

Knowledge about sudden unexpected death in Parkinson's disease among speech-language pathologists and audiologists

Conhecimento sobre morte súbita e inesperada na doença de Parkinson entre fonoaudiólogos

Conocimiento sobre la muerte súbita y inesperada en la enfermedad de Parkinson entre los logopedas y audiólogos

Received: 04/08/2022 | Reviewed: 04/16/2022 | Accept: 04/20/2022 | Published: 04/24/2022

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Abstract

Sudden and Unexpected Death in Parkinson's Disease (SUDPAR) is a sudden and unexpected death without correlated findings at autopsy or in the history of patients with Parkinson's Disease (PD). Our objective was to evaluate the knowledge regarding SUDPAR among Speech-Language pathologists (SLPs) and audiologists in the state of Alagoas, Northeastern Brazil, and to analyze the opinions of these professionals about whether to discuss about the SUDPAR phenomenon with their patients and families. SPLs and audiologists from Alagoas were recruited through an active search on social media, then answered a structured questionnaire with questions about frequency of care for patients with PD; epidemiology and mortality in PD, in addition to questions about SUDPAR. Most SPLs and audiologists (87.2%) did not know about the SUDPAR phenomenon. Among the 26 SPLs and audiologists who knew about SUDPAR, 15 stated that they discuss about the phenomenon with patients and their families/caregivers when asked about the risks related to the possibility of SUDPAR. In conclusion SPLs and audiologists in the state of Alagoas do not know about SUDPAR.

Keywords: Sudden death; Parkinson's disease; Speech language pathology; Audiologists; Health teaching.

Resumo

A Morte Súbita e Inesperada na Doença de Parkinson (SUDPAR) é uma morte súbita e inesperada sem achados correlacionados na autópsia ou na história pregressa de pacientes com Doença de Parkinson (DP). Nosso objetivo foi avaliar o conhecimento sobre SUDPAR entre fonoaudiólogos do estado de Alagoas, Nordeste do Brasil, e analisar a opinião desses profissionais sobre discutir ou não sobre o fenômeno SUDPAR com seus pacientes e familiares. Os fonoaudiólogos de Alagoas foram recrutados por meio de busca ativa nas redes sociais, em seguida responderam a um questionário estruturado com perguntas sobre frequência de atendimento ao paciente com DP; epidemiologia e mortalidade na DP, além de perguntas sobre a SUDPAR. A grande maioria dos fonoaudiólogos (87,2%) não conhecia o fenômeno SUDPAR. Entre os 26 fonoaudiólogos que conheciam a SUDPAR, 15 afirmaram discutir sobre o fenômeno com os pacientes e seus familiares/cuidadores quando questionados sobre os riscos relacionados à possibilidade de SUDPAR. Em conclusão, os fonoaudiólogos do estado de Alagoas não conhecem a SUDPAR.

Palavras-chave: Morte súbita, Doença de Parkinson, Fonoaudiólogos; Ensino em saúde.

Resumen

La muerte súbita e inesperada en la enfermedad de Parkinson (SUDPAR) es una muerte súbita e inesperada sin hallazgos correlacionados en la autopsia o en la historia pasada de pacientes con enfermedad de Parkinson (EP). Nuestro objetivo era Evaluar el conocimiento sobre SUDPAR entre fonoaudiólogos en el estado de Alagoas, Nordeste de Brasil, y analizar la opinión de estos profesionales acerca de discutir o no el fenómeno SUDPAR con sus pacientes

y familiares. Los logopedas y audiólogos de Alagoas fueron reclutados através de una búsqueda activa en las redes sociales, luego respondieron un cuestionario estructurado con preguntas sobre la frecuencia de atención a pacientes con EP; epidemiología y mortalidad en la EP, así como preguntas sobre SUDPAR. La gran mayoría de logopedas y audiólogos (87,2%) no conocían el fenómeno SUDPAR. Entre los 26 logopedas y audiólogos que conocían la SUDPAR, 15 afirmaron que discutían el fenómeno con los pacientes y sus familiares/cuidadores cuando se les preguntaba sobre los riesgos relacionados con la posibilidad de la SUDPAR. In conclusión, los logopedas y audiólogos del estado de Alagoas no conocen la SUDPAR.

