

Treatment Preferences at the End-of-Life in Parkinson's Disease Patients

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Abstract: **Background:** Few studies have been performed on palliative care in Parkinson's disease (PD). This study was undertaken to understand treatment preferences of PD patients toward end-of-life care.

Methods: A questionnaire modified from the Willingness to Accept Life-Sustaining Treatment instrument was administered to participants. Four different scenarios based on the burden of care and outcome of the treatment were presented in detail to obtain decisions for end-of-life care. The responses in each scenario were compared between PD patients and controls. Further analyses were performed to identify factors that influenced treatment preferences among PD patients.

Results: In total, 136 PD patients and 60 controls were recruited. Parkinson's disease patients and controls were demographically similar, except that PD patients had more previous hospital admissions ($P = 0.0195$). Parkinson's disease patients were more likely to opt for high-burden care with poor outcome than controls (odds ratio [OR] = 2.11, $P = 0.04$).

In the subgroup analysis for PD patients, the factors that influenced treatment preference toward end-of-life care were belief in religion (OR: 7.43, 95% confidence interval:1.97–28.07), higher Unified Parkinson's Disease Rating Scale (UPDRS) motor score (2.51, 1.14–5.50) in scenario B; belief in religion (6.93, 2.23–21.43), married patients (6.93, 2.23–21.43) in scenario C; and Chinese patients (0.29, 0.10–0.79), better PD knowledge (0.37, 0.17–0.80), and higher UPDRS motor scores (3.05, 1.35–6.9) in scenario D.

Conclusion: Parkinson's disease patients were more likely to agree to high-burden care with a poor outcome compared to controls. Among PD patients, race, marital status, religious status, knowledge about PD, and severity of motor impairment significantly influenced their end-of-life treatment preferences.

Parkinson's disease (PD) is a chronic, progressive, and debilitating disease that significantly impacts patients physically as well as mentally. Although PD is viewed as a life-limiting condition rather than a terminal illness, studies have shown that the end-of-life suffering of PD patients are comparable to patients with end-stage cancer.^{1,2} However, end-of-life care for PD has not received as much attention when compared with other chronic conditions. As such, a greater awareness of the role of palliative care for patients with advanced PD is needed.

Advance care planning (ACP) is the cornerstone of palliative care. It allows patients to make treatment decisions for end-of-life care and enables clinicians to provide care in accordance

with the patients' treatment preferences. Advance care planning has been widely used for patients with cancer, chronic kidney disease, heart failure, and dementia to communicate their end-of-life treatment preferences.^{3–5} Studies conducted in a range of healthcare settings have shown that ACP can improve patients' and their families' satisfaction with care, as well as reduce the stress, anxiety, and depression of surviving family members.^{6–11} However, only a few studies on ACP for PD patients have been performed.

Previous studies of ACP in palliative care for PD patients have focused on symptom burden and assessment^{1,12}; desired information, timing and initiator for ACP discussion¹³; and

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proxy decision making.¹⁴ Little is known about PD patients' actual treatment preferences toward end-of-life care. We therefore undertook this study to understand treatment preferences of PD patients toward end-of-life care by comparing treatment preferences between PD patients and controls, and to identify factors that influence the treatment preferences of PD patients.

Methods

All patients with PD seen between January and November 2013 in the Movement Disorders Clinic of the National Neuroscience Institute, Singapore, who meet the inclusion and exclusion criteria were invited to participate in the study. Inclusion criteria were PD patients fulfilling National Institute of Neurological Disorders and Stroke diagnostic criteria for Parkinson's disease¹⁵; ability to understand English, Malay, or Chinese; as well as cognitive and physical ability to understand and answer questions. Patients were excluded if they had other parkinsonism disorders, any significant psychiatric problems that interfered with sound judgment, and significant cognitive impairment or dementia. Control participants who did not have any neurodegenerative condition or psychiatric problems that would interfere with sound judgment were invited from neuroscience clinics or the community. Control participants from the clinic included patients with hemifacial spasms, essential tremors, focal dystonia, and chronic headaches, whereas community participants were healthy volunteers. All participants provided informed consent. This study was approved by the institutional review board at Singapore Health Services.

