Articles

Patient-reported Needs, Non-motor Symptoms, and Quality of Life in Essential Tremor and Parkinson's Disease

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Abstract

Background: Non-motor symptoms, quality of life, service needs, and barriers to care of individuals with movement disorders are not well explored. This study assessed these domains within a sample of individuals with essential tremor (ET) and Parkinson's disease (PD).

Methods: A survey exploring symptoms, needs, and barriers to care was disseminated to a convenience sample ($N=96$) of individuals with a primary diagnosis of ET ($N=19$) or PD ($N=77$).

Results: Similarities in overall quality of life and impact on daily functioning were found across individuals with ET and PD. Noteworthy differences included endorsement of different types of service needs and utilization patterns and fewer non-motor symptoms reported among those with ET ($M=6.1$, SD$=2.4$) than those with PD ($M=10.4$, SD$=3.4$). Non-motor symptoms significantly impacted movement disorder-related quality of life for both diagnostic groups, but this relationship was stronger for individuals with ET, $t(12)=3.69$, $p=0.003$, $\beta=0.73$ than with PD, $t(56)=4.00$, $p<0.001$, $\beta=0.47$. Individuals with ET also reported higher rates of stigma (31.6% vs. 7.8%) and greater impact of non-motor symptoms on emotional well-being, $R^2=0.37$, $F(1, 13)=7.17$, $p=0.020$.

Discussion: This is the first study to describe and compare the needs, barriers to care, and impact on quality of life of two distinct movement disorder groups. Our results support the recent efforts of the field to identify interventions to address the non-motor symptoms of movement disorders and indicate need for greater appreciation of the specific differences in symptoms and quality of life experienced across movement disorder diagnoses.

Keywords: Parkinson's disease, essential tremor, non-motor symptoms, needs assessment, quality of life
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Introduction

In the twenty-first century, Parkinson's disease (PD) is now best conceptualized as a neurodegenerative disease with neurocognitive symptoms that gradually develop and progressively compromise individuals' quality of life (QOL) and independence. While essential tremor (ET) was classically considered a monosymptomatic tremor disorder, non-motor clinical symptoms, including cognitive and mood issues, are now increasingly recognized as important features of the disease.[1–3] A shift in the research community's focus to non-motor symptoms (NMS) of movement disorders (MDs) has begun. NMS, including neuropsychiatric symptoms, sleep disorders, autonomic, gastrointestinal, sensory, and cognitive impairments,[4] have been identified as having a significant impact on QOL in individuals with PD[5–7] and risk of institutionalization at advanced stages of PD.[8] Furthermore, in PD, over 90% of patients endorse NMS across all stages of the disorder,[9] and often require additional health care services to manage their disorders and improve their QOL. Research focused on NMS among individuals with ET is just emerging, but recent studies suggest some important differences between those with PD and those with ET in the frequency and type of NMS reported.[10,11]

Despite the prevalence of these disorders and growing awareness of the impact of NMS on QOL, little is known about patient-reported needs and barriers to care of individuals with MDs. While patient needs related to the motor and non-motor symptoms of MDs are

increasingly recognized by MD specialists, patient perspectives about which symptoms are most bothersome and whether other needs exist remain unknown. Barriers to care may also limit access to treatments. Barriers include financial (i.e., cost of service, lack of insurance), social (i.e., stigma, family stressors), and instrumental (i.e., transportation, lack of availability) factors that inhibit access to care.

This study aimed to elicit patient-reported needs and barriers to care and evaluate patient-reported QOL, frequency of NMS, and the impact of NMS on QOL. Caregivers were also studied and their perspectives are under review. Consistent with prior research, we anticipated that a greater number of NMS would impact both health-related and overall QOL, that patients would equally endorse service needs for care of motor and NMS, but that patients would endorse currently receiving services for motor symptoms more frequently than for NMS. We prioritized obtaining patient-reported needs and barriers to care to improve our understanding of patient perspectives.

Methods

Participants

Participants were adults ages 21 years and over who self-identified as having a MD diagnosis ($N=96$), with individuals reporting a primary diagnosis of either ET ($N=19$) or PD ($N=77$) (Table 1). Participants were recruited by advertisements shared through the clinic's listserv, website, partner community organizations, and support groups. The advertisements explained that an online questionnaire had been developed, which would ask individuals with a MD to answer questions about their current use of health care services and barriers to care that prevent access to care for their MD. Potential participants were informed that this information was being gathered to improve understanding of their needs and any barriers to accessing needed care. Interested individuals were provided a link to the online survey or provided paper questionnaires with a pre-paid return envelope if requested. Access to a larger sample, and importantly individuals who may not be accessing care for their MD, was prioritized over limiting the survey to individuals who receive care and have medical records at our center; however, this decision resulted in only patient reports of medical diagnosis, stage, etc.