Palabras clave: Muerte súbita, Enfermedad de Parkinson, Fonoaudiología, Enseñanza en la salud.

1. Introduction

Parkinson's disease (PD) is a progressive, incurable, and systemic neurodegenerative disorder with high mortality rates when compared to the general population (Scorza, *et al.*, 2017; Scorza, *et al.*, 2016). Currently, it is clear in the literature that sudden unexpected death in PD (SUDPAR) contributes to the increased risk of mortality in patients with PD (Scorza, *et al.*, 2017; Scorza, *et al.*, 2016). With these considerations in mind, as a complete understanding of all the risk factors, mechanisms, and specific methods to prevent SUDPAR is yet to be obtained, a careful evaluation of this topic requires an interdisciplinary approach (Cohen, *et al.*, 2016).

This being said, speech-language pathologists (SLPs) and audiologists are supporting professionals in the prevention of SUDPAR, as in the course of their clinical practice they may have to assist patients with PD and can talk to them about SUDPAR. As a syndrome, the clinical speech-language and audiological findings in individuals with PD are extensive and widely discussed in the literature (Suttrup & Warneck, 2016; Yang, *et al.*, 2016; Gillivan-murphy, *et al.*, 2020; Kang, *et al.*, 2019; Bastiaane & Leenders, 2009; Scarpa, *et al.*, 2020). All subsystems of the speech-language pathology and audiology activities are intricate with PD. Dysphagia causes pneumonia due to bronchoaspiration, which is one of the major causes of death in PD, and is the field of action of SLPs (Suttrup & Warneck, 2016). In addition, dysarthria (Yang, *et al.*, 2016), vocal changes (Gillivan-murphy, *et al.*, 2020) and orofacial myofunctional disorders (Kang, *et al.*, 2019) are almost always evident in patients with Parkinson's, as well as language and cognitive difficulties (Bastiaane & Leenders, 2009), often associated with PD, especially due to correlated dementia. Finally, changes in the auditory and vestibular systems (Scarpa, *et al.*, 2020) are found in PD, and are focus of audiologists.

Thus, evaluating the knowledge on SUDPAR among SLPs and audiologists in the state of Alagoas, Northeastern Brazil, and analyzing the opinions of these professionals about whether or not to discuss about the SUDPAR phenomenon with their patients/families has become an important scientific investigation.

2. Methodology

This is a cross-sectional study, in which the sample size was calculated using the Comento calculator and determined by 192 SLPs and audiologists. The following parameters were adopted: population 379, sample error 5, 95% confidence level and heterogeneity (50/50).

After approval by the Research Ethics Committee of the Federal University of São Paulo - UNIFESP, under protocol 4,599,215, the SLPs and audiologists from the state of Alagoas were recruited through an active search on social media: WhatsApp, Instagram, Facebook, Telegram and Twitter. Then, the individuals who agreed to the Informed Consent Form, which was sent remotely, answered a structured questionnaire through Google Forms about the professional's knowledge and experience about SUDPAR. The structured questionnaire asked questions about PD: How many PD patients are evaluated by you semiannually? Do you know the epidemiological data on PD?; The PD mortality is especially related to: pneumonia, cardiovascular or cerebrovascular diseases?; Do you know or have you heard of the sudden and unexpected death in PD

(SUDPAR)? If you answered yes to the previous question: When do you discuss about SUDPAR with PD patients and/or family members/caregivers?

For statistical analysis, the collected data were tabulated on the Microsoft Excel® spreadsheet. In descriptive statistics, qualitative variables were presented in the form of a frequency table. In inferential analysis, the presence of an association between qualitative variables was performed using the Chi-square test and Fisher's test. A significance level of 0.05 was accepted. Statistical tests were used using the BioStat 5.3® application.

3. Results

According to the data from the Federal Speech-Language Pathology and Audiology Council in Brazil, there are 379 active SLPs and audiologists within the state of Alagoas. Of this total population, 203 SLPs and audiologists answered the questionnaire, which represented a level of confidence of over 95% in the found data. Most SLPs and audiologists in Alagoas do not evaluate any PD patient, semiannually. In addition, most of them do not know about the PD epidemiology, and they believe the leading cause of death among individuals with Parkinson's disease is pneumonia. The vast majority do not know about the SUDPAR phenomenon (Table 1).

