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an affiliate of The Parkinson Alliance

Improving the Quality of Life  
in the Parkinson's Community

# Social Support and Parkinson's Disease: The Patient's Perspective

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## INTRODUCTION

People with Parkinson's disease (PWP) are confronted with debilitating symptoms, commonly including progressive physical, cognitive, and psychiatric symptoms. For many, trying to manage their symptoms day-by-day, if not moment-by-moment, can be a challenging task. Although social support is often an aid to physical and psychological comfort, over time, social support becomes a necessity to manage well-being, such as engaging in and completing activities of daily living. Social support in a simplistic sense can be defined as a resource provided by others (Kaptein, 2004). Some have categorized social support into three types: emotional support, guidance support, and tangible support (Oxman & Hull, 1997). Emotional support is thought to include affection, feeling of value and connection, or expression of concern for a person's well-being. Guidance support involves giving knowledge of how to do something or suggesting some action to be taken to better one's situation. Tangible support includes behaviors such as providing transportation, financial assistance, meals, and housing. These types of support can have different influences on function and well-being at different points in the course of medical illness (Fontana, Kerns, Rosenberg, & Coleonese, 1989; Glass & Maddox, 1992).

Although there is an objective benefit from support, perceived adequacy of support (the recipient's subjective assessment that social support is meaningful and can enhance well-being) has been found to significantly impact psychological well-being. For example, the perception of adequate support is associated with decreased depressive symptoms (Bowling & Farquhar, 1991). Cheng and colleagues (2008) found that low social support was found in a depressed group when compared to a non-depressed group of individuals with PD who had greater levels of support. The perception of adequate support (i.e., that one is cared for and valued) appears to buffer the effects of stressful experiences. Further, receipt of practical help, advice, and feedback has been found to contribute significantly to positive well-being among individuals experiencing PD (MacCarthy & Brown, 1989). In addition to the benefits of support on mental well-being, perceived support has been shown to be related to a wide variety of outcomes related to physical health and successful social functioning. Individuals have fared better through life's challenges and travails if they have support, and the lack of social support has been found to contribute to psychological deterioration and worsening illness (Kaplan, Cassel, & Gore, 1977; Lin Ensel, Simeone, and Kuo, 1979; Schaefer, Coyne, & Lazarus, 1981).

Good relations between people with PD and their significant others may assist in reducing symptoms of anxiety and depression (Moore & Seeney, 2007). Social support when confounded with a care provider who is also a family member, however, may have an unintentional outcome of increasing distress for the individual with PD. Moreover, research has found that a burden of caring for a person with chronic disease is associated with persistent stress for the care provider (i.e., family) and might cause emotional distress for the individual with PD (Miller, Berrios, & Politynska, 1996; Schrag, Hovris, et al., 2006). Thus, depending on the relationship and individual adaptation, family playing a dual role (family and care provider) could either reduce distress in an individual with PD or worsen it. Thus, broadening the social support context may be helpful for individuals with PD and family. Moreover, social support in the context of the broader fabric of social connectivity may favorably impact perceived well-being. For example, Morimoto and colleagues (2003) indicated that well-being does not necessarily depend on the provision of support, but is connected with participation in a meaningful social context, implicating that connectivity with friends and significant others and engagement in social activities with others may have psychological benefits.

Although research has identified benefits of social support, additional understanding about the barriers and facilitators of social support from the patient's perspective is of great importance. Receiving social support from others may be complicated by adjustment difficulties experienced by individuals with PD. Moreover, PWP may experience concerns about burden, social withdrawal and a reluctance to be with friends, engage in activities, or leave home (Quelhas & Costa, 2009). The increasing dependence on help from others, which is considered to be the most stressful symptom among disease-

related stressors, and a sense of isolation, may result in alienation even in the context of established social support (Frazier, 2000), whether it be emotional, guidance, and/or tangible support.

Social support may be a predictor of successful adaptation and general psychological well-being for individuals with PD. A deeper understanding about the patient's perspective of social support remains indicated, particularly as it relates to 1. the different dimensions of social support, 2. the barriers to social support, and 3. the perceived opportunities for improving social support from the perspective of PWP.

## OBJECTIVES

1. To understand the patient's perspective about social support using the **Multidimensional Scale of Perceived Social Support** (MSPSS) and its relationship to psychological well-being.
2. To understand the barriers to social support from the patient's perspective.
3. To understand the perceived opportunities for improved social support from the patient's perspective.

## METHODS

- Participants were recruited from prior survey participation that was conducted by The Parkinson Alliance (PA), announcements at PD support groups, announcements in medical clinics, The PA website, or a DBS-focused affiliate website to The PA (DBS4PD.org).
- There were 1,421 individuals who participated in this survey, including 369 participants with PD who underwent **DBS** and 1,052 individuals with PD without DBS (**Non-DBS group**; see Table 1 for demographics and clinical features).
- Participants represented 50 states, with California (13%), Arizona (10%), Texas (10%), Florida (9%), New Jersey (9%), New York (8%), Pennsylvania (5%), Colorado (4%), Minnesota (3%), and Virginia (2%) being the top 10 states with the most participants. Geographical distribution was comparable between groups. There were 38 international participants.
- For participants in this survey, 86% completed their survey independently, whereas, 14% of participants required assistance.

### Measures:

- The questionnaires used in this survey included: the Demographic Questionnaire and additional questions related to social support and emotional functioning, the Multidimensional Scale of Perceived Social Support (MSPSS), and an instrument created to understand the participant's ability to complete activities of daily living.