The study was completed with adequate understanding and consent of the subjects involved and with the ethical approval of the Institutional Review Board. Participants provided electronic waivers or written informed consent for online and paper surveys respectively.

Procedure

This study was conducted at an interdisciplinary MD specialty clinic in southeastern Virginia during the period of May–December 2012 and involved dissemination of a web-based survey. Participants were provided with a link or paper form if requested. Survey data were collected and managed in a secure, web-based database (Research Electronic Data Capture [REDCap]).[12] The survey was disseminated primarily to the local communities surrounding the clinic location to inform clinical and research program development at the center;

however, use of a single site somewhat limits generalizations that can be made from the survey.

Measures

Content of the survey questions was compiled from empirical literature and national resources on the needs of individuals with MD and are described below. To minimize burden while providing opportunity for comments, checklists and free-response options were provided. All responses were provided by the participants themselves, including self-report of cognitive diagnoses and stage of disorder.

Non-motor symptoms and quality of life. Standardized assessment tools for evaluating NMS, overall and health-related QOL, and the impact of health problems on work and daily activity productivity were included in the survey. Importantly, the NMS and health-related QOL scales were originally developed and validated for use in a PD population and while an ET-specific QOL questionnaire exists,[3] we selected the Parkinson's Disease Queotionnaire-39 (PDQ-39) to facilitate comparison to PD and evaluate cognitive and stigma-related symptoms. As a result, we used these tools as a first step to explore comparisons across diagnostic groups and evaluate how these factors differ among various MDs. The wording of these questionnaires was altered only to reflect the inclusion of individuals with MDs rather than exclusively PD.

NMS were evaluated using the Parkinson's Disease Non-Motor Symptom Questionnaire (PD-NMS), a 30-item questionnaire that asks participants to indicate whether or not they have experienced various NMS in the past month.[13] A total raw score is calculated based on the number of NMS experienced in the past month, with higher scores indicating greater number of symptoms.

The PDQ-39 was used to evaluate the impact of a MD on QOL across eight domains, including Bodily Discomfort, Mobility, Activities of Daily Living, Emotional Well Being, Communication, Cognitive Impairment, Stigma, and Social Support.[14] Raw total scores and raw domain scores were transformed to a 0–100 scale to allow for comparison across domains and with other studies using the PDQ-39, with higher scores indicating greater negative impact of the MD on QOL.

General QOL was also assessed using the Linear Analog Scale Assessment (LASA), which has been demonstrated to validly assess general well-being as well as specific domains of QOL (i.e., emotional, physical, intellectual and spiritual) with single items on a 0 (*As bad as it can be*) to 10 (*As good as it can be*) scale.[15]

Work productivity. The impact of disease on work productivity and leisure activities was evaluated with the Work Productivity and Activity Impairment-General Health questionnaire (WPAI-GH).[16] Participants were asked to provide objective information on their number of hours worked, number of hours missed from work due to health problems, and were also asked to rate how much health problems affected work productivity as well as other regular daily activities on a scale ranging from 0 (*Health problems had no effect on my work/my daily activities*) to 10 (*Health problems completely prevented me from working/doing my daily activities*).

Table 1. Sample Characteristics

Sample Characteristic	PD (N=77)	ET (N=19)
Mean age (SD)	66.7 (9.0)	72.0 (13.4)
(Range)	(41–87)	(47–93)
Gender (%)		
Male	54.5	36.8
Female	45.5	63.2
Race/ethnicity (%)		
Caucasian	96.1	100.0
Native American	2.6	0.0
Hispanic/Latino	1.3	0.0
Pacific islander	0.0	5.3
Educational level (%)		
GED	1.3	0.0
High school graduate	7.8	10.5
Vocational training or associate's degree	20.8	21.1
Bachelor's degree	36.4	47.4
Master's degree	22.1	15.8
Professional/doctoral degree	11.7	5.3
Employment status (%)		
Retired	58.4	63.2
Full time	15.6	15.8
Part time	10.4	5.3
On disability	11.7	0.0
Unemployed, but not retired or on disability	3.9	5.3
Household income (%)		
Less than $25,000	9.1	10.5
$25,000–45,000	20.8	15.8
$45,001–65,000	14.3	10.5
$65,001–85,000	10.4	21.1
$85,001–105,000	16.9	10.5
Greater than $105,001	13.0	10.5
Prefer not to answer	15.6	21.1
Insurance holder (%)		
Self	72.7	63.2

