Revista Bioética
Print version ISSN 1983-8042 | On-line version ISSN 1983-8034

Rev. Bioét. vol.29 no.2 Brasília Apr./Jun. 2021

Speech therapy, decision conflicts and dysphagic patients: an integrative review

Márcio José da Silva Moreira [1], *Roberta Nascimento de Oliveira Lemos dos Santos* [2], *Marisa Palacios* [3]

1. Universidade Federal Fluminense (UFF), Nova Friburgo/RJ, Brasil. **2.** Instituto Federal do Rio de Janeiro, Rio de Janeiro/RJ, Brasil. **3.** Universidade Federal do Rio de Janeiro (UFRJ), Rio de Janeiro/RJ, Brasil.

Abstract

Dysphagia presents multidimensional negative impacts on the life of dysphagic patients and may generate decision conflicts related to their diet. This is a review of the literature on speech-language therapy, decision conflicts and the agents involved in the decision making process for deliberations related to the nutrition of this type of patient. This is an exploratory and descriptive study, with content analysis as proposed by Bardin. The databases used were PubMed, Scopus, Web of Science, Cochrane, Embase and Virtual Health Library. Conflicts involving the speech-language therapist, the patient, the family and the multidisciplinary team were identified. In the selected articles, no theory or method was identified to support the mediation of these conflicts. No Brazilian publications that answered the guiding question were found.

Keywords: Deglutition disorders. Bioethics. Speech, language and hearing sciences.

Resumo

Fonoaudiologia, conflitos decisórios e pacientes disfágicos: revisão integrativa

A disfagia tem impactos negativos multidimensionais na vida do paciente disfágico e pode gerar conflitos decisórios relacionados à alimentação. O objetivo deste artigo é revisar a literatura sobre fonoaudiologia, conflitos na tomada de decisão e agentes envolvidos nas deliberações sobre a nutrição desse tipo de paciente. Trata-se de estudo exploratório-descritivo, de revisão integrativa, com análise de conteúdo conforme proposta por Bardin. As bases de dados utilizadas foram: PubMed, Scopus, Web of Science, Cochrane, Embase e Biblioteca Virtual em Saúde. Identificaram-se conflitos envolvendo o fonoaudiólogo, o paciente, a família e a equipe multidisciplinar. Nos artigos selecionados não foi possível identificar uma teoria ou método que fundamentasse a mediação desses conflitos. Não foram encontradas publicações brasileiras que respondessem à pergunta norteadora da revisão.

Palavras-chave: Transtornos de deglutição. Bioética. Fonoaudiologia.

Resumen

Fonoaudiología, conflictos de decisión y disfagia: revisión integradora

La disfagia tiene impactos negativos multidimensionales en la vida del paciente disfágico y puede generar conflictos de decisión relacionados con su alimentación. El objetivo de este artículo fue revisar la literatura sobre fonoaudiología, los conflictos de decisión y los agentes involucrados en el proceso de toma de decisiones para las deliberaciones relacionadas con la nutrición de este tipo de pacientes. Se trata de un estudio exploratorio y descriptivo, donde se realizó una revisión integradora con análisis de contenido y categorización por Bardin. Las bases de datos utilizadas fueron: PubMed, Scopus, Web of Science, Cochrane, Embase y Biblioteca Virtual en Salud. Se identificaron los conflictos entre fonoaudiólogo, paciente, familia y equipo multidisciplinario. En los artículos seleccionados no se identificó ninguna teoría o método que sustente la mediación de estos conflictos. No hay publicaciones nacionales que respondan a la pregunta orientadora.

Palabras clave: Trastornos de deglución. Bioética. Fonoaudiologia.

Research

The authors declare no conflict of interest.

Bioethics relates to other fields of knowledge, making it necessary to understand multidisciplinary content to address bioethical issues more assertively. The health professional may have difficulties to analyze the scenario and identify problems that need a moral analysis and quick resolution. This analysis must consider ethical, moral, religious, legal, scientific, and technical aspects [1].

Pessini and Barchifontaine [2] define bioethics as a domain of plural perception, which arises from demands related to the emergence and use of technologies applied to medical sciences. This field of study encompasses discussions about care and the relationships established within. Its objective is to safeguard the patient's integrity and promote good clinical practices by health professionals, including the speech therapist.

Speech therapy deals with issues related to human communication, giving theoretical support to speech therapists to identify, evaluate and rehabilitate individuals who undergo changes in oral and written communication, voice and hearing [3]. Over the years, speech therapy has expanded its line of action, encompassing new therapeutic scenarios and approaches [4]. Dysphagia is one of the objects of the specialties that emerged within the profession. The speech therapist specialized in this area is qualified to act in the prevention, evaluation, and treatment of deglutition disorders in all life cycles, prioritizing the patient's well-being, minimizing risks, and maximizing health-related benefits. Suspension, indication of alternative feeding route or introduction to oral nutrition depend on the speech therapist's evaluation, in a debate with the multidisciplinary team [5].

Divided into four phases (preparatory phase, oral phase, pharyngeal phase and esophageal phase), deglutition is a function of the stomatognathic system performed by structures that participate in other functions, such as speech, voice, breathing, chewing, and sucking. Any change in the path of food from the mouth to the stomach is called dysphagia, and its etiology may include neuromuscular, tumor, infectious, metabolic and degenerative diseases, or iatrogenic events [6]. Dysphagia is characterized by the presence of penetration, aspiration and bronchoaspiration of food bolus, as well as oral, gastric or liquid fluid, leading, in many situations, to illness. There are more intense biopsychosocial impacts for the dysphagic patient in a situation of vulnerability, because of disease evolution and the impossibility of cure, with damages to well-being and quality of life. Feeding should prioritize the maintenance of nutritional and water status in a safe and effective manner, without jeopardizing the patient's lung health [7].

