

PARKINSONALLIANCE

Spring 2020

Urinary Symptoms and Parkinson's Disease: The Patient's Perspective

INTRODUCTION

Urinary dysfunction, specifically lower urinary tract symptoms (LUTS), for individuals with Parkinson's disease (PD) is highly prevalent, ranging between 27% to 85%¹⁻³. The PRIAMO Study⁴ included 1,072 patients with PD and found that nearly 60% of the participants complained of urinary symptoms, with severity of PD directly impacting the prevalence of urinary symptoms. Although bladder control may become more troublesome as PD progresses, it remains unclear if urinary symptom severity is associated with motor symptoms or duration of PD. Some research has found that urinary symptoms in PD seem to be related to age, disease duration, and neurological disability⁵.

Urinary symptoms can vary in their presentation and experience for individuals with PD. Urinary symptoms can be categorized as **storage (or irritative) symptoms** and **voiding (or obstructive) symptoms**.

<u>Storage or Irritative symptoms:</u>	
Storage Symptoms	Description
Frequency	Increased frequency to urinate again less than 2 hours after previously urinating
Urgency	The sudden urge to urinate with difficulty postponing/delaying urination
Nocturia	The need to urinate often at night (going to the bathroom between the time you went to bed and the time you woke up in the morning)

<u>Voiding or Obstructive symptoms:</u>	
Voiding Symptoms	Description
Incomplete emptying	Not emptying one's bladder completely after having finished urinating
Intermittent urination	Stopping and starting again several times when urinating
Weak urinary stream	Having a weak urination stream to dribbling when urinating
Hesitation when urinating	Trouble starting or maintaining a urine stream

As for the prevalence of **storage** and **voiding** symptoms:

- The majority of urinary symptoms found in PD are storage symptoms, and prevalence rates for specific **storage symptoms** include²:
 - Nocturia: 57% to 86%;
 - Increased frequency: 32% to 71%;
 - Urgency: 32% to 68%
- 25% presented with the **voiding symptoms** of incomplete emptying, urinary intermittence, weak urinary stream, and hesitation¹.
- The most frequent storage urinary symptoms were nocturia followed by urinary frequency and urinary urgency. **Voiding symptoms** (i.e., incomplete emptying, intermittent urination, etc.) are less frequently experienced^{1,5,6}. The most frequent voiding symptom was incomplete emptying.
- **Incontinence**, which is defined as the unintentional loss of urine, is another symptom that may occur for individuals with PD, but such an experience directly related to PD is less frequent.

Of note, although PD can be a direct cause of urinary changes⁷, urination changes can occur with “normal aging” or due to other medical conditions. Moreover, individuals with PD are often in an age group where other conditions may also influence the ability to control one's bladder, such as continence (holding urine) and urination emptying. Urinary changes

can occur for a variety of reasons for both men and women, including, for example, infections, weak pelvic muscles in women, enlarged prostate in men, and medication-induced urination changes. It is known, however, that individuals with PD have significantly more symptoms than “healthy” comparison groups^{8,9}.

Despite increasing awareness of urinary symptoms for individuals with PD, greater insights from the patient’s perspective about the relationship between urinary symptoms, day-to-day living, and quality of life warrants further investigation across disease duration and age cohorts.

OBJECTIVES

- To learn about the prevalence rates and impact of urinary changes on day-to-day function from the patient’s perspective.
- To understand the relationship between urination and quality of life (QOL).
- To provide general comments about and recommendations for treatment related to urinary changes.

METHODS

- Participants were recruited from prior survey participation that was conducted by The Parkinson Alliance (PA), announcements at PD support groups, announcements in neurology clinics, and the PA website.
- There were 960 participants in this survey. Participants included individuals with Deep Brain Stimulation (DBS; 242 (25%) participants) and without Deep Brain Stimulation (Non-DBS; 718 (75%) participants). See Table 1 for demographics and clinical features.
- Approximately 86% completed their survey independently; 14% of participants required assistance from another individual (i.e., family, care provider).
- Participants included individuals from all 50 states, with California (14%), New Jersey (14%), New York (12%), Florida (8%), Pennsylvania (8%), Texas (7%), Arizona (6%), Minnesota (3%), Colorado (2%), Tennessee (2%), Michigan (2%), and Massachusetts (1%) having the most participants. Thirty-two participants (3%) were international.

Questionnaires/Measures:

1. The Demographic Questionnaire; 2. American Urological Association Symptom Score Questionnaire (AUA-7); 3. Health Related Quality of Life Measure, the EQ-5D-5L.

- The Demographic Questionnaire:
The self-report questionnaire inquired about basic demographic information (e.g., sex status, marital status, education) as well as pertinent clinical information pertaining to urinary symptoms and the impact on day-to-day living and quality of life.

