

# Bioethics and speech-language therapy in palliative care: an integrative review

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## Abstract

Speech-language therapists are part of the multidisciplinary palliative and end-of-life care team, playing a fundamental role in swallowing and communication demands. When dealing with the well-being and quality of life of patients with serious and incurable diseases, these professionals may face dilemmas and conflicting issues, given that the techniques suggested and the choices of the patient and their family may be divergent. The objective of this study is to identify, from the literature, whether speech-language therapists who work in this area consider bioethical principles in their treatment decisions. The databases used were SciELO, PubMed, and the Virtual Health Library. It was found that speech-language therapists consider and use bioethical principles in their professional practice in palliative and end-of-life care. The number of articles found on the speech-language therapists' work in this area is small, indicating the need for further studies on the subject.

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

## Resumo

### Bioética e fonoaudiologia em cuidados paliativos: revisão integrativa

O fonoaudiólogo está inserido na equipe multidisciplinar de cuidados paliativos e de fim de vida, exercendo papel fundamental nas demandas de deglutição e comunicação. Ao lidar com o bem-estar e a qualidade de vida de pacientes com doença grave e incurável, pode enfrentar dilemas e questões conflitantes, pois as técnicas indicadas pelo profissional e a escolha do paciente e de seus familiares podem ser divergentes. O objetivo deste estudo é identificar, por meio da literatura, se o fonoaudiólogo que atua nessa área considera os princípios bioéticos em suas decisões de tratamento. As bases de dados utilizadas foram SciELO, PubMed e Biblioteca Virtual em Saúde. Constatou-se que o fonoaudiólogo considera e utiliza os princípios bioéticos em sua atuação profissional em cuidados paliativos e de fim de vida. O número de artigos encontrados sobre atuação do fonoaudiólogo nessa área é reduzido, indicando a necessidade de mais estudos sobre o assunto.

**Palavras-chave:** Bioética. Cuidados paliativos. Fonoaudiologia. Transtornos de deglutição.

## Resumen

### Bioética y fonoaudiología en cuidados paliativos: revisión integradora

El fonoaudiólogo forma parte del equipo multidisciplinario de cuidados paliativos y de final de la vida, desempeñando un papel fundamental en las demandas de deglución y comunicación. Al ocuparse del bienestar y de la calidad de vida de pacientes con una enfermedad grave e incurable, puede enfrentar dilemas y cuestiones conflictivas, ya que las técnicas recomendadas por el profesional y la decisión del paciente y su familia pueden ser divergentes. El objetivo de este estudio es identificar, por medio de la literatura, si el fonoaudiólogo que actúa en este ámbito tiene en cuenta principios bioéticos en sus decisiones de tratamiento. Se utilizaron las bases de datos SciELO, PubMed y Biblioteca Virtual en Salud. Se constató que el fonoaudiólogo considera y utiliza principios bioéticos en su actuación profesional en cuidados paliativos y de final de la vida. El número de artículos encontrados sobre la actuación del fonoaudiólogo en este ámbito es reducido, lo que indica la necesidad de más estudios sobre el tema.

**Palabras clave:** Bioética. Cuidados paliativos. Fonoaudiología. Trastornos de deglución.

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Dilemmas and conflicting issues may arise in the work of health professionals who deal with the well-being and quality of life of patients with serious and incurable diseases, given that the techniques indicated by the professional and the choices of the patient and their family may be divergent. This situation is commonly observed in patients undergoing palliative care and at the end of life, a field in which the speech-language therapist is an active and important member within the multidisciplinary team<sup>1</sup>.

According to the *Universal Declaration on Bioethics and Human Rights* (UDBHR), of the United Nations Educational, Scientific and Cultural Organization (UNESCO)<sup>2</sup>, decision-making on bioethical issues should be handled professionally. This means that transparency and honesty in conduct are necessary, and that scientific knowledge and accessible resources have to be made available to the patient. Nevertheless, the parties involved, that is, professionals, patients, and family members, must dialogue and debate about decisions or practices adopted, and it is necessary to respect all relevant opinions.