This article presents results of an integrative review with content analysis based on Bardin [8]. The entire research was based on the research question: "What are the main actors in decision-making involving dysphagic patients and the conflicts they face?"

Method

Integrative review process

This exploratory-descriptive study used the integrative review method, which allowed the synthesis of data already published and identification of evidence-based practices [9,10]. When the researcher takes a qualitative look at the systematic review, a more global evaluation becomes possible, thus including sociocultural, emotional, and behavioral aspects that are part of health care. Following this line, the researcher can obtain information that will allow them to suggest paths and propose new theoretical tools [11].

According to Souza, Silva, and Carvalho [12], the integrative review is characterized by six well-defined phases that are easy to organize and understand: 1) formulating a guiding question; 2) establishing inclusion and exclusion criteria to only integrate studies that actually answer that question; 3) determining what information will compose the integrative review corpus; 4) interpreting the extracted data; 5) presenting the results obtained; and 6) synthesizing knowledge of the topic defined at the beginning of the review. In this integrative review, another phase was included – content analysis, as proposed by Bardin [8].

Strategies to identify and select studies

The literature search included articles in Portuguese, English or Spanish published until February 29, 2020. Date filter was not applied.

The search was performed on *Portal de Periódicos CAPES* by remote access from Universidade Federal Fluminense and Universidade Federal do Rio de Janeiro.

The keywords selected are registered in the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH) controlled vocabularies: "speech therapy," "bioethics," "ethics" and "decision making." The search also included synonyms and related terms, forming the following search keys: speech therapy and deglutition disorders (speech therapy *or* speech therapy approach *or* deglutition disorders *or* dysphagia rehabilitation), bioethics and ethics (bioethics *or* ethics *or* ethics of health care *or* biomedical ethics *or* bioethical hospital *or* medical ethics *or* ethicists *or* bioethicists *or* bioethical specialist* *or* ethics specialist* *or* health care ethics *or* biomedical ethics *or* ethics, clinical *or* clinical ethics *or* hospital ethics *or* ethical aspects *or* ethics), and shared decision-making (decision making *or* decision making* shared *or* making* shared decision *or* shared decision making* *or* clinical decision-making *or* clinical decision making *or* decision-making clinical *or* medical decision-making *or* decision-making medical *or* medical decision making). The search keys composed of the words *bioethics* and *ethics* were unified to present common terms.

The search keys were combined to refine the results. The survey included six databases: PubMed (four articles), Scopus (32 articles), Virtual Health Library (VHL) (six articles), Embase (13 articles), Cochrane (one article) and Web of Science (17 articles). Such indexers were chosen for returning more articles in a previous search without crossing the keys. OpenGrey was consulted for gray literature, but the database did not return any relevant data. Finally, the results were entered into Mendeley Reference Manager software, which removed duplicates.

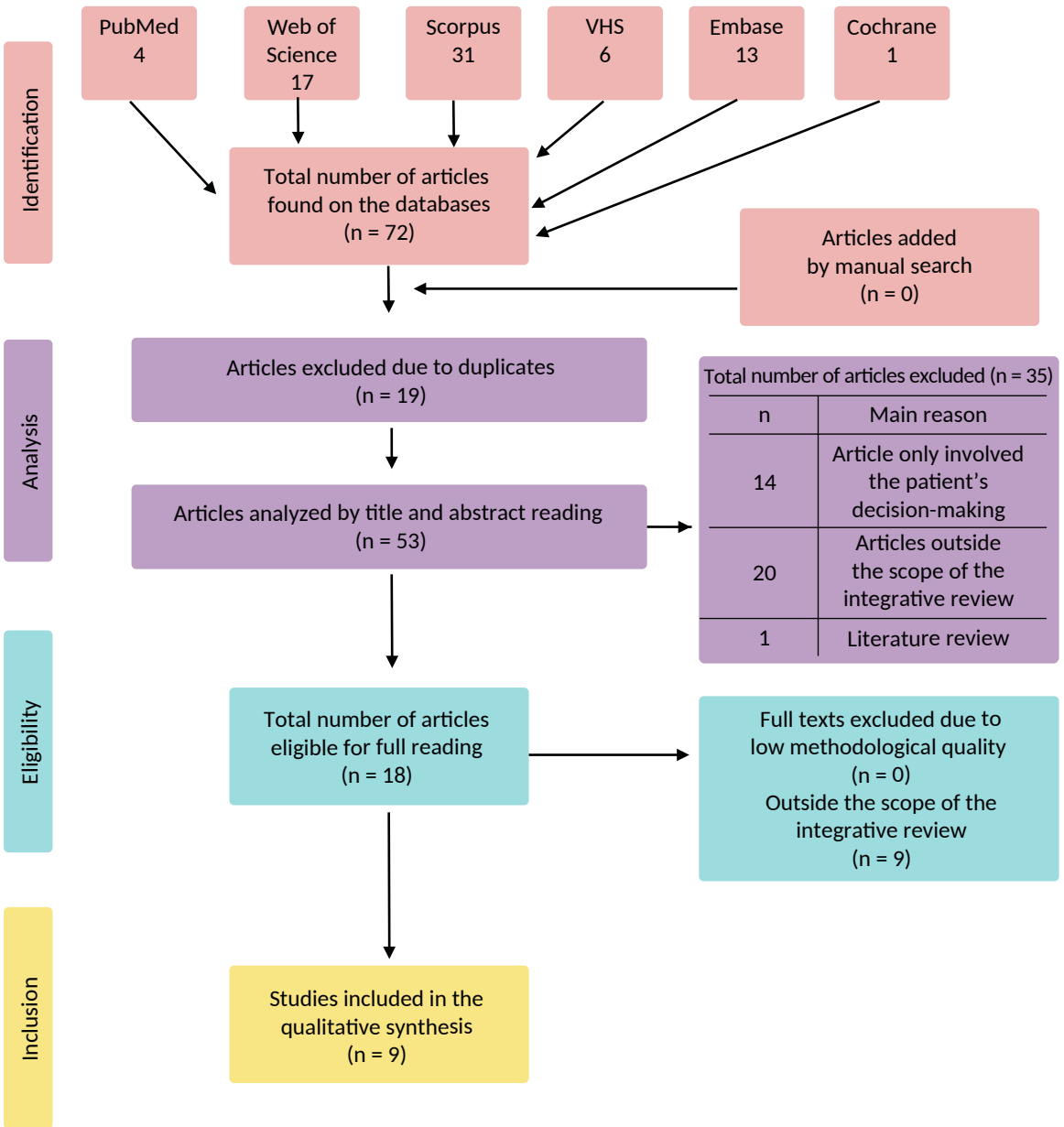
The inclusion criteria considered the research question: "What are the main actors in decision-making involving dysphagic patients and the conflicts they face?" Duplicate articles, review articles, letters to the editor, articles that dealt with decision made exclusively by the patient, the multidisciplinary team or the speech therapist, or studies with animals were excluded.

