


# The difficulties in the care of the patient with neurodegenerative diseases: the speech-language therapist and the multi-professional team

## As dificuldades no atendimento aos indivíduos com doenças neurodegenerativas: o fonoaudiólogo e a equipe multiprofissional

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### ABSTRACT

**Purpose:** To analyze the difficulties of speech-language therapists regarding speech-language intervention in patients with neurodegenerative diseases. **Methods:** This is a cross-sectional study with 74 Brazilian speech-language therapists. The professionals were invited through the social networks to respond an online questionnaire with open and closed questions about their professional performance with patients with neurodegenerative diseases. We included only speech-language therapists who work within the Brazilian territory and who attend, or have attended, individuals with neurodegenerative diseases. Descriptive and inferential analysis of the data was performed. Mann-Whitney *U*, Chi-square and Fisher Exact tests were used. **Results:** The greatest difficulties encountered in the care of patients with neurodegenerative diseases were: difficulty in caregiver adhering to orientations (52.7%), lack of communication among professionals of the team for interdisciplinary care (52.7%), and late arrival for evaluation (50%). The difficulty of patient adherence to speech-language therapist's orientations ( $p=0.015$ ) and difficulty related to communication failure among professionals for interdisciplinary care ( $p=0.036$ ) were associated with shorter time of profession. However, the difficulty of adherence of the caregiver to orientations was associated with non-interdisciplinary teams ( $p=0.014$ ). **Conclusion:** The lack of efficient communication in multiprofessional team, the non-adherence of the caregivers and the late arrival of the individual for speech-language assessment, together with the lack of knowledge about the possibilities of speech-language therapy, were the main obstacles faced by professionals. The time of profession was the main variable associated with difficulties in the work of the speech-language therapists that attend patients with neurodegenerative diseases.

**Keywords:** Degenerative diseases; Speech language; Interdisciplinary communication; Multiprofessional team; Professional training

### RESUMO

**Objetivo:** Analisar as dificuldades de fonoaudiólogos quanto à intervenção fonoaudiológica em indivíduos com doenças neurodegenerativas. **Métodos:** Trata-se de um estudo transversal com 74 fonoaudiólogos brasileiros. Os profissionais foram convidados, por meio de redes sociais, a responder um questionário *online* com perguntas sobre sua atuação profissional com indivíduos com doenças neurodegenerativas. Foram incluídos apenas fonoaudiólogos que atuavam no território brasileiro e que atendiam, ou já haviam atendido, indivíduos com doenças neurodegenerativas. Para verificar a existência de associação entre aspectos da experiência dos fonoaudiólogos e as dificuldades referidas, utilizaram-se os testes estatísticos Mann-Whitney *U*, Qui-quadrado e Exato de Fisher. **Resultados:** As maiores dificuldades encontradas quanto ao atendimento de indivíduos com doenças neurodegenerativas foram: dificuldade de adesão do cuidador às orientações fonoaudiológicas (52,7%), insuficiência na comunicação entre os profissionais da equipe para um cuidado interdisciplinar (52,7%) e chegada tardia para avaliação (50%). A dificuldade de adesão do paciente às orientações fonoaudiológicas ( $p=0,015$ ) e a dificuldade relacionada à insuficiência na comunicação entre os profissionais para um cuidado interdisciplinar ( $p=0,036$ ) foram associadas ao menor tempo de formação profissional. Já a dificuldade de adesão do cuidador às orientações fonoaudiológicas, foi associada a equipes não interdisciplinares ( $p=0,014$ ). **Conclusão:** A falta de comunicação eficiente na equipe multiprofissional, a não adesão dos cuidadores e a chegada tardia do indivíduo para avaliação fonoaudiológica, junto ao desconhecimento das possibilidades de atuação da fonoaudiologia, foram os principais obstáculos enfrentados pelos profissionais. O tempo de formação profissional foi um dos aspectos mais associados às dificuldades no trabalho de fonoaudiólogos que atendem indivíduos com doenças neurodegenerativas.