According to recent research<sup>3</sup>, the emergence of bioethics dates back to 1927, with the publication of an article by German theologian Fritz Jahr, in which the definition of bioethics encompasses all living beings, and not just human ones. The most referenced author worldwide, however, is Van Rensselaer Potter, a biochemist and researcher at the University of Wisconsin, who in 1970 recognized that biological facts may be linked to ethical values. For Potter, bioethics is the wisdom of using knowledge to promote the survival and quality of life of humans and the entire ecosystem.

Lima and Manchola-Castillo<sup>4</sup> state that “bioethics” is a recent term, first appearing in the second half of the 20th century, which emerged due to the sociocultural factor and the great scientific and biotechnological development in the period. The field was defined as a systematic study on the moral dimensions of the life and health sciences and uses a variety of ethical methodologies in an interdisciplinary environment.

Among the various theoretical models of bioethics, this study will emphasize principlism, a model developed by philosophers Tom Beauchamp and James Childress that establishes four basic principles, where two are deontological

(non-maleficence and justice) and two are teleological (beneficence and autonomy)<sup>5</sup>.

For Beauchamp and Childress, an autonomous individual is one who: 1) acts freely, according to a plan intentionally chosen by themselves; 2) does not have limitations that lead to inadequate understanding for their conscious choice, and 3) does not suffer any type of undue interference from third parties in their freedom.

The principle of non-maleficence represents the obligation to actively avoid causing harm and involves acts of abstention. According to these authors, the principle of non-maleficence encompasses more specific moral rules, such as: 1) not to kill; 2) not to cause pain or suffering; 3) not to cause incapacitation; 4) not to cause offense, and 5) not to deprive or impede the enjoyment of life.

The term “beneficence,” in turn, translates acts of gratitude, kindness and charity, in addition to including altruism, love, and humanity. From this perspective, beneficence represents the action performed for the benefit of others and originates from the character trait called “benevolence.”

Finally, the principle of justice is related to what is due to people, with that which, in some way, belongs or corresponds to them. Generally, acting justly means acting in accordance with one’s merits, in an equitable and appropriate manner<sup>3</sup>.

Palliative care emerged in the United Kingdom in the 1960s, where it initially sought to provide patients with a comfortable and safe environment when they received a diagnosis of a serious illness with no possibility of cure<sup>6</sup>. According to the World Health Organization (WHO)<sup>7</sup>, palliative care aims to promote the quality of life of patients facing life-threatening illnesses, as well as that of their families. To this end, preventive care and relief of suffering are necessary through early identification, assessment, and appropriate treatment of pain and other physical, psychosocial, and spiritual problems.

End-of-life care is part of palliative care and refers to the assistance that a patient should receive when approaching death. Therefore, in this case, the proposal for palliative care is essentially ethical<sup>8</sup>.

The speech-language therapist is part of the palliative care team and plays a fundamental

role in swallowing and communication demands, situations in which autonomy is reduced and patient quality of life is affected. In addition to managing dysphagia and training adapted communication, the speech-language therapist have to work with family members and the entire support network, especially when consent is required for procedures<sup>1,9,10</sup>.

In view of this demand, the Federal Council of Speech-Language Therapy, a regulatory and supervisory body, issued Opinion 42/2016. The document defines the role of the interdisciplinary team in palliative care, with the objectives of *minimizing suffering and optimizing the quality of life, well-being and safety of the patient in palliative care, including extensive assistance to their family members and caregivers*<sup>11</sup>.

Opinion 42/2016, in line with the definition by the WHO and the Committee on Speech-Language Therapy and Voice Department of the Brazilian Society of Speech-Language Therapy, establishes that the speech-language therapist is an essential member of the interdisciplinary team and can contribute to issues related to feeding and communication<sup>1</sup>.

This study sought to identify, through a review of the scientific literature, whether the speech-language therapist who works in palliative and end-of-life care considers bioethical principles in their treatment decisions.

## Method

This is an integrative review that uses evidence-based practice (EBP) to group and synthesize research on a topic or issue. For this purpose, it followed the six steps proposed by Mendes, Silveira and Galvão<sup>12</sup>: 1) identification of the topic and selection of the hypothesis or research question for the preparation of the integrative review; 2) establishment of criteria for inclusion and exclusion of studies, sampling and literature search; 3) definition of the information to be extracted and categorization of the selected studies; 4) evaluation of the studies included in the integrative review; 5) interpretation of the results, and 6) presentation of the review and synthesis of knowledge.