Selection of articles from the databases

The first selection was made based on reading titles and abstracts. At this stage, two reviewers eliminated articles that did not meet the inclusion criteria. To assess agreement between reviewers, 10% of the publications were compared randomly. Reading the texts in full was necessary when the title and the abstract did not clarify whether the study was relevant to the research question.

In a second step, the reviewers read the pre-selected articles in full, again applying the inclusion and exclusion criteria. There was an agreement between the two reviewers, thus there was no need for a third reviewer. After the selection, a manual search of references of the articles included in the survey was carried out. The representation of the process can be seen in Figure 1, adapted from a systematic review and meta-analysis [13].

Figure 1. Flowchart adapted for the article selection of the integrative review



Source: Moher and collaborators; 2009[13].

Bias evaluation and methodological risk

To assess the risk of bias, the JBI Critical Appraisal Checklist for Qualitative Research instrument, developed by the Joanna Briggs Institute[11], was used. The items covered by this protocol are: 1) "Is there congruity between the stated philosophical perspective and the research methodology?"; 2) "Is there congruity between the research methodology and the research question or objectives?"; 3) "Is there congruity between the research methodology and the methods used to collect data"; 4) "Is there congruity between the research methodology and the representation and analysis of data?"; 5) "Is there congruity between the research methodology and the interpretation of results"; 6) "Is there a statement locating the researcher culturally or theoretically"; 7) "Is the influence of the researcher on the research, and vice-versa, addressed?"; 8) "Are participants, and their voices, adequately represented?"; 9) "Is the research

ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?"; and 10) "Do the conclusions drawn in the research report stem from the analysis, or interpretation, of the data?"

For each item, four options were admitted: "yes," "no," "unclear" and "not applicable." In the item "overall appraisal," the options were: "include," "exclude" or "seek further information" [14]. The nine articles selected were considered eligible to compose the integrative review; therefore, there was no exclusion at this stage. Again, two reviewers applied the checklist, and there was no disagreement between them. It was not necessary to contact authors to request supplementary data for the analysis.

Treatment of collected data

A qualitative evaluation of the publications was carried out in search for similarities or differences, patterns and general trends in how the studies approach the topic studied. The items included in the data collection were: "year," "author," "title," "objective" "keywords", "decision-making conflicts" and "conclusions" (Chart 1).

Considering the review characteristics, the content analysis technique was adopted, which uses thematic categorization. The application of this technique started with the pre-analysis – planning, organization and floating reading of all the material gathered. Then the articles selected were coded with the help of ATLAS.ti software for Mac, where a report was generated with counting and identification of the codes (subcategories). Based on this report, the content was classified and categorized (Figure 2). Finally, the results were treated, considering the inference and interpretation of these contents and, consequently, the answer to the research question of the integrative review [8].

