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Original Article

Speech-Language Pathology in Palliative Care for Adults and Older Adults: Foundations, Roles, Approaches, and Challenges

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ABSTRACT

Chile's population is aging rapidly, which means a growing number of people is living with chronic illnesses that limit the way they live their life, a situation that requires the presence of palliative care teams. The inclusion of speech-language pathologists in palliative care is recent in most countries, even more so in ours. Consequently, there is a limited number of local guidelines to facilitate the participation of these professionals from a model centered on the care, well-being, and companionship for the person, their family, and/or significant others. Considering this, the objective of this narrative review is to delve into the foundations that support the inclusion of speech-language pathologists in palliative care teams. For this purpose, the scope of practice, roles, and responsibilities of Speech-Language Pathology are described. The information available in this regard shows two major fields of action linked to communication and swallowing, both of which must be addressed in order to promote the participation and autonomy of the person when making decisions about their care, as well as respect for their advance directives, when necessary. Under this paradigm, findings are clear in stating that the speech-language pathologist should move away from the traditional rehabilitation model, and migrate towards a group of actions that allow them to address -in the best possible way- conditions that generate suffering, pain, or discomfort to the person. This review addresses said actions with sufficient detail to allow proposing six major challenges for professionals who work (or want to work) in the area.

Keywords:
Speech-Language Pathology; Palliative Care; End-of-life Care; Communication; Feeding Behavior; Swallowing

Fonoaudiología en cuidados paliativos para adultos y adultos mayores: fundamentos, roles, abordajes y desafíos

RESUMEN

La población chilena envejece rápidamente, lo cual se traduce en un incremento en el número de personas que vive con alguna enfermedad crónica que limita su vida, condición que requiere frecuentemente de equipos especializados en cuidados paliativos. En ellos, la inclusión del/la fonoaudiólogo/a a nivel internacional es reciente, aún más en nuestro país. Por lo anterior, son escasas las orientaciones locales que faciliten la activa participación de este profesional bajo un modelo centrado en el cuidado, bienestar y acompañamiento de la persona, su familia y/o personas significativas. En este contexto, es objetivo de esta revisión narrativa el profundizar sobre los fundamentos que soportan la inclusión del/a fonoaudiólogo/a en equipos de cuidados paliativos. Para lo anterior se describen las áreas de acción fonoaudiológica, sus roles y responsabilidades. Al respecto, la información disponible da cuenta de dos grandes campos de acción, vinculados a la comunicación y alimentación, los que deben ser abordados con el propósito de fomentar la participación y autonomía de la persona en la toma de decisiones sobre sus cuidados y el respeto de sus voluntades anticipadas, cuando sea necesario. Bajo este paradigma, los hallazgos son claros en plantear que el/la fonoaudiólogo/a debe alejarse del modelo rehabilitador tradicional, para migrar hacia un grupo de acciones que le permitan abordar –de la mejor manera posible– aquellas condiciones que generan sufrimiento, dolor o molestia a la persona. Dichas acciones son abordadas en esta revisión, con el detalle suficiente para permitir enunciar y proponer seis grandes desafíos para aquello/as profesionales que se desempeñan (o desean hacerlo) en el área.

Palabras clave:
Fonoaudiología; Cuidados paliativos; Cuidados de fin de vida; Comunicación; Alimentación; Deglución

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INTRODUCTION

The aging of the population, defined as an increase in the proportion of people over 60 years old, is currently a worldly phenomenon (Albala, 2020). This situation is associated with a growing number of chronic illnesses, namely: dementia, chronic obstructive pulmonary disease, cerebrovascular disease, cancer, among others (Prince et al., 2015). In Chile, the absolute number of older adults has increased 6.8 times between 1960 and 2017, representing 16.2% of the population this year, and with a projection for 2031 of 102 older adults for every 100 people younger than 15 (Albala, 2020; *Instituto Nacional de Estadísticas* [Statistics National Institute, INE], 2018). These sociodemographic changes happen within a context where improvements in treatments increase the number of people living with health conditions that limit the way they live their lives. This creates a need for the presence of professional teams that specialize in palliative care (Kelly et al., 2016).

Palliative care is defined as the assistance provided by a healthcare team to improve the quality of life of a person, their family, and/or significant others, who are facing problems typical of a life-threatening health condition. This type of assistance includes early identification, evaluation, and prescription of adequate management of the symptoms and complications - physical, psychosocial, or spiritual - secondary to the disease, from the time of diagnosis until the end of life, and also during the course of grief (*Ministerio de Sanidad, Política Social e Igualdad* [Spanish Ministry of Health, Social Policy, and Equality], 2014; National Institute for Clinical Excellence [NICE], 2004; World Health Organization [WHO], 2020). Although this type of care is usually associated with symptom relief for dying people, it can also be chosen by those who have serious, debilitating, or painful illnesses, either due to the disease itself or to the effects of the treatment (Pollens, 2012). In this context, palliative care must be introduced gradually as the illness progresses, according to the needs of the client, their family, and significant others, and not necessarily only at the end of life (*Ministerio de Sanidad, Política Social e Igualdad*, 2014; WHO, 2020).

On the other hand, the term “end-of-life care” is also commonly used, especially when referring to the service provided during the last weeks of life. However, its use is not necessarily limited to a previously established and specific frame of time. The current consensus sets its use for care -which is part of palliative care- provided when symptoms are a result of an irreversible and terminal illness that shortens a person’s life expectancy (Moreira et al., 2020; National Institute for Clinical Excellence [NICE], 2004; Pollens, 2012). Thus, end-of-life care obliges the healthcare team to reconsider their therapeutic objectives, personalizing therapeutic decisions and always respecting the wishes and decisions of the individual, whilst suspending all treatments that are not aimed at providing relief (Aguirre Bravo & Sampallo Pedroza, 2015).