To identify the components of the research question and its formulation, the method

defined by the acronym PICO<sup>13</sup> was used (in which P=population, I=intervention, C=control, and O=outcome). Thus, the parameters that structured the research were: P=speech-language therapists who work in palliative and end-of-life care; I=bioethical principles; C=not applicable; O=speech-language therapists consider bioethical principles in treatment decisions. The guiding question of the research was “Do speech-language therapists who work in palliative and end-of-life care consider bioethical principles in their treatment decisions?”.

The following descriptors were used, in isolation and/or in combination, to refine the results: bioethics, palliative care, speech-language therapy, and dysphagia. In combination, one used bioethics and palliative care, bioethics and speech-language therapy, bioethics and dysphagia, and speech-language therapy and palliative care. All terms used are available in the Health Sciences Descriptors (DeCS) portal, except for the free term teaching, which was combined with bioethics to compose the discussion.

The bibliographic survey was carried out on the Virtual Health Library (VHL), Scientific Electronic Library Online (SciELO), and PubMed databases between March and July 2023. Complete free-access articles in Portuguese were included, and duplicate articles, theses, dissertations, monographs, articles with a publication date of more than 10 years, and those that did not answer the guiding question were excluded. At this stage, some articles were used to compose the introduction and discussion of this study.

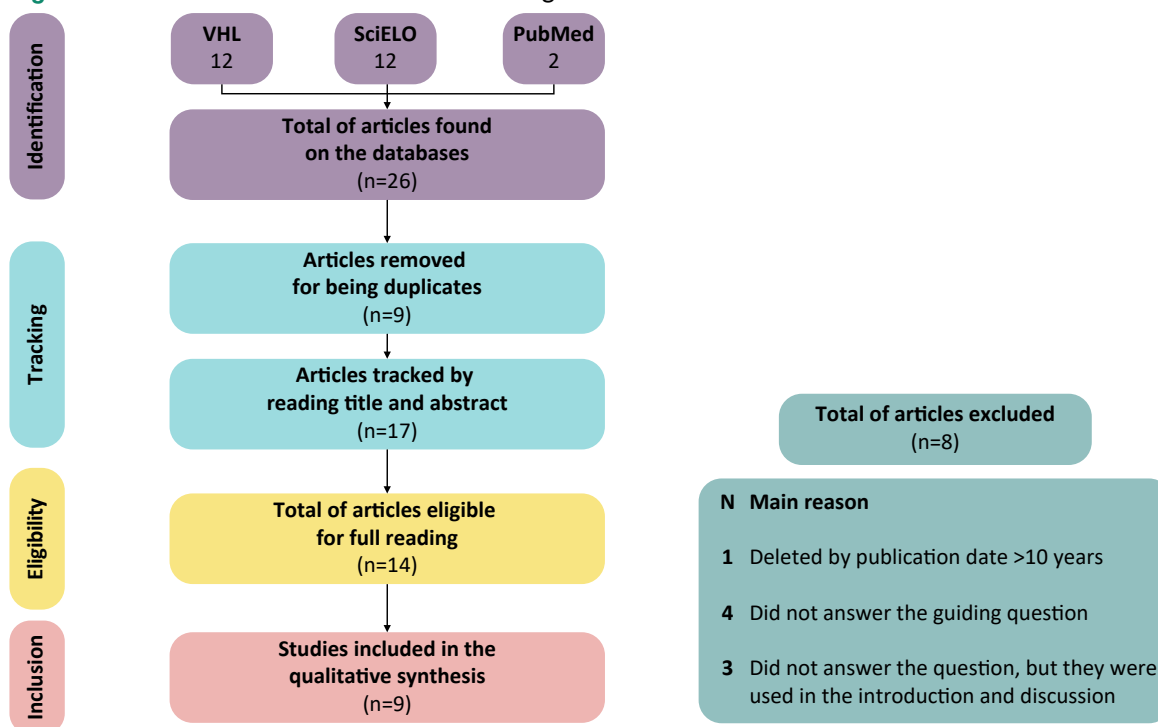
Of the 26 articles found, 12 were retrieved from the VHL database, 12 from SciELO, and two from PubMed. Nonetheless, nine were removed because they were duplicates, one because it was published more than 10 years ago, and seven because they did not answer the guiding question. Of these, three helped in the composition of this study: in the description of the skills of the speech-language therapist who works in palliative care<sup>10</sup>; to discuss the teaching of bioethics in speech-language therapy undergraduate courses<sup>14</sup>, and to contextualize the emergence of bioethics and describe its principles<sup>3</sup>. The representation of this process can be seen in the flowchart (Figure 1).

