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Speech-language pathologists' perception on their performance in the palliative care area at a public hospital in Santa Catarina state, Brazil

Percepção de fonoaudiólogos sobre a atuação na área de cuidados paliativos em um hospital público de Santa Catarina

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ABSTRACT

Purpose: To identify speech-language pathologists' perception on their performance in palliative care at a public hospital in Santa Catarina State, Brazil. **Methods:** It is a descriptive, qualitative study, conducted by 5 speech-language pathologists at a public hospital in Santa Catarina State. Data were collected by means of a semi-structured interview and submitted to content analysis. **Results:** After the content analysis of the participating speech-language pathologists, the following post-defined categories emerged: concept and understanding of palliative care and speech-language pathologists' performance; the importance of the speech-language pathologists in multidisciplinary teams; interpersonal relationship with patients and their families, and constraints in the practice of palliative care. **Conclusion:** According to speech-language pathologists' perception, palliative care is delivered to patients without any possibility of cure, but it is necessary to treat their comorbidities, and provide them with better quality of life; the perception of the speech-language pathology performance in the field of dysphagia stood out; report of other professionals acknowledging speech-language pathologists' performance in the area of dysphagia has been expanded; and such care should be extended to the whole family.

Keywords: Palliative care; Speech-Language Pathology; Patient support team; Perception; Hospital

RESUMO

Objetivo: identificar a percepção de fonoaudiólogos sobre a própria atuação em cuidados paliativos em um hospital público de Santa Catarina. **Método:** trata-se de um estudo qualitativo, descritivo, realizado com cinco fonoaudiólogos atuantes em um hospital público de Santa Catarina. Os dados foram coletados mediante entrevista semiestruturada e submetidos à análise de conteúdo. **Resultados:** após análise do conteúdo do discurso dos fonoaudiólogos participantes, surgiram as seguintes categorias: conceito e entendimento sobre cuidados paliativos e atuação do fonoaudiólogo; reconhecimento da Fonoaudiologia na atuação multiprofissional; relação interpessoal com o paciente e a família e dificuldades na prática de cuidados paliativos. **Conclusão:** a percepção dos fonoaudiólogos revela o conceito de que os cuidados paliativos são prestados a pacientes que não possuem mais possibilidade de cura, mas para os quais há necessidade de tratar comorbidades e proporcionar melhor qualidade de vida. Evidenciaram-se durante as entrevistas: a percepção da atuação fonoaudiológica na área da disfagia, o reconhecimento dos demais profissionais de que a atuação fonoaudiológica tem se ampliado e de que o cuidado deve se estender a toda a família.

Palavras-chave: Cuidados paliativos; Fonoaudiologia; Equipe de assistência ao paciente; Percepção; Hospitalar

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INTRODUCTION

The World Health Organization (WHO) defined the term "palliative care" in 1990, and revised it in 2002, as care delivered to patients suffering from a life-threatening disease. This kind of caring is provided by a multiprofessional team, objectifying to promote better quality of life and relief from suffering(1).

Currently, there have been general goals ruling over professionals' performance in this area, such as pain control and other symptoms, not only physical but also emotional ones; priority for caring, not for curing; the belief that death is a natural process, which should not be anticipated or prolonged; provision of autonomy to the patient; family should be taken in during all the process of the disease, and after that, during the bereavement phase, shared decisions should be privileged, in the most ethical possible way(1).

In order to cover the symptomatology control of the greatest part of the disease in an advanced stage, the speech therapist has recently been included in the team. This professional helps with the patients' communication(2) and swallowing, providing them with better quality of life by means of rehabilitation strategies and function monitoring(3).

The hospital speech therapist works on the prevention and sequel reduction caused to patients' language, swallowing and orofacial motricity, enabling them efficient recovery, thus increasing their possibilities of reintegration to society after hospital discharge(4). In the case of hospital palliative care area specifically, the objective is to keep pleasant, safe deglutition as long as possible, and efficient communication(2), in order for the patients to express their treatment decisions, and for the contact between family members, team and patients, fostering better quality of life and humanized care at the end of their lives, without forgetting the limitations imposed by the baseline disease. Professional palliative care for a patient is also extended to his/her family(3).