**Palavras-chave:** Doenças neurodegenerativas; Fonoaudiologia; Comunicação interdisciplinar; Equipe multiprofissional; Capacitação profissional

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## INTRODUCTION

Pathological processes that affect the central or peripheral nervous system, usually progressive, are known as neurodegenerative diseases<sup>(1)</sup>. As a consequence, there may be alterations at the cognitive or motor levels, or both, being able to reach the mechanism of swallowing and requiring multiprofessional follow-up<sup>(2)</sup>, preferably interdisciplinary and integral.

Interdisciplinarity and comprehensiveness in the care of the individual aim to prevent fragmentation in the care and daily life of services<sup>(3,4)</sup>, as well as to advocate attention to health needs through teamwork<sup>(5)</sup>.

Individuals with neurodegenerative diseases may perceive changes in communication, social isolation, lack of motivation and loss of self-esteem. These changes may make them deprive themselves of contact with others, change their behavior, avoid society in general, or situations that expose them in some way<sup>(6)</sup>.

Speech-language therapy for these individuals presents their particularities. When affected by these diseases, individuals manifest progressive difficulties, the majority of which are speech-language performance of great relevance.

The objective of speech-language therapy in these cases is to provide alternatives, especially for communication and swallowing, aiming above all at the quality of life of the individual and strategies that provide the improvement of the symptoms, when possible<sup>(6)</sup>.

The objective of this study was to analyze the difficulties reported by speech-language therapists regarding intervention in individuals with neurodegenerative diseases in Brazil.

## METHODS

This research complied with the Declaration of Helsinki and Resolution 466/2012, and all participants gave their consent by signing the Terms of Free and Informed Consent (TFIC). The research was approved by the Committee of Ethics in Research with Human Beings of the *Universidade Federal de Santa Catarina* - CEPESH-UFSC (n° 48912515.9.0000.0121).

This is a cross-sectional study with speech-language therapists from several regions of Brazil that attended or had attended individuals with neurodegenerative diseases. Speech-language therapists who did not attend any individual with neurodegenerative disease or who did not work within the country (Brazil) were excluded.

Between July and October 2016, a convenience sampling was performed in which 240 speech-language therapists were invited to participate in the study, through networks and social/electronic media. The invitations were sent twice, with no deadline for response, with an access link for an electronic questionnaire with 11 questions about their experiences in the care of individuals with neurodegenerative diseases.

The questionnaire was composed as follows: 1) individuals with which neurodegenerative diseases had already been treated (free response); 2) vocational training time (free response); 3) workplace (response options: public service, private, autonomous, public university professor, private university professor, or describe another); 4) state and city of professional performance (free response); 5) area of expertise, if available (free answer); 6) area of action (response options: audiology, dysphagia, gerontology, educational phonoaudiology, neurofunctional speech-language therapy, speech-language

therapy, neuropsychology, language, orofacial motricity, voice, collective health, or describe another); 7) how individuals arrived for their evaluation (response options: medical referral, referral from other professionals, free demand, or describe another); 8) the difficulties encountered (response options: lack of theoretical-practical preparation, difficulty in patient adherence to guidelines, difficulty in adhering to the caregiver's guidelines, late arrival of the patient for evaluation, being able to assess the level of patient fatigue during care, lack of communication among professionals for interdisciplinary care, or describe another); 9) in which type of team action was made (response options: unidisciplinary, multidisciplinary, interdisciplinary, transdisciplinary); 10) which professionals worked in the team (response options: physician, nurse, physiotherapist, occupational therapist, psychologist, nutritionist, or describe another); 11) opinion about why, even if speech-language monitoring was necessary, some individuals did not (response options: difficulty in accessing the speech-language therapist, lack of knowledge about speech-language pathology, lack of referral from other professionals, lack of a speech-language therapist trained to deal with dysphagia, lack of patient perception of difficulties, or other).

