

## ORIGINAL PAPER

## UNMET NEEDS OF PEOPLE WITH PARKINSON'S DISEASE

Radka Kozáková<sup>1</sup>, Radka Bužgová<sup>1</sup>, Petra Bártová<sup>2</sup>, Pavel Rössner<sup>2</sup><sup>1</sup>Department of Nursing and Midwifery, Faculty of Medicine, University of Ostrava, Czech Republic<sup>2</sup>Department of Neurology, University Hospital Ostrava, Czech Republic

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## Abstract

**Aim:** The study aimed to identify individual health and social care needs and unmet needs in patients with Parkinson's disease as well as factors related to them. **Design:** A cross-sectional study. **Methods:** The sample comprised 183 Parkinson's disease patients cared for in four outpatient neurology centers in the Moravian-Silesian Region, Czech Republic. Their functional status was assessed with the Hoehn and Yahr Scale, Barthel Index and Schwab and England Scale; their needs for care were evaluated using the Needs and Provision Complexity Scale. The study was carried out from May to December 2019. **Results:** The highest proportions of unmet needs were identified in rehabilitation, related to both frequency (87%) and intensity (85%), followed by family support (53%), residential respite care (41%), skilled nursing care (36%) and equipment (35%). Unmet needs were associated with greater dependence with regard to activities of daily living, poorer functional status and longer disease duration. **Conclusion:** Understanding factors that determine the type of unmet needs of Parkinson's disease patients is crucial for provision of adequate multidisciplinary care. Based on identification of unmet health and social care and support needs, nurses may provide targeted interventions aimed to fulfill the unmet needs and improve the quality of life of patients.

**Keywords:** need, Parkinson's disease, support, unmet.

## Introduction

Parkinson's disease (PD) is the second most common degenerative neurological disorder; its prevalence increases with age (Dorsey et al., 2018). People with PD gradually lose their independence and require higher levels of care and support. Initially, impaired physical functioning is most characteristic. But as the disease progresses, both motor and non-motor symptoms get worse and PD patients have to cope with increasing complexity of their needs (Sagner et al., 2017). Long-term unmet needs negatively reflect in health and well-being and considerably influence one's quality of life (Rizza et al., 2017). Research has shown that PD patients have many unmet needs, either due to their insufficient recognition and inadequate treatment of non-motor symptoms, or due to insufficient focus on psychosocial burden, spiritual well-being and care planning (Chaudhuri et al., 2016). Thus, the identification of perceived needs of PD patients may improve the quality of care and help general nurses and other multidisciplinary team members develop the plan of care (Soh et al., 2013).

To ascertain the needs of PD patients and their carers, numerous comprehensive assessment tools have been adapted. Needs assessment tools are defined as instruments providing a consistent and comprehensive system for rapidly discussing the extent of patient support and care, that are useful for planning necessary services (Richfield & Johnson, 2020). A needs assessment should be based on a holistic care model that also takes into account spiritual, psychological and existential needs (Sleezer et al., 2014). To provide patient-centered nursing care, PD patients' unmet needs and factors that influence them should be ascertained. A needs assessment allows nurses to understand how much their patients' needs have or have not been met, thus helping identify the extent of necessary help and support and provide individualized, person-focused care (Mansfield et al., 2017; van der Eijk et al., 2011). Identification of unmet health and social needs should be part of the comprehensive needs assessment process (Asadi-Lari et al., 2004). Based on such assessment, general nurses should provide support and targeted interventions (Hansen et al., 2013; Sanson-Fisher et al., 2000). Whereas PD patients' unmet needs are multidimensional, little is known about their specific, unique needs. Therefore, nurses should be aware of particular challenges and needs faced by PD patients (Lee et al., 2018).

Corresponding author: Radka Kozáková, Department of Nursing and Midwifery, Faculty of Medicine, University of Ostrava, Syllabova 19, Ostrava, Czech Republic; email: radka.kozakova@osu.cz

By assessing their unmet needs, nurses will be better prepared to provide individualized care and specific nursing interventions that must be clearly defined with regard to both patients' individual characteristics and characteristics of this chronic condition.

## Aim

The study aimed to identify individual health and social care needs and unmet needs in PD patients as well as factors related to them.

## Methods

### Design

A cross-sectional study.

### Sample

The sample comprised 183 patients with PD, of which 100 were males and 83 were females.

The inclusion criteria were consent to participate, meeting the International Classification of Diseases (ICD-10) criteria for PD, disease duration of at least one year and a Mini-Mental State Exam score > 24.

