

Mestrado em Fisioterapia Neuro Funcional

Unidade Curricular: Dissertação

15ª Edição

**Perceived risk of drowning in Parkinson's Disease: Perspectives
from patients, caregivers, and healthcare professionals**

**Dissertação elaborada com vista à obtenção do grau de mestre em
Fisioterapia Neurofuncional**

Ana Beatriz Costa Soeiro

Orientador: Professora Doutora Raquel Bouça-Machado

Setembro, 2025

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Resumo

Introdução: A Doença de Parkinson (DP) é uma doença neurodegenerativa que compromete de forma significativa a funcionalidade dos pacientes. A evidência sugere que a DP prejudica a capacidade para nadar, aumentando assim, o risco de afogamento. Um estudo relatou que 49,9% dos pacientes com DP experienciaram um episódio de afogamento (não fatal), contudo, a investigação sobre este tema permanece limitada.

Objetivo: Explorar as percepções de risco de afogamento e as estratégias de segurança entre pessoas com DP, cuidadores e profissionais de saúde (PS). **Métodos:** Foi realizado um inquérito, com participantes recrutados através do CNS – Campus Neurológico, associações nacionais de pacientes e redes sociais. O estudo foi aprovado pela Comissão de Ética do CNS, e todos os participantes forneceram consentimento informado antes de qualquer procedimento do estudo. **Resultados:** De um total de 228 participantes (115 pessoas com DP; 57 cuidadores; 56 PS) foi reconhecido um risco aumentado de afogamento por 96,4 % (n = 54) dos PS, por 80,7% (n = 46) dos cuidadores e por 57,4% (n=66) das pessoas com DP. Em piscinas de maior profundidade, 55,7% (n=64) dos pacientes dizem sentir-se muito confiantes ou com confiança e 58,3% (n=67) consideram ter um risco baixo ou moderado de afogamento, necessitando apenas de supervisão ocasional. Contextos sem supervisão são apoiados por 42,1% (n = 24) dos cuidadores. As alterações da capacidade de nadar não são discutidas com um PS em 83,4% (n=96) dos pacientes. Entre as medidas de segurança identificadas, a mais reportada por todos os grupos foi supervisão constante (Pessoas com DP: 41,7%, n = 48; Cuidadores: 59,6%, n = 34; PS: 80,4%, n = 45). Em seguida, destaca-se o uso de dispositivos de flutuação referido pelos pacientes (21,7%, n=25) e cuidadores (21,1%, n=12) e a permanência em águas menos profundas mencionada pelos PS (33,9%, n=19). **Conclusões:** A percepção de risco de afogamento nas pessoas com DP é inferior à dos cuidadores e PS. Além disso, alguns pacientes e cuidadores demonstraram preferência por ambientes aquáticos associados a um maior risco de afogamento, acreditando que apenas uma supervisão ocasional é necessária, não sendo este um tema discutido frequentemente com os PS. As medidas de segurança mais sugeridas foram supervisão constante, dispositivos de flutuação e atividades em águas menos profundas.

Palavras-chave: Doença de Parkinson; Percepção de risco de afogamento; Estratégias de segurança.

Abstract

Introduction: Parkinson's disease (PD) is a neurodegenerative disorder that significantly impacts patients' functionality. Evidence suggests that PD impairs swimming ability, thereby increasing drowning risk. One study reported that 49,9% of people with PD (PwPD) had experienced a non-fatal drowning episode, however, research on this topic remains limited. **Objective:** To explore perceptions of drowning risk and safety strategies among PwPD, caregivers, and healthcare professionals (HCPs). **Methods:** A survey was conducted with participants recruited through CNS – Campus Neurológico, national patient's associations, and social media. The study was approved by the CNS Ethics Committee, and all participants provided informed consent prior to study procedures. **Results:** A total of 228 participants were included (115 PwPD; 57 caregivers; 56 HCPs). An increased drowning risk was acknowledged by 96,4% (n = 54) of HCPs, 80,7% (n = 46) of caregivers, and 57,4% (n = 66) of PwPD. In deep pools, 55,7% (n = 64) of PwPD reported feeling confident or very confident, and 58,3% (n = 67) perceived their drowning risk as low or moderate, requiring only occasional supervision. Unsupervised aquatic contexts were supported by 42,1% (n=24) of caregivers. Changes in swimming ability are not discussed with an HCP in 83,4% (n = 96) of patients. Among safety measures identified, constant supervision was the most frequently reported across all groups (PwPD: 41,7%, n = 48; Caregivers: 59,6%, n = 34; HCPs: 80,4%, n = 45). Additionally, use of flotation devices was highlighted by PwPD (21,7%, n = 25) and caregivers (21,1%, n = 12) and staying in low depth areas was emphasized by HCPs (33,9%, n = 19). **Conclusions:** The perception of drowning risk among PwPD is lower compared with caregivers and HCPs. Furthermore, some patients and caregivers express preference for aquatic environments associated with greater drowning risk, believing that only occasional supervision is necessary, not being a topic frequently discussed with HCPs. The most reported safety measures were constant supervision, use of flotation devices, and remaining in low depth areas.

Keywords: Parkinson's disease; Drowning risk perception; Safety strategies.

List of Abbreviations

CADTH	Canadian Agency for Drugs and Technologies in Health
CNS	Campus Neurológico
DBS	Deep Brain Stimulation
e.g.	<i>exempli gratia</i> , significa por exemplo
et al.	ou <i>et alii</i> , <i>et alia</i> , <i>et alibi</i> significa e outros ou e outros colaboradores
EQ-5D-3L	EuroQol 5- Dimension 3-Level
EQ-VAS	EuroQol Visual Analogue Scale
HCPs	Health Care Professionals
MCID	Minimal Clinically Important Difference
n.d	No date
PD	Parkinson's disease
PDQ-39	Parkinson's Disease Quality of Life Questionnaire – 39
PwPD	People with Parkinson's Disease
SF-36v2	Short Form Health Survey 36 Item v2
WHO	World Health Organization

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Introduction

Parkinson's disease (PD) ranks as the second most prevalent neurodegenerative disorder characterized by motor symptoms such as bradykinesia, rest tremor, and rigidity, alongside a wide range of non-motor manifestations (Church, 2021; Luo et al., 2025). Despite therapeutic advances, disease progression often leads to functional decline and loss of autonomy.

Swimming is a multifaceted activity requiring coordinated limb movements, maintenance of horizontal body position, and controlled breathing (Neves et al., 2020; Tosserams et al., 2020). Proficiency in swimming, floating, and other water-related skills are crucial for swimmers safety (Langendorfer et al., 2018; Stallman et al., 2017).

In older adults, drowning is an important concern, being considered a hidden epidemic with severe health implications (Clemens et al., 2021; Mahony et al., 2017; Peden et al., 2022; Royal Life Saving Society, 2021; World Health Organization (WHO), 2014, 2024). Research has shown that overestimating swimming ability or underestimating water-related risks can increase the likelihood of drowning incidents (Abercromby et al., 2022; Stanley et al., 2024; Stanley & Moran, 2016, 2021). Therefore, effective drowning prevention strategies go beyond skill acquisition and must foster risk awareness, particularly among vulnerable populations (Rahman et al., 2021; WHO, 2022). Risk perception in aquatic environments hinges on four variables: aquatic competence, confidence in water, perception of safety measures, and the perceived severity of drowning risks in specific situations (McCool et al., 2009). It is also known that water safety education can enhance understanding of swimming abilities and water hazards (McCool et al., 2009; Stallman et al., 2017; Szpilman et al., 2022).

In PD, swimming ability commonly deteriorates approximately five to six years after diagnosis, primarily due to bradykinesia and impaired interlimb coordination, both of which affect propulsion and the ability to float (Neves et al., 2018, 2020; Tosserams et al., 2020). More recently, underwater freezing has been described during swimming, representing a critical safety concern (Caniça et al., 2025). These impairments contribute significantly to the elevated rates of both fatal and non-fatal drowning incidents among people with PD (PwPD), with evidence showing that 49,1% reported having experienced a non-fatal drowning episode (Neves et al., 2018). Furthermore, PD is associated with a 3.4-fold increased likelihood of drowning incidents among older adults (Mahony et al.,

2017). Patients with Deep Brain Stimulation (DBS) may also experience additional interlimb coordination issues, raising their drowning risk (Lagerweij et al., 2022; Santyr et al., 2024).

Despite evidence suggesting that PwPD have a higher drowning risk, little is known about how they, their caregivers, and healthcare professionals (HCPs) perceive this risk. This study aims to address this gap in PD evidence, aiming to contribute to increase patients' safety.

Methods

Study type

The present study is considered a cross-sectional observational pilot study designed to explore the perspectives of PwPD, caregivers, and HCPs.

Ethical Considerations

The study protocol was approved by the Ethics Committee of CNS, Campus Neurológico, Torres Vedras, Portugal (Ref nº 09.2024-R) (Annex I).

PwPD, caregivers and HCPs were provided with information regarding the study's goals, duration, procedures, voluntary participation, and associated risks before they were asked to give their informed consent. No study procedures were commenced until participants had signed the informed consent form (Annex II).

