteristic of dementia is the development of multiple cognitive deficits, including memory loss and at least one of the following cognitive disorders: aphasia, apraxia, agnosia or executive dysfunction. Cognitive deficits can be severe enough to cause significant impairment in social or occupational function and in the highest level of functionality, not occurring exclusively during confusional state or depression[4]. According to the FAST scale, proposed by Reisberg (1982), the deterioration in dementia has seven stages: normality, subjective complaints, slight memory loss, mild or early-stage dementia, moderate dementia, severe dementia and very severe dementia[6].

During later stages of dementia, the most common symptoms are behavioral changes, abdominal pain (associated with obstipation, urinary retention and fecaloma), feeding difficulties, fever, infections and Retention of respiratory secretions. Assessment of these symptoms and of suffering may be compromised by these patients' difficulty in expressing themselves verbally. Therefore, it is important to recognize states of distress deviating from normal behavior and identify the cause of abnormality[3].

Feeding is considered essential for survival in any disease, however, from a cultural point of view food is sometimes considered an expression of human compassion. Ethical, religious and cultural factors should be considered in the decision-making process, as well as the patient's desires, previously expressed or presumed concerning tube feeding, severity

of disease, patient's prognosis and life expectancy, quality of life with or without tube feeding, complications and anticipated side effects of tube feeding, and patient mobility[7-8].

Regardless of the causes of dementia, these people often develop feeding difficulties, frequently decreased appetite and thirst associated with swallowing difficulty (for solids and liquids) and refusal to eat and drink. Memory loss can result in forgetting the last meal they ate. Difficulties with sight and perception may lead to difficulties in recognizing food and utensils, whereas apraxia may lead to difficulties such as opening the mouth for a spoon or moving the food from front to back of the mouth. Loss of language function caused by dementia may lead to difficulties in understanding instructions during meals and affect patient's capacity of expressing their favorite foods[3,9]. Lack of feeding is not the cause of degradation, but its consequence[3].

Enteral feeding is an option to increase or guarantee nutrients intake when oral feeding is insufficient, both using oral liquid nutritional supplements and tube feeding. The results and the success of nutritional therapy in patients with dementia are strongly influenced by the severity of the disease, the type and extent of comorbidities and its general condition. At dementia early and intermediate stages adequate and high-quality nutrition are important to prevent malnutrition and help maintain a stable general condition[8].

In this work we will identify tube feeding effects, benefits and indications for patients with dementia. Dysphagia in advanced stages of dementia may be in some cases an indication for the use of enteral tube feeding. In the case of people with severe dementia (irreversible, bedridden, unable to communicate, totally dependent, with physical disabilities), however, tube feeding is not recommended (level C evidence)[8].

Enteric tube feeding options are: nasogastric tube (NGT), nasoduodenal (ND) tube, percutaneous endoscopic gastrostomy (PEG) and jejunostomy tube[10]. In cases of short-term tube feeding the nasogastric tube is an option which is difficult to maintain in the correct position and presents significant risk of aspiration and pneumonia([11]. It is easily displaced and pulled, therefore inefficient for the confused elderly patient[8,10]. For people who require tube feeding for more than 6 weeks, a permanent and safe access is indicated, e.g., PEG[11]. PEG use is increasing due to its simplicity and improved safety. The procedure of gastrostomy tube placement is associated with some potential complications: peritonitis, exudate at gastrostomy site, bleeding at the site, infection around the gastrostomy site, esophageal laceration, local pain, buried bumper syndrome, and aspiration pneumonia[13].

About a quarter of tube-fed patients present physical limitation, 29.2% take calming medications to prevent extubation and 39.8% of carers answered that the feeding tube seemed to bother the patient. In the same study about a third of families believed that tube feeding improved the patient's quality of life and only 23.4%, regretted the decision[14].