Although the definitions described above help to operationalize both types of care, it is important to emphasize that these should not be reduced to a series of procedures or one type of therapeutic approach. On the contrary, palliative and end of life care should be considered a public policy that includes the whole healthcare system - and each of its levels of complexity -, considering the work of an interdisciplinary team that delivers comprehensive, holistic, humanized, and high-quality care (Moreira et al., 2020). Thus, the members of these teams should understand and empathize with the needs of the person in palliative care, their family and/or loved ones, supporting the decision-making process towards the end of life, and providing them with dignity, respect, and constant assistance when facing the illness and accepting death as a natural stage of life (Moreira et al., 2020). This professional support should be guided by the ethical principle of autonomy, protecting both the human integrity and respect for beliefs and wishes of the person in palliative care regarding the end of their life (Burlá & Py, 2014; Moreira et al., 2020).

In this context, it is known that people who are at the end of their life have significant changes in their communication and feeding, and this can be found even in those who present health issues that are not associated with these types of disorders (Kelly et al., 2016). This has led to the inclusion of speech-language pathologists (SLPs) in healthcare teams that offer palliative care (Aguirre Bravo & Sampallo Pedroza, 2015; Kelly et al., 2016; Prelock et al., 2017), which requires these professionals to develop new skills and subsequently changing the focus of their interventions, migrating from a rehabilitation approach towards one centered on prevention and symptom relief (Kelly et al., 2016). Thus, the traditional role of the SLP is questioned and revised in the context of an interdisciplinary palliative care team, requiring it to be consistent with the information available in the literature and the particularities of the healthcare system of each country. Considering the above, the objectives of this review are (1) to characterize the role of SLPs in palliative care, documenting the foundations of their activity, (2) to synthesize the evidence of the work of SLPs in palliative care teams, as suggestions for the management of swallowing and communication, and (3) to establish the challenges that arise for SLPs in this field.

SEARCH STRATEGY

In order to reach the objectives, a review was carried out of the literature centered on adult palliative care. The technique described by Arksey & O'Malley (2005) for a scoping review was used, considering the databases PubMed, Scopus, and Scielo. The search words were "palliative care" and "end of life". These were combined separately using the Boolean operator "AND", and truncated terms "speech therap*" and "speech patholog*". Articles published before 1998, lacking an available abstract, or based on conference presentations were excluded. Additionally, a comprehensive review of gray literature was carried out, thus including documents related to the topic that have been published by official health agencies (for example the National Institute for Health and Care Excellence [NICE] in the United Kingdom).

The most relevant results are presented below, which allow answering to the objective of this review. Firstly, the general aspects that frame the professional action of SLPs in palliative care are established. Secondly, the information available in the literature concerning the role of the SLP in this area is synthesized. Subsequently, a series of suggestions based on current evidence is provided for the management of communication and swallowing in palliative care. Lastly, following a pragmatic analysis of the information reviewed, a series of challenges that emerge from the insertion of SLPs in palliative care is proposed, considering the current characteristics of the Chilean healthcare system.

CONTEXT OF PROFESSIONAL ACTION

SLPs who work in palliative care must develop skills that allow them to satisfactorily fulfill new roles, interweaving their services and knowledge with those of other members of the healthcare team, in line with the needs of the person approaching the end of their life, their family, and/or significant others (Pollens, 2012). In this regard, and consistent with the evidence available to this date, it is possible to assert that the professional exercise of the SLP has to be framed by a series of conditions that are characteristic of this type of healthcare. For the purpose of this review, we will address those that allow establishing the general context in which professionals of communication and oral feeding participate and collaborate, namely (a) values and principles and (b) composition of the healthcare team.

Values and Principles in Palliative Care

Concerning the complexity of the healthcare team's decision-making process in palliative care (including end-of-life care), the literature describes a series of guidelines that every health professional - including SLPs - should follow, ensuring strict compliance. Regarding this, and according to *Ministerio de Sanidad, Política Social e Igualdad* (2014), the values that guide respectful treatment for people in palliative care and their loved ones, as well as the principles that frame the healthcare team's actions, are synthesized below (see Table 1).

Table 1. Values and Principles in Palliative Care, developed based on the document "*Estrategias en Cuidados Paliativos del Sistema Nacional de Salud*" [Strategies for Palliative Care in the National Healthcare System] (*Ministerio de Sanidad, Política Social e Igualdad* [Spanish Ministry of Health, Social Policy, and Equality], 2014).

Values	Every person has the right to receive relief from suffering.
	Each person should be valued as an individual, unique and autonomous.
	Each person can have their own definition of quality of life.
	The expectations that the person, their family, and/or significant others have of the healthcare system to satisfy their end-of-life needs should always be considered.
	Solidarity in the face of suffering is an essential attitude.
Principles	The support provided to the person, their family, and/or significant others should be based on their particular needs.
	The healthcare system should safeguard comprehensive, accessible, and equitable care.
	The different levels of care should ensure a degree of coordination that allows continuity of care.
	Communication should always be open and honest.
	The decision-making process should always be based on an ethical reflection, and include the participation of the person, their family, and/or significant others.
	Health professionals must have the necessary skills to properly respond to the needs of people and their families, making sure they have continuous professional development.
	The work of the palliative care team should be at the least based on an interdisciplinary model.
	Therapeutic action should be based on the strongest evidence available.
	There should be no discrimination in the delivery of services.

