



Shared decision-making when choosing the feeding method of patients with severe dementia: a systematic review

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Abstract

Objectives: To evaluate whether the use of a support tool for shared decision-making in the choice of feeding method for patients with severe dementia can benefit the patient/caregiver dyad, and to evaluate the quality of the decision-making process. *Method:* A search was performed in the Medline, LILACS, IBECs, SciELO, WHOLIS databases for randomized controlled trials, whether double-blind or otherwise, and quasi-experimental, cohort, case-control, or cross-sectional observational studies in Portuguese, Spanish, English and French. *Results:* Eight articles were found that showed that the use of a decision support tool, as an aid for the shared decision-making method, is beneficial as it reduces decisional conflict and increases the knowledge of caregivers about the subject. The quality of the decision-making process is unsatisfactory due to the low frequency of discussions between caregivers and the health team and the poor evaluation of caregivers about the participation of the team in the decision-making process. *Conclusion:* Decision support tools provide benefits for caregivers/patients undergoing the difficult task of deciding about feeding methods. Findings suggest that the current quality of decision-making is inadequate.

Keywords: Dementia.
Deglutition Disorders.
Decision Making. Decision
Support Techniques.

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INTRODUCTION

Dementia is important in the context of population aging due to its impact on the mental and physical health of patients and their relatives. Regardless of type (such as Alzheimer's, vascular or frontotemporal), the course of the condition is always progressive and incurable, and the advanced stages are very similar: the patient is restricted to bed with little or no verbal communication, is unable to recognize their closest relatives, incontinent, has feeding difficulties and requires care when taking care of themselves¹⁻³.

At this stage, feeding-related problems are common and include oral dysphagia, pharyngeal dysphagia (causing food aspiration) or the refusal of food, resulting weight loss and reduced food and fluid intake¹. At this stage, there are two possible paths to follow: feeding and hydrating the patient through a tube or continuing to feed them orally with assistance.

Since 1997, when the first study⁴ compared the use of oral feeding in elderly institutionalized patients with recent progression to severe dementia using a prospective cohort sample and found no difference in survival, the discussion surrounding the feeding of these patients has become gradually more important.

The accumulation of information on the subject has subsequently led entities such as the American Geriatrics Society⁵, the American Board of Internal Medicine Foundation and the American Academy of Hospice and Palliative Medicine⁶ to advise against the use of a tube for the feeding and hydration of patients with severe dementia. Choosing between the two paths remains difficult, however, since the act of feeding surpasses merely technical concepts. The need for decisions regarding health to be made by a caregiver for another person adds further complexity to the situation.

The scenario described is a prototypical situation for shared decision making. This can be understood as an approach where the health professional and the patient (or their representative), in order to carry out the decision-making process, share information regarding the best available scientific evidence. This assists the patient or caregiver when evaluating the available options, their respective risks and benefits

and weighing them according to their values^{7,8}.

Shared decision making can be facilitated by what is known as a patient decision aid (PDA), translated into Portuguese as *apoio à decisão*. This instrument aims to serve as a reference in the process of counseling the patient or caregiver by presenting the available options in a balanced manner and guiding them in shared decision making in a specific health-related situation^{9,10}.

The present study aims to evaluate whether the use of a shared decision support instrument to choose the feeding method in patients with severe dementia brings benefit to the patient/caregiver dyad in terms of the outcomes (i) reduction of decisional conflict and (ii) increased caregiver knowledge on the topic. A secondary objective was to evaluate the quality of the decision sharing in this scenario, as measured by the frequency of family conversations with the health provider and by the evaluation of these discussions by the family.

METHOD

The PICO strategy (Population, Intervention, Comparator and Outcome) was used to search for the articles as follows: P- patient with severe dementia/caregiver of a patient with feeding problems in the imminence of deciding the method of feeding; I- shared decision-making using PDA; C- usual care or no shared decision strategy; O- decisional conflict, increased caregiver knowledge, frequency of conversations about feeding method options, evaluation of family members of the quality of the decision-making process.

