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Lessons from the COVID-19 pandemic for improving outpatient neuropalliative care: A qualitative study of patient and caregiver perspectives

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Abstract

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AUTHORSHIP

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- (ii) Drafted the article or revised it critically for important intellectual content,
- (iii) Approved the version to be published,
- (iv) Have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

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The authors declare that there are no additional disclosures to report.

Research Ethics and Patient Consent:

This study received Institutional Review Board (IRB) approval at each of the study sites including the Colorado Multiple Institutional Review Board (COMIRB) at the University of Colorado Anschutz and the Human Research Protection Program (HRPP) at the University of California San Francisco. Informed consent was obtained from all participants prior to enrollment. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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Background: COVID-19 has impacted persons with serious illness, including those with chronic, neurodegenerative conditions. While there are several reports on COVID-19's impact on inpatient palliative care, literature is limited about the impact on outpatient care which may be more relevant for these patients.

Aim: To generate a person-centered description of the impact of COVID-19 from the perspectives of patients living with neurodegenerative disease and caregivers to improve outpatient palliative care delivery.

Design: This qualitative study used rapid analysis via matrix design to identify emergent themes related to participant perspectives on the challenges of COVID-19. Data sources included semi-structured interviews, open-ended survey responses, medical record documentation and participant-researcher communications.

Setting/Participants: Data was collected from 108 patients with Parkinson's disease, Alzheimer's disease or related disorders and 90 caregivers enrolled in a multicenter, clinical trial of community-based, outpatient palliative care between March 20, 2020 - August 8, 2020 ([NCT03076671](#)).

Results: Four main themes emerged: (1) disruptions to delivery of healthcare and other supportive services; (2) increased symptomatic and psychosocial needs; (3) increased caregiver burden; (4) limitations of telecommunications when compared to in-person contact. We observed that these themes interacted and intersected.

Conclusions: Patients and caregivers have unmet care needs because of the pandemic, exacerbated by social isolation. While telemedicine has helped improve access to healthcare, patients and caregivers perceive clear limitations compared to in-person services. Changes in society and healthcare delivery in response to COVID-19 highlight ongoing and novel gaps that must be addressed to optimize future outpatient palliative care for neurologic illness.

Keywords

[360] COVID-19; Neuropalliative care; [165] Parkinson's disease/Parkinsonism; [26] Alzheimer's disease; [113] Quality of life

INTRODUCTION

The novel coronavirus disease 2019 (COVID-19) has affected billions of people globally, posing the highest risk to older adults and those with serious illness.¹ There is mounting evidence showing that this risk is shared by those with chronic, neurologic diseases.^{2, 3} This has led many individuals living with conditions like Parkinson's disease, Alzheimer's disease and other related disorders to self-quarantine. While essential to combatting the virus, these measures affect patients' quality of life through intensified social isolation, emotional stress and greater anxiety and depression.^{4, 5} Patients and caregivers are predisposed to social isolation and the pandemic is likely exacerbating this issue with emerging evidence suggesting that it accelerates disease progression.⁶⁻¹¹

Palliative care for neurologic disease, or neuropalliative care, is an emerging subspecialty within palliative medicine.¹² There is a growing evidence showing that patients with

neurodegenerative disease benefit from a neuropalliative approach.^{13–15} However, there are many unknowns about how to effectively integrate neuropalliative care into outpatient settings. Current knowledge about palliative care delivery in the context of the COVID-19 pandemic focuses on inpatient and intensive care settings but there is a dearth of knowledge examining the impact on outpatient care received by patients with chronic, neurologic disease.^{16–18} Insights may be reached about how to improve outpatient neuropalliative care through examining patient and caregivers' experiences during the pandemic.

The aim of this study is to describe the impact of COVID-19 on patients living with chronic, neurodegenerative disease and their caregivers in order to identify opportunities for improving outpatient neuropalliative care for this patient population.

METHODS

Design

This qualitative, descriptive study leverages data from a multicenter trial of integrated, outpatient palliative care compared to standard care for individuals with Parkinson's disease, Alzheimer's disease and related disorders and their caregivers. The parent study included collection of both quantitative and qualitative data from participants. The analysis for this supplementary study was guided by four questions: 1) What are the healthcare challenges experienced by patients due to COVID-19?; 2) What are the socio-economic challenges related to COVID-19 experienced by patients and caregivers that impact access to care?; 3) How are caregivers managing social isolation associated with social distancing guidelines?; and 4) How have patient and caregivers' lives been impacted by COVID-19?.