Composition of the Palliative Care Team

Regarding its composition, until not many years ago palliative care teams were limited to small groups of professionals, composed mainly of doctors and nurses. However, a gradual change has been observed, showing the progressive incorporation of other professionals such as physical and occupational therapists, psychologists, pharmacists, social workers, and speech therapists. The evidence shows that these changes benefit the delivery of palliative care services (Pollens, 2012). This has occurred under current recommendations to follow the biopsychosocial model as a framework for action, positioning the person in palliative care, their family, and/or significant others as core members of the team, thus favoring their active participation in decision-making.

It is in this context that SLPs are included in palliative care, having the role to promote - together with the rest of the healthcare team and following the biopsychosocial model- an interdisciplinary work format, at the same time fulfilling several roles that the current literature shows as part of their responsibilities. These roles are presented below.

ROLES OF THE SPEECH-LANGUAGE PATHOLOGIST IN PALLIATIVE CARE

At the international level, the first instances in which SLPs were included in palliative care teams resulted from their participation in the management of patients with cancer (Eckman & Roe, 2005). Since then, their incorporation into teams that provide palliative care for people with non-oncological diseases has continued to develop. This process has been accompanied by a change in the perception that people in palliative care, families, and other health professionals have regarding the need for professionals who provide support for the communicative and feeding difficulties experienced by the person in palliative care. Currently, the work of the SLP is recognized in many documents and international clinical guidelines (Eckman & Roe, 2005; NICE, 2004; Prelock et al., 2017; Royal College of Physicians and British Society of Gastroenterology, 2010). However, the value of SLPs specialized in palliative care is still not fully recognized by general speech therapists, mainly due to the limited knowledge that they have about the particularities of the speech therapy work within palliative care teams (Kelly et al., 2016; Toner & Shadden, 2012; Vescovich, 2015).

Added to the above, one of the main limitations in Chile is there is little research on the practice and challenges SLPs face in palliative care, a situation that may hinder their inclusion in this field. Furthermore, there is a lack of specific protocols to guide the action of these professionals in our country.

Considering the foregoing, it is advisable to rescue the aspects that have proven to be relevant for SLPs in palliative care teams from countries with more experience in the area. In this regard, the study by Chahda et al. (2020) provides a detailed analysis of the central elements of the intervention of SLPs, establishing seven pivotal roles for their performance in palliative care (see Table 2).

Table 2. Roles of the Speech-Language Pathologist in Palliative Care, adapted by the authors from Chahda et al. (2020).

Type of Participation (role)	Definition
Intercession	To intercede for the person in palliative care, so they receive information concerning their swallowing and communicative status.
Identification	To identify the need of including speech therapy in the clinical management of the person receiving palliative care- or the need to change the approach -, which allows promoting comfort and respect for the preferences of the person, as opposed to objectives that focus strictly on rehabilitation.
Evaluation	To evaluate the swallowing, communication, and cognitive skills of the person in palliative care, with the purpose of monitoring changes throughout the palliative continuum.
Management	To develop – and modify - a management plan consistent with the changes that occur in the needs and skills of the person in palliative care, ensuring care centered on the person and their comfort.
Support	To provide support and act as an advocate so the individual receives care that respects their preferences in swallowing and communication, under the guide of an experienced SLP.
Advisory and Consultancy	To provide educational advice and emotional support to the person in palliative care and their family, helping them adapt to the swallowing and communicative changes associated with the illness and its progress.
Education	To educate the person in palliative care, their family, and/or significant others, empowering them to be actively involved in the management of their swallowing and communication. To educate the interdisciplinary team on swallowing and communication management, and when to refer the client to an SLP.

The positioning of the SLP in each of these roles necessarily requires modifying their intervention models, which would expand their field of action beyond the traditional interventions offered to the person, their family, and/or significant others in palliative care. In this regard, Holland & Nelson (2007) argue that the professional should assume the role of advisor or consultant to the interdisciplinary team, providing support and guidance for the proper management of communication and feeding disturbances. According to various authors, the foregoing reflects a need for the SLP to have the ability to adjust their evaluation and management procedures to the needs of the person in palliative care, their family, and/or significant others. This would facilitate their proper insertion in the palliative care team (Chahda et al., 2017; Kelly et al., 2016; Prelock et al., 2017).

In addition to what has been stated, the literature emphasizes that each of the roles must be performed flexibly, and always per the particularities of each clinical scenario, including hospitals, long-stay residential care, home hospitalization, among others (Toner & Shadden, 2012). In each of these contexts, the SLP is responsible for two major areas of professional practice: swallowing and communication (Chahda et al., 2017, 2020; Kelly et al., 2016; Pollens, 2012).

It is noteworthy that although the scientific production for both areas is still emerging, the findings described to date are sufficient to provide a series of suggestions to ensure adequate speech therapy management in palliative care. These suggestions are exposed below.

SUGGESTIONS FOR THE MANAGEMENT OF SWALLOWING AND FEEDING IN PALLIATIVE CARE

Swallowing is a skill prioritized in the care of every person, constituting a base for functions that are fundamental for human beings, such as hydration, nutrition, medication, and secretion management. Unfortunately, it has been shown that the health conditions that people in palliative care cope with frequently lead to disturbances in swallowing, either due to the effects of the illness itself or derived from its treatment (Langmore et al., 2009). Said disturbances significantly interfere with the well-being and quality of life of the person (Kelly et al., 2016). This situation represents a complex clinical and ethical challenge, in which not only the healthcare team participates, but also the family, significant others, caregivers, and the person themselves. The available evidence regarding the considerations to guide the clinical practice and decision-making of SLPs when approaching swallowing and feeding in palliative care is synthesized below, within which the clinical characterization of the types of clients as well as alternative systems for feeding and hydration can be found, among other aspects.

