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Article

# Cognitive Impairments in Parkinson's Disease: Professional Support and Unmet Rehabilitation Needs in Patients with and without Self-Reported Cognitive Impairments—A Secondary Analysis

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**Abstract:** Parkinson's disease (PD) is the second most common age-related neurodegenerative disease after Alzheimer's disease. Cognitive impairments are frequent non-motor symptoms in PD and have a significant impact on everyday life and well-being. Still, rehabilitation services for people with PD predominantly target motor symptoms. Drawing on data from a national Danish survey, this study aimed to determine significant differences among people living with PD with or without perceived cognitive impairments regarding (1) contact with different healthcare professionals, and (2) unmet needs for rehabilitation services. Data were analyzed based on whether the person with PD perceived cognitive impairments or not. Statistically significant differences between results for PD patients with and without cognitive impairments were calculated. Data on 6711 individuals with PD were included in the study. Respondents' mean age was 73.5 years, and 31% of them were experiencing cognitive impairments. Significantly more people with PD and cognitive impairments were in contact with almost all professionals compared to those without cognitive impairments. However, individuals experiencing cognitive impairments were less often in contact with the professions most experienced in cognitive rehabilitation.

**Keywords:** Parkinson's disease; cognitive impairments; rehabilitation



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## 1. Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease globally, affecting more than 1% of everyone over 65 years of age [1]. The prevalence is expected to double by 2030 [1]. The most well-known symptoms of PD are motor symptoms, yet non-motor symptoms are equally prevalent and stressful for people with PD and their relatives [1]. Motor, as well as non-motor, symptoms impact quality of life [2,3], and health-related quality of life deteriorates with the development of the disease [2,4]. There is no medical cure for Parkinson's disease, and efforts that may improve quality of life and functional capacity in everyday life are therefore central to the management of the disease [1,3]. Efforts should include interventions targeting both motor and non-motor symptoms in general, as well as more specific problems caused by cognitive impairments [1,5–8].

Cognitive impairments are non-motor symptoms that frequently occur in PD and entail substantial human and societal costs [1,5]. Cognitive impairments in PD occur in all phases of the disease and are up to six times more frequent in people with PD than in the healthy population [1]. Approximately 20% of people with 'de novo' PS (i.e., newly diagnosed or people not receiving L-dopa) experience mild cognitive impairments (MCI), which can be a precursor to dementia in PD [9]. More than 40% of people with PD with normal cognitive functions at the time of diagnosis develop MCI within 6 years [1,10]. PD may affect all cognitive functions, including attention, visual-spatial functions, memory, language, and especially executive functions [1,2,6,11]. Executive functions include mental flexibility, set-shifting, switching, efficiently planning future actions, and solving problems [12]. Cognitive impairments may have a far-reaching impact on behavior, judgment, decision making, apathy, and depression, and may affect motor functions [5,13]. Cognitive impairments affect the quality of life of people living with PD [4,14] and their relatives [2] and may have a significant impact on everyday life and well-being [5], even with mild symptoms [11]. However, the burden in everyday life depends not only on the degree of symptoms, but also on personal circumstances such as duties and responsibilities, and on what support is available [11]. The subjective experience of the disease varies and people with PD may, like others, adapt and revise values and standards for the good life [2].

Despite the high prevalence of cognitive impairments, rehabilitation services for people with PD have predominantly been targeting motor symptoms in Denmark [4], as well as internationally [5,15–18]. Within recent years, there has been a call for more attention to cognitive impairments in PD and for rehabilitation services targeting cognitive impairments and related disabilities [17]. This corresponds with current trends in PD research; according to a publication trends analysis at PubMed, the number of publications about non-motor aspects in PD is increasing.

To develop services that meet the needs of people with PD and cognitive impairments, there is a need for knowledge about the formal support and unmet needs of this specific target group, compared to their counterparts without cognitive impairments. The literature on rehabilitation from the perspective of people with PD in general is sparse [19]. A national Danish survey from 2020 identified unmet needs concerning interventions targeting non-motor symptoms [4]. This study aims to further analyze these national survey data to explore professional support and unmet rehabilitation needs among people living with PD with and without perceived cognitive impairments. More specifically, we aim to determine any significant differences among people living with PD with and without perceived cognitive impairments regarding (1) which health professionals they have been in contact with and (2) which unmet needs for rehabilitation services they have reported.

## 2. Materials and Methods

### 2.1. Design and Participants

The study draws on data from a national survey [4] including self-reported and proxy-reported data from 7039 people with PD. The national survey had a cross-sectional design using routinely collected health registry data to identify adults,  $\geq 18$  years of age and resident in Denmark, with PD from either the Danish National Patient (DNP) registry or Danish Prescription Medicines (DPM) registry. Those identified were asked to confirm their PD diagnosis using a national self-report survey [20]. The national survey questionnaire consisted of three sections addressing (a) demographic information, (b) health-related quality of life, functioning, and disease stage, and (c) rehabilitation services. For further information on the questionnaire, please see [4]. In the survey, the questionnaire was answered in three different ways: (1) by individuals living with PD on their own, (2) by individuals living with PD and their proxies jointly, or (3) in full by proxy respondents on behalf of an individual with PD. Since the proxy's perspective may influence the answers to the questionnaire [21], the dataset was split into two, i.e., data representing answers from individuals with PD only (group 1—'self-respondents'), and data representing answers from individuals with PD and/or their proxies (group 2—'proxy-respondents'). Merging

data from joint responses and proxy is based on the assumption that when you tick that a proxy has taken part in answering, it indicates that they have had an influence on the answer.

