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Original articles

Speech therapy aspects in patients' palliative care

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ABSTRACT

Purpose: to describe the speech therapy aspects of patients treated by the palliative care team in a hospital.

Methods: an observational and cross-sectional study, performed from medical records of patients treated under Palliative Care Program, in a hospital, from July to September 2018. Information from the anamnesis and speech-language assessments, which were analyzed by frequency measures, were collected.

Results: the sample was composed by 41 medical records, including 25 males and 16 females, with an average age of 61.2 years and hospitalization average time of 20.7 days. Oral feeding was present in 73% of the sample. It was observed that 24% of the patients had impaired expressive language, 56% had reduced maximum phonation times and 34% showed altered mobility phonoarticulatory organs. For swallowing, 22% showed difficulty in some consistency. A nutritional feeding was verified in 74% of the sample and the remaining was making use of comfort feeding. In relation to assistance, 46% of the sample was under management, 7% in therapy, and the remaining did not have follow-up indication.

Conclusion: relevant alterations to orofacial motricity, voice, language and swallowing were found in patients under palliative care.

Keywords: Palliative Care; Rehabilitation of Speech and Language Disorders; Deglutition Disorders; Communication Disorders

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INTRODUCTION

Effective palliative care requires a broad multidisciplinary approach, including the family and the use of the community resources available[1]. This approach should begin as early as possible to allow for more directed interventions to anticipate and/or minimize unnecessary suffering[2]. Offering a multidisciplinary approach to focus on the needs of patients and their families is a way of taking a comprehensive look at ill individuals, valuing and paying attention to each one of their facets, so that, ideally, the best therapeutic approach can be established[3].

In this context, the speech therapist acts preventively, also treating and helping on the management of symptoms related to feeding and communication[4]. In dysphagia cases, they can collaborate in the decision making along with other team members regarding the use, or not, of an alternative method of feeding, when the oral ingestion is not safe. It also seeks oral intake of feeding maintenance (whenever possible), using posture adjustment, swallowing maneuvers, and further consistency adaptation to favor a comfort feeding[5].

This professional should also seek for more efficient communication alternatives, when it is impaired[4]. In view of this, speech therapy has a key role, because deglutition and communication disorders make great impact in the quality of life of patients and their families[4].

Despite the need of including Speech Therapists in Palliative Care Teams, it is observed a lack of publications who describes speech therapy aspects of palliative care patients, as well as the treatment conducts. It is believed that the profile description of this type of patients allows a better understatement of these individuals' characteristics and enables Speech Therapists, in other services, to compare and find alternatives to each situation, improving the assistance quality[6].

Therefore, this study aimed at describing the speech therapy aspects of patients treated by the palliative care team in a hospital complex.

METHODS

This is an observational, cross-sectional and exploratory study based on data collected from medical records. The collection period was from July to September 2018.

This study complied with the ethical requirements of Resolution 466/12 and was authorized by the Irmandade Santa Casa de Misericordia of Porto Alegre Research's Ethics Committee, Brazil, under decision no. 2,657,416.

Study Population

The sample included medical records of patients treated under the Palliative Care Program in a private hospital, whit philanthropic character in southern Brazil. All patients assisted by the program were assessed by a Speech Therapist member of the team.

The inclusion criteria were medical records of inpatients treated by the palliative care team of the hospital, of both sexes, over 18 years of age. Medical records that have incomplete general data of interest were not collected. In some cases, the patient did not have clinical conditions to go through certain assessments and it has been understood that this fact is inherent to the clinical practice and it is part of the condition of the individual to be assessed, being considered a relevant information. By this reason this item was not used as exclusion criteria.

For data collection, a protocol prepared by the researchers themselves was used to complete the relevant information that should be consulted in the medical records. The protocol covered information on anamnesis (age, sex, if the informant was the patient itself or caregiver, main speech-language complain), the general state (medical diagnosis, length of stay in the hospital, comorbidities, feeding route and ventilatory pattern), speech and language conditions, with aspects related to hearing (use of Hearing Aids and hearing loss and tinnitus complaint), language (comprehensive and expressive language), voice (maximum phonation time and s/z ratio), orofacial motricity (phono-articulatory organs' mobility, sensitivity and strength) and swallowing (laryngeal elevation, penetration/aspiration signs, type of diet, oral feeding consistency and Speech Therapist's conduct). Information on functionality of oral intake, which was analyzed using the FOIS Scale (Functional Oral Intake Scale), assessing the amount of oral intake from level 1 (no oral intake) to 7 (total oral intake without restrictions)[7,8], has also been collected.

Data analysis

Data were stored in the Microsoft Excel® program. An analysis of frequency measures was performed for categorical variables and central tendency and dispersion measures for continuous variables.