American Urological Association Symptom Score Questionnaire (AUASS¹⁰):

The AUA-7 provides a patient rating of urinary symptom frequency on seven symptoms: **Incomplete Emptying, Frequency, Intermittency, Urgency, Weak-stream, Straining, and Nocturia**. Scores range from 0 to 5 (0=none; 1=less than 1 in 5 times; 2=less than half the time; 3=about half the time; 4=more than half the time; 5=Almost always). A Total Score is also calculated, with higher scores reflecting greater urinary symptoms. The total score can assist in classifying symptom severity: 0 to 7 = Mild; 8 to 19 = Moderate; 20 to 35=Severe.

Health Related Quality of Life Measure (EQ-5D-5L11):

The QOL measure is a 5-item questionnaire assessing 5 dimensions: Mobility, Self-care, Usual Activities, Pain/Discomfort, and Anxiety/Depression. Scores range from 1 to 5, with 1=none or no problems, 2=slight problems, 3=moderate problems, 4=severe problems, and 5= extreme problems or unable. A Total Score is also calculated, with higher scores reflecting greater urinary symptoms.

Comparisons based on age and disease duration groups:

- **Age:** For the purpose of the survey report, age groups were divided into a **Younger PD group** (≤ 69 years of age) and an **Older PD group** (≥ 70 years).
- **Disease Duration:** Research pertaining to individuals with PD has noted that the average time from symptom onset to development of motor complications was 6 years. Thus, research has divided groups into **Early Stage (<6 years)** and **Advanced Stage PD (6+ years)** to define a valid partition between early and advanced disease states^{12,13}. To better illustrate the impact of disease duration on urinary variables in individuals with PD, the **Advanced Stage PD group** was further divided into **Early Advanced Stage PD (6-10 years)** and **Late Advanced Stage PD (11+ years)**.
- The results will be presented using the entire sample and groups matched on age (**Younger PD and Older PD groups**) and disease duration.

Factors to consider when interpreting the results:

- Survey-based methodology was used for this study. Generalizability of the results may be limited. Sample sizes noted in the sections below may vary somewhat within specific groups (e.g., younger, older, early, advanced, etc.), since some individuals may not have responded to a specific question. Research has found that some individuals with PD, particularly as cognitive difficulties become more apparent, may have reduced insight/awareness into or appreciation of their difficulties, a factor warranting consideration when interpreting self-report questionnaires. Importantly, the subjective report in this survey serves to highlight the “patient’s perspective” about his or her experience with dyskinesias.

RESULTS

- The summary of the demographic information and clinical characteristics of the participants in this study can be found in Table 1.
 - There were 960 individuals who participated in this survey.
 - The average age of the participant was 71 years, with an average disease duration of 10 years.
 - Just over half of the participants were male and the majority of the participants were Caucasian with over half of the participants having a college degree or graduate degree.
 - The **Non-DBS group** was slightly older than the **DBS group (average: 72 versus 69 years, respectively)**. By contrast, the **DBS group** had a significantly younger average age at PD diagnosis (**52 years**) than the **Non-DBS group (64 years)** and a longer duration of PD (**DBS: 16 years; Non-DBS: 8 years**). Sex (male greater than female), marital status (the majority being married), race (the majority being White/Caucasian), and education (the majority having higher education) were comparable between groups.
 - The average age at the time of DBS surgery was 61 (range: 38-80 years), with the average duration since DBS being 7 years (range: 0-28 years).