Two books were also used, one to assist in the review method<sup>13</sup> and the other to define

concepts related to bioethics<sup>5</sup>, as well as a letter to the editors of a journal of speech therapy systematic reviews<sup>1</sup>. Moreover, publications from organizations such as the WHO<sup>7</sup> and the Federal Council of Speech-Language Therapy<sup>11</sup> were consulted.

To analyze the contents of the nine publications that answered the study question, a table was created with the following items: authors, year of publication, title, method, objective, and bioethical principles considered in professional practice (Chart 1).

**Figure 1.** Article selection flowchart for the integrative review



**Chart 1.** Characterization of articles that answered the study question: year of publication, authors, title of articles, method, objective, and bioethical principles considered in professional practice

Authors; year	Title	Method	Objective	Bioethical principles
Lima, Manchola-Castillo; 2021 <sup>4</sup>	“Bioética, cuidados paliativos e libertação: contribuição ao ‘bem’”	Qualitative/ hermeneutic and reflective	To demonstrate that liberation can contribute to training professionals and patients who are more critical, committed and free, capable of facing a moment of such vulnerability as death.	Autonomy, beneficence, non-maleficence and justice.
Cecconello, Erbs, Geisler; 2022 <sup>6</sup>	“Condutas éticas e o cuidado ao paciente terminal”	Qualitative/ integrative review	To clarify the concepts of the end of life, addressing ethical conduct.	Autonomy, justice, beneficence and non-maleficence.

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Chart 1. Continuation

Authors; year	Title	Method	Objective	Bioethical principles
Barriguinha, Mourão, Martins; 2017 <sup>9</sup>	“Dificuldades de comunicação e deglutição em doentes em cuidados paliativos: visão dos doentes e familiares e/ou cuidadores informais”	Quantitative It analyzes the opinion of patients in palliative care and their family members and/or informal caregivers about the difficulties experienced in communication and swallowing.	To analyze the opinion of patients in palliative care and their family members and/or informal caregivers about the difficulties experienced in communication and swallowing.	Beneficence, non-maleficence, autonomy and justice.
Langaro, Schneider; 2022 <sup>15</sup>	“Aspectos existenciais e bioéticos nos cuidados paliativos oncológicos”	Qualitative/ exploratory descriptive	To analyze the phenomenological perspective, with a description of the axes of meaning produced in the narratives	Beneficence, non-maleficence, autonomy and justice.
Maingué and colaboradores; 2020 <sup>16</sup>	“Discussão bioética sobre o paciente em cuidados de fim de vida”	Quantitative/ descriptive	To identify factors that influence decision-making by health professionals when dealing with patients receiving end-of-life care in intensive care units	Autonomy, beneficence and non-maleficence.
Jacinto-Scudeiro, Ayres, Olchik; 2019 <sup>17</sup>	“Tomada de decisão: papel do fonoaudiólogo em cuidados paliativos”	Quantitative/ exploratory/ case study and case report	To correlate the clinical findings of dysarthria, dysphagia, and cognition with the health decision-making process in a patient with a confirmed molecular diagnosis of ataxia/telangiectasia in palliative care in the terminal phase.	Beneficence, autonomy and justice.
Luchesi, Silveira; 2018 <sup>18</sup>	“Cuidados paliativos, esclerose lateral amiotrófica e deglutição: estudo de caso”	Quantitative/ exploratory	To discuss aspects of speech-language therapy in dysphagia, focused on palliative care and quality of life in swallowing.	Autonomy, beneficence and non-maleficence.
Moreira, Santos, Palacios; 2021 <sup>19</sup>	“Fonoaudiologia conflitos decisórios e pacientes disfágicos: revisão integrativa”	Qualitative/ integrative review	To review the literature on speech therapy, conflicts in decision-making and agents involved in deliberations on the nutrition of this type of patient.	Autonomy, beneficence, non-maleficence and justice.
Pereira, Andrade, Theobald; 2022 <sup>20</sup>	“Cuidados paliativos: desafios para o ensino em saúde”	Qualitative/ integrative review	To analyze the production on palliative care and health professionals' training during undergraduate studies.	Autonomy, beneficence, non-maleficence and justice.