Types of clients and general considerations for management

The changes that occur in swallowing and feeding during the palliative care continuum allow the characterization of palliative care patients that show different clinical expressions. In this regard, and taking as a basis what has been described by Evans & Best (2015), we propose two large groups below:

a. People in palliative care who have dysphagia, who as a consequence of their underlying condition/etiology present a swallowing disorder that reduces their ability to protect their airway, resulting in a high risk of aspiration and/or choking.
b. People in palliative care with a disturbance in feeding, who may present functional swallowing but when approaching the end of their life lose the ability to recognize hunger and/or thirst cues, the desire to eat and/or drink, the ability to recognize what goes into their oral cavity, or develop disordered eating behaviors due to cognitive and/or emotional changes.

In this context, the evidence encourages SLPs within palliative care to put their knowledge and skills to practice, providing a detailed description of the condition of each person, placing special emphasis on determining how safe swallowing is and how effective and comfortable the intake is, when possible (Kelly et al., 2016; Langmore et al., 2009; Royal College of Physicians and British Society of Gastroenterology, 2010; Toner & Shadden, 2012). Subsequently, said information should be shared with the members of the healthcare team, the family, significant others, and the person in palliative care, searching jointly for specific directives (recommendations, guidelines, and decisions), always aiming towards the best quality of life possible. Concerning this, the literature emphasizes that all the guidelines resulting from the process should be based on an in-depth analysis of the benefits (and risks) that may derive from maintaining (or not) oral feeding, or from using an artificial route; decisions in which the SLP should actively participate as educator, advisor, consultant, and auditor.

Considerations for decision-making regarding swallowing and feeding

As for the practices the literature recommends for evaluation, clinical assessment is predominant, since it allows a contextualized description of the functional performance of the person’s swallowing and feeding, as well as of the environment in which they occur, the barriers, and facilitators. The evidence shows that the use of instrumental evaluation can be useful, as long as the benefits obtained from its results allow increasing the person’s well-being, by optimizing and/or maximizing their ability to eat or drink (Kelly et al., 2016).

As previously mentioned, it is important to emphasize that the literature separates the speech therapy approach to swallowing and feeding in palliative care, from the principles of the classical model of rehabilitation. Considering this, the evidence allows establishing other kinds of objectives more suitable for palliative care, namely the reduction of aspiration, management of variables that can trigger pneumonia (for example, oral hygiene), and the reduction of malnutrition and/or dehydration (Kelly et al., 2016). These objectives are particularly relevant for cases where it is not possible to eliminate aspiration, a situation in which the professional must shift from an approach focused on the “minimization of risks”, towards “management of risks” (Eckman & Roe, 2005). The foregoing is proposed under a model that contemplates continuous evaluation throughout the course of the illness, allowing necessary adjustments to the management plan, in accordance with the changes in the person's condition.

In practice, precedents determine that the SLP should assist in the development of strategies to maximize the ability of the person to enjoy eating and/or drinking in the safest and most comfortable way, for as long as possible (Chahda et al., 2017; Pollens, 2012). During this journey, several variables are described that should be considered to achieve a balance between risks and benefits during the development or implementation of an intervention plan. This is especially relevant in the case of people in palliative care who have a high risk of aspiration. Concerning this, a guide that may be useful for clinicians is the study by Berkman et al. (2019) on the management of swallowing in people with advanced dementia. Five central topics stand out in this study (see Table 3), that are suggested to be considered - with necessary adjustments for the national context - during the joint decision-making process of the SLP with the interdisciplinary team, the person, their family, and significant others.

Table 3. Central topics that the SLP should consider for the management of swallowing and communication in palliative care, adapted by the authors from Berkman et al. (2019).

Topic	Descriptors
Wishes of the Person	The recommendation to maintain oral intake or to consider artificial feeding should be supported by the advance directive of the person in palliative care. Ideally, this should be communicated to the family in a timely manner, with the SLP having the important role to facilitate conversations between both parts, addressing the topic with sufficient notice. In situations where the subject has not been addressed, the family should be encouraged to make their decision based on what the person in palliative care would want, acknowledging they are who know the person best.
Quality of Life	Maintaining oral feeding is recommended for comfort and pleasure, particularly in those who are at the end of their lives. This type of feeding should be particularly considered for people who maintain the ability to eat/drink and who show interest or pleasure in the feeding process, always based on a rationale that prioritizes quality of life.
Minimization of the risk of pneumonia	Oral feeding should be recommended in a clinical context where it is possible to minimize the risk of aspiration. However, this is not always feasible, and the main objective of the SLP’s intervention should be to minimize the risk of pneumonia. This includes at the very least the use of compensatory adaptations, maximizing oral hygiene, and modifications to the diet.
Informed decision-making	Most of the time, it is the family (or person responsible for the client) who makes the final decision to maintain or not oral feeding. To this end, the SLP – together with the healthcare team – must inform them about the benefits and risks of maintaining oral intake, allowing an informed decision supported by the information available about the particular condition of the person in palliative care.
Evidence of the use of artificial feeding	Current evidence does not support the use of systems of artificial feeding in people who enter an end-of-life care stage. The use of tubes or ostomies in this population does not reduce the risk of aspiration or malnutrition, they do not improve quality of life either, and they even carry other related risks.

Use of alternative routes for nutrition and hydration

It is noteworthy that the evidence available to date does not recommend the use of alternative routes that facilitate artificial nutrition and hydration. In this regard, the current precedents describe that the indication of tubes or ostomies as a final solution for dysphagia in people in palliative care could have negative consequences that are difficult to manage. The use of tubes in people who still maintain a degree of participation has been linked to situations such as the exclusion from meals, increasing their social isolation, and subsequently an increase in time spent in bed, favoring the failure of any attempt to optimize their condition, and in some cases accelerating death, even if the intention is to improve their health (Langmore et al., 2009). Concerning ostomies, current evidence reports that their use in those approaching the end of their life –especially elderly people with cognitive impairment– does not generate any improvement in prognosis or quality of life (Gillick, 2000; Mamun & Lim, 2005; Naruishi & Nishikawa, 2018).