## 2.2. Instrumentation

### 2.2.1. The 39-Item Parkinson's Disease Questionnaire (PDQ-39)

PDQ-39 is a 39-item quality-of-life questionnaire for Parkinson's disease covering eight domains [22]. It was designed to propose domains of specific concern to people living with PD. It is widely used worldwide and has good psychometric properties [23]. PDQ-39 data may be presented either in a profile form or as a summary index. In the national survey, all items were included. In the present study, data from the cognition domain were used to identify participants with and without perceived cognitive impairments.

The PDQ-39 cognition domain includes four items; Unexpectedly fallen asleep during the day (item 30), Had problems with concentration (item 31), Felt your memory was bad (item 32), and Had distressing dreams or hallucinations (item 33). Past research has questioned whether the PDQ-39 cognition domain [24,25] represents the concept of cognition, as it does not seem to correlate with cognition assessed using neuropsychological measures [26–28]. Still, the concentration item (item 31) and memory item (item 32) may be considered useful for the assessment of perceived cognitive impairments [27]. These items are rated on a rating scale with the response categories never, seldom/occasionally, sometimes, often, and always.

### 2.2.2. Questionnaire Addressing Rehabilitation and Unmet Needs for Rehabilitation Services

Response categories regarding rehabilitation services were generic and developed for national surveys across different diseases. Hence, there were no specific response categories covering cognitive training and/or cognitive rehabilitation.

Respondents were asked whether they had been offered interventions in specific domains, according to patient education, lifestyle, psychosocial support, functioning, and environmental adaptations (please see Backmann et al. 2020 [4] for further background regarding response categories). When respondents had not been offered specific interventions, they were asked whether they experienced a need for these interventions. Subsequently, positive answers ('yes'-answers) were conceived as 'unmet needs'.

### 2.2.3. Questions Regarding Contacts with Healthcare Professionals

Respondents were asked which healthcare professionals they had been in contact with. In these categories, no timeframe was defined. Furthermore, they were asked about contacts with neurologists within specified timeframes. Both types of data were analyzed to describe contacts with health professionals.

### 2.2.4. Defining the Groups for This Study

The two groups were formed based on whether it was the person with PD (group 1) who responded to the questionnaire or a proxy was involved (group 2). Next, each of these groups was split in two based on whether the person with PD did not (groups 1a and 2a) or did perceive cognitive impairments (group 1b and 2b).

To form the groups with and without cognitive impairments, items 31 (concentration item) and 32 (memory item) of PDQ-39 were used, using a cut-off between 'sometimes' and 'often' on the PDQ-39 rating scale. A positive score on both items was required. This criterion for defining the groups was agreed upon among all authors after expert consultation. According to neuro-psychological studies, the PDQ-39 total score correlates with cognitive functioning [29]. Hence, the criterion was tested by comparing the PDQ-39 total scores between groups 1a and 1b, and 2a and 2b, respectively, using Kruskal–Wallis test. The criterion was supported by the fact that the total PDQ-39 score was significantly different in both sets of groups (1a–1b and 2a–2b).

### 2.3. Statistical Analysis

Data reported by PD patients (group 1) and by PD patients and proxies together or proxies alone (group 2) were analyzed separately. All results are presented and compared for PD patients without (groups 1a and 2a) and with (groups 1b and 2b) cognitive impairments in each of the two groups.

Based on the descriptive statistical analyses, categorical variables are presented as counts (percentages in each group) and continuous variables with normal distribution were presented as means (SD). Differences between groups 1a and 1b, and 2a and 2b, respectively, were evaluated using chi-square tests for categorical data, and the Kruskal–Wallis test was applied for the continuous variables since they were not normally distributed. A value of  $p < 0.05$  was considered as statistically significant.

Statistical analyses were performed with SAS Enterprise Guide version 7.15 Copyright c 2017 (SAS Institute Inc., Cary, NC, USA).

### 2.4. Ethical Considerations

The study complied with ethical principles and with the practices of the Danish National Committee on Health Research Ethics [30], and with the guidelines from the Danish Data Protection Agency [31]. In Denmark, this kind of research does not require approval from an ethics committee. Data use and protection were legally based on informed consent from participants, following General Data Protection Regulation, article 6, litra a. [32].

## 3. Results

### 3.1. Participants

Overall, survey data on  $n = 7039$  individuals with PD were available. Of these, data on items 31 and 32 in PDQ39 were missing for  $n = 328$  (4.7%) respondents, excluding these from the analyses. Hence, data on  $n = 6711$  (95.3%) individuals with PD were included in the study (Table 1).

**Table 1.** Background characteristics of the population with Parkinson’s disease, separated into groups of self-reported and proxy-reported with and without cognitive impairments.