## Results and discussion

Of the nine studies selected, five are case studies<sup>9,15-18</sup>, three are literature reviews<sup>6,19,20</sup>,

and one is a reflective study<sup>4</sup>. It is important to note a few studies have been found when searching for articles on speech-language therapy in palliative and end-of-life care. Therefore, to compose this

review, articles that mention the multidisciplinary team in which the speech-language therapist may be inserted were considered.

Only five articles<sup>9,10,17-19</sup> mention speech-language therapy in palliative and end-of-life care, and one of them did not answer the research guiding question but described this professional's skills. Among those that answered the guiding question, only one explicitly named and described the four bioethical principles, citing their importance as a theoretical framework for treatment decisions and conduct.

In the other three articles<sup>9,17,18</sup>, the theoretical principles were not named as described by philosophers Tom Beauchamp and James Childress. However, the principles of autonomy, beneficence and justice were implicitly identified during the reading. In these articles, speech-language therapy practice considers joint decision-making, taking the patient's wishes into account, in addition to the constant concern for quality of life.

### **Speech-language therapy, palliative care, end of life and bioethics**

The role and contribution of speech-language therapy in palliative and end-of-life care is well defined within the multidisciplinary team, and its competence is to contribute to issues related to swallowing and communication<sup>1,9,10</sup>. According to Barriguinha, Mourão and Martins<sup>9</sup> and Silva and collaborators<sup>10</sup>, patients in palliative care have swallowing, voice and communication difficulties, and swallowing difficulties are more frequently reported than communication difficulties<sup>9</sup>.

The speech-language therapist assesses the risk of bronchoaspiration, and prevents and rehabilitates swallowing disorders, in a safe and pleasant way for the patient. The suspension, indication of an alternative feeding route, and release of nutrition by mouth are also assessed by the speech-language therapist. At this time, disagreements between professionals, family and patient may occur and the conduct should be discussed among those involved to avoid conflicts, therefore the deliberation should be shared.

The principle of autonomy, which presupposes that the patient is capable of making choices and expressing their will have to be respected. The principles of beneficence (always doing good),

non-maleficence (never doing harm) and justice (equitable distribution and weighing up of risks and benefits) are considered in the decisions made by team professionals, and reinforce the need for dialogue and sharing in deliberations<sup>19</sup>.

Luchesi and Silveira<sup>18</sup> used the quality of life questionnaire in patients with dysphagia, showing concern with this issue in speech-language therapy practice. Such study considered the bioethical principles of autonomy and beneficence, as it reported that, even though there is evidence that a given type of food is the most suitable for swallowing by patients in palliative care, it is suggested that the conduct take the individual's wishes into account.

The authors also emphasize that oral feeding is pleasurable and maintains the individual's quality of life, since food represents socialization, motivation to live with the disease, and demonstration of love, affection, and happiness<sup>18</sup>. Therefore, to promote quality of life in palliative care, the speech-language therapist must know the patient's desires regarding their diet and how significant this is to them, giving them autonomy and providing positive assistance throughout the progression of the disease<sup>19</sup>.

Regarding difficulties in human communication, the speech-language therapist has to develop communication strategies that facilitate the relationship between family, caregivers, and the multidisciplinary team. They offer the patient the opportunity to have autonomy in their decisions, promote quality of life, and maintain social relationships<sup>9</sup>. They also consider other bioethical principles: beneficence, non-maleficence, and justice.

According to Jacinto-Scudeiro, Ayres and Olchik<sup>17</sup>, from diagnosis to end-of-life procedures, the shared decision of the speech-language therapist with the multidisciplinary team and family, to prioritize the patient's wishes, minimizes suffering and asserts the right to autonomy.

Therefore, this professional's role in the palliative and end-of-life care team involves everything from technical management to management of the team, caregivers, and patient. Their role should aim at the patient's comfort and quality of life, in addition to respecting the ethical principles of all those involved in the process.

### **Healthcare professionals, palliative care, end-of-life care and bioethics**

The other articles that are part of this review<sup>4,6,15,16</sup> mention the health professionals' performance in general. In these studies, bioethical principles are also considered and named according to Beauchamp and Childress.