The professionals were instructed to check how many alternatives they considered sufficient to answer the questions and complement, in the open field, if there was something that was not listed in the response options offered.

A descriptive analysis of the data was performed by obtaining the relative and absolute frequency of the responses to the questionnaire. For inferential analysis, years of training, type of service (public or private), type of team (multidisciplinary, unidisciplinary, interdisciplinary or transdisciplinary) and the professionals that composed the team (physician, nurse, physiotherapist, psychologist and/or nutritionist) were considered. The difficulties encountered in the care of the individual with neurodegenerative diseases (lack of theoretical-practical preparation, difficulty in adherence of the individual or the caregiver to the guidelines, evaluation of the level of fatigue, late arrival of the individual and lack of communication among the professionals of the team) were considered as dependent variables. We used the Statistical Package for the Social Sciences (SPSS) for Windows and the statistical tests Mann-Whitney U test,  $\chi^2$  and Fisher's exact test. Statistical significance was defined as  $p$ -value  $<0.05$ .

## RESULTS

A total of 74 speech-language therapists with an average of 12 years of training, with a 10-year standard deviation, with some trained less than 1 year prior and others for more than 30 years (minimum = 0, maximum = 39 years) participated in the study. The sample was divided almost equally between speech-language therapists who worked in public service (41 participants; 55.40%) and private (45 participants; 60.81%), and 12 (16.21%) professionals worked in both.

Fifty-seven (77.02%) participants reported postgraduate academic training, with more prevalence in orofacial motor skills (13 participants; 22.8%) and audiology (13 participants; 22.8%).

A large proportion (52.2%) of the speech-language therapists were from the South Region, 15 (20.27%) were from the Southeast, 3 (4.05%) from the North, 2 (2.70%) from the Northeast and 2 (2.70%) from the Midwest.

The majorities were inserted in multidisciplinary teams (57 participants; 77.02%). Thirteen (17.56%) reported participating in an interdisciplinary team, 12 (16.21%) described unidisciplinary team performance and only 1 (1.35%) reported composing a transdisciplinary team.

Fifty-five (74.32%) speech-language therapists attended individuals with Parkinson's disease, 43 (58.10%) of individuals with amyotrophic lateral sclerosis and 34 (45.94%) with Alzheimer's disease, the latter being the most frequent diagnosis. Less frequently, the diagnoses of muscular dystrophies, multiple sclerosis, Guillain-Barré syndrome, Huntington's disease and different types of ataxias were reported.

The lack of knowledge about speech-language pathology, referred to by 63 (85.13%) speech-language therapists and the lack of referral by other professionals, cited by 53 (71.62%) participants, were cited as the main factors for not following-up many individuals.

The greatest difficulties encountered during the care given to individuals with neurodegenerative diseases were: difficulty of adherence of the caregiver to speech-language guidance and lack of communication among the professionals of the team for

interdisciplinary care, although 71 (95.94%) speech-language therapists reported having worked in some kind of multiprofessional team (Figure 1; Table 1).

Regarding factors that could be associated with the difficulties in attending to individuals with neurodegenerative diseases, it was observed that the patient's difficulty in adhering to the guidance given by speech-language therapists and the difficulty related to the lack of communication between the professionals for interdisciplinary care were associated with shorter duration of training time. However, the difficulty of adherence of the caregiver to the speech-language therapist was associated with non-interdisciplinary teams. Of the 39 speech-language therapists who referred to this difficulty, 28 were not from interdisciplinary teams. Speech-language therapists enrolled in teams with nursing professionals reported more difficulties related to the adherence of the caregiver to speech-language pathology and self-assessed with less theoretical-practical preparation. The results of the exploratory analysis related to the factors that could be associated with difficulties in the care of individuals with neurodegenerative diseases are presented in Table 2.