A questionnaire modified from the Willingness to Accept Life-Sustaining Treatment instrument¹⁶ (see Appendix S1) was administered by an in-person interview to assess the treatment preference of participants to different clinical scenarios. Four different scenarios were presented in detail to participants to obtain their views on their treatment preference toward end-of-life care. In scenarios A and B, participants were asked if they were willing to receive low-burden care that involved undergoing simple procedures such as X-rays and blood draws, along with basic treatment such as intravenous antibiotics and oxygen therapy. Accepting low-burden care would result in a good outcome with a return to the current state of health (scenario A), or a poor outcome with physical disability (bedbound state requiring assistance with all activities of daily living) but intact cognition (scenario B). In scenarios C and D, participants were asked if they were willing to receive high-burden care that involved undergoing procedures such as computerized tomography and surgery, along with care in an intensive care unit with a mechanical ventilator. Accepting high-burden care would result in a good outcome with a return to the current state of health (scenario C), or a poor outcome with physical dependency but intact cognition (scenario D). In each scenario, participants were informed that rejecting treatment would result in death, whereas accepting treatment will result either a good outcome (scenarios A and C) or poor outcome (scenarios B and D). All four interviewers for the study underwent a 1-day training and standardization in administering the questionnaire.

Basic demographic data and health-related profiles were obtained for each participant. Participants were also assessed on their knowledge of PD by answering six basic PD-related questions (see Appendix S2). Parkinson's disease patients were evaluated using the Unified Parkinson's Disease Rating Scale (UPDRS) motor score, Hoehn and Yahr stage, Parkinson's Disease Questionnaire-8 (PDQ-8), Mini-Mental Status Examination (MMSE),¹⁷ and Schwab and England Activities of Daily Living Scale.

Statistical analysis

Simple frequency was used to describe the study population's demographics and health-related profiles. Parkinson's disease and control groups were compared to detect differences using Fisher's exact tests. Frequency was also used to summarize participants' treatment preferences for each scenario. Comparisons were made between PD patients and controls using Fisher's exact tests. Participants who were unable to decide on their choice of treatment in a particular scenario were excluded from that analysis. When differences in subjects' characteristics between the two groups were detected, the effects of PD status on treatment choices were further adjusted using multivariate logistic regression. The effects were represented as odds ratio (OR) and 95% confidence interval (CI). Subgroup analysis was performed to analyze the participant characteristics, as well as disease-specific characteristics that influenced treatment preferences among PD patients. Multivariate logistic regression with stepwise variable selection was employed. Statistical analyses were performed using SAS 9.2 for Windows (SAS Institute Inc., Cary, NC). Statistical significance was set as $P \leq 0.05$.

Results

A total of 196 participants were recruited into the study. Of these, 136 were PD patients and 60 were controls. The demographics and health characteristics of participants are summarized in Table 1. The characteristics between PD and control groups were similar, except that PD patients were significantly more likely to have had previous hospital admissions compared to controls.

Participants' treatment preferences

Figure 1 shows treatment preferences of PD patients and controls according to the burden and outcome of treatment. The proportion of participants (73%) opting for treatment in the low-burden scenarios (A + B) was higher than those (57%) in the high-burden scenarios (C + D) ($P < 0.0001$). The proportion of participants (87%) opting for treatment with the good-outcome scenarios (A + C) was higher than those (43%) with the poor-outcome scenarios (B + D) ($P < 0.0001$).

There was no statistically significant difference in the treatment preferences between the PD and control group for scenarios A, B, and C in the both unadjusted and adjusted analysis