### The Demographic Questionnaire:

- The self-report questionnaire inquired about basic demographic information (e.g., gender, marital status, education) as well as pertinent clinical information pertaining to social support, emotional functioning, and instrumental activities of daily living.

### Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, et al., 1988):

- The MSPSS is a self-report measure assessing perceived adequacy of support. The scale provides three subscale scores: Family, Friends, and Significant Others. The group "significant others" includes persons who are relevant for the

participants, who may include partner or spouse, health care professionals, other individuals with PD, among other “significant” individuals to the person completing the questionnaire. The participants rated their perceived support using a 5-point Likert scale: Strongly Disagree, Mildly Disagree, Neutral, Mildly Agree, Strongly Agree, ratings being measures as 1 to 5, respectively. In each domain, the values were added together to create a total score for Family, Friends, and Significant Others. Higher scores mean higher levels of social support. A total score was also calculated by using the sum of all of the items within each domain.

### **Instrumental Activities of Daily Living Scale (created by The Parkinson Alliance):**

- This self-report questionnaire has 12 items addressing the following functional skills pertaining to basic activities of daily living and instrumental activities of daily living:
  - Basic Activities of Daily Activities (BADLS): Bathing, maintaining self-care, toileting, dressing, eating
  - Instrumental Activities of Daily Living (IADLS): Preparing meals/cooking, shopping, doing laundry, house cleaning, managing finances, managing medications, driving, and using the telephone.
- Items permit the participant to identify the best descriptor of his or her capability within each domain: “no difficulty,” “minimal assistance,” “moderate assistance,” “major assistance,” “unable to perform.”

### **Comparisons based on age and disease duration groups:**

- The results will be presented using the entire sample for individuals who completed the survey (N=1,421) and in the context of groups matched on age and disease duration.
  - Age: Age groups were divided into a **Younger PD group** (ages 50-69 years of age) and an **Older PD group** (ages 70+ years)
  - Disease Duration: In previous research pertaining to individuals with PD, the average time from symptom onset to development of motor complications was 6 years<sup>20,21</sup>. Previous 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. To better illustrate the impact of disease duration on exercise 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)**.

### **Factors to consider when interpreting the results:**

- This study used a survey-based methodology. 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.

## **RESULTS**

The summary of the demographic information and clinical characteristics of the participants in this study can be found in Table 1. The **Non-DBS group** was significantly older than the **DBS group (average: 71 versus 67 years, respectively)**. By contrast, the **DBS group** had a younger average age of PD diagnosis (**52 years**) than the **Non-DBS group (63 years)** and a longer duration of PD (see Table 1). Gender (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 these two groups.

**Table 1. Demographics and Clinical Features of the Sample**

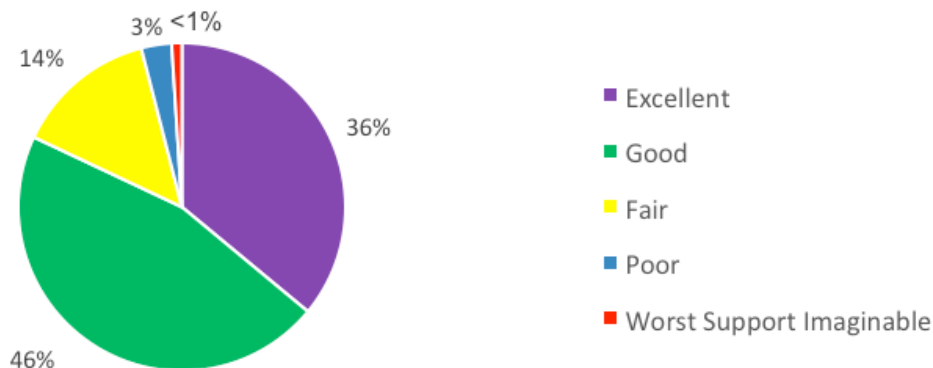
	<b>DBS (n =369)</b>	<b>Non-DBS (n =1,051)</b>
Average Age in Years (range)*	67 (44-90)	71 (42-96)
Duration of PD in Years (range)*	15 (0-37)	8 (0-39)
Average Age of PD Diagnosis (range)*	52 (29-77)	63 (27-93)
Average Age at Time of DBS in Years (range)	61 (36-86)	n/a
Average Duration since DBS in Years (range)	6 (0-30)	n/a
Target: STN	50%	n/a
GPI	8%	n/a
Not Sure	42%	n/a
Male	57%	53%
Female	43%	47%
Married	80%	77%
Lives Alone	11%	16%
Race		
Caucasian	96%	94%
Latino/Hispanic	3%	3%
African American	<1%	<1%
Asian	<1%	2%
American Indian	n/a	<1%
Native Hawaiian or Pacific Islander	n/a	1%
Other	n/a	n/a
Education		
<12 years	5%	3%
High School	8%	8%
Some College or Associate's Degree	25%	21%
College	29%	32%
Graduate/Advanced Degree	33%	36%
* Clinically significant difference between groups n/a = not applicable		

**PERCEIVED SOCIAL SUPPORT (N=1,421):**

- When asked from whom the participants received STRONG support, the top most frequently endorsed support systems included spouse, significant other, friends, and children followed by medical providers and individuals in the PD community.
  - Percent of participants reporting strong support from the following support systems (N=1,421):
    - Spouse and Significant Other: 78%
    - Friends: 66%
    - Children: 64%
    - Medical Providers: 49%
    - PD Community: 42%
    - Siblings: 33%
    - Neighbors: 26%
    - Animals: 23%
    - Church and Spiritual Groups: 22%

- Care Providers: 15%
  - Support Groups: 9%
  - Parents: 9%
  - Co-worker: 7%
- The majority of participants (82%) in this survey reported “good” to “excellent” satisfaction with social support (See Figure 1).
  - For the participants who receive practical help (meaning help with day-to-day activities, such as assisting with tasks to be completed, chores around the house, and completion of instrumental activities of daily living) due to their symptoms of PD (N=1,018), the majority of participants (84%) experience good to excellent satisfaction with the practical help they receive. 11% reported fair satisfaction with practical support; 4% reported poor satisfaction with practical support, and less than 1% reported “worst imaginable” satisfaction with practical help.
    - Notably, 28% of the participants reported that they did not receive “practical help” in the context of their symptoms of PD.