Rev. bioét. (Impr.). 2021; 29 (2): 401-15

Chart 1. Organization of the corpus

Year	Author	Title	Objective	Keywords:	Decision-making conflicts	Conclusions
1992	Serradura-Russell A[15]	"Ethical dilemmas in dysphagia management and the right to a natural death"	Discuss the bioethical dilemmas faced by the speech therapist in the management of dysphagic patients.	Autonomy; informed consent; terminal illness; living will; deglutition; deglutition disorders.	Patient's refusal of speech therapy; acceptance of changes in food consistency by the capable patient; management of the incapable patient's feeding.	The speech therapist cannot decide to interrupt artificial nutrition and hydration (ANH). The family and the multidisciplinary team must analyze ethical issues, risks and benefits.
1996	Kirschner KL, Sorties BC[16]	"Ethical dilemmas in dysphagia practice"	Discuss two scenarios that contain many ethical dilemmas.	Clinical practice; conflict; dysphagia.	A capable patient refuses to eat and does not adhere to the proposed treatment. A family member decides that the speech therapist's services are dispensable.	Stimulate discussions about medical procedures, patient and family preferences, and quality of life. Use of the country's Code of Ethics and professional help in the decision-making process. Ethical decisions always generate conflicts. The more severe the state of the dysphagic patient, the more frequent the ethical dilemmas involving the care process.
2003	Sharp HM, Bryant KN[17]	"Ethical issues in dysphagia: when patients refuse assessment or treatment"	Review criteria to assess the patient's ability to make autonomous choices and participate in decision-making.	Deglutition disorders; enteral nutrition; clinical decision-making; advance directives; withholding and withdrawing treatment.	Introduction to oral nutrition; acceptance or refusal of clinical recommendations; the challenge of obtaining informed consent from patients with limited capacity to participate in decision-making; clinical staff responsibilities when the patient chooses high-risk treatment options.	Balance ethical duties to respect patients' autonomy; weigh ANH risks and benefits. Prior informed consent to assess deglutition; assessment of the patient's refusal and its impacts. It is necessary to consult the advance directives of the patient without autonomy to decide at the moment.

continues...

http://dx.doi.org/10.1590/1983-80422021292478

Chart 1. Continuation

Year	Author	Title	Objective	Keywords:	Decision-making conflicts	Conclusions
2006	Sharp HM [18]	"Ethical issues in the management of dysphagia after stroke"	Analyze ethical issues in the management of dysphagic patients after stroke.	Advance directives; artificially administered nutrition and hydration; deglutition disorders; tube feeding.	Use of an alternative feeding route after stroke; decrease in the patient's ability to choose or have their will respected; absence of advance directives.	Good communication between the multidisciplinary team. Health professionals and patients benefit from clear guidelines, which encourage staff to resolve the moral and ethical dilemmas of clinical care.
2007	Sharp HM, Wagner LB [19]	"Ethics, informed consent, and decisions about non-oral feeding for patients with dysphagia"	Discuss requirements for informed consent to food and artificial hydration, offering practical solutions to ethical issues related to the rehabilitation of dysphagic patients.	Advance directives; deglutition disorders; enteral nutrition; informed consent; speech-language pathology.	Absence of informed consent, or informed refusal, by the incapable patient; lack of care plan and advance directives.	Ethical dilemmas can be avoided with clarifications to the family and patient. The patient has to be informed about the negative impacts of dysphagia on quality of life and general health. The fasting patient may continue aspirating oral secretions and stomach contents. Patient and family can indicate prior preferences for or against the use of ANH. Speech therapists should offer a decision-making model that addresses the risks and benefits of oral and non-oral feeding.

continues...

http://dx.doi.org/10.1590/1983-80422021292478

Chart 1. Continuation

Year	Author	Title	Objective	Keywords:	Decision-making conflicts	Conclusions
2012	Groher ME, Groher TP [20]	"When safe oral feeding is threatened: end-of-life options and decisions"	Discuss dysphagia as a manifestation of diseases that anticipate end-of-life decisions.	Aspiration pneumonia; dysphagia; end-of-life; medical ethics; speech-language pathologist; tube feeding.	Problems involving the safety of deglutition and the ingestion of food and liquids for end-of-life dysphagic patients. Are there possibilities for ANH (end-of-life consensus)? The patient, the team and the family must assess eating behavior, which is important for human existence. Use of principlism to guide shared decision-making.	End-of-life decision, especially in cases of patients unable to obtain nutrition by mouth (to place a tube or not?). It is necessary to weigh risks and benefits, consider the patient's preferences and beliefs and make autonomy feasible.
2012	Kaizer F, Spiridigliozzi AM, Hunt MH [21]	"Promoting shared decision-making in rehabilitation: development of a framework for situations when patients with dysphagia refuse diet modification recommended by the treating team"	Examine the clinical context of diet modifications for dysphagic patients undergoing rehabilitation in hospitals; explore ethical aspects of the clinical algorithm; discuss the authors' experience with the development and use of the tool.	Dysphagia; shared decision-making; diet modification; ethics; rehabilitation; adherence; deglutition; deglutition disorders.	Clinical decision-making process for modifying diets for dysphagia; management of dysphagia; refusal to modify the diet and non-adherence to the team's recommendations regarding oral feeding.	Safeguard autonomy through shared decision-making. Patient-centered care; creation of an algorithm to help resolve conflicts (refusal or non-adherence to the consistency modification). The algorithm improves the communication between components.

continues...