TABLE 1 Characteristics of the Study Participants

Characteristics		PD n = 136(%)	Control n = 60(%)	P Value*
Age group	>65 years old	61 (44.9%)	29 (48.3%)	0.756
	≤65 years old	75 (55.1%)	31 (51.7%)	
Gender	Male	84 (61.8%)	31 (51.7%)	0.2696
	Female	52 (38.2%)	29 (48.3%)	
Race	Chinese	110 (80.9%)	52 (86.7%)	0.4144
	Non-Chinese ^a	26 (19.1%)	8 (13.3%)	
Religion	With Religion ^b	115 (84.6%)	53 (88.3%)	0.6583
	Without religion ^c	21 (15.4%)	7 (11.7%)	
Employment	Employed	50 (36.8%)	26 (43.3%)	0.4279
	Unemployed	86 (63.2%)	34 (56.7%)	
Marital status	Married	114 (83.8%)	49 (81.7%)	0.6849
	Others ^c	22 (16.2%)	11 (18.3%)	
Years of education	>10 years	60 (44.1%)	19 (31.7%)	0.1156
	≤10 years	76 (55.9%)	41 (68.3%)	
Past hospital admissions	At least 1	71 (52.2%)	20 (33.3%)	0.0195
	0	65 (47.8%)	40 (66.7%)	
Charlson weighted index	>2	72 (52.9%)	27 (45.0%)	0.3533
	≤2	64 (47.1%)	33 (55.0%)	
Hoehn and Yahr stages	>2	29 (21.3%)		
	≤2	107 (78.7%)		
UPDRS motor scores	>17	64 (47.1%)		
	≤17	72 (52.9%)		
Duration of PD	>5 years	71 (52.2%)		
	≤5 years	65 (47.8%)		
Mini-Mental Status Examination	≥24	114 (83.8%)		
	<24	22 (16.2%)		
Parkinson's Disease Questionnaire-8	>7.63	68 (50%)		
	≤7.63	68 (50%)		
Schwab and England Activities of Daily Living Scale	>90	36 (26.5%)		
	≤90	100 (73.5%)		

*From Fisher's exact test.

^aIncludes Malay, Indian, and minority races.

^bIncludes Buddhism/Taoism, Christianity, Islam, and Hinduism.

^cIncludes single, divorce/separated, and widow.

PD, Parkinson's disease; UPDRS Motor scores, Unified Parkinson's Disease Rate Scale Motor Scores.

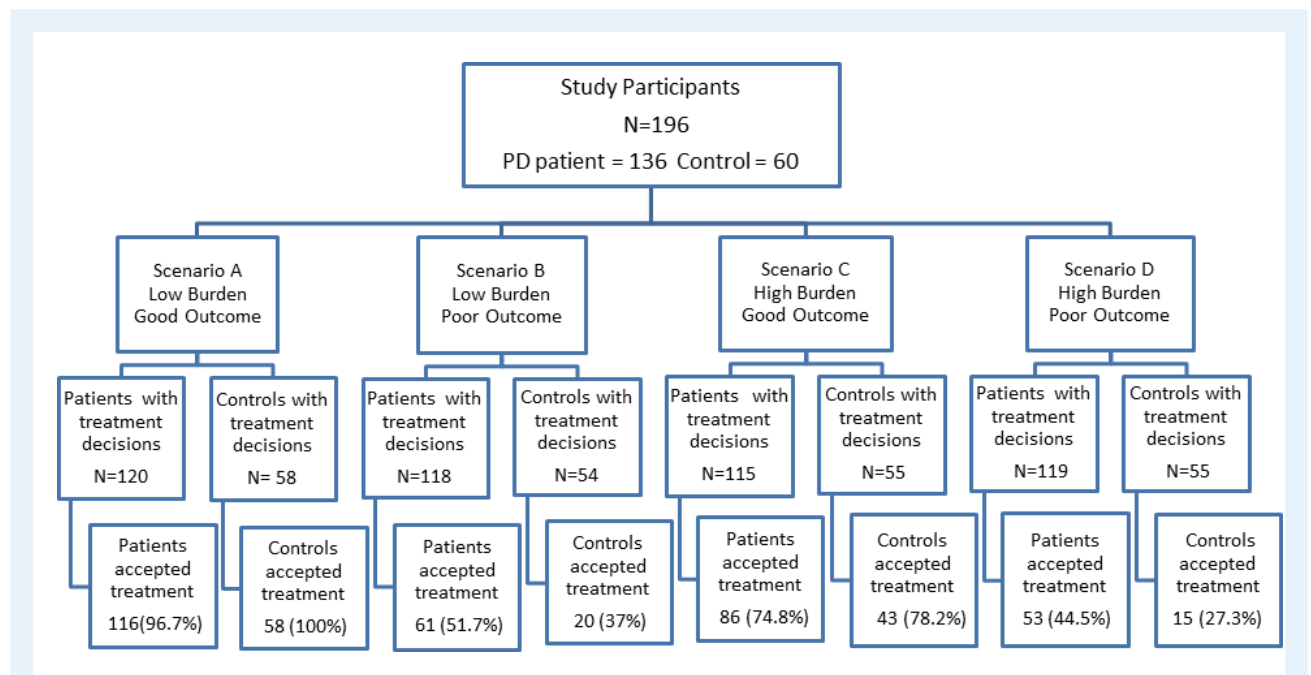


Figure 1 Treatment preference to each scenario. The number of participants who made treatment decisions and accepted treatment under each scenario are listed.

