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Barriers to Mental Health Care Utilization in Parkinson's Disease

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Abstract

Background—Parkinson's disease (PD) is frequently complicated by co-occurring psychiatric problems, such as depression and anxiety, that negatively affect the course and management of the illness. Yet, in the majority of cases, these psychiatric comorbidities are neither recognized nor treated to remission. The primary purpose of this study was to identify and describe barriers to mental health care utilization for people with PD. Secondary objectives included the assessment of attitudes and preferences regarding the need for mental health services in the PD community and the acceptability of tele-health interventions as a method for improving access and quality of care.

Methods—Seven hundred sixty-nine people with PD completed an anonymous cross-sectional questionnaire assessing barriers to mental health care utilization in this medical population. Respondents were drawn from a national sample.

Results—Commonly endorsed barriers to mental health care utilization in PD reflect the patients' incomplete understanding of mental health problems, access issues, and illness-specific concerns, as well as the inadequate screening and detection of psychiatric complications by medical providers, and the need for more effective treatments in this medical population. Several

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demographic, medical, and psychiatric variables also influenced the likelihood of accessing mental health care. Interest in tele-health approaches to mental health treatment was high and, in several instances, correlated with perceived barriers to mental health care utilization.

Conclusions—People with PD may encounter a multitude of barriers that impede their pursuit of mental health care. Clinical implications are discussed and further research is needed to replicate and extend these findings.

Keywords

Parkinson's disease; depression; anxiety; mental health care utilization; barriers

Parkinson's disease (PD) is the second most common neurodegenerative disorder in the elderly. In the majority of individuals, the illness is complicated by co-occurring psychiatric problems, such as depression and anxiety¹ that negatively affect the course and management of the illness^{2,3,4}. Yet, in the majority of cases, these psychiatric comorbidities are neither recognized nor treated to remission^{5,6}. For example, Shulman and colleagues found that neurologists failed to recognize depressive and anxious symptoms in people with PD during routine office visits, more than 50% of the time⁵. Other research groups have also demonstrated that a substantial proportion of PD patients (i.e., 40–66%) reporting significant depressive symptoms had neither been treated nor referred for further psychiatric evaluation by their personal physicians, while more than half of those who had been prescribed antidepressant medication remained depressed^{4,6}. Most recently, an NIH-funded trial (MOOD-PD) reported that while improving access to an initial psychiatric consult enhanced the rate at which depression treatment was initiated, it did little to reduce the rate of PD patients with un-remitted depressive episodes⁷.

Collectively, the above findings suggest that improved screening and detection of psychiatric complications may be only two of many factors related to the use of and benefit from mental health care in PD. Effective mental health treatment in this medical group may also be impeded by the fact that treatment outcome research regarding the psychiatric complications in PD is just beginning to burgeon^{8,9} and optimal treatment recommendations have yet to be developed. Nonetheless, several patient variables may also be implicated in the suboptimal management of psychiatric disorders in PD. Factors such as physical disability, transportation problems, geographic location, age, poor mental health literacy (i.e., knowledge and beliefs about psychiatric symptoms, treatment options, and their potential effectiveness), and distrust of medical professionals, to name a few, may limit the PD patients' ability to derive maximum benefit from the healthcare system both before and after a psychiatric complication has been detected. Several of these aforementioned variables have been identified as important barriers to health care utilization in other populations but none have been systematically evaluated in PD^{10,11,12,13,14,15}.

The primary purpose of this study is to identify and describe barriers to mental health care utilization for people with PD. Secondary objectives include the assessment of attitudes and preferences regarding the need for mental health services in the PD community and the acceptability of tele-health interventions (i.e., treatment delivered via the phone or internet) as a method for improving access and quality of care. Telemedicine was purposely explored as a specific strategy for disseminating evidence-based mental health care in PD given the success that this approach has demonstrated in other medical groups^{16,17}. The information gleaned from this research may be used to inform clinical practice recommendations for the psychiatric complications frequently observed in Parkinson's disease. To our knowledge, this is the first study to systematically examine barriers to mental health care utilization in PD in a national sample.

Method

Participants

People with Parkinson's disease throughout the United States (US) were recruited from several sources. Study flyers were distributed through the National Chapter of the American Parkinson's disease Association (APDA) as well as local APDA chapters and PD support groups across the US. The study was also posted on ClinicalTrials.gov, PDTrials.org, Craig's list, the Michael J. Fox Foundation for Parkinson's Research-Fox Trial Finder, and on websites for various PD related organizations (i.e., National Parkinson Foundation). All individuals with a diagnosis of PD, who were at least 18 years of age, were eligible to participate.

Measures

Barriers survey—Survey questions were generated based on a review of the PD literature^{18,19}, as well as barriers to mental health care utilization in other populations^{10–15}, the research team's previous experience working with PD, and consultation with geriatric psychiatrists and movement disorder specialists. The survey assessed several domains related to mental health care utilization in PD and was pilot-tested (for clarity, readability, and ease of administration) at a local PD support group prior to distribution to the national sample.