http://dx.doi.org/10.1590/1983-80422021292478

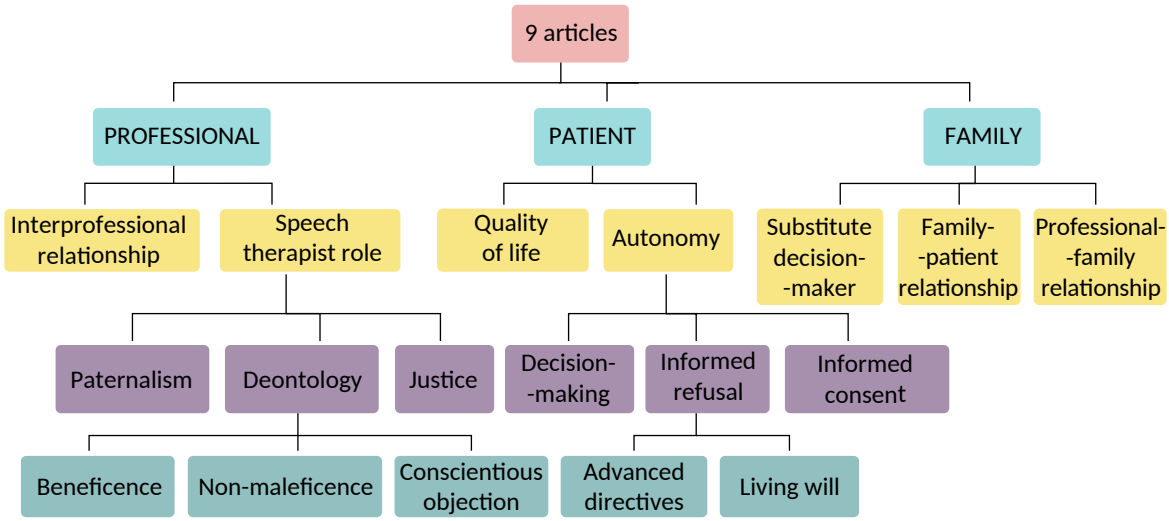
Chart 1. Continuation

Year	Author	Title	Objective	Keywords:	Decision-making conflicts	Conclusions
2015	Kenny B [22]	"Food culture, preferences and ethics in dysphagia management"	Reflect on ethical issues identified in speech therapy practice with the aim of showing some of the concerns in the management of dysphagia; examine the role of the speech therapist in supporting the patient's autonomy when they disagree with the caregivers in relation to objectives and values.	Clinical; dysphagia; food culture and preferences; shared decision-making; speech pathology.	Ethical issues involving enteral diet and diet modification; devaluation, by the care team, of the food and liquids offered; conflict between physical, sociocultural and health objectives due to the dysphagic patient's food preferences.	Assess the risks and benefits of oral feeding in dysphagic patients; maintain individual choice safely and effectively. The dysphagia algorithm is a tool to promote partnerships and shared decision-making.
2019	Askren A, Leslie P [23]	"Complexity of clinical decision making: consent, capacity, and ethics"	Discuss the bases of clinical decision-making with the intention of minimizing clinical discomfort; accept the patient's right to refuse thickened liquids; eliminate the practice of defensive medicine (paternalism).	Ethics; consent; capacity; decision-making.	Patient's right to refuse diet modifications (texture and thickening of liquids); non-adherence to the recommendations of the care team on oral feeding or indication of alternative route of short or long term.	Promote the patients' well-being and ensure their autonomy. The professional code of ethics says that the speech therapist must use informed consent to guarantee autonomous choices.

continues...

http://dx.doi.org/10.1590/1983-80422021292478

Figure 2. Categorization of codes (subcategories) found in the corpus



Results and discussion

Bibliometrics of selected articles

Nine articles were selected to compose the integrative review, all written and published in the English language. As there was no limitation on filtering by time, the year of publication varied between 1992 and 2019. The only year that had more than one publication was 2012 (two articles). The restricted number is due to selecting exclusively texts that answered the research question of the review. Other publications related to the topic were identified, but they were outside the scope of this research.

Regarding the nine articles selected, seven are case studies that analyze ethical dilemmas and conflicts in the therapeutic environment [15-20,22]. Two other articles presented models and algorithms for decision-making in care for dysphagic patients [21,23]. Five articles are signed by researchers from the United States [16-20], country with the greatest volume of publications, followed by Australia, with two publications [22,15], and Canada [21] and the United Kingdom [23], with one publication each. Five journals are specifically focused on speech therapy. The journal with the highest impact factor identified in this integrative review is *Dysphagia* (impact factor 3.034), with two publications: one in 1992 (case study) and another in 2012 (observational study). Only one journal, *Bioethics* (impact factor of 1.665), is specific to the bioethics area.

What are the agents involved in decision-making conflicts in speech therapy?

For the categorization of articles – following the content analysis method proposed by Bardin – the reports generated in ATLAS.ti software were used. Three main actors of decision-making conflicts in speech therapy practice (in increasing order of occurrences) were identified: 1) family (18%, 18 occurrences); 2) patient (35%, 36), and 3) health professionals (47%, 48). Within this scope, the subcategories incorporated in the "family" category were "substitute decision maker," "family-professional relationship" and "family-patient conflicts." In the "patient" category, there were two main subcategories: "quality of life" and "autonomy" – "decision-making"; the "informed refusal," "informed consent," "advance directives" and "living will" subcategories were added to the latter. Finally, in the "health professionals" category, two main subcategories were established: "interprofessional relationship" and "speech therapist's role," with the latter including the "paternalism," "deontology," "justice," "beneficence," "non-maleficence" and "conscientious objection" subcategories (Figure 2).

Conflicts related to speech therapist and health professionals

In the "health professional" category, eight subcategories were included (the percentages in parentheses refer to the occurrence in the

corpus): beneficence (19%), speech therapist's role (17%), justice (15%), interprofessional relationship (15%), deontology (14%), non-maleficence (8%), paternalism (8%), and conscientious objection (4%).

Interprofessional relations must be based on the discussion of cases and the sharing of information, as to avoid misunderstandings. When there is dialogue about how each professional can contribute to the management and the patient's prognosis, conflicts and confusions are avoided. In the case of a dysphagic patient with no possibility of cure, there will always be many decision-making conflicts over the best way to manage their demands [15]. In short, the relationship between professionals and specialties must be based on the sharing of information so as not to allow confusion and divergences in the treatment of the patient and the management of their needs, respecting the specifics of each case.