(adjusted for previous hospital admission). In scenario D, PD patients were significantly more (approximately 2 times) likely to opt for treatment than controls, even after adjustment for previous admission. The details are shown in Table 2.

Within the control group, male participants were more likely to agree to treatment (OR = 5.06, $P = 0.028$) in scenario C after multivariate analysis. This was the only significant factor that was associated with treatment preferences among controls.

Analysis of Parkinson's disease patients

Among 136 patients with PD, 84 were males and 52 were female. Their mean age was 63 years old. The summary of PD-associated features is shown in Table 1. Further analyses were performed to identify the factors that influenced the treatment preferences of PD patients in each scenario. These findings are summarized in Table 3. In scenario A, almost all (96.7%) patients opted for treatment and no factor was found that influenced their decisions. In scenario B, PD patients who had a religion and with higher UPDRS motor scores were significantly more likely to agree to treatment. After multivariate analysis, patients with a religion were 7.43 times more likely to agree to treatment compared to patients without a religion ($P = 0.003$). Parkinson's disease patients having higher UPDRS motor score (>17) were 2.51 times more likely to be agreeable to treatment compared to patients with less motor impairment ($P = 0.022$). In scenario C, patients who had a religion were about 7 times more likely to agree to treatment ($P = 0.001$). Married PD patients were similarly more likely to agree to treatment (OR = 6.93, $P = 0.001$) in scenario C. For scenario D, Chinese patients were about 70% less likely to agree to treatment compared to other races ($P = 0.016$). In the same scenario, PD patients who had better knowledge about the disease were also less likely agree to treatment (OR = 0.37, $P = 0.012$), whereas patients with higher UPDRS motor score were 3 times more likely to be agreeable to treatment (OR = 3.05, $P = 0.008$).

Discussion

There has been limited research performed on palliative care or end-of-life decisions among PD patients. Although there have

been a few articles addressing advanced care planning in PD, to our best knowledge this is the first publication to evaluate the treatment preference of PD patients when faced with end-of-life decisions. In this study using a standardized, previously validated questionnaire,¹⁶ we found that the treatment preferences toward end-of-life care of PD patients differed from controls. Parkinson's disease patients were significantly more likely to agree to high-burden care with poor outcomes compared to controls. Among PD patients, the factors that significantly influenced their end-of-life treatment preferences were race, marital status, religious status, knowledge about PD, and severity of motor impairment. All these predictors for treatment preferences found in PD group were not found in the control group.

The proportion of participants opting for treatment in the low-burden care scenarios was significantly higher than those in the high-burden care scenarios. Similarly, the proportion of participants opting for treatment in good-outcome scenarios was significantly higher than those with the poor-outcome scenarios. Our results are consistent with previous studies that showed the burden of care and treatment outcomes were important considerations in end-of-life treatment preferences.¹⁶ The participants' choices are understandable because minimal intervention and suffering, together with a good outcome and quality of life, are important considerations for many individuals when faced with an end-of-life decision.

When the treatment choices of PD patients were compared to controls, PD patients were more likely to agree to treatment in the high-burden care scenario with a poor outcome. These results contrast with previous studies on patients with chronic disease,⁵ which showed that patients who had poorer health status tended to want less aggressive treatments.¹⁸ However, another study among cancer, congestive heart failure, and chronic obstructive pulmonary disease patients showed that these patients were willing to undergo high-burden therapy despite a high likelihood of an undesirable outcome.¹⁹ The authors attributed these findings to their patients' uncertainty of their disease prognosis and their perception that death was not imminent. For the PD patients in this study, we believe that the chronic nature of the disease may have resulted in their ability to cope and adapt well to their disabilities.^{20,21} As such, they were more willing to accept and tolerate further physical disability rather than face death when compared to controls.