Table 1. Continued

Sample Characteristic	PD (*N*=77)	ET (*N*=19)
Family member	18.2	31.6
Uninsured	3.9	5.3
Other	5.2	0.0
Type of medical insurance (%)		
Medicare	61.0	52.6
Anthem Blue Cross Blue Shield	36.4	21.1
United Health Care	11.7	21.1
Tricare	5.2	0.0
Aetna	5.2	0.0
Other	27.3	31.6
Cognitive diagnoses[1] (%)		
Cognitive impairment	0.0	0.0
Mild cognitive impairment	16.9	5.3
Dementia	1.3	0.0
Mean number of years since diagnosis[1]	6.00	13.00
(*N*=98) (SD)	(5.68)	(12.75)
(Range)	(0–28)	(0–38)
Stage of disorder[1] (%)		
Stable	45.5	26.3
Progressive	42.9	57.9
Rapidly progressive	1.3	0.0
Other	2.6	0.0
Do not know	6.5	15.8

ET, Essential Tremor; GED, General Educational Development; PD, Parkinson's Disease; SD, Standard Deviation.
[1]All responses were self-reported.

Needs and barriers. In the needs assessment section, participants were asked to review a list of topics and select their current needs, services they are receiving, most important services for managing a MD, and most needed services. In the barriers to care section, participants were asked to select barriers that have affected their ability to access services. The list of needs and barriers presented in Table 2 reflects the wording of the checklist included in the survey.

The aims and hypotheses of this study were evaluated using descriptive statistics and regression analyses. Descriptive statistics were used to summarize the most frequently endorsed patient needs and barriers to accessing care. Exploratory regression analyses were used to model relationships between NMS and QOL and examine the individual contribution of NMS to specific aspects of QOL.

Results

Needs and barriers to care assessment

Areas of need are presented in Table 2. As predicted, areas of need related to NMS (i.e., wellness strategies, thinking changes) were rated

Table 2. Needs and Barriers to Care Assessment for Individuals with PD or ET

Patient Need	PD Patients (N=77)	ET Patients (N=19)
	Endorsed Need (%)	Endorsed Need (%)
Symptom management	67.5	52.6
Tremor/gait/balance problems	50.6	31.6
Speech/communication problems	40.3	5.3
Common medication side effects	28.6	21.1
Issues with swallowing	22.1	0
Incontinence	23.4	0
Sexual problems	15.6	0
Vision changes/issues	18.2	0
Communicating with treating doctors	13.0	10.5
Planning for the future	59.7	21.1
Long-term care planning	42.9	5.3
Financial concerns	36.4	5.3
Resource identification and accessing resources	27.3	15.8
Legal issues	18.2	0.0
Wellness strategies	54.5	26.3
Beginning an exercise regime or adapting one to fit personal needs	44.2	21.1
Nutritional changes and healthy eating strategies	36.4	15.8
Spirituality	13.0	15.8
Lifestyle changes	54.5	15.8
Driving	39.0	5.3
Vacationing and travel tips	35.1	10.5
Fall prevention	32.5	5.3
Safety in the home	31.2	5.3
Thinking changes	50.6	15.8
Expressing self	40.3	10.5
Memory	37.7	10.5
Attention	26.0	5.3
Problem solving	19.5	0.0
Stress management	31.2	36.8
Relationship changes	29.9	5.3
Maintaining a social life	22.1	5.3

Table 2. Continued

Changes in personal relationships post diagnosis	11.7	0.0
Identifying emotional support systems	13.0	5.3
Role changes	6.5	0.0
Parenting-related issues	0.0	0.0
Emotional changes	29.9	10.5
Experiencing anxiety, depression and apathy	24.7	10.5
Work-related issues	23.4	21.1
Disclosing your diagnosis: how to and if you should	10.4	15.8
Balancing family, medical and health responsibilities with work duties	10.4	10.5
Transitioning from FT to PT work	7.8	0.0
Analyzing transferable skills and new/different job possibilities	3.9	5.3
Advocating for accommodations	3.9	0.0
Caregiver stress	26.0	5.3
Personality/behavioral changes	20.8	0.0
Visual hallucinations	7.8	0.0
Inappropriate behaviors	3.9	0.0
Aggression	2.6	0.0
Patient education about diagnosis	19.5	5.3
Adjustment to diagnosis	15.6	10.5
Early onset diagnosis	13.0	5.3
Other	2.6	0.0
Barriers to Care	**PD Patients (N=77)**	**ET Patients (N=19)**
	Endorsed Need (%)	**Endorsed Need (%)**
Cost of service	27.3	10.5
Insurance does not cover cost of service	18.2	15.8
Service/specialist not available in local area	14.3	5.3
Balancing family, work and medical issues	13.0	26.3
Stigma associated with having a movement disorder	7.8	31.6
Limited transportation	7.8	0.0
Lack of coordinated care	13.0	5.3
Limited support from family	7.8	5.3

