Validation and Preliminary Results of a Questionnaire for Physicians about Bioethical Aspects Related to Enteral Feeding in Patients with Dementia

Validación y resultados preliminares de un cuestionario a médicos acerca de los aspectos bioéticos relativos al uso de la alimentación enteral en pacientes con demencia

Validação e resultados preliminares de um questionário para médicos sobre questões bioéticas relacionadas ao uso de nutrição enteral em pacientes com demência

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Abstract
Introduction: Enteral feeding in patients with dementia poses an ethical-clinical challenge. This article presents the validation process of a questionnaire to know doctors' opinions on the matter and its preliminary results. Materials and methods: An anonymous questionnaire was prepared to obtain doctors' views about enteral feeding. I was aimed at palliative care, geriatrics, internal medicine, and neurology specialists from public and private care centers attending to three clinical cases of patients with dementia at different stages of evolution. The questions addressed four fields: motivations for starting or stopping enteral feeding, therapeutic adequacy, euthanasia, and decision-making. Results: A response rate of 64 % was attained. The questionnaire turned out to be a tool with acceptable validity and reliability. Palliative care and geriatrics specialists were more likely to adapt therapeutic efforts and integrate the family into decisions. Internal medicine and neurology professionals tended to be more invasive in their treatments. Conclusion: The results allow us to recommend the questionnaire to assess professionals' attitudes toward the most relevant bioethical issues in the care of patients with dementia.
Keywords (Source: DeCS): palliative care; dementia; survey; enteral nutrition; bioethics.

Resumen
Introducción: el uso de la alimentación enteral en pacientes con demencia resulta un desafío ético-clínico. El objetivo de este artículo es exponer el proceso de validación de un cuestionario para conocer la opinión de los médicos al respecto y sus resultados preliminares. Metodología: se desarrolló un cuestionario anónimo para conocer la opinión de médicos acerca del uso de la alimentación enteral, dirigido a especialistas de cuidados paliativos, geriatría, medicina interna y neurología, de los ámbitos público y privado. Se presentaban allí tres casos clínicos de pacientes con demencia en diferente grado de evolución. Las preguntas abordaban cuatro campos específicos: motivaciones del inicio o suspensión de la alimentación enteral, adecuación terapéutica, eutanasia y toma de decisiones. Resultados: se obtuvo un índice de respuesta del 64 %. El cuestionario resultó una herramienta con validez y fiabilidad aceptables. Los especialistas en cuidados paliativos y geriatría eran más propensos a adecuar el esfuerzo terapéutico y a integrar a la familia en las decisiones. Los profesionales de medicina interna y neurología tendían a ser más invasivos en los tratamientos. Conclusión: los resultados obtenidos permiten recomendar el cuestionario como metodología para valorar la actitud de los profesionales ante las cuestiones bioéticas más relevantes en la atención a pacientes con demencia.
Palabras clave (Fuente: DeCS): cuidados paliativos; demencia; encuesta; nutrición enteral; bioética.

Resumo
Introdução: o uso de nutrição enteral em pacientes com demência é um desafio ético-clínico. O objetivo deste artigo é apresentar o processo de validação de um questionário para conhecer a opinião dos médicos sobre essa questão e seus resultados preliminares. Metodologia: foi desenvolvido um questionário anônimo para conhecer a opinião dos médicos sobre o uso da nutrição enteral, destinado a especialistas em cuidados paliativos, geriatria, medicina interna e neurologia, tanto no setor público quanto no privado. Foram apresentados três casos clínicos de pacientes com demência em diferentes estágios de evolução. As perguntas abordavam quatro domínios específicos: motivações para iniciar ou interromper a nutrição enteral, adequação terapêutica, eutanásia e tomada de decisão. Resultados: foi obtida uma taxa de resposta de 64 %. O questionário foi considerado uma ferramenta com validade e confiabilidade aceitáveis. Os especialistas em cuidados paliativos e geriatria tinham maior probabilidade de ajustar o esforço terapêutico e de envolver a família nas decisões. Os profissionais de medicina interna e neurologia tenderam a ser mais invasivos nos tratamentos. Conclusão: os resultados obtidos nos permitem recomendar o questionário como uma metodologia para avaliar a atitude dos profissionais com relação às questões bioéticas mais relevantes no atendimento a pacientes com demência.
Palavras-chave (Fonte: DeCS): Cuidados paliativos; demencia; encuesta; nutrición enteral; bioética.