The professionals who work in the area of palliative care have a different perspective. Their focus is not on the diagnosis, as caring, in this case, does not aim at curing measures of the baseline disease, but the relief of suffering and the improvement of their quality of life, which varies for each case(5). That aspect may mean emotional suffering not only for patients, but also for the professionals who care for them. Therefore, not all professionals from each category will be willing to work in the area of palliative care.

The perception of professionals from the multiprofessional team is reflected in the hospital daily activities, once it is by means of their awareness in relation to the local social needs and the scientific knowledge that they will refine their performance(6). That is the reason why it is important to understand the views of the professionals from that team.

As literature on speech therapists' work perception in palliative care is scarce, there is little research material specifically for the speech therapists who wish to work in this area. Recently published studies related to Speech-Language Therapy and palliative care evidence the importance of working in this area(7,8). However, little is known about the professionals' perception on their current practice. The proposal for discussion in the object of this study will contribute to the Science of the Speech-Language Therapy and its professional performance within hospital settings.

Therefore, this study aimed to identify speech-language therapists' perception on their own performance in palliative care at a public hospital in Santa Catarina, Brazil.

METHODS

It is a descriptive, exploratory, qualitative, crosscutting study.

The current research project was approved by the Ethic Research Board of the Associação Educacional Luterana BOM JESUS/IELUSC (opinion number 4,055,458).

The inclusion criteria for the research participants were: to be a speech therapist, and have professional experience in hospital palliative care. The exclusion criteria were: speech-language therapists who worked for less than six months in hospital settings, as they would not have enough experience for the accounts. The sampling was selected by means of non-probabilistic convenience sampling, resulting in six speech-language therapists who worked at a hospital in the north of Santa Catarina, Brazil. Five of those professionals responded the request for the study. It is a public hospital, which meets the high-complexity demands in the region.

Due to the Covid-19 pandemic and its restrictive measures, data collection was held online, using the Google Meet platform. The collection was conducted during August/2020, at previously set times between the researcher and the participants, individually, by means of a semi-structured interview, recorded with the participants' consent. The semi-structured questionnaire (Appendix 1) used for the interview, was based on the literature(9) and on the researchers' experience, as qualitative studies, addressing the same aspects of this current work, were not found.

The interviews were recorded and, subsequently, fully transcribed. Then, the obtained data were grouped by the similarities among the themes, verifying the aspects that stood out for the definition of the content addressed by the participants, that is, their perceptions. All the participants signed the Free Informed Consent Form.

The steps to conduct the data survey followed Minayo's proposal (2015)(10): data collection, content reading, category separation and definition. Subsequently, data were analyzed according to Bardin's proposal (2011)(11) for the content analysis.

In order to warrant their anonymity, the research participants were identified according to their occupation, followed by a number, for example: Speech Therapist 1, Speech Therapist 2, expressed by the symbols ST1, ST2, and so on..

RESULTS

Six (6) professionals, who worked at the hospital where the research was conducted, were invited to participate, and five of them accepted the invitation. Considering that it was a qualitative study, the profile of the participants was previously presented.

Females were prevalent, comprising 4 (80%) of the 5 subjects. Their graduation time ranged from 10 to 32 years, prevalence between 10 and 20 years. As for their length of work in hospital settings, it ranged from 2 to 20 years, prevalence between 6 and 9 years, according to the described in Table 1.

By means of detailed analysis of the speech-language therapists' interviews, the following categories, further defined, emerged: concept and understanding on palliative care and

Table 1. Participants' profile

Interviewees	Gender	Graduation time	Llength of work in the hospital field
ST1	F	32 years	9 years
ST2	M	12 years	2 years
ST3	F	20 years	20 years
ST4	F	10 years	7 years
ST5	F	23 years	6 years

Source: research data, 2020
Subtitle: ST1, 2, 3, 4 = speech-language therapist 1, 2, 3, 4; F = female; M = male

speech therapist's performance; recognition of the Speech-Language Therapy in the multiprofessional team; interpersonal relationship to the patient, his/her family and difficulties in the practice of the palliative care.