ET, Essential Tremor; FT, Full Time; PD, Parkinson's Disease; PT, Part Time.

as highly as areas of need related to motor symptoms (i.e., symptom management of tremor/gait/balance problems); however, this was primarily true for individuals with PD. Patients with ET endorsed fewer needs overall, and this was especially true with regards to non-motor needs, although stress management was highly endorsed. Overall, participants selected symptom management as their area of greatest need, and other highly ranked areas included planning for the future, wellness strategies, lifestyle changes, stress management, and thinking changes. Financial and instrumental barriers were endorsed most often in our sample, with cost of service, non-coverage of the service, and unavailability of a local specialist, as the most frequently endorsed barriers (Table 2).

While individuals with PD rated neurology as the service most highly needed, contrary to prediction, none of the services related to care of NMS were selected as frequently (Table 3). However, exercise groups and support groups were rated as highly needed services. Importantly, individuals with ET endorsed greatest need for support groups. As expected, a large percentage of participants reported currently receiving neurology and pharmacy services, but smaller percentages reported receiving services specifically for care of NMS (Table 3). Notably, individuals with ET reported receiving counseling services more frequently than individuals with PD.

Non-motor symptoms and quality of life

On the PD-NMS questionnaire, individuals with PD endorsed 10 NMS per month, while individuals with ET endorsed fewer, at approximately six NMS per month (Table 4). Overall QOL assessed with the LASA was positive and not notably different in PD and ET. On the PDQ-39 mean scaled scores generally ranged from seven to 31 across the domains. The greatest negative impact on QOL was found for Bodily Discomfort. Individuals with PD reported greater negative impact on domains of Mobility, Communication, and Cognitive Impairment, whereas those with ET reported more difficulty with Stigma, Activities of Daily Living, and Emotional Well Being. The domain with the least MD-related impact was Social Support for both groups.

On the WPAI-GH, approximately one-quarter of patients reported currently being employed. Of those currently working, individuals with ET reported working nearly full time, while those with PD reported working just over part-time hours. The reported impact of health problems on work attendance and productivity was minimal. Within the full sample, average ratings of the impact of health problems on other regular daily activities were also low, indicating minimal effects of health problems on activities of daily living in this sample.

Two exploratory linear regressions were performed to test the hypothesis that non-motor symptom frequency would be significantly, negatively related to PD- and ET-related QOL. For both analyses of those with PD and ET, the models were significant and indicated that a higher score on the PD-NMS was significantly associated with higher scores on the PDQ-39 total scaled score, PD, $R^2=0.22$, $F(1, 56)=16.02$, $p<0.001$, ET, $R^2=0.53$, $F=(1, 12)=13.64$, $p=0.003$. The individual contribution of the PD-NMS was 1.74, $t(56)=4.00$,

$p<0.001$, $\beta=0.47$ for those with PD and was 3.05, $t(12)=3.69$, $p=0.003$, $\beta=0.73$ for those with ET, which indicated that for every additional NMS reported, participants' health-related QOL negatively increased by nearly 2 and 3 additional points, for PD and ET respectively. Thus, the contribution of NMS in estimating QOL was somewhat stronger for those with ET than PD.

Linear regressions were also performed to evaluate the predictive value of the PD-NMS in determining general QOL, measured with LASA single items. The PD-NMS was not found to be significantly related to overall well-being, physical well-being, or spiritual well-being for both individuals with PD and ET. The PD-NMS was found to be significantly associated with intellectual well-being in PD, $R^2=0.11$, $F(1, 57)=6.89$, $p=0.011$ and with emotional well-being in ET, $R^2=0.37$, $F(1, 13)=7.17$, $p=0.020$.