The search was carried out on the Medline database via PubMed on August 24, 2017 using the following descriptors: ("shared decision making" or "decision aid") AND ("dementia" or "tube feeding" or "gastrostomy" or "hand feeding") limited to the English, Portuguese, Spanish and French languages. Another search was carried out in the LILACS, IBECs, SciELO, WHOLIS databases, via the Virtual Health Library (VHL) on August 30, 2017. The descriptors ("shared decision making" or "*tomada de decisões*" or "*toma de decisiones*" or "decision aid" or "*técnicas de apoio para la decisión*" or "*técnicas de apoio para a decisão*") AND ("dementia" or "*demência*" or "tube

feeding" or "*nutrición enteral*" or "*nutrição enteral*" or "gastrostomy" or "*gastrostomía*" or "*gastrostomia*") were used. No date limits were applied to the searches.

The titles and abstracts of all the articles identified were read by the researcher who carried out the search and those selected were exported to the EndNote® X5.0.1 reference manager for more detailed analysis. The researcher also manually reviewed the bibliographic references of these studies in search of new studies.

The researcher who carried out the search was responsible for the selection of the studies and the references selected for full text reading were read by another researcher in order to ascertain the adequacy to the objectives of the systematic review. Divergences were resolved by consensus. Data extraction was performed without the use of a specific form for this purpose. Randomized or double-blind randomized controlled trials (RCTs), quasi-experimental, cohort, case-control, or cross-sectional studies were included. Narrative review, case reports or articles with a qualitative approach were excluded.

RESULTS

The database search resulted in 161 articles. After duplicates were removed, 156 articles remained. Of these 119 were discarded after reading the title and the abstract as they did not meet the inclusion criteria. The full texts of the 37 remaining references were examined in more detail. The analysis revealed that 30 studies did not meet the inclusion criteria. One article was added after reviewing the references of the articles included. The systematic review resulted in a total of eight studies, as shown in Figure 1. Five

studies were conducted in the United States. Canada, Japan and Spain contributed one study each.

Increase in knowledge and reduction in decisional conflict

The oldest study found that evaluated these outcomes was Mitchell et al.¹¹. This described the preparation of a PDA for the choice of feeding method in patients with severe dementia. The study involved the application of a questionnaire to evaluate knowledge about the subject and to measure decisional conflict through the Decisional Conflict Scale (DCS)¹² before and after reading the PDA. It used a convenience sample of 15 caregivers who were in the decision process of the feeding method. The DCS score (1 to 5 points) was lower after exposure to the intervention: 2.88 (± 0.62) vs 2.29 (± 0.52), $p=0.004$. Caregivers also achieved a higher percentage of responses in knowledge after exposure to the PDA questionnaire: 50.4% (± 13.5) vs 84.0% (± 13.5), $p=0.004$, as shown in Chart 1. The study had a quasi-experimental design and a small sample.

Kuraoka and Nakayma¹³ studied the same PDA, adapting the instrument to Japanese and their study. Thirteen inpatient caregivers in two hospitals in Japan deciding on a feeding method were interviewed before and after the use of the PDA. The percentage of correct answers in the questionnaire that evaluated knowledge on the subject increased from 38.1% (± 13.5) to 64.6% (± 25.9), $p<0.001$ and the score in the DCS declined from 3.24 (1.37) to 2.56 (± 1.16), $p<0.001$. In addition to the small sample, the researchers provided the PDA to only five caregivers, with attending physicians distributing it to the other members of the sample. The study had a quasi-experimental design.