TABLE 2 Effect of Parkinson's Disease Status on Treatment Preferences According to Scenario

Parameters	Scenario A Low Burden Good Outcome		Scenario B Low Burden Poor Outcome		Scenario C High Burden Good Outcome		Scenario D High Burden Poor Outcome	
	OR (95% CI)	P-value	OR (95% CI)	P-value	OR (95% CI)	P-value	OR (95% CI)	P-value
Unadjusted ^a								
PD vs. control	0.22(0.01–4.28)	0.32	1.82(0.94–3.52)	0.08	0.83(0.39–1.78)	0.63	2.14(1.07–4.29)	0.03
Adjusted ^b								
PD vs. control	0.17(0.01–3.16)	0.24	1.68(0.86–3.29)	0.13	0.84(0.39–1.82)	0.65	2.11(1.04–4.27)	0.04

^aUnadjusted: univariate analysis by using logistic regression.

^bAdjusted: multivariate analysis by using logistic analysis, adjusted for admission. OR, odds ratio; CI, confidence interval; PD, Parkinson's disease.

TABLE 3 Predictors for Treatment Preferences of Parkinson's Disease Patients

Scenarios	Parameters	Odds Ratio	95% Confidence Interval	P Value
Scenario B*				
Low burden	Religion vs. free thinker	7.43	1.97–28.07	0.003
Poor outcome	Motor score >17 vs. motor score ≤17	2.51	1.14–5.50	0.022
Scenario C*				
High burden	Religion vs. free thinker	6.93	2.23–21.43	0.001
Good outcome	Married vs. others ^a	6.93	2.23–21.43	0.001
Scenario D*				
High burden	Chinese vs. non-Chinese	0.29	0.10–0.79	0.016
Poor outcome	Knowledge about PD high vs. low	0.37	0.17–0.80	0.012
	Motor score >17 vs. motor score ≤17	3.05	1.35–6.90	0.008

*Multivariate logistic regression with stepwise selection. Variables entered: age, gender, race, religion, employment status, marital status, education level, admission status, Charlson's weighted index, knowledge about PD, Hoehn and Yahr stage, duration of PD, UPDRS Motor Score, Schwab and England Activities of Daily Living Scale, Parkinson's Disease Questionnaire-8, Mini-Mental Status Examination.

^aIncludes single, divorced/separated, and widow.

PD, Parkinson's disease; UPDRS Motor Score, Unified Parkinson's Disease Rate Scale Motor Scores.

The only PD-specific feature found to bear an influence on end-of-life treatment preference was the UPDRS motor score. In this study, patients with greater motor impairment were more likely to opt for either low-burden or high-burden care despite poor outcomes (scenarios B and D). Such a finding may be counterintuitive because many would expect that patients with greater motor impairment would not be willing to accept care that would result in further physical disability. This result could be explained as follows: Firstly, these patients could have adapted to their disability over time and may be more willing to accept further disability, especially in the scenario in which their cognitive ability remains intact. Secondly, the majority of our participants were relatively young (mean age 63 years old) and at early stages of the disease (median disease duration of 5 years, 78% ≤ Hoehn and Yahr stage 2) and may not have perceived themselves to be near the end of life.

Religion has an important influence on an individual's treatment preferences at the end of life.²² Previous studies have found that cancer or terminally ill patients who had a religion were more likely to opt for life-sustaining measures compared to similar patients who did not have a religion.^{23–25} This has been attributed to the role of religion in providing hope for patients to accept their condition and faith to believe that their condition may be healed. These same reasons likely explain why our patients who had a religious faith were more likely to opt for high-burden care if the outcome was good and for low-burden treatment even if the outcome was poor. Interestingly, religion was not a significant factor in the scenario of high-burden care with poor outcome. Previous studies have revealed that by better addressing spiritual needs such as finding acceptance and spiritual peace in dying, coupled with quality-of-life discussions, aggressive treatment in terminally ill patients might be reduced.²⁵ This acceptance of death could possibly explain why PD participants with religion did not opt for high-burden treatment if the outcome was poor. However, further research is needed to confirm this.