Participants reported demographic information such as age, gender, education, income, health insurance, work and marital status, and region of residence in the country, and key aspects of medical (i.e., length of illness [PD], primary provider of PD care, comorbid medical conditions, number of medications, assessment of overall health, number of medical specialist visits in past year, PD-related physical impairment) and psychiatric history (i.e., need and receipt of past mental health treatment, helpfulness of and satisfaction with previous interventions, provider and type of past mental health services, treatment provider knowledge of PD). Past barriers to mental health care utilization (i.e., physical disability, no transportation, perceived benefit of treatment; 22 questions) were assessed. Participants were also given the opportunity to describe changes they desired about the mental health services they received. Attitudes and preferences regarding mental health care services in the PD community, perceived future barriers to mental health treatment (11 questions), and the acceptability of tele-health interventions as a method for improving access and quality of care were also assessed. The questions were presented in many forms, including multiple choice, open-ended, and Likert rating scales. See Appendix 1.

Procedure

This research study had the full approval of the Robert Wood Johnson Medical School IRB and consisted of the one-time administration of an anonymous cross-sectional survey that took 15–30 minutes to complete. In order to accommodate people with varying levels of disability, interested participants had the option to complete the survey either online (by accessing the study specific link on Survey Monkey), on paper (by requesting that a hard copy be mailed to their home), or over the phone (by calling the research team at designated periods of time). All potential participants read (or were read) a statement of informed consent before beginning the survey, that was specific to the method of survey administration (paper, online, phone). No identifying information was collected.

Overview of Statistical Analyses

Data was analyzed with SPSS Version 18. All available data, from all participants, was used in conducting statistical tests. Descriptive statistics (i.e., means, frequencies, cross-tabs)

were generated for most survey items. Where appropriate, One-Way Analysis of Variance (ANOVA) or Chi Square Tests were used to compare survey responses (i.e., endorsement of barriers) based on demographic factors as well as key aspects of medical and psychiatric history as described above. Correlation analyses were conducted to explore the inter-relationships between variables. Logistic regressions were used to examine predictors of each proposed past and future barrier to mental health care utilization in this medical population. Potential predictors for each logistic regression model (one regression model per barrier) were determined based on the results of significant chi square tests ($p < .05$) and were entered into the respective model simultaneously. All variables were dichotomized as appropriate based on inspection of the data prior to their inclusion in statistical analyses. For example, a barrier to mental health care utilization was dichotomized as “present” by a rating of at least a 5 (moderate) on the 10-point Likert rating scale provided, absent otherwise. Open-ended responses were coded via text analysis software provided by Survey Monkey. The large “N’s” reported throughout the text and tables reflect the total number of participants that answered each individual question, that belong to a particular category (i.e., received psychotherapy only), or that were included in a specific statistical analysis. The small “n’s” correspond to the “percentages” reported in text and tables.

Results

Eight-hundred eighty three (883) people with PD gave informed consent to participate in the study. Of these, 769 (87%) provided survey responses [599 (78%) online; 170 (22%) phone or paper]. Detailed demographic information and characteristics of the sample can be found in Table 1.

Mental Health Care Utilization

See Table 2 for specific information regarding patterns of mental health care utilization for study participants. Among those who expressed need for mental health treatment, 73.4% ($n = 354$) actually received treatment for their mental health concerns. For those who received psychotherapy alone ($N = 38$), or in combination with medication ($N = 125$), the therapist’s knowledge of PD was significantly related to the participants’ perceived satisfaction with ($r = .293, p < .001; N = 153$) and helpfulness ($r = .352, p < .001; N = 154$) of the intervention. Satisfaction with services also varied based on the type of treatment received [$F(2,336) = 4.44, p = .01; N = 339$], with those receiving combination treatment (antidepressant medication and psychotherapy) reporting higher levels of satisfaction than those who were prescribed medication only ($p = .01$). Aspects of mental health care that recipients of past treatment would like to see improved (based on 149 open-ended text responses) included improved access to care (13.4%, $n = 20$), increased knowledge of PD amongst community-based mental health treatment providers (13.4%, $n = 20$), improved dialogue (with their neurologist and other treatment providers) regarding the link between mental health and PD (20.1%, $n = 30$), better coordination of care between neurologists and mental health professionals (5.4%, $n = 8$), greater focus on psychotherapy vs. medication management (20.8%, $n = 31$), decreased cost (14.1%, $n = 21$), and the availability of more effective treatment choices (11.4%, $n = 17$).