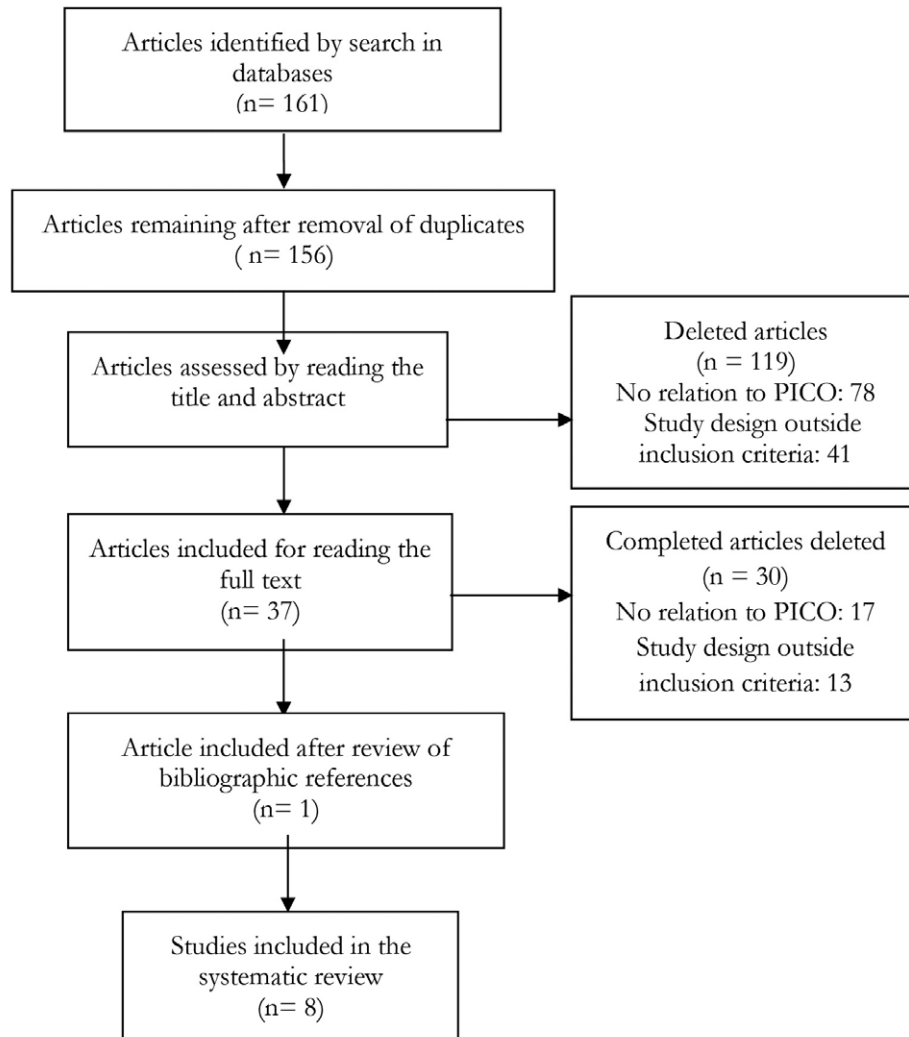


Figure 1. Flowchart for identification, selection and inclusion of studies. City of Santa Catarina, 2017.

After ten years, this same instrument was improved and updated by Hanson et al.¹⁴ and generated a PDA that was tested in an RCT. Twelve elderly long-term care facilities (LTCF) were randomly selected and caregivers received a PDA and were encouraged to discuss it with the health care team. Another 12 LTCF were randomly selected to receive normal care in the form of information from the health team. The primary outcome was the decisional conflict (measured by the DCS) of the caregiver after a three-month follow-up. The secondary outcomes were knowledge about dementia and feeding options, measured shortly after the use of the PDA by 19 true-false questions about the topic. One hundred and twenty-seven caregivers were in the intervention

group and 129 received normal care. Those who received the intervention had a greater reduction in DCS score in three months (-1.97 vs -1.65, $p < 0.001$) while after receiving the PDA caregivers increased their number of correct responses (15.1 vs 16.8, $p < 0.001$). After three months, caregivers in the intervention group discussed feeding options more frequently (46% vs 33%, $p = 0.04$). The study was a randomized clinical cluster trial. Due to the type of randomization and the nature of the intervention, the investigators and participants [(caregivers of patients with severe dementia with feeding problems) were not blinded. Residents of the LTCF who underwent the intervention had more problems with chewing and swallowing (91% vs 71%, $p < 0.001$).

