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The Decision-Making Process For Nutritional Support in Palliative Care According to Bioethics: An Integrative Literature Review

Tomada de Decisão Para Suporte Nutricional nos Cuidados Paliativos à Luz da Bioética: Revisão Integrativa

Toma de Decisiones Para el Soporte Nutricional en Cuidados Paliativos a la Luz de la Bioética: Revisión Integrativa

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ABSTRACT

Objective: This study aims to investigate the scientific production about the decision-making process for nutritional support in palliative care in light of bioethics. **Methods**: It is an integrative literature review where the data collection took place over May 2009 in the following databases: MEDLINE/PubMed, *LILACS*, SciELO and VHL-Bireme. **Results**: After analyzing the 14 selected studies, three themes were considered: (I) Principles of bioethics in the nutrition framework; (II) Nutrition as a bioethical dilemma; (III) Approaches to solving bioethical dilemmas in nutrition. **Conclusion**: For approaching the decision-making process in nutritional support with patients undergoing palliative care, the focus should be on patient-centered care under the pillars of autonomy, beneficence, nonmaleficence, and justice. The respect for autonomy guarantees to the patient that he/she receives treatment according to his/her desire; moreover, the respect for the principles of beneficence and nonmaleficence make it possible to provide care towards patients aiming at their quality of life and the maintenance of human dignity.

Descriptors: Palliative care, Nutritional therapy, Enteral Nutrition, Parenteral nutrition, Bioethics.

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RESUMO

Objetivo: Investigar a produção científica acerca da tomada de decisão para suporte nutricional (SN) em cuidados paliativos (CP) à luz da bioética. **Métodos:** Revisão integrativa da literatura, com coleta de dados em maio de 2009, nas bases de dados MEDLINE/PubMed, LILACS, SciELO e BVS-Bireme. **Resultados:** após análise dos 14 estudos selecionados, considerou-se três temáticas: (I) Princípios da bioética no contexto da nutrição; (II) Nutrição como dilema bioético; (III) Abordagens para a resolução de dilemas bioéticos em nutrição. **Conclusão:** para tomada de decisão no SN em pacientes em CP, o foco deve ser o cuidado centrado no paciente sob os pilares da autonomia, beneficência, não maleficência e justiça. O respeito à autonomia garante ao paciente que ele receba o tratamento conforme o seu desejo; e o respeito aos princípios da beneficência e da não maleficência oportunizam cuidados aos pacientes que visem à qualidade de vida e à manutenção da dignidade humana.

Descritores: Cuidados paliativos, Terapia Nutricional, Nutrição Enteral, Nutrição Parenteral, Bioética.

RESUMEN

Objetivo: Investigar la producción científica sobre la toma de decisiones para el soporte nutricional (SN) en cuidados paliativos (PC) a la luz de la bioética. **Métodos:** Revisión integradora de la literatura, con recolección de datos en mayo de 2009, en las bases de datos MEDLINE/PubMed, LILACS, SciELO y BVS-Bireme. **Resultados:** Después del análisis de los 14 estudios seleccionados, se consideró pertinente tres temas: (I) Principios de la bioética en el contexto de la nutrición; (II) Nutrición como dilema bioético; (III) Enfoque para resolución de dilemas bioéticos en nutrición. **Conclusión:** Para la toma de decisión en el SN en pacientes en CP, el punto principal debe ser el cuidado centrado en el paciente bajo los pilares de la autonomía, beneficencia, no maleficencia y justicia. El respeto a la autonomía asegura al paciente recibir el tratamiento conforme su deseo; y el respeto a los principios de la beneficencia y de la no maleficencia posibilitan a los pacientes cuidados que visen a la calidad de vida y a la manutención de la dignidad humana.

Descriptores: Cuidados paliativos, Terapia Nutricional, Nutrición Enteral, Nutrición Parenteral, Bioética.

INTRODUCTION

Bioethics, as ethics applied to life and as it is currently recognized, came about in the United States (USA) in the early 1970s, based on the theory of Beauchamp and Childress.[1] In recent decades, it has become of great relevance to clinical practice, given the fact that it provides theoretical tools for decision-making by health professionals.[2] Among the various bioethical dilemmas that require preparation and reflection on what is how to do it is Palliative Care (PC) and therapeutic decisions, including the decision for Nutritional Support (NS).