In fact, when disagreements occur in the management of dysphagic patients – especially when they refuse specialized speech therapy assessment or treatment –, there is a need for discussing the case between physicians, family members and caregivers. Sharp and Bryant [17] also reinforce that the team must always communicate and share the deliberations. Information is important to decide the best way to safeguard autonomy and respect the patient's decisions.

The speech therapist's role in managing dysphagia is very well defined, reason why this professional has to understand the possible decision-making conflicts and know how to manage the patient's demands. Many authors emphasize the importance of decision-making being shared between family, patient and multidisciplinary team. The patient's wishes and desires must be considered so that their autonomy is respected [15-23].

In matters regarding the professional, one can perceive the occurrence of three of the four *prima facie* principles of principlism: beneficence (always doing good), non-maleficence (never doing evil) and justice (related to distributive justice and the weighting between risks and benefits) [16,17,20-23]. The speech therapist can use principlism to maintain a balance in health care, always evaluating the specifics of each case to assess which of the four principles is more important than the others. The professional, therefore, must avoid unilateral decisions, which hinder participation and disrespect the patient's autonomy. This type of decision reinforces paternalism (when the physician or professional makes decisions without the patients' consent and active participation) [15,17-21].

As Bertachini [24] points out, speech therapy manages ethical, human and technical demands, focusing on prevention and intervention in the areas of health, education and research. The speech therapist is qualified to intervene in issues related to human communication that hinder social interaction, family life, learning and people management. One of the mechanisms to avoid these negative impacts is empathic listening, which in turn allows assertive communication, enabling the patient to be a protagonist in decision-making, expressing their feelings and wishes [24].

Bertachini [24] also states that speech therapy and bioethics share the same purposes and principles: confidentiality, privacy, alterity, prudence, vulnerability, acceptance, respect for life, and quality of life. Thus, bioethics is a tool that helps the speech therapist deal with decision-making conflicts.

Another situation that can lead to conflict concerns conscientious objection. The health professional may refuse to perform any procedure out of respect for personal beliefs and values. The concept of morality and what is ethical is well defined, but the understanding can differ from person to person – which generates conflicts in decision-making [17,19]. In these cases, the patient's right to autonomy suffers interference and ends up being disrespected.

As deontological documents, the professional code of ethics addresses ethical issues related to care and interactions that involve therapist and patient, service provider and client. In short, deontology concerns the ethical regulation of interprofessional and interpersonal relationships [16-23]. Thus, the Speech Therapy Ethics Code [25], based on the principles of the *Universal Declaration on Bioethics and Human Rights* [26], also provides the speech therapist with a theoretical basis that can be used to resolve decision conflicts.

Conflicts related to speech therapists and patients

In the "patients" category, seven subcategories were included (the percentages in parentheses refer to the occurrence in the corpus): autonomy (25%), advance directives (25%), informed refusal (14%), living will (14%), quality of life (8%), shared decision-making (8%), and informed consent (6%).

The concept of quality of life determines the well-being of dysphagic patients, and their condition to maintain human dignity and autonomy. The patient can manage their wishes according to their own understanding of what quality of life is and how it impacts their daily life. The concept also relates to functionality, which is highly valued in limiting situations, when the patient is affected by an incurable and progressive disease. In summary, quality of life is a parameter to define behaviors when managing dysphagic patients [16,20-22].

Respect for autonomy is another principle related to the "patient" category and emerges from the principle proposed by Beauchamp and Childress [27]. An autonomous patient is the one capable of making their own choices and expressing their own desires through informed consent, deciding on their well-being, health situation and care process [15-21,23]. The patient may also refuse procedures they deem extraordinary or that may cause more suffering. This refusal, like consent, must be reported [15-23].

Patient autonomy is related to shared decision-making. In this process, to reach a consensus that meets the patient's needs, deliberation must be based on collaboration and the division of responsibilities [15-23]. Article 5 of the *Universal Declaration on Bioethics and Human Rights* [26] clearly states the duty to respect the person's autonomy, advocating the individual's independence in deciding what they want for their own life. Shared decision-making aims to safeguard these rights. The speech therapist can help in this process, respecting both the patient's refusal and consent.

Regarding autonomy, patients can benefit from the advance directives, whose main objective is to ensure that their decisions about whether or not to undergo certain procedures are respected. The Federal Council of Medicine (CFM) [28] defines advance directives as a set of wishes, previously and expressly expressed by the patient, about care and treatments that they want, or not, to receive when unable to express, freely and autonomously, their will. This set of wishes of the patient or their legal representative must comply with the Medical Code of Ethics – if there is disagreement, the physician may ignore it.

Advance directives prevail over any other opinion that is not given by the physician, including the family's. Advance directives must be registered in medical record, and registration with a registry office is optional, given that today its execution by physicians is not guaranteed by law. It is also noteworthy that there are judicial decisions that prevent certain procedures, even with the patient's express wish. In the absence of advance directives, the physicians can consult the hospital's clinical bioethics committee, the medical ethics committee or the CFM itself to guide their decisions [28]. Finally, it is worth remembering that the patient who registered advance directives can change their decisions at any time [17-20]. In this way, the patients' right to express their wishes in advance is assured, anticipating possible situations of inability to decide for themselves.

There are two modalities of advance directive: living will and durable power of attorney. In the living will, the patient registers disagreements and agreements regarding certain medical procedures. In this case, the patient exercises pure autonomy, as advocated by Beauchamp and Childress [27], as they actively and consciously participates in decision-making about their care. The durable power of attorney, on the other hand, is a model of substitutive judgment, whereby the patient appoints a prosecutor to decide for them in case of incapacity. These two models can be put together or in different documents, but both have the goal of guaranteeing respect for autonomy. When the patient explains in these documents what they want, it becomes easier to manage the decision-making conflicts [29].