	Self-Reported			<i>p</i> -Value (Group 1a vs. 1b)	Reported by Proxy			<i>p</i> -Value (Group 2a vs. 2b)
	Total (Group 1) N = 4113	Without CI (Group 1a) n = 3383 (82.3%)	With CI (Group 1b) n = 730 (17.7%)		Total (Group 2) N = 2598	Without CI (Group 2a) n = 1260 (48.5%)	With CI (Group 2b) n = 1338 (51.5%)	
<b>Age (mean (std) [range])</b>	71.3 (8.9) [18.1–95.6]	71.3 (8.8) [18.1–94.9]	71.1 (9.7) [34.1–95.6]		77.1 (7.6) [20.3–97.7]	76.5 (7.8) [20.3–96.3]	77.7 (7.4) [34.1–97.7]	
<b>Age group</b>				NS				<0.0001
18–59 years	468 (11%)	368 (11%)	100 (14%)		59 (2%)	38 (3%)	21 (2%)	
60–79 years	3021 (73%)	2511 (74%)	510 (70%)		1607 (62%)	818 (65%)	789 (59%)	
80+ years	624 (15%)	504 (15%)	120 (16%)		932 (36%)	404 (32%)	528 (39%)	
<b>Gender</b>				NS				<0.001
Male	2445 (59%)	2033 (60%)	412 (56%)		1678 (65%)	773 (61%)	905 (68%)	
<b>School</b>				NS				<0.001
Less than High school	2684 (65%)	2209 (65%)	475 (65%)		2088 (80%)	1047 (83%)	1041 (78%)	
High school	1135 (28%)	929 (27%)	206 (28%)		387 (15%)	152 (12%)	235 (18%)	
Other/missing	294 (7%)	245 (7%)	49 (7%)		123 (5%)	61 (5%)	62 (5%)	
<b>Education</b>				NS				<0.05
No or short	2329 (57%)	1904 (56%)	425 (58%)		1806 (70%)	911 (72%)	895 (67%)	
Medium or long	1527 (37%)	1274 (38%)	253 (35%)		593 (23%)	259 (21%)	334 (25%)	
Other or missing	257 (6%)	205 (6%)	52 (7%)		199 (8%)	90 (7%)	109 (8%)	

Table 1. Cont.

	Self-Reported				Reported by Proxy			
	Total (Group 1) N = 4113	Without CI (Group 1a) n = 3383 (82.3%)	With CI (Group 1b) n = 730 (17.7%)	p-Value (Group 1a vs. 1b)	Total (Group 2) N = 2598	Without CI (Group 2a) n = 1260 (48.5%)	With CI (Group 2b) n = 1338 (51.5%)	p-Value (Group 2a vs. 2b)
<b>Living arrangement</b>				<0.001				<0.05
Living alone	1153 (28%)	918 (27%)	235 (32%)		755 (29%)	330 (26%)	425 (32%)	
Living with someone	2953 (72%)	2461 (73%)	492 (67%)		1827 (70%)	928 (74%)	899 (67%)	
Missing	7 (0%)	4 (0%)	3 (0%)		16 (1%)	2 (0%)	14 (1%)	
<b>Employment</b>				<0.0001				<0.0001
Non-employed	3448 (84%)	2819 (83%)	629 (86%)		2515 (97%)	1204 (96%)	1311 (98%)	
Partly employed	310 (8%)	253 (7%)	57 (8%)		30 (1%)	21 (2%)	9 (1%)	
Fully employed	282 (7%)	259 (8%)	23 (3%)		25 (1%)	22 (2%)	3 (0%)	
Other or missing	73 (2%)	52 (2%)	21 (3%)		28 (1%)	13 (1%)	15 (1%)	

Respondents' mean age was 73.5 years, and 31% of them were experiencing cognitive impairments. The group of self-respondents (group 1) was younger than the group of proxy respondents (group 2). The proportion of respondents with cognitive impairments was larger in group 2 than in group 1 (51.5% and 17.8%, respectively).

### 3.2. Contact with Healthcare Professionals

In the group of self-respondents, significantly more people with PD and cognitive impairments were in contact with almost all professionals than their counterparts without cognitive impairments (Table 2). Only regarding contact with a sexologist and palliative team, no differences were found. In the group represented by proxy respondents as well, significantly more people with PD with cognitive impairments were in contact with almost all professionals, with sexologists as the only exception. Within both groups, the profession that most people with PD had contact with, was physiotherapists (71% resp. 79%).

Table 2. Contact with health professionals in 6711 Danish Parkinson's patients, separated into groups of self-reported and proxy-reported with and without cognitive impairments.

	Self-Reported				Reported by Proxy			
	Total (Group 1) N = 4113	Without CI (Group 1a) n = 3383	With CI (Group 1b) n = 730	p-Value (Group 1a vs. 1b)	Total (Group 2) N = 2598	Without CI (Group 2a) n = 1260	With CI (Group 2b) n = 1338	p-Value (Group 2a vs. 2b)
Physiotherapist	2943 (72%)	2401 (71%)	542 (74%)	NS	1992 (77%)	937 (74%)	1055 (79%)	<0.05
Nurse	937 (23%)	716 (21%)	221 (30%)	<0.0001	931 (36%)	343 (27%)	588 (44%)	<0.0001
Assistive aids consultant	634 (15%)	444 (13%)	190 (26%)	<0.0001	1100 (42%)	411 (33%)	689 (51%)	<0.0001
Care manager (visitor)	466 (11%)	317 (9%)	149 (20%)	<0.0001	1026 (39%)	354 (28%)	672 (50%)	<0.0001
Speech and language therapist	710 (17%)	555 (16%)	155 (21%)	<0.05	466 (18%)	205 (16%)	261 (20%)	<0.05
Occupational therapist	488 (12%)	363 (11%)	125 (17%)	<0.0001	644 (25%)	244 (19%)	400 (30%)	<0.0001
Dentist	533 (13%)	421 (12%)	112 (15%)	<0.05	427 (16%)	167 (13%)	260 (19%)	<0.0001
Dementia or Parkinson-consultant	93 (2%)	58 (2%)	35 (5%)	<0.0001	429 (17%)	89 (7%)	340 (25%)	<0.0001

Table 2. Cont.