The patients' mean age was 70.1 years (SD = 9.1) and mean disease duration was 10.3 years (SD = 5.6). The most frequent marital status was married (60.7%), followed by widow / widower (23.5%), divorced (13.1%) and single (2.7%). Only 23.6% of the patients were employed. The others were disability (16.4%) or old-age (59%) pensioners. The mean Barthel Index (BI) score was 58.1 (SD = 21.0; range, 0–80); the mean Schwab and England Scale (SCH-E) score was 63.6 (SD = 18.2; range, 0–90) and the mean Hoehn and Yahr Scale score was 2.8 (SD = 1.13; range, 1–5). The sociodemographic characteristics of the sample are shown in Table 1.

**Table 1** Sociodemographic and health characteristics of patients

Characteristic	n (%)		n (%)
<b>Gender</b>		<b>Occupation</b>	
male	100 (54.6)	employed	43 (23.6)
female	83 (45.4)	unemployed	1 (0.5)
<b>Education</b>		homemaker	1 (0.5)
primary	27 (14.8)	disability pensioner	30 (16.4)
secondary	55 (30.1)	old-age pensioner	108 (59)
secondary (examination)	70 (30.8)	<b>H-Y stage</b>	
tertiary professional	9 (4.5)	1.0	24 (13.1)
higher	22 (12)	2	48 (26.2)
<b>Children</b>		2.5	8 (4.4)
yes	169 (92.3)	3	54 (29.5)
no	14 (7.7)	4	34 (18.6)
<b>Marital status</b>		5	15 (8.2)
single	5 (2.7)	<b>Barthel Index</b>	
married	111 (60.7)	0–40	48 (26.2)
divorced	24 (13.1)	45–60	74 (40.4)
widow/er	43 (23.5)	65–95	61 (33.3)
<b>Disease duration</b>		<b>SCH-E</b>	
less than 5 years	60 (32.7)	< 70	83 (45.4)
5–10 years	65 (35.5)	≥ 70	100 (54.6)
more than 10 years	58 (31.8)		

*n* – number of participants, *H-Y* – Hoehn and Yahr Scale, *SCH-E* – Schwab and England Scale

### Data collection

The assessment itself was carried out in four outpatient neurology centers in the Moravian-Silesian Region, Czech Republic. After health professionals were trained, all patients meeting the inclusion criteria were approached to participate between May and December 2019.

Needs were assessed using the Needs and Provision Complexity Scale (NPCS) (Turner-Stokes et al., 2013). The NPCS contains 15 items. First, the actual

needs for care are assessed (Part A); subsequently, the level of services, or inputs, provided are evaluated (Part B). The items in Part A and Part B are identical. Part A items are rated by physicians or other health professionals; Part B items are rated by physicians or other health professionals based on information obtained from patients or their family members regarding inputs that are already provided. The total score ranging from 0 to 50 points is a sum of scores for six subscales within two principal

domains, *Health and personal care* (score: 0–25 points) and *Social care and support* (0–25 points). The *Health and personal care* domain comprises three subscales: *Healthcare* (0–6 points), *Personal care* (0–10 points) and *Rehabilitation* (0–9 points). Personal care means caring for the patient.

The *Social care and support* domain also contains three subscales: *Social and family support* (0–13 points), *Equipment* (0–3 points) and *Accommodation* (0–9 points). The difference between the needs and services provided is referred to as unmet needs. Higher scores in all subscales means more services needed and more unmet needs.

The severity of functional impairment was assessed with the Hoehn and Yahr (H-Y) Scale (Hoehn & Yahr, 1967). The tool, including seven stages of involvement, looks at two basic aspects. The first is whether the impairment is unilateral or bilateral; the other is concerned with impaired balance and walk. The stages are classified based on disease progression, from unilateral involvement (stage 1), to bilateral motor involvement without impairment of balance (stage 2). Stage 3 is characterized by postural instability but the patient is still physically independent. In stage 4, balance is impaired and physical independence is lost but the patient is still able to walk or stand unassisted. In stage 5, the patient is unable to walk and stand and is confined to wheelchair or bed.

The ability to perform activities of daily living (ADLs) was evaluated using two tools, the BI and SCH-E Scale.

The BI, or Barthel Scale (Mahoney & Barthel, 1965), is a tool used worldwide for measuring performance in basic ADLs. The following 10 variables are assessed on a three-point ordinal scale: feeding, dressing, walking, climbing stairs, chair to bed transfer, grooming, bathing, toilet use, urinary and fecal incontinence. The total score (0–100) provides information about the patient's functional independence (totally dependent, severely dependent, moderately dependent, slightly dependent, independent).

