

International Journal of Palliative Nursing

Nursing strategies to reduce the risk of therapeutic obstinacy in artificial nutrition with the person near the end of life: an integrative review

--Manuscript Draft--

Manuscript Number:	
Full Title:	Nursing strategies to reduce the risk of therapeutic obstinacy in artificial nutrition with the person near the end of life: an integrative review
Short Title:	Nursing strategies in artificial nutrition with the person near the end of life
Article Type:	Review
Keywords:	nursing; terminal care; nutritional support; therapeutic obstinacy; integrative review
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Suggested Reviewers:	
Additional Information:	
Question	Response
Please enter the word count of your manuscript	2649

Nursing strategies to reduce the risk of therapeutic obstinacy in artificial nutrition with the person near the end of life: an integrative review

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Abstract

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Acknowledgment and Conflict of interest statement

This study has no conflicts of interest and there are no funding sources involved in the study conduct or respective conclusions.

Abstract

Nurses have an important role in the nutrition near the end of life. This integrative literature review aims to: define nursing nutrition strategies with the person near the end of life and their families; systematize the elements to be considered in artificial nutrition decision making and evaluate the nursing interventions influence on the therapeutic obstinacy risk.

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Keywords: nursing; terminal care; nutritional support; therapeutic obstinacy; integrative review

1. Introduction

End of life nutrition is a constant in any health care process. The person referred to in this article will henceforth be referred to as the person near the end of life (EoL), considered to be *"(...) who presents advanced, incurable and evolving disease, (...) and who, on average, expected survival between 3-6 months"* or even *"(...) the one whose estimated survival is hours or days, made based on the symptomatology and clinical evidence that presents; (...)"* ⁽⁴⁾. As Palliative Care we mean the approaches of care, considering the person with an incurable or severe disease, with the aim to enhance quality of life and comfort. ⁽⁴⁾.

It is known that the person near the EoL has an effective alteration of self-image, which is associated with a decrease in intake, due to anorexia, dysphagia, altered taste and disease progression ⁽²⁾. Although it is permissible to have new treatments, with an increase in the average life expectancy, it is also assumed that many of these treatments will contribute to the obstinacy of treatment instead of guaranteeing the best quality of life, comfort and well-being for the person near the EoL ⁽⁵⁾. It is understood by therapeutic obstinacy *"diagnostic and therapeutic procedures that are disproportionate and futile, in the overall context of each patient, without there being any benefit to it, and which may, in themselves, cause increased suffering."* ⁽⁷⁾.

Food itself has a psychological, social, emotional, spiritual, cultural, rather than physiological component as we first associate. Eating is our feeling, the moment of family reunion, the pleasure of food, the fear of hunger, and sometimes the last aspect of control ^(2,3,16). Knowing that eating in today's society is increasingly

associated with pleasure and comfort, it is understood the complexity of this issue when approached in the person near the EoL particularly in cases where the decision to start, not start or stop artificial nutrition is a reality. Alternative forms of supporting nutrition when physiological ways are not viable, by a nasogastric intubation or parental nutrition, involving painful procedures ^(10,13).

This issue is very controversial in the palliative context, in view of the questioning about the quality of life that will be provided in the application of one of these procedures and, simultaneously, by the ethical questioning ^(2,3,15).

It is the nurse responsibility to inform and clarify the person near the EoL/family, to manage nutritional needs, to consider nutrition in the advanced plan of care, as well as to integrate in decision making on this issue ⁽²⁾. We wonder if these interventions are effective in reducing the risk of therapeutic obstinacy. And when we talk about the person near the EoL, we are also mentioning the family, who accompany and watch the reduction of a set of technical procedures and, finally, can see suspended the last element that associates with the survival of the person, the food.

In this sense, the family care by the health team constitutes a very important issue in advanced care plans ⁽³⁾. The person's and family's needs are complex, ranging from physical aspects (physiological changes, eating and drinking alterations) to feelings of anguish, distress and fear of the inevitable finitude of life.

2. Methodology

This study intends to answer the following questions throughout this integrative review:

Q1. What are the nursing interventions that promote end of life nutrition?

Q2. What are the evaluation criteria near the end of life, in the decision-making process of the nurse in introduction, not introduction or suspension of artificial nutrition?

Q3. Does the intervention of the nurse towards the end of life reduce the risk of therapeutic obstinacy associated with artificial nutrition?