There was no clear evidence on survival of patients receiving enteral tube feeding. Incapacity to improve survival rates has been frequently a central argument against tube feeding in persons with dementia without the risk of unnecessarily prolonging patient's life, an advantage of tube feeding[15]. Survival after gastrostomy tube placement is very low in people with dementia, compared with other cases of gastrostomy tube placement. Comorbidities (particularly diabetes), low body mass index, current or recent pneumonia, low serum albumin and C-reactive protein levels are predictors of high mortality rates following procedure[1].

Weight loss is one of dementia most frequent complications, occurring at all stages, even at early stages before diagnosis is confirmed. Malnutrition (especially underfeeding) contributes to change general health status in frequency and severity of complications, especially infections and quick loss of independence[16].

The use of nasogastric tube or PEG for prevention of aspiration is controversial. Due to the heterogeneity of patients and the lack of data on prevalence of aspiration before tube feeding, it is difficult to draw a firm conclusion if overcoming dysphagia, the use of NGT or PEG reduces incidence of pneumonia. It certainly has potential to increase reflux and aspiration. Data on incidence of aspiration pneumonia during PEG tube feeding, compared to SNG are also controversial. It is also not proved that jejunostomy prevents this complication.

Available studies on the effects of tube feeding report that it does not have expressive effects on cicatrization and preventing pressure ulcers. Overall quality of studies, however, is poor[8].

The use of gastrostomy has also an impact on quality of life of the person, however its impact remains unclear. This factor may be associated with removing the patient from social interaction during meals or special attention they receive during assisted oral feeding[12,13,17].

As dementia progresses, patients become unable to make their own decisions and complex situations may arise, doctors and families being responsible to decide whether artificial nutrition and hydration will be beneficial for the person[18]. Conflicts may be avoided if the patient and the family discuss the issue with the health care team as the disease evolves[19]. Therefore, any decision of this kind should be focused on the person, not based on convenience of health care professionals or carers[20]. With this type of intervention the family usually hopes to see the benefits on survival, decreased aspiration, pain reduction, improved functional status, and prevention of suffering by hunger or thirst[7,17]. Doctors can also be optimistic on tube feeding results based on evidence, what may influence their decision-making[7].

Patients with dementia at the end of their lives are not seen as palliative and not always receive appropriate palliative care, receiving "non-palliative care" with increased cost, but without necessarily increasing survival or quality of life[5]. Each person with dementia deserves a holistic assessment by an expert health care team, including a dysphagia specialist[15]. In this sense, tube feeding may have multiple effects (positive and negative), some of them with no consensus among authors.

In this work we aim to clarify the use of enteral nutrition in the person with dementia. Both by my professional experience and exchange of clinical practice with my colleagues, and not only, there is no consensus between nurses and other professionals from the health care team, as well as within users' families/carers.

Starting from the central issue *Which are the indications on the use of enteral nutrition in the person with dementia?* we defined descriptors and essential parameters for selecting articles effectively, achieved using the PICOD method (Participants, Interventions, Comparisons, Outcomes and Study design), described in Table 1.

From studies published in the 2008-2013 period, we first selected 30 papers by reading the abstract. After reading some of the papers and applying inclusion and exclusion criteria, we selected eight papers (among which three are systematic literature reviews).

METHODOLOGY

Systematic literature review consists in critically analyzing research publications relevant to the field of research[21]. Thus, through the information obtained in relevant studies, common elements and interests were identified, which were pondered over.

This literature review focuses on the search for quality studies to clarify the effects of enteral nutrition in the person with dementia, which would help us answer a fundamental question: *"Which are the indications on the use of enteral nutrition in the person with dementia?"*

The main objective was defined as: *Clarify the indications on the use of enteral nutrition in the person with dementia.*

Thus, in line with the abovementioned question the following keywords were selected as descriptors: end of life, palliative care, advanced dementia, artificial nutrition, tube feeding, enteral nutrition, indication, effects, benefits.