Standard Protocol Approvals, Registrations, and Patient Consents

This study was approved by institutional review boards at all study sites and the clinical trial was registered on [ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT03076671) (NCT03076671). All participants provided informed consent or, if they lacked capacity to consent, provided assent with informed consent obtained from a legally authorized representative.

Setting and Participants

A total 401 patients diagnosed with Parkinson's disease, Alzheimer's disease or a related disorder and 340 caregivers were enrolled in the larger clinical trial. Participants came from community-based, outpatient neurology practices associated with two study sites: University of Colorado and University of California San Francisco. Eligibility for enrollment included English-speaking fluency, age ≥ 40 years, diagnosis of probable Parkinson's disease or related disorder (PDRD), or a diagnosis of probable Alzheimer's disease or related dementia (ADRD), and moderate to high palliative care needs identified by the Brief Needs Assessment Tool (BNAT) which screens for psychosocial issues, complex symptoms and caregiver burden.¹⁹ Participants were randomized using a step-wedge design to either the palliative care intervention plus standard care or standard care alone. Routine data collection occurred at baseline and every three months for 12 months followed by every six months for 12 months. The study time period occurred between March 1, 2017 and

December 31, 2020. A subset of participants engaged in semi-structured interviews as part of the larger clinical trial.

Data Collection Strategy

Data for this supplementary study was collected between March 20, 2020 and August 8, 2020 using three strategies.

First, the subset of participants took part in a qualitative study using semi-structured interviews to understand their overall experiences with the trial (targeting a goal 40 interviews). Interviews were conducted by teleconference or telephone using an iterative interview guide per the parent trial protocol. A question was added to the interview guide to ensure the impact of COVID-19 on this patient and caregiver population was captured, asking “How has COVID-19 impacted your care?”. Interviews were led by authors Z.A.M., R.A., M.D., and J.J. with expertise in behavioral neurologist (Z.A.M.), qualitative methodology (R.A., J.J.) and study coordination (M.D.). Audio recordings were transcribed and analyzed in written form.

Second, patients and caregivers were asked to complete a healthcare utilization focused survey for the clinical trial. All participants were asked to respond to an open-ended question within the survey soliciting “any other comments” regarding healthcare utilization in the previous 3 months. Surveys related to participants’ healthcare utilization were administered as part of the clinical trial protocol. These were extracted for coding and analysis if there was mention of the COVID-19 pandemic.

Finally, opportunistic data pertaining to COVID-19 was collected from documentation of communications between participants, study personnel, and palliative care team members. This included medical record documentation completed by palliative care team members at outpatient visits. Documentation of participant-study personnel communications were included if COVID-19 was discussed.

Data Analysis

Our analysis used a team-based, inductive and deductive approach to identify key themes as data saturation regarding the impact of COVID-19 on patients and caregivers was achieved.^{20, 21} Transcripts were de-identified with the exception of participant type (patient or caregiver), date interviewed, and study site. Rapid analysis via a matrix design was used to explore emergent themes related to COVID-19.²² Matrix design is an approach that summarizes qualitative data in a table of columns and rows, allowing for comparison of coded data. Microsoft Excel for Mac (Microsoft Office 2019, Version 16.46.21021202) was used for data management.

Qualitative personnel (Z.A.M., R.A., M.D., and J.J.) individually coded the data, held regular consistency checks to ensure rigor and routinely met to discuss any discrepancies and thematic emergence.²⁰ Triangulation is a strategy used in qualitative research where multiple sources of data are used to develop a complete understanding of emerging themes with greater reliability of results.²³ In our study, triangulation was achieved through the use of multiple sources of data. Informational saturation is a qualitative endpoint where no new

information is gleaned from additional data collection.²⁴ Data collection concluded once informational saturation regarding the impact of COVID-19 on patients and caregivers was reached.

Data Availability

The authors confirm that deidentified data supporting the findings of this study are available upon request.

RESULTS

A total of 108 patients and 90 caregivers mentioned COVID-19 or the pandemic during 77 outpatient visits, 39 open-ended survey responses, 40 semi-structured interviews and 43 separate communications with study personnel by way of documented telephone calls and emails. Participant characteristics at the time of data collection are described in Table 1.