**Figure 1. Level of Satisfaction with perceived social support.**



- The extent to which the participants believe their support system understands their experience with PD was rated as follows:
  - Quite a bit to extremely understanding: 57%
  - Moderately understanding: 26%
  - A little bit of understanding: 13%
  - Not at all: 4%
- **Despite a high level of satisfaction with social support for the majority of participants:**
  - Changes in relationships within their support system have occurred due to PD:
    - Individuals reported reduced access to support due to PD:
      - 25% reported quite a bit to extremely reduced access to support
      - 26% reported moderately reduced access to support
      - 19% reported a little bit of reduced access to support
      - 30% reported that they have not experienced reduced access to their support.
  - PD symptoms (i.e., physical symptoms/limitations, speech disturbance, sleep disturbance, and/or cognitive difficulties) have adversely impacted the quality of support from others for 79% of individuals in this survey:
    - PD’s adverse impact on the quality of support from others:
      - A little bit: 24%
      - Moderately: 28%

- Quite a bit: 21%
  - Extremely: 6%
  - Not at all: 21%
  - 2% reported that support has improved due to PD
- Strain and stressors have emerged between the individual with PD and family for 44% of the participants.
- Strain and stressors have emerged between the individual with PD and care providers for 42% of the participants who have a care provider.
  - Of the participants who responded about whether or not they have a care provider:
    - 67% of the participants (771 participants) reported receiving assistance from a care provider:
      - 57% receive assistance 1 to 4 hours per day
      - 10% receive assistance 5 to 8 hours per day
      - 8% receive assistance 9 to 12 hours per day
      - 25% receive assistance greater than 12 hours per day.
    - 74% participants receiving assistance having 1 care provider; 17% have 2 care providers; 6% have 3 care providers; 3% have 4 care providers.
- Disagreements between the PWP and the support system about how much assistance needed were reported as:
  - 48% not at all
  - 43% sometimes
  - 9% frequently
- When disagreements occur (N=802), there is often an appropriate solution:
  - 43% not at all
  - 49% sometimes
  - 8% frequently
- 46% of the participants indicated that they have engaged in unsafe behaviors even when instructed to do something different (N=1,034).
  - Reasons for engaging in unsafe behaviors included:
    - The desire for the pleasure of the activity
    - Desire for control
    - Disbelief that there was a significant consequence
- 15% of the participants feel lonely more often than not, and 44% of the participants “sometimes” feel lonely.
- On-Line Resources have been found to be a source of support.
  - 65% of the participants reported being aware of on-line resources (N=1,396).
  - 38% of the participants consider on-line resources a source of support (N=1,377).
    - On-line resources accessed by participants in this study include:
      - Websites (30%)
      - Email (27%)
      - Facebook (12%)
      - On-line support groups (11%)
      - Blogs (6%)
      - Chat rooms (2%)
      - Instagram/Twitter (2%)
  - When asked about how much support participants receive from on-line resources (N=544), 3% reported feeling

“extremely” supported from on-line resources, 33% reported receiving “quite a bit” of support, 38% reported moderate levels of support, 21% reported a little bit of support, 5% reported no support.

**Multidimensional Scale of Perceived Social Support (Friend, Family, Significant Other):**

- The majority of participants across age and disease duration groups reported that they have social support from **Friends** (See Table 2).
  - There was not a clinically significant difference between age and disease duration groups.
- The majority of participants across age and disease duration groups reported that they have social support from **Family** (See Table 3).
  - There was not a clinically significant difference between age and disease duration groups.
- The majority of participants across age and disease duration groups reported that they have social support from **Significant Other** (See Table 4).
  - There was not a clinically significant difference between age and disease duration groups.
- There was a trend towards the **Advanced 11+ years Group** for both **Younger and Older participants** to perceive lower levels of social support when compared to the other disease duration groups.
- Across age and disease duration groups, when comparing the level of support from Friends, Family, and Significant Others (See Tables 2, 3, and 4), **the level of support was perceived as higher for Significant Others when compared to Friends and Family.**
- Although a large number of the participants indicated that they feel a sense of social support from friends, family, and significant others, **there is a significant number of individuals who do not feel supported by these respective resources** (see Tables 2, 3, and 4).