Palliative care is active and total care of patients whose disease does not respond to curative treatment, has an interdisciplinary approach and encompasses the patient, family, and community. It seeks to preserve the best possible quality of life without delaying or hastening death through a holistic approach, alleviating not only physical or psychological but also social and spiritual symptoms.[3–7] Food is critical so the patients' life quality can meet not only physical but psychological, social and cultural needs.[8,9]

PC patients experience symptoms that reduce appetite, impair nutrient use and/or restrict their ability to obtain, consume and enjoy food.[9,10] The consequent malnutrition of this process has an important impact on quality of life, immune status, and performance, and may be responsible for increased morbidity and mortality.[11] Thus, when unable to ingest food and fluid orally, decisions about Artificial Nutrition and Hydration (ANH) methods may be necessary.[8]

Many factors must be considered when deciding on the NS to ensure the best care. This should be consistent not only in terms of physiological benefits, but anchored in the values, culture, faith, preferences, and priorities of patients, families or care takers, and should involve optimal communication and decision-making practices.[12] The decision to feed via Artificial disease is particularly difficult, becoming a true bioethical dilemma, especially in end-of-life situations or when the individual is unable to be involved in the decision,[8] or when its interruption is indicated.

Hence, it is understood that the NS in PC is fully inserted in the scope of bioethical reflection, especially with regard to the decision-making process. Bearing this framework in mind, the aim of this study was to investigate the scientific production of the decision-making process for nutritional support in palliative care in light of bioethics.

METHODS

An integrative literature review study was performed through a five-stages methodology,[13] specifically: problem formulation, literature search, data assessment, data analysis and presentation of results. In formulating the problem, the PICO strategy was used,[14] which is defined as follows: In adult patients undergoing palliative care (P), how the application of bioethics (I) can help in decision making (C) for nutritional support (O)?

The bibliographic survey was performed by electronic search in the following databases: the Medical Literature Analysis and Retrieval System Online (MEDLINE) and PubMed, the *Literatura Latino-americana e do Caribe em Ciências da Saúde* (*LILACS*) [Latin-American and Caribbean Literature in Health Sciences], the Scientific Electronic Library Online (SciELO) and Virtual Health Library (VHL).

As inclusion criteria, articles published in Portuguese, English or Spanish, published between January 2009 - May 2019 and which directly addressed the research problem in the title, abstract or descriptors, were selected. Exclusion criteria were duplicate articles and those not fully available in the databases searched.

The descriptors used were, as a reference, the Descriptors in Health Sciences (DeCS) and were combined with each other through the Boolean connectors "AND"

and "OR", in English. The survey of the articles was carried out in May 2009 and, as search strategies, the keywords were used as follows: Palliative Care OR Palliative Medicine AND Feeding OR Nutrition Therapy OR Enteral Nutrition OR Parenteral Nutrition AND Bioethics OR Ethics. The search in the databases resulted in the identification of 368 articles.

After applying the inclusion criteria, titles and abstracts were read to ensure that the selected publications addressed the research problem and met the inclusion and exclusion criteria. In case of doubt, it was decided to select the publication and final decision after the full reading.

Following the final sample selection phase of the articles included in the review, the information that would be extracted from the studies was defined. Afterwards, the content analysis was performed reducing the most relevant data in themes or categories that allowed answering the research question.

RESULTS AND DISCUSSION

Considering all the 368 articles obtained from the databases, 14 comprised the sample of the present study. **Figure 1** outlines the flowchart of the steps taken. The country that published the most on this topic was the United States of America with seven articles (50%), with Brazil and other countries with only one publication. Thirteen articles were published in English (92.9%) and only one in Portuguese. Most were found and indexed in the PubMed platform (85.7%) and were of the literature review type (57.1%), whose articles were published in nutrition (57.1%) or bioethics (21.4%). All papers analyzed addressed the theme under study and are presented in **Table 1** and **Table 2**.