INTRODUCTION

Dementia is one of the most prevalent pathologies in the elderly population worldwide (1,2). The disease causes substantial physical and cognitive deterioration (3) and raises some bioethical questions, one of which is whether to start, not start or stop feeding by nasogastric tube (NGT) or percutaneous endoscopic gastrostomy (PEG) (4-7).

These concerns are difficult to address in clinical practice, which could be due to a lack of bioethical foundations to guide decision-making in health care.

These problems are common to the different specialties that are involved in caring for patients with dementia, including palliative care, which facilitates both clinical care and comprehensive decision-making centered on the patient and their family (8-15).

Several reviews have concluded that enteral feeding does not prolong life or improve the quality of life of patients in certain circumstances and conditions. In these studies, enteral feeding did not prevent aspiration, pneumonia or pressure ulcers; did not prevent or reverse malnutrition; and did not improve survival or functional status. The authors reported that enteral feeding produces different types of adverse effects, such as local, pulmonary, and abdominal effects (16-18). These findings have been corroborated by recent publications, including a Cochrane review (19-22).

These differences have resulted in a debate over whether enteral feeding could be suspended if the risks and inconveniences exceed the benefits (23,24,19). Pereira et al. argued the importance of explaining this point to families and health teams to facilitate ethically appropriate decision-making (25). However, Brody et al. suggested that some professionals from health teams and family members view enteral nutrition as a treatment that prolongs the patient's life (26). For these individuals, although the patients do not experience hunger or thirst, discontinuing enteral feeding is equivalent to causing death (27-29).

Although there is clinical evidence on the benefits and limitations of enteral feeding in the specialized literature (30-35), few publications discuss the bioethical problems that arise (36-38). Therefore, a more in-depth analysis of enteral feeding according to bioethical principles has potential value (1).

The main objective of this study was to describe the process of constructing and validating a questionnaire that assesses physician decisions about diet in patients with dementia from a personalistic bioethical perspective. The secondary objective was to present some preliminary results regarding certain bioethical aspects, such as the principle of therapeutic proportionality (39,40).

METHODOLOGY

Clinical and bioethical bibliographic review

To find articles that would serve as a basis for constructing the questionnaire and provide bibliographic background on the topic, a bibliographic search was initially carried out in PubMed for articles with abstracts in English and Spanish from the last 10 years.

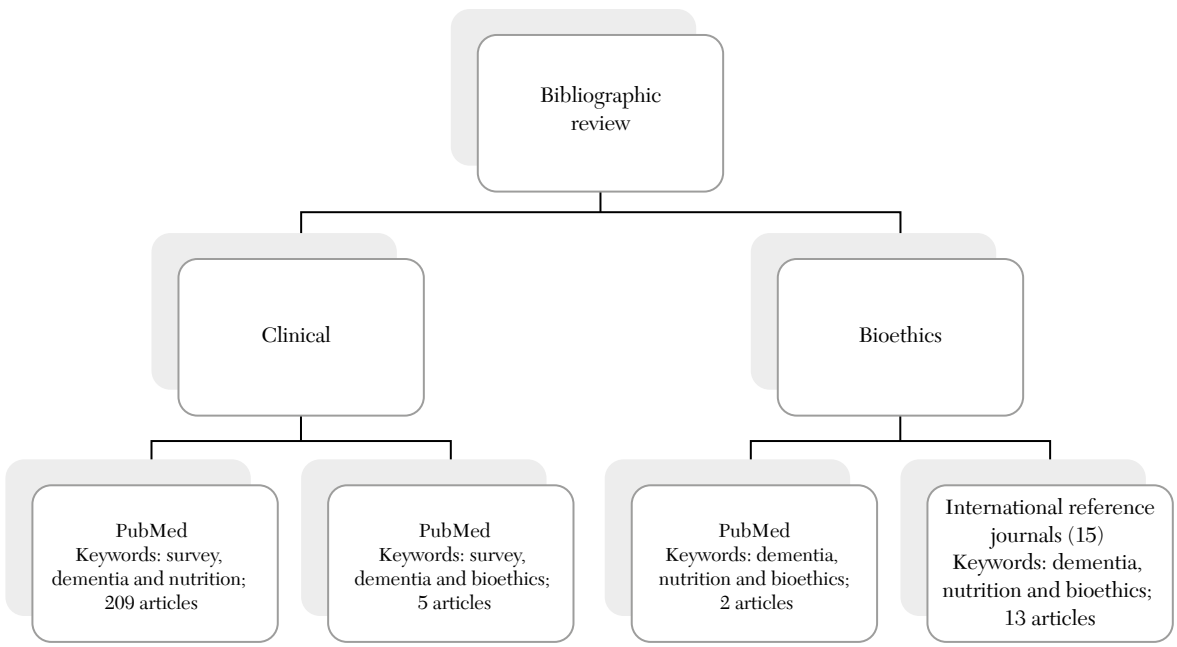
The following English keywords were used as the search terms: *survey, dementia* and *nutrition.* The