Barriers to mental health treatment—Several past and perceived future barriers to mental health care utilization in PD were endorsed by respondents and are displayed in Tables 3–4. Commonly endorsed past barriers included “Anyone in my situation would be struggling (74.8%, $n = 77$), Doctors are not sensitive enough to PD related issues (54.8%, $n = 57$), No quality options were available to me (32.4%, $n = 33$), and PD related physical impairment (28.3%, $n = 30$).” Commonly perceived future barriers included “Services not available in my local community (52%, $n = 344$), PD related physical impairment (45.3%,

$n=296$), and No transportation (30.8%, $n=205$).” Several demographic (e.g., education, income, age, gender, marital status), medical (e.g., overall health, duration of PD), and psychiatric (e.g., helpfulness of past treatment) variables also influenced the likelihood accessing mental health care as indicated in Tables 3–4.

Mental Health Needs Assessment and Tele-health Interventions

Approximately 93% ($n = 640$) of respondents believed that treatment for depression, anxiety, and the stress of living with a chronic medical condition would be beneficial to people with PD. Yet, 60% ($n = 412$) were unaware of any local services available for this purpose. Telephone-based interventions designed to meet this need were of interest to 68% of respondents ($n = 468$). Almost all participants [97% ($n = 661$)] felt it important that mental health professionals working with people with PD have an advanced level of understanding of the medical condition. Interest in phone psychotherapy was also significantly correlated with several perceived barriers to mental health care utilization in PD, including lack of services in the local community ($r = .167$, $p < .0001$; $N = 654$) insensitivity of doctors to PD related issues ($r = .148$, $p < .0001$; $N = 652$), and difficulty controlling feelings and utilizing coping skills ($r = .148$, $p < .0001$; $N = 646$).

Participants also reported that they traveled far distances in order to receive medical care for PD [mean number of miles = 52.00 ($SD = 140.98$); $N = 309$]. However, on average, the distance required to receive medical care (as described above) was further than participants were able to drive themselves [mean number of miles able to drive self = 33.34 ($SD = 65.89$); $N = 261$]. Respondents reported having access to multiple methods of communication [Telephone (71.9%, $n = 641$); Cell Phone (67.3%, $n = 600$); Computer (70.1%, $n = 625$); Internet (69.2%, $n = 617$); Email (70.4%, $n = 627$); Webcam (27.7%, $n = 247$)] and to feeling comfortable communicating with their physicians via these modalities [Telephone (87.6%, $n = 584$), Email (81.2%, $n = 540$), Webcam (58.9%, $n = 379$)]. While 91.7% ($n = 604$) of respondents reported that they were motivated to receive all of the specialty care (i.e., speech therapy, physical therapy, psychological services) that was recommended to optimize the treatment PD, in addition to routine visits with their treating neurologist, 84.8% ($n = 559$) of sample indicated that they would be even more motivated to do so if they could receive this help in the comfort of their own home. On average, participants reported that they were able to speak on the phone for 51.95 minutes ($SD = 49.84$; $N = 636$) and use the computer for 86.31 minutes ($SD = 89.56$; $N = 639$) at a time.

Discussion

This was the first study to identify and describe barriers to mental health care utilization in Parkinson’s disease in a national sample. The majority of respondents reported that they required mental health intervention for depression or anxiety in the past. Almost half of those needing help were not given a formal referral and a significant proportion (i.e., approximately 30%) remained untreated. Participants who had received mental health treatment identified several aspects of their care that could benefit from improvement, including better access, improved knowledge of PD amongst treatment providers, and a greater focus on psychotherapy vs. medication management. Related to this, reported satisfaction with and helpfulness of mental health services rendered were associated with the receipt of combination treatment (psychotherapy and medication) and the treatment provider’s knowledge of PD.

Importantly, results also suggest that people with PD encounter a multitude of barriers that impede their pursuit of mental health treatment. Commonly endorsed barriers reflect low mental health literacy (e.g., Anyone in my situation would be struggling; I cannot control how I am feeling or coping; It was not necessary; It could not help me), access issues (e.g.,

No transportation, Services not available in the local community, No quality options were available to me), and illness-specific concerns (e.g., PD-related physical impairment, Doctors are not sensitive enough to PD related issues). Previously documented barriers to treatment optimization in PD, such as inadequate screening and detection of psychiatric complications by medical providers (e.g., Referral not given, Doctor did not support or recommend treatment), and the need for more effective treatments in this medical population (e.g., Treatment did not help in the past), were also observed in this sample. Several demographic, medical, and psychiatric variables also influenced the likelihood of accessing mental health care. Of note, participants treated by movement disorder specialists were just as likely to experience all assessed barriers to mental health care utilization, as those treated by other physicians.

Finally, on average, PD patients need to travel further distances to receive specialty care than they are able to drive themselves. They have access to and are comfortable with various modes of technology, particularly telephone-based approaches, and are able to use both the phone and computer for the typical time required to complete a treatment session for depression or anxiety (45–50 minutes). Interest in tele-health approaches to mental health treatment was high and, in several instances, correlated with perceived barriers of mental health care utilization. Overall, the present findings are both consistent with and extend the published literature regarding barriers to health care utilization in other populations^{10–15}, as well as prior research regarding the suboptimal detection and management of depression in PD^{4–6} and patient treatment preferences for co-morbid psychiatric complications in PD²⁰.