Discussion

In this study, both similarities and unique differences were found among individuals with ET and PD. Consistent with the previous literature,[1–8] participants endorsed need for care of NMS as often as motor symptoms. Yet, only a small percentage of our sample reported currently receiving services for NMS. This discrepancy between NMS needs and actual service delivery indicates that efforts to increase both evaluation and treatment of NMS remains a priority in managing MDs. New focus on developing research trials targeting NMS is also critical to improve patient-centered care for individuals with MD, as noted by the Movement Disorder Society.[17] Patient education about available NMS services and research trials are important first steps in closing the gap between unmet needs and existing services.

Sleep, cognitive, and mood problems and symptoms were most highly endorsed, but untreated in our sample. Given the high prevalence of cognitive and mood symptoms in MDs,[18] development and adaptation of psychosocial and neurocognitive interventions for the MD population is a research priority. There is a dearth of research evaluating psychosocial interventions for individuals with MDs; yet, substantial support in other chronic illnesses of advanced age (i.e., psychosocial interventions in Alzheimer's[19] and age-related macular degeneration[20]) show promise for their application in MDs. Exploration of protective factors (i.e., social support, religion/spirituality, relationships with health care providers) that allow individuals with MDs to thrive despite the challenges of living with chronic illness may also reveal strategies to help foster resilience and optimize quality of life.

Interestingly, participants rated exercise groups and, especially among those with ET, support groups, as highly needed services, indicating patient preference for psychosocial supports to help them manage their disease. These findings are consistent with overall endorsement in our sample for needing assistance with planning for the future, wellness strategies, lifestyle changes, stress management, and thinking changes.

However, our barriers to care assessment revealed the necessity of going beyond patient education and research development to provide services. Over a quarter of our participants endorsed financial and

Table 3. Patient-ranked Services of Greatest Need

Service	Individuals with PD	Individuals with ET
	Ranked Service as "Greatest" Need (%)	Ranked Service as "Greatest" Need (%)
Neurology	20.8	15.8
Exercise groups	18.2	5.3
Support group	10.4	31.6
Physical therapy	13.0	5.3
Speech/language therapy	9.1	0.0
Sleep specialist	2.6	0.0
Pharmacy	2.6	0.0
Clinical trials/research	1.3	5.3
Online/video support groups	1.3	5.3
Nutritionist	1.3	0.0
Service	**Individuals with PD**	**Individuals with ET**
	Currently Receiving Service (%)	Currently Receiving Service (%)
Neurology	72.7	31.6
Pharmacy	31.2	36.8
Physical therapy	29.9	5.3
Sleep specialist	10.4	0.0
Psychology	9.1	5.3
Speech/language therapy	6.5	0.0
Counseling	6.5	15.8
Nutrition	3.9	0.0
Neuropsychology	3.9	0.0
Occupational therapy	2.6	0.0
Genetic counseling	1.3	0.0
Social work	0.0	0.0

ET, Essential Tremor; PD, Parkinson's Disease.

instrumental barriers to accessing needed services, suggesting increased need for low or no-cost treatment options and service access beyond major urban centers. In addition, stigma was reported as a barrier specifically affecting individuals with ET. Advocating for greater insurance coverage or low-cost delivery of NMS treatments and developing telehealth services are potential ways to limit these barriers to care. Increased community education may also target reduction of stigma associated with ET in particular.

NMS were more highly reported among individuals with PD than those with ET, which is consistent with one recent study examining the differences in NMS reporting of those with PD and ET at 1 year post diagnosis.[11] While greater NMS predicted worse health-related QOL, this was especially true for those with ET. For every additional NMS reported, participants' health-related QOL negatively increased by nearly 2 and 3 additional points, for PD and ET respectively. Interestingly, a relationship between NMS and emotional well-being

