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The “Surprise Question” for Prognostication in People With Parkinson’s Disease and Related Disorders

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Abstract

Context.—Parkinson’s disease and related disorders (PDRD) are fatal neurodegenerative disorders characterized by a fluctuating course that can complicate prognostication. The “surprise question” (SQ: “Would you be surprised if your patient died in the next year?”) has been used to identify patients with limited prognosis but has not been assessed in PDRD.

Objectives.—To determine the validity of the SQ in predicting 12-month mortality in PDRD.

Methods.—Data was analyzed from 301 patients and 34 community-based neurologists who were participating in a clinical trial of outpatient palliative care for patients with PDRD. Clinicians answered the SQ for each patient at baseline. Descriptive statistics at baseline, chi-square tests of independence, 2×2 and 2×3 cross tables were used. Survival analysis compared SQ responses using Kaplan-Meier curves. Risk estimate analyses identified patient characteristics associated with clinicians’ responses.

Results.—Mortality was 10.3% ($N = 31$) at 1 year. The sensitivity and specificity of the SQ was 80.7% and 58.9%, respectively with AUC = 0.70, positive predictive value of 18.4% and negative

predictive value of 96.4%. Older age, atypical parkinsonism, and dementia were associated with responding “no” to the SQ.

Conclusion.—The SQ is sensitive to 12-month mortality in PDRD, with a high negative predictive value. The SQ may be useful for identifying patients less likely to die within a year and may be useful for identifying patients with palliative care needs outside of end-of-life care. This latter use may assist in mobilizing early and timely referral to specialist palliative care.

Keywords

Parkinson’s disease; surprise question; palliative care; prognostication

Introduction

Parkinson’s disease and related disorders (PDRD) are a group of neurodegenerative diseases that impair both cognitive and motor function.¹ PDRDs are inevitably fatal with mortality rates for Parkinson’s disease in patients over age 65 estimated at 65.3 per 100,000 individuals in 2017.² It is expected that over the next decade, approximately 1,238,000 individuals in the US will be living with Parkinson’s disease.³ In addition to debilitating motor symptoms, many people with PDRD experience non-motor symptoms including depression, fatigue, psychosis, and dementia that can be difficult to treat and contribute to overall disease burden and severity.⁴

Prognostication is traditionally viewed as a core clinical skill for clinicians.⁵ Accurate prognostication has many benefits relevant to PDRD such as the ability to formulate individual risk assessments, stratifying treatment options, providing patients and families with information for shared decision-making, and making timely referrals for palliative care services.⁶ However, predicting death in PDRD is complex as symptoms may wax and wane, progression is often marked by periods of stability and acceleration, and causes of death can vary.⁷

One approach to estimating prognosis is the “surprise question”, which asks clinicians to consider the following: “Would you be surprised if this patient died within the next 12 months?”⁸ Prior research in non-neurologic, chronic illnesses such as advanced heart failure, cancer, and end-stage renal failure, show that the surprise question is relatively accurate as a predictor of mortality, with 1 meta-analysis of 22 studies showing a pooled accuracy of 74.8%.⁹ There are currently no studies looking at the use of the “surprise question” in the setting of PDRDs. This study’s aim was to determine the validity of the “surprise question” when used by community neurologists as a predictor of mortality among patients with PDRD.

Methods

Design

This was a secondary analysis of data collected as part of a multisite, randomized clinical trial of integrated, outpatient palliative care for patients with PDRD. This study was approved by the institutional review board at the University of California, San Francisco

(UCSF) and the University of Colorado Anschutz Medical Campus (CU) and the clinical trial was registered on [ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT03076671) (NCT03076671).