Subsequent analysis of this same population was performed in an American study by Ersek et al.¹⁵ with the main objective of examining how the working hours of nurses and physicians influence the number of conversations about eating disorders between the health team and caregivers who used or did not use a PDA. A secondary objective was to assess the degree of decisional conflict. A total of 256 caregiver-patient pairs were identified and divided into two groups of LTCF (12 who received the intervention and 12 who received the usual care). The LTCF were placed in three distinct groups: those that did not have a nurse practitioner and an attending physician, those with such staff in a part-time role, and those who had them in a full-time capacity. A nurse practitioner is a nursing professional who is qualified to treat certain conditions without the direct supervision of a physician. Decision aid only increased the frequency of caregivers who talked about feeding options at the LTCF with part-time workers or those without a physician/assistant nurse (26% vs 51%, $p<0.001$ and 13% vs 41%, $p<0.001$, respectively). In LTCF with full-time workers, the PDA did not change the DCS score (reduction -0.15 control vs. -0.68 intervention, $p=0.121$). The use of the instrument resulted in a difference in this outcome in LTCF with part-time professionals (reduction -0.08 control vs -0.47 intervention, $p=0.008$) or those that lacked such staff (reduction -0.30 control vs -0.68 intervention, $p=0.014$). The Hanson et al.¹⁴ study was a randomized clinical trial and data from telephone interviews was analyzed.

A study published by Snyder et al.¹⁶ also used the population studied by Hanson et al.¹⁴ and the interviews performed before and after the administration of a PDA to 126 caregivers, together with a control group of 129 individuals. This study reported that decisional conflict was reduced (2.24 vs 1.91, $p<0.001$) shortly after the use of the PDA. There was an increase in the knowledge score (before 15.5 vs after 16.8, $p<0.001$). The study featured a quasi-experimental design.

Quality of the shared decision-making process when choosing the feeding method of patients with severe dementia

Five studies summarized in Table 1 contributed data. Hanson et al.¹⁴ showed that after three months

of PDA use, a higher percentage of caregivers in the intervention group discussed feeding options with physicians or nurses (46% vs 33%, $p=0.04$).

Teno et al.¹⁷ conducted a study with data from interviews with 486 caregivers of people with dementia and feeding problems who had died in an LTCF. One of the objectives of the study was to evaluate how frequently tube feeding was discussed. For 58.9% of the interviewees, there was no discussion about the management of feeding problems between family members and the health team. Among patients who underwent tube feeding, 13.7% of caregivers reported that they did not discuss the issue with the health team before insertion. Of these, 91.1% believed that the discussion should have taken place. Among those who had had some type of conversation, 41.6% reported that the discussion lasted less than 15 minutes. The option of assisted oral feeding was not discussed in approximately one third of cases and the doctor was present in the conversations one third of the time. The interviews were conducted by telephone and took place an average of 23.8 months after the patient's death. A cross-sectional method was applied.

The study by Ersek et al.¹⁵ describes that in LTCF with full-time attending physicians or nurses, the number of caregivers who had had conversations about feeding options with the health team was not associated with a PDA (41% control and 46% intervention, $p=0.450$). In LTCF with part-time professionals (26% control and 51% intervention, $p<0.001$) or without a responsible physician or nurse (13% control and 41% intervention, $p<0.001$), there was a difference in this outcome between the group that received the PDA and the control group.

Givens et al.¹⁸ used data from a prospective cohort with 323 LTCF residents to determine the types of decisions made during the final stage of dementia and identify factors associated with greater satisfaction with the decision-making process. Caregivers were asked if they had made any health decisions in biweekly interviews during a follow-up period of 18 months or until the patient's death. In this event, the caregiver was interviewed two months after the event. To evaluate satisfaction, the Decision Satisfaction Inventory¹⁹ (DSI) scale (0-100 points,

with higher scores indicating greater satisfaction with the decision process) was used. The mean DSI score was 78.4 (± 19.5), indicating a high level of satisfaction. However, the items with the highest incidence of reasonable or bad evaluations were related to support, to the amount of information received and to the time spent with the main person responsible for the health care in the institution. The study evaluated several types of decisions. The management of feeding problems was the reason in 27.2% of cases. The interviews were conducted by telephone.