Clinical Implications

Tele-health interventions (both pharmacological and non-pharmacological in nature) for the psychiatric complications of PD, based out of movement disorder specialty clinics and PD Centers of Excellence across the country (locations in which multi-disciplinary providers have both exceptional knowledge of PD and the ability to coordinate care), may provide a mechanism for eliminating some of the more commonly perceived barriers to mental health care utilization in this medical population. Though randomized-controlled trials are required to evaluate efficacy prior to widespread implementation, past pilot research suggests that telemedicine may be an effective strategy for managing both the motor and non-motor complications of PD^{18, 19}. Increased efforts (i.e., educational initiatives) to improve mental health literacy in the PD community may also be helpful, especially given the overlap between the physical symptoms of PD and many of the common correlates of depression and anxiety (i.e., fatigue, insomnia). The prospect of training community-based mental health providers across the country (with interest in working with medical populations) in the motor and non-motor aspects of PD also warrants consideration. The Movement Disorder Society, in conjunction with local and national psychological and psychiatric organizations, provides an excellent forum for this work and may ultimately result in a directory of interested providers, a web-based system to facilitate referrals, and a forum for ongoing training and consultation. Ideally, this process could be bridged with the preliminary initiatives that the Movement Disorder Society has already taken in this regard. Finally, as resources permit, efforts should be made to refer people with PD for combination treatment to address their comorbid psychiatric concerns and to provide extra follow-up to sub-groups of patients (i.e., those in poorer health, not married) who may have particular difficulty accessing mental health care.

Limitations

This study has several limitations. First, participants expressed interest in this research study by responding to various advertisements and were not drawn from a random sample. Related to this, the study population was self-selected and the denominator of potential respondents

in not known. Second, participant responses may have been biased by low mental health literacy, inaccurate recall, and/or the desire to respond in a favorable (or unfavorable) manner. For example, limited knowledge about the psychiatric complications in PD may have led to the under-reporting of depression and anxiety by some respondents, as well as to the participants' perception that they have not needed mental health services during the course of their medical illness (even if such treatment may have been of benefit). Third, given the anonymous nature of survey participation, a diagnosis of idiopathic PD could not be confirmed for study participants. Fourth, results may not generalize to all people with PD. The majority of the sample was treated by movement disorders specialists, internet savvy, connected with PD support groups around the country, and in earlier years of the illness (PD). It is likely that barriers to mental health care use may be even more pronounced in those who lack these resources or have more advanced stage disease. Lastly, the majority of respondents who acknowledged that they previously needed mental health treatment, reported receiving some type of psychiatric intervention (even if unsatisfactory) for their concerns. Thus, in this sample, the share of unidentified subjects with mental health problems may be small.

Conclusions

In summary, the sub-optimal treatment of the psychiatric comorbidities in PD is of great clinical concern as these psychiatric complications negatively affect the course and management of the illness. Yet, our results suggest that people with PD encounter a multitude of barriers that impede their pursuit of mental health care. Tele-health interventions for the psychiatric complications of PD may provide a mechanism for eliminating some of the more commonly perceived barriers to mental health care utilization in this medical population. Training community-based mental health providers in the psychiatric complications of PD, as well as increased efforts to improve mental health literacy in the PD community may also prove beneficial. As this was the first study to identify and describe barriers to mental health care utilization in PD, results should be viewed as preliminary. Future research is needed to replicate and extend these findings.

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Appendix I: Barriers Survey

I have read the consent letter explaining the details of this research study and I agree to participate:

Yes: _____ No: _____ (If no, please do not proceed)

Demographics

Gender: 1=Male; 2=Female Age: _____

Year PD diagnosed: _____ State in which you reside: _____

Race:

1= *White*; 2= *Black*; 3= *American Indian*; 4= *Asian*; 5= *Pacific Islander*; 6= *Other*

Ethnicity:

1= *Hispanic*; 2= *Non-Hispanic*

Marital Status:

1= *Married*; 2= *Separated*; 3= *Divorced*; 4= *Widowed*; 5= *Never Married*; 6= *Living with partner*

Highest level of education:

1= *8th grade and below*; 2= *Some high school*; 3= *High school graduate*; 4= *Some college*
5= *College graduate*; 6= *Some graduate school*; 7= *Graduate degree*

Work Status: Current or most recent occupation: _____

1= *Full-time*; 2= *Part-time*; 3= *Not employed*; 4= *On Disability*; 5= *Retired*; 6= *More than 1*

Average household income:

1= { *less than 20K* }; 2= { *20K–30k* }; 3= { *30K–40K* }; 4= { *40K–50K* }; 5= { *50K–60K* }; 6= { *60K–70K* }; 7= { *70K–80K* }; 8= { *80K–90K* }; 9= { *90K–100K* }; 10= { *greater than 100K* }; 11= { *greater than 150K* }; 12= { *greater than 200k* }

Health Insurance:

1= *Medicare only*; 2= *Medicare plus a secondary insurance*; 3= *Medicaid*; 4= *Private or Commercial Insurance Only (e.g., Aetna, Blue Cross)*; 5= *None*

Current living arrangement:

1= *Own*; 2= *Rental*

Type of residence:

1= *House*; 2= *Apartment/condo*; 3= *Independent living*; 4= *Assisted living*; 5= *Nursing home*

From whom do you primarily receive ongoing medical care for your PD?