Despite the above, the indication of alternative feeding routes –especially ostomies– is still frequent in the practice of palliative care in Chile, under the argument of its alleged benefits such as the prevention of aspiration pneumonia, improvement of nutritional parameters, and avoidance of pressure injuries (Portales, 2015). These arguments are reviewed below, from the perspective of the review carried out:

Alternative feeding routes as a measure to prevent aspiration

The ever-growing scientific literature has shown that the use of tubes and ostomies does not prevent aspiration when prescribed to people, including those in palliative or end-of-life care. Similarly, they have proven to be insufficient to reduce the prevalence of pneumonia. On the contrary, and specifically in people in palliative care, their use seems to be associated with an increase in the incidence of pneumonia when compared to those who maintain some type of oral intake oral (Cintra et al., 2014).

In particular, the use of tubes in people with advanced dementia has been shown to increase the incidence of aspiration pneumonia, which is doubled when compared to people with the same health condition who have no indication for the use of a tube (Alvarez-Fernández et al., 2005; Arinzon et al., 2008; Cintra et al., 2014; Ijaopo & Ijaopo, 2019). Two possible causes are described in this regard (Gomes et al., 2003): (1) the administration of food through a tube increases gastric pH, resulting in bacterial colonization of gastric secretions which can migrate using the tube to climb from the stomach –through the esophagus– and colonize the pharynx, and (2) the restriction of oral intake is responsible for a decrease in salivary secretion, which leads to the colonization of the oropharyngeal cavity and the enteral tube by gram-negative bacteria, which later enter the lower respiratory tract together with secretions.

The use of ostomies has shown a risk of aspiration pneumonia similar to that of enteral tubes, observing only a probable decrease through the use of jejunostomy in populations with very specific conditions (Luk & Chen, 2014). One of the most common causes of pneumonia in people with an ostomy is hyperalimentation, which can cause the formula to flow back into the esophagus and pharynx, generating aspiration (Levy et al., 2004). Poor oral hygiene is also a relevant cause since it has been shown that caregivers of people in palliative care tend to neglect oral care when enteral feeding is used (Ijaopo & Ijaopo, 2019; Teramoto et al., 2006).

Similarly, no differences have been found regarding how food is introduced into the artificial feeding system. The use of continuous infusion pumps has not shown to be better than intermittent feeding for the prevention of pneumonia (Luk & Chen, 2014).

Alternative feeding routes as a measure to improve nutritional and physical condition

Artificial feeding does not always achieve improvements in physical function, weight gain, nutritional status, or wound healing. In fact, it has been shown that its use has no effect on malnutrition in people with chronic diseases, nor does it help in the recovery of pressure injuries. On the contrary, it has been associated with an increased risk of death and poorer quality of life (Alvarez-Fernández et al., 2005; Arinzon et al., 2008; Cintra et al., 2014; Finucane et al., 1999; Ijaopo & Ijaopo, 2019; Levy et al., 2004). However, improvements have been observed in the quality of life of caregivers, by reducing the overload and stress associated with feeding the person in palliative care (Nakanishi & Hattori, 2014). This becomes relevant when assessing the pertinence of indicating/maintaining (or not) an alternative feeding route, since many times there is access only to the opinion of the caregiver, which does not necessarily reflect the needs/wishes of the person in palliative care.

For people beginning end-of-life care there are additional considerations. It is established that closer to the end of life - in the context of a person with cancer, for example - a prognostic indicator that life expectancy has decreased to weeks or days is the loss of interest in food or liquids (NICE, 2004; Royal College of Physicians and British Society of Gastroenterology, 2010), a situation that is replicated in other terminal conditions (Carter, 2020; Rochford, 2021). In this context, the use of strategies that favor good oral hygiene is more appropriate than interventions aimed at attempting oral intake. This also involves assessing whether nutrition and hydration through an alternative route continue to be appropriate, if it has already been implemented (Carter, 2020; Rochford, 2021; Royal College of Physicians and

British Society of Gastroenterology, 2010). In this regard, the discontinuation of parenteral fluids should be considered, taking into account that in advanced stages of the illness it may favor the exacerbation of pulmonary and peripheral edema, increasing the production of secretions which a person with a lower level of consciousness is not able to handle (Rochford, 2021; Royal College of Physicians and British Society of Gastroenterology, 2010).

In line with the above, the few clinical guidelines that exist to date (for example, Royal College of Physicians and British Society of Gastroenterology (2010)) establish that any artificial nutrition and hydration system is inappropriate for health situations where:

(1) The risk of the procedure is greater than the expected benefits,

(2) The person in palliative care rejects its implementation, or has made this known to the team and/or family as an advance directive,

(3) The person in palliative care has a poor prognosis and a low chance of survival, and

(4) The person in palliative care has advanced dementia.

These situations count with very little evidence showing a contribution of alternative feeding to the quality of life or prolonging survival.

Finally, even though the evidence presented is aimed at avoiding the use of artificial feeding routes in palliative care - especially during end-of-life care-, each interdisciplinary team must evaluate the decision on a case-by-case basis, together with the family and/or significant others. They should avoid using the aforementioned data as blind arguments and without an adequate clinical correlate, recognizing the wide variability that exists among people receiving palliative care.