In the living will, the patient can register the refusal or desire to suspend extraordinary measures that prolong their life and increase suffering. These measures may include: artificial nutrition and hydration (ANH), mechanical

ventilation and resuscitation, especially in palliative or end-of-life care [17-19]. Much discussed in the literature because of controversies about its benefits, ANH can have legal implications for health professionals [17-19]. For this reason, based on the medical literature or even with the approval of the patient or substitute decision-maker [29], physicians tend to be cautious when suspending ANH.

Conflicts related to speech therapist and family

In the "family" category, three subcategories were included (the percentages in parentheses refer to the occurrence in the corpus): "family and patient conflict" (22%), "professional-family relationship" (39%) and "substitute decision-maker" (39%). In the relationship between family and patient, disagreements are very common. For different reasons, the family often tends to make decisions without including the patient. This may be due, for example, to an attempt to save the patient from knowing their real health condition, or even to disagreements regarding the patient's choices. Without knowledge of the medical diagnosis or the existing therapeutic possibilities, the patient's autonomy is compromised [16-19,22]. Thus, it is reinforced that the patient has the right to make decisions and be fully respected as a human being.

In the relationship between professional and family, disagreements can be resolved when the professional presents all the possibilities of treatment and interventions, allowing for shared decision-making. The family's demands provide detailed information about how the patient lived, their habits and preferences, and therefore must be considered. The speech therapist has to be sensitive to the anguish of family members in relation to patient care and record the decisions made at meetings with the family [15-18,20-22].

Patients can define a family member or close person to be the substitute decision-maker in the event of an inability to self-manage and decide for themselves. Questions about suspension or refusal of procedures related to feeding can be deliberated by the substitute decision-maker [29], who must legislate in favor of the person who instituted it, without confusing their wishes, beliefs and wills with those of the patient [15-20,23].

Final considerations

Answering the research question of this integrative review ("What are the main actors in decision-making involving dysphagic patients and the conflicts they face?"), we identified that the speech therapist has to manage decision-making conflicts, which mainly involve three actors: patient, professional, and family. The review also identified possible conflicts (subcategories) related to each of these actors. Such conflicts most often involve the professional and then the patient.

We concluded that attitudinal changes of the multidisciplinary team and caregivers in relation to the dysphagic patient are necessary. The deliberations must involve everyone so that the decision-making is more assertive and safeguards the patient's autonomy, treating them as the protagonist of their actions and choices.

Family demands should also receive attention, as the family's distress and lack of information can interfere with patient care, especially in matters related to feeding. It was clear that suspending ANH or administering comfort food for end-of-life patients can generate disagreements between health professionals, family and patients themselves. To avoid conflicts, deliberation must be shared.

We observed that there is no theory or model that the speech therapist can use to resolve ethical conflicts involving the dysphagic patient's feeding. Ideally, the professional's clinical decisions are based on good practices and scientific evidence, but few studies discuss the topic. We suggested, therefore, that the Code of Ethics in Speech Therapy and the theoretical framework of bioethics should be used as a support for the resolution of decision-making conflicts.