**Table 2. Multidimensional Scale of Perceived Social Support: SUPPORT FROM A FRIEND**

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =192-193) <sup>1</sup>	Older (70+) (n =207-210)	Younger (50-69) (n =188-189)	Older (70+) (n = 188-189)	Younger (50-69) (n =244-248)	Older (70+) (n =287-292)
<b>My friends really try to help me.</b>						
Disagree (Mildly to Strongly)	5%	8%	6%	9%	10%	9%
Neutral	22%	21%	20%	23%	15%	22%
Mildly Agree	29%	30%	31%	31%	38%	30%
Strongly Agree	43%	42%	43%	37%	37%	39%
<b>I can count on my friends when things go wrong.</b>						
Disagree (Mildly to Strongly)	8%	8%	7%	9%	14%	11%
Neutral	17%	17%	15%	23%	17%	21%
Mildly Agree	24%	26%	29%	30%	31%	30%
Strongly Agree	51%	49%	48%	39%	39%	39%
<b>I have friends with whom I can share my joys and sorrows.</b>						
Disagree (Mildly to Strongly)	8%	7%	11%	12%	19%	14%
Neutral	14%	14%	15%	19%	17%	21%



Mildly Agree	29%	36%	29%	36%	28%	27%
Strongly Agree	49%	43%	46%	33%	35%	38%
<b>I can talk about my problems with my friends.</b>						
Disagree (Mildly to Strongly)	10%	8%	12%	13%	21%	14%
Neutral	16%	14%	19%	17%	16%	19%
Mildly Agree	33%	38%	25%	39%	31%	31%
Strongly Agree	41%	40%	44%	30%	33%	36%
1. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.						

**Table 3. Multidimensional Scale of Perceived Social Support: SUPPORT FROM FAMILY**

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =192-193) <sup>1</sup>	Older (70+) (n =209-211)	Younger (50-69) (n =185-188)	Older (70+) (n = 238-241)	Younger (50-69) (n =243-245)	Older (70+) (n =290-294)
<b>My family really try to help me.</b>						
Disagree (Mildly to Strongly)	7%	7%	9%	7%	9%	9%
Neutral	10%	11%	9%	9%	12%	9%
Mildly Agree	22%	16%	27%	24%	21%	26%
Strongly Agree	61%	67%	55%	61%	57%	56%
<b>I get the emotional help and support I need from my family.</b>						
Disagree (Mildly to Strongly)	10%	7%	12%	8%	14%	13%
Neutral	12%	12%	13%	11%	13%	13%
Mildly Agree	22%	22%	32%	31%	26%	31%
Strongly Agree	55%	59%	44%	51%	48%	43%
<b>I can talk about my problems with my family.</b>						
Disagree (Mildly to Strongly)	10%	8%	13%	8%	17%	14%
Neutral	15%	11%	14%	11%	15%	15%
Mildly Agree	22%	25%	29%	32%	26%	31%
Strongly Agree	53%	56%	43%	49%	41%	40%
<b>My family is willing to help me make decisions.</b>						
Disagree (Mildly to Strongly)	8%	8%	14%	6%	14%	11%
Neutral	15%	10%	12%	11%	21%	13%
Mildly Agree	23%	22%	28%	29%	23%	26%
Strongly Agree	54%	60%	47%	54%	42%	51%
1. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.						

**Table 4. Multidimensional Scale of Perceived Social Support:  
SUPPORT FROM A SIGNIFICANT OTHER**

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =183-185) <sup>1</sup>	Older (70+) (n =199-200)	Younger (50-69) (n =184-185)	Older (70+) (n = 228-229)	Younger (50-69) (n =241-243)	Older (70+) (n =281-284)
<b>There is a special person who is around when I am in need.</b>						
Disagree (Mildly to Strongly)	9%	8%	14%	9%	14%	12%
Neutral	5%	10%	7%	9%	3%	8%
Mildly Agree	14%	15%	14%	15%	15%	15%
Strongly Agree	73%	68%	65%	67%	68%	65%
<b>There is a special person with whom I can share my joys and sorrows.</b>						
Disagree (Mildly to Strongly)	11%	8%	14%	10%	14%	9%
Neutral	7%	12%	9%	10%	6%	12%
Mildly Agree	15%	14%	20%	18%	18%	19%
Strongly Agree	67%	67%	57%	62%	62%	59%
<b>I have a special person who is a real source of comfort to me.</b>						
Disagree (Mildly to Strongly)	11%	9%	15%	10%	13%	10%
Neutral	9%	9%	8%	10%	8%	13%
Mildly Agree	13%	17%	20%	18%	15%	16%
Strongly Agree	67%	65%	58%	63%	64%	61%
<b>There is a special person in my life who cares about my feelings.</b>						
Disagree (Mildly to Strongly)	10%	9%	11%	9%	12%	9%
Neutral	8%	8%	10%	10%	7%	11%
Mildly Agree	12%	15%	20%	16%	18%	16%
Strongly Agree	70%	69%	59%	65%	64%	64%

1. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.

### **Perceived Barriers to Having a Strong Support System (see Table 5)**

- Motor symptoms including walking, balance disturbance, tremor, stiffness, slowness of movement, swallowing difficulties) and non-motor symptoms such as fatigue, speech disturbance, cognitive difficulties, depression, anxiety, and apathy can impact support.
- Many participants in this survey reported that motor and non-motor symptoms of PD are significant barriers to having a strong support system (See Table 5).
- As age and disease duration increases, a greater number of participants reported that motor and non-motor symptoms interfere with their support system.
- In the **Younger PD Group and Early Disease Duration Group**, the top four frequently endorsed symptoms reported as a perceived barrier to social support included:
  - Fatigue, physical symptoms, cognitive changes, and emotional disturbance.

- In the **Older PD Group and Early Disease Duration Group**, the top four most frequently endorsed symptoms reported as a perceived barrier to social support included:
  - Fatigue, physical symptoms, speech disturbance, cognitive changes and apathy (the latter two being endorsed by 30% of the participants).
- In the **Younger PD Group and Advanced Disease Duration (6-10 years) Group**, the top four frequently endorsed symptoms reported as a perceived barrier to social support included:
  - Fatigue, physical symptoms, speech disturbance, and cognitive difficulties.
- In the **Older PD Group and Advanced Disease Duration (6-10 years) Group**, the top four frequently endorsed symptoms reported as a perceived barrier to social support included:
  - Fatigue, physical symptoms, cognitive difficulties, and speech disturbance.
- In the **Younger PD Group and Advanced Disease Duration (11+ years) Group**, the top four frequently endorsed symptoms reported as a perceived barrier to social support included:
  - Fatigue, physical symptoms, speech disturbance, and apathy.
- In the **Older PD Group and Advanced Disease Duration (11+ years) Group**, the top four frequently endorsed symptoms reported as a perceived barrier to social support included:
  - Physical symptoms, fatigue, speech disturbance, and cognitive difficulties.