General guidelines for the clinical practice in swallowing and feeding

From what is described in this section, it appears that it is the job of the SLP to constantly determine – while monitoring the changes associated with the underlying illness - swallowing functionality, feeding ability, oral hygiene, and cognitive-behavioral performance of the person in palliative care. These findings should be analyzed together with other factors – contextual and environmental– that could favor (or not) any type of feeding. For this, the professional should take into consideration all the strategies –especially compensatory– that are part of their clinical arsenal, that allow to maintain oral intake for as long as possible and, above all, the preservation of the oropharyngeal swallow response for the management of secretions.

In the case of people in palliative care that present severe dysphagia or enter an end-of-life care program, it is recommended to consider approaches oriented towards comfortable intake. In this regard, the evidence establishes that these should be introduced as soon as possible, provided that the person requests or requires it to improve their quality of life. The current recommendation is that the professional chooses an approach that minimizes the risks of aspiration pneumonia (over one that minimizes aspiration), using minimum amounts of food or liquids, which allow the person to enjoy or feel pleasure through different flavors, textures, and/or aromas (Fong et al., 2020; Palecek et al., 2010). In addition to the above, the literature also considers the moistening of the oral cavity with liquids as a strategy to increase comfort, reducing the sensation of thirst or the discomfort of a dry oral cavity (Aguirre Bravo & Sampallo Pedroza, 2015; Palecek et al., 2010). This group of actions has been proposed as a relevant strategy in all of the most recent guidelines, promoting its inclusion in the management of all people in palliative care without oral feeding, regardless of whether they have an alternative route of nutrition and hydration.

SUGGESTIONS FOR THE MANAGEMENT OF COMMUNICATION IN PALLIATIVE CARE

As a result of the progress of the illness, the communicative skills of the person in palliative care decrease progressively, requiring a series of strategies aimed at increasing their communicative effectiveness (Pollens, 2012). The evidence shows that these strategies should be guided by an SLP adequately trained in palliative care, thus facilitating the pursuit of objectives underlying the communicative intervention.

Objectives of communicative intervention

In general, the communication skills of the person in palliative care affect the interaction with their communications partners, making it unpredictable due to the fluctuations in the level of alertness, fatigue, pain, response to medication, and the disease progression itself (Chahda et al., 2017; Pollens, 2012). In this regard, various authors suggest that the clinician has to determine the cognitive-communicative abilities of the person and share this information with the interdisciplinary team, to support them in determining the capacity of the person to make decisions and express their wishes or needs (Kelly et al., 2016). This information should be considered in the decisions of the team and the family, encouraging the participation of the person for as long as possible. At the same time, speech therapy interventions should maximize communicative effectiveness, as a strategy essentially aimed at reducing the suffering of the person in palliative care (Goldberg, 2007; Toner & Shadden, 2012).

In this context, the current literature shows that the use of strategies to facilitate communication between the person in palliative care and their environment has three universal objectives, being the responsibility of the healthcare team's SLP to ensure they are achieved (Chahda et al., 2017; Eckman & Roe, 2005; Pollens, 2012). Said objectives are:

(1) To maintain the emotional and social closeness of the person in palliative care with their family, caregivers, and significant others.

(2) To optimize the ability of the person in palliative care to express their needs, concerns, and preferences related to their daily care and decisions at the end of life.

(3) To maintain the ability of the person in palliative care to express their emotional states, as well as any other concern regarding death. This includes achieving a sense of spiritual and emotional closeness before death.

Taking into consideration these objectives, the speech therapy intervention of communication aims to maintain (for as long as possible), the person's control over their care and end-of-life plans, as well as allowing meaningful interactions with their family, friends, and loved ones (Kelly et al., 2016).

General structure of the communicative intervention plan

The current evidence establishes the strategies that increase communicative effectiveness as pillars of any communication intervention plan in people in palliative care (Chahda et al., 2017; Pollens, 2012), prioritizing those that best reduce the gaps in the interaction between the person and their communication partners. For didactic purposes and to facilitate their conceptualization, these strategies can be grouped into two large categories, remembering they are diverse and dependent on the characteristics of the person and their environment (Chahda et al., 2017; Kelly et al., 2016):

a. Training of communication partners in conversational scaffolding strategies, allowing them to understand more clearly the communicative intentions of the person in palliative care, and

b. Implementation of augmentative or alternative communication systems, maximizing the communication capabilities of the person in palliative care and reducing interferences, particularly in their expression.

As has been the tendency for other interventions already described, the evidence poses as a fundamental feature of the communicative intervention in palliative care –unlike that provided to people with non-progressive conditions– great flexibility to adapt to the frequent communicative and cognitive changes that the person copes with as their health status declines (Kelly et al., 2016; Salt & Robertson, 1998). This places the SLP and their intervention in a role of support and accompaniment, maintained until the person's end of life, with a continuity that is often described as intermittent, in response to the changes that occur in the person (Chahda et al., 2017; Pollens, 2012).

The role of communication in the relief of suffering

Coping with a terminal illness generates changes in the person's personality, being forced to move from independence to dependence, from health to illness, from being in control to not having it (Goldberg, 2007). This situation generates a profound modification in their concept of the world, as well as of the place they have in it. This reality becomes evident especially when they wish to communicate their psychological suffering, an instance in which the SLP has an important role in providing relief, acting as a partner and/or facilitator (Goldberg, 2007). Concerning this, the literature emphasizes communication not only as a tool that allows exchanging information, but also as a way of supporting and enhancing the psycho-emotional well-being of the person. Goldberg (2007) proposes a framework for approaching communication in the areas most frequently linked to the suffering of people in palliative care. This approach is one of the most used in clinical guidelines or recommendations for SLPs in palliative care, especially those that focus on the humanization of end-of-life care. The central elements of this framework are reviewed below, establishing guidelines for the use of communication as a therapeutic tool for people in palliative care and their significant others.