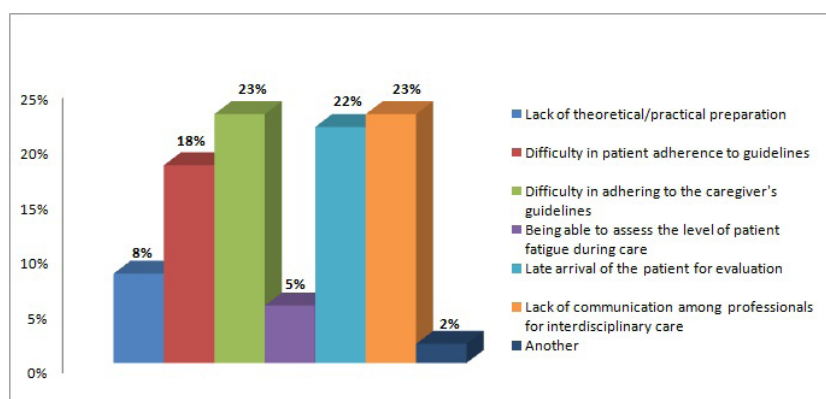


Figure 1. Relative frequency of difficulties reported by speech therapists in the care of individuals with neurodegenerative diseases (n=79)

Table 1. Absolute and relative frequency of difficulties reported by speech therapists in the care of individuals with neurodegenerative diseases, according to training time, place of work and type of professional team (n=79)

Difficulties mentioned by speech-language therapists	n(%)	Time of profession Mean (SD) (years)	Sector		Team type n (%)	Professionals of the team					
			Public n (%)	Private n (%)		Physiotherapist n (%)	Doctor n (%)	Psychologist n (%)	Occupational therapist n (%)	Nurse n (%)	Nutritionist n (%)
Lack of theoretical/practical preparation	14 (18.91)	7.42 (6.5)	8 (57.14)	8 (57.14)	Unidisciplinary 3 (21.42) Interdisciplinary 2 (14.28)	11 (78.57)	10 (71.42)	5 (35.71)	1 (7.14)	3 (21.42)	5 (35.71)
Difficulty of adherence of the individual	31 (41.89)	8.61 (7.86)	16 (51.61)	20 (64.51)	Unidisciplinary 6 (19.35) Multidisciplinary 26 (83.87) Interdisciplinary 6 (19.35)	25 (80.64)	24 (77.41)	14 (45.16)	10 (32.25)	16 (51.61)	19 (61.69)
Difficulty of adherence of the caregiver	39 (52.70)	9.96 (9.19)	15 (20.27)	19 (25.67)	Unidisciplinary 6 (15.38) Multidisciplinary 30 (76.92) Interdisciplinary 11 (28.20)	33 (84.61)	31 (79.48)	18 (46.15)	15 (38.46)	26 (66.66)	29 (74.35)

Subtitle: SD = standard deviation

Table 1. Continued...

Difficulties mentioned by speech-language therapists	n(%)	Time of profession Mean (SD) (years)	Sector		Team type n (%)	Professionals of the team					
			Public n (%)	Private n (%)		Physiotherapist n (%)	Doctor n (%)	Psychologist n (%)	Occupational therapist n (%)	Nurse n (%)	Nutritionist n (%)
Ability to assess level of fatigue	9 (12.16)	11.41 (9.33)	18 (24.32)	18 (24.32)	Unidisciplinary 2 (22.22) Multidisciplinary 7 (77.77) Interdisciplinary 1 (11.11)	7 (77.77)	6 (66.66)	4 (44.44)	2 (22.22)	5 (55.55)	7 (77.77)
Late arrival	37 (50.00)	12.04 (9.60)	10 (13.51)	13 (17.56)	Unidisciplinary 5 (13.51) Multidisciplinary 31 (83.78) Interdisciplinary 8 (21.62)	29 (78.37)	30 (81.08)	17 (45.94)	15 (40.54)	21 (56.75)	26 (70.27)
Insufficiency in communication among the professionals	39 (52.70)	12.92 (9.70)	31 (41.89)	29 (39.18)	Unidisciplinary 7 (17.94) Multidisciplinary 30 (76.92) Interdisciplinary 5 (12.82%)	30 (76.92)	34 (87.17)	15 (38.46)	11 (28.20)	21 (53.84)	24 (61.53)