	Self-Reported				Reported by Proxy			
	Total (Group 1) N = 4113	Without CI (Group 1a) n = 3383	With CI (Group 1b) n = 730	p-Value (Group 1a vs. 1b)	Total (Group 2) N = 2598	Without CI (Group 2a) n = 1260	With CI (Group 2b) n = 1338	p-Value (Group 2a vs. 2b)
Neuropsycholo	271 (7%)	192 (6%)	79 (11%)	<0.0001	172 (7%)	65 (5%)	107 (8%)	<0.05
Social counselor	288 (7%)	210 (6%)	78 (11%)	<0.0001	121 (5%)	48 (4%)	73 (5%)	<0.05
Psychologist	273 (7%)	192 (6%)	81 (11%)	<0.0001	119 (5%)	47 (4%)	72 (5%)	<0.05
Dietician	193 (5%)	142 (4%)	51 (7%)	<0.05	156 (6%)	52 (4%)	104 (8%)	<0.0001
Other	86 (2%)	69 (2%)	17 (2%)	NS	74 (3%)	41 (3%)	33 (2%)	NS
Palliative team	36 (1%)	26 (1%)	10 (1%)	NS	40 (2%)	11 (1%)	29 (2%)	<0.05
Sexologist	45 (1%)	37 (1%)	8 (1%)	NS	8 (0%)	3 (0%)	5 (0%)	NS
None, except from general practitioner or neurologist	1025 (25%)	869 (26%)	156 (21%)		379 (15%)	246 (20%)	133 (10%)	
None of the above	692 (17%)	610 (18%)	82 (11%)		251 (10%)	159 (13%)	92 (7%)	

Respondents were asked how often they were in contact with a neurologist (Table 3). Findings showed that in the group of self-respondents, as well as in the group represented by proxy respondents, individuals experiencing cognitive impairments were less often in contact with a neurologist.

Table 3. Contact with neurologist reported by 6711 Danish Parkinson’s patients, separated into groups of self-reported and proxy-reported with and without cognitive impairments.

	Self-Reported				Reported by Proxy			
	Total (Group 1) N = 4113	Without CI (Group 1a) n = 3383	With CI (Group 1b) n = 730	p-Value (Group 1a vs. 1b)	Total (Group 2) N = 2598	Without CI (Group 2a) n = 1260	With CI (Group 2b) n = 1338	p-Value (Group 2a vs. 2b)
<b>Contact with neurologist</b>				<0.05				<0.001
More often than 3 times per year	530 (13%)	412 (12%)	118 (16%)		346 (13%)	165 (13%)	181 (14%)	
Three times per year	750 (18%)	634 (19%)	116 (16%)		379 (15%)	192 (15%)	187 (14%)	
Twice a year	1803 (44%)	1506 (45%)	297 (41%)		1027 (40%)	529 (42%)	498 (37%)	
Once a year	701 (17%)	574 (17%)	127 (17%)		496 (19%)	235 (19%)	261 (20%)	
Less than once a year	243 (6%)	189 (6%)	54 (7%)		220 (8%)	91 (7%)	129 (10%)	
Never	64 (2%)	49 (1%)	15 (2%)		113 (4%)	42 (3%)	71 (5%)	
Missing	22 (1%)	19 (1%)	3 (0%)		17 (1%)	6 (0%)	11 (1%)	

Unmet Needs

Results for unmet needs are presented in Table 4. Overall, across almost all types of interventions, the group of self-respondents experiencing cognitive impairments were more likely to report unmet needs than self-respondents without cognitive impairments. Exceptions were found for physical exercise, smoking cessation, and interventions targeting the ability to work. In terms of these types of interventions, unmet needs were equally

distributed in people without and with perceived cognitive impairments. The unmet needs most frequently reported (by more than 20% of the respondents in the respective group) included interventions targeting disease education, diet and nutrition, eating issues, teeth and oral hygiene, and social support from the community.

**Table 4.** Unmet needs reported by 6711 Danish Parkinson’s patients, separated into groups of self-reported and proxy-reported with and without cognitive impairments.

Interventions Targeting:	Self-Reported				Reported by Proxy			
	Total (Group 1) n = 4113	Without CI (Group 1a) n = 3383	With CI (Group 1b) n = 730	p-Value (Group 1a vs. 1b)	Total (Group 2) n = 2598	Without CI (Group 2a) n = 1260	With CI (Group 2b) n = 1338	p-Value (Group 2a vs. 2b)
Disease education	1022 (25%)	797 (24%)	225 (31%)	<0.0001	626 (24%)	295 (23%)	331 (25%)	NS
Diet and nutrition	774 (19%)	591 (17%)	183 (25%)	<0.0001	387 (15%)	187 (15%)	200 (15%)	NS
Eating issues	501 (12%)	350 (10%)	151 (21%)	<0.0001	301 (12%)	124 (10%)	177 (13%)	<0.05
Teeth and oral hygiene	571 (14%)	424 (13%)	147 (20%)	<0.0001	332 (13%)	130 (10%)	202 (15%)	<0.001
Speech disorders	498 (12%)	368 (11%)	130 (18%)	<0.0001	348 (13%)	136 (11%)	212 (16%)	<0.001
Physical exercise	375 (9%)	297 (9%)	78 (11%)	NS	152 (6%)	77 (6%)	75 (6%)	NS
Smoking cessation	50 (1%)	37 (1%)	13 (2%)	NS	13 (1%)	6 (0.5%)	7 (0.5%)	NS
Alcohol	117 (3%)	88 (3%)	29 (4%)	<0.05	34 (1%)	17 (1%)	17 (1%)	NS
Psychological support	575 (14%)	435 (13%)	140 (19%)	<0.0001	292 (11%)	108 (9%)	184 (14%)	<0.0001
Daily activities	363 (9%)	276 (8%)	92 (13%)	<0.0001	235 (9%)	89 (7%)	146 (11%)	<0.001
Sexuality and living together	426 (10%)	331 (10%)	95 (13%)	<0.001	146 (6%)	61 (5%)	85 (6%)	NS
Working situation	157 (4%)	124 (4%)	33 (5%)	NS	26 (1%)	15 (1%)	11 (1%)	NS
Social support from the municipality	691 (17%)	523 (15%)	168 (23%)	<0.0001	348 (13%)	162 (13%)	186 (14%)	NS
Assistive devices	399 (10%)	292 (9%)	107 (15%)	<0.0001	205 (8%)	95 (8%)	110 (8%)	NS
Home adaptation	352 (9%)	264 (8%)	88 (12%)	<0.001	194 (7%)	79 (6%)	115 (9%)	<0.05