To ensure that the required informed consent had been obtained prior to the completion of the survey, the following procedure was implemented: Patients invited via email or social media initially received a link directing them to the participant information document and to a page where they were required to confirm their understanding of the information and their consent to participate in the study. To do so, they were asked to respond "yes" to the question regarding their agreement to participate, enter their initials, and provide the date. Upon submission of this information, the participants received automatically a second link granting access to the survey. Within the survey, they were

again asked to enter their initials and the date. They were also asked whether they had previously completed the survey and whether they had already signed the consent form.

For the paper-based version, the investigator provided the information, along with the informed consent form and the survey, at the conclusion of a routine medical appointment or at the end of the rehabilitation sessions attended by patients at the centre.

If the survey was conducted via telephone, the informed consent was obtained and recorded before any survey questions were asked.

Regardless of the three options, the informed consent was obtained by the main researcher.

Any information collected during the research was kept confidential. Data collected from the surveys were entered into a database for statistical analysis, which was accessible only to the study team. The data obtained were used exclusively for the purposes of this research.

Participants

Given the exploratory nature of this study, a convenience sample of 100 PwPD, 50 caregivers and 50 HCPs was deemed appropriate to address the study's objective. Fowler, (2014) suggests that a sample size of around 100-200 is often sufficient to provide reasonably precise estimates in survey research.

Participants were recruited from the CNS-Campus Neurológico, a specialized centre in movement disorders in Portugal, from national PD patient's associations and social media.

PwPD were required to have a clinical diagnosis of PD and either possess the ability to swim or report at least occasional visits to aquatic environments (beaches, pools, rivers, or hot springs). Eligible caregivers had to provide care to PwPD, who were able to swim or who reported at least occasional visits to aquatic environments. HCPs were included if they had current experience with PD. All participants were also required to be available and willing to participate in the study, and to be capable of providing informed consent. Atypical parkinsonisms were excluded. Given the nature and objectives of the study, the participation of patients with associated comorbidities was not ruled out. To address this, the survey included a specific item regarding the presence of other

comorbidities, allowing researchers to identify any additional health conditions among the participants.

Instruments

A questionnaire was developed for this study, with specific versions for patients, caregivers and HCPs (Annex IV). The main sections included: sample characterization, previous engagement in aquatic activities, aquatic capacity, level of confidence in aquatic environment, perception of drowning risk, and strategies for minimizing this risk.

Sample characterization

Sample characterization included questions on demographic data (age, gender, level of education). The patient's version also included questions about clinical data (diagnosis duration, comorbidities, presence of DBS, motor symptoms and health status). For caregivers and HCPs, the number of years they have cared for or worked with PD was also asked, as well as their professional category in this last group.

This section in the patient's survey included the self-reported EuroQol 5-Dimension 3 Level (EQ-5D-3L). This tool is a self-report measure of the patient's quality of life, being also a valid instrument for the Portuguese population and for PwPD (Ferreira et al., 2013; Zahra et al., 2020). The first part has five dimensions (Mobility, Self-Care, Usual activities, Pain/ Discomfort, Anxiety/Depression), graded from 1 to 3 (higher scores, indicate a worst health status) and the second part consists of a visual analogue scale (EQ-VAS) on which the patient rates his/her perceived health from 0 (the worst imaginable health) to 100 (the best imaginable health) (Ferreira et al., 2013).

The EQ-5D-3L questionnaire has demonstrated acceptable reliability, with a Cronbach's alpha of 0.716 and moderate to good test–retest agreement ($\kappa = 0.308–0.647$) (Ferreira et al., 2013). The EQ-VAS also showed high reliability, with an intraclass correlation coefficient of 0.862 (Ferreira et al., 2013). Construct validity was supported by expected associations with age, gender, illness status, and with Short Form Health Survey 36 Item v2 (SF-36v2) scores (Ferreira et al., 2013). The EQ-5D-3L is also a valid instrument in PD, since it correlates strongly with other specific measures, such as the Parkinson's Disease Quality of Life Questionnaire – 39 (PDQ-39) and with the disease severity (Ferreira et al., 2013; Zahra et al., 2020). Regarding the minimal clinically

important difference (MCID) for PwPD, the index score ranges between 0.10 and 0.11 (Canadian Agency for Drugs and Technologies in Health (CADTH), 2018). In PD, this scale is also responsive to changes in health status over a four-year period (Luo et al., 2010).

Practice of aquatic activities

The patient's survey included questions about the frequency and location of their aquatic activities. All aquatic activities were included, even those that do not require swimming, but only general mobility, such as aquatic physiotherapy sessions. The caregiver's section included questions about unsupervised water activities and venturing into deeper waters. This section was omitted from the HCPs' survey.

Aquatic Capacity

Aquatic capacity questions covered the patient's swimming ability, the need for a flotation device, ability to float, main difficulties when swimming, difficulties like accidental water ingestion and any past drowning incidents along with the circumstances. The caregiver's section also focused on changes in the patient's swimming ability, difficulties such as accidental water ingestion, and any history of drowning incidents. HCPs were asked if a PD diagnosis affects swimming capacity and what factors should be evaluated to identify potential causes of swimming difficulties. This group was also asked if patients were aware of changes in their swimming abilities and if they knew any past drowning incidents among their patients.

Level of confidence in aquatic environment

This section included questions about confidence in different situations and in several aquatic environments as well as concerns while swimming or moving in the water. HCPs did not participate in this section of the survey.

Perception of risk in aquatic activities

This section covered the drowning risk across different aquatic settings with varying levels of supervision. It also explored how PD influences perceived risk, from both the patient's, caregiver's and HCPs' viewpoints.

Strategies for minimizing risk

This section aimed to identify a potential strategy to enhance safety for PwPD during aquatic activities. It was also explored whether patients had previously discussed their swimming difficulties with an HCP and if they had undergone an evaluation of their swimming ability. Additionally, this section aimed to determine if patients and caregivers recognize the importance of such evaluations and to identify and justify the optimal timing for conducting them. HCPs were asked if they routinely inquire about swimming challenges in their patients, the optimal disease stage to address these issues, and to suggest three practical drowning prevention strategies.

Study procedures

Prior to the wide release of the survey, a feasibility pretest was conducted with five PwPD, five caregivers, and five HCPs to identify and rectify comprehension and usability issues. Participants completed both paper and online versions of the survey. Feedback was received, from this pretest, allowing an improvement in the quality of the survey. Based on the results, two questions were added to improve the survey: one in the section 'Sample Characterization' in the patient's survey and another in the section 'Strategies for Minimizing Risk' in the HCP's survey. An online, phone, and paper-based survey was conducted between November 2024 and February 2025.

Through national patient's associations and CNS – Campus neurológico, the survey was disseminated by email and social networks (e.g., Facebook, LinkedIn, Google+ and Instagram), along with the contact information of the principal investigator. Inpatients and outpatients from CNS | Campus Neurológico were contacted by email or phone with the respective centre authorization, as documented in Annex III. For the paper-based version, the printed documents of information to the participant, informed consent

and survey were handed at the end of the routine medical appointment by the main researcher.

Before having access to the survey itself, all participants were informed about the objectives, duration, procedures and voluntariness of the study and gave their informed consent.

Data collected during the research was maintained confidential. Data was collected through a Google Forms questionnaire, and was extracted and stored in an Excel file, which served as the basis for the analysis, only available to the study team. The Excel file included sample characterization data, as well as data that help to understand the perception of drowning risk. The information was then analysed.

Data analysis

Descriptive analysis was performed for all variables to characterize the sample. Mean, standard deviation, median and range of values were calculated for all continuous variables while absolute and relative frequencies were used for the categorical data.

Variables can be categorized into numerical (continuous/discrete) and categorical (nominal and ordinal) variables. For numerical variables (Age; Year of Diagnosis; Health status (0-100); Years of caregiving; Working Time with PD patients; Stage of PD suitable for questioning swimming ability), mean, standard deviation, median, and range values were calculated. For categorical variables (Yes/No questions; Level of education; Gender; Other comorbidities; Motor symptoms; Health status questions; Frequency of the aquatic environments that can be visited; Types of aquatic environments that can be frequented; Types of floating devices; Level of confidence to frequent certain aquatic environments; Level of concern about confidence in swimming ability; Degree of drowning risk associated with PD; Level of risk associated with drowning in various aquatic environments; Stage of the disease at which it is considered important to address the assessment of swimming ability; Degree of relationship with the patient; HCP professional's category) absolute and relative frequencies were used to describe the data.

Due to high heterogeneity in the results, only those mentioned more than twice were considered as distinct categories. All other responses were classified as "Others".

Statistical analysis was conducted using Microsoft Excel (Microsoft, Seattle, WC, USA).

Results

A total of 228 participants answered the survey. Participant's characteristics are provided in Table 1. Among the participants: 115 were PwPD (mean age of $68 \pm 10,2$ years; mean years since diagnosis of 10 ± 6 ; 55,7 % (n= 64) were males); 57 were caregivers (mean age of $59,4 \pm 12,8$; mean years of caring of $11,2 \pm 7,4$; 80,7 % (n=46) were female) and 56 were HCPs (median professional experience with PwPD: 7 years [0.3-30]).

Table 1- Demographical and clinical characteristics of PwPD, Caregivers and HCPs.