Synthesis of themes

Four main themes emerged: (1) disruptions to delivery of healthcare and other supportive services; (2) increased symptomatic and psychosocial needs; (3) increased caregiver strain; and (4) limitations of telecommunications when compared to in-person contact.

Theme 1: Disruptions to delivery of healthcare and other supportive services

Patients and caregivers described a variety of ways in which COVID-19 disrupted access to healthcare services, with subthemes related to loss and postponement of healthcare services and avoidance of living facilities out of fears of contracting the virus.

Participants reported a loss of ambulatory services, extending beyond palliative care services to include primary care and preventative services, with a shared perception that these interruptions were indefinite. The most commonly mentioned services included home health aides home-based rehabilitation services, like physical therapy, and home hospice:

“[We have] been unable to receive [physical therapy] home health care due to COVID stay at home orders.” (PDRD Caregiver, Semi-structured interview)

Across patients and caregivers, many voiced fears and worries about their personal vulnerability to COVID-19, stating that this was a reason for deferring healthcare:

“...everybody’s vulnerable and with the virus we’re even more vulnerable...”
(PDRD Caregiver, Semi-structured interview)

Participants were concerned about the risk of COVID-19 when traveling far distances for medical care, with worries about local precautions instituted in areas of travel. Deferral of care was attributed to changes made within healthcare systems including system-wide cancellations of routine appointments and elective procedures:

“A challenge has been cancellations of tests/procedures. They had a DATscan set for early March that was cancelled by [the hospital], who thought it wasn’t essential enough to be worth the additional risk.”(PDRD Caregiver, Palliative care visit note)

Participants chose to avoid healthcare settings including outpatient services in which the caregiver would not be able to accompany the patient:

“Felt like there was just too much danger going into a hospital setting just to get more clarity about diagnosis – especially when she is not able to take anyone in with her and she has cognition and communication problems.” (ADRD Caregiver, Palliative care visit note)

Avoidance of assisted living facilities was also mentioned with postponement of pre-COVID-19 plans for transitioning into congregate or assisted living settings. Postponement of living facility placement was most commonly done out of fear of contracting COVID-19 or in order to prevent spread from the community. Some patients and caregivers mentioned avoiding congregate living facilities because of strict visitor restrictions. One caregiver delayed a patient’s move to assisted living because they feared that inflexible quarantine rules would prevent them from seeing their loved one:

“[The caregiver] is not following through with placing him in a nursing home because she is afraid she will never see him again.” (PDRD Caregiver, Palliative care outpatient visit note)

Others delayed placement because they perceived living facilities and their residents as high-risk for rapidly spreading the virus.

Theme 2: Increased symptomatic and psychosocial needs

Participants credited their experience with social isolation to observed declines in patients’ mental and physical health. Subthemes related to patients’ experiences included social isolation, increasing neuropsychiatric symptoms and worsening motor symptoms due to physical inactivity.

Social isolation was seen as a contributing factor to decline in patients’ mental health. Many were concerned with being able to safely see their loved ones and stated they had not seen many of their family or friends since the onset of the pandemic. This was especially true for institutionalized patients who described severe isolation because of quarantine policies and procedures:

“I have been quarantined for over 30 [days] which has affected my life completely. I feel like I am in prison, and so do my friends. We cannot talk to anyone...”
(PDRD Patient, Study coordinator communication documentation)

Patients residing in congregate living situations described isolation precautions using terms like “prison” and “solitary confinement.” Many patients described being unable to leave their rooms for prolonged periods of time when facility-wide quarantine measures were in place.

Patients experienced more neuropsychiatric symptoms with depression being the most common manifestation, along with increases in hallucinations and fluctuations in cognition. For one patient, worsening depression resulted in “self-harm” and subsequent admission to a psychiatric inpatient facility for treatment:

“Patient became depressed due to COVID which resulted in self-harm and was admitted to a psychiatric facility.” (PDRD Patient, Palliative care visit note)

Participants expressed a general sense of increased stress and specific concerns about their local community’s social distancing and mask adherence. Caregivers also ascribed a lack of social stimulation amongst patients with ADRD to accelerations in cognitive decline, observing more frequent confusion and more functional decline.

Physical health declined and motor symptoms worsened amidst the pandemic. Patients with PDRD reported a sense of physical decompensation as result of limited physical activity due to social distancing. Many patients added that exercise routines had been an essential part of managing their disease in the before the pandemic. In their absence, patients reported increasing motor symptoms and even relapsing symptoms that had previously been well-controlled:

“[My] symptoms are increasing due to loss of exercise routine...” (PDRD Patient, Semi-structured interview)

This was also described in the context of ADRD with some patients and caregivers observing an overall decline in mobility. For a few participants who had contracted the virus, there was appreciable deterioration in physical health with caregivers describing a slow, prolonged recovery.