Concept and understanding on palliative care and the speech therapist's performance

This theme emerged from the question about the perception on palliative care. Most respondents reported that palliative care is rendered to those patients who have no possibilities of cure, but their comorbidities can be treated and, primarily, it provides better quality of life, according to what was observed in the following accounts:

ST1: "*It means caring for the patient, whose treatment will not have healing power, his/her disease will not be reversed, and death is an imminent possibility. It aims to comfort, a dignified way for him/her to live his/her terminal days, without suffering* [...] *without pain, without agonizing physical suffering." ST3 agreed with ST1's understanding when she addressed the quality of life in its several facets in her account by saying:* "[...] *religious and healthy. It doesn't mean to cure, but pain and symptoms can be relieved*." (ST3).

However, participant ST4, besides mentioning better quality of life to be provided, ST4 also referred to a relevant point in palliative care, that is, the finitude of life: "[...] *if possible, the patient must be aware of his/her finitude, because the end is coming only for the Science, you can still do maybe what you haven't done yet*."

According to ST3, the concept of palliative care is something minor, comparing to its daily application, not being entirely applied in caring, according to the following account: "*The concept of what is palliative I can see that people have, that is, delivering the patient full treatment, then, making use of all the resources that you have, but when you refer to palliative care in daily routine, people think that nothing will be done to the patient anymore, and then the actual concept of palliative care is lost*".

ST3 also pointed out: *"Speech therapists' role is communication and dysphagia, we cannot only think about swallowing. Making the patients communicate and eat, even if it isn't to supply their nutritional needs, but for being pleasant, always searching for their quality of life."*

ST4 and ST1 referred more deeply to their specific work on dysphagia: "[...] *sometimes we recommend, or not, an alternative feeding route, it all depends on the prognosis, the pathology. Sometimes, we adapt the food consistency or liberate some things, even being aware of the risk for aspiration, only for the food pleasure*." (ST4). "[...] *when the patient wishes to try something he/she used to enjoy, we can find a way to promote such tasting, without causing him/her any harm*." (ST1).

Participant ST3 added and explained ST4 comments by mentioning that "[...] *there are cases that the patient aspirates but his/her family opts for providing him/her food. He/she may have the risk of pneumonia, but it doesn't change his/her clinical condition, as recovery is not expected anymore, then, they keep the only pleasure he/she has*".

Participant ST1 reported her lived experience: "[...] *there was a patient with amyotrophic lateral sclerosis who couldn't communicate, and she wanted to speak, then we set an alternative language for her to say what she was feeling and thinking about*."

In this category, it could be identified that the concept of palliative care is partially applied. However, the respondents understand what this kind of caring entails. Regarding the speech therapists' work, in all of their accounts, the area of dysphagia stands out.

Recognition of the Speech-Language Therapy in the multiprofessional performance

Therefore, the recognition, not only in the area of the palliative care, but also in all the activities within hospital settings, has been rising in the life of speech therapists, as observed in ST5 and ST1 speeches, "[...] *currently, I can notice a lot of respect on the part of the medical team about my job, they respect my procedures, often request my assessment, and make this link, they only liberate if the speech therapist does. It has improved a lot*" (ST5). "*Nowadays, we are really recognized. At first, there was a lot of painstaking work, and the neurology valued us more, but over the years, the other medical clinics have also respected us* [...]" (ST1).

Regarding ST3, apart from reporting the progress of the recognition, she mentioned the difficulty for professionals and patients to understand all the work areas of speech therapists within a hospital: "[...] *many don't know what we do, even health professionals, technicians, radiologists, including patients, who think that we only deal with speech disorders*".

ST4 also expressed, in her speech, the wish of spreading the knowledge on palliative care within the referred hospital:

> *We have a long way to trail with the palliative care, we'd like to have a team of palliative care only, or at least, to have a team for guiding and lecturing about that, just like the lectures already held on dysphagia for residentes and kitchen maids.*

Participant ST2 reported another relevant point, about the large attention given to dysphagia, which consequently generates greater recognition in this area: "[...] *when a patient is rehabilitated, and returns to normal feeding, the tube is removed, he/she is decannulated, we surely notice the recognition of those professionals*", complemented by ST4 speech, mentioning that: "*That happens more when we can make a progress, level up. If I authorize some food, some consistency, remove a tube, remove a gastrostomy tube, then they recognize it, but it has to do with the evolution*."

Interpersonal relationship with the patient and family, and difficulties in the practice of palliative care

By means of the accounts, it was evidenced that the family is one of the major pillars for effective care, as mentioned in ST4 speech, when she states that: "*Sometimes you're only the voice, a bridge between the patient, the family member and the doctor or the responsible for the team. When we take a bit longer, patience, we can apprehend family and patient's issues that are important, then we pass them on to the team, or we are a bridge between the family member and the patient*."