Standard Protocol Approvals, Registrations, and Patient Consents

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 359 patients were enrolled in the parent clinical trial. Participants were recruited from community-based, outpatient neurology practices in Colorado, Wyoming, and California. Eligibility for enrollment included English-speaking fluency, age ≥ 40 years, diagnosis of PDRD, including probable idiopathic Parkinson's disease, Dementia with Lewy Bodies, Progressive Supranuclear Palsy, or Multiple Systems Atrophy, 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 (Supplement 1). To be included patients (and caregivers if present) needed to meet any positive response on the BNAT. Clinicians were randomized using a step-wedge design to either the palliative care intervention plus standard care or standard care alone and patients followed the randomization of their respective clinician in this cluster design. A total of 34 clinicians took part in the study and referred patients and their caregiver for possible enrollment.

Data Collection Strategy

Participating clinicians used the BNAT when referring patients for the study, which included the "surprise question" as the first item (Supplement 1). The clinician was asked the question: "Would you be surprised if this patient passed away within the next 12 months?", indicating "Yes" if they would be surprised if the patient died within the next 12 months and "No" if they would not be surprised if the patient died within the subsequent 12 months. To minimize burden for referring clinicians, they needed to answer a minimum of 1 out of the 9 BNAT questions, identifying at least 1 palliative need or as many as they felt relevant. Survival status was ascertained by follow-up telephone calls made by study coordinators to patient's caregivers and other family members after completion of the study and through a search of online, public obituary records.

Data Analysis

Descriptive statistics were used to summarize patient and clinician characteristics. Sensitivity, specificity, and positive and negative predictive values were assessed with a 2×2 frequency table. Proportions and 95% confidence intervals were calculated. The area under the ROC curve measured the predictive power of the surprise question for death within 12 months. A chi-square test of association between the surprise question and mortality was performed. Relative risk models and Spearman correlations assessed the relationship of baseline patient characteristics with the surprise question. Kaplan-Meier compared time to death between surprise question responses. Analyses were performed on an available case basis. Univariate 2-sided $\alpha = 0.05$ was used for all tests unless otherwise stated. Statistical analysis was performed in SAS 9.4.

Data Availability

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

Results

Of 359 patients enrolled in the study, physicians provided responses to the SQ for 301 and of those 136 (45.2%) responses to the SQ were “no”, indicating that clinicians would not be surprised if the patient died within 12 months. The average age of the participating patients was 74.7 years old, and 67.9 years for the caregivers (Table 1). Most participants (84.4%) had a caregiver participating in the study, and 81.1% of participating caregivers shared a household with the patient. Approximately two thirds of the clinicians were women with an average age of 45 years old and a mean of 16 years in practice (Table 2).

Time to death was available for 88 patients (63 for “no” and 25 for “yes”). Dates of death were obtained for patients who had completed or left the study; 213 patients without a record of death then were censored (73 for “no” and 140 for “yes”). Deaths were recorded for 46.3% of “no” responses, compared to 15.2% of “yes” responses. Over the course of the study, 31 patients died within 1 year of enrollment. Of those who did not die, the clinicians responded “Yes” for 159 patients, resulting in a sensitivity of 80.7% and a specificity of 58.9% (Table 3) with an area under the curve (AUC) of 0.70 (Fig. 1). The positive predictive value of “No” on the SQ for predicting death was 18.4%. The negative predictive value of “Yes” on the SQ, with a BNAT score = 1, for predicting survival was 96.4%.

Comparison of the Kaplan-Meier survival curves for time to death, stratified by surprise question response, (Figure 2) found the estimated survival probability decreased for “no” responses faster than for “yes” responses (log rank test P value < 0.0001, Peto-Peto test P value < 0.0001). Older patient age, presence of dementia, presence of a care partner, atypical parkinsonism, worse motor symptoms, more comorbidities, poor self-reported quality of life, poor cognition, and presence of grief, depression and anxiety were associated with clinicians responding “No” to the SQ (Table 4).