1= *Neurologist who specializes in PD/movement disorders*; 2= *General neurologist*;
3= *Family doctor*; 4= *Other*; 5= *More than one*

In what type of setting do you receive your routine medical care for PD?

1= *Private Practice*; 2= *VA Medical Center*; 3= *Movement Disorders Specialty Clinic*;
4= *Hospital Based Clinic*; 5= *Academic Medical Center*; 6= *Other*

Mental Health Care Utilization

Since you have been diagnosed with PD, have you felt that you have needed help managing concerns such as depression, anxiety, or the stress of living with a chronic medical condition?

0= *No*; 1= *Yes*

If NO- please proceed to next section- “Mental Health Needs Assessment”

If YES-

Age at which you first needed help with depression, anxiety, or stress: _____

Age at most recent time you needed help with depression, anxiety, or stress: _____

Please answer the following questions regarding the most **recent** time that you felt you needed help with depression, anxiety, or stress.

Who was the problem diagnosed by?

1=*Self*; 2=*Family member*; 3= *Neurologist*; 4= *Family doctor*; 5= *Mental health professional (psychiatrist, psychologist, social worker)*; 6=*Other*

Were you referred for treatment?

0= *No*; 1= *Yes*

Did you receive treatment?

0= *No*; 1= *Yes*

IF YES (I RECEIVED TREATMENT)-

Who treated your concerns?

1=*Neurologist*; 2=*Family doctor*; 3=*Mental health professional (psychiatrist, psychologist, social worker)*; 4=*Other*

What type of treatment did you receive?

1=*Medication*; 2=*Psychotherapy*; 3=*Both medication and psychotherapy*

How satisfied were you with the type of services that you received?

1	2	3	4	5	6	7	8	9	10
not at all			moderately				very much		

How helpful were the services that you received?

1	2	3	4	5	6	7	8	9	10
not at all			moderately				very much		

Were you able to be seen as frequently as you needed?

0= *No*; 1= *Yes*

Was there anything you would like to change about the mental health services you received?

If so, please list. _____

IF YOU WERE PRESCRIBED MEDICATION

Please list the medication(s) and dosage(s) you were given to treat your concerns:

How long did you remain on the medication (s)? _____

Are you still taking medication?

0= *No*; 1= *Yes*

IF YOU RECEIVED PSYCHOTHERAPY

How frequently did you attend therapy sessions?

1= *Weekly*; 2= *Biweekly*; 3= *Monthly*; 4= *Bimonthly*

For what period of time did you remain involved in psychotherapy?

1=Less than 1 month, 2=3–6 Months, 3=6–9 Months, 4= 9–12 Months, 5=1 Year,
6=2 Years, 7=3 Years, 8=4 Years, 9= 5+ Years

Approximately how many separate psychotherapy sessions did you attend?__

Are you still receiving psychotherapy at the current time?

0= No; 1= Yes

How knowledgeable was the therapist about PD?

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

IF NO (I DID NOT RECEIVE TREATMENT), please rate the extent to which each barrier below influenced that choice on the scale provided:

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

No transportation: _____

Unable to drive: _____

Too far to drive: _____

No parking: _____

PD related physical impairment: _____

Services not available in my local community: _____

No quality options were available to me: _____

A specific referral (with names and numbers) was not given: _____

Referral did not work out: _____

I was not actively involved in the decision as to how to best handle my care: _____

My primary physician (neurologist/family doctor) didn't recommend treatment: _____

Doctors are not sensitive enough to cultural issues: _____

Doctors are not sensitive enough to PD related issues: _____

Out of pocket cost was too high: _____

No time to go: _____

I don't trust doctors: _____

I can't control how I am feeling/coping: _____

It could not help me: _____

It was not necessary: _____

Anyone in my situation would be struggling: _____

I have been treated unfairly or disrespected by doctors in the past: _____

Treatment did not help in the past: _____

I was embarrassed: _____

Mental Health Needs Assessment

To what extent do you think that counseling services to help individuals cope with depression, anxiety, and/or the stress of living with a chronic medical condition would be useful or beneficial to persons with PD?

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

To what extent are you aware of mental health services in your local community that are available to help individuals with PD cope with depression, anxiety, and/or the stress of living with a chronic medical condition?

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

To what extent do you think that it is important that a mental health professional working with a person with PD has an advanced level of understanding of the medical condition?

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

If you could have counseling over the telephone to help you cope with living with PD, how interested would you be in receiving this service?