PwPD's characteristics (n=115)		
Age (Mean, SD)		$68 \pm 10,13$
Male sex % (n)		55,7 % (n=64)
Education Level % (n)	Postgraduate education	27% (n=31)
	Secondary education	27% (n=31)
	Post secondary education	26,1% (n=30)
	Primary education or less	11,3% (n=13)
	Basic education	8,7% (n=10)
Years since diagnosis (Mean, SD)		$10 \pm 5,97$
Other Comorbidities % (n)	No	64,4 % (n=74)
DBS % (n=110)	No	85,5 % (n=94)
Main difficulties % (n)	Balance Problems	69,6% (n=80)
	Motor fluctuations	69 % (n=79)
	Freezing	34,8% (n=40)
	Dual task activities	33 % (n=38)
	No difficulties	5,2 % (n=6)
	*EQ-5D-3L	
Mobility % (n)	No problems in walking	40% (n=46)
	Some problems in walking	60% (n=69))
Self-Care activities % (n)	No problems with washing or dressing	67,8% (n=78)
	Some problems with washing or dressing	28,7% (n=33)
	Unable to wash or dress	3,5% (n=4)
Usual activities % (n)	No problems with usual activities	51,3% (n=59)
	Some problems with usual activities	47,8% (n=55)
	Unable to do usual activities	0,9% (n=1)
Pain or Discomfort % (n)	No pain or discomfort	38,3% (n=44)
	Moderate pain or discomfort	57,4% (n=66)
	Extreme pain or discomfort	4,4% (n=5)

Anxiety or Depression % (n)	<i>No anxiety or depression</i>	40% (n=46)
	<i>Moderate anxiety or depression</i>	53,9% (n=62)
	<i>Extreme anxiety or depression</i>	6,1% (n=7)
Level of Health Status (Mean, SD)		70 ± 15,47
Caregiver's characteristics (n=57)		
Age (Mean, SD)		59,40 ± 12,77
Female sex (n (%))		80,7 % (n=46)
Years of caring (Mean, SD)		11,2 ± 7,44
Degree of relationship with PwPD % (n)	<i>Wife</i>	54,4% (n=31)
	<i>Husband</i>	21,1% (n=12)
	<i>Daughter</i>	17,5% (n=10)
	<i>Others</i>	7 % (n=4)
HCPs' characteristics (n=56)		
Age (Mean, SD)		31 ± 8,55
Profession % (n)	<i>Physiotherapist</i>	58,9% (n=33)
	<i>Nurse</i>	28,6% (n=16)
	<i>Medical doctor (Neurologist)</i>	12,5 % (n=7)
Experience with PD (Median)		7 [0,3-30]

*Higher EQ-5D-3L (EuroQol 5- Dimension 3-Level) scores indicate higher health utility.

Practice of aquatic activities

PwPD

Seventy-seven percent (n=89) reported knowing how to swim and 97% (n=112) frequented aquatic environments at least occasionally. Sixty-six percent (n=76) of patients engaged in aquatic activities during vacations. The most frequented environments were beaches (75,7%, n=87), followed by public pools (43,5%, n=50) and private pools at home (35,7%, n=41). (Table 2).

Caregivers

Eighty-six percent (n=49) reported caring for patients who could swim and 93% (n=53) carried for patients who visited aquatic environments at least occasionally. Fifty-eight percent (n=33) required patient supervision when engaging in aquatic environments and 68,4% (n=39) preferred to limit access to deep water (Table 2).

Table 2- Practice of aquatic activities among PwPD and Caregivers.

PwPD		
Know how to swim % (n)	Yes	77,4% (n=89)
Engage in aquatic environments % (n)	Yes	97,4% (n=112)
Aquatic environments % (n)	Beach	75,7 % (n= 87)
	Public Pool	43,5 % (n=50)
	Private Pool at home	35,7 % (n=41)
	Aquatic physiotherapy pool	23,5 % (n=27)
	River	22,6 % (n= 26)
	Thermal pools	14,8 % (n=17)
	Others	7 % (n=8)
Frequency of engaging in aquatic activities	Occasionally (eg: During vacations)	66,1 % (n=76)
	Weekly	28,7% (n=33)
	Monthly	2,6 % (n=3)
	Never	2,6 % (n=3)
Caregivers		
Patients who know how to swim from the family member perspective % (n)	Yes	86% (n=49)
Patients who engage in aquatic environments from the perspective of a family member % (n)	Yes	93% (n=53)
Supervision of a PD patient in water % (n)	With Supervision	57,9% (n=33)
	Without supervision	42,1% (n=24)
Engaging in deep water % (n)	No	68,4% (n=39)
	Yes, if accompanied	22,8% (n=13)
	Yes	8,8% (n=5)

Aquatic Capacity

PwPD

Regarding ability to float, 52,2 % (n=60) reported being able to float normally, and 12,2% (n=14) reported the need of flotation devices during aquatic activities. Thirty-five percent (n=40) indicated having swallowed water (Table 3).

The factors most frequently reported by patients, affecting swimming or aquatic mobility were loss of vertical balance and discoordination (25,2%, n=29) (Table 3). Regarding experiences of non-fatal drowning, 14,8% (n=17) reported past episodes

(Table 3). In these incidents involving PwPD, loss of vertical balance was identified as the main factor in 47,1 % (n=8) of cases (Table 3).

Caregivers

Regarding to aquatic capacity, 63,2% (n=36) believed PD impairs swimming, with 24,6% (n=14) answered their relatives swallowed water during aquatic activities (Table 3).

Caregivers most identified discoordination (22,8%, n=13), followed by insecurity and loss of vertical balance (8,8%, n=5) as the main factors affecting swimming or aquatic mobility (Table 3). Regarding non-fatal drowning incidents, 19,3% (n=11) reported past occurrences (Table 3). In these incidents involving PwPD, loss of vertical balance was the primary contributing factor in 33,3 % (n=4) of cases from the caregiver's perspective (Table 3).

HCPs

Ninety-eight percent (n=55) believed that PD impairs swimming ability and 59% (n=33) felt patients lack awareness of their swimming skills (Table 3).

The most popular factors affecting swimming or aquatic mobility among HCPs were bradykinesia (58,9%, n=33), followed by discoordination (44,6%, n=25) and by rigidity (39,3%, n=22) (Table 3).

Overall, 44,6 % (n=25) reported contact with PD patients who experienced non-fatal drowning incidents (Table 3).

Table 3- Aquatic capacity among PwPD, Caregivers and HCPs.

PwPD		
Use of flotation devices % (n)	Yes	12,2 % (n=14)
Perspectives on floating capacity % (n)	Yes	52,2 % (n=60)
	Yes, but only for short periods	27,8 % (n=32)
	No	20 % (n=23)
Accidental water ingestion % (n)	Yes	34,8 % (n=40)
Factors that contribute to difficulties in swimming or moving in water % (n)	Loss of vertical balance	25,2 % (n=29)
	Discoordination	25,2 % (n=29)
	Fatigue	13,9 % (n=16)
	Decreased propulsion	12,2 % (n=14)
	Difficulties with floating	11,3 % (n=13)
	Coordinating breathing	10,4 % (n=12)
	Fear	7 % (n=8)
	Loss of strength	6,1 % (n=7)
	Swimming long distances	6,1 % (n=7)
	Rigidity	6,1 % (n=7)
	Difficulties with accessibility	5,2 % (n=6)
	Diving	5,2 % (n=6)
	Cramps	4,3 % (n=5)
	Bradykinesia	3,5 % (n=4)
	Freezing	2,6 % (n=3)
I do not know	6,1 % (n=7)	
Others	9,6 % (n=11)	
No difficulties	17,4 % (n=20)	
Cases of non-fatal drowning % (n)	Yes	14,8 % (n=17)
Circumstances of non-fatal drowning % (n)	Loss of vertical balance	47,1 % (n=8)
	Tried to dive/swim	41,2 % (n=7)
	Others	11,8 % (n=2)
Caregivers		
Perspectives on whether PD affects swimming ability % (n)	Yes	63,2 % (n=36)
Accidental water ingestion % (n)	Yes	24,6 % (n=14)
Factors that contribute to difficulties in swimming or moving in water % (n)	Discoordination	22,8 % (n=13)
	Insecurity	8,8 % (n=5)
	Loss of vertical balance	8,8 % (n=5)
	Decreased propulsion	5,3 % (n=3)
	Rigidity	5,3 % (n=3)
	Others	22,8 % (n=13)
Cases of non-fatal drowning among relatives % (n)	Yes	19,3 % (n=11)
Circumstances of non-fatal drowning among	Loss of vertical balance	33,3% (n=4)
	Going out of depth	25% (n=3)