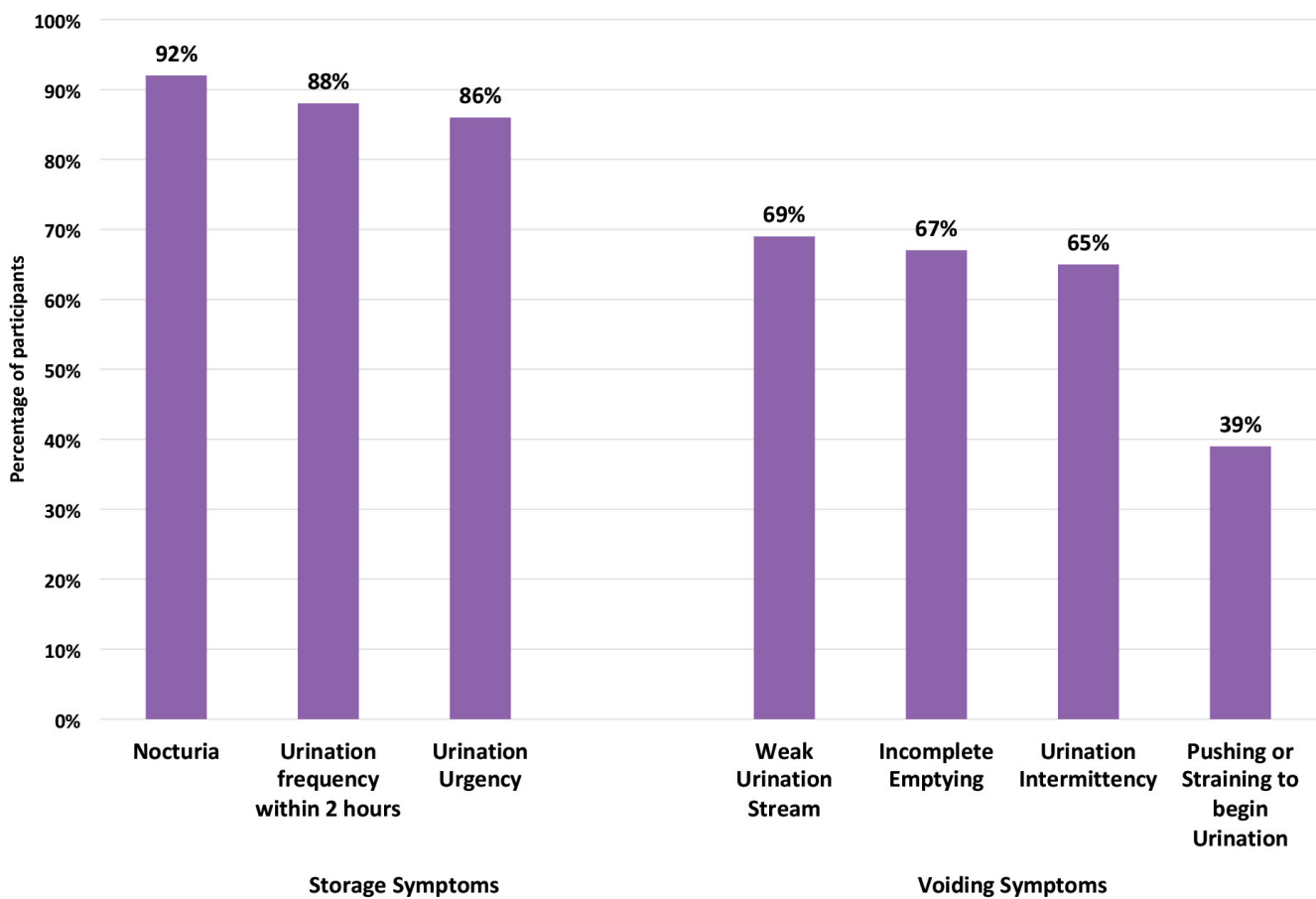
Table 1. Demographics and Clinical Features of the Sample

	DBS (n =242)	Non-DBS (n =718)
Average Age in Years (range)	69 (48-86)	72 (42-97)
Duration of PD in Years (range)*	16 (2-40)	8 (0-36)
Average Age of PD Diagnosis (range)*	52 (28-73)	64 (30-89)
Average Age at Time of DBS in Years (range)	61 (38-80)	n/a
Average Duration since DBS in Years (range)	7 (0-28)	n/a
Target: STN	44%	n/a
GPI	7%	n/a
Not Sure	49%	n/a
Male	56%	54%
Female	44%	46%
Married	84%	73%
Lives Alone	12%	18%
Race		
Caucasian	93%	96%
Latino/Hispanic	<1%	<1%
African American	4%	2%
Asian	1%	<1%
American Indian	1%	1%
Native Hawaiian or Pacific Islander	<1%	<1%
Other	0%	<1%
Education		
<12 years	3%	3%
High School	8%	8%
Some College or Associate's Degree	25%	24%
College	28%	26%
Graduate/Advanced Degree	36%	39%
* Clinically significant difference between groups n/a = not applicable		

URINARY SYMPTOMS: PREVALENCE

- **Storage symptoms**, inclusive of nocturia (going to the bathroom at night), urination frequency (urinating within 2 hours of having previously urinated), and urination urgency were highly prevalent and were reported in greater frequency than **voiding symptoms** (See Figure 1).
 - The **most bothersome** urinary symptom was urinary urgency, followed by nocturia and urination frequency. Percentage of participants reporting the most bothersome urinary symptom:
 - Urinary Urgency: 39%
 - Nocturia: 29%
 - Urination frequency within 2 hours of previously voiding: 19%
 - The remainder of the participants (<13%) rated either incomplete emptying, weak stream, intermittent stopping and starting when urinating, or straining as their most bothersome symptom.