ST5 speech showed caring clarified by the literature: "*I think that besides the palliative patient, we have to involve the family, who must be treated and deserves such care*".

While referring to the family, in ST4 speech, one of the dilemmas in experiencing palliative care emerged when she reported that "*There are cases in which the family wants to conceal the diagnosis, and that's not nice because the patient has the right to know it under the law, and that may cause changes in him/her.* [...] *Then, you need to tell his/her family members to accept the end, that's the path of life*". It is corroborated by Silva and Sudigursky(12) when they claim that there are ethical principles ruling over palliative care, and the truth is one of them, that is, always tell patient and family the truth, even in relation to the termination of life, in order to promote a less painful and peaceful process of dying.

Focusing on those dilemmas, the reflection on cases of cachexia emerged. In those cases, the patient undergoes extreme loss of weight and the nutritional deficiencies cannot be balanced anymore, generating intense family suffering, mainly because they associate them to the idea that the patient will die because he/she does not eat. Thus, effective communication and psychosocial support are necessary, as exposed by ST3:

> *The family dilemma, because they want the patient to eat, but he/she doesn't need it anymore or he/she is not able to, so when the patient is conscious, with the preserved cognitive function, and wishes that, then we do it, but there is a moment when the hospitalized patients are not conscious anymore, that's the biggest problem in my opinion, when the family thinks they must eat, and they don't need to, and offers the asleep patient some food, which is harmful, that happens very often.*

Apart from the family difficulty in understanding the procedures, ST4 raised, in her speech, professionals' difficulty towards that conception: "[...] *it's not only the family, but professionals as well, even myself, to understand that in the beginning, aren't they gonna insert a tube, but why not? Maybe he/she would live one more week if they inserted the feeding tube. It's more in the sense of understanding the procedure*."

DISCUSSION

The obtained results, according to the participants' accounts in the category "concept and understanding on palliative care and the speech therapist's performance" agree with an author(13:17) who understands death as a natural process in the life cycle, making it less painful, and enabling patients to have more autonomy to live their own way or simply choose not to suffer with invasive procedures anymore.

Most respondents were working at hospital settings for many years, and they probably went through the evolution and change in the philosophy of the palliative care, having possibly re-meant some understandings about that along the years. Thus, the standpoint that "there is nothing else to do" has been replaced, along the years, by the current view of "don't focus on the impossibility of curing but on the possibility of relieving the disease symptoms and, consequently, on the patient's quality of life" (14:7). According to the literature(15), a professional only gets the skills for humanized caring when it is put in practice, thus developing greater competency and professional development.

Concerning the accounts on the respondents' concepts and understanding, it was proceeded to the speech therapist's performance on palliative care, whose goal was to provide better communication, making it possible for the patients to think over their wishes while they were conscious, and enable them safer and more pleasant feeding as possible(2). A study(16) reports that when the option is for an alternative feeding route, usually the minimum oral food intake is prioritized, so that the patients' desire is satisfied(5).

Another publication(17) claims that the great importance attributed to dysphagia is due to speech therapists' traditional procedure, prioritizing the reduction of risks related to that disorder, aiming at the prevention of more complications, such as pneumonia or respiratory failure. However, by focusing on palliative care, there are cases in which the patient opts for keeping the oral feeding, despite the risks. In these cases, a discussion must be held among the multidisciplinary team for a shared patient-centered decision about the oral intake(5,18). It is the speech therapists' competency to inform about the risks, respect the patients' decision and reduce the possibility of bronchoaspiration by means of maneuvers, guidance and adaptations.

Regarding the cases in which the underlying disease has affected the patients' communication, hindering their possibility to express their wishes, the speech therapist should try the use of alternative communication, such as gestures, writing, drawings and communication boards(2). This specific task regarding communication was scarcely reported by the interviewees, which can be explained by the fact that the aforementioned hospital does not have a specific team on palliative care, that is, there is not a hospital unit with professionals focusing only on patients under palliative care. Thus, speech therapists work at the sectors that they are assigned for, as well as the patients who are under palliative care in those sectors. Another factor favoring greater attention to dysphagia is the fact that, in general, there has been more and more increasing demand for the services of speech therapists at hospitals, but their number is still reduced, which probably limits their time to spend with all patients under palliative care on communicative issues. Moreover, the history of the Speech Therapy area at hospitals began with care delivered to patients with dysphagia, due to their neurological diseases and, subsequently, those professionals covered the language-related cases(12).