<i>relatives % (n)</i>	<i>Attempted to dive and unable to swim</i>	<i>16,7 % (n=2)</i>
	<i>Others</i>	<i>25% (n=3)</i>
HCPs		
<i>Perspectives on whether PD affects swimming ability % (n)</i>	<i>Yes</i>	<i>98,2 % (n=55)</i>
<i>Factors that contribute to difficulties in swimming or moving in water % (n)</i>	<i>Bradykinesia</i>	<i>58,9 % (n=33)</i>
	<i>Discoordination</i>	<i>44,6 % (n=25)</i>
	<i>Rigidity</i>	<i>39,3 % (n=22)</i>
	<i>Freezing</i>	<i>19,6 % (n=11)</i>
	<i>Postural deviations</i>	<i>19,6 % (n=11)</i>
	<i>Loss of vertical balance</i>	<i>16,1 % (n=9)</i>
	<i>Cognition</i>	<i>16,1 % (n=9)</i>
	<i>Tremor</i>	<i>14,3 % (n=8)</i>
	<i>Aerobic capacity</i>	<i>10,7 % (n=6)</i>
	<i>Dyskinesia</i>	<i>8,9 % (n=5)</i>
	<i>Blood pressure</i>	<i>8,9 % (n=5)</i>
	<i>Muscular strength</i>	<i>8,9 % (n=5)</i>
	<i>Motor fluctuations</i>	<i>7,1 % (n=4)</i>
	<i>Dual Task</i>	<i>5,4 % (n=3)</i>
	<i>Difficulties with floating</i>	<i>5,4 % (n=3)</i>
	<i>Others</i>	<i>14,3 % (n=8)</i>
<i>Perspectives on patient's awareness of their swimming difficulties % (n)</i>	<i>Do not have awareness</i>	<i>59 % (n=33)</i>
<i>Cases of non-fatal drowning among patients % (n)</i>	<i>Yes</i>	<i>44,6 % (n=25)</i>

Table 4- Perspectives on the level of confidence in aquatic environments among PwPD and Caregivers.

Global concerns regarding the ability to swim or move safely in the water % (n)		
PwPD	<i>I am concerned in deep water and without supervision</i>	36,5 % (n=42)
	<i>I am not concerned</i>	25,2 % (n=29)
	<i>I am concerned in deep water and under supervision</i>	20,9 % (n=24)
	<i>I am concerned in shallow water and without supervision</i>	13,9 % (n=16)
	<i>I am concerned in shallow water and under supervision</i>	3,5 % (n=4)
Caregivers	<i>I am concerned in deep water and without supervision</i>	42,1 % (n=24)
	<i>I am concerned in shallow water and without supervision</i>	22,8 % (n=13)
	<i>I am not concerned</i>	17,5 % (n=10)
	<i>I am concerned in deep water and under supervision</i>	14 % (n=8)
	<i>I am concerned in shallow water and under supervision</i>	3,5 % (n=2)
Level of confidence in aquatic environments % (n)		
Low depth pool % (n)		
	PwPD	Caregivers
<i>Very confident, not requiring supervision</i>	67,8 % (n=78)	47,4 % (n=27)
<i>Confident, requiring only occasional supervision outside the water (caregiver or lifeguard)</i>	23,5 % (n=27)	36,8 % (n=21)
<i>Little confident, requiring constant supervision in the water</i>	8,7% (n=10)	15,8 % (n=9)
Low depth beach/river % (n)		
	PwPD	Caregivers
<i>Very confident, not requiring supervision</i>	52,2 % (n=60)	38,6 % (n=22)
<i>Confident, requiring only occasional supervision outside the water (caregiver or lifeguard)</i>	29,6% (n=34)	29,8 % (n=17)
<i>Little confident, requiring constant supervision in the water</i>	13% (n=15)	22,8 % (n=13)
<i>Not confident</i>	5,2 % (n=6)	8,8 % (n=5)
Deep depth pool % (n)		
	Pw PD	Caregivers
<i>Very confident, not requiring supervision</i>	27% (n=31)	21,1% (n=12)
<i>Confident, requiring only occasional supervision outside the water (caregiver or lifeguard)</i>	28,7 % (n=33)	22,8 % (n=13)
<i>Little confident, requiring constant supervision in the water</i>	18,3 % (n=21)	15,8 % (n=9)
<i>Not confident</i>	26,1% (n=30)	40,4 % (n=23)
Deep depth beach/river % (n)		

	PwPD	Caregivers
<i>Very confident, not requiring supervision</i>	14,8% (n= 17)	8,8 % (n=5)
<i>Confident, requiring only occasional supervision outside the water (caregiver or lifeguard)</i>	26,1% (n=30)	26,3 % (n=15)
<i>Little confident, requiring constant supervision in the water</i>	15,7 % (n=18)	14 % (n=8)
<i>Not confident</i>	43,5 % (n=50)	50,9 % (n=29)

Level of confidence and risk of drowning perception

PwPD

Regarding overall concerns related to swimming ability and aquatic mobility, 36,5% (n = 42) expressed concern only when unsupervised in deep water. Concerning confidence levels in specific aquatic environments, PwPD felt very confident in low depth pools (67,8%, n=78) and in low depth beaches/rivers (52,2%, n=60). Moreover, PwPD reported feeling confident with occasional supervision in deep depth pools (28,7%, n=33) and feeling unconfident entering in deep depth beaches/rivers (43,5%, n= 50) (Table 4).

Overall, 42.6% (n=49) had not considered the association between PD and drowning risk. In specific aquatic settings, PwPD reported a low risk of drowning in low depth pools (74,4%, n=89) and in low depth beaches/rivers (57,4%, n=66). Additionally, PwPD mentioned a moderate risk in deep depth pools with occasional supervision (33,9%, n=39) and a higher risk when in deep depth beaches/rivers (43,5%, n=50) (Table 5).

Caregivers

Regarding overall concerns related to swimming ability and aquatic mobility, 42,1% (n = 24) expressed concern, when patients are unsupervised in deep water. Concerning confidence levels in specific aquatic environments, caregivers felt very confident in supporting access to low depth pools (47,4%, n = 27) and in supporting access to low depth beaches/rivers (38,6%, n=22) Additionally, caregivers mentioned feeling unconfident about patients entering in deep depth pools (40,4% , n=23) and entering in deep depth beaches/rivers (50,9%, n=29) (Table 4).

Regarding overall risk perception, 80,7 % (n=46) recognized a drowning risk linked to PD. In specific aquatic environments, caregivers associated a low risk of drowning with aquatic activities in low depth pools (66,7 %, n=38) and in low depth beaches/ivers (47,4 %, n=27). They also reported a very high risk in deep depth pools (36,8%, n=21) and in deep depth beaches/ivers (47,4%, n=27) (Table 5).

HCPs

Nighty-six percent (n=54) agreed that PD is linked to drowning risk (Table 5). Fifty-five percent (n=31) had not addressed this risk with their patients (Table 6).

Table 5- Perspectives on drowning risk among PwPD, Caregivers and HCPs.

Overall drowning risk perception		
<i>PwPD</i>	<i>I have not thought about risks before</i>	42,6% (n=49)
	<i>Moderate Risk</i>	27,8% (n=32)
	<i>High Risk</i>	20,9% (n=24)
	<i>Low Risk</i>	8,7% (n=10)
<i>Caregivers</i>	<i>Yes, there is risk.</i>	80,7% (n=46)
<i>HCPs</i>	<i>Yes, there is risk</i>	96,4% (n=54)
Drowning risk level by aquatic environment		
Low depth pool % (n)		
	PwPD	Caregivers
<i>Low risk, not requiring supervision</i>	77,4 % (n=89)	66,7% (n=38)
<i>Moderate risk, requiring occasional supervision by someone outside the water (caregiver or lifeguard)</i>	14,8 % (n=17)	21,1% (n= 12)
<i>High risk, requiring constant supervision by someone in the water</i>	7 % (n=8)	12,3 % (n=7)
<i>Very high risk, not entering the aquatic environment</i>	0,9% (n=1)	
Low depth beach/river % (n)		

	PwPD	Caregivers
<i>Low risk, not requiring supervision</i>	57,4 % (n=66)	47,4 % (n=27)
<i>Moderate risk, requiring occasional supervision by someone outside the water (caregiver or lifeguard)</i>	27,8 % (n=32)	28,1 % (n=16)
<i>High risk, requiring constant supervision by someone in the water</i>	9,6% (n=11)	19,3 % (n=11)
<i>Very high risk, not entering the aquatic environment</i>	5,2 % (n=6)	5,3 % (n=3)

Deep depth pool % (n)

	PwPD	Caregivers
<i>Low risk, not requiring supervision</i>	24,4 % (n=28)	21,1 % (n=12)
<i>Moderate risk, requiring occasional supervision by someone outside the water (caregiver or lifeguard)</i>	33,9 % (n=39)	29,8 % (n=17)
<i>High risk, requiring constant supervision by someone in the water</i>	12,2 % (n=14)	12,3 % (n=7)
<i>Very high risk, not entering the aquatic environment</i>	29,6% (n=34)	36,8 % (n=21)

Deep depth beach/river % (n)

	PwPD	Caregivers
<i>Low risk, not requiring supervision</i>	11,3 % (n=13)	8,8 % (n=5)
<i>Moderate risk, requiring occasional supervision by someone outside the water (caregiver or lifeguard)</i>	31,3 % (n=36)	28,1 % (n=16)
<i>High risk, requiring constant supervision by someone in the water</i>	13,9 % (n=16)	15,8 % (n=9)
<i>Very high risk, not entering the aquatic environment</i>	43,5 % (n=50)	47,4 % (n=27)

Table 6- Perspectives on swimming assessments and appropriate timing of evaluation among PwPD, Caregivers and HCPs.

