

# Importance of quality of life in people with dementia treated with enteral nutrition: the role of the nurse

Nicola Veronese,<sup>1,2</sup> Serena Minto,<sup>3</sup> Ornella Bonso,<sup>4</sup> Andrea Merlo<sup>5</sup>

<sup>1</sup>National Research Council, Neuroscience Institute, Ageing Branch, Padova; <sup>2</sup>Unità Locale Socio Sanitaria 3, Primary Care Department, Venice; <sup>3</sup>Relaxxi SRL, Noale, Venice; <sup>4</sup>School of Nursing, Padova University, Padova; <sup>5</sup>Management of Public and Health Organizations, Managing Director of Senior Care Residences in Venice, Italy

#### **Abstract**

Nutritional problems are common in dementia and can lead to enteral nutrition, a nutritional treatment option in severe stages of dementia. However, the benefits of enteral nutrition in people with dementia are still weak. The decision to use artificial nutrition in these patients is often emotional and complex and the attitudes of health personnel (physicians and nurses) in this sense they are very different. The objective of this review is to show the role of enteral nutrition on quality of life in patients affected by dementia and the possible implications for practice and research, with a special focus on nurse role. We made a literature search in PubMed and Scopus, searching for studies dealing with enteral nutrition and quality of life in dementia. We were able to find only a few observational studies related to enteral nutrition and quality of life, with a lack in the scientific literature regarding the management of nutritional problems in dementia, particularly taking in account quality of life. Furthermore, by orienting the research on a possible role of nurses, there were limited studies on properly nursing aspects. From this work emerges the need for further research in this context for which the training and education of health personnel result of fundamental importance, with a view to improving the quality of life of the patients with dementia and their family.

#### Introduction

Dementia is a chronic-degenerative disease whose natural history is characterized by the appearance and progression of cognitive deficits, behavioral disorders and impairment in functional autonomy.<sup>1</sup> In many cases, Behavioral and Psychological Symptoms in Dementia (BPSD) such as agitation, apathy, delusions, aggressiveness, are present and all these factors have a negative impact on the patient's quality of life.<sup>1-3</sup>

Maintaining an adequate nutritional status is of fundamental importance particularly in older people having a diagnosis of dementia. The aging process itself modifies the nutritional requirements of the subject, altering the *pleasure* that comes from eating and reducing the sense of taste and smell.<sup>4</sup> All these pathological transitions are, unfortunately, accelerated in dementia.

In this review, we will summarize some concepts of nutritional status in dementia, the importance of quality of life and the clinical importance of artificial nutrition in people affected by dementia.

#### Nutritional status in dementia

The guidelines of the European Society for Parenteral and Enteral Nutrition (ESPEN)5,6 recommend the evaluation of nutritional status and a close monitoring of body weight in every person affected by dementia with mono (e.g. weight) and multidimensional tools (e.g. Mini Nutritional Assessment, MNA) tools. In general, among the strategies to support oral nutrition it is important to maintain a pleasant and welcoming atmosphere during meal consumption.5,6 In fact, environmental factors such as noise, smells, lighting, distractions and routines can strongly influence food intake and therefore also the autonomy of the person.<sup>7</sup>

It should be emphasized that, although caregivers constitute a resource in ensuring a good quality of life for the patient, assistance generates a great deal of physical and psychological stress, which in turn can aggravate the patient's nutritional problems.2 According to the 2006 National Institute of Health and Care Excellence (NICE) guidelines, socio-medical personnel should encourage people with dementia to have oral food and hydration for as long as possible.8 In general, if a state of malnutrition or risk for this condition has been ascertained, the nutritional intervention should be given by oral, enteral or parenteral nutritional support, alone or in combination, depending on the stage of dementia. Potential swallowing problems must also be taken into consideration.9 Patients suffering from severe dementia often develop dysphagia, anorexia, apraxia, refusal of food, with consequent difficulty or impossibility to feed by mouth. 10,11

Correspondence: Nicola Veronese, National Research Council, Neuroscience Institute, Ageing Branch, via Giustiniani, 2 35128

Padova, Italy. Tel.: +39.0498.211476. Fax: +39.0498.211476.