Discussion

In patients with PDRD being cared for by community neurologists, the SQ was moderately accurate for predicting 12-month mortality and highly sensitive but not specific in predicting survival. These findings indicate that the surprise question may provide helpful information for prognostication for people with PDRD. While this tool will have limited use in predicting mortality, it may be more useful in helping clinicians identify patients who may benefit from specialty palliative care referral and advance care planning.

As PDRD progresses, symptoms become more prominent, often requiring more attention from the caregiver, which can result in both a physical and emotional burden, especially towards the end of life. Palliative care needs should be assessed regularly in PDRD as the disease worsens to identify needs and mobilize resources such as social work, home health, and caregiver support.¹⁰ The simplicity of the SQ, even if its accuracy is modest at best,

can identify patients in whom palliative care needs should be assessed in greater detail and specificity. The SQ may also serve as a trigger for fostering discussions with caregivers regarding unmet care needs.

The surprise question's accuracy in predicting mortality is limited, however it may serve as a useful tool to identify factors predictive of mortality. The data in Table 4 compares patient variables and clinical scales to a "No" response to the surprise question. A PD patient's life expectancy can be affected by many factors, related to their demographics or degree of symptoms. People with PD who have dementia, atypical symptoms, or a care partner is indicative of higher palliative care needs and were found to be independent factors of mortality. The presence of these characteristics can be useful information to a clinician regarding a patient's treatment plan. The surprise question may be useful to trigger providers to consider specialist palliative care referrals sooner to maximize utilization of services throughout the end-of-life. In addition to hospice referral, the surprise question may also be useful in recognizing the palliative care needs of a patient if administered alongside needs assessment tools like the BNAT. Implementing the surprise question could help patients gain access to palliative services in a timely manner.

Strengths and Limitations

Our study has several limitations. We asked only physicians to respond to the SQ. Asking only physicians may have resulted in more accurate data for prognostication, however obtaining data from advanced practice providers, nurses, or social workers can help us understand the SQ from a different provider's perspective. Additionally, the SQ was presented to clinicians in the context of additional questions relevant to patient and caregiver needs assessment (i.e., BNAT) and may have influenced clinicians' responses when identifying palliative care needs. However, clinicians responded to the surprise question first, before answering the BNAT questions to avoid influencing clinicians' responses to the SQ. The SQ was also used in the context of a clinical trial of a palliative care intervention for PDRD and may not accurately reflect real-world application of this tool. Future studies should consider the use of the SQ tool across a variety of clinical settings including general neurology practices, movement disorder specialty clinics, primary care, academic and nonacademic centers.

Conclusion

Overall, only about 10 percent of the patients died during the first year after enrollment in our study. Despite the low 1-year mortality rate, the proportion of patient deaths considered to be non-surprising were significantly higher compared to patients whose death was not considered surprising. Among patients with PDRD, most of the patients who died within 1 year were modestly predicted by the surprise question. While the SQ was not sufficiently sensitive or specific to be used as a sole prognostic tool for people with PDRD, it may be a good tool for identifying people with PDRD who are likely to have palliative care needs. Patient characteristics such as atypical parkinsonism, quality of life, cognition, and depression and anxiety were associated with answering "No" to the SQ and provide opportunities to address challenges and needs. Prognostic information is important for

patients and their families and further research is needed to develop tools that can provide this information to help patients make more informed decisions about their care and how they want to spend the rest of their lives. The surprise question is quick tool that may be useful to identify patients with PDRD who have palliative care needs and may assist clinicians with needs assessment and prognostication.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Disclosures and Acknowledgments

This work was part of a registered clinical trial ([ClinicalTrials.gov NCT03076671](https://clinicaltrials.gov/NCT03076671)) and was supported by the National Institute of Nursing Research (R01NR016037) and the National Institute on Aging (T32AG044296; K02AG062745). The authors declare no conflicts of interest.

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Key Message

This article describes findings from a longitudinal study on the validity and accuracy of the surprise question for predicting mortality among patients with Parkinson’s disease and related disorders. The results indicate that clinicians’ responses to the surprise question are modestly predictive but may assist clinicians with needs assessment, triaging referrals for specialist palliative care.