PwPD		
PwPD assessed for swimming ability	Yes	13% (n=15)
PwPD who discussed changes in swimming ability	Yes	16,6% (n=19)
PwPD who value discussing swimming challenges or professional evaluation	Yes	91,3% (n=105)
Stage of disease for swimming assessment	After the diagnosis	60% (n=63)
	5 years after the diagnosis	26,7% (n=28)
	10 years after the diagnosis	13,3% (n=14)
Caregivers		
Caregivers who value discussing swimming challenges or professional evaluation	Yes	68,4% (n=39)
Stage of disease for swimming assessment	After the diagnosis	48,7% (n=19)
	5 years after the diagnosis	28,2% (n=11)
	10 years after the diagnosis	23,1% (n=9)
HCPs		
HCPs' who discussed changes in swimming ability of their patients	Yes	44,6% (n=25)
Stage of disease for initiating swimming assessment	Hoehn & Yahr 1	42,9% (n=24)
	Hoehn & Yahr 2	35,7% (n=20)
	Hoehn & Yahr 3	19,6% (n=11)
Reasons for choosing the stage Hoehn & Yahr 1 (n=23)	Initial education and prevention.	52,2% (n=12)
	Slight motor symptoms (unilateral)	26,1% (n=6)
	Stable cognitive capacity	13% (n=3)
	I do not know	8,7% (n=2)
Reasons for choosing the stage Hoehn & Yahr 2 (n=17)	Motor changes (bilateral)	68,8% (n=11)
	Initial education and prevention	12,5% (n=2)
	Stable cognitive capacity	12,5% (n=2)
	Others	6,3% (n=1)
	I do not know	6,3% (n=1)
Reasons for choosing the stage Hoehn & Yahr 3 (n=10)	Mild to moderate motor changes	57,1% (n=4)
	I do not know	42,3% (n=3)
	Loss of vertical balance	28,6% (n=2)
	Others	14,3% (n=1)

Minimization Strategies

PwPD

Of all PwPD, 87 % (n=100) reported their swimming abilities had never been assessed and 83,4 % (n=96) had never discussed aquatic skills with an HCP. Ninety-one percent (n=105) supported a swimming evaluation, with 60% (n=63) favouring it after diagnosis (Table 6).

Constant supervision was the most frequently suggested risk minimization strategy (41,7%, n=48), followed by using flotation devices (21,7 %, n=25) and remaining in low depth areas (13,9 %, n=16) (Table 7).

Caregivers

Regarding the importance of addressing swimming challenges or undergoing an evaluation by an HCP, 68,4% (n=39) supported it, with 48,7% (n=19) endorsing assessments primarily after the diagnosis (Table 6).

Constant supervision was the most reported minimization strategy (59,6 %, n=34), followed by using flotation devices (21,1 %, n=12) and swimming ability assessments (8,7 %, n=10) (Table 7).

HCPs

Forty-three percent (n=24) selected 'Hoehn & Yahr 1' as the most appropriate stage to initiate a swimming assessment, mainly to adopt initial education and prevention strategies (52,2%, n=12) (Table 6).

The most frequently suggested was constant supervision (80,4%, n=45), followed by remaining in low depth areas (33,9%, n=19) and swimming assessments with aquatic physiotherapy (25%, n=14) (Table 7).

Table 7- Strategies for minimizing risk among PwPD, Caregivers and HCPs.

Strategies for minimizing risk			
	PwPD	Caregivers	HCPs
Constant Supervision	41,7 % (n=48)	59,6 % (n=34)	80,4 % (n=45)
Use of flotation devices (buoys, arm bands, life jacket)	21,7 % (n=25)	21,1 % (n=12)	14,2 % (n=8)
Remain in shallow areas	13,9 % (n=16)	5,3 % (n= 3)	33,9 % (n=19)
Conduct an assessment of swimming ability	7% (n=8)	8,7 % (n=10)	25% (n=14)
Initiate aquatic physiotherapy for teaching safety strategies			25% (n=14)
Avoid entering aquatic environments while in OFF Stage			19,6 % (n=11)
Stay near the edge of the pool	8,7 % (n=10)		
Accessibility in swimming pools (ramps and handrails)			8,9 % (n=5)
Teaching CPR to family members			5,4 % (n=3)
Avoid entering more turbulent aquatic environments			5,4 % (n=3)
I do not know	7 % (n=8)	5,3 (n=3)	
Others	5,2 % (n=6)	5,3 (n=3)	35,7 % (n=20)

Discussion

This study examined perceptions of drowning risk and prevention strategies among 228 participants: 115 PwPD, 57 caregivers and 56 HCPs. PwPD had a mean age of 68 years and a mean disease duration of 10 years. Most PwPD reported being able to swim (77,4%, n=89) and frequented aquatic environments at least occasionally (97,4%, n=112), primarily beaches (75,7%, n=87), public pools (43,5%, n=50), and private home pools (35,7%, n=41).

Overall, HCPs (96,4%, n=54) and caregivers (80,7%, n=46) perceived a higher drowning risk than PwPD themselves (57,4%, n=66). PwPD reported higher confidence when engaging in aquatic activities compared with caregivers and HCPs.

Safety of Aquatic Activities for PwPD

Beaches were the most frequently visited aquatic environment, predominantly during vacations. Natural water environments carry higher drowning risk than pools due to strong currents, limited lifeguard supervision, hypothermia, and restricted emergency access (WHO, 2024). In the general population, beaches and rivers account for 19% and 27% of drowning deaths, respectively, and older individuals with medical conditions represent 30,7% of fatal cases during summer (Mahony et al., 2017; Peden et al., 2022; Royal Life Saving Society - Australia, 2023; Scarr et al., 2021). These data underscore that unpredictable aquatic environments can significantly elevate drowning risk for PwPD.

All participant groups recognized that PD may impair swimming and aquatic mobility. The most reported contributing factors were motor impairments, including discoordination, bradykinesia, rigidity, and loss of vertical balance. These findings align with prior literature linking PD motor symptoms to difficulties with propulsion, floating, and coordinated movements in water (Langendorfer et al., 2018; Neves et al., 2020 e 2018; Stallman et al., 2017; Szpilman et al., 2022; Tosserams et al., 2020). Loss of vertical balance may result from water turbulence, displacing the body's center of mass, particularly when feet are fixed on the substrate (Elbar et al., 2013). Insecurity was also mentioned as a main concern. Insecurity and fear of water were also frequently reported, reflecting lower swimming ability and an established association with higher drowning risk (Misimi et al., 2020).

Notably, 19,6% of HCPs identified freezing in water as a safety concern, consistent with recent reports of “underwater freezing” in PwPD (Caniça et al., 2025). Flotation difficulties were observed in a minority of participants, with 52% of PwPD reporting no flotation problems. This contrasts with prior findings in which flotation deficits were a leading reason for discontinuing swimming in PD (Neves et al., 2018). Accidental water ingestion, potentially reflecting impaired breathing coordination, was reported less frequently than expected based on the literature (Neves et al., 2018 e 2020; WHO, 2022). These discrepancies highlight the need for further research to clarify aquatic capacity limitations in PD.

Despite the availability and potential benefits of flotation devices, 87,8% of PwPD did not use them, suggesting limited awareness of their protective role (Leavy et al., 2023;

WHO, 2017). Barriers to use include perceived stigma, as flotation aids are often viewed as markers of poor swimming ability or functional impairment (Quistberg et al., 2014).

Approximately 15% of PwPD reported prior non-fatal drowning, compared with 19% of caregivers. Patients were not matched to caregivers, and the higher proportion reported by caregivers may indicate underreporting or underestimation by PwPD, consistent with literature describing similar phenomena in older adults for falls (Freiberger & Vreed, 2011).

The observed incidence in this study is lower than prior reports, such as Neves et al. (2018), in which 49,1% of PwPD with swimming experience reported non-fatal drowning, potentially reflecting differences in disease stage or type of aquatic exposure. Among HCPs, 45% had encountered patients with past drowning events, likely reflecting broader clinical experience (Inoue et al., 2023). Future studies should further investigate this topic, including whether a history of drowning predicts future risk, as observed with falls (Allen et al., 2013).

Recognition of Drowning Risk

Overall, HCPs and caregivers perceived a higher drowning risk than PwPD, who often display greater confidence and lower risk perception when engaging in aquatic settings. This discrepancy may reflect PwPD difficulty in attributing drowning events to PD, instead attributing them to external factors, relying on prior swimming skills, and underestimating current risks, similar to what is observed in older people (Stanley & Moran, 2021; Royal Life Saving Society, 2025) and in milder stages of PD regarding falls (Inoue et al., 2023; Lee et al., 2016; Sangarapillai et al., 2021). It also highlights the lack of discussion with HCPs, regarding aquatic hazards, underscoring the need for greater awareness and water safety education (Luo et al., 2024).

A further point of concern is that, although 22,6% of PwPD were unable to swim, they nonetheless continued to frequent aquatic environments. It is important to recognize that within this percentage lies an even higher likelihood of drowning events. However, this risk perception may be influenced by the type of aquatic activity, supervision type, water depth and aquatic setting, according to our findings.

