



Feature Article

Caregiver-identified needs and barriers to care in Parkinson's disease



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ABSTRACT

Perceptions of service needs and barriers to care among caregivers of individuals with Parkinson's disease have not been well explored. The purpose of this study was to assess caregiver perceptions of their own and patients' medical and supportive service needs. An online and paper survey was disseminated to a sample of caregivers ($n = 66$) of individuals with Parkinson's disease. Although caregivers reported positive quality of life and adjustment to caregiving, nearly half of the sample endorsed feeling stressed about caregiving. Caregivers reported that services for symptom management, coping with changes in lifestyle, future planning, relationships, and cognition, and wellness strategies were most needed. Reported barriers to patients accessing care included limited service availability and a lack of insurance coverage for services. These findings suggest a need to improve access to services for patients and increased efforts to promote caregiver wellness at movement disorder specialty clinics.

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Exploration of caregiver needs in Parkinson's disease (PD) has been limited despite PD being the second most common neurodegenerative disorder, involving progressive changes in both motor and non-motor symptoms (NMS) that result in disability.¹ Historically, over a quarter of individuals with PD were reported to be institutionalized within 10 years of diagnosis; however, recent studies show that over 90% of samples of individuals who have had PD for 10 years are living at home.² Moreover, health comorbidities (i.e., arthritis, heart/circulation problems, and diabetes) among individuals with PD are common and these conditions negatively impact cognition.¹ Individuals with PD have also been found to require greater assistance with instrumental activities of daily living (IADLs) and activities of daily living (ADLs) than other individuals with activity limitations.³ With these changes, family members are increasingly providing caregiving to individuals with PD and managing complex symptoms.²

Caregivers play an important role in improving patient outcomes, and among individuals with neurodegenerative disorders,

the presence of caregivers is associated with reduced rates of institutionalization.^{3,4} However, caregiving can negatively impact the caregiver, especially in neurodegenerative illnesses such as PD. Increased caregiver burden has been documented among family members caring for an individual with PD for 10 or more years.² Strong relationships exist between caregiver burden, health-related quality of life (QOL), and well-being and patients' physical and emotional functional status.^{5,6} With the increased focus on NMS and an understanding of PD as a whole body illness, there is a need to assess patient and caregiver perspectives on care needs and factors impacting QOL across the disease trajectory. While patient-reported needs and outcomes^{7,8} have increasingly been the focus of efforts to improve patient care, investigation of caregiver perspectives has been historically lacking and there has been no investigation of how increased residence of individuals with PD at home has impacted family caregivers.

This study assesses specific caregiver-identified needs and barriers to care in PD and examines the needs of primarily spouse/partner caregivers, who provide a unique perspective regarding the impact of PD on the family unit. Study objectives were to: 1) assess caregivers' perceptions of both patient and caregiver needs and critical health care and support services for managing PD-related symptoms and 2) examine barriers to these services.

Conflict of interests: None.

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Methods

Participants and procedure

Participants were part of a larger needs assessment completed by both individuals with PD and self-identified caregivers.⁷ The data in this study are comprised only of the caregiver perspectives. Participants ($n = 66$) were English-speaking adults age 21 and over who self-identified as caregivers to patients with PD. Participants were recruited through clinic listserv e-mails, community health fairs, and support groups from May to December 2012. Eligible participants were provided a web-based survey link or paper survey. Survey data were collected and managed in a secure, web-based database (Research Electronic Data Capture (REDCap)).⁹ The study was completed with adequate understanding and informed consent of the participants and with ethical approval of Virginia Commonwealth University's Institutional Review Board. Participants provided electronic waivers or written informed consents for online and paper surveys, respectively.

Measures

Needs and barriers

Content of the survey questions was compiled from empirical literature describing the impact of PD symptoms on caregiver health status and QOL,^{5,6,10–13} national resources on PD, and through consultation with multidisciplinary health care providers about commonly reported patient and caregiver needs at an interdisciplinary movement disorders clinic. Survey items are described below and summarized in Table 1. A complete list of the needs and barriers to care is detailed in the patient perspectives manuscript, which is available online.⁷ Checklists and free-response options were provided to minimize burden while providing opportunity for comments.