A study<sup>16</sup> identified the factors that influence the decision-making of health professionals when faced with patients undergoing end-of-life care and concluded that there is concern about respecting the principle of autonomy, both of the patient and of their family members. However, it was observed that there is therapeutic obstinacy in fulfilling the professional duty. Thus, only 14% of patients indicated for palliative care are provided with it.

Furthermore, a number of hospitals have inadequate assistance in the palliative and end-of-life care sector, so that the multidisciplinary team is often incomplete, without a speech-language therapist. In this way, the principle of justice is not being followed<sup>16</sup>.

In a reflection on dying and the contributions of bioethics<sup>4</sup>, the principle of autonomy is mentioned again, but they defend a new category called "liberation." This term, defined by Paulo Freire, is used to convey the notion that, even amid vulnerability, the patients need to know that they can control their lives.

Besides, liberation should be extended to professional training, so that both teaching and learning with the patient can build knowledge. The principles of beneficence and non-maleficence are also elucidated when they state that a "good death" is anchored in the quality of life promoted by palliative care<sup>4</sup>. Finally, the principle of justice is considered when mentioning the role of the State in guaranteeing citizens' rights to this type of care.

When analyzing 23 scientific publications on terminal illness and palliative care, Ceconello, Erbs and Geisler<sup>6</sup> discuss the therapeutic approach to the patient. They sought to demonstrate that the characteristics of terminal illness can help and establish an adequate prognosis, with assistance based on bioethical principles.

They also addressed the extreme importance of palliative care for the population, in order to improve the quality of life, offering comfort and relief from physical and psychosocial suffering.

For the authors, the multidisciplinary team plays an essential role in this care and have to be aligned in the conduct and development of a unique therapeutic plan, using simple and frank communication, followed by active listening<sup>6</sup>. Respect for biopsychosocial and spiritual aspects is also mentioned, as these must be considered to guarantee the right to justice and autonomy, even in the process of illness and death<sup>6,15</sup>.

In all studies analyzed in this review, health professionals, including speech-language therapists, base their interventions on autonomy, justice, beneficence and non-maleficence when faced with ethical dilemmas and conflicts in their work. On the other hand, in two studies on speech-language therapy, the authors did not mention the theoretical concepts of principlism to reinforce and protect their decisions. This observation may demonstrate little connection between the theory of bioethics and speech-language therapy practice.

### **Teaching in health and bioethics**

Health teaching, a topic highlighted by Pereira, Andrade and Theobald<sup>20</sup>, addressed the importance of bioethics in health professionals' training. The authors mentioned the theoretical, practical, and psychological unpreparedness of these professionals to work in palliative and end-of-life care. This statement corroborates the findings of Maingué and collaborators<sup>16</sup>, who found that 86.7% of professionals working in palliative care do not have training in the area.

Regarding the bioethics teaching in the curricula of speech-language therapy courses, a study that analyzed the academic profile of teachers who teach ethics and bioethics in Rio Grande do Sul<sup>14</sup> found that one institution did not offer such subject, contrary to what is established by the National Curricular Guidelines for undergraduate speech-language therapy courses and the National Education Plan.

The study highlighted that the professors' training in this subject is heterogeneous, not always in speech-language therapy, and questioned whether professors from other areas would be prepared and know how to deal with practical cases and, in contrast, whether speech-language therapists would have the theoretical resources to teach ethics and bioethics. In addition, the study

on ethics is often limited to deontology and the presentation of professional codes of conduct containing rights, duties, and infractions<sup>14</sup>.

## Final considerations

Despite the small number of articles found and analyzed in this review, results show that speech-language therapists consider and use bioethical principles in their professional practice in palliative

and end-of-life care. However, although the principles are considered, only one article mentioned the theoretical basis of bioethics to support decision-making. Given this scenario, the question is: do speech-language therapists recognize and value the subject of bioethics in their academic training?

The expectation is, therefore, that this question will give rise to new research, considering the need for more studies on speech-language therapy practice in palliative and end-of-life care.


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#### Participation of the authors

Milene Valente Lopes conceived the study and carried out the general critical review of the paper. Anna Julia Cantuária França carried out the bibliographic survey, prepared the flowchart and the article table. Both authors wrote the paper.

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