Within the group represented by proxy respondents, more unmet needs were reported by respondents experiencing cognitive impairments regarding eating issues, interventions targeting teeth and oral hygiene, speech, psychological support, daily activities, and home adaptation. The unmet needs most frequently reported (by more than 20%) included interventions targeting disease education.

#### 4. Discussion

This study comprises a secondary analysis of data from a national survey on functioning, quality of life, and professional support among Danes living with PD. Drawing on the existing dataset, we analyzed and compared responses from people with and without cognitive impairments in terms of significant differences in which health professionals they had been in contact with and which unmet needs for rehabilitation services they had



reported. Differences within the group of self-respondents and the group represented by proxy respondents were analyzed and findings are presented separately for the two groups.

We found that people with PD and cognitive impairments reported a wide range of unmet needs, in particular in the group of self-respondents. The most frequently reported unmet needs were in interventions targeting disease education, diet and nutrition, eating issues, teeth and oral hygiene, and social support from the community. Most of these should be included in rehabilitation, according to the WHO package of interventions [33]. Nutrition is not explicitly mentioned by the WHO and neither is oral issues. Nutrition plays an emerging role in PD management [34], and oral health is often overlooked by professionals [35].

The findings indicate that unmet needs are composite and to some extent, the unmet needs identified mirror international literature about rehabilitation and Parkinson's. In Parkinson's rehabilitation in general, there appears to be a focus on physical outcomes and physical symptom management, and clinicians and researchers have called for a wider scope in Parkinson's rehabilitation to meet the complex and heterogeneous needs of people with PD, including needs associated with cognitive impairments [5,15–18]. As the questionnaire had no response category concerning cognitive issues, we identified no unmet needs for interventions targeting cognitive impairments, specifically. Still, other research has shown that interventions targeting cognitive impairment and everyday functioning while living with cognitive impairments are needed. Clare et al. [5] completed a scoping review aiming to map studies of cognitive rehabilitation interventions targeting different progressive neurodegenerative diseases except for Alzheimer's disease and vascular dementia. They surprisingly found that only 14% of the included studies targeted Parkinson's disease. Still, there seems to be an increasing focus on cognitive impairments in Parkinson's rehabilitation. In July 2023, the WHO presented a package of interventions for rehabilitation in neurological conditions, including PD. Here, interventions targeting PD include a focus on cognitive functioning. It is stated, that in PD, cognitive and everyday functioning should be assessed and appropriate interventions initiated [33]. This is supported by a Global Consensus of Rehabilitation in PD, published in 2024 [8].

According to our findings, the people living with PD and cognitive impairments reported to be more often in contact with a range of health professionals compared to those without cognitive impairments. According to current recommendations, professions often mentioned in relation to cognitive impairments, cognitive rehabilitation, and cognitive interventions are neuropsychologists, occupational therapists, and speech and language therapists [1,18,33,36]. Within the group of self-responders with cognitive impairments, 11%, 17%, and 21% have been in contact with these professions, and within the group of proxy-responders with cognitive impairments, the number is respectively 8, 30, and 20%. That is, a minority meets one of the professions recommended for people with PD and cognitive impairments. According to our findings, the profession people with PD and cognitive impairments meet most frequently is by far the physiotherapist. Physical exercise may have a positive effect on cognitive function [1]. Finally, it is noteworthy that 21% in the group of self-responders with cognitive impairments, and 10% in the group of proxy-responders with cognitive impairments, report that they had no contact with professionals other than general practitioners or neurologists. None of these professions is specialized in cognitive rehabilitation. Furthermore, people with PD and cognitive impairments in both groups are less often in contact with the neurologist than those without cognitive impairments. According to the analysis, far from all people with PD and cognitive impairments have had contact with the professionals who are most experienced in cognitive impairments, cognitive rehabilitation, and cognitive interventions.

Across both groups, respondents reported sparse contact with sexologists and palliative teams. Regarding sexologist services, the findings align with the international literature [37]. Sexual dysfunction in PD is an underrated problem and when asked, many people living with PD experience sexual dysfunction [37]. Still, past studies indicate that sexual health is considered a taboo subject in the communication between patients and

healthcare professionals. While patients may have a need to talk about sexual problems and receive information about the sexual health consequences of PD, they rarely receive such information [38].

The rare contact with palliative teams was to be expected, as palliative services in Denmark predominantly target cancer diagnosis, despite the fact that more life-threatening conditions may be associated with palliative needs [39]. In 2021, a national audit revealed that while 47% of palliative cancer patients were in contact with a specialized palliative team, the number for other palliative patient groups was only 3%, including a small group of patients with neurological diseases [40]. According to the UK NICE guidelines, palliative care should be available to PD patients as well [41].

#### *Strengths and Limitations*

The dataset was divided into two groups, and data from self-respondents and proxy respondents (including partly self-respondents) were analyzed separately. Considering the differences between the two groups, this may be a strength. Differences between the two groups regarding age, contact with professionals, and unmet needs tended to exceed differences within groups. If the dataset had not been split, some differences between people with and without cognitive impairments would likely not have emerged. Still, it may be questioned whether the differences are due to factors other than respondent type.

