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The Experience of Women Who Care for Spouses With Parkinson's Disease and Lower Urinary Tract Symptoms

Helene Moriarty, Lisette Bunting-Perry, Joanne P. Robinson, and Christine W. Bradway

Correspondence
Helene Moriarty, PhD, RN, FAAN, College of Nursing, Villanova University, 800 Lancaster Ave., Villanova, PA 19085.
Helene.moriarty@villanova.edu

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ABSTRACT

Objective: To describe the symptoms, bother, impact, and attribution of lower urinary tract symptoms (LUTS) and management strategies from the perspective of the spouse caregiver.

Design: A qualitative descriptive design with semistructured interviews was guided by the Theory of Unpleasant Symptoms and family systems theory.

Setting: Women were recruited from a Parkinson's Center at a Veterans Affairs hospital in the northeastern part of the United States. Their veteran husbands received care for Parkinson's disease at the center.

Participants: Participants were 15 female spouse caregivers of men with Parkinson's disease and associated LUTS.

Methods: Purposive sampling was used to select caregiver participants for audiotaped interviews. Semistructured interviews were conducted with the participants. A directed content analysis was used to code transcribed interviews and field notes.

Results: The cognitive, affective, and behavioral dimensions of caring for a spouse with LUTS were identified. Participants were knowledgeable about the direct effect of Parkinson's disease on the bladder. Their affective responses included experiencing bother, emotional distress from the impact of LUTS on their lives, and empathy for their husbands. Participants tried many behavioral strategies to manage LUTS but received limited professional assistance for daily LUTS management.

Conclusion: Multidisciplinary, patient- and family-centered approaches that provide education, treatment, and support are needed to promote better management of LUTS, maintain patient dignity, and reduce burden for the patient and family.

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Parkinson's disease (PD), the second most common neurodegenerative disorder in the United States, contributes to considerable disability and diminished quality of life (Jones, Malaty, Price, Okun, Bowers, 2012; National Institute of Neurological Disorders and Stroke, 2015). A large body of research has concentrated on the motor symptoms of PD, but nonmotor symptoms, such as lower urinary tract symptoms (LUTS), have received less attention. Lower urinary tract symptoms are common in persons with PD, and prevalence rates range between 27% and 64% when assessed with validated instruments (Araki & Kuno, 2000; Lemack, Dewey, Roehrborn, O'Suilleabhain, & Zimmern, 2000; Sakakibara, Uchiyama, Yamanishi, Shirai, & Hattori, 2008). LUTS encompass "symptoms that result from conditions and diseases affecting the bladder and urethra" (International Continence Society, 2013, p. 3). In men with PD, LUTS may include incontinence, nocturia, urgency, frequency, hesitancy, postmicturition dribble, weak stream, and the sensation of incomplete bladder emptying (Robinson et al., 2013), and symptoms worsen with disease severity (Campeau, Soler, & Andersson, 2011). Loss of dopaminergic neurons in the substantia nigra of the brain and possibly the ventral tegmental area are theorized to cause loss of bladder control through loss of inhibitory bladder reflexes (Winge, 2015). Motor disturbances, including postural instability, festination, freezing episodes, and dyskinesia (Stacy, 1999), can prevent or delay access to a toilet and lead to urinary incontinence (Giladi et al., 2000).

Previous researchers addressed the prevalence, etiologies, pathophysiology, impact, and treatment of LUTS in PD patients (Badri, Purohit,

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Lower urinary tract symptoms are challenging nonmotor symptoms common in people with Parkinson's disease.

Helene Moriarty, PhD, RN, FAAN, is a nurse researcher for the Corporal Michael J. Crescenz Veterans Affairs Medical Center, Philadelphia, PA and a professor and Diane & Robert Moritz Jr. Endowed Chair in Nursing Research for the College of Nursing at Villanova University, Villanova, PA.

Lisette Bunting-Perry, PhD, RN, is an adjunct faculty member for the School of Nursing at the University of Delaware, Newark, DE.