E-mail: ilmannato@gmail.com; nicola.veronese1@aulss3.veneto.it

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#### Artificial nutrition in dementia

Artificial nutrition is a common solution for giving appropriate calorie intake in people affected by dementia. Artificial nutrition can be achieved in two ways:<sup>12</sup>

- The parenteral route, in which the nutrient is directly infused into the blood by catheters (central or peripheral). This route should be given only to people having significant intestinal absorption diseases that, overall, constitute, a limited part of people affected by dementia;
- The enteral route which uses the physiological channel represented by the gastro-intestinal tract. Main devices used for enteral nutrition are: i) the enteric probe (gastric, duodenal or jejunal nose). It is a silicone tube that can be placed at the patient's bed by passing it through a nostril, the esophageal sphincter, until it reaches the gastric cavity. It can be used if the duration of the artificial nutrition is expected to be short (<30 days); and ii) percutaneous endoscopic gastrostomy (PEG) that is indicated when artificial nutrition is required for a period longer than 30 days.

The conditions that can indicate ab enteral nutrition are inadequate or unsafe oral intake and a functioning and accessible gastro-intestinal tract. Other indications are neurological dysphagia, where this condition is considered as transient. PEG represents the most correct and complete method to guarantee a balanced long-term nutritional intake (often identified as more than 30 days) in those subjects who for various rea-





sons are unable to feed themselves orally. It is also a widely used technique due to the low presence of complications and the good cost-benefit ratio.8

#### The concept of the quality of life

There is no single definition of quality of life, as it can have different meanings for each person. The World Health Organization (WHO) working group proposed the following definition in 1995: The perception of the individual of his own position in life in the context of the cultural systems and of the reference values in which he is inserted and in relation to his own goals, expectations, standards and interests.<sup>13</sup>

Another expression introduced more recently in the scientific literature is health related quality of life (HRQol).<sup>14</sup> This expression assumes a great relevance in the medical field, since it refers to the health condition of the subject and to how much a possible illness and/or medical interventions can affect his life.<sup>13</sup>

The main QoL measures can be roughly divided into generic and specific tools.15 The generic tools are questionnaires that can be used to describe the subjective health status and the QoL of different types of patients regardless of the pathology. Among these, a noteworthy tool is the 36-item short-form health survey (better known by the acronym of SF-36)16 and its abbreviated forms such as the SF-12.<sup>17</sup> Specific tools, on the other hand, evaluate a series of aspects that can affect the QoL of patients with specific pathologies or who are subjected to certain treatments. In this case the questionnaires allow understanding which aspects of the disease or treatment impact on the quality of life and to what extent. One of these is the QLQ-C30 of the EORTC (European Organization for Research and Treatment of Cancer)18 or the QUALID in people affected by dementia.19

Quality of life is also used in clinical research as an important outcome measure for assessing the effectiveness of a medical intervention. The measurement of this parameter in the medical field allows healthcare professionals to obtain information from the patient that is useful in guiding the planning of therapeutic interventions and in documenting their effectiveness, as well as describing the impact of pathology.

#### Aim of the review

The decision to use artificial nutrition in dementia patients is complex. Family members may require this type of intervention in order not to make the person die of hunger or thirst and to prolong the life of their relatives. However, clinical evidence on its benefits in subjects with advanced dementia is still weak. As summarized by an important Cochrane review in this field,<sup>20</sup> enteral nutrition does not seem to have a relevant impact on increasing survival, preventing pressure ulcers or other medical geriatric syndromes. As mentioned by the same authors, the effect of enteral nutrition on quality of life is limited.<sup>20</sup> Furthermore, the attitude of the healthcare personnel (medical, nursing) is often different and affected by moral, religious and personal beliefs.

Given these assumptions, the purpose of this review is to understand what the effect of enteral nutrition on quality of life in dementia patients is, and, based on the results obtained, analyzing the possible implications for nursing practice and research.

#### **Materials and Methods**

A systematic search was made in PubMed and Scopus until 1st January 2019, using the following keywords: Enteral nutrition/ nutrition/ Parental Gastrostomy/Feeding methods/ Nutritional Support/ Artificial nutrition/ Artificial feeding/ PEG/Percutaneous endoscopic gastrostomy/ ANH/ Naso gastric tube/ NG tube/ Nasogastric feeding/ Total parental nutrition/ TPN/ Quality of life/ quality of life/ gol/hrgl/ hrgol/ Dementia/ Alzheimer's disease. The references of the included papers were manually scrutinized for searching other potentially eligible works.