Subtitle: SD = standard deviation

Table 2. P-values referring to the exploratory statistical analysis of the difficulties reported by speech therapists in the care of individuals with neurodegenerative diseases, according to training time, place of work and type of professional team ( $n = 79$ )

Difficulties	Years of profession	Sector		Team type			Professionals of the team					
		Public	Private	Uni	Multi	Inter	Physiotherapist	Doctor	Psychologist	Occupational therapist	Nursing	Nutritionist
Lack of theoretical/practical preparation	0.064	1.000	0.764	0.687	0.289	1.000	1.000	0.405	1.000	0.054	<b>0.016*</b>	0.050
Difficulty of adherence of the individual	<b>0.015*</b>	0.634	0.808	0.54	0.274	0.765	1.000	0.188	0.479	0.802	0.812	0.620
Difficulty of adherence of the caregiver	0.179	0.479	0.810	1.000	1.000	<b>0.014*</b>	0.384	0.208	0.337	0.131	<b>0.032*</b>	0.069
Ability to assess level of fatigue	0.412	0.722	1.000	0.63	1.000	1.000	0.332	1.000	0.429	1.000	0.442	0.088
Late arrival	0.978	0.482	0.634	0.75	0.269	0.543	0.768	0.516	0.345	0.076	0.813	0.459
Insufficiency in communication among the professionals	<b>0.036*</b>	0.485	1.000	0.76	1.000	0.361	0.773	0.329	1.000	0.802	1.000	0.805

Statistical tests: Mann-Whitney U test,  $\chi^2$ , Fisher's exact test; \*p-value < 0.05

Subtitle: Uni = Unidisciplinary; Multi = Multidisciplinary; Inter = Interdisciplinary

## DISCUSSION

Speech-language therapists from different regions of Brazil expressed their difficulties regarding intervention in individuals with neurodegenerative diseases. Unfortunately, there was no representation of speech-language therapists from all regions of Brazil, mainly because the sample was obtained by convenience. There was greater participation of the South region, region of the origin of the study and the researchers.

Historically, the South and Southeast regions of Brazil have the largest number of speech-language therapists, especially

in the Unified Health System (SUS). However, an ecological study conducted in the 27 federative units of the country showed a significant increase in the number of professionals in the Northeast, between 2008 and 2013<sup>(7)</sup>.

It should be noted that it is extremely necessary that the increase of speech-language therapists in SUS be constant and equitable in all regions of the country, in order to meet the demand for comprehensive and interdisciplinary care, especially for the better quality of life of individuals with neurodegenerative diseases.

Fortunately, the sample had a similar amount of public and private sector speech-language therapists, which shows



that many difficulties can be found regardless of the type of employment relationship, or funding of the service.

Most of them presented postgraduate education, with specialization in some area of speech-language therapy, which may refer to the participation of differentiated individuals, because they are in a way concerned with professional tendencies.

The three diseases most attended by professionals (Parkinson's disease, amyotrophic lateral sclerosis and Alzheimer's disease), are neurodegenerative diseases empirically frequent in speech-language work, with amyotrophic lateral sclerosis being more frequent in middle-aged adults<sup>(8)</sup> and Parkinson and Alzheimer's disease prevalent in the elderly population, which by itself, already presents fragilities<sup>(9)</sup>. These are diseases with very peculiar evolutions; however, they require in a very similar way the search for specific knowledge, professional updating, continuous care with the patient and active participation of the family and / or caregivers.

The difficulty related to the lack of communication between the professionals for interdisciplinary care to the individual with neurodegenerative diseases was one of the most cited by the participants. This and the difficulty of adherence of the patient to speech-language pathology, also referred to frequently, were significantly associated with participants with shorter professional training time.