The quality of the proxy responses may be questioned. Studies where proxies report for patients who cannot self-report, and patients who can self-report do so, are well known [42]. The use of proxy responses may be well justified in certain contexts [43], also when reporting about cognitive impairment [44], but a review from 2023 revealed a lack of clarity in capturing, interpreting, and reporting data from proxies [43]. When including proxies, some issues should be considered. In correspondence with the checklist from Lapin et al. [43], it was defined in the questionnaire who could serve as a proxy and how the proxy should respond. Clear instructions for the proxy were listed in the introduction, not prior to the questions as suggested by Lapin et al. [43]. Questions were not validated for proxy respondents, but proxies were told to include the person with PD when answering, and if this was not possible, they were told to answer what they believed best fits the person's experience. Finally, as suggested by Lapin et al. [43], patients and proxies were differentiated in the results. Summing up, we consider the use of proxy data justified as long as they are kept separated from the self-reported data in the analyses. Drawing on data from a large Danish survey study, it was possible to define the groups of people with PD with or without cognitive impairments using the concentration and the memory item in the PDQ39 scale. This may be considered a limitation, as problems with concentration and memory are not the only cognitive impairments prevalent in PD. Impairments in executive functions may be just as prevalent [1] but do not define the study groups. Further studies should therefore be based on assessment tools more sensitive to detect cognitive impairments. Yet, following Jones et al., the two PDQ-39 items may still be considered useful for the assessment of perceived cognitive impairments [27]. Consequently, the prevalence of cognitive impairments may exceed the number identified in this study.

The questionnaire included no questions specifically regarding interventions targeting cognitive impairments. This may be considered a limitation. Still, the study has indicated a wide range of unmet needs among people living with PD and cognitive impairments.

#### **5. Conclusions**

The study analyzed and compared responses from people without and with cognitive impairments as regards significant differences in (1) which health professionals they have been in contact with and (2) which unmet needs for rehabilitation services they have reported. The findings indicate that many people living with PD and cognitive impairments may not meet professionals specializing in cognitive impairments and functioning. Moreover, they have composite and complex needs that are not always met. To meet those needs, rehabilitation for people with PD and cognitive impairments should consist of a

wide range of available interventions. The study results have implications for recognizing cognitive impairments and for planning support for people with PD. Still, more research is needed concerning the significance of cognitive impairments in the everyday life of people living with PD and how they should be supported.

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## References

1. Aarsland, D.; Batzu, L.; Halliday, G.M.; Geurtsen, G.J.; Ballard, C.; Ray Chaudhuri, K.; Weintraub, D. Parkinson disease-associated cognitive impairment. *Nat. Rev. Dis. Primers* **2021**, *7*, 47. [[CrossRef](#)]
2. Kudlicka, A.; Clare, L.; Hindle, J.V. Quality of life, health status and caregiver burden in Parkinson’s disease: Relationship to executive functioning. *Int. J. Geriatr. Psychiatry* **2014**, *29*, 68–76. [[CrossRef](#)]
3. García, D.S.; Fonticoba, T.d.D.; Castro, E.S.; Borrué, C.; Mata, M.; Vila, B.S.; Foraster, A.C.; Saucó, M.; Pérez, A.R.; Vela, L.; et al. Non-motor symptoms burden, mood, and gait problems are the most significant factors contributing to a poor quality of life in non-demented Parkinson’s disease patients: Results from the COPPADIS Study Cohort. *Park. Relat. Disord.* **2019**, *66*, 151–157. [[CrossRef](#)]
4. Backmann, T.; Mikkelsen, T.B.; Juel, K.; Winge, K.; Thuesen, J. *Livet med Parkinson og Behovet for Rehabilitering: En Undersøgelse af Behov for Fase-Specifik Rehabilitering ved Parkinsons Sygdom i Danmark*; REHPA, Videncenter for Rehabilitering og Pallation: Nyborg, Denmark, 2020.
5. Clare, L.; Teale, J.C.; Toms, G.; Kudlicka, A.; Evans, I.; Abrahams, S.; Goldstein, L.H.; Hindle, J.V.; Ho, A.K.; Jahanshahi, M.; et al. Cognitive rehabilitation, self-management, psychotherapeutic and caregiver support interventions in progressive neurodegenerative conditions: A scoping review. *NeuroRehabilitation* **2018**, *43*, 443–471. [[CrossRef](#)]
6. Davies, S.J.; Gullo, H.L.; Doig, E. The Priority Goals and Underlying Impairments Contributing to Goal-Related Problems of People with Parkinson’s Disease Receiving a Community-Based Rehabilitation Program. *Park. Dis.* **2024**, *2024*, 9465326. [[CrossRef](#)]
7. Weintraub, D.; Aarsland, D.; Biundo, R.; Dobkin, R.; Goldman, J.; Lewis, S. Management of psychiatric and cognitive complications in Parkinson’s disease. *BMJ* **2022**, *379*, e068718. [[CrossRef](#)]
8. Goldman, J.G.; Volpe, D.; Ellis, T.D.; Hirsch, M.A.; Johnson, J.; Wood, J.; Aragon, A.; Biundo, R. Delivering Multidisciplinary Rehabilitation Care in Parkinson’s Disease: An International Consensus Statement. *J. Park. Dis.* **2024**, *14*, 135–166. [[CrossRef](#)]
9. Aarsland, D.; Brønnick, K.; Larsen, J.; Tysnes, O.; Alves, G. Cognitive impairment in incident, untreated Parkinson disease: The Norwegian ParkWest study. *Neurology* **2009**, *72*, 1121–1126. [[CrossRef](#)]
10. Pigott, K.; Rick, J.; Xie, S.X.; Hurtig, H.; Chen-Plotkin, A.; Duda, J.E.; Morley, J.F.; Chahine, L.M.; Dahodwala, N.; Akhtar, R.S.; et al. Longitudinal study of normal cognition in Parkinson disease. *Neurology* **2015**, *85*, 1276–1282. [[CrossRef](#)]
11. Kudlicka, A.; Hindle, J.V.; Spencer, L.E.; Clare, L. Everyday functioning of people with Parkinson’s disease and impairments in executive function: A qualitative investigation. *Disabil. Rehabil.* **2018**, *40*, 2351–2363. [[CrossRef](#)]
12. Harvey, P.D. Domains of cognition and their assessment. *Dialogues Clin. Neurosci.* **2019**, *21*, 227–237. [[CrossRef](#)] [[PubMed](#)]