RESULTS

Forty-one medical records of palliative care patients treated by the speech therapy team were analyzed. The information collected from the anamnesis was provided mainly by the patients themselves (39%), followed by the patients together with their families (29%), and their families (27%), with a small percentage being answered by formal caregivers (5%). It was found that 12 (29%) walked and 17 (41%) said that they were able to feed themselves without being aided by others. The use of a dental prosthesis was found in 16 individuals (39% of the total), and these were completely or partially edentulous. Sociodemographic and clinical characteristics are described in Table 1.

Regarding complaint data related to speech-language pathology, during the anamnesis, this type of complaint was observed in 24 (59%) of the patients or mentioned by their relatives, often being related to difficulty communicating, inappetence, and symptoms of risk for dysphagia. Speech-language impairments are described in Table 2.

As described in the medical records, the conditions of 14 (34%) participants were observed to prevent them from being assessed for food deglutition. As a result, 27 (65%) of these could undergo a complete assessment, and the results of the aspects characterizing deglutition and its dysphagia signs are described in Table 3. As can be seen, only three (11%) of the patients needed the use of maneuvers to protect their lower airways during deglutition. Among the maneuvers used, the head flexion maneuver (n=1) and the combination of head flexion and cleaning of pharyngeal recesses stand out (n=2).

Table 1. Characteristics of treated patients by the palliative care team

Variables	**Distribution**	
Age		
Mean	61.2	
Standard Deviation	15.3	
Age group	**n**	**%**
20-40	4	10%
41-60	15	37%
61-80	16	39%
>80	6	15%
Sex	n	%
Males	25	61%
Females	16	39%
Hospital stay (days)		
Mean	20.7	
Standard Deviation	22.8	
Diagnosis	**n**	**%**
Oncological disease	31	76%
Neurological disease	2	5%
Others	8	20%
Comorbidities	**n**	**%**
DM	7	17%
SAH	10	24%
Cardiopathy	1	2%
COPD	3	7%
Hypothyroidism	5	12%
Hypoacusis	2	5%
Dyslipidemia	2	5%
Stroke	2	5%
Depression	2	5%
Asthma	2	5%
Others	13	32%
None	8	20%
Ventilatory Pattern	**n**	**%**
AA	29	71%
NIV	1	2%
Tracheotomy	2	5%
O2 support	9	22%
Feeding route	**n**	**%**
Oral	30	73%
Oral + NET	3	7%
NET	5	12%
Gastrostomy	1	2%
Jejunostomy	2	5%

Captions: DM: Diabetes Mellitus; SAH: Systemic arterial hypertension; COPD: Chronic obstructive pulmonary disease. NET: Nasoenteral tube; NGT: Nasogastric tube; AA: Ambient air; NIV: Non-invasive ventilation.

Table 2. Speech language disorders verified in patients treated by the palliative care team

Variables	Distribution					
	Yes		No			
	n	%	n	%		
Audiology						
Difficulty hearing	5	12%	36	88%		
Use of hearing aid	0	0%	41	100%		
Tinnitus complaint	2	5%	39	95%		
	Yes		No		Unable to assess	
	n	%	n	%	n	%
Language						
Impaired understanding	11	27%	25	61%	5	12%
Impaired expression	10	24%	26	63%	5	12%
Voice						
Decreased MPT	23	56%	5	12%	13	32%
S/Z ratio	6	15%	14	34%	21	51%
Orofacial Motricity						
Altered PAO mobility	14	34%	14	34%	13	32%
Altered PAO sensitivity	7	17%	20	49%	14	34%
Altered PAO strength	24	59%	6	15%	11	27%
Reduced laryngeal elevation	11	27%	21	51%	9	22%

Captions: MPT: Maximum phonation time; PAO: Phono-articulatory organs.

Table 3. Characterization of deglutition aspects in patients treated by the palliative care team

Variables	n	%
Penetration/aspiration signs		
Difficulty in a particular consistency*	6	22%
Cough and/or choking	4	15%
Wet voice	1	4%
Oral stasis of food	1	4%
Slow oral transit	2	7%
Altered cervical auscultation	1	4%
Use of maneuvers to protect the lower airways	3	11%
FOIS		
Level 1	4	15%
Level 2	3	11%
Level 3	2	7%
Level 4	9	33%
Level 5	2	7%
Level 6	0	0%
Level 7	11	41%
Type of diet		
Nutrition	20	74%
Comfort	7	26%
Oral feeding consistency		
Normal	7	26%
Mild	3	11%
Pasty	6	22%
Liquefied pasty	11	41%

Variables	n	%
Liquids		
Thin	21	78%
Thickened	6	22%
Speech Therapist's Conduct		
Speech-language management**	19	46%
Comfort actions***	7	37%
Follow-up and advice***	12	63%
Therapy	3	7%
No follow-up indication	10	24%

* percentage based on a total of 27 people who were able to undergo assessment; ** based on a total of 41 patients; *** based on 19 patients who were undergoing speech and language management.