Table 1 - Criteria used to formulate the research question

				Keywords
P	Participants	Who was studied?	Patients with dementia with health condition monitored (both in hospitals and in the community)	End of life Palliative care Advanced dementia Artificial nutrition Tube feeding Enteral nutrition Indication Effects Benefits
I	Interventions	What has been done?	Evaluation of enteral nutrition effects Evaluation of enteral nutrition benefits Evaluation of enteral feeding indications	
(C)	Comparisons	May be drawn or not?	Which ones?	
O	Outcomes	Outcomes/effects or consequences	Identification of enteral nutrition effects	
D	Study design	How the evidence was gathered?	Qualitative and prospective method, systematic literature reviews, etc.	

Sources of information/research strategies

We defined some criteria to identify relevant research studies that helped conduct the research.

Inclusion criteria were: empirical and qualitative studies, including systematic reviews in English, Spanish and Portuguese, in the context of follow-up of dementia, both in hospitals and in the community.

We selected papers from the 2008-2013 period, for the number of papers found was high.

Exclusion criteria were also determined to conduct the research. Studies on:

- Alternatives for drug administration in patients with dementia
- Cancer patients with dementia
- The effects of oral liquid nutritional supplements in patients with dementia
- Decision-making process for enteral tube feeding in patients with dementia
- Health care professionals perception of the effects of enteral nutrition in patients with dementia
- Ethical issues in enteral nutrition in patients with dementia
- Complications after PEG placement
- Advanced life policies

In application of previously mentioned PICOD method (Table 1) the research parameters were established, which would determine paper selection. Finally, in accordance with the previously established period, database search was carried out at:

- Online Knowledge Library (B-on), EBSCO (eBook collection (EBSCOhost), Nursing Reference Center, CINAHL (Cumulative Index to Nursing and Allied Health Literature) Plus With full text, Medline with full text, Cochrane Database of systematic reviews, Nursing & Allied Health Collection: Comprehensive, MedicLatina, PubMed, BioMed, Opendoar, Dovepress, Amadeo;
- We used complementarily Google Scholar search engine;
- We consulted theses, dissertations and monographs at RCAAP (Portugal Open Access Scientific Repository) and RCIPCB (Castelo Branco Polytechnic Institute Scientific Repository).

References cited in the papers analyzed were also considered.

To obtain one of the articles, given access difficulty, we contacted directly via e-mail the author Zeev Arinzon, doctor, to whom is our profound gratitude for his generosity, total availability and precious scientific aid.

Identification and selection of relevant studies

The first stage of the research was a complex process given the high number of papers found. After determining precise and clear search criteria, however, the process was simplified.

From studies published in the 2008-2013 period, we first selected 30 papers by reading the abstract. After reading and applying inclusion and exclusion criteria, we selected 8 papers (5 primary sources and 3 secondary sources - systematic literature reviews). We found many publications in several countries on health care professionals' perceptions (nurses, doctors, speech therapists) of tube feeding in the person with dementia. These papers were excluded according to previously established criteria. These different views and perceptions of health care professionals may be an important challenge for future discussions and investigations.

RESULTS

As mentioned, after laborious research 8 qualitative studies were selected, which answered the central question and met the inclusion criteria. They have different countries of origin: Spain, England, Israel, Japan, the United States of America and Canada. Regarding

year of publication, there was homogenous distribution in 2008, 2009, 2012, and 2013. There was not publications in 2010 and 2011.

All papers answer the central question of this study, showing enteral feeding effects in the person with dementia, in different areas: mortality/survival rate, nutritional status, functional and cognitive status, aspiration, pressure ulcers and quality of life.

Clinical indications for tube feeding are neurological disability, followed by food refusal, poor oral intake, weight loss, dysphagia and stroke, ensure a safe swallowing, prevent aspiration pneumonias and pressure ulcers, provide more comfort and improve survival[22-24]. Most tubes (2/3) are placed in acute hospitalization[23].

A study showed that 61% of patients with dementia with NGT experienced at least one complication or symptom related to feeding, whereas in control group (oral feeding) only 34%[25]. 20% of patients had to return to the hospital due to complications with the tube[23]. There are no significant differences in the frequency of complications between patients with and without dementia after PEG placement[26].