Figure 1. Prevalence of Urinary Symptoms (N=960)



- **Table 2** shows the prevalence rates of urinary symptoms across age and disease duration-matched groups.
 - Across age and disease duration groups, both storage symptoms and voiding symptoms were highly prevalent.
 - Consistent with previous research, storage symptoms were more prevalent than voiding symptoms.
 - Disease duration had an impact on three urinary symptoms; specifically, with increased disease duration, the greater frequency reporting incomplete emptying and weak stream (**see Table 2**) and nocturia (**see Table 3**).
- Nocturia was reported in greater frequency for the Older PD group (>70 years) as compared to the Younger PD group (<70 years). With increased disease duration, the frequency of nocturia increased modestly. **See Table 3.**

Incontinence:

- Incontinence was reported by many participants, with the frequency of incontinence subtypes being depicted in **Figure 2**.
 - Urgency incontinence (loss of urine during times of urgency)
 - Stress incontinence (involuntary loss of urine with physical exertion, or coughing or sneezing)
 - Overflow incontinence (frequent or constant dribbling of urine due to incomplete emptying)
 - Functional incontinence (functional difficulties that keep you from making it to the toilet on time, resulting in incontinence)
- **Urgency incontinence** was reported in the greatest frequency, with the other three forms of incontinence being reported in comparable frequencies. **See Figure 2.**

Figure 2. Percentage of participants reporting incontinence at least once per week (N=96)

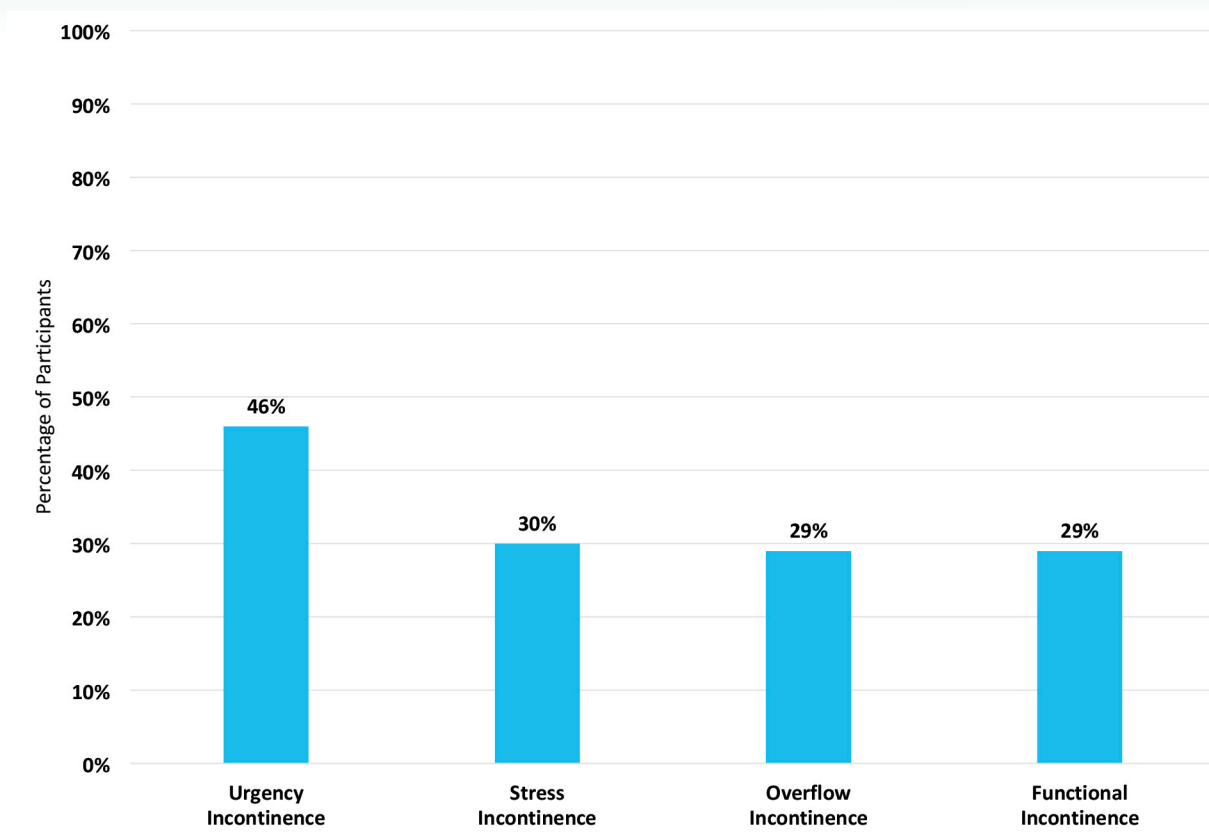


Table 2. The prevalence of urinary symptoms across age and disease duration-matched groups

	AGE GROUP:YOUNGER (<69 years)			AGE GROUP:OLDER (>70 years)		
	Early PD Group	Advanced PD Group		Early PD Group	Advanced PD Group	
	<6 yrs duration (n=101)	6-10 yrs PD (n=110)	11+ yrs PD (n=153)	<6 yrs duration (n=147)	6-10 yrs PD (n=176)	11+ yrs PD (n=223)
INCOMPLETE EMPTYING						
None/Normal	39%	36%	33%	42%	35%	25%
LESS THAN 50% of on-time during the day	43%	27%	34%	27%	34%	41%
APPROXIMATELY 50% of the time	9%	16%	13%	13%	14%	13%
GREATER THAN 50% of on-time during the day	9%	21%	20%	17%	17%	21%
URINATION FREQUENCY WITHIN 2 HOURS						
None/Normal	9%	8%	13%	16%	10%	13%
LESS THAN 50% of on-time during the day	49%	40%	37%	38%	36%	39%