A great heterogeneity was observed in the sample regarding the time of profession, since the average was 12 years and the standard deviation of ten years. There was participation of highly experienced professionals, with 39 years of training, while others, had graduated less than a year prior. Thus, in the present study, participants with shorter training time reported more of such difficulties in the care of individuals with neurodegenerative diseases.

Often, newly trained professionals feel incapable and unprepared to perform their jobs, as often they cannot successfully perform the function that would be their responsibility, generating situations of anxiety and anxiety. The opposite is also true because, even if confident in their professional performances, often others may judge them for their younger age or lack of experience.

It is understood that the adherence of the patient to the guidelines depends to a large extent on the convincing and eloquence of the professional, who should transmit safety during the care. After graduation, the professional's engagement in the continuous search for new knowledge becomes a fundamental part of consolidating the baggage acquired during the course<sup>(10)</sup>.

The time of professional experience is generally seen as a positive factor for good care, being partly responsible for the performance of the speech-language therapist. Self-confidence, the ability to communicate and professional attitude are aspects that consolidate over time, through lived experiences.

In the present study, the shorter time of professional performance was also associated with difficulties in communication among professionals, for interdisciplinary care. Even if one of the principles in the training of the speech-language therapist is communication<sup>(11)</sup>, it is believed that this is perfected with years of experience.

Communication among health professionals is fundamental and occurs mainly through the need to share experiences. It is essential to use dialog for a quality service<sup>(12)</sup>.

When inserted in a multiprofessional team, or even in the context of general health, it is clear the need for professionals to use interpersonal communication, either to the service user or to the team. The work of health professionals is based on human

relations, with the communicative process being inserted in the great majority of the activities of their daily life, if not at all<sup>(13)</sup>.

It is assumed that over time the speech-language therapist will be able to leave their nucleus of knowing and thinking beyond the boundaries of their academic training. The time of experience may be able to expand performance and communication with professionals from other areas, by building a wide field of knowledge.

The nucleus in which the speech-language therapist is centered at the beginning of their professional life is nothing more than the set of specific knowledge and attributions of their specialty, which contributes to the construction of the identity and specificity of their profession<sup>(14)</sup>.

In addition to this specific core, there is a need to build a broader field of knowledge. This field comprises a situational conceptualization, which covers a possible set of knowledge and attributions that a profession must appropriate to achieve effectiveness and efficiency. In this sense, the field represents the opening of a closed content of a single profession to a medium of interdisciplinarity and interprofessionality, highly expected and desired in the current Brazilian context of health<sup>(14)</sup>.

The difficulties experienced by some teams in articulating themselves in order to offer integral assistance and to develop a multidisciplinary work are a reality for several services. These difficulties contribute to the fragmentation of care, making it insufficient to meet the complexity of providing assistance to many individuals<sup>(4)</sup>.

Professionals point out the necessity of teamwork, since it allows for more discussions and greater solvency of problems, besides strengthening the organization and management of the services<sup>(5)</sup>. In this aspect, unidisciplinary performance is not recommended, and the importance of completeness in the performance of neurodegenerative diseases is reinforced.

Interdisciplinary action consists in invalidating the individualistic model in a team either by sharing the planning, the division of tasks, or by collaborating so that the group of professionals is able to contribute more and more to health<sup>(15)</sup>.

With regard to interdisciplinary care, professionals are integrated at the level of concepts and methods. In this model, certain areas of action constitute new approaches and interventions with their own theoretical content<sup>(16)</sup>.

In the present study, the majority of professionals with difficulties of adherence of the caregiver to their guidelines did not belong to interdisciplinary teams. Interdisciplinarity should be understood as the degree of integration between the disciplines and the breadth in the exchange of experiences among specialists. With this process of interaction, all disciplines must be enriched, necessitating not only the lending of elements of other disciplines, but to comparing, incorporating and aggregating such elements in the production of a modified and improved discipline<sup>(17)</sup>.