The other specific tool measuring ADLs in PD patients was the SCH-E Scale (Schwab & England, 1969). The scale is used to evaluate difficulties PD patients have with performing everyday activities. It uses percentages to represent how much effort and dependence they need to complete daily chores. A person reaching 100% is completely independent and able to do all chores without difficulty; 90% mean that they are able to do all chores, but with some degree of slowness, difficulty or impairment, and that they might take two times longer than

normal to complete chores. Patients with 80% independence take two times longer than normal to complete chores. Those with 70% independence have more difficulties with some chores, might take three to four times longer than normal to complete them and spend a large part of the day performing them. Patients reaching 60% can do most chores, but exceedingly slowly and with much effort; errors are possible when completing them. Fifty percent mean the patient needs help with half of every chore and everything is difficult to them. Patients with 40% independence can assist with chores and can complete some alone. Those reaching 30% can complete few chores with effort and help. Very dependent patients (20%) cannot complete any chores alone. Ten percent represent full dependence and helplessness. Fully dependent patients (0%) are bedridden and almost completely comatose.

### Data analysis

The normality of data distribution was determined by the Shapiro-Wilk test. Data were analyzed using SPSS v 24.0 software (IBM, Armonk, NY, USA). Basic descriptive statistics were used to process the data: frequency (n), arithmetic mean ( $\bar{x}$ ), standard deviation (SD), median and range. The Wilcoxon test evaluated differences between groups. Spearman's rank correlation coefficient was used to evaluate relationships between unmet needs and selected factors. The statistical tests were performed at a significance level of 5%.

### Results

#### *Actual needs, service provision and unmet needs*

One objective of the study was to quantify individual health and social care needs in PD patients. First, the actual needs for care were assessed; subsequently, the level of services, or inputs, provided were evaluated. Differences between the actual needs and services provided is referred to as unmet needs. The most frequently identified actual needs in the *Health and personal care* domain were those related to Personal care ( $\bar{x}$  = 4.2; SD = 2.1); at the same time, these services were most frequently provided.

In the *Social care and support* domain, the most frequently identified actual needs were those in the Social and family support subscale ( $\bar{x}$  = 2.6; SD = 2.3). However, the most frequently provided services were those related to Accommodation ( $\bar{x}$  = 1.8; SD = 2.2). An overview of the assessment of patients' actual needs, services provided to them and their comparison is shown in Table 2.

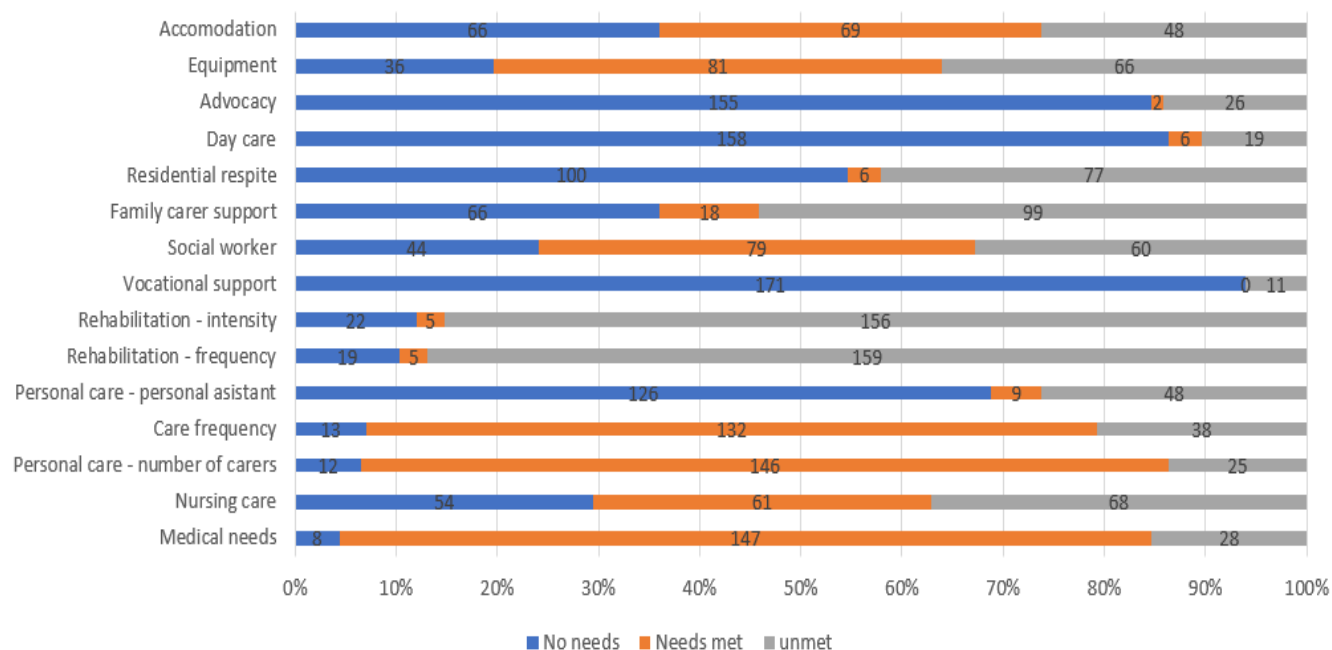
Further, differences between identified actual needs and services provided were determined. In all subscales, statistically significant differences were observed. Patients with PD generally received services at levels lower than needed (Table 2).