Most PwPD, in agreement with caregivers, reported greater confidence and a lower perception of drowning risk, not considering supervision necessary in low depth environments. Although such environments are generally considered safer than deeper

ones (WHO, 2022), it is important to highlight that, as the disease progresses, motor symptoms may worsen and become unpredictable, which may increase the risk (Masood & Jimenez-Shahed, 2023). Being alone in water with medical conditions quadruples drowning risk (Mahony et al., 2017; Scarr et al., 2021). Notably, over 40% of caregivers supported unsupervised access to water environments, without specifying the type of setting, consistent with prior reports of misperceptions of water safety knowledge among caregivers (Johnson & Lawson, 2023).

In deep-water environments, PwPD and caregiver perceptions diverged, particularly in pools. PwPD often felt confident and perceived only moderate risk, requiring occasional supervision, whereas most caregivers reported low confidence and high perceived risk. Some patients reported feeling very confident without supervision, a concerning finding given motor limitations and the higher risk of drowning in deep water (Armstrong & Erskine, 2018; Neves et al., 2020; Peden & Franklin, 2020; Rahman et al., 2021). Occasional supervision in these settings may be insufficient (Peden & Franklin, 2020). In deep beaches/rivers, both groups reported low confidence and perceived high risk, consistent with prior literature on open-water hazards (Stanley et al., 2024; Stanley & Moran, 2021; WHO, 2024). Nevertheless, over a quarter of PwPD and caregivers reported moderate confidence with occasional supervision, highlighting persistent misperceptions and the need for targeted water safety education (Johnson & Lawson, 2023; Collete et al., 2025; Love-Smith et al., 2022).

Risk Minimization Strategies

Despite recognizing PD-related drowning risk, 55,4% of HCPs did not routinely assess swimming ability in practice. Most PwPD had never undergone skill assessment (87%) or discussed aquatic limitations with an HCP (83%). However, over 90% of PwPD and 68% of caregivers supported formal swimming assessments. Early involvement of HCPs could promote awareness, identify deficits, and implement prevention strategies.

All groups favored early evaluation, in line with literature recommending early self-management and preventive measures to preserve function and reduce risk (Osborne et al., 2022; Keus et al., 2014). Across groups, the most frequently suggested safety strategies were constant supervision, use of flotation devices, and remaining in low-depth water, in line with general aquatic safety recommendations (Ashraf et al., 2024; Johnson & Lawson, 2023; Laksham, 2024; Leavy et al., 2023; Scarr et al., 2021; WHO, 2022).

Effective supervision involves continuous observation, proximity, readiness to assist, CPR preparedness, and minimizing distractions, while flotation devices provide low-cost buoyancy support (Royal Life Saving, n.d.; Laksham, 2024).

Given these findings and the recognition of swimming impairment as a significant safety concern, this might represent an opportunity for HCPs to assess drowning risk and risk perception among PwPD and caregivers, particularly before periods of increased aquatic exposure, such as summer holidays. Participants most commonly perceived supervision, use of flotation devices and remaining in low-depth water as key preventive strategies. Future research is needed to confirm the effectiveness of these strategies in PwPD. Future studies should also aim to elucidate the specific factors contributing to swimming and aquatic mobility difficulties, determine the disease stage at which these changes emerge, and formally evaluate swimming ability. Additionally, research should examine the predictive value of prior non-fatal drowning events and assess the effectiveness of structured interventions in reducing drowning risk among PwPD.

This study is limited by recruitment primarily from a specialized movement disorders center, which may confer greater PD knowledge and influence risk perception. Future studies involving larger multicenter cohorts, would provide a more generalizable perspective. Nevertheless, these exploratory findings provide valuable insight into an under-researched aspect of PD safety.

Conclusion

This is the first study to assess drowning risk perception in PwPD, caregivers and HCPs. PwPD appear to have lower drowning risk perceptions and exhibiting greater confidence comparing with caregivers and HCPs. However, a porpotion of caregivers support risky water practices, with limited supervision and sometimes in deep depth environments, highlighting the need for greater risk awareness. It is important to remember that most drowning incidents can be prevented by managing risks. As so, there might be an opportunity for HCPs to assess risk factors and perception of drowning risk in routine clinical evaluations, particularly before periods of increased aquatic exposure. Instead of avoiding water, water safety education can help patients build confidence,

recognize their limitations, be aware of drowning risks and associated factors and adhere to appropriate safety measures.

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Glossary

Bradykinesia – Motor symptom characterized by slowness of movement.

Rigidity – Motor symptom characterized by stiffness impairing range of motion.

Discoordination – Difficulties coordinating body movements.

DBS (Deep Brain Stimulation) – Neurosurgical treatment, that involves implanting electrodes into basal ganglia, being considered in Parkinson's Disease when motor symptoms are no longer being manageable by medication.

Interlimb coordination – Synchronization of arms and legs movements.

Aquatic Capacity – The ability to move, float, coordinate breathing and swim in water.

Flotation ability – Capacity to maintain buoyancy in water.

Flotation device – A device that provides buoyancy, helping the person to float.

Loss of vertical balance – Inability to maintain the upright position in water often caused by water turbulence.

Aquatic physiotherapy – Rehabilitation sessions in water to improve overall function.

Drowning – Respiratory impairment due to submersion or immersion in liquid. Can be classified into fatal drowning (results in death) or non-fatal drowning (implies surviving).

Risk perception – An individual's awareness of potential drowning hazards.

Minimization strategies – Safety measures to reduce drowning risk.

Occasional supervision – Does not provide constant monitoring and therefore cannot be ready to intervene quickly.

Constant supervision – Continuous monitoring and readiness to intervene in water.

Annex I – Approval of the Ethics Committee’s review



**Exma. Doutora
Ana Beatriz Soeiro**

Torres Vedras, 12 de setembro de 2024

Nossa Ref. N° 09.2024-R

Assunto: Projeto de Investigação “Assessing Drowning Risk and Prevention Strategies in Parkinson's Disease: Perspectives from Patients, Caregivers, and Healthcare Professionals”

Relator: Professora Doutora Sofia Reimão e Professor António Corado.

Pela presente, informamos V^o Ex^a que o projeto acima indicado, obteve, no dia 12 de setembro de 2024, parecer positivo desta Comissão de Ética. Pedimos, no entanto, que os seguintes aspetos sejam corrigidos/clarificados antes do início do estudo:

1. Uma vez que o objetivo não será validar o questionário como ferramenta, mas sim os dados recolhidos, escrever “validação do questionário” não será o mais correto.

No final do estudo, pedimos que os resultados sejam partilhados com a CES.

Cordiais saudações,

O Presidente da Comissão de Ética

Annex II – Informed Consent

“Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde”

Informação aos participantes

A doença de Parkinson (DP) é caracterizada por um conjunto de sintomas motores, que podem dificultar as capacidades aquáticas.

Gostaríamos de o (a) convidar a participar num questionário anónimo que tem como objetivo perceber qual a perspetiva de doentes, cuidadores e profissionais de saúde sobre o impacto da doença de Parkinson nas capacidades aquáticas.

Ao aceitar participar, ser-lhe-á pedido que preencha um questionário (tempo média de preenchimento de 15 minutos) com perguntas relacionadas com a prática das atividades aquáticas.

Responda a este questionário se tiver como diagnóstico Doença de Parkinson. Preencha somente se souber nadar ou, se pelo menos ocasionalmente, frequenta ambientes aquáticos (praia, piscina, rio, termas).

No caso de já ter preenchido, por favor não o faça novamente. No final, certifique-se que respondeu a todas as questões e que carrega no botão para submeter as respostas.

Caso decida não participar, quer antes de iniciar o questionário, quer a meio, não será prejudicado. Para tal, basta fechar o questionário sem submeter as respostas ou, caso preencha em papel, comunicar ao investigador a sua decisão. Todos os seus dados recolhidos até ao momento serão apagados de forma definitiva.

Para quaisquer dúvidas ou questões, pode contactar a equipa via e-mail através do seguinte contacto: beatrizsoeiro@cns-campus.com ou contacto telefónico: +351 910630844. A equipa tratará de responder com a maior celeridade possível.

Agradecemos desde já a sua colaboração e vontade em participar.

Aceita participar no estudo?

Sim

Não

Data: _____

Iniciais do seu Nome: _____

Consentimento informado para participação em estudo de investigação

Eu, abaixo-assinado, li o documento de informação ao participante e foi-me dada a oportunidade de esclarecer todas as dúvidas. Voluntariamente aceito participar no estudo intitulado “Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde”.

Nome completo _____

Data _____

Assinatura _____

“Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde”

Informação aos participantes

A Doença de Parkinson (DP) é caracterizada por um conjunto de sintomas motores, que podem dificultar as capacidades aquáticas.

Gostaríamos de o (a) convidar a participar num questionário anónimo, que tem como objetivo perceber qual a perspetiva de doentes, cuidadores e profissionais de saúde sobre o impacto da Doença de Parkinson nas capacidades aquáticas.

Ao aceitar participar, ser-lhe-á pedido que preencha um questionário (tempo médio de preenchimento de 15 minutos) com perguntas relacionadas com a prática de atividades aquáticas.