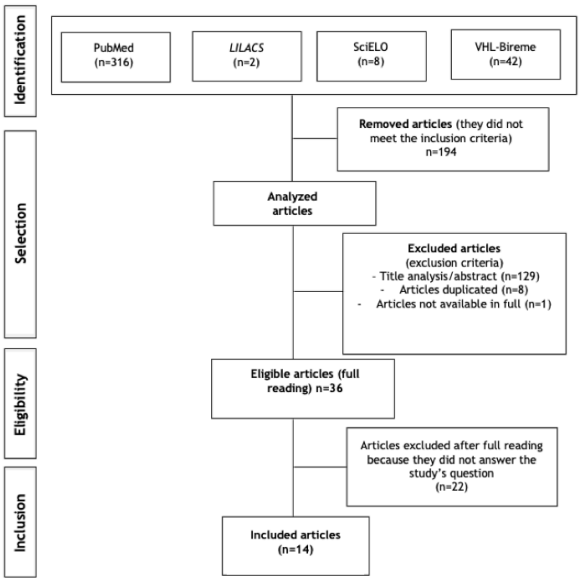

Figura 1 - Flowchart addressing the searching steps followed in this integrative review, according to PRISMA.[15] *João Pessoa* city, *Paraíba* State, Brazil, 2019.

Table 1 – Characterization of articles included in this review, *João Pessoa* city, *Paraíba* State, Brazil, 2019.

Title	Author/Year/Country	Design
Islamic views on artificial nutrition and hydration in terminally ill patients	Alsolamy S/ 2014/ Saudi Arabia[16]	Background briefing (N = 37)
ASPEN *Ethics Position Paper Task Force*	Barrocas A et al/ 2010/USA[17]	Special Report (N = 54)
Bioética e nutrição em cuidados paliativos oncológicos em adultos	Benarroz M, Faillace G, Barbosa L/ 2009/Brazil[3]	Review (N = 50)
Artificial Nutrition and Hydration: The Evolution of Ethics, Evidence, and Policy	Brody H et al./ 2011/USA[18]	Review (n = 88)
Eating and drinking interventions for people at risk of lacking decision-making capacity: who decides and how?	Clarke G et al./ 2015/UK[8]	Qualitative study (N = 158)
Biethical principles and nutrition in paliative care	De Andrade, Almeida e Pinho-Reis/2017/Portugal[4]	Review (N = 44)
ESPEN *guideline on ethical aspects of artificial nutrition and hydration*	Druml C et al./ 2016/ Austria[5]	Guideline (N = 80)
Ethical Issues in Artificial Nutrition and Hydration: A Review	Geppert C, Andrews M, Druyan M/ 2010/USA[10]	Review (N = 91)
Nasogastric feeding at the end of life: A virtue ethics approach	Krishna L/ 2011/ Singapore[19]	Review N = 75
To Feed or Not to Feed? A Case Report and Ethical Analysis of Withholding Food and Drink in a Patient With Advanced Dementia	Meier CA, Ong TD/ 2015/USA[20]	Case study
Ethical issues in nutrition support of severely disabled elderly persons: a guide for health professionals	Monod S et al./ 2011/ Switzerland[21]	Review N = 42
Position of the academy of nutrition and dietetics: ethical and legal issues in feeding and hydration	O'Sullivan Maillet J et al./ 2013/USA[22]	Position Paper (N = 41)
Integrating patient-centered care and clinical ethics into nutrition practice	Schwartz DB/ 2013/USA[23]	Review N = 27
Incorporating Palliative Care Concepts into Nutrition Practice: Across the Age Spectrum	Schwartz DB et al./2016/USA[12]	Review N = 58

ASPEN: The American Society for Parenteral and Enteral Nutrition; ANH: Artificial Nutrition and Hydration; NS: Nutritional Support; PC: Palliative Care.

Note: The titles were kept as in their original language.

Table 2 - Presentation of the synthesis of articles included in this study, *João Pessoa* city, *Paraíba* State, Brazil, 2019.