Figure 1 shows patients' unmet needs. The highest proportions of unmet needs were identified in rehabilitation, related to both frequency (87%) and intensity (85%), followed by family support (53%), residential respite care (41%), skilled nursing care (36%) and equipment (35%).

**Table 2** Actual needs of and services provided to PD patients (n = 183)

Subscales	Actual needs			Services provided			p-value
	$\bar{x}$	SD	median	$\bar{x}$	SD	median	
<b>Total NPCS</b>	17.9	7.9	17.0	10.7	6.1	10.0	< 0.001
<b>Health and personal care domain</b>							
Healthcare	4.0	1.5	4.0	3.1	1.4	3.0	< 0.001
Personal care	4.2	2.1	4.0	3.6	2.0	3.0	< 0.001
Rehabilitation	3.7	1.7	4.0	0.6	1.3	0.0	< 0.001
Total	11.9	4.2	12.0	7.3	3.6	7.0	< 0.001
<b>Social care and support domain</b>							
Social and family support	2.6	2.3	2.0	1.0	1.3	1.0	< 0.001
Equipment	1.1	0.7	1.0	0.7	0.7	1.0	< 0.001
Accommodation	2.3	2.3	2.0	1.8	2.2	1.0	< 0.001
Total	6.0	4.4	6.0	3.4	3.2	3.0	< 0.001

SD – standard deviation;  $\bar{x}$  – mean; The total NPCS score range is 0-50 points; The total Health and personal care domain score range is 0-25 points; The total Social care and support domain score range is 0-25 points; Higher scores mean more need for care; Wilcoxon test  $p < 0.05$



**Figure 1** Patients' unmet needs

#### Factors related to unmet needs

Unmet needs subscales and selected factors were correlated (Table 3). There were associations between patients' unmet needs in some subscales and functional scales (H-Y, BI, SCH-E). Limited ADLs (as measured with the BI) resulted in unmet needs in

the following subscales: *Healthcare* ( $r = -0.321$ ), *Rehabilitation* ( $r = -0.207$ ), *Social and family support* ( $r = -0.260$ ) and *Accommodation* ( $-0.224$ ). Patients with decreased functional status had more unmet needs. When using the SCH-E Scale, unmet needs were related to all subscales in the *Social care and*

**Table 3** Correlations between unmet needs and selected factors

	BI	SCH-E	H-Y	Disease duration	Age
<b>Health and personal care domain</b>					
healthcare	-0.321*	-0.081	0.131	0.282*	-0.090
personal care	-0.162	-0.123	0.082	0.135	-0.085
rehabilitation	-0.207*	0.123	0.246**	0.231*	-0.163
total	-0.264*	-0.026	0.221**	0.271**	0.016
<b>Social care and support domain</b>					
social and family support	-0.260*	-0.234*	0.253**	0.201*	0.030
equipment	-0.047	-0.243*	0.234**	0.089	0.042
accommodation	-0.224*	-0.235*	0.075	0.051	0.125
total	-0.182*	-0.266*	0.241**	0.121	-0.133

BI – Barthel Index; H-Y – Hoehn and Yahr Scale; SCH-E – Schwab and England Scale

support domain. Disease duration was associated with higher scores for unmet needs in the following subscales: *Healthcare* ( $r = 0.282$ ), *Rehabilitation* ( $r = 0.231$ ) and *Social and family support* ( $r = 0.201$ ). Patients with long disease duration had more unmet needs. No relationship was found between age and unmet needs.

## Discussion

Parkinson's disease is a chronic, incurable disease. The variability of both progression and daily functioning of PD patients is great (Muslimović et al., 2007; Post et al., 2011). Gradually, PD leads to disability and escalates into an increased need for health and social care (Read et al., 2013).