This study was performed in a multiracial society. We found that Chinese PD patients were less likely to opt for high-burden care if the outcome was poor when compared to non-Chinese. The Chinese are thought to be more face-conscious. *Face* is an

important Chinese cultural concept that is embedded in every aspect of life. It represents the respect, pride, and dignity of an individual as a consequence of personal social achievement.²⁶ It also relates to a person's image and status within a social structure.²⁷ As such, it is hypothesized that physical disability arising from this scenario that would result in a “loss of face” or loss of dignity had influenced the decision to decline treatment so as to avoid an embarrassing, disabling physical condition. Our finding is consistent with that of a study among the Chinese in Macau who similarly declined aggressive medical treatment when faced with a terminal illness.²⁸

In our study, PD patients who had better knowledge of PD were less likely to opt for high-burden care if the outcome of treatment was poor. We believe that when equipped with adequate knowledge of the disease, PD patients are able to make better decisions. A previous Cochrane review of randomized trials of decisional aids showed that better knowledge of the disease and its treatment options led to improved patient-practitioner communication and increased medication adherence in the setting of various chronic diseases.²⁹ Our study also highlights that a better knowledge of PD has an influence on the treatment preferences of patients relating to end-of-life issues.

In this study, married PD patients—when compared to singles, divorcees, or widows—were more likely to opt for high-burden care if the outcome was good. This reflected the willingness of married patients to undergo intensive, high-burden care in order to recover to their baseline function. This treatment decision is similar to the finding of a study done among geriatric inpatients, which found that married patients were more willing to undergo cardiopulmonary resuscitation in the event of a collapse than unmarried patients.³⁰ Our finding highlights the attachment that patients have to their spouses, which results in their willingness to prioritize survival over other factors.

There is likely to be a significant cultural influence on end-of-life medical decisions because different societies and cultures hold different values and perceptions toward death. As such, our findings in an Asian context may not be applicable to a non-Asian context. A second limitation of our study is that PD

is not only a motor disorder; nonmotor symptoms such as cognition may contribute to the severity of PD. We only studied the poor-outcome scenario in which patients were physically disabled without cognitive disability. We did not study other poor-outcome scenarios, such as cognitive disability without physical disability or when both cognitive and physical disabilities were the outcomes. As such, our ability to interpret the participants' responses is limited. A third limitation of the study is that although we only recruited participants with no significant cognitive decline, no detailed psychometric testing was performed. There is a possibility that participants with some cognitive impairment may inevitably have been recruited into the study, which may affect their answers provided in the study. We have nevertheless corrected for MMSE scores in the final analysis. Fourthly, we recognize that our study participants may not be representative of the group of PD patients at their end of life. However, there would be many challenges if we restricted our study participants to those who were at their end of life; by then, many will have cognitive impairment or may be too ill to participate in such a study.

Conclusion

The results of our study show that different choices are made between PD patients and controls when faced with end-of-life decisions. Various demographic and disease-related factors appear to influence some of these decisions. Although some of these associations make sense, others appear counterintuitive. Our study suggests that knowledge of the disease and cultural factors (religion, race, and marital status) have an important influence on end-of-life decisions. Another factor at play appears to be the adaptation of PD patients to their disabilities during the course of their illness. Given the many individual factors that contribute to end-of-life decisions, it is difficult for healthcare providers and family members to accurately predict a patient's end-of-life treatment preference. As such, a well-facilitated ACP discussion is essential to empower patients to exert their autonomy to make well-informed decisions. Patients and family members need to be equipped with the knowledge of PD, disease prognosis, treatment options, and treatment burden as well as possible outcomes. Healthcare professionals who facilitate these ACP sessions ought to sensitively blend together patients' values, sociocultural backgrounds, and wishes into the end-of-life discussion.

Author Roles

(1) Research Project: A. Conception, B. Organization, C. Execution; (2) Statistical Analysis: A. Design, B. Execution, C. Review and Critique; (3) Manuscript: A. Writing of the First Draft, B. Review and Critique.

WEI L.: 1A, 1B, 1C, 2A, 2B, 2C, 3A, 3B

H.L.N.: 1A, 1B, 1C, 2A, 2C, 3A, 3B

WENYUN L.: 2B, 2C, 3A, 3B

A.N.P.: 1A, 1B, 1C, 2A, 2C, 3A, 3B

S.A.K.: 1A, 1B, 1C, 2A, 2C, 3A, 3B

K.Y.T.: 1A, 2C, 3A, 3B

W.L.A. 1A, 2C, 3A, 3B

L.CS.T.: 1A, 1B, 2A, 2B, 2C, 3B

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1: A questionnaire modified from the Willingness to Accept Life-Sustaining Treatment (WALT) instrument

Appendix S2: Knowledge of Parkinson Disease Questionnaire