Table 2. The prevalence of urinary symptoms across age and disease duration-matched groups (con't)

	AGE GROUP:YOUNGER (<69 years)			AGE GROUP:OLDER (>70 years)		
	Early PD Group	Advanced PD Group		Early PD Group	Advanced PD Group	
	<6 yrs duration (n=101)	6-10 yrs PD (n=110)	11+ yrs PD (n=153)	<6 yrs duration (n=147)	6-10 yrs PD (n=176)	11+ yrs PD (n=223)
APPROXIMATELY 50% of the time	20%	17%	20%	21%	24%	24%
GREATER THAN 50% of on-time during the day	22%	34%	31%	25%	30%	24%
URINARY INTERMITTENCY						
None/Normal	45%	31%	35%	38%	38%	28%
LESS THAN 50% of on-time during the day	32%	36%	34%	32%	35%	40%
APPROXIMATELY 50% of the time	9%	10%	13%	17%	14%	13%
GREATER THAN 50% of on-time during the day	14%	23%	18%	13%	13%	19%
URINARY URGENCY						
None/Normal	20%	13%	18%	15%	10%	12%
LESS THAN 50% of on-time during the day	32%	36%	33%	38%	34%	33%
APPROXIMATELY 50% of the time	18%	20%	18%	14%	18%	17%
GREATER THAN 50% of on-time during the day	30%	31%	31%	33%	38%	38%
WEAK URINATION STREAM						
None/Normal	42%	31%	34%	29%	37%	21%
LESS THAN 50% of on-time during the day	35%	35%	29%	36%	30%	39%
APPROXIMATELY 50% of the time	11%	11%	18%	15%	15%	14%
GREATER THAN 50% of on-time during the day	12%	23%	19%	20%	18%	26%
PUSHING OR STRAINING TO URINATE						
None/Normal	65%	64%	59%	64%	63%	54%
LESS THAN 50% of on-time during the day	26%	27%	26%	26%	27%	32%
APPROXIMATELY 50% of the time	5%	4%	8%	6%	6%	7%
GREATER THAN 50% of on-time during the day	4%	5%	7%	4%	4%	7%

Table 3. Nocturia (The need to urinate often at night)

	AGE GROUP:YOUNGER (<69 years)			AGE GROUP:OLDER (>70 years)		
	Early PD Group	Advanced PD Group		Early PD Group	Advanced PD Group	
		<6 yrs duration (n=101)	6-10 yrs PD (n=110)		11+ yrs PD (n=153)	<6 yrs duration (n=147)
None	9%	6%	12%	9%	5%	6%
Less than 1 in 5 times	20%	16%	17%	16%	16%	13%
Less than half the time	26%	31%	22%	30%	22%	27%
About half the time	9%	5%	11%	5%	13%	8%
More than half the time	14%	15%	12%	15%	13%	15%
Almost always	22%	27%	26%	26%	31%	31%

URINARY SYMPTOMS AND THE IMPACT ON DAY-TO-DAY EXPERIENCES

- Urinary symptoms can impact day-to-day activities. Participants in this study reported that nocturia, urgency, and incontinence resulted in the most interference in day-to-day activities.
 - Participants reported “major interference:”
 - Nocturia: 37%
 - Urgency: 36%
 - Incontinence: 23%
- 27% of the participants reported “moderate” to “extreme” ALTERED INTEREST IN SOCIAL ACTIVITIES due to urinary symptoms.
 - 32% Not at all
 - 31% a little bit
 - 18% Moderately
 - 18% quite a bit
 - 1% extremely
- 34% of the participants reported “moderate” to “extreme” EMBARRASSMENT due to urinary symptoms.
 - 32% Not at all
 - 34% a little bit
 - 19% Moderately
 - 9% quite a bit
 - 6% extremely
- 22% of the participants reported “moderate” to “extreme” ISOLATION due to urinary symptoms.
 - 54% Not at all
 - 24% a little bit
 - 14% Moderately
 - 7% quite a bit
 - 1% extremely

EMOTIONAL WELL-BEING AND QUALITY OF LIFE (QOL):

