

Carta aos Editores
Letter to the editorMárcio José da Silva Moreira^{1,2,3} Michelle Ferreira Guimarães^{1,2,4} Leonardo Lopes^{1,5} Felipe Moreti^{1,6,7} Contributions of Speech-Language
Pathology in Palliative and
End-of-Life Care*Contribuições da Fonoaudiologia nos
cuidados paliativos e no fim da vida*

Dear Chief Editor of CoDAS Journal,

Palliative Care should be seen as a public policy and integrate the health system at all levels of complexity. This policy must include the performance of an interdisciplinary team that enables comprehensive and integrated care, humanized and with technical quality. The palliative care professional must understand the patient and his/her family as the center that generates decisions, providing them with dignity and respect, helping them to cope with the disease and accept death as a natural stage of life.

The speech therapist has become an active and important member of this team. Considering the reality in the performance in Phononcology, it was noticed the need for the positioning of the Phononcology Committee and the Voice Department of *Sociedade Brasileira de Fonoaudiologia* in relation to the performance of the speech-language pathologist in this team and care for patients at the end of life.

According to the World Health Organization (WHO) (2004)⁽¹⁾, palliative care prioritizes the quality of life of individuals affected by a serious and incurable disease, also including support for family members and the care network. The management of this patient must be based on symptom control and pain management, if it is physical, psychological, social and/or spiritual⁽¹⁾.

Another concept that needs to be clarified is what defines end-of-life care. This type of care is part of palliative care and must be applied when the patient has a decrease in quality of life, in other words, when someone sees the increasingly close finitude.

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An ethical assessment is carried out based on autonomy, the safeguarding of human integrity, respect for the end-of-life patient's beliefs and desires⁽²⁾.

The Federal Council of Speech-Language Pathology issued report No. 42/2016, which defines the role of the interdisciplinary team in palliative care, with the objectives of: [1] minimizing suffering and [2] optimizing the quality of life, well-being and safety of the patient in palliative care, including here extensive assistance to family members and caregivers. This document is in line with the WHO definition. The speech-language pathologist participates in this team and can contribute to issues related to food and communication. It is up to the speech-language pathologist to evaluate and indicate strategies to overcome the negative impacts related to dysphagia and inefficient communication⁽³⁾. Although the Tripartite/MS Commission (2018)⁽⁴⁾ has published Resolution No. 41, which includes palliative care in the provision of long-term care, this document does not directly mention the participation of the speech-language pathologist it only states the need for a multidisciplinary team to the management of this type of patient.

Inserted in this context, the speech-language pathologist must participate in shared decision-making in the demands that involve swallowing and communication. Swallowing changes impact the patient's Quality of Life (QoL) and, when associated with impaired communication, reduce the individual's autonomy. Thus, the performance of the speech-language pathologist is of paramount importance, as it helps in the management of the patient in palliative care and enables comfort and possibilities for the patient to make his/her choices and express his/her wishes in the outcome of his/her life⁽⁵⁾.

The patient's desire to eat must be taken into consideration and the role that food plays in his/her daily life, aiming at pleasure and quality of life, especially when there is the presence of a progressive and incurable disease⁽⁶⁾.

The decision-making process is participatory and deliberative and involves dilemmas such as refusal of treatment, choice or refusal of a certain procedure, desire by the care team, family beliefs and the clinical reality of the patient⁽⁷⁾. Considerations regarding the release or suspension of the diet orally and the indication for the use of an alternative feeding route should consider the patient's clinical history, physical conditions, laboratory tests and the presence of the lower airway protection mechanism in the palliative patient. In some cases, the patient or the family member may leave the recorded decision not to use the alternative route of feeding in advance directives of will and this must be respected⁽⁸⁾.

The advance directives of the will or informed consent have indication and function to safeguard the patient's autonomy and desire in relation to the acceptance or refusal of certain treatment procedures and devices and, if the patient has not left his/her wish expressed in any way, this responsibility must be passed on to a close relative or a decision maker must be determined to assert that individual's autonomy in the decision-making process⁽⁹⁾.

In the conventional model of care, the work of the speech-language pathologist consists predominantly of reducing risks related to dysphagia, which involve lung health, dehydration and

malnutrition of the patient. In speech-language pathology with patients in palliative care or at the end of life, the suspension of the diet by oral route and the indication of the alternative route can be refused by the patient and it is up to the speech-language pathologist to optimize oral feeding safely and minimize the risks of food bronchoaspiration into the lower airway, activating existing or adapted functional protective mechanisms⁽¹⁰⁾.

In this context of action, the speech-language pathologist must contribute to the performance of objective examinations for the management of dysphagia, continuing education for family members and for the support network, indication of compensatory strategies for safe swallowing, management of the risk of bronchoaspirations, modification and adaptation of food volumes and consistencies⁽¹¹⁾. Adapted communication training must be available to the patient and the support network, in view of the effectiveness and clarity in the transmission of the message to the patient, and between him/her and his/her interlocutors, especially when the objective is to obtain consent for some procedure⁽¹¹⁾.

Dysphagia management must prioritize the analysis of the risks and benefits of food and liquids intake, respecting the patient's dietary preferences, culture, social identity and religion. Therefore, it is mandatory to use this individual's autonomy or to use mechanisms to help in shared decision-making between the patient or the decision maker, the care team and the support network. The shared decision must be based on assertive communication, with a focus on managing the patient's wishes and desires, with the active participation of all⁽¹²⁾.

When it comes to the patient's desire, the individual may decide not to eat and not to drink fluids voluntarily based on some type of discomfort associated with such ingestion, in the absence of associated psychological distress. Although this patient's desire can be interpreted as an abbreviation of life or acceleration of death, it must be understood that this choice may be related to the individual's objective of not getting nausea, abdominal distension, motion sickness, among other discomforts. At this point, a medical and psychological evaluation can help to identify more precisely the objective of these patients: whether they really want to have an outcome for death more quickly or not⁽¹³⁻¹⁴⁾.

Therefore, the role of the speech-language pathologist in the palliative care team and in the management of end-of-life patients involves fundamental aspects of the human condition, communication and food, which reinforces the importance of their participation. Professional performance is based on evaluating the feasibility of procedures grounded in scientific evidence and professional ethics that meet the patients' speech-language pathology demands. These demands are related to communication, which guarantees the patient's autonomy and swallowing, especially when these patients have dysphagia and an increased risk of massive bronchospasm. Decision-making must be shared and deliberative, with the objective of maintaining the patient's quality of life and comfort in palliative care or at the end of life.

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Authors contributions

MJSM, MFG, LL and FM idealized the need for this letter to the editor, wrote the manuscript and revised the final version.