#### Results

Table 1 reports the main findings of the studies investigating quality of life and enteral nutrition in dementia.

#### **Cross-sectional studies**

Ligumsky *et al.*<sup>21</sup> conducted a survey to understand the attitudes of health professionals about the placement of PEG in older people affected by dementia. The sample studied included 126 patients with dementia with PEG, 126 family members, 72 doctors who had sent their patients to place a PEG and 34 gastroenterologists. Regarding the expectation of improvement in the patient's quality of life, the main results of this study report that most referring physicians believed that PEG improved quality of life, whereas gastroenterologists did not expect any improvement.

The Japanese study by Nakanishi and

Hattori<sup>22</sup> in 2014 was conducted on a sample of 3,359 patients (hospitalized and in nursing home), of whom the majority (2087; 62.1%) had advanced dementia. According to the health personnel, PEG placement was expected to prolong survival by 51.1% in hospitalized patients with advanced dementia. Furthermore, health personnel expected that quality of life would improve in a substantial part of the participants having dementia.

Simionato et al.23 investigated the decisions perceived as relevant to the quality of life of people with severe dementia in a sample of 115 health workers (35 doctors, 80 nurses) serving in residential areas and district services in two areas in Italy. Almost half of doctors and 23% of nurses reported having been called often or very often to make critical therapeutic decisions, mainly related to artificial nutrition/hydration. Decisions perceived as important for survival or quality of life of demented patients are frequent, but overall, they don't expect any significant improvement in quality of life in people affected by dementia after placing an enteral nutrition tool.

### Longitudinal and retrospective studies

Suzuki *et al.* in 2012<sup>24</sup> conducted a retrospective cohort study on a sample of 1353 patients with dementia carrying PEGs, followed for 2 years. The results of this study suggested that an improvement in quality of life after PEG insertion could be expected more in the milder forms of dementia than in the advanced stages by health personnel.

The study by Monteleoni and Clark<sup>25</sup> considered a sample of 71 patients with advanced dementia with PEG/PEJ in an acute care hospital. This seminal study found no evidence that artificial feeding devices in this population prevent aspiration, prolong life, improve functional status or reduce the number of pressure ulcers. In addition, the quality of life of the patient with advanced dementia can be negatively affected when a feeding device is placed. It may also be necessary to use means of restraint to prevent the patient from pulling the device or developing an infection on the gastrostomy site, developing pressure ulcers or being deprived of social interaction and meal-related pleasure and is necessary admission to a nursing home.

In 1993, Weaver carried out a study<sup>26</sup> to evaluate the benefits of PEG in a population of 100 older patients with various diseases, including dementia, through an objective and subjective measurement of quality of life. The follow up had duration of one year. The overall results did not report a significant change in the objective assessment of





Table 1. Main findings of the studies investigating quality of life in dementia and enteral nutrition.

Author, year	Setting	Type of nutrition used	Sample size	Type of study	Results	Nurse's role
Golan, 2007	Hospital	PEG	126 patients, 72 doctors, 126 family members, 34 gastroenterologists	Cross-sectional	Most referring physicians believed that PEG improved quality of life, while gastroenterologists did not expectany improvement in quality of life	This study does not report anything significant about a possible role of the nurse
Monteleoni, Clark, 2004	Hospital for acute care	PEG, PEJ	71	Longitudinal	The study found no evidence that artificial feeding devices prevent aspiration, prolong life, improve overall function or reduce pressure ulcers. In addition, the quality of life of the patient with advanced dementia can be negatively affected when inserted a nutrition device. It may be necessary to put up containments to avoid that the patient pulls the device or develop an infection on the site of the PEG, develops pressure ulcers or can be private of social interaction and pleasure about meals and admission to a nursing home is necessary	Importance of the palliative care team where enteral nutrition is considered for patients with advanced dementia. In this study emerges the figure of the nurse manager and the nurse case manager, who collaborate with the doctor in contacting the palliative care team and who participate in educational programs to provide greater assistance quality
Nakanishi, Hattori, 2014	Hospital	PEG	3359 patients in total (2087 with advanced dementia)	Cross-sectional	As reported by health personnel, PEG placement was expected to prolong survival by 51.1% in patients hospitalized with dementia advanced. Furthermore, health personnel expected that QOL would improve in 39.1% of cases. In nursing home patients, 61.7% had a diagnosis of advanced dementia. The percentage of patients with a good quality of life was only 4.2% and lower than those with PEG but with other diagnoses (16.4%). In the nursing home, about 60% of relatives reported one certain degree of satisfaction with the QOL of patients, regardless of whether they are affected or not dementia severe	This study does not report anything significant about a possible role of the nurse
Simionato et al., 2010	Nursing home, health district	Nutrition and hydration artificial	115 (35 doctors and 80 nurses)	Cross-sectional	35 doctors and 80 nurses responded to the questionnaire, 48% of doctors and 23% of nurses reported that they were often/very often called to make critical therapeutic decisions mainly related to artificial nutrition/hydration. Decisions perceived as important for survival or there quality of life of demented patients are frequent	Nurses believe their role in feeding decisions is minor and they are also reluctant to play a role in them decisions