Table 1. Number of patients evaluated per semester, knowledge about PD epidemiology, knowledge about PD mortality, and knowledge about SUDPAR by speech-language pathologists and audiologists in the state of Alagoas.

Patients evaluated per semester	None	01-05	06-10
	134 (66%)	64 (31.5%)	05 (2.5%)
PD Epidemiology	Yes	No	
	13 (6.4%)	190 (93.6%)	
PD Mortality	Pneumonia	Cerebrovascular	Cardiovascular
	95 (47.3%)	84 (41.8%)	22 (10.9%)
SUDPAR	Yes	No	
	26 (12.8%)	177 (87.2%)	

Note: PD = Parkinson's disease, SUDPAR = Sudden Death in Parkinson's. Source: Authors.

Among the 26 SLPs and audiologists who knew about the SUDPAR, 15 stated that they discussed about the phenomenon with patients and their family members/caregivers when asked about the risks related to the possibility of the SUDPAR; seven when adherence to treatment by the PD patient is low; two when the patient considers the alternative of not following the proposed treatment; and two when polytherapy is needed.

There was no association between gender and age with the knowledge on SUDPAR by speech-language pathologists and audiologists in the state of Alagoas (Table 2).

Table 2. Association between sex and age with the knowledge on SUDPAR by speech-language pathologists and audiologists in the state of Alagoas.

Gender	Yes	No				P
Female	24	161				1.000
Male	02	14				
Age	20-30	31-40	41-50	51-60	>60	0.1427
Yes	09	08	11	0	0	
No	54	80	34	05	01	

Fisher's exact test; Chi-square test. Source: Authors.

4. Discussion

It is the first study in the world carried out on the knowledge of the SUDPAR phenomenon among SLPs and audiologists. Speech-Language Pathology and Audiology is a profession that encompasses a large field of action in the various age groups. Progressive neurodegenerative diseases, including PD is a small fraction within this possibility, which justifies the fact that the majority of SLPs and audiologists in the state of Alagoas 166 (66%) do not provide any assistance to PD patients, semiannually; 64 (31.5%) provide semiannually assistance from 1-5 PD patients; and only 05 (2.5%) serve between 06-10 PD patients, semiannually. While 33,9% of SLPs and audiologists in the state of Alagoas work in PD, in the United Kingdom, the rate of speech language therapists working in PD is even lower, estimated to be below 1 out of 5, corresponding to 10% of the professionals (Miller, *et al.*, 2011).

Interestingly, the vast majority (93.6%) of SLPs and audiologists in Alagoas do not know about the epidemiology related to PD and, the searched literature retrieved no studies addressing this knowledge among any health professionals. This study found that despite the increase in the prevalence of individuals affected by PD in the world and, PD considered as the fastest growing neurodegenerative disease (GDB, 2016), the epidemiological knowledge in PD among health professionals has not been evaluated by the scientific community. This fact deserves attention, as health surveillance allows the planning of strategies for resource adaptations, adjustment of measures, as well as the identification of factors that may contribute to the prevention and improvement of care for people with PD.

Several studies have postulated that the main causes of mortality in PD is due to pneumonia, as a result of aspiration, cerebrovascular and cardiovascular changes (Pinter, *et al.*, 2015) and, SLPs and audiologists in the state of Alagoas demonstrated knowledge on these causes, as 47.3% stated that the main cause of death among PD patients is due to pneumonia, followed by 41.8% stating that it is due to cerebrovascular changes, and 10.9% due to cardiovascular problems.

The lack of knowledge about the SUDPAR phenomenon was the most striking result found among SLPs and audiologists in Alagoas, representing 87.2% of the professionals. An impressive reality is that people with PD die and, many of them die early and without autopsy findings (Scorza, *et al.*, 2017; Scorza, *et al.*, 2016). However, SLPs and audiologists in Alagoas, regardless of gender and age (table 2) do not know about SUDPAR and, therefore, the majority of SLPs and audiologists do not discuss about the fatal event with their patients and/or family members/caregivers. Interestingly, only 26 (12.8%) SLPs and audiologists claimed to know about SUDPAR and, of these, 15 professionals discuss with their patients and/or caregivers/family members in case they are asked about the risks of the tragic outcome.