search returned a total of 300 articles. Through abstract screening, articles that were not related to the research topic, including those on other types of pathologies in older adults and those that focused on the opinions of caregivers rather than the medical team, were excluded. Finally, 209 articles were selected.

Another search was carried out with the search terms *survey, dementia* and *bioethics*, resulting in the identification of 25 articles. None of these articles discussed an ethical questionnaire on eating in dementia patients; therefore, a new search was carried out with an expanded range for publication date beginning in 2000. This search yielded a total of 40 articles, 5 of which contained surveys of doctors and clinicians on ethical aspects related to enteral nutrition in patients with advanced dementia (41-45).

In the second stage, a bioethical bibliography was investigated in PubMed and 15 international reference journals in bioethics. The search terms *dementia, nutrition* and *bioethics* in English and Spanish were used over the period from 2000 to the present. Eight articles were found in PubMed, 6 of which were discarded because they did not address the research topic, and the remaining two articles were selected (25,46). An additional 13 articles were obtained and selected according to a topic search in international bioethics journals (47-59) (Figure 1).

Figure 1. Bibliographic review



Preparation of the questionnaire

The bibliographic review allowed us to understand the background of the topic, define the research fields and develop the corresponding questions in accordance with the proposed objective. Thus, an *ad hoc* questionnaire with closed questions was developed for physicians involved in the care of dementia patients.

The questionnaire included two sections. In the first section, the objective of the study was detailed, anonymity was assured, and demographic data related to sex, age and specialty were requested. Information was also collected on the influence of religious beliefs, Argentine legal context and economic resources.

The second section described three clinical cases of patients with different degrees of dementia according to the Global Deterioration Scale–Functional Assessment Staging Tool (GDS-FAST) (1,60,61) and the Mini Mental State Examination (62,63,64) for the assessment of severe cognitive impairment. The hypothetical cases are described below.

- Case A: An 85-year-old patient with dementia grade 7 on the GDS. He is bedridden and does not recognize his relatives, and his language is incomprehensible. For two weeks, he has had difficulty swallowing liquids and solids, which was associated with decreased appetite and weight loss. Reversible causes have been ruled out.
- Case B: A 72-year-old patient with dementia grade 6 on the GDS. She lives at home and is cared for by her husband. She is able to move with assistance. She presents short-term and long-term memory loss with time–space disorientation (Mini Mental State Examination, 13/30). For two weeks, she has been aspirating semisolids when swallowing, which explains the reduced oral intake. Reversible causes have been ruled out.
- Case C: A 60-year-old patient with dementia grade 5 on the GDS. He lives at home with his wife. He exhibits short-term memory loss and is sometimes disoriented (Mini Mental State Examination, 20/30). He is able to move autonomously. He has had a cough when swallowing liquids for two weeks, which explains the reduced oral intake. Reversible causes have been ruled out.

In the original version, after each of the three cases, 20 questions were presented about the main ethical questions faced by medical professionals regarding feeding in dementia patients (Annex 1).

These questions covered 4 research themes. Questions 1 to 4 addressed the decision to start, not start or stop feeding in dementia patients when considering survival and quality of life.

Questions 5 and 6 evaluated the therapeutic appropriateness, that is, the ethical proportionality, of placing an NGT or PEG in patients with dementia. Clinical aspects and bioethical criteria were taken into account when determining whether to establish a moral obligation.

Questions 7 and 8 assessed whether there was potential confusion between not feeding and requesting euthanasia among the family, the patient or the doctor.

Finally, Questions 9 and 10 evaluated the decision-making process, including the consideration of advance directives

signed by the patient and the participation of the family or the medical team in the case of noncompetent patients. All the questions were answered via a Likert scale with the following options: totally agree, agree, disagree, totally disagree and do not know/no answer.