quality of life at follow up. Male patients, over the age of 76 years, suffering from chronic diseases such as multiple strokes or dementia, showed the poorest response on the quality of life scale. The subjective evaluation of patients or their families was positively correlated with an objective assessment on the quality of life scale.

# **Discussion Gaps in the literature**

This literature search has reported very different data from study to study and sometimes conflicting. To place an enteral nutritional device is, in fact, seen by some professionals as useful for lengthening life and improving quality of life, whilst other figures involved in demented patient management have very different and often conflicting ideas. The results of this revision work show a gap, or a lack, in the scientific literature, regarding the effect of enteral nutrition on the quality of life of the patient suffering from dementia. Moreover, the number of studies, above all original, appears limited.

In the included studies a standard scale is not used, but the criteria and the measurement scales are several (Table 1). This may be due to the lack or reduced availability of reproducible and valid tools that measure the quality of life in patients affected by dementia. Many scales of evaluation are also often constructed starting from other scales, which are used for other pathologies or that measure different aspects related to dementia, such as depression, the presence of BPSD.

The difficulty in measuring quality of life in general is to be found in the lack of an agreement on the definition of quality of life in patients with dementia and also in the disease itself, since memory and communication problems, especially in the advanced stage of dementia, make it difficult to collection of information from the patient. In this regard, we have some tools for directly measuring quality of life in older people affected by dementia that are based on objective signs (e.g. irritability, cries, facial expression of discomfort and many others) that can help health professional in better understanding quality of life in these vulnerable patients.<sup>27</sup> As for the evaluation of pain, the future studies should take in account these scales that can give important information regarding if enteral nutrition can improve quality of life in people with severe dementia.

#### Ethical and legal considerations

Even if we believe that ethical and legal issues are among the most important in deciding for enteral nutrition in people

affected by dementia, other aspects are of importance as summarized in Figure 1. In carrying out this review it was possible to see how the decision to start enteral nutrition in dementia (especially in its advanced stage), is often controversial and influenced by clinical reasons, by the context in which we are called to operate, or by the doubtful availability and legitimacy of advance directives for the treatment of patients.28 Moreover, cultural-religious convictions of health personnel and family members, emotional experience linked to the illness, and legal implications are among the most important factors to take in account.29

The choice to perform this procedure becomes complex in the case in which it must be operated against a person suffering from cognitive impairment, or where the patient's involvement is limited by the underlying pathology, since it becomes necessary to reconstruct the will, guaranteeing compliance with the system of the values, of the convictions that he expressed during his life, as the dementia patient must be recognized as a person, at every stage of his illness, regardless of the change in cognitive conditions, gradual or immediate or change of personality and behavior.8

In order to favor health professionals, family members, patients and caregivers in decision-making, the guidelines provided by international guidelines and ethics committees must be taken into consideration. In this sense, the guidelines developed by the ESPEN on nutrition in dementia, recommend not to enter enteral nutrition in the case of dementia in advanced stage. 5,6,12 In view of the available evidence and the

opinion of the Experts seem to have very few circumstances in which the use of enteral nutrition is advantageous. Furthermore, according to many studies, its positioning can cause harm to the patient, with the need to position restraints, which further worsen the quality of life. If it is necessary to start it, it is advisable to carry out strict monitoring of its effects and, like any medical treatment, if the risks and disadvantages outweigh the benefits, it can be interrupted.<sup>5,6,12</sup>