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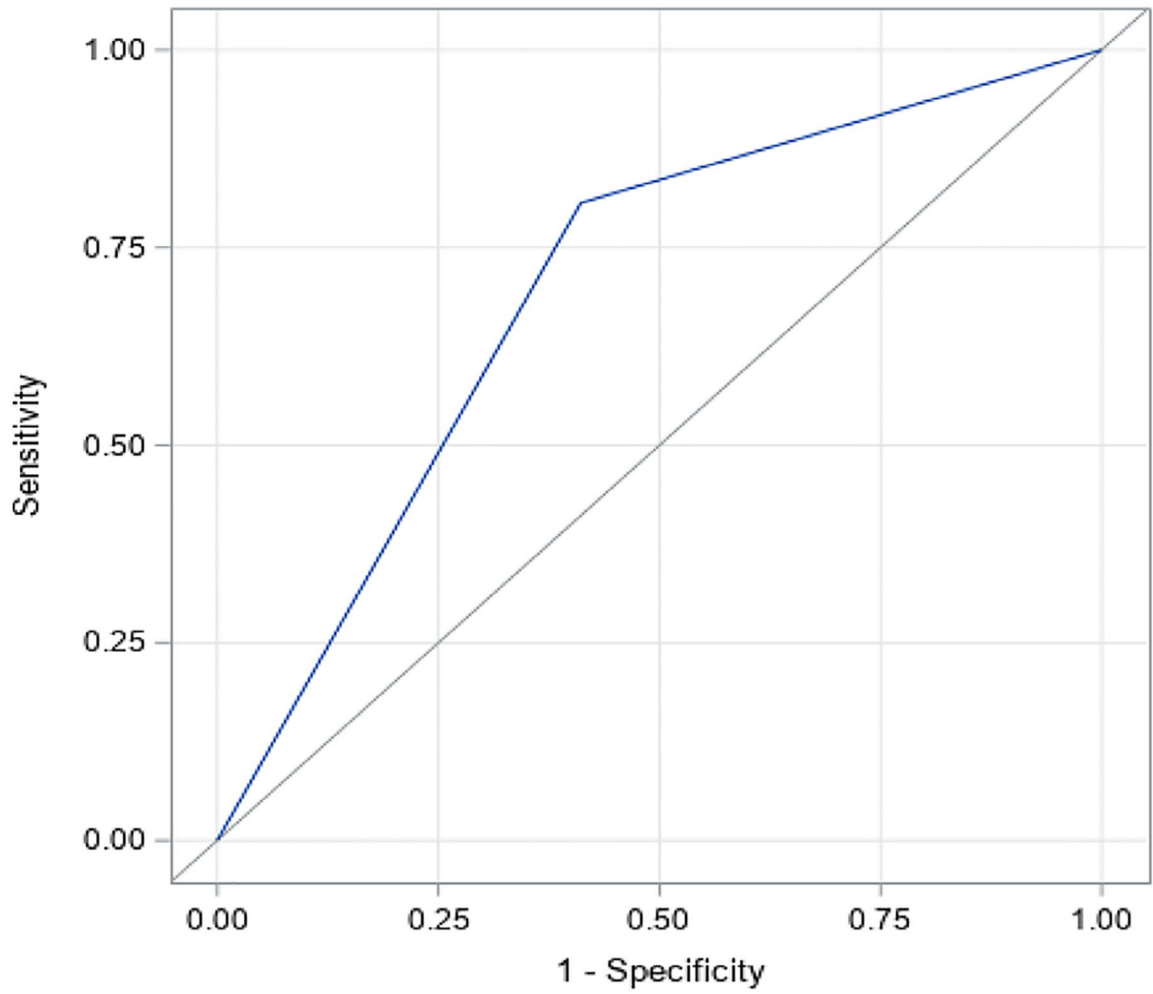


Fig. 1. Receiver operating characteristic (ROC) curve for validation testing of the surprise question. AUC = 0.70, sensitivity = 80.7%, specificity = 58.9%.