13. Baiano, C.; Barone, P.; Trojano, L.; Santangelo, G. Prevalence and clinical aspects of mild cognitive impairment in Parkinson's disease: A meta-analysis. *Mov. Disord.* **2020**, *35*, 45–54. [[CrossRef](#)] [[PubMed](#)]
14. Jaramillo-Jimenez, A.; Bocanegra, Y.; Buriticá, O.; Salazar, D.A.P.; Gómez, L.M.; Quintero, C.A.T.; Lopera, F. Subjective Cognitive and Communicative Complaints and Health-Related Quality of Life in Parkinson's Disease with and without Mild Cognitive Impairment. *Rev. Colomb. Psiquiatr.* **2023**, *52*, 305–313. [[CrossRef](#)]
15. Vaartio-Rajalin, H.; Rauhala, A.; Fagerström, L. Person-centered home-based rehabilitation for persons with Parkinson's disease: A scoping review. *Int. J. Nurs. Stud.* **2019**, *99*, 103395. [[CrossRef](#)] [[PubMed](#)]
16. Cerasa, A.; Quattrone, A. The effectiveness of cognitive treatment in patients with Parkinson's disease: A new phase for the neuropsychological rehabilitation. *Park. Relat. Disord.* **2015**, *21*, 165. [[CrossRef](#)] [[PubMed](#)]
17. Kalbe, E.; Kessler, J. Task force WANTED: Many reasons to promote research on cognitive rehabilitation to prevent, delay, and treat cognitive dysfunctions in patients with Parkinson's disease. *Park. Relat. Disord.* **2015**, *21*, 166–167. [[CrossRef](#)]
18. Hindle, J.V.; Watermeyer, T.J.; Roberts, J.; Brand, A.; Hoare, Z.; Martyr, A.; Clare, L. Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease—A pilot randomised controlled trial. *Int. J. Geriatr. Psychiatry* **2018**, *33*, 718–728. [[CrossRef](#)] [[PubMed](#)]
19. Nørgaard, B.; Titlestad, S.B.; Abrahamsen, C.; Marcussen, M. The perspectives of patients with Parkinson's disease: A qualitative systematic review. *J. Nurs. Educ. Pract.* **2023**, *13*, 8–17. [[CrossRef](#)]
20. Joshi, V.L.; Juel, K.; Thuesen, J.; Backmann, T.; Winge, K.; Tang, L.H.; Zwisler, A.-D.; Mikkelsen, T.B. Identifying the prevalence of Parkinson's disease in Denmark using healthcare registries and self-reported survey data. *Park. Relat. Disord.* **2024**, *120*, 106011. [[CrossRef](#)]
21. Fleming, A.; Cook, K.F.; Nelson, N.D.; Lai, E.C. Proxy reports in Parkinson's disease: Caregiver and patient self-reports of quality of life and physical activity. *Mov. Disord. Off. J. Mov. Disord. Soc.* **2005**, *20*, 1462–1468. [[CrossRef](#)]
22. Peto, V.; Jenkinson, C.; Fitzpatrick, R. PDQ-39: A review of the development, validation and application of a Parkinson's disease quality of life questionnaire and its associated measures. *J. Neurol.* **1998**, *245*, S10–S14. [[CrossRef](#)] [[PubMed](#)]
23. Ruotolo, I.; Sellitto, G.; Berardi, A.; Simeon, R.; Panuccio, F.; Amadio, E.; Galeoto, G. Psychometric properties of the Parkinson's disease Questionnaire-39 and its short form Parkinson's disease Questionnaire-8: A systematic review and meta-analysis. *J. Clin. Neurosci.* **2024**, *123*, 100–117. [[CrossRef](#)] [[PubMed](#)]
24. Hagell, P.; Nygren, C. The 39 item Parkinson's disease questionnaire (PDQ-39) revisited: Implications for evidence based medicine. *J. Neurol. Neurosurg. Psychiatry* **2007**, *78*, 1191–1198. [[CrossRef](#)] [[PubMed](#)]
25. Hagell, P.; Nilsson, M.H. The 39-item Parkinson's Disease Questionnaire (PDQ-39): Is it a unidimensional construct? *Ther. Adv. Neurol. Disord.* **2009**, *2*, 205–214. [[CrossRef](#)] [[PubMed](#)]
26. Walton, C.C.; Szeto, J.Y.; Shine, J.M.; Lewis, S.J. The 'Cognitions' index of the Parkinson's Disease Questionnaire-39 relates to sleep disturbance and hallucinations. *Park. Relat. Disord.* **2015**, *21*, 349–350. [[CrossRef](#)] [[PubMed](#)]
27. Jones, J.D.; Hass, C.; Okun, M.S.; Bowers, D. Reply: The 'cognitions' index of the Parkinson's disease questionnaire-39 relates to sleep disturbances and hallucinations. *Park. Relat. Disord.* **2015**, *21*, 351–352. [[CrossRef](#)] [[PubMed](#)]
28. Jones, J.D.; Hass, C.; Mangal, P.; Lafo, J.; Okun, M.S.; Bowers, D. The cognition and emotional well-being indices of the Parkinson's disease questionnaire-39: What do they really measure? *Park. Relat. Disord.* **2014**, *20*, 1236–1241. [[CrossRef](#)] [[PubMed](#)]
29. Lawson, R.A.; Yarnall, A.J.; Duncan, G.W.; Breen, D.P.; Khoo, T.K.; Williams-Gray, C.H.; Barker, R.A.; Collerton, D.; Taylor, J.-P.; Burn, D.J. Cognitive decline and quality of life in incident Parkinson's disease: The role of attention. *Park. Relat. Disord.* **2016**, *27*, 47–53. [[CrossRef](#)]
30. De Videnskabsetiske Komiteer i Region Syddanmark. National Videnskabsetisk Komité. 2024. Available online: <https://komite.regionsyddanmark.dk/nvk> (accessed on 29 May 2024).
31. University of Southern Denmark. Notat vedr. Behandling af Personoplysninger og Anonymisering til Forskning. 2019. Available online: [https://www.sdu.dk/da/forskning/service\\_til\\_forskere/juridiske-spoergsmaal](https://www.sdu.dk/da/forskning/service_til_forskere/juridiske-spoergsmaal) (accessed on 29 May 2024).
32. GDPR.DK. Databeskyttelsesforordningen. 2024. Available online: <https://gdpr.dk/databeskyttelsesforordningen/kapitel-2-principper/artikel-6-lovlig-behandling> (accessed on 29 May 2024).
33. World Health Organization. *Package of Interventions for Rehabilitation: Module 3: Neurological Conditions*; Report No.: 924007113X; World Health Organization: Geneva, Switzerland, 2023.
34. Bianchi, V.E.; Rizzi, L.; Somaa, F. The role of nutrition on Parkinson's disease: A systematic review. *Nutr. Neurosci.* **2023**, *26*, 605–628. [[CrossRef](#)]
35. Auffret, M.; Meuric, V.; Boyer, E.; Bonnaure-Mallet, M.; Vérin, M. Oral health disorders in Parkinson's disease: More than meets the eye. *J. Park. Dis.* **2021**, *11*, 1507–1535. [[CrossRef](#)]
36. Rafferty, M.R.; Nettnin, E.; Goldman, J.G.; MacDonald, J. Frameworks for Parkinson's disease rehabilitation addressing when, what, and how. *Curr. Neurol. Neurosci. Rep.* **2021**, *21*, 12. [[CrossRef](#)]
37. Bhattacharyya, K.B.; Rosa-Grilo, M. Sexual dysfunctions in Parkinson's disease: An underrated problem in a much discussed disorder. *Int. Rev. Neurobiol.* **2017**, *134*, 859–876.
38. Van Overmeire, R.; Vesentini, L.; Vanclooster, S.; Bilsen, J. Discussing sexual health among Flemish patients with Parkinson's disease. *Acta Neurol. Belg.* **2023**, *123*, 497–505. [[CrossRef](#)]
39. Rigsrevisionen. *Rigsrevisionens Notat om Beretning om Adgangen til Specialiseret Palliation*; Folketinget: Copenhagen, Denmark, 2021.