The integrative literature review development considers the artificial nutrition issue at the EoL based on the PRISMA guidelines ⁽¹³⁾. Three starting questions were elaborated, the eligibility criteria was defined, the sample was selected from the articles consulted and the analysis and discussion of the results achieved were carried out.

The Boolean research strategy resorted to the following healthcare descriptors: (nutrition OR artificial nutrition OR feeding OR eating OR enteral nutrition OR enteral feeding OR tube feeding OR feeding tube OR parental nutrition OR nutritional status OR nutritional therapy OR nutritional assessment OR nutrition disorders) (TI) AND (palliative care OR terminal care OR palliative OR palliative nursing OR end of life OR therapeutic obstinacy) (AB) AND Nurs* (AB).

This study was conducted between the 15th of May and the 15th of June 2017 considering articles available in full text, written in French, Spanish, English

and/or Portuguese and peer-reviewed, in the period from 2000 to 2017, in how this period presents itself as the best development of evidence on the care of the person near the EoL ⁽²⁾.

Regarding the subject under study, eligibility criteria were defined (Figure 1).

The databases used were: Academic Search Complete, Complementary Index, CINAHL Plus with Full Text®, Psychology and Behavioral Sciences Collection, ScieELO, MEDLINE®, Directory of Open Access Journals, Supplemental Index, ScienceDirect, Education Source, Business Source Complete and MedicLatina.

The inclusion and/or exclusion criteria were applied to the researched articles. From a set of 728 references, 691 were excluded by reading the title, 26 by reading the abstract, constituting, after reading in full text, the final sample of 11 articles (Figure 2). As main reasons for exclusion in the sampling process we highlight references that insinuate about:

- The investigation of decision-making that is not related to end of life nutrition;
- The investigation of nutrition without consideration for the intervention of the nurse;
- The investigation of the relationship between nutrition and the context of dementia.

The 11 articles were classified according to their level of evidence, in which distribution is more centered on level IIa, reviewing a qualitative investigation with

designs of non-randomized, well-controlled and designed studies ⁽²⁾. There were no studies in the remaining levels of evidence (Figure 3).

3. Results

The results found in the research are presented in the form of a table, with an analysis of each study considering the following data: author (s) – year / country; participants; interventions; results and design (Table 1). Each study was explored considering its contribution to each of the three research questions, being gathered in a sample of 11 articles, with 2 articles of mixed study and 9 articles of qualitative study, between 2008 and 2016.

4. Discussion

The articles analysed are qualitative studies, two of them with mixed method, having an average sample of 10 participants. Of the 11 articles selected, four of these corresponded to literature reviews with important considerations about decision making in end of life nutrition. Despite the differences between the studies, a common line between these in the answers to the questions is perceived.

The following issues are integrated in the accompanying of the person and family in this decision making on the introduction / maintenance of a means of artificial nutrition.

These strategies are an important answer to one of the questions posed – *"What nursing interventions promote end of life nutrition in people without artificial nutrition criteria?"*.

The main strategies and interventions of nurses in end of life nutrition include:

- Be aware of the person's preferences for food, whether in food type, presentation, temperature or texture, in order to value food as long as it is the person's desire ^(1,2,10);

- Be responsible for the proper positioning in the bed or in a chair / highchair during meal times ^(1,2,10);

- Check the suitability of the environment – consider outdoor space for meal – in light, temperature, sound and odor, in relation to the moment of the meal ^(1,2,10);

- Recognize situations of odynophagia and / or dysphagia that may make pasty, cold or warm food available and enhance fluid intake, when indicated using food thickener to prevent aspiration of food content ^(2,10);

- Indicate dry mouth, alterations of the palate and act in case of nausea and / or vomiting, securing the person in the face of new episodes ^(1,2,10);

- To manage pharmacological and non-pharmacological therapy with the multidisciplinary team: antiemetics, fractional feeding, increasing the number of meals, cold or warm and hypolipidic ^(1,2,10);

- To manage diarrheal syndromes, guaranteeing the absence of fiber and lactose of meals ^(2,10);

- Consider, in constipation, the increase of liquids in the diet, the presence of fibers and intervene with their evaluation in the therapeutic management, to use laxative therapy ^(2,10);

- Privilege the highest number of meals, if anorexia was maintained, with lower volume and less calories ^(1,2,10);

- To promote the presence of corticosteroid or other therapy, such as megestrol acetate, to weigh food supplementation and to guarantee the maintenance of good oral hygiene, observing the signs of mucositis ^(1,2,10).