Communication for adjusting to change

According to Goldberg (2007), the person approaching the end of their life goes through a profound change, their world becoming something unstable, where the person they were before the illness progressively disappears and they become someone who is in constant transformation and unpredictability. In this context, the author states that communication should be flexible enough to adapt to the changes that occur. This quality of communication becomes one of the main axes of the speech therapy intervention, being essential to make sufficient adjustments and compensations for the person to receive the support they need from their significant others.

Communication to give and receive gratitude

Giving and receiving gratitude becomes a highly important act for psycho-emotional well-being in the context of palliative care (Goldberg, 2007). It allows the person to close cycles and processes with their loved ones, in addition to strengthening the bonds with their caregiver(s). Although for many individuals this occurs naturally and spontaneously, for many people it is a difficult process to tackle (Emmons & McCullough, 2004; Goldberg, 2007). In both cases, the recommendation is to offer speech therapy to the person and their significant others, to ensure efficient communication that functions as a scaffold for this type of interaction.

Communication and regret

It is not uncommon for those approaching death to regret things they have done and/or wish they had done. In this context, communication should facilitate the giving and receiving of apologies, as well as a positive elaboration on goals not reached (Goldberg, 1997, 2007). When faced with situations like these, many professionals tend to respond by minimizing concerns, or by shifting the conversation to less painful topics. However, when not resolved they can become barriers to a peaceful death (Goldberg, 2006, 2007). In this regard, the role of the SLP is to promote adequate support that favors – according to the individual conditions of each person in palliative care - the optimization of communication to resolve pending issues.

Communication and the need to simplify

When death approaches, communication undergoes a simplification process that is often not understood by the environment, especially the family. Everyday communication, mainly verbal, is gradually replaced by other forms. Gestures, music, or simply a hug become more relevant than overextended and/or elaborate conversations (Goldberg, 1997, 2007). Therefore, the author proposes that the responsibility of the SLP is to develop strategies that enhance this type of communication, as well as including a prior psychoeducation process –particularly to the family, significant others, and the healthcare team– in order to favor a positive resignification of other forms of communication.

Recommendations for accompanying the dying person

Undoubtedly, one of the most complex elements for the SLP in palliative care is facing death closely. Therefore, it is not surprising that communication (and even the bond) is interfered with by variables that are not only dependent on the condition of the person in palliative care, but also by aspects specific to the person of the clinician (Goldberg, 2006).

In this regard, Goldberg (2006), one of the pioneers in addressing communication in palliative care from a speech-language therapy and humanized perspective, gives a series of minimum recommendations for the accompaniment of people in end-of-life care (see Table 4). It is expected that these will be facilitated by the SLP, thus allowing their consideration by the family, significant others, and the rest of the healthcare team.

Table 4. Recommendations for accompanying a dying person, adapted by the authors from Goldberg (2006).

"DOs"	Treat the person who is dying as someone who is profoundly respected. When talking to the person who is dying, do it at a short distance, allowing face-to-face interaction. Touch, if the person feels comfortable with this. Understand that mourning does not start with the death of this person. Graciously accept the gratitude that the person who is dying can express. Say goodbye each time you leave the room. Learn the physical signs of active dying.
"DON'T"	Pretend the person is better when it is clear they are not. Avoid talking about death, when the dying person wishes to do so. Talk about death when the dying person has not addressed the subject. Be afraid to say "I do not know". Advise the person on things they should or should not do. Assume death is the same for everyone.

Assume that the dying person can talk honestly to people other than you.
Be afraid to be affected emotionally.
Assume that you will see this person next week (or day).
Be afraid of death and of mourning the person.

DISCUSSION

This article provides relevant information, based on a review of the literature, on speech therapy practice in adults who require palliative care. To this end, we explore the considerations that are cross-sectional to any intervention, allowing us to collect updated information on the roles, areas of action, and responsibilities of the SLP. Basic guidelines have also been described that allow the adequate management of changes in the communication and feeding of people in palliative care, to maximize their psycho-emotional well-being –and that of their family and significant others–, reducing their pain and suffering, and increasing their comfort.

Thus, it is recognized that clinical practice in palliative care requires complex skills and competencies, which must be combined with evidence-based procedures, ethical principles, and an interdisciplinary work model (Kelly et al., 2016). Below we discuss the scope of the elements involved, proposed as challenges to consolidate the speech therapy practice in palliative care teams in our country.

First Challenge: A change in paradigm

When observing the inclusion of palliative care in Chile and the limitations in its implementation, it is important to reconsider the paradigm at the base of healthcare services. These have historically been attached to the idea of curing, improving functions, and restoring deficits, ideas inserted in the biomedical model (Baeta, 2015), which is far from the requirements in palliative and end-of-life care. It is for this reason that many health professionals – and even many of the people in palliative care and their families or significant others - still consider the support during the death process as a renunciation of life (García-Caro et al., 2010).

Therefore, it is necessary to introduce the biopsychosocial model as a paradigm that better understands the global situation of the person, which goes beyond the biological and considers emotional, social, and spiritual aspects, among others. Under this paradigm, it is important to understand the complexities of each person and their environment, this being particularly relevant when facing complex, multifactorial health situations and in processes that involve death. Considering the above, a real application of palliative care implies evolving from the traditional rehabilitation model towards one that approaches the well-being of people considering both their quality of life and their right to have a dignified death. This is a central element in the reflection that health professionals, including SLPs, should include in their clinical practice, thus putting the biopsychosocial paradigm into practice and approaching a model based on care, while moving away from the rehabilitation model. This highlights the relevance of starting palliative care when the person needs it, understanding that it should not be relegated to the last option.