From the ethical point of view, in fact, but from a legal point of view, there is no difference between not starting a treatment and interrupting a treatment that is already in progress, if there is a disproportion due to excess or inadequate treatment. It is also recommended not to start artificial nutrition/hydration in the terminal stages of life. If it is started it must be interrupted if it causes complications or symptoms to the patient.<sup>28,30</sup>

## The role of nurses in the enteral nutrition in dementia

The management of nutritional problems in dementia is of particular interest in the advanced stage of the disease, representing a challenge from many points of view for the health staff, but especially for the nurse, as nurses spend a lot time in contact with patients and family members, especially in hospitals and nursing homes. The nurse could therefore have an important role in the management of these patients, in the evaluation of nutritional status, in the decision-making process related to artificial nutrition, in the management of medical devices, in monitoring possible complica-

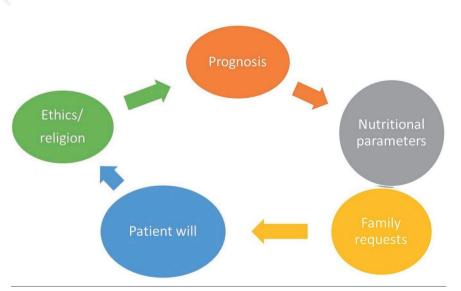


Figure 1. Factors that play a role in placing or not enteral nutritional tools in patients with dementia.



tions and in supporting caregivers.<sup>31</sup> According to the new deontological Italian code ...the nurse enhances and welcomes the person's contribution, his point of view and his emotions and facilitates the expression of suffering. The nurse informs, involves, educates and supports the person concerned and, with his free consent, the reference persons, to encourage adherence to the care path and to evaluate and activate the available resources.<sup>32</sup>

Most of the studies included in this review showed a lack of proper nursing taking care of the patients of severe dementia and with the need of enteral nutrition. However, in some studies there are some references to the attitudes of nurses. Monteleoni and Clark<sup>25</sup> mentioned the figure of the nurse manager and case manager who collaborate with the physician in contacting the palliative care team, if needed. These two professional figures in the nursing field have advanced skills and play an important role in the management of care. Both reflect a patient-centered care model. The nurse manager is a specialized nurse with responsibility for managing a nursing unit, which is found particularly in the British and American realities. The nurse case manager instead is a professional who provides and/or coordinates the social and health services for the clinical management of a specific population of users (for example terminal patients and older people) from admission to discharge, guaranteeing continuity of care. Simionato et al.23 instead, investigating which decisions are perceived as most impacting on the quality of life by health personnel, underline how nurses consider their role in feeding decisions to be limited and how they are reluctant to perform a role in such decisions, mainly for the lack of education in this field. In contrast, Clarke et al.33 attributed a key role to nurses in initiating a discussion on artificial nutrition, even with respect to assessing the patient's nutritional status.

The review by Sanders, Leeds and Drew<sup>34</sup> has instead highlighted the role of the endoscopy nurse in the peculiar aspect of PEG positioning, as it could evaluate the cases in which the patient is to be considered at risk for the procedure. The endoscopy nurse in this study needed to have solid basic knowledge and experience to provide support and information to patients and family members, to facilitate decision-making. Unfortunately, data on the quality of life in this study are not reported and therefore we cannot tell whether endoscopy nurses think whether or not the PEG positioning can improve this parameter.

#### **Conclusions**

The effect of enteral nutrition on quality of life in patients with dementia is uncertain. The studies included in this review report limited data and it is therefore not clear whether enteral nutrition leads to an improvement or deterioration in the quality of life in these patients. Furthermore, in most studies the quality of life was measured according to the expectation of health workers or family members and the evaluation scales used were different. Research on a possible role of the nurse in this context has highlighted a lack of studies in the literature regarding the aspects of nursing. However, the importance of a global care of the patient by a multidisciplinary and specialized team emerges from this work. We believe that we need future studies better showing the pivotal role of the nurse in the context of this topic that includes not only medical aspects, but also relevant emotional and ethical issues.

With a view to improving quality of life, even considering nutritional problems, all this opens a reflection on a palliative approach towards these patients. For future developments it is therefore desirable for more research into the management of nutritional problems in dementia, particularly from the point of view of nursing.

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