Theme 3: Increased caregiver strain

Caregivers experienced compounded stress and strain since the onset of the pandemic. Subthemes related to sources of increased strain including shifts in the roles and responsibilities of caregivers, declines in caregiver mental health, and loss of community-based caretaker services.

Several caregivers stated that quarantine precautions had prevented outside medical providers and family members from providing help in the home. The responsibilities of caregiving also interfered with their ability to manage the household or fulfill employment duties. Patients were also apprehensive about family members taking on new roles as caregiver, endorsing distrust in the capabilities of family members who had limited caretaking experience:

“[I’m] relying on my spouse who does not know how to handle Parkinson’s...”
(PDRD Patient, Semi-structured interview)

Caregivers experienced increased stress related to the societal effects of the pandemic. Many described their own social isolation as a source of depression and admitted to increased burnout:

“Before the pandemic, [care partner] was receiving assistance from Home Instead for nonmedical care. Right now, they are able to manage caring for the patient. Although, the [family caregiver] is starting to get burned out.” (ADRD Caregiver, Palliative care visit note)

Increased strain was related to lost caretaking services previously provided through community programs (e.g. adult daycare and caregiver respite programs) as well as cancelled home health services like personal aides. For patients with greater family support, there was increased reliance on other family members to supplement these lost caretaking services.

Theme 4: Limitations of telecommunications when compared to in-person contact

Many participants reported increasing use of telecommunications for both healthcare and personal purposes. Telecommunication services allowed patients to attend virtual visits with healthcare providers and helped them remain connected with family and friends. While many participants described the conveniences of telecommunications, social isolation continued to be a recurring problem despite these technological solutions.

Telehealth was a common means by which patients continued to receive outpatient healthcare. Along with a general sense of dissatisfaction some patients described a loss of motivation to take part in telehealth visits. The overall perspective amongst patients and caregivers was that this method was subpar compared to in-person services or the care they received before the pandemic:

“...Zoom is a possibility but it’s not the same and I suppose it will never be the same [as being in-person] or a long time.” (PDRD Caregiver, Semi-structured interview)

Telehealth was not viewed as a long-term solution and nor could it supplant pre-COVID-19 levels of care.

Social isolation was not fully alleviated by the use of telecommunication platforms. The use of such technology was identified as one means for staying connecting with loved ones but was seen as a less than equal supplement for the lack of social stimulation experienced during self-quarantine or when local “shelter-in-place” orders were enacted by local governments:

“Mentioned how the shelter-in-place rules have created a downhill motion of events... now was very difficult for [the patient] to display that level of social energy, and that Zoom meetings did not compensate for the lack of social stimulation...” (ADRD Caregiver, Study coordinator communication documentation)

DISCUSSION

People living with neurodegenerative disease are experiencing the heightened consequences of the COVID-19 pandemic. Disruptions in healthcare, social isolation and worsening symptoms have intensified the burdens of these diseases. Patients and caregivers are having to rapidly adapt to the shift towards telemedicine and do not perceive this as a substitute for in-person contact and support. Lastly, these themes intersect and interact with each other. For example, loss of exercise programs contributes to caregiver strain, social isolation, and symptomatic worsening.

COVID-19 has derailed healthcare systems forcing many to modify the ways they deliver care. As a consequence many patients are being left behind. The Centers for Disease Control and Prevention (CDC) estimates that nearly 41% of adults in the United States delayed or avoided medical care because of COVID-19.²⁵ Our findings expand on this within the context of neurodegenerative disease and outpatient palliative care, providing a person-centered understanding of rationales for avoiding healthcare settings. As initiatives to combat the pandemic are implemented, special emphasis should be placed on those services with the greatest risk for negative outcomes should they be interrupted or delayed. In a post-pandemic world, healthcare workers should remain cognizant of patient and caregiver perspectives which may be a barrier to seeking out healthcare.