Responda a este questionário se for familiar ou cuidador de uma pessoa com Doença de Parkinson que saiba nadar ou, que pelo menos ocasionalmente, frequente ambientes aquáticos.

No caso de já ter preenchido, por favor não o faça novamente. No final, certifique-se que respondeu a todas as questões e que carrega no botão para submeter as respostas.

Caso decida não participar, quer antes de iniciar o questionário, quer a meio, não será prejudicado. Para tal, basta fechar o questionário sem submeter as respostas ou, caso preencha em papel, comunicar ao investigador a sua decisão. Todos os seus dados recolhidos até ao momento serão apagados de forma definitiva.

Para quaisquer dúvidas ou questões, pode contactar a equipa via e-mail através do seguinte contacto: beatrizsoeiro.ft@gmail.com ou contacto telefónico: +351 910630844. A equipa tratará de responder com a maior celeridade possível.

Agradecemos desde já a sua colaboração e vontade em participar.

Aceita participar no estudo?

Sim

Não

Data: _____

Iniciais do seu Nome: _____

Consentimento informado para participação em estudo de investigação

Eu, abaixo-assinado, li o documento de informação ao participante e foi-me dada a oportunidade de esclarecer todas as dúvidas. Voluntariamente aceito participar no estudo intitulado “Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde”.

Nome completo _____

Data _____

Assinatura _____

“Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde”

Informação aos participantes

A Doença de Parkinson (DP) é caracterizada por um conjunto de sintomas motores, que podem dificultar as capacidades aquáticas.

Gostaríamos de o (a) convidar a participar num questionário anónimo que tem como objetivo perceber qual a perspetiva de doentes, cuidadores e profissionais de saúde sobre o impacto da Doença de Parkinson nas capacidades aquáticas.

Ao aceitar participar, ser-lhe-á pedido que preencha um questionário (tempo médio de preenchimento de 15 minutos) com perguntas relacionadas com a prática das atividades aquáticas.

Responda a este questionário se for um profissional de saúde que trabalhe com pessoas com o diagnóstico de Doença de Parkinson.

No caso de já ter preenchido, por favor não o faça novamente. No final, certifique-se que respondeu a todas as questões e que carrega no botão para submeter as respostas.

Caso decida não participar, quer antes de iniciar o questionário, quer a meio, não será prejudicado. Para tal, basta fechar o questionário sem submeter as respostas, ou caso preencha em papel, comunicar ao investigador a sua decisão. Todos os seus dados recolhidos até ao momento serão apagados de forma definitiva.

Para quaisquer dúvidas ou questões, pode contactar a equipa via e-mail através do seguinte contacto: beatrizsoeiro.ft@gmail.com ou contacto telefónico: +351 910630844. A equipa tratará de responder com a maior celeridade possível.

Agradecemos desde já a sua colaboração e vontade em participar.

Aceita participar no estudo?

Sim

Não

Data: _____

Iniciais do seu Nome: _____

Consentimento informado para participação em estudo de investigação

Eu, abaixo-assinado, li o documento de informação ao participante e foi-me dada a oportunidade de esclarecer todas as dúvidas. Voluntariamente aceito participar no estudo intitulado “Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde”.

Nome completo _____

Data _____

Assinatura _____

Annex III - Authorizations



DECLARAÇÃO

Para os devidos efeitos se declara que a Administração do CNS – Campus Neurológico autoriza o acesso a dados clínicos dos seus doentes, bem como a utilização das suas instalações, no contexto do projeto “Assessing Drowning Risk and Prevention Strategies in Parkinson’s Disease: Perspectives from Patients, Caregivers, and Healthcare Professionals”, desde que obtida a aprovação do estudo por uma Comissão de Ética competente e garantindo o acordo de confidencialidade por parte dos investigadores.

Torres Vedras, 27 de julho de 2024

Enf. Tiago Pama
Diretor Técnico
do CNS

Annex IV – Questionnaires

Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde

Questionário para pessoas com doença de Parkinson

Responda a este questionário se tiver diagnóstico Doença de Parkinson. Preencha somente se souber nadar ou, se pelo menos ocasionalmente, frequenta ambientes aquáticos (praia, piscina, rio, termas).

No caso de já ter preenchido, por favor não o faça novamente. No final, certifique-se que respondeu a todas as questões.

Por favor, volte a indicar:

Data: _____

Iniciais do seu Nome: _____

Já preencheu anteriormente este questionário em formato papel, online ou telefone?

Sim

Não

Já assinou o consentimento informado?

Sim

Não

Tem diagnóstico Doença de Parkinson?

Sim

Não

Qual o Médico que realizou o diagnóstico?

Nome _____

Especialidade _____

Considera que sabe nadar?

Sim

Não

Considera que ocasionalmente frequenta ambientes aquáticos (praia, piscina, rio, termas)?

Sim

Não

1. Caracterização Geral

1.1 Por favor, especifique a sua idade: _____

1.2 Especifique o seu sexo:

Feminino

Masculino

1.3 Qual o seu nível de estudos?

Sem estudos

Ensino Primário

Ensino Básico

Ensino Secundário

Ensino Pós-Secundário (licenciatura, bacharelato, curso profissional)

Ensino Pós-Licenciatura (pós-graduação, mestrado, doutoramento)

2. Caracterização Clínica

2.1 Ano do diagnóstico de doença de Parkinson: _____

2.2 Tem alguma outra doença diagnosticada?

- Se sim, qual? _____
- Não

2.3 Já realizou o seguinte procedimento: Estimulação Cerebral Profunda ou Deep Brain Stimulation (DBS)?

- Sim
- Não

2.4 Assinale quais destas dificuldades apresenta atualmente:

- Problemas de equilíbrio
- Freezing (sensação dos pés colarem ao chão)
- Flutuações motoras (existência de períodos ao longo do dia em que se sente mais bloqueado)
- Dificuldade em realizar duas tarefas em simultâneo (ex. falar ao telefone e andar)
- Nenhuma dificuldade

2.5 Por favor, indique o seu estado de saúde nas seguintes circunstâncias:

2.5.1 Mobilidade

- Não tenho problemas em andar
- Tenho alguns problemas em andar
- Tenho de estar na cama

2.5.2 Cuidados Pessoais

- Não tenho problemas em cuidar de mim
- Tenho alguns problemas a lavar-me ou vestir-me
- Sou incapaz de me lavar ou vestir sozinho/a

2.5.3 Atividades Habituais

- Não tenho problemas em desempenhar as minhas atividades habituais
- Tenho alguns problemas em desempenhar as minhas atividades habituais
- Sou incapaz de desempenhar as minhas atividades habituais

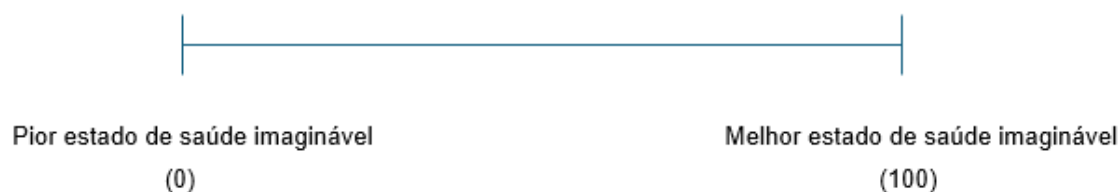
2.5.4 Dor/mal-estar

- Não tenho dores ou mal-estar
- Tenho dores ou mal-estar moderados
- Tenho dores ou mal-estar extremos

2.5.5 Ansiedade/Depressão

- Não estou ansioso/a ou deprimido/a
- Estou moderadamente ansioso/a ou deprimido/a
- Estou extremamente ansioso/a ou deprimido/a

2.5.6 Por favor identifique o seu estado de saúde de hoje (indique um valor de 0 a 100) _____



3. Prática de atividades aquáticas

3.1 Com que frequência experimentou nadar ou realizar atividades aquáticas após o diagnóstico?

- Nunca
- Semanalmente
- Mensalmente
- Ocasionalmente (por exemplo: férias)

3.2 Liste todos os ambientes aquáticos que costuma frequentar.

- Piscina pública
- Piscina particular/no domicílio
- Praia
- Praia fluvial
- Termas
- Fisioterapia aquática
- Outro (s) _____

4. Capacidade Aquática

4.1 Necessita de algum flutuador quando está dentro de água?

- Sim
- Não

Se sim, qual (ais)?

- Prancha
- Barbatanas
- Insuflável
- Outros: _____

4.2 Atualmente, consegue flutuar sem auxílio de flutuadores?

- Sim
- Sim somente por curtos períodos, indo um pouco ao fundo
- Não

4.3 Na sua opinião, quais as principais dificuldades de uma pessoa com Doença de Parkinson quando tenta nadar/movimentar-se dentro de água? Liste três dificuldades.

1. _____
2. _____
3. _____

4.4 Alguma vez aconteceu ter engolido água quando estava dentro de água após o diagnóstico de doença de Parkinson?

Sim

Não

4.5 Já teve algum episódio de afogamento/ quase afogamento após o diagnóstico de doença de Parkinson?

Sim

Não

Se sim, descreva em que circunstância

5. Nível de confiança no meio aquático.

5.1 Qual o nível de confiança para frequentar os seguintes ambientes aquáticos?
Selecione com (X) a resposta que mais se adequa.