Joanne P. Robinson, PhD, RN, FAAN, is Dean and professor for the Rutgers School of Nursing–Camden at Rutgers University, Camden, NJ.

Christine W. Bradway, PhD, RN, FAAN, is associate professor for the School of Nursing at the University of Pennsylvania, Philadelphia, PA.

Skenazy, Weiss, & Blaivas, 2014; Ragab & Mohammed, 2011; Winge, 2015; Winge & Fowler, 2006), and almost all researchers have used quantitative methods of data collection and analysis. In one qualitative study, the authors described the cognitive, affective, and behavioral dimensions of the LUTS experience in male veterans with PD (Moriarty, Robinson, Bunting-Perry, & Bradway, 2016). In the affective dimension, the men reported many emotional responses to LUTS, particularly embarrassment, that had a profound impact on their social activities, relationships with friends and their spouses, partner intimacy, and overall quality of life. They also enumerated multiple behavioral strategies they used to manage LUTS that consisted primarily of trial-and-error efforts. These findings led us to question how the spouses/partners of men with PD experience and manage the LUTS of their partners. Our subsequent search of CINAHL, Medline, and Psych Info databases with the terms *PD, LUTS, urinary incontinence (UI), caregiver, spouse, family,* and *qualitative research* (individually and in combination) did not yield any studies about caregivers' experiences of LUTS.

The purpose of this study was to explore how spouse caregivers of men with PD experience their partners' LUTS. The study was guided by The Theory of Unpleasant Symptoms (Lenz, Pugh, Milligan, Gift, & Suppe, 1997) and family systems theory (Minuchin, 1974). According to the first theory, every symptom is a multidimensional experience that may influence quality of life. According to family systems theory, illness in one family member affects the entire family, and thus PD and associated LUTS in men are also likely to affect their spouse caregivers.

Literature on Stress in Persons Who Care for Individuals With PD

Early investigators documented the presence of increased depression and reduced quality of life in family members who cared for patients with PD compared with healthy control subjects (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Miller, Berrios, & Politynska, 1996; O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996). In a 2014 review of research published between 2008 and 2013, Bhimani concluded that persons who care for patients with PD commonly experienced negative sequelae: increased anxiety and depression, social isolation, lack of time for self-care, sleep disturbances, changes in mutuality of the relationship with the person with PD (the balance of give and take), increased stress as the disease progresses, and financial strain.

No investigators of caregiver stress have explicitly focused on the experiences of the caregiver as related to the patient's LUTS or challenges in the management of LUTS. To our knowledge, we are the first to address this gap. Anecdotal evidence from our clinical practice and support groups suggests that caregivers expend much time, emotional energy, and resources in the management of the LUTS of their partners. For example, wives reported how they were awakened four to five times per night when their partners used the bathroom or needed help with condom catheters, pad changing, or escorting to the bathroom to prevent falls. They also recounted feelings of hypervigilance at night that resulted in interrupted sleep and poor sleep quality. Men with PD in our earlier study (Moriarty et al., 2016) also discussed distress and changes in their sexual relationships because of LUTS. These earlier data and the anecdotal reports of their wives led to our current investigation.

In this study, we extend our earlier investigation of the LUTS experience in men with PD (Moriarty et al., 2016) by describing the experiences of caregivers related to their partners' LUTS. Specifically, our study aim was to describe the symptoms, bother, impact, and attribution of LUTS and management strategies from the perspective of the spouse caregiver.

Methods

Design

A qualitative descriptive design with semi-structured interviews was used. The interviews were part of a larger mixed-methods study. The institutional review board of the participating site approved the study.

Sample and Setting

Participants were recruited from the Parkinson's Disease Research, Education and Clinical Center, an outpatient clinic at an urban Veterans Affairs Medical Center. Spouses/partners who were caregivers of veterans with PD enrolled in our earlier study (Moriarty et al., 2016) were eligible for this study. The sample for interviews was