Parallel analysis was applied to the results to identify the number of factors. To investigate differences among the different specialties, multivariate analysis of variance (MANOVA) was performed using the 4 specialties as the independent variable and the factors of each of the three cases as the dependent variable.

FIRST PILOT TEST

The first version of the questionnaire was prepared with 3 clinical cases and the original 20 questions. This version was evaluated by 10 renowned specialists from Argentina, the United States and Spain who worked in both public and private hospitals. Some evaluators also had postgraduate training in medical ethics.

The time spent completing the questionnaire and the understanding of the clinical cases and corresponding questions were evaluated. The results of this pilot test indicated a consensus regarding the time necessary to complete the questionnaire (5-8 minutes), the relevance of the questions and the need to clarify the acronyms PEG and NGT.

SECOND PILOT TEST

After making the modifications proposed in the first pilot test, a second pilot test was conducted with five doctors from the province of Buenos Aires in the specialties of medical clinics, family medicine and surgery.

The results of the second pilot test suggested the inclusion of the degree of cognitive impairment according to the GDS-FAST and Mini Mental State Examination in the clinical case descriptions. A reformulation of the questions on the repositioning of NGTs and PEGs was also proposed, and greater precision of the term "enteral" and the concept of proportionality with respect to feeding was recommended. Once both pilot tests had been completed and the pertinent changes had been made, the field work began.

ETHICAL ASPECTS

The questionnaire was evaluated and approved by the Research Ethics Committee of the Faculty of Biomedical Sciences of Austral University (protocol no. CIE P20-004). Because the questionnaire was for medical professionals and anonymous, informed consent was not required. No conflicts of interest are declared.

POPULATION AND SAMPLE SIZE CALCULATION

For the selection of professionals, the following inclusion criteria were established:

1. Physicians with a certified specialty in palliative care, geriatrics, internal medicine, or neurology.
2. Doctors who work in the hospital environment (public and private) or home care in the Autonomous City and/or the Province of Buenos Aires.

These criteria were chosen to select professionals who usually treat patients with dementia in their clinical practice and must make decisions regarding their diet.

Doctors from the Autonomous City and the Province of Buenos Aires, which contain the largest number of

registered professionals, were included. The data were obtained from the official national list of the Medical Professionals Certification Council (65)[4] from 2020. This entity gathers data related to 40 societies of medical specialties in the country and has the endorsement of the national Ministry of Health.

According to this registry, 118 professionals were specialists in palliative care, 58 in geriatrics, 441 in internal medicine and 100 in neurology. In total, 717 certified doctors of these specialties were included. Although these numbers do not necessarily represent the total number of practicing professionals, these data were used for the sample calculation because it is the official record.

The sample size was obtained using the Survey Software calculator.[5] The total population of certified physicians (717), a confidence level of 95% and a confidence interval of 0.05 were used for the calculation. The results yielded a recommended sample size of 250 doctors.

The selected doctors were invited to answer the anonymous, self-administered questionnaire, which was distributed via the Google platform through a link received by email. The doctors' email addresses were obtained from the websites of public health institutions and privately managed social security, the LinkedIn network of professionals or colleagues.

After accepting the invitation to participate, the professional completed the questionnaire without entering any identifying data. All the responses were collected automatically through the Google form, which does not include email addresses or identifying data. In this way, the anonymity of the participants was ensured.

RESULTS

Analysis of the validity and reliability of the questionnaire

Data collection began in March 2020 and ended in March 2022. The questionnaire was sent to a total of 350 doctors to achieve the necessary sample size (250), accounting for a probable response rate of 70%. Ultimately, 223 professionals responded (64% response rate) and participated in the validation process (Table 1).

Factor analysis

To assess the validity of the questionnaire, first, the Kaiser–Meyer–Olkin (KMO) sample adequacy index was calculated, which yielded a coefficient of 0.82 for Case A, 0.80 for Case B and 0.75 for Case C. These results indicated that the data matrices were appropriate for factor analysis.

Subsequently, three factor analyses were carried out, with the 20 questions of the questionnaire for each of the cases analyzed separately. The principal components method with a varimax rotation was applied. This type of rotation was chosen since the factors were not believed to be correlated with each other. Parallel analysis was used to identify the number of factors. Three factors were found in the questionnaire for each case. The description of the factors included the variables that presented a factorial load of 0.35 or higher, as suggested by Streiner and Norman (66). Of the 20 original questions, only 13 were included in the final version of the questionnaire.