We observed that participants in our study were experiencing greater symptom burden and accelerated disease as an indirect consequence of the pandemic, complementing observations of excess deaths amongst patients with ADRD and descriptions of worsening severity in Parkinson's disease.^{26, 27} This highlights the need for increased awareness of issues like social isolation which impact disease and are important to patients and families. Palliative specialists caring for patients with neurodegenerative conditions should recognize social isolation and lost supportive services as factors which complicate symptom management. This requires providers to screen for social isolation and monitor situations where supportive services are lost.

Caregivers are experiencing the strains of COVID-19 and are finding themselves spending more time caretaking. Research shows that more daily caregiving hours is associated with higher levels of caregiver burden in the setting of ADRD,^{28, 29} and caregiver anxiety and depression in PDRD is associated with overall higher caregiver burden.³⁰ Our caregivers' experiences suggest that interruptions in caretaking services represent another factor contributing to caregiver burden. One solution is to utilize social workers embedded in specialized palliative care clinics or primary care settings to help identify respite services, personal care aids and home health resources. Another is to utilize an integrated approach where palliative specialists work with primary care physicians and neurologists to address unmet needs driving caregiver burden. Although further study is needed to determine appropriate methods for implementation, this model has shown beneficial for patients with PDRD, improving caregiver burden and patient quality of life, and may be useful for addressing unmet needs of patients and caregivers created by the pandemic.³¹

Our participants' experiences with telemedicine tempers previous commentaries describing the shift to telemedicine as "overwhelmingly positive."³² While telehealth has certainly improved healthcare delivery for many patients and has enormous potential for improving the lives of patients and caregivers,^{33, 34} our study highlights its limitations especially when offered without adjunctive in-person care. This may require a compromise between healthcare that is delivered entirely virtual or primarily in-person. Home-based and outpatient palliative services adhering to infection control measures in tandem with vaccination efforts may help preserve those essential, in-person services.

Outpatient palliative providers should be aware of the challenges facing patients with neurologic illness and their families while anticipating the effects of social isolation and

lost healthcare or other community-based supportive services. As the use of telemedicine continues to expand, outpatient palliative services looking to integrate this method of delivery should ensure it retains value for patients and caregivers and avoids exacerbating healthcare disparities.³⁵ It also remains incumbent on clinicians to acknowledge the limitations of telemedicine and seek ways to make meaningful virtual contact.³⁶

Our study has limitations. For one, our cohort lacks diversity regarding race, ethnicity and was highly educated. As such, we cannot conclude how minority populations or non-English speaking patients with neurodegenerative conditions who are receiving outpatient palliative care are impacted by COVID-19. Given the additional challenges faced by patients within these groups, and their disproportionate COVID-19 burden, we would expect that patients and their caregivers of lower socioeconomic status or with less education would report more challenges related to the pandemic. Strengths of this study include the use of qualitative methods to provide a person-centered understanding of the impact of COVID-19 on this patient population. The use of multiple data sources across multiple sites increases the variety of patient and caregiver perspectives.

CONCLUSION

Our study provides a unique, person-centered description of COVID-19's impact on patients living with chronic, neurodegenerative disease who are receiving outpatient neuropalliative care and comes at a critical moment during the pandemic. The pandemic has imposed additional burdens and intensified many existing challenges faced by patients and their caregivers as well as palliative care specialists and non-palliative providers alike. Palliative care providers should ensure availability and safety of in-person visits for those patients need them. Given that the pandemic is far from over with expected long-term consequences in the years to come, neuropalliative services should work to optimize telemedicine and mitigate disruptions in healthcare services.

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KEY STATEMENTS

What is already known about the topic?

- Emerging evidence suggests that patients with neurodegenerative conditions are at high-risk for the direct and indirect effects of the COVID-19 pandemic.
- Delivery of palliative care services has radically shifted to address changing needs amongst patients.
- There remains a dearth of literature describing the pandemic's impact on outpatient palliative care and even more limited knowledge on the unmet needs of patients and caregivers with neurodegenerative conditions in this context.

What this paper adds

- Shifts in healthcare delivery have led to significant disruptions for patients with neurodegenerative conditions who are receiving outpatient, specialized palliative care.
- Loss of services and social isolation is perceived as contributing to worsening symptoms, accelerated disease, and increasing strain for caregivers.
- From the perspectives of patients and caregivers, telemedicine, although useful in many regards, is not a panacea for supplementing lost healthcare services.

Implications for practice, theory or policy

- Outpatient palliative providers should be aware of the challenges facing patients with neurologic illness and their families and anticipate the effects of social isolation and lost supportive services.
- Palliative services looking to incorporate telemedicine should do so in a way that balances remote and essential in-person services.
- Future neuropalliative care models should look for ways to screen for psychosocial factors that worsen disease and caregiver strain.