When, despite the resources mobilized, the possibility of introducing, not introducing or, if already applied, suspending artificial nutrition, this complex issue implies a decision, on which the following questions are asked: “- *What are the evaluation criteria in the person near the EoL, in the decision-making of the nurse in starting or not initiating or suspending artificial nutrition?*”.

Decision making is a preponderant act in the provision of care and, as such, in guaranteeing its quality, covering different aspects until the final decision. In the analyzed articles, one considers the fact that artificial nutrition decision-making presupposes ⁽⁸⁾:

- The existence of a clinical indication / treatment;
- Be part of the definition of a therapeutic goal to be achieved and the existence of informed consent by the person near the EoL.

This process includes the nurses, who base their decision-making on the underlying ethical principles – autonomy, beneficence, non-maleficence and justice – considering it to be appropriate, case by case, with the guidelines already mentioned ^(6,8,11,12).

The criteria to be considered in these processes will be ^(2,3,6,8,10):

- Symptomatology – with the inherent difficulty of symptom assessment, often associated with hydration (feeling thirsty or perceived confusional state), nutritional status or resulting from the toxicity of treatments performed;

- Survival prediction – prognosis;
- The consideration of the social role of food – the food that is pleasure, equally, representation of love, affection and moment of family reunion;
- The psychological aspects associated with eating, as a voluntary act, but main element of control in the face of the changes that the disease may have introduced in the person's life.

Thus, the decision on artificial nutrition should integrate the person near the EoL and family, in the interdisciplinary team, considering the definition of the prognosis and the effectiveness of the applied treatment. In addition, both the suspension and the institution of nutrition measures should consider the person's advanced health plan ⁽²⁾, thinking about the nutritional need integrated in the care plan, evaluating and re-evaluating the objectives defined by the person near the EoL / family¹.

When asked if *"the nurse's intervention with the person near the EoL reduces the risk of therapeutic obstinacy associated with artificial nutrition?"*. The answers obtained did not directly address the topic of therapeutic obstinacy but correlate it with the best quality of care to be borrowed. It emphasizes that the nurse is the professional who manages to guarantee the best comfort and defence of the autonomy of the person, namely in the orientation of the decision-making process regarding nutrition at the EoL ^(11,12).

There is also no consensus on the opinion of nurses regarding the use of artificial nutrition in the person near the EoL ^(11,12). Therapeutic obstinacy opposes the quality of care, with no evidence of benefit to the person. We can understand that the nurse's intervention in the comfort of the person near the EoL and family will reduce the risk of therapeutic obstinacy. This health professional sees his or

her decisions influenced by several external factors, from the context of the person to the context of other health professionals ⁽¹⁷⁾.

It is for health professionals and families a question with different interpretations: artificial nutrition as a procedure with few end of life benefits for professionals, while for family members their emotional impact, synonymous with comfort and wellbeing. This divergence proves the importance of the proximity between nurse and person/family and of the intervention in communication, safety and follow-up of the health-disease process ^(10,18).

Despite the above, it is verified in the literature that there are limitations in nurses' intervention, in which nurses feel that their role is not always clearly defined, assuming little training and difficulty in acting. Although they act in the decision-making process, they don't seem to identify their participation, considering the doctor as the final decision-maker. Nurses devaluing their action and the role of the multidisciplinary team. These fragilities are associated with avoidance of the person/family when complex issues are involved, although the importance of their evaluation, intervention and follow-up is assumed ^(2,6). The lack of professional training of nurses is the main limiting factor in the decision-making process on nutrition, and the feeling of these professionals who wish to intervene and feel part of it is ambiguous, although simultaneously they recognize difficulty in understanding the associated phenomenon and lack of training in palliative care ^(6,9,14).

The evaluated studies present scattered data about the evidence, reason why this revision makes possible the seriation of the knowledge when gathering the main data in three relevant issues of the nursing knowledge. The systematization of information allows better care orientation, clarification of questions and

confirms not only the relevance of the nurse's intervention, but also specifies the role of the nurse in the interdisciplinary team.

5. Conclusions

The present study responds to the questions presented, highlighting the set of Nutrition Nurses interventions in end of life persons and their families, systematizing the elements to be considered in decision making and emphasizing the importance of nurses' intervention in reducing the risk of therapeutic obstinacy.

There are limitations on the present study: the research with descriptor Nurs * limiting the research to the context without perception of the other health professionals; the predominance of qualitative data; the databases considered, and others were not included in the sampling process; no articles were bought to obtain full text, limiting the search to the article availability without additional costs; the sample selection process, which was carried out by a single reviewer. In the last point it is important to note that the sample presented is reduced, being unanimous the need to increase research on this subject, especially in nursing cares.