4 Available at: http://www.ccpm.org.ar/index.php/listado-de-la-seleccion-solicitada/

5 Available at: http://surveysoftware.net/sscalce.htm

Table 1. Comparison between the number of physicians invited and the number of physicians who responded by specialty

Specialty	Number of doctors invited	Number of doctors who responded	Proportion of the total number of participants
Palliative care	75	64 (87%)	29%
Geriatrics	37	33 (89%)	14.8%
Internal medicine	188	101 (54%)	45%
Neurology	50	25 (50%)	11.2%
Total	350	223	100%

Source: Own data.

The three factors identified were named as follows:

- Factor 1: motivation
- Factor 2: therapeutic adequacy
- Factor 3: decision-making

The first factor, motivation, included 3 aspects related to feeding: 1) the initiation of feeding with an NGT/PEG, 2) the reasons for initiating or not initiating feeding, and 3) the decision to reposition an NGT/PEG before an episode of bronchial aspiration. The second factor, therapeutic adequacy, included aspects of feeding with NGT/PEG. Finally, the third factor considered aspects related to decision-making. This factor included a question related to euthanasia, asking whether the doctor would cause the death of the patient if he was suffering, as well as a question about who should decide if the patient lacks lucidity, the medical team or the family (Tables 2, 3 and 4).

Table 2. Factor analysis applied to Case A (advanced dementia)

	Factor 1	Factor 2	Factor 3
1. Initiate feeding with NGT/PEG.	0.639		
2. Reasons for feeding despite the progression of dementia in this patient			
a) To avoid malnutrition.	0.789		
b) To ensure an adequate quality of life.	0.522		
c) Because not initiating it would be a cause of death.	0.723		

	Factor 1	Factor 2	Factor 3
3. If this patient already has an NGT/PEG, before an episode of aspiration, you place a new NGT/PEG to continue feeding.	0.699		
4. Considerations of feeding via NGT/PEG in this patient			
a) It is an extraordinary measure.		0.492	
b) It does not reverse the clinical situation of the patient.		0.867	
c) It does not modify the course of the disease.		0.814	
d) It is burdensome for the patient.		0.485	
e) There is no moral obligation to establish it.		0.490	
5. If the patient suffers, you administer euthanasia out of compassion.			0,404
6. If the patient loses lucidity, the decision must be made by:			
a) The medical team exclusively			0.730
b) The family exclusively			0.749

Source: Own data.

Table 3. Factor analysis applied to Case B (moderate dementia)

	Factor 1	Factor 2	Factor 3
1. Initiate feeding with NGT/PEG.	0.359		
2. Reasons for feeding despite the progression of dementia in this patient			
a) To avoid malnutrition.	0.774		
b) To ensure an adequate quality of life.	0.677		
c) Because not initiating it would be a cause of death.	0.658		
3. If this patient already has an NGT/PEG, before an episode of aspiration, you place a new NGT/PEG to continue feeding.	0.454		
4. Considerations of feeding via NGT/PEG in this patient			
a) It is an extraordinary measure.		0.748	
b) It does not reverse the clinical situation of the patient.		0.774	
c) It does not modify the course of the disease.		0.656	

	Factor 1	Factor 2	Factor 3
1. Initiate feeding with NGT/PEG.	0.359		
2. Reasons for feeding despite the progression of dementia in this patient			
a) To avoid malnutrition.	0.774		
b) To ensure an adequate quality of life.	0.677		
c) Because not initiating it would be a cause of death.	0.658		
d) It is burdensome for the patient.		0.658	
e) There is no moral obligation to establish it.		0.704	
5. If the patient suffers, you administer euthanasia out of compassion.			0.394
6. If the patient loses lucidity, the decision must be made by:			
a) The medical team exclusively.			0.832
b) The family exclusively.			0.870

Source: Own data.