- 27% of the participants reported feeling moderately to severely depressed or anxious. There was a significant relationship between urinary symptoms and emotional well-being.
- 62% of the participants reported “good” to “excellent” QOL, while 37% reported “poor” to “fair” QOL, and <1% reporting worst imaginable QOL (See Figure 3).
- Urinary symptoms had a significant impact on QOL (See Figure 4).
 - 41% of the participants indicating that QOL was “somewhat” to “extremely” impacted by urinary symptoms.
 - 23% Not at all
 - 37% a little bit
 - 24% somewhat
 - 14% quite a bit
 - 2% extremely

Figure 3. Quality of Life

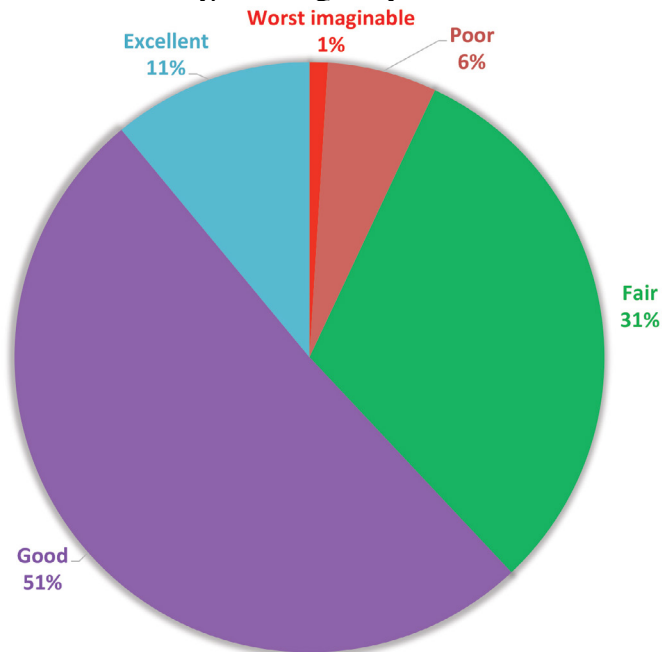
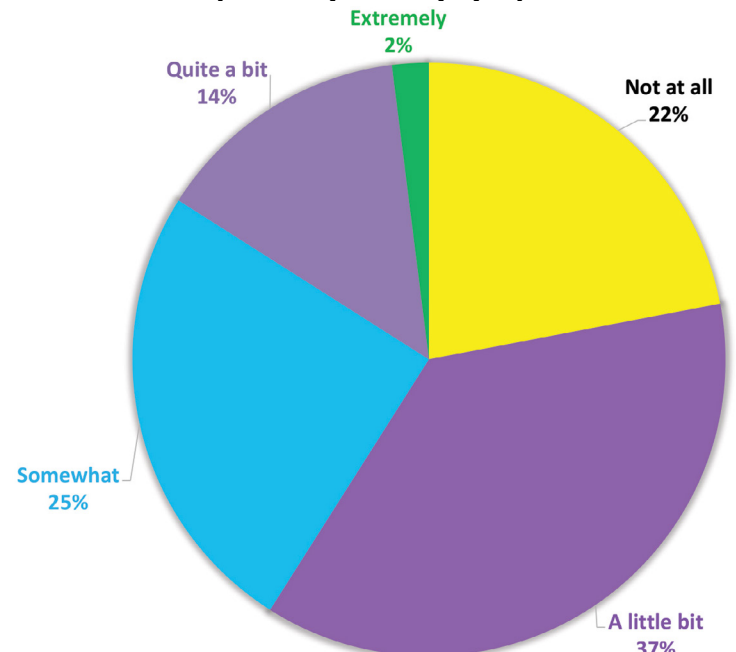


Figure 4. Quality of Life: adversely impacted by urinary symptoms



ASSESSMENT AND TREATMENT

- **Assessment:**
 - 43% of the participants reported that urinary symptoms have been assessed, while 51% indicated that urinary symptoms have not been assessed. 6% were not sure if urinary symptoms had been assessed.
 - For those who have undergone an assessment, the assessment was conducted by:
 - Urologist (82%)
 - Internist or Primary Care Physician (10%)
 - Neurologist or Movement Disorder Specialist (4%)
 - Other (4%)

- **Treatment:**
 - 39% of the participants indicated that they take medications for their urinary symptoms.
 - 33% of the participants have heard of non-medication techniques, with 18% reporting that they have tried such techniques.
 - Techniques participants reported having tried:
 - Bladder retraining (4%)
 - Managing fluid intake (7%)
 - Reducing caffeine (6%)
 - Pelvic floor exercises (11%)
 - Biofeedback or digital teaching (<1%)
 - Self-monitoring diary (3%)
 - Satisfaction with treatment:
 - Satisfied: 58%
 - Not satisfied: 28%
 - Not sure: 14%

PARTICIPANT COMMENTS: SOME EXAMPLES

- “I was beginning to realize that my Parkinson’s is now playing a role in my urinary changes.”