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

To what extent do you believe that you would seek out mental health services if you or your doctor felt such treatment was warranted in the *future*?

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

If you or your doctor felt that mental health treatment was necessary in the *future*, to what extent might each of the following barriers stand in your way of accessing such services (please rate each potential barrier on the scale below):

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

No transportation: _____

Services not available in my local community: _____

PD related physical impairment: _____

Doctors are not sensitive enough to cultural issues: _____

Doctors are not sensitive enough to PD related issues: _____

Out of pocket cost is too high: _____

No time to go: _____

I don't trust doctors: _____

I can't control how I am feeling/coping: _____

I have been treated unfairly or disrespected by doctors in the past: _____

Treatment did not help in the past: _____

Medical History

Deep Brain Stimulation: *0= No; 1= Yes*

If yes, how long ago? _____

How many different medications do you currently take for Parkinson's disease (i.e., Sinemet, Requip)? _____

Please list: _____

To what extent do you worry about falling?

1	2	3	4	5	6	7	8	9	10
not at all				moderately					extremely

To what extent are you able to walk without aid, support, or frequent rests?

1	2	3	4	5	6	7	8	9	10
not at all				sometimes					all the time

To what extent do the symptoms of PD affect your ability to participate in activities of daily living (i.e., slow you down, prevent you from doing things, make activities more difficult for you, confine you to the house)?

1	2	3	4	5	6	7	8	9	10
mildly				moderately					extremely

How many medical conditions other than PD have you been diagnosed with or treated for by your personal physicians? _____

Please list: _____

How many medications do you currently take for other medical conditions? _____

How many medications do you currently take for concerns such as depression, anxiety, or sleep problems (i.e., Lexapro, Ambien, Klonopin)? _____

Healthcare Utilization- General

How would you rate your overall health?

1	2	3	4	5	6	7	8	9	10
extremely poor				average					excellent

In the past year, how often have you seen the physician who manages the care of your Parkinson's disease?

Number of visits _____

In the past year, how satisfied have you been with the care that you have received from the physician who manages your PD?

1	2	3	4	5	6	7	8	9	10
not at all				moderately					extremely

In addition to the care of your neurologist, how many visits to each of the following specialists have you made (or received) in the past year?

Speech therapist: _____

Physical therapist: _____

Occupational Therapist: _____

Mental Health Professional (psychiatrist, psychologist, social worker): _____

Home Health Care Visit: _____

Inpatient hospital admissions (number of days): _____

Skilled nursing in a short-term care/rehabilitation facility (number of days): _____

Skilled nursing in a long-term care facility (number of days): _____

Do you drive?

0= No; 1=Yes

Do you have access to public transportation?

0= No; 1=Yes

How much do your physical symptoms affect your use of transportation (driving yourself, public transportation)?

1 2 3 4 5 6 7 8 9 10
not at all moderately extremely

How much of the time do your physical symptoms cause you to cancel or postpone your doctors' appointments?

1 2 3 4 5 6 7 8 9 10
not at all some of the time very much

How far do you currently have to travel to receive medical care (neurologist, speech therapist) for your PD? _____(minutes/hours/miles)

How far are you able to drive yourself to receive medical care? _____(minutes/hours/miles)

How far are others able to drive you to receive medical care? _____(minutes/hours/miles)

How reliable is the transportation you depend upon to travel to regularly scheduled doctor's appointments?

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

Comfort Level with Telemedicine

To which of the following do you have access?

Telephone: ____Yes ____No

Cell Phone: ____Yes ____No

Computer: ____Yes ____No

Internet: ____Yes ____No

E-mail: ____Yes ____No

Webcam: ____Yes ____No

How comfortable do you feel using the telephone (land-line) or cell-phone?

1 2 3 4 5 6 7 8 9 10
not at all moderately very much

How comfortable do you feel using the Internet?

1	2	3	4	5	6	7	8	9	10
not at all				moderately		very much			

How comfortable do you feel using e-mail?

1	2	3	4	5	6	7	8	9	10
not at all				moderately		very much			

How comfortable do you feel using a webcam?

1	2	3	4	5	6	7	8	9	10
not at all				moderately		very much			

How comfortable would you be communicating with your doctor via telephone/cell phone?

1	2	3	4	5	6	7	8	9	10
not at all				moderately		very much			

How comfortable would you be communicating with your doctor via Internet/email?

1	2	3	4	5	6	7	8	9	10
not at all				moderately		very much			

How comfortable would you be communicating with your doctor via Internet/webcam?

1	2	3	4	5	6	7	8	9	10
not at all				moderately		very much			

How likely are you to seek out all of the specialized care (psychological counseling, speech therapy, physical therapy) that is recommended to you for your Parkinson's disease in addition to your routine visits with your neurologist?

1	2	3	4	5	6	7	8	9	10
not at all				moderately		very much			

How much more likely would you be to seek out all of the specialized care (psychological counseling, speech therapy, physical therapy) that is recommended to you for PD if you were able to receive the care in the comfort of your home via internet or phone?