Table 4. Factor analysis applied to Case C (mild dementia)

	Factor 1	Factor 2	Factor 3
1. Initiate feeding with NGT/PEG.	0.387		
2. Reasons for feeding despite the progression of dementia in this patient			
a) To avoid malnutrition.	0.934		
b) To ensure an adequate quality of life.	0.723		
c) Because not initiating it would be a cause of death.	0.657		
3. If this patient already has an NGT/PEG, before an episode of aspiration, you place a new NGT/PEG to continue feeding.	0.441		
4. Considerations of feeding via NGT/PEG in this patient:			
a) It is an extraordinary measure.		0.719	
b) It does not reverse the clinical situation of the patient.		0.743	
c) It does not modify the course of the disease.		0.735	
d) It is burdensome for the patient.		0.688	

	Factor 1	Factor 2	Factor 3
e) There is no moral obligation to establish it.		0.736	
5. If the patient suffers, you administer euthanasia out of compassion.			0.35
6. If the patient loses lucidity, the decision must be made by:			
a) The medical team exclusively.			0.882
b) The family exclusively.			0.825

Source: Own data.

Reliability

To analyze the internal consistency of the questionnaire on feeding in dementia patients, Cronbach's alpha coefficient was calculated. In Case A, Cronbach's alpha was 0.84 for Factor 1, 0.83 for Factor 2, and 0.65 for Factor 3. In Case B, Cronbach's alpha was 0.79 for Factor 1, 0.86 for Factor 2, and 0.71 for Factor 3. Finally, in Case C, Cronbach's alpha was 0.76 for Factor 1, 0.85 for Factor 2, and 0.71 for Factor 3.
Thus, the questionnaire showed acceptable levels of reliability, considering the number of questions.

Preliminary results of the questionnaire

A total of 223 questionnaires were analyzed. A total of 61.9% of the respondents were women. With respect to age, most participants were aged between 30 and 60 years. A total of 77.1% of the participants declared themselves Catholic, and 17% said they had no religious beliefs.

Group differences by professionals

The main statistically significant differences were observed in the cases of advanced and moderate dementia for motivational factors and therapeutic adequacy.

For Case A (advanced dementia), with respect to the motivation factor, specialists in internal medicine (t = .58 $p \leq .001$) and neurology (t = .80 $p \leq .001$) decided to initiate feeding via NGT/PEG more frequently than specialists in palliative care and geriatrics. The same trend was observed for Case B (moderate dementia) for internal medicine (t = .39 $p \leq .01$) and neurology (t = .63 $p \leq .001$).

In Case A (advanced dementia), with respect to the therapeutic adequacy factor, specialists in palliative care and geriatrics were more likely than those in internal medicine (t = .58 $p \leq .001$) and neurology (t =. 83 $p \leq .001$) to adapt the treatments; that is, they considered that feeding via NGT/PEG was an extraordinary means, did not reverse the clinical situation of the patient, did not modify the course of the disease, and was burdensome for the patient, and there was no moral obligation to establish it.

In Case B (moderate dementia), the same trend was observed for specialists in palliative care and geriatrics compared with specialists in internal medicine (t = .39 $p \leq .05$) and neurology (t = .54 $p \leq .05$).

There were no significant differences among the physicians of different specialties for any factors in Case C (mild dementia) or for the decision-making factor in any of the cases.

DISCUSSION

The validation results show that the questionnaire meets the conditions to evaluate the decisions of physicians about enteral feeding in patients with dementia from an ethical perspective. Three factors were validated, including questions about motivation for feeding, therapeutic adequacy, and decision-making. Internal consistency was analyzed via Cronbach's alpha coefficient, establishing an acceptable level of reliability.

There are few surveys reported in international studies that collect the opinions of doctors, nurses and family members about decision-making regarding nutritional aspects at the end of life (42,43,67,68). Moreno Villares published a survey in 2007 on the ethical aspects of home artificial nutrition aimed at physicians and other health professionals (67). The survey presented two clinical cases, one of which involved a patient with advanced dementia who was unable to make decisions. The opinions of the professionals regarding the convenience of placing an NGT/PEG were evaluated. Despite the relevance of this work, the study was not carried out via a validated instrument and only evaluated perceptions of professionals from one medical specialty. Falvy-Bockos et al. sought the opinion of geriatricians on the management of a patient with advanced dementia, investigating the convenience of using NGT or PEG (68). The reliability and feasibility of this survey were also not measured via factorial analysis, and the population studied was only geriatricians.

In the present study, the main statistically significant differences were observed in the cases of patients with severe and moderate dementia, in which palliative care and geriatrics doctors tended to feed patients via NGT/PEG less frequently than internal medicine and neurology doctors did. These doctors tended to consider that this method of feeding is an extraordinary measure, does not reverse the clinical situation or modify the course of the disease, and is burdensome for the patient. Therefore, there is no moral obligation to establish it.