**Table 5. Perceived Barriers to having a Strong Support System**

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =195) <sup>1</sup>	Older (70+) (n =211)	Younger (50-69) (n =190)	Older (70+) (n = 244)	Younger (50-69) (n =250)	Older (70+) (n =300)
<b>Physical Symptoms: (i.e., walking, balance, tremor, stiffness, slowness of movement)</b>	35%	43%	41%	46%	55%	61%
<b>Fatigue/Tiredness</b>	49%	51%	51%	50%	58%	54%
<b>Speech Disturbance</b>	19%	33%	33%	32%	50%	57%
<b>Difficulties with eating/ swallowing</b>	5%	14%	12%	15%	18%	27%
<b>Cognitive Difficulties (i.e., slowness of thinking; difficulties with attention, memory, understanding others)</b>	35%	32%	33%	38%	37%	44%
<b>Depression and/or Anxiety</b>	28%	29%	27%	28%	34%	31%
<b>Apathy/Diminished interest in spending time with others</b>	24%	31%	30%	28%	36%	25%
<b>Aesthetics: (do not feel comfortable socializing due to your appearance)</b>	12%	10%	12%	14%	22%	18%
<b>Your perception that others do not feel comfortable around you</b>	11%	12%	18%	14%	30%	23%

1. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.

## Aspects of One’s Support System That Participants Wish to Improve (See Table 6)

- In the context of support manifesting in physical support, intellectual support, emotional support, spiritual support, financial support, and practical support, the most frequently endorsed domain of social support that the **participants would like to improve was “emotional support.”**
  - Across Age and Disease Duration groups, the following range of frequency of the participants wishing to improve a support domain included (see Table 6):
    - Emotional Support: 21% to 44%
    - Physical Support: 13% to 25%
    - Practical Support: 10% to 24%
    - Financial Support: 10% to 23%
    - Intellectual Support: 11% to 17%
    - Spiritual Support: 8% to 16%

**Table 6. Aspects of one’s support system that participants wish to improve**

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =195) <sup>1</sup>	Older (70+) (n =211)	Younger (50-69) (n =190)	Older (70+) (n = 244)	Younger (50-69) (n =250)	Older (70+) (n =300)
Physical Support	15%	13%	20%	17%	25%	21%
Intellectual Support	15%	11%	15%	17%	14%	15%
Emotional Support	36%	21%	36%	36%	44%	35%
Spiritual Support	16%	8%	13%	9%	14%	12%
Financial Support	18%	10%	17%	12%	23%	16%
Practical Support	10%	15%	16%	19%	24%	24%

1. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.

## Psychological Well-being (Table 7):

- Depression and anxiety were endorsed in high frequency by participants in this study across age and disease duration groups.
  - 23% to 38% of the participants endorsed moderate to severe depression, reflecting high levels of anxiety across groups.
    - Greater reports of depression were experienced for the **Younger and Older Advanced 11+ years PD group** when compared to other groups.
  - 33% to 48% of the participants endorsed moderate to severe anxiety, reflecting high levels of anxiety across groups.
- Greater reports of frustration were reported in the **Advanced Disease Duration groups** for both **Younger and Older** participants.
- Stress levels were highly endorsed across groups with 37% to 51% of the participants endorsing moderate to severe stress levels.
- There was a significant relationship between emotional distress and perceived social support, such that the greater the perceived social support, the less emotional distress was reported.

- For a significant percentage of participants, the social support system did create anxiety for the participants of this survey (see Table 7).

<b>Table 7. Current Emotional Well-being</b>						
	<b>Early PD Group</b>		<b>Advanced PD Group</b>			
	<b>(&lt;6 years duration)</b>		<b>6-10 years duration</b>		<b>11+ years duration</b>	
	<b>Younger</b>	<b>Older</b>	<b>Younger</b>	<b>Older</b>	<b>Younger</b>	<b>Older</b>
	<b>(50-69)</b>	<b>(70+)</b>	<b>(50-69)</b>	<b>(70+)</b>	<b>(50-69)</b>	<b>(70+)</b>
	<b>(n =191-192)<sup>1</sup></b>	<b>(n =210-211)</b>	<b>(n =185-188)</b>	<b>(n = 239-241)</b>	<b>(n =245-248)</b>	<b>(n =290-293)</b>
<b>Frustration</b>						
Not at all	15%	14%	14%	11%	5%	11%
Mild	48%	49%	39%	44%	41%	40%
Moderate	29%	31%	36%	39%	41%	40%
Severe	9%	7%	11%	6%	14%	9%
<b>Stress:</b>						
Not at all	12%	18%	9%	12%	7%	13%
Mild	39%	46%	42%	46%	42%	44%
Moderate	36%	33%	38%	33%	37%	34%
Severe	13%	4%	12%	9%	14%	9%
<b>Depression:</b>						
Not at all	35%	34%	30%	25%	21%	25%
Mild	42%	41%	38%	46%	41%	38%
Moderate	19%	21%	24%	24%	30%	28%
Severe	4%	5%	8%	5%	8%	8%
<b>Anxiety:</b>						
Not at all	22%	21%	15%	19%	13%	22%
Mild	31%	46%	44%	42%	44%	37%
Moderate	35%	26%	31%	30%	30%	31%
Severe	13%	7%	10%	10%	14%	11%
<b>Support system creates Anxiety: (i.e., nervousness; fear; worry; feeling overwhelmed)</b>						
Not at all	37%	42%	32%	30%	22%	27%
Mild	31%	40%	37%	45%	42%	43%
Moderate	28%	17%	24%	19%	27%	26%
Severe	5%	1%	8%	7%	9%	5%
1. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.						
2. Categories: None: Ratings of 0; Mild: Ratings of 1-3; Moderate: Ratings of 4 to 7; Severe: Ratings of 8 to 10.						