Patients with PD have been found to have many unmet needs (physical, psychosocial and spiritual) (Lee et al., 2019). Since the variability in disease progression results in diverse individual needs, the established diagnosis may not clearly determine the needs. Therefore, identification of unmet needs becomes crucial for provision of targeted health and social services and support as well as individualized patient-centered care (Mansfield et al., 2017).

The present study revealed that in all areas of care, patients received fewer services than they actually needed. Similarly, Calvert et al. (2013) found that patients with long-term neurological conditions were not accessing the level of health and social care they needed. Either these services were unavailable to patients or they were not adequately informed. Due to poor communication among health professionals and unawareness of services available, patients and their families often feel insecure and frustrated (Boersma et al., 2016; Sharpe & Curran, 2006). Other authors also pointed to considerable inadequacies in health and social service provision (Bunn et al., 2017; Toms et al., 2015). Those were mainly a lack of coordination and integration of social and health services. In the Czech Republic, a common problem

in caring for patients requiring qualified assistance from health and supportive services is the lack of interaction and functional cooperation. These chronic patients with limited mobility need nursing care, rehabilitation, assistance, support and various other services. According to Kalvach et al. (2015), the current practices lack integrity, flexibility and usefulness. The weaknesses of the existing system for supporting persons needing health care and social services include unsystematicity, fragmentation, incoherence and, very often, ignorance and unawareness of the entire spectrum, or portfolio, of services and activities that may contribute to comprehensive support provided to a particular individual. Generally, effectiveness may be achieved through optimal integrity, interconnection, networking as well as more rapid and accurate identification of needs. Using the NPCS for a needs assessment may help health professionals not only focus treatment on the patient's disease but also apply the principles of patient-centered care (Mareš, 2019) that considers their biological, psychological and social characteristics as well as their health status and that is not purely aimed at disease treatment.

The present study found that unmet needs were mainly related to rehabilitation. Similarly, Srp et al. (2018) reported very low rates of physiotherapy prescription in PD patients. Besides physiotherapy, other specialties such as occupational therapy, speech therapy or cognitive rehabilitation may be beneficial to patients. Further, unmet needs were identified with regard to personal, nursing and social care. Holmøy et al. (2019) stated that patients with myotonic dystrophy had unmet needs with respect to social care, personal care and rehabilitation. In their study involving neurological patients, Siegert et al. (2014) found unmet medical and nursing care needs in 30% of the participants, with more than half of the patients having unmet needs with regard to rehabilitation and



therapy, both the number of therapy disciplines and their intensity. As for the *Social care and support* domain, more than half of the patients had unmet needs related to social support. While only a small proportion of the sample reported unmet accommodation needs, 40% of the participants had unmet equipment needs. Similarly, Bužgová et al. (2019) reported numerous unmet needs in patients with progressive neurological diseases. An important finding was that patients were lacking information about their disease, prognoses, care options, aids and social support. The lack of information about the diagnosis and course of disease was also reported by other authors (Lode et al., 2007; Solari et al., 2007).

The present study also aimed to determine factors related to the level of unmet health and social care needs. Dunatchik et al. (2019) listed significant predictors for unmet needs in patients, namely being relatively young, living alone, not having longstanding illness, losing a spouse and developing more severe needs. This is consistent with findings by Sibley and Glazier (2009) who claimed that in the general population, higher levels of unmet needs were associated not only with sociodemographic factors but also with poorer health status and chronic conditions. Finally, the present study showed associations with functional scales (H-Y, BI, SCH-E) and disease duration. This is consistent with other studies that showed correlations between unmet health and social care needs and patients' functional status (Pappa et al., 2013; Smith et al., 2013).

## Conclusion

The present study identified unmet needs in health and personal care and in social care and support in PD patients and factors related to them. A care needs assessment is one of the key principles for ensuring adequate care for PD patients. Based on unmet needs identification, nurses may provide targeted interventions and individualized care aimed to positively influence the quality of life of patients and their family members.

## Ethical aspects and conflict of interest

The authors state that the manuscript was not submitted for review by another journal, nor was it published in another journal. No conflict of interest has been declared by the authors. Ethical rules were followed when writing the manuscript. The manuscript was read and approved for publication by all co-authors, the requirements for authorship were met.

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## Author contributions

Conception and design (RK, RB, PB, PR), data and analysis and interpretation of data (RK, RB), were involved in drafting the manuscript (RK), revising it critically for important intellectual content (RK, RB, PB, PR), gave final approval of the version to be published (RK, RB).

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