Author	Main findings
Alsolamy S[16]	The NS considered primary care and not medical treatment, and there is an obligation to provide ANH for the terminally ill patient.
Barrocas A et al[17]	It describes ASPEN's main ethical stance on the use of ANH.
Benarroz M, Faillace G, Barbosa L[3]	The patient demands integral and humanized care in care. Technical-scientific knowledge supported by the pillars of principled bioethics must be considered in favor of quality of care.
Brody H et al.[18]	The history of the ANH debate over the last 60 years.
Clarke G et al.[8]	The outcome of the decision-making process depends on the balance and balance of information available along four different axes.
De Andrade, Almeida e Pinho-Reis[4]	The principles of autonomy, beneficence, nonmaleficence, and justice, combined with technical and scientific knowledge, should be applied in nutritional practice.
Druml C et al.[5]	Respect for autonomy is an important focus of the guideline, as is careful communication with patients and families.
Geppert C, Andrews M, Druyan M[10] Krishna L[19]	Ethical principles and reasoning should be applied in making individualized treatment decisions. The article pursues to review the ethical and clinical impact of NS and to provide some understanding for such decisions in light of PC principles.
Meier CA, Ong TD[20]	Patients able of making decisions have the right to refuse ANH. There is still controversy regarding the lack of nutrition in patients who do not have the ability to make decisions.
Monod S et al.[21]	This article is based on an eight-step process to identify the components of a situation, analyze the conflicting values that result in the ethical dilemma, and reach consensus for the care plan.
O'Sullivan Maillet J et al.[22]	The nutritionist should work collaboratively with the interprofessional team to make recommendations on providing or withdrawing from the ANH and being an active member of institutional ethics committees.
Schwartz DB[23]	The NS is a life-sustaining medical treatment, and the use of this therapy requires knowledge of patient-centered care concepts, preventive clinical ethics, religion/spirituality and cultural diversity, the role of the CP team, and early care plan.
Schwartz DB et al.[12]	The current model of clinical health ethics does not yet include optimized use of advance directives and early communication among patients, family members and health professionals about treatment options, including the NS.

ASPEN: The American Society for Parenteral and Enteral Nutrition; ANH: Artificial Nutrition and Hydration; NS: Nutritional Support; PC: Palliative Care.

After analyzing the selected studies for this integrative review, and the scientific evidence found, three subjects were considered pertinent from the research question: (I) Principles of bioethics in the nutrition framework; (II) Nutrition as a bioethical dilemma; (III) Approaches to solving bioethical dilemmas in nutrition.

I - Principles of bioethics in the nutrition framework

The studies presented in this thematic point out that attitudes towards health care are influenced by various ethical theories.[4,17,21,22] Ethical theories propose a set of coherent principles, obligations or virtues that can underpin for action evaluation, decision making, and ethical reasoning. When these theories are used to analyze specific clinical issues, such as the decision about NS, it is called applied ethics.[17] The three main groups of theories that are most relevant to nutritional practice are as follows: deontological, consequentialist, theories of which the best known is utilitarianism and principlism.[17]

Principlism is based on ethical decisions and formulates arguments by specifying and balancing a set of fundamental ethical principles: autonomy; charity; nonmaleficence and justice.[5,17] These ethical principles guide decision making in clinical ethics and, therefore, in NS.[10] First proposed by Beauchamp and Childress,[1] they are independent of any specific ethical theory and can be universally applied.[5]

These principles, combined with scientific and technical knowledge, should be applied in nutritional practice for the quality of patient care.[3,4] In case of conflict between them, as they do not obey hierarchical order, the situation in question and the circumstances must decide. which will take precedence.[4]

The bioethical principle of respect for autonomy is the beginning of the patient's right to question his treatment and ensure that the care plan is in accordance with his desire.[3] The focus is on the individual and his ability to make decisions.[5,10] A competent patient has the right to refuse treatment after being informed, even if the refusal leads to death.[5]

The informed consent is needed to promote autonomy by protecting the patient from unwanted NS and allowing decisions to be made in line with their values and culture. The ability to give informed consent is central to the decision-making process. So, if patients reject a treatment, the patient's desire overrides the duty of charity of health professionals.[4]

Proper informed consent requires from the patient or legal guardian three essential elements: sufficient information; decision-making ability; and ability to exercise it voluntarily (the ability to make a decision free of coercion). Appropriate information includes, but is not limited to diagnosis, prognosis, nature of the proposed intervention (risks and benefits of NS), and alternative treatment.[10]

In the case of previously competent patients who by accident or illness have become unable to make health care decisions, the practitioners involved should seek guidance on any previously expressed communication by the patient about the types of treatments desired. Legal conflicts can arise when a patient who has not provided the health care team with an advance NS guidance loses the ability to speak for himself and conflicts arise between family and health professionals.[17]