It is verified that there is little evidence on the benefit of maintenance of nutrition in the final stage of life, and the care of the person should be prioritized. The follow-up of the person and family during the course of their health-illness process is assumed, and the nurse is a privileged member in the team, due to the closeness of the person/family and the main defender of the person's comfort

and autonomy considering the emotional, psychological, spiritual and cultural component of nutrition.

Further research should be undertaken on the nurses' role within the interdisciplinary team in follow-up of the person near the EoL regarding the assistance of their nutritional needs; it will be pertinent to understand how the nurses present the assessment of the needs of the person and family, together with the other interdisciplinary team, on the subject of nutrition.

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Tables and Figures

SELECTION CRITERIA	INCLUSION CRITERIA	EXCLUSION CRITERIA
Population	Health professionals caring for the person near the EoL	The participation of other health professionals, other than just nurses
Intervention	Study nurse intervention with the nutrition of the person near the EoL	
Results	<div>1. Nursing interventions to promote of end of life nutrition;</div> <div>2. Criteria to be considered in decision-making on the introduction, not introduction or suspension of artificial nutrition means;</div> <div>3. Nursing care evidence that promote reduction of the risk of therapeutic obstinacy associated with the nutrition of the person near the EoL.</div>	Nursing interventions not directed at the nutrition of the person near the EoL
Time Horizon	Between 2000 and 2017	Studies previous to 2000
Study Drawings	Without paradigm limitation	Lack of empirical study
Language	French, Spanish, English and Portuguese	Other language than French, Spanish, English and Portuguese
Figure 1 – Eligibility criteria		