References

1. Rego S, Palacios M, Siqueira-Batista R. A bioética e suas teorias. In: Rego S, Palacios M, Siqueira Batista R. Bioética para profissionais de saúde. Rio de Janeiro: Editora Fiocruz; 2014. p. 39-62.
2. Pessini L, Barchifontaine P. Problemas atuais de bioética. 11ª ed. São Paulo: Loyola; 2014.
3. Brasil. Lei nº 6.965, de 9 de dezembro de 1981. Dispõe sobre a regulamentação da profissão de Fonoaudiólogo, e determina outras providências. Diário Oficial da União [Internet]. Brasília, 10 dez 1981 [acesso 3 mar 2021]. Disponível: https://bit.ly/3e2u6QT
4. Brasil. Decreto nº 87.218, 31 de maio de 1982. Regulamenta a Lei nº 6.965, de 09 de dezembro de 1981, que dispõe sobre a regulamentação da profissão de Fonoaudiólogo, e determina outras providências. Diário Oficial da União [Internet]. Brasília, 1982 [acesso 3 mar 2021]. Disponível: https://bit.ly/2PwM6Js
5. Conselho Federal de Fonoaudiologia. Resolução nº 492, 7 de abril de 2016. Dispõe sobre a regulamentação da atuação do profissional fonoaudiólogo em disfagia e dá outras providências. Diário Oficial da União [Internet]. Brasília, 18 abr 2016 [acesso 3 mar 2021]. Disponível: https://bit.ly/3vzQgQp
6. Costa M. Disfagia oral e/ou faríngea e distúrbios referentes. In: Costa M. Deglutição e disfagia: bases morfofuncionais e videofluoroscópicas. Rio de Janeiro: Medbook; 2013. p. 179-95.
7. Jotz GP, Dornelles S. Fisiologia da deglutição. In: Jotz GP, Carrara-de-Angelis E, Barros, APB. Tratado de deglutição e disfagia: no adulto e na criança. Rio de Janeiro: Revinter; 2009. p. 16-9.
8. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 2016.
9. Whittemore R, Knafl K. The integrative review: updated methodology. J Adv Nurs [Internet]. 2005 [acesso 3 mar 2021];55(5):546-53. DOI: 10.1111/j.1365-2648.2005.03621.x
10. Cullum N, Ciliska D, Haynes RB, Marks S. Enfermagem baseada em evidências: uma introdução. Porto Alegre: Artmed; 2010.
11. Joanna Briggs Institute. Joanna Briggs Institute Reviewers' Manual. Adelaide: Joanna Briggs Institute; 2008.
12. Souza MT, Silva MD, Carvalho R. Revisão integrativa: o que é e como fazer? Einstein [Internet]. 2010 [acesso 3 mar 2021];8(1):102-6. DOI: 10.1590/s1679-45082010rw1134
13. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med [Internet]. 2009 [acesso 29 abr 2021];6(7). DOI: 10.1371/journal.pmed.1000097
14. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. Int J Evid Based Healthc [Internet]. 2015;13(3):179-87. DOI: 10.1097/XEB.0000000000000062
15. Serradura-Russell A. Ethical dilemmas in dysphagia management and the right to a natural death. Dysphagia [Internet]. 1992 [acesso 3 mar 2021];7(2):102-5. DOI: 10.1007/BF02493440
16. Kirschner KL, Sorties BC. Ethical dilemmas in dysphagia practice. Top Stroke Rehabil [Internet]. 1996 [acesso 3 mar 2021];3(3):87-93. DOI: 10.1080/10749357.1996.11754124
17. Sharp HM, Bryant KN. Ethical issues in dysphagia: when patients refuse assessment or treatment. Semin Speech Lang [Internet]. 2003 [acesso 3 mar 2021];24(4):285-99. DOI: 10.1055/s-2004-815578
18. Sharp HM. Ethical issues in the management of dysphagia after stroke. Top Stroke Rehabil [Internet] 2006 [acesso 3 mar 2021];13(4):18-25. DOI: 10.1310/tsr1304-18
19. Sharp HM, Wagner LB. Ethics, informed consent, and decisions about nonoral feeding for patients with dysphagia. Top Geriatr Rehabil [Internet]. 2007 [acesso 3 mar 2021];23(3):240-8. DOI: 10.1097/01.TGR.0000284768.32334.96
20. Groher ME, Groher TP. When safe oral feeding is threatened: end-of-life options and decisions. Top Lang Disord [Internet]. 2012 [acesso 3 mar 2021];32(2):149-67. DOI: 10.1097/TLD.0b013e3182543547
21. Kaizer F, Spiridigliozzi AM, Hunt MH. Promoting shared decision-making in rehabilitation: development of a framework for situations when patients with dysphagia refuse diet modification recommended by the treating team. Dysphagia [Internet]. 2012 [acesso 3 mar 2021];27(1):81-7. DOI: 10.1007/s00455-011-9341-5

22. Kenny B. Food culture, preferences and ethics in dysphagia management. Bioethics [Internet]. 2015 [acesso 3 mar 2021];29(9):646-52. DOI: 10.1111/bioe.12189

23. Askren A, Leslie P. Complexity of clinical decision making: consent, capacity, and ethics. Semin Speech Lang [Internet]. 2019 [acesso 3 mar 2021];40(3):162-9. DOI: 10.1055/s-0039-1688838

24. Bertachini L. Fonoaudiologia e bioética: reflexões (bio)éticas na prática profissional. In: Sganzerla A, Chemim MRC, Rauli PMF, editores. Bioética nas profissões: ciências da saúde e áreas afins. Curitiba: CRV; 2019. p. 79-98.

25. Conselho Federal de Fonoaudiologia. Código de Ética da Fonoaudiologia [Internet]. Brasília: Conselho Federal de Fonoaudiologia; 2016 [acesso 10 jan 2020]. Disponível: https://bit.ly/3gClLF5

26. Organização das Nações Unidas para a Educação, Ciência e Cultura. Declaração Universal sobre Bioética e Direitos Humanos [Internet]. Paris: Unesco; 2005 [acesso 27 mar 2021]. Disponível: https://bit.ly/3u5C2pR

27. Beauchamp TL, Childress JF. Respect for autonomy. In: Beauchamp TL, Childress JF. Principles of biomedical ethics. 8ª ed. New York: Oxford University Press; 2019. p. 99-159.

28. Conselho Federal de Medicina. Resolução CFM nº 1.995/2012. Dispõe sobre as diretivas antecipadas de vontade e dá outras providências. Diário Oficial da União [Internet]. Brasília, p. 269-70, 31 ago 2012 [acesso 27 mar 2021]. Seção 1. Disponível: https://bit.ly/2RdnS7q

29. Dadalto L, Tupinambás U, Greco DB. Diretivas antecipadas de vontade: um modelo brasileiro. Rev. bioét. (Impr.). [Internet]. 2013 [acesso 28 mar 2021];21(3):463-76. DOI: 10.1590/S1983-80422013000300011

Márcio José da Silva Moreira – PhD – marciomoreira@id.uff.br
0000-0003-0072-9507

Roberta Nascimento de Oliveira Lemos dos Santos – PhD – roberta_o_lemos@hotmail.com
0000-0001-9658-1185

Marisa Palacios – PhD – marisa.palacios@gmail.com
0000-0001-6507-4199

Correspondence
Marcio José da Silva Moreira – Rua Noronha Torrezão, 407, bloco 12, apt. 601 CEP 24240-181. Niterói/RJ, Brazil.

Authors' participation
Márcio José da Silva Moreira and Roberta Nascimento de Oliveira Lemos dos Santos contributed equally to writing the article. Marisa Palacios advised the project and carried out a critical review of the final version.

Received: 10.9.2020
Revised: 3.25.2021
Approved: 4.6.2021

Research