A research conducted in Lao (The Lao People's Democratic Republic) found that the greatest lack of knowledge among doctors is in relation to non-motor symptoms and the impact of drugs on PD (Phokaewvarangkul, *et al.*, 2020). In

Thailand, a group of researchers detected gaps in the knowledge of neurologists, residents, intensivists, general practitioners and nurses about diagnosis, pharmacological options, and progression of PD, thus, the authors suggested didactic training, conference presentations, journal articles, meetings and small group discussions to promote the professionals' reflection on the phenomenon so that this knowledge gap is filled (Bhidayasiri, *et al.*, 2014).

Another study carried out in the United States evaluated an interprofessional education program for PD composed of physicians, nurses, occupational therapists, music therapists, medical assistants, social workers, SLPs and audiologists, and concluded that the knowledge in PD was beneficial regarding improvements on team strategies and their role in other areas and team attitudes, in addition to important practical improvements, indicating that interdisciplinary educational programs are a good alternative for improving knowledge about PD among health professionals (Cohen, *et al.*, 2016).

Through a questionnaire applied to PD specialists, certified by competent bodies in the United Kingdom, geriatricians, neurologists and nurses highlighted that the greatest barrier to the treatment of PD patients during hospitalization is the team's lack of training and knowledge (Skelly, *et al.*, 2015). In the Netherlands, researchers identified complaints from caregivers and PD patients living in nursing homes about the lack of empathy and nurses' knowledge about the fluctuations in motor symptoms of PD patients, about the importance of administering Levodopa at the prescribed time, about the drug contraindications, and about investigations needed in PD patients (magnetic resonance imaging in patients with deep brain stimulation or antipsychotics). The study justified these difficulties in professionals' knowledge due to the program *ParkinsonNet*, a national network of health professionals specialized in the treatment of PD patients who train professionals in the country; however, the program has only recently included professionals from nursing homes (Van Rumunda, *et al.*, 2014).

Despite the number of studies addressing the knowledge of health professionals correlating with PD (Cohen, *et al.*, 2016, Phokaewvarangkul, *et al.*, 2020; Bhidayasiri, *et al.*, 2014; Skelly, *et al.*, 2015; Van Rumund, *et al.*, 2014), a lack of research on the knowledge of SUDPAR among them is observed, reflecting the urgent need to use educational strategies so that the concept of SUDPAR is recognized among health professionals in order to prevent the tragic outcome in PD patients. Whereas, health professionals can alert them about this tragic event, as well as protective measures, such as the importance of correct daily water intake (Menezes-Rodrigues, *et al.*, 2019), cardiac routine exams (Scorza, *et al.*, 2018) and physical exercise (Scorza, *et al.*, 2018), about the care with polypharmacy (Scorza, *et al.*, 2016) and the need to control the symptoms of the disease in order to prevent SUDPAR and ensure a better quality of life.

5. Conclusion

Despite understanding about the mortality factors in PD, most SLPs and audiologists in the state of Alagoas do not know about the PD epidemiological data or about the SUDPAR phenomenon, therefore, they do not discuss about this tragic outcome with patients and/or with their family members/caregivers. Thus, educational strategies are urgent to make SLPs and audiologists aware of the SUDPAR, preventing early death in patients affected by PD.

This study was carried out among SLPs and audiologists from Alagoas, a small state in Brazil. It would be interesting for the research to be replicated with SPLs and audiologists throughout the national territory and world. It would allow the insertion of the SUDPAR concept in a greater number of SLPs and audiologists, who, during their clinical practice, present a great possibility of finding patients with PD and are auxiliaries in the prevention of the tragic outcome in these patients.

Acknowledgment

“This work was carried out with the support of the Coordination for the Improvement of Higher Education Personnel Brazil (CAPES) Financing Code 001”.

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