### Activities of Daily Living (See Table 8):

- The majority of the participants in this survey reported being independent or requiring minimal assistance when completing basic activities of daily living, though there were a considerable number of individuals who required assistance.
- As it relates to the completion of instrumental activities of daily living, many participants required assistance from others, with increased frequency of individuals who reported the need for assistance as age and disease duration increased.

- There was a significant but low correlation between the level of assistance needed and emotional distress. Thus, although emotional distress is related to increased need for assistance, the increased need for assistance does not necessarily result in increased emotional distress.

**Table 8. Functional independence in activities of daily living/IADLs**

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =183-188) <sup>1</sup>	Older (70+) (n =196-208)	Younger (50-69) (n =181-187)	Older (70+) (n = 227-240)	Younger (50-69) (n =233-240)	Older (70+) (n =271-287)
<b>Basic Activities of Daily Living</b>						
<b>Bathing:</b>						
No Difficulty	89%	87%	87%	79%	70%	57%
Minimal Assistance	8%	9%	10%	13%	19%	23%
Moderate Assistance	1%	2%	1%	3%	8%	8%
Major Assistance/ Unable to perform	2%	2%	2%	5%	3%	13%
<b>Maintaining Self-care:</b>						
No Difficulty	88%	84%	82%	73%	68%	53%
Minimal Assistance	9%	12%	14%	18%	22%	27%
Moderate Assistance	3%	3%	4%	3%	8%	9%
Major Assistance/ Unable to perform	1%	2%	1%	6%	3%	12%
<b>Toileting/Bowel &amp; Bladder:</b>						
No Difficulty	95%	88%	86%	80%	75%	65%
Minimal Assistance	3%	6%	12%	11%	18%	16%
Moderate Assistance	2%	3%	1%	4%	5%	9%
Major Assistance/ Unable to perform	1%	3%	1%	5%	3%	11%
<b>Dressing/Clothing Yourself:</b>						
No Difficulty	80%	75%	69%	64%	57%	46%
Minimal Assistance	16%	18%	25%	23%	32%	31%
Moderate Assistance	4%	5%	5%	7%	8%	13%
Major Assistance/ Unable to perform	0%	2%	1%	6%	3%	11%
<b>Feeding Yourself:</b>						
No Difficulty	94%	91%	86%	82%	77%	70%
Minimal Assistance	5%	6%	11%	12%	16%	19%
Moderate Assistance	1%	2%	3%	3%	5%	8%
Major Assistance/ Unable to perform	0%	1%	0%	3%	2%	3%
<b>Preparing Meals/Cook:</b>						
No Difficulty	74%	65%	60%	50%	39%	31%
Minimal Assistance	13%	10%	26%	15%	28%	20%
Moderate Assistance	8%	10%	8%	10%	14%	14%

Major Assistance/ Unable to perform	4%	14%	6%	26%	19%	35%
<b>Shopping (in stores or online):</b>						
No Difficulty	74%	63%	66%	53%	40%	35%
Minimal Assistance	17%	13%	17%	14%	27%	22%
Moderate Assistance	5%	11%	10%	10%	16%	14%
Major Assistance/ Unable to perform	4%	13%	8%	23%	17%	30%
<b>Doing the Laundry/Cleaning Clothes:</b>						
No Difficulty	75%	66%	67%	57%	47%	38%
Minimal Assistance	17%	12%	15%	16%	21%	15%
Moderate Assistance	4%	9%	11%	8%	14%	12%
Major Assistance/ Unable to perform	4%	14%	8%	19%	19%	35%
<b>Cleaning the House/Home:</b>						
No Difficulty	59%	49%	46%	37%	28%	26%
Minimal Assistance	18%	13%	28%	16%	23%	14%
Moderate Assistance	15%	18%	13%	17%	23%	16%
Major Assistance/ Unable to perform	9%	19%	13%	30%	26%	44%
<b>Managing Finances/Pay Bills:</b>						
No Difficulty	72%	67%	65%	55%	48%	38%
Minimal Assistance	13%	12%	20%	14%	20%	16%
Moderate Assistance	6%	8%	7%	8%	15%	12%
Major Assistance/ Unable to perform	9%	13%	8%	23%	18%	34%
<b>Using the Telephone (i.e., Dial 911):</b>						
No Difficulty	96%	87%	90%	77%	77%	61%
Minimal Assistance	4%	9%	7%	8%	10%	17%
Moderate Assistance	1%	1%	2%	7%	7%	9%
Major Assistance/ Unable to perform	0%	2%	1%	7%	6%	13%
<b>Driving:</b>						
No Difficulty	72%	58%	52%	46%	42%	27%
Minimal Assistance	13%	12%	28%	12%	15%	13%
Moderate Assistance	6%	5%	5%	8%	9%	5%
Major Assistance/ Unable to perform	8%	25%	15%	34%	34%	55%
<b>Managing Medication:</b>						
No Difficulty	80%	73%	75%	62%	64%	47%
Minimal Assistance	12%	9%	16%	13%	18%	18%
Moderate Assistance	4%	7%	7%	6%	9%	10%
Major Assistance/ Unable to perform	4%	12%	2%	20%	9%	25%

1. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.