	Muito confiante, não necessitando de supervisão	Confiante, necessitando somente de supervisão esporádica fora de água (cuidador; nadador- salvador)	Pouco confiante, necessitando de supervisão constante dentro de água	Nada confiante
1. Piscina com pé				
2. Praia/Rio com pé				
3. Piscina fora de pé				
4. Praia/Rio fora de pé				

5.2 Atualmente, a sua confiança relativamente à capacidade de nadar/movimentar-se dentro de água preocupa-o?

- Nada
- Preocupa-me se estiver fora de pé e sem supervisão
- Preocupa-me se estiver fora de pé e com supervisão
- Preocupa-me se estiver com pé e sem supervisão
- Preocupa-me se estiver com pé e com supervisão

6. Nível de risco nas práticas aquáticas

6.1 Na sua opinião, considera que a doença de Parkinson está associada a um risco de afogamento/ quase afogamento?

- Risco baixo
- Risco médio
- Risco elevado
- Nunca pensei sobre o assunto

6.2 No seu caso, qual considera ser o nível de risco de afogamento / quase afogamento, ao frequentar os seguintes ambientes aquáticos? Selecione com (X) a resposta que mais se adequa.

	Risco baixo, não necessitando de supervisão	Risco médio, necessitando de supervisão esporádica de alguém fora de água (nadador-salvador; cuidador)	Risco elevado necessitando de supervisão constante de alguém dentro de água	Risco muito elevado, não entrando no meio aquático
1. Piscina com pé				
2. Praia/Rio com pé				
3. Piscina fora de pé				
4. Praia/Rio fora de pé				

7. Estratégias de minimização do risco

7.1 Refira uma estratégia que na sua opinião possa contribuir para promover a segurança de pessoas com Doença de Parkinson quando realizam atividades aquáticas:

7.2 Já alguma vez discutiu as dificuldades no nadar ou em atividades aquáticas com o seu médico ou outro profissional de saúde que o acompanhe?

- Sim
- Não

7.3 Já alguma vez realizou ou lhe foi recomendado realizar uma avaliação da capacidade de nadar?

- Sim
- Não

7.4 Considera que faz sentido abordar este tema em consulta ou propor este tipo de avaliação a pessoas com doença de Parkinson?

- Sim
- Não

Se sim, em que fase da doença:

- Após o diagnóstico
- Após 5 anos do diagnóstico
- Após 10 anos ou mais anos do diagnóstico

Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde

Questionário para Familiares ou Cuidadores

Responda a este questionário se for cuidador de uma pessoa com doença de Parkinson que saiba nadar ou que pelo menos ocasionalmente, frequente ambientes aquáticos (praia,piscina,rio,termas).

No caso de já ter preenchido, por favor não o faça novamente. No final, certifique-se que respondeu a todas as questões.

Por favor, volte a indicar:

Data: _____

Iniciais do seu Nome: _____

Já preencheu anteriormente este questionário em formato papel, online ou telefone?

Sim

Não

Já assinou o consentimento informado?

Sim

Não

É familiar ou cuidador de uma pessoa com Doença de Parkinson?

Sim

Não

Considera que o seu familiar sabe nadar?

Sim

Não

Considera que o seu familiar ocasionalmente frequenta ambientes aquáticos (praia, piscina, rio, termas)?

Sim

Não

1. Caracterização Geral

1.1 Por favor, especifique a sua idade _____

1.2 Especifique o seu sexo:

Feminino

Masculino

1.3 Qual o seu grau de parentesco / relacionamento para com o doente de Parkinson?

1.4 Há quanto tempo cuida de uma pessoa com Doença de Parkinson? _____

2. Prática de atividades aquáticas do seu familiar.

2.1 O seu familiar costuma estar dentro de água sem supervisão?

Sim

Não

2.2 O seu familiar tem por hábito nadar em zonas que não tem pé?

- Sim
- Sim, se estiver acompanhado (a)
- Não

3. Capacidade Aquática do seu familiar

3.1 Depois do diagnóstico, notou alguma alteração na capacidade para nadar do seu familiar?

- Sim
- Não

Se sim, descreva numa frase porquê:

3.2 Alguma vez aconteceu ao seu familiar ter engolido água durante a realização de atividades aquáticas?

- Sim
- Não

3.3 O seu familiar já teve algum episódio de afogamento/quase afogamento após o diagnóstico de doença de Parkinson?

- Sim
- Não

Se sim, descreva em que circunstância

4. Nível de confiança do seu familiar no meio aquático.

4.1 Qual o seu nível de confiança em deixar o seu familiar frequentar os seguintes ambientes? Selecione com (X) a resposta que mais se adequa.

	Muito confiante, não necessitando de supervisão	Confiante, necessitando somente de supervisão esporádica fora de água (cuidador; nadador-salvador)	Pouco confiante, necessitando de supervisão constante dentro de água	Nada confiante
1. Piscina com pé				
2. Praia/Rio com pé				
3. Piscina fora de pé				
4. Praia/Rio fora de pé				

4.2 Atualmente, a confiança relativamente à capacidade de nadar/movimentar-se dentro de água do seu familiar preocupa-o (a)?

- Nada
- Preocupa-me se estiver fora de pé e sem supervisão
- Preocupa-me se estiver fora de pé e com supervisão
- Preocupa-me se estiver com pé e sem supervisão
- Preocupa-me se estiver com pé e com supervisão

5. Nível de risco do seu familiar nas práticas aquáticas

5.1 Na sua opinião, considera que a doença de Parkinson está associada a um maior risco de afogamento?

- Sim
- Não

5.2 Qual o nível de risco de afogamento, que se aplica ao seu familiar ao frequentar os seguintes ambientes aquáticos? Selecione com (X) a resposta que mais se adequa.

	Risco baixo, não necessitando de supervisão	Risco médio, necessitando de supervisão esporádica de alguém fora de água (nadador-salvador; cuidador)	Risco elevado necessitando de supervisão constante de alguém dentro de água	Risco muito elevado, não entrando no meio aquático
1. Piscina com pé				

2. Piscina sem pé				
3. Praia/Rio com pé				
4. Praia/Rio sem pé				

6. Estratégias de minimização de risco

6.1 Considera que faz sentido abordar este assunto em consulta ou ser proposta uma avaliação da capacidade de nadar?

- Sim
 Não

Se sim, em que fase da doença:

- Após o diagnóstico
 Após 5 anos do diagnóstico
 Após 10 anos do diagnóstico

6.2 Refira uma estratégia que na sua opinião possa contribuir para promover a segurança de pessoas com Doença de Parkinson quando realizam atividades aquáticas:

Avaliação do risco de afogamento e estratégias de prevenção na Doença de Parkinson: Perspetivas dos Pacientes, Cuidadores e Profissionais de Saúde

Questionário para Profissionais de Saúde

Responda a este questionário se for um profissional de saúde que trabalhe com pessoas com Doença de Parkinson.

No caso de já ter preenchido, por favor não o faça novamente. No final, certifique-se que respondeu a todas as questões.

Por favor, volte a indicar:

Data: _____

Iniciais do seu Nome: _____

Já preencheu anteriormente este questionário em formato papel, online ou telefone?

Sim

Não

Já assinou o consentimento informado?

Sim

Não

É um profissional de saúde que trabalhe com pessoas com o diagnóstico de Doença de Parkinson?

Sim

Não

1. Caracterização Geral

1.1 Por favor, especifique a sua idade _____

1.2 Qual a sua categoria profissional? _____

1.3 Há quanto tempo tem prática profissional com pessoas com Doença de Parkinson?

2. Capacidade aquática na doença de Parkinson.

2.1 Na sua opinião, considera que a doença de Parkinson afeta a capacidade de nadar?

Sim

Não

2.2 Na sua opinião, que fatores podem contribuir para esta dificuldade e merecem ser avaliados? Por favor, liste três exemplos.

1. _____

2. _____

3. _____

2.3 Considera que uma pessoa com Doença de Parkinson tem percepção das alterações para nadar?

Sim

Não

2.4 Já teve contacto com casos onde um paciente/cuidador relatou um episódio de afogamento/quase, afogamento?

Sim

Não

3. Nível de risco

3.1 Na sua opinião, considera que a doença de Parkinson pode estar associada a um maior risco de afogamento?

- Sim
 Não

4. Estratégias de minimização de risco

4.1 Costuma abordar o tema das alterações na capacidade para nadar com pessoas com Doença de Parkinson?

- Sim
 Não

4.2 Selecione qual a fase da doença de Parkinson que considera ser mais adequada para questionar o doente sobre a capacidade de nadar?

- Hoehn & Yahr 1
 Hoehn & Yahr 2
 Hoehn & Yahr 3
 Hoehn & Yahr 4
 Hoehn & Yahr 5

4.3 Indique qual o principal motivo para ter escolhido essa resposta:

4.4 Que conselhos práticos considera úteis para fornecer a pessoas com Doença de Parkinson e/ou cuidadores a fim de prevenir episódios de afogamento / quase afogamento? Por favor, liste três exemplos.

1. _____

2. _____

3. _____