Cultural and religious preferences for ANH are expressions of patient autonomy and many cases may outweigh clinical considerations. In situations where these values conflict with clinical judgment, expert religious and ethical consultation is necessary to facilitate their resolution.[10] The American Society for Parenteral and Enteral Nutrition (ASPEN) advises respect for the religious, ethnic and cultural background of patients and insofar as it is compatible with other ethical principles and duties.[17]

Another important ethical principle for NS in PC is beneficence which means "doing good" and reflects the obligation of the healthcare professional to act on behalf of the patient and to put the patient's best interests above all other considerations.[10] Patients should not be exposed to additional risk or suffering unless there is a reasonable expectation of proportional benefit. If the risks of treatment outweigh the benefits, it is imperative to remove the NS. Putting the principle of beneficence into practice is a challenge as it conflicts with respect for autonomy.[4]

The principle of nonmaleficence is to minimize potential or actual harm. This concept can cause conflict when treatment is disproportionate, so maintaining it causes more suffering (maleficence). If the risks and burdens of a particular therapy for a specific patient outweigh the potential benefits, then there will remain an obligation not to provide it.[5]

There is insufficient evidence about the benefits of NS on the quality of life of patients undergoing PC.[24] Nevertheless, different religious or cultural beliefs and viewpoints may lead to different interpretations of indications, objectives, and effects of treatment by patients and families. This must be taken into account in communication and can influence the decisions to be made.

The principle of justice suggests that every patient has an equal right to receive ANH and that the decision on how resources will be spent should be made as fairly as possible since equity is independent of ethnic, social and economic factors.[4] Economic considerations are more appropriately done at the macro level, in the context of political decisions rather than at the bedside.[10]

II - Nutrition as a bioethical dilemma

The ethical issues surrounding eating are complex, as it has strong symbolic significance and both physiological and emotional implications, based on cultural and spiritual beliefs, and often plays an essential role in total care.[3,4,22]

One of the biggest controversies in the area of nutrition

and PC is whether NS should be considered medical treatment or basic care. As basic human care, if the patient desires and can receive, there is an obligation to provide.[21] Nonetheless, the opposite view indicates that from the moment it is administered by artificial means, it should be considered as any other treatment and be subject to an assessment of therapeutic proportionality, and as such there are circumstances in which it is legitimate not to start, maintain or stop.[4,5,10]

Looking at this perspective, however, nutrition cannot only be considered from a health standpoint because even if administered artificially, it can be considered by patients and families a basic need that not only sustains life but also provides comfort, so it is associated with respect for human dignity.[21]

Nevertheless, the findings of the present study indicate that with few exceptions, health professionals, ethicists, and various professional organizations view NS as medical treatment, not unlike any other treatment that may be refused, withheld, or withdrawn.[10] Disagreement about the futility of treatment results in a bioethical dilemma, where it is discussed whether the NS is morally obligatory or morally optional. The ASPEN,[17] in a special publication on ethical positioning, clarifies that an ethical dilemma can be created when the NS is clinically contraindicated, ineffective or potentially harmful when conflicts between clinical, legal and ethical obligations are observed.

Lack of communication between patient and family about the quality of life goals and health care options or the absence of an advance directive may result in patients receiving medical treatment, including NS, not based on their wishes and conflicts with family members and the health team. In these situations, ethical dilemmas are more likely to occur than when patients communicate and document their wishes.[17,23] Failure to either offer or withdraw NS can have an emotional impact on everyone involved and make the decision-making process stressful and hard.[25]

III - Approaches to solving bioethical dilemmas in nutrition

Some approaches are available to help practitioners identify, analyze and resolve ethical dilemmas. In the decision-making process, the literature consulted describes from the practice of patient-centered care[12,26] to the use of a series of steps for ethical reflection.[8,21] Because it is a complex process, decision-making in the context of nutrition in PC requires that a multidisciplinary and interdisciplinary team integrate technical knowledge with legal, cultural, religious and ethical knowledge,[21] and make decisions consistent with other ethical principles and duties.[17] However, as long as these approaches do not help to resolve ethical conflicts, practitioners should consider consulting with the institution's ethics committees or specialized clinical ethics services.[17]