40. Hansen, M.B.; Adersen, M.; Grønvold, M. Dansk Palliativ Database (DPD): Årsrapport 2021; 2022. Available online: [http://www.dmcgpal.dk/files/4\\_7\\_22\\_aarsrapport\\_dpd\\_2021\\_med\\_3\\_reglen.pdf](http://www.dmcgpal.dk/files/4_7_22_aarsrapport_dpd_2021_med_3_reglen.pdf) (accessed on 29 May 2024).
41. Rogers, G.; Davies, D.; Pink, J.; Cooper, P. Parkinson's disease: Summary of updated NICE guidance. *BMJ* **2017**, *358*, j1951. [[CrossRef](#)]
42. Roydhouse, J.K.; Cohen, M.L.; Eshoj, H.R.; Corsini, N.; Yucel, E.; Rutherford, C.; Wac, K.; Berrocal, A.; Lanzi, A.; Nowinski, C.; et al. The use of proxies and proxy-reported measures: A report of the international society for quality of life research (ISOQOL) proxy task force. *Qual. Life Res.* **2021**, *31*, 317–327. [[CrossRef](#)]
43. Lapin, B.; Cohen, M.L.; Corsini, N.; Lanzi, A.; Smith, S.C.; Bennett, A.V.; Mayo, N.; Mercieca-Bebber, R.; Mitchell, S.A.; Rutherford, C.; et al. Development of consensus-based considerations for use of adult proxy reporting: An ISOQOL task force initiative. *J. Patient Rep. Outcomes* **2023**, *7*, 52. [[CrossRef](#)]
44. Brandvold, M.; Rustøen, T.; Hagen, M.; Stubberud, J.; van den Boogaard, M.; Hofsvø, K. Inter-rater agreement between patient-and proxy-reported cognitive functioning in intensive care unit patients: A cohort study. *Aust. Crit. Care* **2024**. Available online: <https://www.sciencedirect.com/science/article/abs/pii/S1036731424000572?via=ihub> (accessed on 29 May 2024). [[CrossRef](#)]

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