Table 4. Non-Motor Symptoms and Psychosocial Functioning

Domain of Functioning	Individuals with Parkinson's disease (N=77)	Individuals with Essential Tremor (N=19)
	Mean Score (SD)	Mean Score (SD)
	(Range)	(Range)
Non-motor symptoms (PD-NMS)	**10.4** (3.4)	**6.1** (2.4)
Overall quality of life (LASA)	**7.2** (1.8)	**7.3** (2.2)
Spirituality	7.5 (1.9)	7.5 (2.3)
Emotional health	7.0 (2.2)	6.8 (2.2)
Intellectual functioning	6.8 (1.8)	7.8 (1.4)
Physical health	6.4 (2.0)	7.0 (2.7)
MD-related Quality of Life (PDQ-39)	**22.5 (13.4)**	**22.0 (11.0)**
	(0–60.8)	**(6.8–40.5)**
Bodily discomfort	31.4 (22.9)	28.5 (20.1)
	(0–83.3)	(0–66.7)
Mobility	27.5 (23.2)	20.7 (21.0)
	(0–97.5)	(0–77.5)
Communication	24.9 (18.6)	13.6 (19.9)
	(0–75.0)	(0–75.0)
Activities of daily living	23.5 (17.7)	28.3 (21.0)
	(0–83.3)	(4.2–62.5)
Cognitive impairment	23.5 (15.0)	19.1 (13.6)
	(0–62.5)	(0–56.3)
Emotional well-being	22.8 (17.7)	28.5 (15.5)
	(0–79.2)	(4.2–50.0)
Stigma	16.1 (17.5)	30.3 (30.2)
	(0–87.5)	(0–81.3)
Social support	10.4 (17.2)	7.2 (11.9)
	(0–75.0)	(0–41.7)
Work Productivity and Activity Impairment (WPAI-General Health)		
Are you currently employed (working for pay)?	27.3%	21.1%
During the past 7 days, how many hours did you miss from work because of your health problems? (N=20)	1.2 (2.1)	2.0 (3.5)

Table 4. Continued

Domain of Functioning	Individuals with Parkinson's disease (N=77)	Individuals with Essential Tremor (N=19)
	Mean Score (SD)	Mean Score (SD)
	(Range)	(Range)
During the past 7 days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study? (N=22)	0 (.0)	2.2 (3.8)
During the past 7 days, how many hours did you actually work? (N=23)	25.3 (16.6) (0–60)	38.7 (12.1) (26.0–50.0)
During the past 7 days, how much did your health problems affect your productivity while you were working? (N=26)	3.6 (2.1)	3.5 (2.9)
During the past 7 days, how much did your health problems affect your ability to do your regular daily activities, other than work at a job? (N=99)	3.8 (2.5)	2.4 (2.4)

LASA, Linear Analog Scale Assessment; MD, Movement Disorders; PDQ-39, Parkinson's Disease-39; PD-NMS, Parkinson's Disease Non-Motor Symptom Questionnaire; SD, Standard Deviation.

was found only among those with ET. Taken together, these findings suggest that, although more rarely experienced, the impact of NMS in ET may be larger than it is in PD, and tailored treatments designed to optimize emotional functioning in ET appear warranted.

This study is limited by its use of a cross-sectional, convenience sample largely comprising Caucasian individuals from above-average household incomes, with college education or higher, who reported relatively limited impact of their MD on daily QOL. We also did not ask participants about their medication usage, which could play a role in symptom presentation and QOL; therefore, future studies should assess for these possible treatment effects. Selection bias may have also been present, given that participants who were willing and able to complete the survey may be less functionally impaired than those who did not complete the survey. Bias related to our focus on engagement with local communities may also somewhat limit generalizability of our results. Despite efforts to recruit participants with various MDs, this ET sample size is low and warrants further study. Statistical tests performed on the ET group only may have lacked statistical power or could have been skewed by a single participant's responses; therefore, these findings should be interpreted with the low sample size in mind. The predominate diagnosis of PD in our sample is likely attributed to initial focus of our clinic on PD, with inclusion of other MDs as MD specialists joined the center. Both a strength and limitation of this study is its reliance on self-report. Our findings may be subject to reporting bias and psychometric limitations of self-report instruments. However, focus on patient self-report is consistent with our commitment to partner with community members to establish clinical research programs responsive to patient-identified needs.

This non-motor needs and QOL assessment in individuals with MDs represents an important step towards improving treatment and QOL. Our focus on patient-reported areas of need helps us determine gaps in clinical care and identify future directions for clinical research trials. Patient-reported outcomes are just now being used to evaluate whether new therapies for MDs are effective, such as recent PRO evaluation of deep brain stimulation, intrajejunal levodopa infusion, and subcutaneous apomorphine infusions.[21]

In the upcoming years, advances in the care of NMS are likely to be as important, if not of even greater importance, as continued efforts to manage the motor symptoms of these diseases. Given the impact of NMS on QOL[5–7] and risk of institutionalization at advanced stages,[8] overcoming barriers to existing care options and empirically evaluating novel treatment options are major priorities. This needs assessment survey provides patient directives regarding improving access and existing clinical care options and launching a patient-centered, needs-based research agenda. Future research of a more representative sample of MD patients and longitudinal examination of the relationship between patients' needs and barriers, NMS, and QOL is encouraged to further advance our understanding of the MD community's needs.

Acknowledgments

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