Notably, the evaluation of enteral nutrition must consider the different stages of dementia. Birchley et al. reported that, in some cases, the health team may insist on sustaining enteral feeding due to difficulties in identifying the terminal stage of the disease (52). This perspective is supported by Sampson et al. in their article on advance directives of dementia patients (69). The theory that palliative care physicians and geriatricians more easily recognize the final stages of dementia could explain the differences in the study responses.

Currently, the international consensus is not to provide enteral feeding to patients with advanced dementia, that is, with a terminal disease whose prognosis is less than six months, since enteral feeding carries greater risks than benefits (70,71). The ethics committee of the American Geriatrics Society recommends that these patients be fed orally, also called hand-feeding, so that they can enjoy flavors and textures and maintain social interaction (34). Similarly, the Hastings Center Report affirms that, given the adverse effects produced by enteral feeding, the cognitive deficits of patients and the terminal stage of dementia, the principle of therapeutic proportionality should guide decision-making and highlights the convenience of maintaining and stimulating

oral intake in patients (56,57). Barker and Lynch argued that this decision-making should be carried out jointly between the family and the health team and considering the values and beliefs of the patient (72). Some studies suggest that a lack of prior discussion about the patient's situation with their relatives may lead them to demand parenteral tube feeding (73).

This bibliographic review highlights the discussion held by health professionals and family members about the advisability of suspending enteral nutrition in patients with advanced dementia. However, it also highlights the scarcity of publications from a bioethical perspective to guide decision-making in these situations.

Our work has several limitations. The original instrument contained some interesting questions that were not included in any of the three validated factors. One question referred to euthanasia at the request of the family, and another considered advance directives drawn up by the patient. Both questions addressed causes and possible reasons for the suspension of feeding, aspects that unfortunately remain unanalyzed.

Performing an exhaustive bioethical analysis of the results obtained in our questionnaire exceeds the objective of this article. However, exploring these aspects from a bioethical perspective in future research is necessary.

Finally, the questionnaire did not ask whether the professional's work environment was public or private or about the experience of each professional with this type of patient, which may have conditioned the responses. It would be interesting to evaluate these aspects in future studies.

CONCLUSIONS

Our questionnaire is an instrument with acceptable validity and reliability for determining the decisions and motivations of different medical specialists regarding enteral feeding in patients with dementia and its ethical implications. The preliminary results allow us to recommend it as an open survey that provides a valid approach to understand the opinions of physicians on these issues.

Preliminarily, compared with specialists in internal medicine and neurology, palliative care and geriatric doctors are more likely not to initiate or to suspend enteral feeding in patients with advanced dementia, viewing enteral feeding as an extraordinary measure that does not modify the course of the disease.

A study of the literature revealed that there are gaps in which it is necessary to clarify decision-making. Although there is clinical evidence that supports not recommending enteral feeding in certain patients with advanced dementia (grade 7 on the GDS), there is insufficient ethical evidence for this viewpoint.

An in-depth study of the final results from the perspectives of personalistic bioethics and the principle of therapeutic proportionality is highly important for elucidating these questions in light of the dignity of the patient.

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ANNEX 1

Anonymous survey of physicians on enteral feeding in dementia

Dear professional, we invite you to participate in this anonymous survey about the use of enteral feeding in advanced dementia patients. If you agree, we invite you to continue reading the clinical cases and answer the corresponding questions.

Objective: To determine, for academic purposes, the use of a nasogastric tube (NGT) and percutaneous endoscopic gastrostomy (PEG) by various medical specialists in patients with advanced dementia.

Please tick the correct option.

Age:

	M	F
Sex		

Specialty:

Internal medicine		Neurology	
Geriatrics		Palliative care	

Religion:

Catholic		Muslim	
Jewish		Other	
Protestant		None	

How much do the following factors influence your decisions?	A lot	Somewhat	Indifferent	Little	Not at all
Your religious beliefs					
Argentine legal context					
Scarcity of economic resources					

Below, you will find three different clinical cases. Mark with an X the option that you consider appropriate for each of them.