DISCUSSION

Main findings of this study

It was observed in the context of a philanthropic hospital, with major hospital beds from the Brazilian Health System, the presence of informal caregivers, especially family members. Empowering the family and their caregivers so that these can be active agents in improving the quality of life of an individual who is suffering from a life-threatening disease and aiming at their autonomy is a responsibility of the entire team who is seeing them, as this can reduce the anxiety of those receiving care[9,10]. As the elderly population increases, there is a greater incidence of chronic non-communicable diseases that usually require palliative care. According to World Health Organization (WHO)[11], the estimated number of people needing palliative end-of-life care is 20.4 million, 94% are adults and 69% of these are over 60 years old, with a slight predominance of males. These data support the findings of this study as its sample is made up mostly of elderly men. An older age is also related to the cause of death.

Cardiovascular diseases are the number one cause of demand for palliative care, followed by oncological diseases[11]. In this study sample, it can be noted that oncological diagnoses prevailed, these data can be explained by the fact that the institution where this study was conducted includes a hospital complex with different specialties, and the greatest demand placed on the palliative care team during the collection period was at the cancer center. When present, cardiovascular diseases were considered comorbidities.

Sample characterization showed that a large number of patients were fed orally, while the others were fed through alternative artificial routes. It should be noted that when a team follows the precepts of the palliative care philosophy, food and nutrition are always observed to carry a great cultural, social and emotional burden for patients and their families. Thus, it is necessary to reflect on the pros and cons of artificial feeding in an individual's life[12].

The number of patients orally fed was similar to those who had an ambient air ventilatory pattern. Studies infers that the ventilatory pattern can be related to efficient deglutition[13-15]. Since dyspnea is one of the most prevalent end-of-life symptoms[16,17], some patients require some type of oxygen support to maintain their breathing pattern and oxygen saturation stable or the use of opioids to indirectly help with the management of this symptom[17]. This set of breathing disorders can create greater susceptibility to breathing-swallowing discoordination, which is characterized as inappropriate timing of swallow in the respiratory cycle, leading to dysphagia[18].

As for hearing issues, most data showed that patients denied any hearing loss or tinnitus complaint. A possible explanation is that, in more severe contexts, these symptoms may not attract the attention of the patient or their family as speech frequencies have not been reached and because there are more urgent needs. However, it should be noted that changes in communication may be related to hearing disorders, which can lead to depression and social isolation[19,20]. Within the study sample, more than half did not show difficulty on comprehensive language and, in those who did, the cause of their difficulty may be connected with auditory issues that, as previously mentioned, may not have been reported or that are connected with the natural aging and cognitive decline process related to disease progression.

Oral language expression impairments may be followed by impaired mobility of the phono-articulatory organs seen in speech and specific mobility tests. It must be observed that the presence of motor disorders, dysarthria, difficulties in evoking thought, delirium and the use of medications that can depress the sensory level cannot be ruled out as potential causes of these disorders[21]. When possible, the speech therapist can manage expression and comprehensive impairments by means of direct therapy, train family members and caregivers in facilitating communication and adopt alternative measures such as gestural or non-verbal using Augmentative and Alternative Communication resources (AAC)[22].

Concerning vocal issues, a reduced maximum phonation time was seen. This measure reveals information about the neuromuscular and aerodynamic control of an individual's vocal production[23]. Possible pneumo-phono-articulatory discoordination and consequently worse performance in the maximum phonation time test may be associated with dyspnea and fatigue, which are prevalent at the end of life[16,17].

Although a significant portion of the study sample showed changes in the mobility, sensitivity and strength of the phono-articulatory organs, decreased laryngeal movement and use of dental prosthesis for edentulism, few had clinical signs suggestive of laryngotracheal aspiration. This is explained by the fact that it is not necessary to have fully satisfactory structural conditions to be able to perform a function. People with structural changes may have adapted functions and compensate for the masticatory and swallowing process, allowing for safe oral feeding[24] and effective communication.

Regarding deglutition issues, the role of feeding for palliative care patients and its ethical aspects were initially discussed. When the patient has a poor prognosis and is nearing death, food intake reduction or refusal causes distress to family members and caregivers[12,25].

Thus, the professionals involved must be prepared to identify whether there is a real benefit from feeding for that patient. In some cases, ill patients choose not to feed themselves anymore, and this attitude must be respected by the health team and family members, taking the principles of autonomy into account. An artificial diet does not promote quality of life and well-being and, when associated with refractory cachexia, contributes to persistent weight loss[26], causing discomfort[27], and there is evidence that it does not extend survival time[28].