In the following diagram are organized the effects of enteral nutrition in the person with dementia.

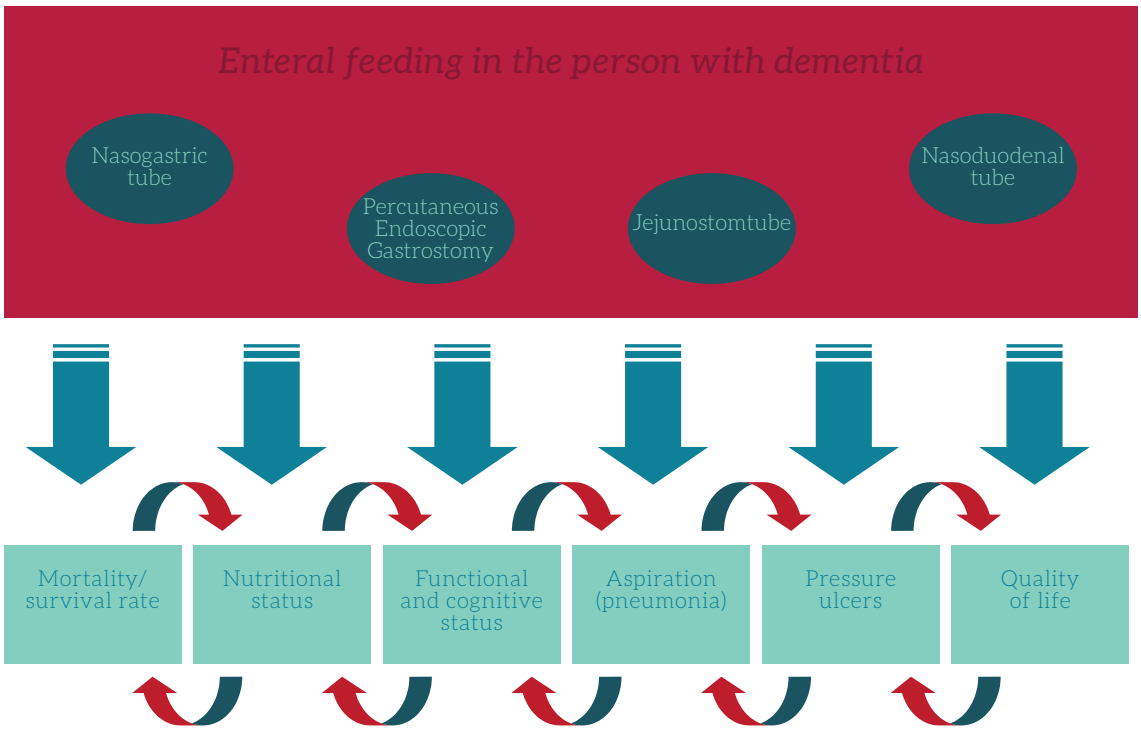

Figure 1 - Diagram.

Mortality/survival rate

The majority of authors studied suggests lack of significant benefits of enteral nutrition on patient's survival rate compared with those fed orally, even in patients with dementia[22,24,25,27,29].

By contrast, when we compare survival rates of patients with dementia/severe cognitive impairment due to neurological injury who received PEG with patients with other diagnoses who received PEG (oropharyngeal cancer, stroke and other neurological injuries), the mortality rate at 30 days was 28% for the group without dementia and 54-58% for the group with dementia. After one year, respectively, between 63 to 70% for the group without dementia and 90% for the group with dementia[23-24]. Another author refutes these data with survival rates of 51% and 49% after 12 months[26].

Only one study examines survival rate of patients who received PEG and of patients fed by nasogastric tube, which increased by 27 months[28].

Moreover, survival time since the need of feeding assistance and time of PEG placement are not associated. In other words, early PEG placement after need for feeding assistance is not associated with higher survival rates after placement[29].