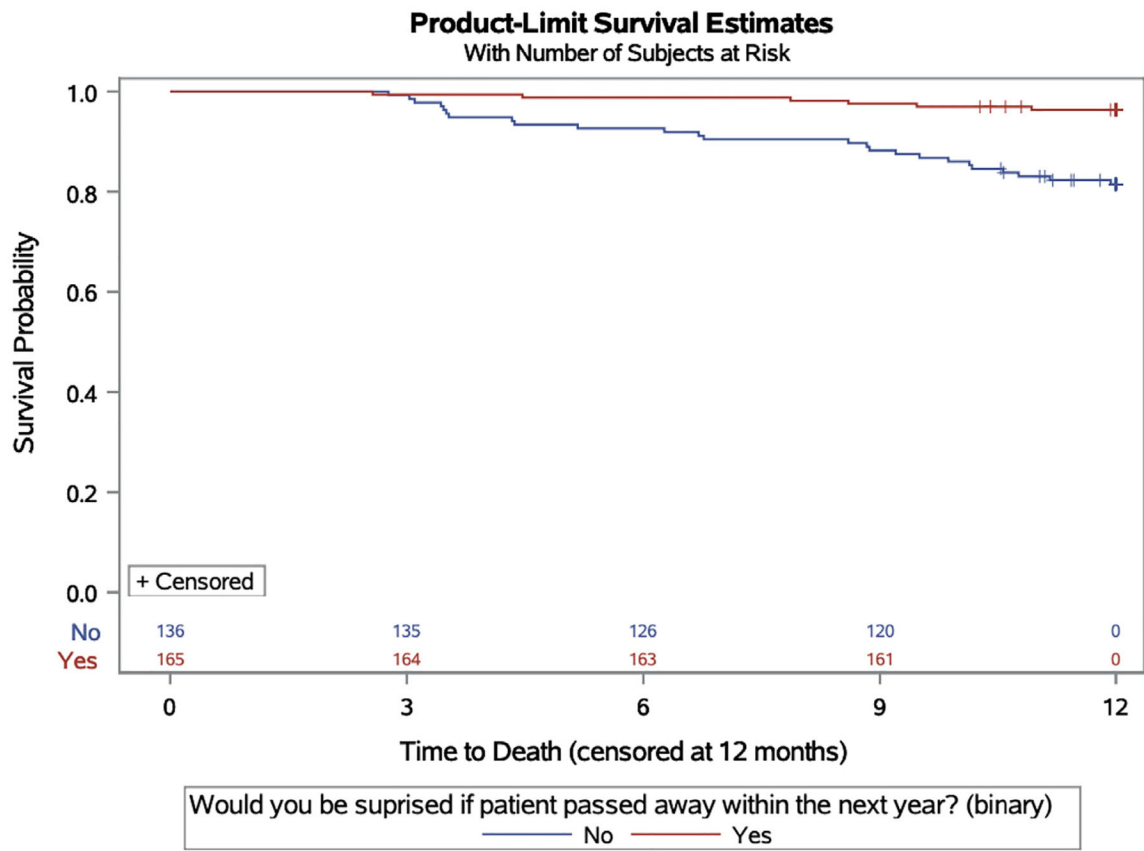


Fig. 2. Kaplan-Meier curve for survival based on surprise question answer with significant differences in 12-month mortality between “yes” vs “no” responses to the surprise question.