EMOTIONAL AND QOL: Range of responses:

- Significant impact on QOL and emotional well-being:
 - “Urinary problems have been one of the most disturbing symptoms. I have to think about it 24/7. It is a life altering symptom.”
 - “This is one of the worst side effects of Parkinson’s, at least for me.”
 - “Urgency issue is a quality of life issue.”
 - “This is an area that is commonly quite a problem, but shame and embarrassment tend to minimize it being discussed or treated.”
 - “I am not ashamed of urinary incontinence issues but anxious about it with regards to my work. I quit working as a school RN because I was changing my clothes more than once a day at work.... I would call my incontinence more of a public nuisance than an embarrassment.”
- Functional aspects to urinary symptoms:
 - “One bladder problem I have is as soon as I am done voiding, I dribble the minute I stand up, no matter how much I try to void.”
 - “I always need to know where a bathroom is when I walk into a room...Some days I have complete control, other days I am washing 3 times a day. It is constantly on my mind.”
 - “Urinary frequency is 3 times an hour when off.”
 - “Very often while sitting in a chair I feel like I have to urinate I get up go to the bathroom, stand there and nothing happens.”

- “The problem I am having at this time that is the most bothersome is not knowing or having the feeling that I need to urinate until it is too late, and I am dripping a little and must hurry to get to the toilet.”
- Intervention:
 - “Nocturnal frequency has improved with medication.”
 - “I have received Botox injections in my bladder.”
 - “I constantly wear a pad with “ultimate” absorbency. The biggest problem is in disposing them discreetly and in getting replacement into my purse discreetly after I have used one when I am not home.”
 - “I go to urinate on the clock as much as I can, because I don’t feel I have a full bladder.”
 - “If I am going someplace that I cannot use a restroom, I am careful about how much fluid I drink.”

SUMMARY & DISCUSSION

Urinary dysfunction, specifically lower urinary tract symptoms (LUTS), for individuals with Parkinson’s disease (PD) is highly prevalent, ranging between 27% to 85%¹⁻³. Urinary symptoms have been categorized as **storage or irritative symptoms** and **voiding or obstructive symptoms**. Urinary frequency, urinary urgency, and nocturia are examples of storage symptoms, while incomplete emptying, urinary intermittence, weak urinary stream, and hesitation are examples of voiding symptoms. Despite increased awareness of urinary symptoms for individuals with PD, greater insights from the patient’s perspective about the relationship between urinary symptoms, day-to-day living, and quality of life warrants further investigation across disease duration and age cohorts.

TAKE HOME POINTS FROM THIS SURVEY:

Objective 1. To learn about the prevalence rates and the impact of urinary changes on day-to-day function from the patient’s perspective.

- **Storage (irritative) symptoms**, inclusive of nocturia (going to the bathroom at night), urination frequency within 2 hours, and urination urgency were highly prevalent for the majority of the participants and were reported in greater frequency than **voiding (obstruction) symptoms**.
 - Consistent with research studies, nocturia, urination frequency and urination urgency were more prevalent than the voiding symptoms (incomplete emptying, urinary intermittence, weak urinary stream, and hesitation).
 - Urinary urgency was the **most bothersome** urinary symptom, followed by urinary frequency and nocturia.
 - Disease duration appeared to have an impact on some urinary symptoms, notably incomplete emptying, weak stream, and nocturia.
 - Nocturia was reported in greater frequency for the Older PD group (>70 years) as compared to the Younger PD group (<70 years).
- Urgency incontinence (loss of urine during times of urgency) was reported in the greatest frequency when compared to other forms of incontinence.
- Participants in this study reported that nocturia, urgency, and incontinence resulted in the **most interference in day-to-day activities**; approximately one-third of the participants described the interference as “major.”
- 27% of the participants reported “moderate” to “extreme” **altered interest in social activities** due to urinary symptoms.
- 34% of the participants reported “moderate” to “extreme” **embarrassment** due to urinary symptoms.

- 22% of the participants reported “moderate” to “extreme” **isolation** due to urinary symptoms.

Objective 2. To discuss the relationship between urinary symptoms and quality of life (QOL).

- There was a significant relationship between emotional well-being and urinary symptoms.
- 27% of the participants rated their level of depression or anxiety as moderate to severe.
- 62% of the participants reported “good” to “excellent” QOL, while 37% reported “poor” to “fair” QOL, and <1% reporting worst imaginable QOL.
- Urinary symptoms had a significant impact on QOL.
 - 41% of the participants indicating that QOL was “somewhat” to “extremely” impacted by urinary symptoms.

GENERAL COMMENTS AND RECOMMENDATIONS:

Recommendations to follow are for general points of education that have been sighted in the literature and which may be worthwhile to discuss with your doctor.