The shared decision about a patient intervention is a key point among the professionals in the multiprofessional team, as caring for those patients comprise the physical, psychological, spiritual and social symptoms. Therefore, they need the intervention of the most diverse professionals, and it is the competence of the speech therapists and the other health professionals to spread that idea and seek for recognition(18).

The role of the speech therapist in the multiprofessional team of palliative care is relatively new, arising from the concept that patients' communication and safe feeding are necessary to obtain the humanized care(19). Therefore, the recognition of the speech therapists' performance at hospital settings has been increasing among the professionals, which was clarified by the participants' speeches.

The excerpt where ST4 mentioned "*I remove a tube, I remove a gastrostomy tube*", depicted the importance that the multiprofessional team at this hospital grants to the speech therapist regarding the responsibility for the patients' conditions with exclusive oral feeding. ST4 certainly referred to the fact that the therapist had suggested the removal of the alternative feeding route, as it is the medical team that prescribes that procedure.

In addition, it is necessary to disclose and inform patients, their families and health professionals, in general, about the possibilities of speech therapists' performance in the area of palliative care, so that they have the chance to request their services whenever it is necessary and, consequently, they will not consider this professional's job exclusively at a clinic office(20). In the area of palliative care, the procedures towards the patients are re-adaptive, not curative(3), which does not usually cause improvement from the disease. Thus, it is understandable that the recognition of the speech therapists by the multiprofessional team in this area becomes even more complex.

Family is one of the great pillars for effective care. Building a good relationship with the family enables better communication between the team and the patient, apart from allowing the family to voice their opinion on the care delivered. Therefore, they can work with the multiprofessional team for the most possible humanized care(21). Caring, in this case, does not only refer to the patient, but also to his/her family, trying to keep them informed, guided and reassured about the performed interventions(21,22).

One aspect that may hinder palliative caring in relation to the families is the fact that, during the professionals' graduation course, issues about the process of dying are not addressed, which makes it difficult their insertion and coping in the team of palliative care(18).

In addition to the complexity of this theme, decisions and general procedures are suggested to be made by means of case discussions with all the participants in the team, always keeping the family and patients informed, and with the possibility of their participation in the process(23).

The current study stands out for being the first, until the date of its elaboration, to evidence speech therapists' perception in the area of palliative care in Brazil, apart from demonstrating a local reality. However, as a limitation in the study, it can be mentioned the fact that it was applied in a single institution. Thus, in further studies, the increase in the number of participants is suggested in order to verify and ratify their points of view, and get to know distinct realities experienced by speech therapists who work in the area of palliative care.

The obtained results contribute to Science in the field of the Speech-Language Therapy, unveiling a perspective on the reality of the palliative care by the speech therapists, not only for students, but also for other speech therapists and professionals from different healthcare areas.

CONCLUSION

Speech therapists' perception unveils the concept that palliative care is rendered to patients without any possibility of cure, but they need treatment for their comorbidities, as well as better quality of life. During the interviews, speech therapists' performance stood out in the area of dysphagia, in addition to the recognition of the other professionals that the phonoaudiological performance has been expanded, and care must be extended to the families.

Among the difficulties mentioned by the interviewed speech therapists, the family understanding, apart from other professionals, on the procedures towards the patient, the recognition of the multiprofessional team only in the area of dysphagia, and the effective practice of the ethical principle of veracity stood out.

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APPENDIX 1. Interview

Name:
Gender:
Professional Identification/ academic title:
Work:
Work length as a SpeechTherapist:
Work length in the hospital field:
Length of time from graduation:

1. Have you already worked with patients under palliative care?
2. What is your perception on what palliative care is?
3. In your opinion, what is the role of the Speech-Language Therapy with patients under palliative care?
4. In your opinion, what are the differences between your tasks under palliative care and your other tasks in the hospital settings?
5. What is your view about the work of the multidisciplinary team in palliative care?
6. What are the difficulties that you've found delivering palliative care?
7. Can you perceive if the other professionals recognize your performance as a speech therapist? Why?