Table 1Patient Characteristics (*n* = 301)

| Patient Characteristics | Mean ± SD or N (%) |
|-------------------------------------|--------------------|
| Age (years) | 74.7 ± 8.2 |
| Disease duration (years) | 9.1 ± 7.4 |
| Sex (N, % Male) | 202 (67.11) |
| PDRD diagnosis: | |
| PD ^a | 210 (69.77) |
| DLB ^b | 32 (10.63) |
| PSP ^c | 18 (5.98) |
| CBD ^d | 14 (4.65) |
| MSA ^e | 12 (3.99) |
| Vascular parkinsonism | 3 (1) |
| AD ^f | 1 (0.33) |
| Vascular Dementia | 1 (0.33) |
| Other | 10 (3.32) |
| Race | |
| Caucasian | 281 (93.36) |
| Asian | 11 (3.65) |
| African American | 2 (0.66) |
| American Native/Indian | 3 (1) |
| Other | 3 (1) |
| Married | 219 (73.0) |
| Education | |
| Less than a bachelor's degree | 132 (44.15) |
| Bachelor's degree or more | 167 (55.85) |
| Income | |
| \$0–29,999 | 54 (17.93) |
| \$30,000–49,999 | 54 (17.93) |
| \$50,000–74,999 | 51 (17) |
| \$75,000–99,999 | 40 (13.33) |
| \$100,000+ | 70 (23.33) |
| Unknown | 10 (3.33) |
| Prefer not to Answer | 21 (7) |
| Charlson Comorbidity Index | |
| <5 | 74 (35.4) |
| 5 | 135 (64.6) |
| Missing | 92 |
| Palliative Performance Scale | |
| 70% | 244 (81.61) |
| >70% | 55 (18.39) |

| Patient Characteristics | Mean ± SD or N (%) |
|---|--------------------|
| Hospital Anxiety & Depression Scale (depression), mean | 7.88± 3.83 |
| Hospital Anxiety & Depression Scale (anxiety), mean | 7.28±3.89 |
| Baseline MoCA ^g, mean | 21.69± 5.91 |
| Baseline UPDRS^hIII mean | 26.00± 11.35 |
| Participating caregiver | |
| Yes | 254 (84.39) |
| No | 47 (15.61) |

^aParkinson’s Disease.

^bDementia with Lewy Bodies.

^cProgressive Supranuclear Palsy.

^dCorticobasal Degeneration.

^eMultiple System Atrophy.

^fAlzheimer’s Disease.

^gMontreal Cognitive Assessment.

^hUnified Parkinson’s Disease Rating Scale.

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Table 2Neurologist Characteristics (*n* = 34)

| Characteristic | Mean ± SD orN(%) |
|---|-------------------------|
| Sex (N, % female) | 21 (61.76) |
| Age (years) | 44.97 ± 8.87 |
| Clinical experience (years) | 16.79 ± 9.18 |
| Race | |
| Caucasian | 26 (76.47) |
| Asian | 4 (11.76) |
| African American | 0 (0) |
| American Native/Indian | 1 (2.94) |
| Mixed | 1 (2.94) |
| Unknown | 1 (2.94) |
| Prefer not to answer | 1 (2.94) |
| Other | 1 (2.94) |
| Type of medical practice | |
| Individual Provider | 4 (12.50) |
| Independent multi-provider office | 9 (28.13) |
| Network multi-provider office | 8 (25.00) |
| Hospital affiliated office | 10 (31.25) |
| Other | 1 (3.13) |
| Did you complete a Movement Disorder Fellowship? | |
| Yes | 14 (46.67) |
| No | 16 (53.33) |

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Table 3

Sensitivity-Specificity Table

| | | Would You be Surprised if Patient Passed Away Within the Next Year? (Binary) | | Deceased Within 1 Year | | |
|----------------|-------------------------------|---|-------|-------------------------|-----|-------|
| | | | | No | Yes | Total |
| Frequency | No | 111 | 25 | 136 | | |
| | | 41.11 | 80.65 | | | |
| Column Percent | Yes | 159 | 6 | 165 | | |
| | | 58.89 | 19.35 | | | |
| | Total | 270 | 31 | 301 | | |
| | Frequency missing = 58 | | | | | |
| | | | | <i>P</i> value < 0.0001 | | |