Case A: An 85-year-old patient with dementia grade 7 on the GDS. He is bedridden and does not recognize his relatives, and his language is incomprehensible. For two weeks, he has had difficulty swallowing liquids and solids, which was associated with decreased appetite and weight loss. Reversible causes have been ruled out.	Totally agree	Agree	Disagree	Strongly disagree	Do not know/ do not answer
1. Start an oral diet with thickeners.					
2. Initiate feeding with NGT/PEG.					
3. Reasons for feeding despite the progression of dementia in this patient:					
To avoid malnutrition.					
To ensure an adequate quality of life.					
Because not initiating it would be a cause of death.					
4. If this patient already has a NGT/PEG, before an episode of bronchial aspiration:					
You withdraw the NGT/PEG.					
You place a new NGT/PEG to continue feeding.					
5. Comfort measures that exclude NGT/PEG feeding.					
6. Considerations of feeding via NGT/PEG in this patient:					
It is an extraordinary measure.					
It does not reverse the clinical situation of the patient.					
It does not modify the course of the disease.					
It is burdensome for this patient.					
There is no moral obligation to establish it.					
7. If requested by the patient or their family, you agree to not initiate or to suspend NGT/PEG feeding to hasten death.					
8. If the patient suffers, you administer euthanasia out of compassion.					
9. Respect advance directives written by the lucid patient, even if they are not in accordance with clinical recommendations.					
10. If the patient loses lucidity, the final decision must be made by:					
The medical team exclusively.					
The family exclusively.					
The medical team and the family together.					

Case B: A 72-year-old patient with dementia grade 6 on the GDS. She lives at home and is cared for by her husband. She is able to move with assistance. She presents short-term and long-term memory loss with time–space disorientation (Mini Mental State Examination, 13/30). For two weeks, she has been aspirating semisolids when swallowing, which explains the reduced oral intake. Reversible causes have been ruled out.	Totally agree	Agree	Disagree	Strongly disagree	Do not know/ do not answer
1. Start an oral diet with thickeners.					
2. Initiate feeding with SNG/PEG.					
3. Reasons for feeding despite the progression of dementia in this patient:					
To avoid malnutrition.					
To ensure an adequate quality of life.					
Because not initiating it would be a cause of death.					
4. If this patient already has a NGT/PEG, before an episode of bronchial aspiration:					
You withdraw the NGT/PEG.					
You place a new NGT/PEG.					
5. Comfort measures that exclude NGT/PEG feeding.					
6. Considerations of feeding via NGT/PEG in this patient:					
It is an extraordinary measure.					
It does not reverse the clinical situation of the patient.					
It does not modify the course of the disease.					
It is burdensome for this patient.					
There is no moral obligation to establish it.					
7. If requested by the patient or their family, you agree to not initiate or to suspend NGT/PEG feeding to hasten death.					
8. If the patient suffers, you administer euthanasia out of compassion.					
9. Respect advance directives written by the lucid patient, even if they are not in accordance with clinical recommendations.					
10. If the patient loses lucidity, the final decision must be made by:					
The medical team exclusively.					
The family exclusively.					
The doctor and the family together.					

Case C: A 60-year-old patient with dementia grade 5 on the GDS. He lives at home with his wife. He exhibits short-term memory loss and is sometimes disoriented (Mini Mental State Examination, 20/30). He is able to move autonomously. He has had a cough when swallowing liquids for two weeks, which explains the reduced oral intake. Reversible causes have been ruled out.	Totally agree	Agree	Disagree	Strongly disagree	Does not know/ does not respond
1. Start an oral diet with thickeners.					
2. Initiate feeding with NGT/PEG.					
3. Reasons for feeding despite the progression of dementia in this patient:					
To avoid malnutrition.					
To ensure an adequate quality of life.					
Because not initiating it would be a cause of death.					
4. If this patient already has a NGT/PEG, before an episode of bronchial aspiration:					
You withdraw the NGT/PEG.					
You place a new NGT/PEG.					
5. Comfort measures that exclude SNG/PEG feeding.					
6. Considerations of feeding via NGT/PEG in this patient:					
It is an extraordinary measure.					
It does not reverse the clinical situation of the patient.					
It does not modify the course of the disease.					
It is burdensome for this patient.					
There is no moral obligation to establish it.					
7. If requested by the patient or their family, you agree to not initiate or to suspend NGT/PEG feeding to hasten death.					
8. If the patient suffers, you administer euthanasia out of compassion.					
9. Respect advance directives written by the lucid patient, even if they are not in accordance with clinical recommendations.					
10. If the patient loses lucidity, the final decision must be made by:					
The medical team exclusively.					
The family exclusively.					
The doctor and the family together.					