## Quality of Life (see Table 9):

- “Good” to “Excellent” quality of life was reported in greater frequency earlier in the disease course when compared to the **Advanced 11+ year group**.
- Quality of life was significantly related to social support, where the greater the perceived social support from friends and significant others, the higher the rating of quality of life.

**Table 9. Quality of Life: The Patient’s Perspective**

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =183-188) <sup>1</sup>	Older (70+) (n =196-208)	Younger (50-69) (n =181-187)	Older (70+) (n = 227-240)	Younger (50-69) (n =233-240)	Older (70+) (n = 271-287)
The worst imaginable	0%	1%	1%	0%	2%	1%
Poor	5%	2%	2%	5%	4%	7%
Fair	14%	21%	26%	25%	26%	31%
Good	54%	55%	47%	56%	53%	48%
Excellent	28%	21%	24%	15%	15%	14%

## SELECTED COMMENTS FROM PARTICIPANTS

### Acknowledgements and perceived anecdotes as it relates to a support system:

“Thank God for my PD support group, they really care and are everything to me ... they talk to me about PD in a non-judgmental way.”

“The importance of social support cannot be overrated....It takes courage to reach out for support once physical symptoms or mobility are bad... You must believe in your own worth as a human being, and continue to reach out to and encourage others as well. Volunteer — even if online. Call people who are grieving or in pain — or email if you can’t be heard clearly on the phone. Stay connected. Fight to do so.”

“For those of us who belong to a club we never wanted membership to, I thank you for your interest and all the time and effort you put towards finding a cure for this ugly thing. Thank you.” “I appreciate your request to complete this survey.”

“Without the support of my wife, I’d be in much more difficult straights.”

“I am a blessed man, loved and cherished by family and friends, and we speak about Parkinson’s freely, without shame or hesitation.”

### Challenges within the support system:

“I think there needs to be a greater understanding of the social impact PD has on patients’ lives. Before PD, I would often hear how I ‘immediately light up a room,’ or how ‘charming’ I am. I haven’t heard such compliments in years, and in fact, my ‘support system’ often scolds me for not getting out enough, or ‘always worrying.’ I feel like my emotions are no longer expressed correctly. Unless I make a concerted effort to smile, my family and friends will ask me ‘what’s wrong?’ or ‘quit worrying.’ Thank you so much for exploring the ‘social’ impact of PD. I have very little tremor, so I feel frowned upon for being on disability. Few know the constant cognitive frustrations of this disease — the difficulties making choices, planning, going out in public, or just getting up, dressed, and making it through the day.”



“I have two adult children with their own families ... I do not think they even begin to appreciate how much my life is affected by PD. .. I do sometimes feel like my Parkinson’s is an elephant in the room — everyone tries to ignore it, but, oh, it takes up so much space.”

“I need a friend who truly cares about me ... someone who will truly listen.”

“I really would like to find some support groups out there.”

“[Family and PWP]...we rarely talk ... More than anything I need her emotional support, but she doesn’t seem to realize how I feel, even when I tell her. ... Wish I had someone special, but that’s unlikely given my age and diagnosis. I don’t feel particularly depressed, just sad ...”

“I just wish that my family would understand what I go through every day. I try to talk to them and it becomes about their problems. I have no support whatsoever.”

## SUMMARY AND DISCUSSION

People with Parkinson’s disease (PWP) are confronted with debilitating symptoms, commonly inclusive of progressive physical, cognitive, and psychiatric symptoms. For many, trying to manage their symptoms day-by-day, if not moment-by-moment, social support is not only an aid to physical and psychological comfort, over time, social support becomes a necessity to manage well-being, such as engaging in and completing activities of daily living.

Social support may be a predictor of successful adaptation and general psychological well-being for individuals with PD. A deeper understanding about the patient’s perspective of social support remains indicated, particularly as it relates to 1. the different dimensions of social support, 2. the barriers to social support, and 3. the perceived opportunities for improving social support from the perspective of PWP.

### **General Findings:**

- Many participants in this survey indicated that they have strong support systems, inclusive of family, friends, significant others, the medical community, and the PD community.
- On-line resources were also perceived as part of a social support for individuals with PD.
- The majority of individuals in this survey reported high satisfaction with their support system. Specifically, 82% of the participants in this survey reported “good” to “excellent” satisfaction with social support.
  - **Despite a high level of satisfaction with social support:**
    - Changes in relationships have occurred due to symptoms of PD, with 49% of the participants reporting moderately to extremely reduced access to the support due to PD symptoms.
    - PD symptoms have adversely impacted the quality of support from others for 77% of individuals in this survey.
    - Strain and stressors have emerged between the individual with PD and family and care providers for 40% of the participants.

**OBJECTIVE 1:** To understand the patient’s perspective about social support using the Multidimensional Scale of Perceived Social Support (MSPSS) and its relationship to psychological well-being.

- The majority of participants across age and disease duration groups reported that they have social support from **Friends, Family, and Significant Others**. There was not a clinically significant difference between age and disease duration groups.