1	2	3	4	5	6	7	8	9	10
not at all				moderately		very much			

How long are you able to comfortably speak on the phone? _____ (number of minutes)

How long are you able to comfortably work on the computer? _____ (number of minutes)

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Table 1**Characteristics of the Sample**

Gender ^a (N=755) ^b		
Male	380	(50.3%)
Female	375	(49.7%)
Age ^c (N=755)	63.83	(10.45)
Parkinson's Disease Duration (years) (N=739)	8.37	(5.78)
Race (N=766)		
White	736	(96.1%)
Black	7	(0.9%)
American Indian	2	(0.3%)
Asian	11	(1.4%)
Other	10	(1.3%)
Ethnicity (N=737)		
Hispanic	23	(3.1%)
Non-Hispanic	714	(96.9%)
Region of Country (N=765)		
Northeast	252	(32.9%)
Southeast	135	(17.6%)
Midwest	126	(16.5%)
Southwest	112	(14.6%)
West	122	(15.9%)
Other	18	(2.4%)
Education (N=759)		
No High School Degree	21	(2.7%)
High School Graduate	82	(10.8%)
Some College	161	(21.2%)
College Graduate	178	(23.5%)
Some Graduate School	75	(9.9%)
Graduate Degree	242	(31.9%)
Work Status (N=750)		
Full time	110	(14.7%)
Part time	51	(6.8%)
Unemployed	50	(6.7%)
On disability	173	(23.1%)
Retired	351	(46.8%)
More than one	15	(2%)
Married (N=760)		
Yes	574	(75.5%)
Average Income (N=695)		
Less than 30K	120	(17.2%)
30K – 50K	150	(21.6%)

50K – 80K	191	(27.6%)
80K – 100K	90	(12.9%)
100K – 150K	94	(13.5%)
150K – 200K	32	(4.6%)
More than 200K	18	(2.6%)
Health Insurance (N=758)		
Medicare only	50	(6.6%)
Medicare and a secondary	375	(49.5%)
Medicaid	13	(1.7%)
Private/Commercial only	294	(38.8%)
None	26	(3.4%)
Primary Provider of Parkinson's Disease Care (N=763)		
Movement Disorder Specialist	512	(67.1%)
General Neurologist	176	(23.1%)
Family Doctor	18	(2.4%)
Other	11	(1.4%)
More than one	46	(6.0%)
Deep Brain Stimulation (N=685)		
Yes	69	(10.1%)
Drive (N=678)		
Yes	540	(79.6%)
Number of Parkinson's Disease Medications (N=679)	2.19	(1.29)
Can walk without aid, support, or rests (1–10 scale) ^d (N=697)	7.03	(2.97)
Worries about falling (1–10 scale) ^e (N=695)	5.05	(2.77)
Impairment in activities of daily living (1–10 scale) ^e (N=693)	4.87	(2.74)
Global rating of overall health (1–10 scale) ^d (N=672)	6.13	(2.08)
Number of Comorbid Medical Conditions (N=664)	2.28	(2.09)
Number of Medications for Comorbid Medical Conditions (N=651)	3.03	(4.34)
Number of Current Psychiatric Medications (N=672)	0.96	(1.05)
Number of Medical Specialist Visits in the Past Year		
Neurologist (N=662)	3.43	(2.33)
Speech Therapist (N=551)	1.69	(9.54)
Physical Therapist (N=586)	7.53	(20.19)
Occupational Therapist (N=554)	1.29	(8.50)
Mental Health Professional (N=573)	3.51	(9.28)
Home Health Care Visit (N=549)	1.27	(6.96)
Inpatient Hospital Admissions (Days) (N=554)	0.97	(2.77)
Short-term Rehabilitation Facility (Days) (N=541)	0.69	(4.69)
Long-term Care Facility (Days) (N=534)	0.83	(16.01)

Note:

^aFrequencies and percentages (based on number of responses per question) are presented for categorical variables.

^b As sample size varies between survey items, the total number of respondents who answered each specific survey question is listed in parentheses, following the variable name.

^c Means and standard deviations are presented for continuous variables.

^d Higher scores on the Likert scale indicate less impairment.

^e Higher scores on the Likert scale indicate more impairment.