In PC, a patient and family-centered approach is characterized by being proactive and consequently preventing suffering associated with treatments. It is a change in the focus of the disease and treatments for the patient involved in the process, with shared decision making. This is facilitated by a consistent approach by the healthcare team and appropriate communication directed to the best interests of the patient, including NS decision making. If the patient is unable to make his own decisions, a well-informed caregiver continues to express his wishes.[12]

Schwartz *et al.*[12,23] presents guiding principles for patient-centered care applied to clinical ethics in the context of nutrition practice. According to the authors, the health team, including the nutritionist, should establish patient-centered treatment goals, respecting their personal values and decisions.[22] The identification of treatment goals, as well as the NS, should advocate collaboration between the patient, family, caregivers and health professionals, along with the application of the institution's policies and procedures.[12]

Another approach was described by Clarke *et al.*,[8] in an observational study conducted in a UK hospital with a multidisciplinary team on feeding issues. The authors described that the outcome of the decision-making process depended on the balance and balance of information available along four different but interdependent axes: (1) risks, burdens, and benefits; (2) treatment goals; (3) ethical-normative values; (4) interested parties.

In the "risks, burdens and benefits" axis, the authors found a method of constant comparison between the bioethical principles of nonmaleficence and beneficence to continually reassess and reflect possible options; In the "treatment goals" axis, risks and benefits were considered concerning treatment goals and expected health outcomes, which could change with the clinical course of the disease; For 'ethical-normative values', any treatment or course of action was weighted in terms of these values and decision making was easier where the values aligned; According to the "stakeholders" axis, decisions involved health professionals, relatives and, where available, the patient's wishes. Through these types of discussions, the principle of autonomy has been respected, although the patient cannot make decisions.[8]

The use of a guide for ethical reflection was another approach found and suggested by Monod *et al.*[21] According to the authors, this proposal can help health professionals overcome the difficult decision-making process, concretely assisting the deliberation process. and the confrontation between professionals, family, and others involved. The structuring of the decision-making process helps professionals to retreat in this situation and to analyze the ethical issue with less emotion. According to the authors, the application of the ethical reflection guide is best accomplished through a formal deliberative meeting that brings together all health professionals involved. Under

these circumstances, it is discussed using an eight-step process summarized in **Chart 1**.

History, context and resignification of the ethical issue	1) Identify the clinically relevant facts and clarify the ethical issue(s). 2) Identify the socio-family context of the patient and all parties involved in the situation.
Care responsibilities and values of each ethical interested part	3) Identify the care responsibilities of each interested part. 4) Identify the values considered by each interested part as essential to address the issues. This stage includes the identification of cultural and religious values.
Ethical analysis of the clinical situation	5) Analyze the ethical conflicts involved in the clinical situation.
Medical options	6) Identify all possible options for resolving ethical conflicts. 7) 7) Identify the consensus option that best fits the values of the patient, interested parties, and health professionals.
Moral justification	8) Deliberate about the moral justification of the choice.

Chart 1 - Guide for ethical reflection.

Source: Adapted from Monod et al.[21]

An article published by the Academy of Nutrition and Dietetics[22] adds, concerning the decision-making process, that the nutritionist should play an active role in collaborative ethical deliberation, either informally or as part of a formal committee. The nutritionist is the professional responsible for assessing the feeding strategy that will achieve the desired goals; therefore, they must take responsibility for maintaining the individual's understanding of therapeutic options and goals at the center of deliberations and that appropriate options are considered.[22]

CONCLUSIONS

According to the studies included here, for making a decision towards NS in patients with PC, the focus should be on patient-centered care under the pillars of autonomy, beneficence, nonmaleficence, and justice. Respect for autonomy guarantees the patient that he receives treatment according to his desire; and respect for the principles of beneficence and nonmaleficence provide care to patients aiming at the quality of life and the maintenance of human dignity. The priority should be to promote dignity and minimize patient discomfort, regardless of the choice of NS.

The tools used to support the decisions for NS described in this study present a brief and simple approach, thus being viable options to be incorporated into the daily routine of the nutritionist and the other members of the multidisciplinary team that provides care to these patients.

Nonetheless, it was found that most of the studies included in this series were of the literature review type, a study located at the base of the pyramid of scientific evidence. Therefore, there is a need for further studies with the adequate methodological design that can support the decision-making process and promote the integration of clinical practice with better evidence, considering the ethics in nutritional care for patients undergoing palliative care.

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