Table 1.

Patient and Caregiver Characteristics

	Patients (n=108), No. (%)	Caregivers (n=90), No. (%)
Age, years (SD)	73.3 (17.3)	66.6 (12.1)
Disease duration, years (SD)	9.4 (7.3)	-
Duration of caregiving, years (SD)	-	6.1 (5.7)
Sex (% Male)	64 (59.3)	23 (25.6)
PDRD diagnosis		
PD	76 (70.4)	-
DLB	8 (7.4)	-
CBD	3 (2.8)	-
MSA	3 (2.8)	-
PSP	1 (0.9)	-
Vascular parkinsonism	1 (0.9)	-
Other	8 (7.4)	
ADRD diagnosis		
AD	6 (5.6)	-
FTD	1 (0.9)	-
Vascular Dementia	1 (0.9)	-
Race		
Caucasian	99 (91.7)	84 (93.3)
Asian	5 (4.6)	2 (2.2)
American Native/Indian	4 (3.7)	0 (0.0)
Other	3 (2.8)	3 (3.3)
Prefer not to answer	1 (0.9)	1 (1.1)
Education		
Less than high school diploma	4 (3.7)	0 (0.0)
High school diploma/GED	18 (16.7)	13 (14.4)
Some college	23 (21.3)	18 (20.0)
Associate degree	9 (8.3)	6 (6.7)
Bachelor's degree	21 (19.4)	22 (24.4)
More than a 4-year degree	32 (29.6)	30 (33.3)
Unknown/No Response	1 (0.9)	1 (1.1)
Income		
\$0-29,000	19 (17.6)	9 (10.0)
\$30,000-49,999	18 (16.7)	17 (18.9)
\$50,000-74,999	18 (16.7)	13 (14.4)
\$75,000-99,999	15 (13.9)	16 (14.8)
\$100,000+	27 (25.0)	26 (28.9)
Unknown/No Response	11 (10.2)	9 (10.0)

	Patients (n=108), No. (%)	Caregivers (n=90), No. (%)
Patient's living situation		
Independent living	66 (90.4)	-
Assisted living facility	5 (6.8)	-
Clinical Global Impression scale		
1 = normal, not at all ill	0 (0.0)	-
2 = borderline ill	4 (4.0)	-
3 = mildly ill	20 (19.8)	-
4 = moderately ill	49 (48.5)	-
5 = markedly	22 (21.8)	-
6 = severely ill	5 (5.0)	-
7 = among the most extremely ill patients	1 (1.0)	-
Hoehn and Yahr stage (PDRD patients)		
< Stage 3	4 (4.0)	-
Stage 3	97 (96.0)	-
Charlson Comorbidity Index		
< 5	43 (44.3)	-
5	54 (55.6)	-
Palliative Performance Scale		
70%	75 (78.1)	-
> 70%	21 (21.9)	-
Hospital Anxiety & Depression Scale (depression), mean (SD)	7.6 (3.7)	5.0 (3.7)
Hospital Anxiety & Depression Scale (anxiety), mean (SD)	7.2 (4.4)	6.8 (4.0)
Baseline MOCA, mean (SD)	22.5 (6.1)	-
Baseline UPDRS III (PDRD patients), mean, (SD)	25.8 (11.5)	-
DBS implantation status (Yes)	5 (5.2)	-
Participating caregiver		
Yes	90 (83.3)	-
No	18 (16.7)	-
Patient-caregiver relationship		
Spouse or partner	76 (50.9)	76 (85.6)
Child or other	18 (3.7)	16 (18.9)
No caregiver	9 (8.3)	-
Unknown	5 (4.6)	-
Care partner shares household with patient, yes	-	75 (84.4)
Zarit Caregiver Burden Interview, mean (SD)	-	17.1 (9.0)

Abbreviations: AD = Alzheimer's disease; ADRD = Alzheimer's disease and related dementias CBD = Corticobasal degeneration; DBS = Deep brain stimulation; DLB = Dementia with Lewy bodies; FTD = Frontotemporal dementia; MOCA = Montreal Cognitive Assessment; MSA = Multiple systems atrophy; PD = Parkinson's disease; PSP = Progressive supranuclear palsy; PDRD = Parkinson's disease and related disorders; SD = standard deviation.