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Table 4
 Bivariate Model of Patient Characteristics Predictive of a “no” response to the Surprise Question

| Experimental Variable | Reference Question | | | |
|---|------------------------|-------------------|---------|--|
| | Relative Risk Estimate | Confidence Limits | P-Value | |
| <i>Patient demographics</i> | | | | |
| Age (per 5 years) | 1.2166 | 1.1169 1.3252 | <0.0001 | |
| Sex/Gender: Male vs Female | 0.9281 | 0.7163 1.2024 | 0.5768 | |
| Education: (Bachelor’s degree or more) vs (Less than a Bachelor’s degree) | 1.1929 | 0.9318 1.5270 | 0.1641 | |
| Married: Yes vs No | 1.2080 | 0.9319 1.5660 | 0.1711 | |
| Income: (>= 25k) vs (< 25k) | 1.2262 | 0.8858 1.6974 | 0.2554 | |
| Income: (>= 40k) vs (< 40k) | 1.4528 | 1.1260 1.8744 | 0.0062 | |
| <i>Disease characteristics</i> | | | | |
| Dementia: Yes vs No | 2.4045 | 1.8194 3.1779 | <0.0001 | |
| Atypical parkinsonism (yes) | 2.1758 | 1.7300 2.7366 | <0.0001 | |
| Care partner present (yes) | 1.9121 | 1.1548 3.1658 | 0.0023 | |
| Charlson Comorbidity index: (>=5) vs (< 5) | 2.3861 | 1.5299 3.7213 | <0.0001 | |
| Palliative Performance scale (per 10% decrease) | 0.6820 | 0.6248 0.7444 | <0.0001 | |
| Palliative Performance scale: (>70) vs (<=70) | 0.2407 | 0.1193 0.4858 | <0.0001 | |
| Disease duration (per 5 years) | 1.0180 | 0.9395 1.1030 | 0.6680 | |
| Quality of Life – Alzheimer’s Disease Score (per 5 units) | 0.7708 | 0.6974 0.8519 | <0.0001 | |
| ESAS PD ^a Score (per 20 units) | 1.3296 | 1.2074 1.4642 | <0.0001 | |
| ESAS PD ^a Score (14 items) (per 20 units) | 1.3582 | 1.2177 1.5150 | <0.0001 | |
| UPDRS ^b III Score (per 10 units) | 1.6205 | 1.4530 1.8073 | <0.0001 | |
| MOCA ^c Score (per 5 units) | 0.7290 | 0.6614 0.8036 | <0.0001 | |
| HADS ^d Anxiety Score (per 1 unit) | 1.0634 | 1.0317 1.0962 | 0.0006 | |
| HADS12 Depression Score (per 1 unit) | 1.0781 | 1.0444 1.1130 | <0.0001 | |
| Prolonged Grief Questionnaire Score (per 5 units) | 1.2199 | 1.1442 1.3007 | <0.0001 | |
| McGill QOL ^e Score (per 1 unit) | 0.8197 | 0.7564 0.8882 | <0.0001 | |
| NEST Score ^f (per 10 units) | 1.2124 | 1.0190 1.4425 | 0.0377 | |

| Reference Question | | | |
|---|------------------------|-------------------|---------|
| <i>Would You Be Surprised of The Patient Passed Away Within the Next Year? (binary)</i> | | | |
| Experimental Variable | Relative Risk Estimate | Confidence Limits | P-Value |
| Levodopa Equivalence (per 100 units) | 0.9761 | 0.9476 1.0054 | 0.1082 |

^aEdmonton Symptom Assessment.

^bUnified Parkinson's Disease Rating Scale.

^cMontreal Cognitive Assessment.

^dHospital Anxiety and Depression Scale.

^eMcGill Quality of Life.

^fNeeds Near the End-of-life care Screening Tool.