1. When considering management of intervention for urinary symptoms, it is recommended that you speak with a urologist (bladder specialist), who is familiar with PD, and one who can collaborate with the neurologist/movement disorder specialist. Such collaboration can help address assessment and treatment recommendations.
 - a. Your doctor can help explain the causes of urinary changes, such as whether or not symptoms are related to PD (or other central nervous system issues) versus other causes (i.e., infections; weak pelvic muscles in women; enlarged prostate in men; medication-induced urination changes; overactive bladder, etc.).
2. The specific treatments for urinary symptoms in PD depend on the underlying mechanisms. Some options (depending on the cause and mechanism) include:
 - a. Medications - Drugs, such as antimuscarinic drugs, which are a group of anticholinergic drugs, may be helpful for some people, but the difficulty with using medications for urinary symptoms for individuals with PD is that many of these medications can worsen other symptoms.
 - i. Unlike the motor symptoms of PD, urinary dysfunctions do not respond to levodopa therapy and other treatments often need to be considered. There are several medications that have been found to help manage urinary difficulties, including Detrol® (tolterodine), Ditropan® (oxybutynin), Enablex® (darifenacin), Myrbetriq® (mirabegron), and Vesicare® (solifenacin). These medications work to block or reduce overactivity in the bladder.
 - b. Bladder training: consulting with an Occupational Therapist or other specialist to discuss bladder training may be helpful.
 - c. Botulinum toxin (also known as Botox) placed into the bladder; Botulinum prevents the release of the neurotransmitter acetylcholine.
 - d. Functional aids, such as a commode at the bedside and “incontinence underwear” (i.e., Depends).
 - i. Products have been made to assist with managing urination difficulties within the home and as it relates to facilitating engagement in social activities with less stigma or embarrassment with the use of incontinence underwear.
 - (1) Incontinence underwear: “Depends”, a fast absorbing underwear feature for women and men, is commonly used to assist individuals with urination leakage or incontinence. There are a variety of products that help with comfort and discretion.

(2) Bedside commode: For increased frequency of using the bathroom at night, a bedside commode (movable toilet that does not use running water) may be helpful.

e. Use of a urinary catheter.

i. There are several types of catheters that are used to treat urinary changes. Three main types of catheters include:

(1) Indwelling catheter: a thin, hollow tube that is inserted through the urethra (Foley catheter) or a small opening in the abdomen (suprapubic catheter). These tubes are designed to remain inside the body to continuously drain the bladder.

(2) Intermittent catheter: known as “in and out” catheters because they are inserted and removed multiple times a day. When inserted, they are designed to drain the bladder all at once and then be removed.

(3) Condom catheters (male external catheter): A tube connects to the front of the condom catheter allowing the urine to flow out into a collection bag.

ii. Talk with your health care team (i.e., nurse or physician) about ways of managing comfort with the use of a catheter and reducing the risk for infections.

f. Neuromodulation or Deep Brain Stimulation for PD may have a secondary benefit to urination changes¹⁴.

3. Regarding Depression and Anxiety:

a. Have a conversation about anxiety and depression (psychological and biological contributions; physical and psychological symptoms of anxiety and depression) and related treatments with a specialist in movement disorders (e.g., a neurologist, psychiatrist, neuropsychologist, psychologist who are familiar with PD).

i. Cognitive-behavioral psychotherapy (CBT) for individuals with PD (and treatment for family members too, if appropriate) can be an effective treatment for addressing emotional difficulties that are secondary to, if not directly related to (biological changes) Parkinson’s disease³. Psychotherapy can assist in validating one’s personal experiences, feeling supported, and developing coping strategies to reduce and manage symptoms of depression and anxiety and adjustment difficulties. Such intervention can aid in coping and adjustment to help improve with function, relationships with others, and quality of life.

ii. Medications for psychological/psychiatric difficulties may be beneficial.

***Please visit The Parkinson Alliance website pertaining to patient-centered research to review previously written reports about specific topics related to PD. More comprehensive understanding and treatment guidelines are referenced in each report.**

ACKNOWLEDGEMENTS

There are many contributors to make this research happen. THANK YOU to all who participated. These surveys would not be meaningful without the valuable insights and contributions from the many participants in this survey. I also want to acknowledge my appreciation of the participants who continue to participate in our surveys year-after-year; thank you for your continued support and contributions to our work. I want to extend my appreciation to Jeffrey Wertheimer, Ph.D., ABPP-CN, our Chief Research Consultant and Chief of Neuropsychology Services at Cedars-Sinai Medical Center, Los Angeles, California, who assists in creating the research surveys, analyzing the data, and writing our manuscripts. I would like to thank Stephen Freedland, MD, Urologist and Professor of Surgery at Cedars-Sinai Medical Center, for his assistance with reviewing the manuscript. Additionally, I want to thank Terri Hamran, Director, Information Services, for her assistance with database management, Jennifer McNamara, Administrative Assistant and data entry specialist, and Gloria Hansen, Graphic Designer for The Parkinson Alliance.

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