Tables and Figures

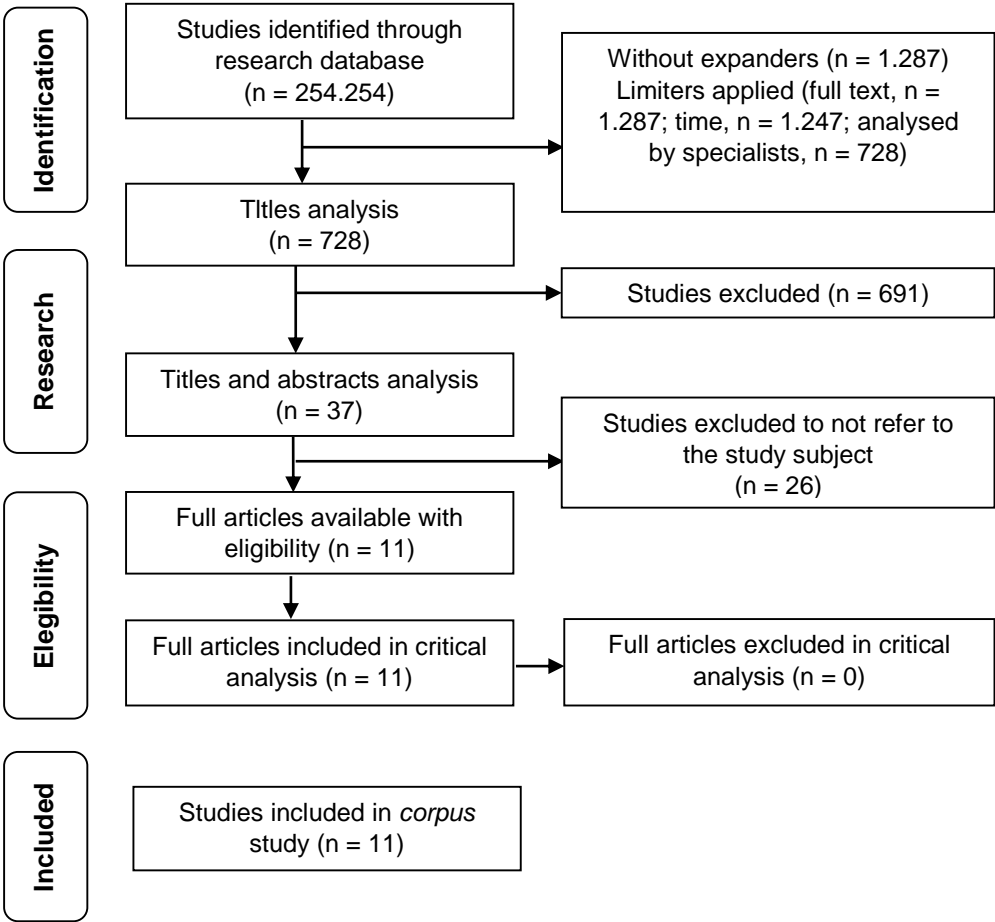


Figure 2 – Article selection flowchart

Tables and Figures

Evidence Level ⁽¹⁹⁾		Selected Articles
Ia	Evidence obtained from the meta-analysis of randomized controlled trials.	No study found
Ib	Evidence obtained from at least one randomized controlled trial.	No study found
IIa	Evidence obtained from at least one well-controlled study without randomization.	Higgins <i>et al.</i> , 2013; Lopez <i>et al.</i> , 2010; Druml <i>et al.</i> , 2016; Stiles, 2013; Alves, 2013; Holmes (a), 2010; Holmes (b), 2010; Van der Riet, 2008; Acreman, 2009; Holmes, 2011, Bryon, 2008
IIb	Evidence obtained from at least one other well-designed, almost experimental study.	No study found
III	Evidence obtained from non-experimental descriptive studies, such as comparative studies, correlatives and clinical cases.	No study found
IV	Evidence obtained from expert reports, opinions and / or clinical experiences of respected authorities.	No study found
Figure 3 – Articles classification according to the level of evidence		

Tables and Figures

Authors	Participants	Interventions	Results	Design
Lopez <i>et al.</i>, 2010 (EUA)	Eleven nurses caring for people with dementia in nursing homes	Eleven semi-structured interviews were carried out	Q1. Doesn't answer Q2. The nurses have little empirical information and ambiguous feeling and uncertainty about the suitability regarding with the decision making in intubate a end of life person; Nurses play secondary role, caused by lack of training, giving their evaluation information to other health professionals, without being directly involved in the decision-making process. Q3. Doesn't answer	Qualitative study
Higgins <i>et al.</i>, 2013 (Inglaterra)	Ten nurses of acute care units - medicine, oncology and hematology	Realization of three focus groups.	Q1. Doesn't answer Q2. Perception of the nurse's importance to develop training in palliative care so that they can commit to palliative intervention and be more involved in decision making at this stage of life; lack of training in the subject, with consequent ambiguity in the consideration of Artificial at the EoL Q3. Doesn't answer	Qualitative study
Holmes, 2011 (Inglaterra)	People with palliative needs and their nutritional monitoring	Narrative literature review to consider the different types of nutritional support and ethical aspects underlying decision making	Q1. Dietary management resources, pharmacological intervention and / or oral supplementation in the promotion of appetite and ingestion. Q2. Perceived that EoL person's comfort and autonomy are aspects to defend and to attend in the decision-making process at the EoL Q3. Doesn't answer	Qualitative study
Druml <i>et al.</i>, 2016 (Europa)	No data to present	Guideline guidance on the underlying ethical aspects of nutrition management and artificial hydration	Q1. Doesn't answer Q2. Approached the ethical principles - autonomy, beneficence, non-maleficence and justice - underlying decision making, considering to be appropriate case by case. Q3. Doesn't answer	Qualitative study
Stiles, 2013 (Inglaterra)	Nurses in England	Integrative literature review to investigate nurses' consideration of nutrition and artificial hydration	Q1. Doesn't answer Q2. Consensus on the perception of nurses' opinions regarding the use of artificial nutrition in people with palliative; decision making is influenced by innumerable external factors, from the person, to the family, to the underlying clinical aspects and to the intervention of other health professionals. The lack of training in this area	Mixed study