Ortín et al.²⁰ performed a cross-sectional study with data from patients who had undergone gastrostomy. The aim of the study was to describe how decisions about nutrition and patient participation were made. The informed consent document for gastrostomy was included in 88% of the medical records ($n=36$), but only 49% of these records ($n=20$) reported a discussion with the family about the decision over gastrostomy. The study had a cross-sectional design. The information was based on surveys of 41 medical records and only seven patients had a diagnosis of dementia (17%).

Chart 1. Selected studies based on type of research, intervention/control, outcomes evaluated and results. City of Santa Catarina, 2017.

Type of study/ author/year of publication	Study context	Intervention/ Control	Objectives	Results
ECR Hanson et al., 2011 ¹⁴	LTCF in USA.	PDA for choice of feeding method in patient with severe dementia. Usual care, represented by information by the health team.	To evaluate decisional conflict (by DCS) and knowledge (questionnaire with 19 questions) of caregivers before and after intervention. Measure the frequency of conversations on the subject with the doctor or nurse.	24 LTCF. 127 caregivers received PDA and 129 usual care. Greater reduction in the DCS score at three months with PDA. Increase in knowledge scores. Caregivers in intervention group discussed feeding options more.
Quasi-experimental study Kuraoka and Nakayama, 2014 ¹³	Hospitals, LTCF and community in Japan.	PDA for choice of feeding method in patient with severe dementia.	Analyze decisional conflict (by the DCS) and knowledge of caregivers before and after intervention.	DCS declined after PDA. Increase in knowledge scores after use of PDA.
Quasi-experimental study Mitchell et al., 2001 ¹¹	Hospitals in Canada.	PDA for choice of feeding method in patient with severe dementia.	Compare decisional conflict (using DCS) and knowledge of caregivers before and after intervention.	DCS declined after PDA. Greater number of correct answers in questionnaire of knowledge on subject after exposure to PDA.

to be continued

Continuation of Chart 1

Type of study/ author/year of publication	Study context	Intervention/ Control	Objectives	Results
Cross-sectional study Teno et al., 2011 ¹⁷	Hospitals, LTCFs, residences for the elderly or hospices in USA.	No intervention.	Examine how often tube feeding is discussed. To ascertain the quality of the discussion (DSI scale).	58.9% of caregivers did not report talking about management of feeding problems. For those who received a tube, 13.7% had no discussion with the health team. Of those who did discuss the issue, 41.6% reported doing so for less than 15 minutes. Discussion of the risks of insertion of the catheter in 49.7% of the cases. The option to continue mouth feeding was not discussed in 1/3 of the cases.
<i>Post hoc</i> analysis of RCT Ersek et al., 2014 ¹⁵	LTCF in USA.	PDA for choice of feeding method in patient with severe dementia. Usual care.	To determine how nurses and physicians' working hours influence the number of conversations about feeding options of caregivers who used PDA with the health team. Measure decisional conflict according to the use or not of the PDA in LTCF with different working regimes of professionals.	PDA increased the frequency of conversations and reduced the DCS score in only in LTCF with less active professionals.
Quasi- experimental study Snyder et al., 2013 ¹⁶	LTCF in USA.	PDA for choice of feeding method in patient with severe dementia.	To analyze the decision- making conflict by DCS and knowledge (questionnaire of 19 questions) of caregivers before and after intervention.	Increase in knowledge score after use of PDA. Decisional conflict declined after intervention.
Cross-sectional study Ortín et al., 2005 ²⁰	Hospital in Spain.	No intervention.	Identify how artificial nutrition decisions were made.	Twenty medical records (49%) referred to discussion with the family on decisions about gastrostomy. Informed consent document for gastrostomy was recorded in 88% of the medical records.

to be continued

Continuation of Chart 1

Type of study/ author/year of publication	Study context	Intervention/ Control	Objectives	Results
Prospective cohort Givens et al., 2009 ¹⁸	LTCF in USA.	No intervention.	To determine the types of health decisions made in patients with severe dementia. Identify factors associated with greater satisfaction with the decision-making process (DSI scale).	The mean score on the DSI scale indicated satisfaction with the decision-making process. However, the items with the highest index of reasonable or poor answers were related to the support of the main person responsible for health care in the institution, the amount of information received and the time spent with the physician responsible.