In this respect, transdisciplinarity is able to go beyond, not restricted to interactions and reciprocal exchanges between disciplines, but proposing the end of boundaries between them from the perspective of many researchers. Although it is correct to consider health as a transdisciplinary field, due to the complexity of its object, when we observe health services that count on multiprofessional team care, it is clear that the organization of services still occur in a fragmented way<sup>(17)</sup>.

The results of the present study reaffirmed that interdisciplinarity or transdisciplinarity are realities today, necessary in all the services in which actions are carried out that aim to improve the health and life quality of the population. The question is how

to make them work in a homogeneous, democratic, inclusive and cooperative way.

Speech-language therapists in the UK, who worked with individuals with Parkinson's disease, reported that they performed in a multidisciplinary way, most of which could rely on specialists such as neurologists. They cited as the main difficulty the fact that the referral for speech-language intervention takes place late, when the disease is already at a more advanced and complex stage, and it is not possible to perform many interventions<sup>(18)</sup>.

Individuals with Parkinson's disease who underwent speech-language therapy reported that the experience was valid and positive, not only when the greatest changes occurred, but also because of ongoing counseling and support. Individuals who were never in speech-language therapy mentioned believing in the possibility of improvement with the assistance of the speech-language therapist. The most reported reasons for the absence of such follow-up were related to lack of mobility and / or transportation, lack of referral from other professionals and lack of knowledge about the profession<sup>(19)</sup>.

The time elapsed between the onset of symptoms and the beginning of speech-language therapy was one of the factors most cited in the present study, as compromising the therapeutic process and the care of individuals attended by the participating professionals. Currently, early speech-language therapy is widely advocated, especially in progressive neurodegenerative diseases, in favor of better quality of life, even with low life expectancy.

The results of this study also showed that speech-language therapists inserted in teams with nursing professionals reported more difficulties related to the adherence of the caregiver to the guidelines and self-assessed with less theoretical and practical preparation.

It is believed that the speech-language therapist inserted in teams with nursing professionals work in hospital and home environments, in which the complexity of cases with neurodegenerative diseases is greater, and in most cases, in advanced stages.

It is understood that during a home care, the reality of the individual's family and interpersonal context is also observed, demanding more skills to understand all dimensions of the health-disease process.

Home care gives the health professional greater perception of the individual's social, economic and cultural reality. For this reason, the training of caregivers can be better evaluated and seen more critically by the health team<sup>(20)</sup>.

It is believed that over time, interdisciplinary teams should perform activities that bring professionals closer to users of the service and their families. In daily practice, these spaces can contribute to a broader view of the subject and their needs, favoring the participation of the individual and the family / caregiver, which should favor autonomy in care<sup>(21)</sup>.

Faced with the progression of neurodegenerative diseases, many individuals need more care and are hospitalized. Speech-language pathology in hospitals is still recent, but of great importance for prognostic perspectives and improvement of the individual's quality of life. Thus, the theoretical / practical preparation of the speech-language therapist is essential to perform in hospital settings, whether in nursing beds or intensive care units<sup>(22,23)</sup>.

As limitations of the present study, the lack of representativity of speech-language therapists in the different regions of Brazil and the specifications regarding the functioning of the health services of each participant are highlighted in order to deepen the discussions about the mentioned difficulties.

## CONCLUSION

The lack of efficient communication in the multiprofessional team, the non-adherence of the caregivers and the late arrival of the individual for speech-language assessment, together with the lack of knowledge of the possibilities of speech-language therapy were the main obstacles faced by professionals.

Speech-language therapists with a shorter duration of professional activity were the ones that most self-referred some of the difficulties in the care of individuals with neurodegenerative diseases. In addition, the work in non-interdisciplinary teams was the aspect most associated to the difficulty of adherence of the caregiver to speech-language pathology.

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