Q3. Doesn't answer			
Alves, 2013 (Portugal)	Four studies review	Systematic literature review concerning the intervention of the nurse involved in the care of the end of life person with eating and drinking alterations	<p>Q1. Perception of the importance of the nurse's intervention with the end of life person with eating and drinking problems.</p> <p>The intervention and food promotion strategy considers: the recognition of the desires and needs of the person and family; directed and preventive intervention; promote the presentation of the meal, positioning, management of feeding times, feeding preferences, understand the cause of anorexia, if applicable; promotion of oral hygiene. Intervention based on a multidimensional approach, recognizing the feeding as more than a physiological aspect, to be associated with comfort, care, compassion and affection.</p> <p>Q2. Decision-making is characterized as difficult intervention for health professionals, especially for nurses considering the lack of knowledge about the end of life care. They are, the family and the doctor, the main actors of decision making; nurses tend to be the health professionals closest to the person and family, with a privileged contribution in the decision making by the established therapeutic relationship, although the intervention is limited and indirect. Nurses consider their role as important - support, guidance and information. There is greater uncertainty in the decision-making process for nutrition when it is a neurological, rather than oncological, patient due to the unpredictability of disease evolution in the first case.</p> <p>Q3. Without a direct reference to the subject, the reduction of the risk of therapeutic obstinacy is deduced from the intervention of the nurse, as the study characterizes - being the health professional who knows the desires and needs of the person / family better and who personalizes the care to them</p>
Holmes, 2010 (a) (Inglaterra)	Health professionals accompanying people at end of life	Narrative literature review that addresses the nutritional goals at the EoL and the intervention of the nurse together with the person and family	<p>Q1. Perceiving the impact of nutrition on the person near the EoL, considering the physical, psychological, emotional, spiritual and cultural perspective; Nurses' intervention in eating and drinking: positioning and environment; support for symptom reversal; fractional meals; food preferences to consider; fortify feeding moments; take into account the texture / type of food; intervention in symptomatic control; use of food stimulants and availability of food variety.</p> <p>Q2. The intervention of the nurse is highlighted as the promoter of the best care in this stage of life and as an important member in guaranteeing the autonomy of the person</p> <p>Decision-making based on ethical principles - autonomy, justice, beneficence and non-maleficence - and taking into account the benefits and losses of nutritional</p>

			support. Involvement of the person in decision making. Decision that will take into account the best interests of the person Q3. Doesn't answer	
Holmes, 2010 (b) (Inglaterra)	Health professionals accompanying people near the EoL	Narrative literature review on the application of artificial nutrition in people in end of life	Q1. Doesn't answer Q2. Decision-making should be based on the main objectives of the advanced plan of care, informed consent and due ethical principles - autonomy, beneficence, non-maleficence and justice. The intervention of the nurses should consider the defence of the person, in support and guidance Q3. Doesn't answer	Qualitative study
Van der Riet, 2008 (Inglaterra)	15 nurses and 4 physicians from two palliative care units	A qualitative study using a focus group	Q1. Promotion of oral hygiene care and xerostomia prevention. Q2. Distinct perceptions among health professionals and family members, considering the former artificial nutrition as a medium with few end of life benefits, while for the family, their consideration has emotional impact, being synonymous with comfort for the person and well-being. The intervention of nurses in communication and education is highlighted as a means to better approach this issue Q3. Doesn't answer	Qualitative study
Acreman, 2009 (Inglaterra)	Health professionals accompanying people near the EoL	Narrative literature review that addresses the main aspects to be developed in end of life nutrition and nutritional promotion strategies	Q1. The understanding that nutrition is more than providing nutrients, which has an emotional meaning for people and that there should be a correct training and professional preparation for the follow-up of these, in the final stage of life; Improvement of intake: feed the person when this desire is manifested; make small portions of food; suggest and not insist; consider the presentation of the dish; make the feeding moment pleasant; promote the person's exit to an airy space, preferably outdoors, before the meal; promote meals in outer space if possible; consider the use of nutritional supplements. Promote the achievement of nutritional goals through: evaluation; consideration of the problems of the person / family; integrate nutrition into the care plan and reassess the objectives defined throughout the health-disease process Q2. It takes into account the answer to questions such as: what is the desired good with the application of nutrition?; what is the discomfort caused by eating and / or drinking?; what is the person's interest in continuing to eat or drink? The decision-making aspects should take into account the person, its context and course Q3. Doesn't answer	Qualitative study

Bryon, 2008 (Bélgica)	12 studies review	Integrative literature review in research on the intervention and perception of the nurse in the decision making on artificial nutrition in people at end of life	<p>Q1. Doesn't answer</p> <p>Q2. Definition that the role of nurses in this decision-making process is limited, but important because of the proximity of the person, as an element that guarantees the autonomy and defence of the person, through the communication and orientation that he gives both the person and the family; the nutritional evaluation of the person near the EoL by the nurse has a direct influence on the decision making process, as well as the communication that appears as an aspect of nurses' involvement in decision making. Although nurses understand the importance of their intervention in decision making in artificial nutrition, they simultaneously indicate that it is not well defined and is not properly considered</p> <p>Q3. Without a specific mention of this issue, however, the description of the nurse's involvement in the decision-making process, which, in the proximity and consequent knowledge of the person and family binomial, contributes to the reduction of the risk of therapeutic obstinacy</p>	Mixed study
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Table 1 – Studies analysis from integrative literature review