RCT: Randomized Clinical Trial; LTCF: Long Term Care Facility for the Elderly; DCS: Decisional Conflict Scale; DSI: Decision Satisfaction Inventory.

DISCUSSION

The use of a PDA as a shared decision support strategy reduces decisional conflict and increases the knowledge of caregivers of patients with severe dementia who need to decide on the method of feeding^{11,13-16}. The quality of shared decision making in this scenario is low. This information is based on results from five studies^{14,15,17,18,20} which suggest a low frequency of discussions about feeding options between the family and the health team, as well as dissatisfaction with the role played by the health provider in the decision-making process.

This systematic review did not identify multinational studies and the concentration of studies in North America suggests the need for care when interpreting the data in Brazil. In addition, outcomes are described using different scales, making statistically significant differences difficult to interpret clinically, since clinical significance was not established *a priori*.

Studying a complex intervention such as a shared decision is extremely challenging. The inclusion of cognitive deficit due to neurodegenerative dementia and consequent loss of autonomy adds complexity. Research in LTCF presents challenging methodological barriers. The selected studies evaluate an auxiliary tool in the process, the PDA. No information is provided to establish whether

the integration of the use of these tools with communication skills training⁷ would represent an advance in terms of outcomes such as increased knowledge and frequency of decisions based in values or reductions in decisional conflict and passivity in health decision-making.

While there is no other option other than seeking shared decision-making among these patients, there is still much to be done on this subject, especially in Brazil. The review found no Brazilian studies, not even among excluded works. Some barriers to shared decision-making are common to many countries, such as time constraints on health care, resistance of health professionals due to the fear of loss of control in their relationship with the patient, and the belief that people do not want to be involved in decision-making about their health or do not have this ability and may make inappropriate decisions, putting themselves at risk, even in the presence of scientific uncertainty^{7,21}.

However, there appear to be aggravating factors in the case of Brazil. The more traditional model of Brazilian medical education does not favor the embracing of this subject, since the development of communication skills has only recently been formally inserted in the country's medical education²². The low educational level of the Brazilian population may have been a limiting factor for the development of the shared decision-making habit, since people

with lower levels of education take fewer health decisions²³. This may, however, be an opportunity, as these people derive more benefits from shared decisions than groups with a higher educational level. These include a greater increase in knowledge and more defined reductions in decisional conflict levels and uncertainty in treatment choices. In this way, shared decisions can reduce health disparities²⁴. It is also possible that the belief that patients are unable to decide has limited the role of physicians as educators in health practice.

The practice of medicine cannot be dissociated from scientific evidence, nor can it be performed without respecting the informed choice of patients. Without shared decisions, Evidence-Based Medicine (EBM) may become a dictatorship of evidence, but without attention to the principles of EBM, shared decision-making is limited, as preferences of the individual will not be based on reliable estimates of the risks and benefits of the available options, resulting in poorly informed decisions²⁵. Brazilian medicine appears to have a long way to go in terms of the advancement of technical knowledge, the socialization of this knowledge and the democratization of choices in the doctor-patient relationship.

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This study has limitations. The fact that two separate searches were not performed may have resulted in selection bias and the failure to find important articles for review. The fact that some databases were not used in the selections process may also have contributed to this. The researchers did not use appropriate instruments to evaluate the quality of the articles chosen. However, to minimize this limitation the main shortcomings of the studies were described in the results.

CONCLUSION

The use of a shared decision support tool in the choice of feeding method in severely demented patients reduces the intensity of decisional conflict and increases the level of awareness of caregivers to a statistically significant degree. The quality of the decision-making process in this situation appears to be very poor, due to the lack of discussion on the topic between caregivers and health staff, and the negative evaluations of the participation of health providers in the decision-making process. This study represents a step towards fostering the use of shared decisions in the difficult scenario of choice of feeding method in patients with severe dementia.

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