Table 2Patterns of Mental Health Care Utilization in Parkinson's Disease (PD)^a

Item	n ^b	%
Needed treatment for depression, anxiety, or stress since PD diagnosis (N=763) ^c		
Yes	492	(64.5%)
Problem diagnosed by (N=471)		
Self	183	(38.9%)
Neurologist	106	(22.5%)
Mental Health Professional	77	(16.3%)
Family Doctor	58	(12.3%)
Family Member	37	(7.9%)
Other	10	(2.1%)
Formal referral given (N=481)		
Yes	270	(56.1%)
Received treatment (N=482)		
Yes	354	(73.4%)
<i>If received treatment: Type of treatment received (N=348)</i>		
Medication Management	185	(53.2%)
Psychotherapy	38	(10.9%)
Medication and Psychotherapy	125	(35.9%)
<i>If received treatment: Problem primarily treated by (N=344)</i>		
Mental Health Professional	170	(49.4%)
Neurologist	121	(35.2%)
Family Doctor	37	(10.8%)
Other	16	(4.7%)

Note:^aData in this table is presented only for those who needed treatment for depression, anxiety, or stress since PD diagnosis, not the entire sample^bFrequencies and percentages are based on the number of respondents per question.^cAs sample size varies between survey items, the total number of respondents who answered each specific survey question is listed in parentheses, following the variable name.

Table 3Past Barriers to Mental Health Care Utilization in Parkinson's Disease (PD) ^a

Barriers	n ^b	%	Predictors
• Anyone in my situation would be struggling (N=103) ^c	77	(74.8%)	Poorer Overall Health *
• Doctors are not sensitive enough to PD related issues (N=104)	57	(54.8%)	
• Out of pocket cost was too high (N=103)	42	(40.8%)	
I can't control how I am feeling/coping (N=102)	40	(39.2%)	Lower Education *
• A specific referral was not given (N=104)	40	(38.5%)	
• It was not necessary (N=100)	35	(35.0%)	Male Gender *
• No quality options were available to me (N=102)	33	(32.4%)	
• My primary physician (neurologist/family doctor) didn't support or recommend treatment (N=103)	33	(32.0%)	Higher Income ** Lower Education * Not Referred *
• PD related physical impairment (N=106)	30	(28.3%)	Longer PD Duration ** Poorer Overall Health **
• I have been treated unfairly/disrespected by doctors in the past (N=100)	28	(28.0%)	Lower Education *
• Treatment did not help in the past (N=101)	26	(25.7%)	
• Services not available in my local community (N=102)	26	(25.5%)	
• I don't trust doctors (N=101)	24	(23.8%)	
• It could not help me (N=101)	24	(23.8%)	Poorer Overall Health *
• I was not actively involved in the decision as to how to best handle my care (N=99)	23	(23.2%)	
• I was embarrassed (N=101)	22	(21.8%)	
• Unable to drive (N=107)	19	(17.8%)	
• Too far to drive (N=105)	17	(16.2%)	Longer PD Duration *
• No time to go (N=102)	16	(15.7%)	Younger Age **
• Referral did not work out (N=100)	15	(15.0%)	Referred *
• No transportation (N=105)	13	(12.4%)	
• No parking (N=104)	8	(7.7%)	

Note:^aData reflects past barriers endorsed for those who needed but did not receive treatment (N=128).^bFrequencies and percentages are based on the number of respondents per question.^cAs sample size varies between survey items, the total number of respondents who answered each specific survey question is listed in parentheses, following the variable name.*
 $p < .05$ **
 $p < .01$

Table 4Future Barriers to Mental Health Care Utilization in Parkinson's Disease (PD)^a

Barriers	n ^b	%	Predictors
• Out of pocket cost is too high (N=659) ^c	422	(64.0%)	Lower Income ** Younger Age *
• Doctors are not sensitive enough to PD related issues (N=658)	386	(58.7%)	
• Services not available in my local community (N=661)	344	(52.0%)	Past Treatment Not Helpful **
• PD related physical impairment (N=654)	296	(45.3%)	Poorer Overall Health *
• I can't control how I am feeling/coping (N=652)	240	(36.8%)	
• Doctors are not sensitive enough to cultural issues (N=645)	218	(33.8%)	Lower Education *
• No transportation (N=666)	205	(30.8%)	Female Gender ** Lower Income * Region of country ** (Northeast vs. Midwest) ^d Not Married * Past Treatment Helpful ** Poorer Overall Health *
• Treatment did not help in the past (N=639)	187	(29.3%)	
• I don't trust doctors (N=651)	139	(21.4%)	Fewer Comorbid Medical Conditions ** Lower Income * Past Treatment Provider * (family doctor vs. neurologist ^e)
• I have been treated unfairly or disrespected by doctors in the past (N=650)	127	(19.5%)	Past Treatment Provider ** (mental health professional vs. neurologist ^e) Lower Education *
• No time to go (N=653)	123	(18.8%)	Working ** Not Needed Help in Past *

Note:^aData collected from the entire sample.^bFrequencies and percentages are based on the number of respondents per question.^cAs sample size varies between survey items, the total number of respondents who answered each specific survey question is listed in parentheses, following the variable name.^dLack of transportation was a greater barrier in the Northeast vs. Midwest.^eTrust was a bigger concern for those who received mental health care from a family doctor vs. neurologist. Fears about being treated unfairly or disrespected were greater for those who received mental health care from a mental health professional vs. neurologist. However, data is correlational and causality cannot be assumed.*
 $p < .05$ **
 $p < .01$