Second challenge: Defining the roles of SLPs in palliative care

The value of SLPs who specialize in palliative care does not seem to be fully recognized by general SLPs nor by other professionals who have not worked alongside SLPs specialized in palliative care (Kelly et al., 2016; Toner & Shadden, 2012; Vescovich, 2015). This makes it necessary to educate the population, healthcare teams, and public policymakers on the benefits of the early inclusion of SLPs in palliative care.

The foregoing would allow changing the perception of speech therapy as a service additional to palliative care, a situation that explains why its inclusion frequently occurs after the ideal moment to improve the person's quality of life (Kelly et al., 2016; Roe & Leslie, 2010). Thus, a necessary challenge emerges to develop a consensus among SLPs in palliative care, in order to establish a common language and guidelines specific to the area, moving away from the rehabilitation model and giving greater value to the role they play in palliative care.

Third challenge: Training future professionals

In a context where Chile’s population is progressively aging (Albala, 2020), the probability that an SLP will provide services to a person in palliative care is increasingly high. This contrasts with the training that most universities provide during undergraduate courses, where the intentional development of competencies aimed at working with dying people is limited. The effectiveness of creating spaces for reflection and critical thinking guided by professionals with experience in the area has been recognized; this would allow the inclusion of the rationale behind palliative care throughout the undergraduate training (Kelly et al., 2016; Mathisen et al., 2011). Ideally, these instances should be carried out using methodologies that integrate SLP students with students from different disciplines (Mathisen et al., 2011) such as social work, nursing, and/or medicine, promoting early interdisciplinary work based on consensus. Regarding this, a new challenge arises for those who work as trainers to develop and implement curricula that include the principles and competencies related to palliative care.

Fourth challenge: Skills to work with dying people

It is not uncommon to see the erroneous belief emerge that every professional with a speech-language pathology degree can perform satisfactorily in palliative care teams, thereby ignoring the particularities they must face, not only technically or professionally, but often personally. Working in palliative care implies a profound challenge where: (a) the setting of objectives, (b) the uncertainties, and (c) the definition of how far to go in care create a complex scenario, especially for those who are used to performing under a rehabilitative model (Kelly et al., 2016; Roe & Leslie, 2010). Working in an area where death and dying are dealt with daily contributes to stress and burnout among professionals, which may lead to a decrease in the quality of services and care provided (Kelly et al., 2016). Similarly, being exposed to suffering daily can lead to compassion fatigue, seriously compromising the professional's capacity for empathy (Kelly et al., 2016; Toner & Shadden, 2012).

Working in palliative care is a complex job, one that requires sufficient skills to properly deal with dying people. This highlights the need for training that is specific to palliative care, and for adequate processes of clinical supervision, debriefing, peer support, mentoring, and education (Kelly et al., 2016). At present, there are few opportunities to address these needs, with continuing education programs in palliative care –generally aimed at doctors and nurses– being oriented towards technical aspects, to the detriment of competencies aimed at facing death.

Fifth challenge: Creating guidelines for speech therapy practice in palliative care

Chile is not unfamiliar with a condition generalized in most countries: a lack of clinical guidelines that allow SLPs to have a framework to work in palliative care. This means that the transfer of knowledge and clinical recommendations generally comes from more experienced professionals. These professionals are generally nurses, and they are frequently recognized as fundamental support until the SLP achieves greater confidence in their actions (Chahda et al., 2020). Therefore, there is a challenge for professionals in our country to develop guidelines specific to the actions of SLPs in palliative care. These documents should be structured as a broad guide for SLPs rather than a step-by-step structure, given the characteristics of the work in palliative care (Chahda et al., 2020).

Sixth challenge: Modifications in palliative care policies

Currently, health services in Chile have a single program specifically oriented to palliative care, which is "Pain Relief for Cancer and Palliative Care" [*Alivio del Dolor por Cáncer y Cuidados Paliativos*], created in 1994 as part of the National Plan for Cancer [*Plan Nacional de Cáncer*]. This has as a pillar the continuity of care model proposed by the WHO's Fight Against Cancer Program (*Ministerio de Salud* [MINSAL, Chilean Ministry of Health], 2011). However, it is not until 2011 that this program is included in *Garantías Explícitas de Salud* [GES, Explicit Health Guarantees], for the Chilean population. Unfortunately, this program does not consider the SLP as part of the support team, despite the evidence that shows how treatments, and the evolution of cancer itself, significantly impact feeding (Sarría et al., 2007).

From the above two challenges arise that must be tackled both by SLPs and the rest of the professionals in palliative care: First, the inclusion of speech therapy services in programs like the one described before becomes obvious, this would allow an improvement in the quality of life of those who need it; secondly, it is necessary to join forces to promote a broader vision of palliative care, encouraging the development of health policies that allow welcoming people who require this type of care, whether as a result of a degenerative disease or not. In this regard, the generation of evidence that shows its benefits at the national level becomes one of the most appropriate means.

CONCLUSIONS

Considering the still incipient development of speech therapy practice in palliative care, this document provides relevant guidelines under a model of service oriented to care and well-being. We have explored roles, areas of action, responsibilities, and theoretical frameworks to describe the characteristics of the professional working in palliative care, giving an account of competencies that are distinctive of the SLP who specializes in this area.

In particular, the results of this review allow us to establish a series of challenges for clinicians, that we hope will be addressed with an orientation towards generating changes in our clinical practice. Said changes would come from a need to move away from traditional models of intervention, and towards those that seek to transform professionals into suitable companions on the path of dying well. We hope that this work generates further discussion on the topic among health professionals, while providing a guide for those who are entering the field of palliative care (or want to do so). Lastly, we invite those who already work in the area to share their experiences and encourage the development of our work for the benefit of those who need it.

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