Table 1
Caregiver-identified areas of need and barriers to care.

Caregiver-identified needs	Caregivers reporting need (%)
Symptom management (e.g., motor, non-motor, medications)	80.3
Lifestyle changes (e.g., safety, travel, driving)	71.2
Planning for the future (e.g., financial, legal, resources)	60.6
Relationship changes (e.g., role changes, social connections, emotional support)	59.1
Wellness strategies (e.g., exercise, nutrition, spirituality)	57.6
Thinking changes (e.g., attention, memory, problem-solving)	57.6
Caregiver stress	45.5
Stress management	37.9
Emotional changes (e.g., anxiety, depression, apathy)	31.8
Personality & behavior issues (e.g., aggression, hallucinations, impulsivity)	27.3
Work-related issues (e.g., work/life balance, accommodations, disclosure)	22.7
Adjustment to diagnosis	19.7
Patient Education about diagnosis	13.6
Early onset diagnosis	15.2
Caregiver-identified barriers to care	Caregivers reporting barrier (%)
Service/specialist not available in local area	24.2
Cost of service	21.2
Lack of coordinated care	21.2
Insurance does not cover service	18.2
Limited transportation	16.7
Balancing family, work and medical issues	15.2
Stigma associated with having Parkinson's disease	10.6
Limited support from family	3.0

Quality of life

QOL was assessed using the Parkinson's Disease Questionnaire for Carers (PDQ-Carer),¹⁴ a 29-item measure developed for evaluation of QOL among caregivers for individuals with PD. It yields a global score and four domain scores: personal/social activities, anxiety/depression, self-care and strain, which are derived from item scores, and then transformed into standard scores, ranging from 0 to 100. Standard scores ≥ 60 demonstrate clinically significant areas of difficulty for caregivers.

Burden

Caregiver burden was assessed using the 12-item short form of the Zarit Burden Inventory (ZBI),¹⁵ which assesses the impact of caregiving on caregivers' emotional and physical health and ability to engage in social activities. A global score was derived by summing individual items. Total scores range from 0 to 48, with higher scores indicating increased caregiver burden. Bédard et al¹⁵ suggest using a score of 17 and above (consistent with the top quartile in their sample) to identify high burden.

Adaptive functioning

Caregiver perception of patient adaptive functioning was assessed using the Physical Self-Maintenance Scale (PSMS) and the Instrumental Activities of Daily Living Scale (IADLS).¹⁶ The PSMS is a six-item assessment of a patient's ability to independently complete ADLs (e.g., toileting, feeding, grooming and ambulation). Total scores range from 0 to 20, with higher scores indicating increased dependence on caregivers. The IADLS is an eight-item measure assessing patients' abilities to independently complete IADLs (e.g., food preparation, medications, and finances). Total scores range from 0 to 31, with higher scores indicating increased dependency on caregivers.

Work productivity

The Work Productivity and Activity Impairment Questionnaire-Caregiver (WPAI-CG)¹⁷ is a six-item measure of caregivers' current employment, total hours worked in the past week, time missed from work due to caregiving, and perceived effect of caregiving on work- and non-work-related daily activities using a rating scale of 0 (*Caregiving had no effect*) to 10 (*Caregiving completely prevented me from working/engaging in non-work activities*).

Results

Data analysis

All caregiver participants who provided complete or near complete data were included in the final analyses. Summary scores for all measures were calculated in accordance with standard procedures. Means, standard deviations, and ranges were calculated for continuous variables, as appropriate. Frequencies were calculated for categorical variables.

Sample characteristics

Sixty-six caregivers of individuals with PD completed the survey and were predominately spouses or partners (see Table 2). Caregivers reported spending an average of 110 h/week caregiving, and 22.7% reported caring 24/7 for their loved one. Thirty-three percent of caregivers reported their care recipients had some form of cognitive impairment (excluding dementia). However, caregiver ratings of the patients' adaptive functioning demonstrated that patients had little to no difficulties with independently completing ADLs and IADLs and only 28.7% of caregivers reported that patients needed assistance with ambulation. Participants reported positive

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