- There was a trend for the **Advanced 11+ years Group** for both **Younger and Older participants** to perceive lower levels of social support when compared to the other disease duration groups.
  - In Quelhas and Costa's research (2009), individuals with PD may experience concerns about burden, social withdrawal and a reluctance to be with friends or other support systems, engage in activities, or leave home. Over time, the increasing dependence on others, which is considered to be the most stressful symptom among disease-related stressors, and a sense of isolation, may result in alienation even in the context of established social support (Frazier, 2000).
- Across age and disease duration groups, **the level of support was perceived as higher for Significant Others when compared to Friends and Family** (See Tables 2,3, and 4).
  - Such findings warrant further investigation. One plausible explanation is that the term "significant other" is a broad range of individuals who provide emotional support and feelings of being valued (i.e., spouse; social contacts in support groups). As another explanation, the strain that may manifest between patient and family/care provider may have influenced the response of the participant, thus leading towards the endorsement of greater support for a significant other, as supported by other research (Miller, et al., 1996).
  - Quality of life was significantly related to social support, where the greater the perceived social support from friends and significant others, the higher the rating of quality of life.
- Depression and anxiety were endorsed in high frequency by participants in this study across age and disease duration groups.
  - 23% to 38% reported moderate to severe depression.
  - 33% to 48% reported moderate to severe anxiety.
  - 37% to 51% reported moderate to severe levels of stress.
- Vulnerability to high reports of depression and anxiety is evident during the course of PD (early or advanced, and across age groups).
- There was a significant relationship between emotional distress and perceived social support, such that the greater the perceived support, the less emotional distress. Thus, perceived adequate social support may be a buffer, in part, for psychological distress, consistent with previous research (i.e., Schaefer, Coyne, & Lazarus, 1981).

**OBJECTIVE 2:** To understand the barriers to social support from the patient's perspective.

- Although many individuals reported satisfaction with their support system, participants in this survey reported that many motor and non-motor symptoms are significant barriers to having a strong support system.
  - Fatigue, physical symptoms, speech disturbance, cognitive difficulties, and emotional disturbance were the most highly reported barriers to having a strong support system.
  - As age and disease duration increases, a greater number of participants reported that motor and non-motor symptoms interfered with their support system.

**OBJECTIVE 3:** To understand the perceived opportunities for improved social support from the patient's perspective.

- In the context of support manifesting in physical support, intellectual support, emotional support, spiritual support, financial support, and practical support, the most frequently endorsed domain of social support that the **participants would like to improve was "emotional support."** Oxman and Hull (1997) proposed categories of support: emotional support, guidance support, and tangible support. Thus, in this context, the most frequently reported domain that the participants in this survey wanted to be improved related to emotional support when compared to factors that may

fall into the categories of guidance support (receiving knowledge or some action to better one's situation) and tangible support (such as providing transportation, financial assistance, meals, and housing).

## GENERAL RECOMMENDATIONS:

- This survey adds an additional dimension to the ripple effect of the constellation of motor and non-motor symptoms on the well-being of PWP. Moreover, PWP perceived that motor and non-motor symptoms can be barriers to having a strong support system.
  - Thus, treating the whole person from an interdisciplinary treatment team perspective is further underscored by this report.
  - Serial assessment of and intervention for both motor and non-motor symptoms (i.e., fatigue, sleep disturbance, speech disturbance, cognitive changes, psychiatric disturbance, autonomic dysfunction, and psychosocial variables) is indicated.
- Given the vulnerability to perceived reduced social support and heightened psychological distress, increased attention towards patients and their support system as the disease progresses is indicated. That said, early education about the importance and establishment of social support systems may prove advantageous to the preparation for challenges that are faced in the advanced stages of PD.
- Recommendations for an interdisciplinary treatment team approach is becoming increasingly recognized as being of great importance for individuals with PD. As part of the inter-disciplinary treatment team, Parkinson's expert social workers are in a unique position to help address the full range of social support and psychosocial needs that are experienced by PWP, care partners and families.
  - Most patients who have been referred to a Parkinson's expert social worker have never worked with this service before and are not aware of the full range of options that can be provided. **A referral to a Parkinson's expert social work team can be a doorway to tailored support programs and services for patients, families and care partners.**
  - Based on a comprehensive needs assessment, a proactive, tailored support program can be developed.
  - Patients, care partners and families can be connected to a range of specialized services for PD, including:
    - Emotional Support through supportive counseling and psychotherapy tailored to PD patients, care partners, couples, and families, as well as through psychosocial and/or psychoeducational support groups which can be professionally or peer led.
    - Tangible Support through referrals to medical or community based Parkinson's exercise and wellness programs and Parkinson's specific home visit programs for individuals with advanced PD.
    - Guidance support through disease specific education and care coordination.
  - It is recommended that individuals with PD be referred early in the disease course to introduce appropriate services for motor and non-motor symptoms and social support, and to help build relationships that will be beneficial throughout the disease process.
- PWP are encouraged to speak with their movement disorders specialist or neurologist about the motor and non-motor symptoms that may be adversely impacting social support and general well-being. Interventions tailored to the individual's needs can then be pursued.
- The frequency and severity of emotional distress reported in this survey highlight the need for monitoring psychological well-being and providing intervention. Specialists such as licensed clinical social workers, psychologists/neuropsychologists, and psychiatrists/neuropsychiatrists are important members of the treatment team.
- Medications, in conjunction with psychotherapy, may be helpful for participants who suffer from depression or

anxiety. It is recommended that use of medications for psychological well-being be monitored by a specialist in PD.

- Using resources in the community, such as support groups, exercise groups, yoga classes, public parks, on-line resources, and the like, may bring about a stronger sense of social support, thereby aiding in one's general physical and psychological well-being.
- Continued research on social support and its relationship to psychological well-being is needed.

**Ask your provider for a referral to a Parkinson's expert social worker near you. Or contact the Parkinson Alliance or Parkinson's Foundation for more resources in your area.**

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