Many factors affect negatively survival of these patients: malnutrition, hypoalbuminemia prior to PEG placement, advanced age, existence of comorbidities, C-reactive protein, cognitive impairment, advanced dementia, presence of pressure ulcers, gastrectomized, cardiac pathology, diabetes, male, karnofsky index > 50[24,26].

We assert from data analysis that there is not a consensus, nor evidence that enteral nutrition is effective to prolong survival in patients with dementia.

Nutritional status

Weight is a marker for mortality risk in elder patients[25]. Tube feeding does not improve malnutrition, defined by biomarkers, e.g., serum albumin concentration, in patients with dementia, suggesting weight loss[22,27,28]. Comparatively, after six months of feeding either by NGT or PEG, no significant differences were found between the two groups in albumin levels, not confirming their effect on improvement of albumin levels[28].

Only one author referred to positive effects on blood levels (hemoglobin and lymphocytes), renal function and electrolytes, hydration, osmolarity and serum proteins, of enteral nutrition group compared to control group[25].

The studied authors report the lack of definitive evidence on enteral feeding effectiveness in improving nutritional status or preventing the consequences of poor nutrition. Many patients with later-stage dementia can normally eat and therefore do not lose weight[24-25].

Functional and cognitive status

Only two studies have examined this field and they agree that tere is no definite improvement of functional and cognitive status in tube-fed patients with dementia[25,27].

Aspiration

Aspiration pneumonia includes not only pneumonia developed after vomiting and aspirating gastric contents, but also pneumonia that developed insidiously due to wrong direction of pharyngeal content and airway secretions[11].

Tube feeding does not reduce the risk of aspiration of oral secretions or regurgitated gastric content, nor the risk of infections[24,27]. Three studies state that after 6 months 53 to 58% of tube-fed patients had aspiration pneumonia, whereas 17% of orally fed patients had aspiration pneumonia. 53% of tube-fed patients with NGT, 52 to 67% with gastrostomy and 75% with jejunostomy had aspiration pneumonia, a statistically significant difference[22,23,28].

Therefore, enteral feeding is not effective to prevent aspiration pneumonia and infections in patients with dementia.

Pressure ulcers

There is no definitive proof that enteral feeding is more effective in reducing the risk of pressure ulcers than oral feeding in the person with dementia, it could otherwise has higher incidence[22,24,25,27]. A grade III and IV pressure ulcer may even have higher incidence in the group of patients with NGT than in the control group[25].

Quality of life

None of the studies has examined patient quality of life, however, they mention physical or even chemical restrictions to maintain artificial feeding, limiting the quality of life of individuals, decreasing their interaction with others, pleasure of tasting food, dignity and autonomy[22-24]. There is not also data on tube-fed patient's comfort[27].

CONCLUSIONS

The choice of this theme and initial question of the study of such nature came from a personal need for clarifying and deepening technical and scientific knowledge in this field of study, and for working as a nurse in an institution that provides care mostly to people with dementia. At the beginning of research it became clear the huge number of scientific papers on the subject and it was necessary to define more precisely our research theme.

Despite all studies that have already been carried out, evidences were not conclusive on enteral feeding in people with dementia improving survival and mortality rates; quality of life; nutritional, cognitive and functional status; and reducing the incidence of pressure ulcers. Moreover, there is still little information about adverse effects of these invasive procedures, as well as scarce objective assessment of quality of life, functional status, behavior, pain, discomfort and psychiatric symptoms of dementia.

Given the lack of consensus, tube feeding sometimes remains as a reasonable solution to feed and hydrate the person with dementia. Hence, this could be a plausible reason for the high number of tube-fed patients with dementia.

On the other hand, I believe it is important to think about the opposite effect of enteral nutrition on patients according to some studies: increased mortality, morbidity, change in quality of life, increased pulmonary secretions and higher risk of pressure ulcers.

Difficulties in acknowledging dementia as a terminal illness can make decision-making difficult for health care professionals or the family. I believe that the evidence produced in this study will help their decision-making, taking into account the patient desires, autonomy, overall situation and comfort. Because removing a feeding tube is more difficult than putting it in.

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