Some of the patients who underwent clinical assessment of swallowing experienced difficulties in some of the consistencies tested and cough and/or choking. Knowing that people who are nearing the end of life usually have their feeding safety compromised[17,29], the speech therapy team can: help accept the risks involved, determine what strategies will help enhance the swallowing capacity of a person who wants to enjoy the pleasure of eating again, find the most favorable food consistency and use postural techniques and maneuvers to minimize the risks of aspiration[30].

As for functional oral intake, which is analyzed using the FOIS Scale[7,8], one third of the patients were observed to have total oral intake of a single consistency (FOIS level 4), which is an aspect that points to the risk of dysphagia. The most common consistency was the liquefied pasty one, which is characterized by containing food that was mechanically liquefied to become homogeneous, without residues, in the institution where the study was conducted. When food is presented in this consistency, swallowing becomes easier, there is no need for mastication, a greater oral motor control is not recruited, and the risk of residues that cause stasis is decreased. The reduced mobility of the phono-articulatory organs compromises oral motor control and requires adaptation to the liquefied pasty consistency for safe oral intake.

As for liquids, thickening can provide greater safety in the swallowing process for those experiencing some difficulty in this consistency, since it increases oroesophageal transit time and reduces the risk of aspiration[31,32].

Concerning the prescribed diet, approximately three fourths of the individuals were on an oral diet aimed at nutrition, that is, a diet was prescribed to meet the caloric and protein needs calculated for that specific person. This differed from the oral diet aimed at comfort and pleasure feeding only. Usually, a diet for comfort feeding is most often indicated at the end of life, when the patient may have anorexia and minimum oral intake[16]. On this occasion, the speech therapist will not seek to adapt or rehabilitate deglutition but rather to use strategies to minimize the risk of aspiration and to maintain meal time with the family as pleasant as possible[33]. This type of intervention is in agreement with the palliative therapy concept, already used in other healthcare professions, which prioritizes the provision of comfort and emotional support[34].

However, palliative care is not indicated at the end of life only, and, in these cases, therapeutic procedures can be performed for deglutition, including traditional speech therapy. A therapy that is regarded as supportive and seeks to maximize function following the deficiencies caused by an underlying disease[34] is often used when a person has a condition that is considered manageable and can be performed simultaneously with the Nothing By Mouth status and/or forms of artificial feeding together with speech therapy[29].

The individuals undergoing speech and language management were classified into two subgroups: follow-up and advice or comfort actions. Follow-up and advice were used when intervention benefits or the prognosis and the chance of recovery were uncertain. This stage adopts strategies to change food consistencies and minimize the risk of laryngotracheal aspiration, as well as passive stimulation, among others[29]. In speech therapy, comfort actions were contemplated when the patient was nearing the end of life and care focused on the quality of life and the relief of patients and their families. The definition of comfort relied on patients' preferences[29], regardless of the stage in which they were when the follow-up by the palliative care team began. Speech therapy intervention is important because the progressive disability of the phono-articulatory organs caused by the disease may lead to depression, poor quality of life, increased need for care, and, sometimes, need for admission to a hospice[34]. Auxiliary rehabilitations, which attempt to maximize function after enduring deficiencies caused by treatment, and palliative rehabilitation optimize function and provide patients with greater comfort[34].

The speech therapist's work in palliative care is seen as a challenge to most professionals who are unaware of this philosophy. Many speech therapists around the world perceive their field as often misunderstood and unrecognized internationally[34,35]. Surveys claim that many speech therapists feel unprepared to care for patients from this population[36,37]. Although the role of speech therapists in palliative care has been documented in the literature, mostly by conceptual articles[30], working with this population may be clinically and ethically complex, and professionals would benefit from appropriate training to better manage palliative care patients, including the understanding of death and the dying and grief processes[37,38].

Limitations of the study

Although all the information from the medical records available during the collection period was analyzed, the topic should be further studied involving a more significant number of participants to contemplate more robust statistical analyses. The records indicated a late referral to the speech therapist, which may restrict therapeutic options.

CONCLUSION

The speech therapy aspects inherent in palliative care, in the service under study, included care for individuals at a mean age of 61.2 years, most of them men suffering from oncological diseases. They presented changes related to orofacial motricity, voice, language, and deglutition. There is greater expressiveness of individuals who received diet for nutrition and made use of liquefied pasty consistency, under speech therapy management. The results found in the speech therapy evaluation may suggest the professional's attention as much in the evaluative approach as in the selection of strategies for therapy.

The profile description of the treated patients, the identification of main symptoms, and the approach report of a service share life-experiences with their peers, promote quality of life for the patients and their relatives, and also points out ways to enable studies with greater power of evidence.

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