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# Perceived Embarrassment and Caregiver Burden in Essential Tremor Caregivers

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## Abstract

Essential tremor (ET) is a progressive neurological disease associated with functional disability, diminished quality of life and, in some individuals, poorer balance, cognitive impairment, depression and sleep dysregulation. Individuals with ET may rely on family members and friends to act as informal caregivers to assist with daily activities and provide emotional support. There is a high prevalence of embarrassment among individuals with ET, which may be a result of the outwardly visible nature of tremor. Studies in populations with outwardly visible disability have shown that perception by caregivers of a care-recipient's social distress can contribute to caregiver burden. We hypothesize that in ET, perception by caregivers of ET participant embarrassment is a predictor for caregiver burden. Data were collected from 57 ET participants and their caregivers. We measured ET participant embarrassment using the Essential Tremor Embarrassment

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Assessment (ETEA), and measured perception by caregivers of ET participant embarrassment using a modified version of the ETEA. The Zarit Burden Interview was used to measure caregiver burden. Perceived embarrassment was associated with ET participant embarrassment. In linear regression models, perceived embarrassment was a stronger predictor for caregiver burden than measures of ET participant cognitive and physical impairment. The results indicate that perception of ET participant embarrassment can be burdensome for caregivers. Clinicians may wish to address patient embarrassment and perceived embarrassment to better support caregivers and ET patients.

## Keywords

Essential tremor; caregiver burden; embarrassment; clinical

## 1. Introduction

Essential tremor (ET) is a progressive neurological disease that is associated with functional disability (1) and diminished quality of life (2). In addition to tremors, individuals with ET may have other motor and non-motor symptoms (3) including poorer balance (4, 5), cognitive impairment (6, 7), depression (8), and sleep dysregulation (9).

Tremor is often very outwardly visible and this may be responsible for the high prevalence of embarrassment among individuals with ET (10–13). In general, embarrassment is felt when one fails to meet social expectations; it can result in loss of self-esteem and uncertainty as to how to navigate social situations (14, 15). Embarrassment is often accompanied by physical signs of emotional distress such as sweating, stuttering, increased heart rate and blood pressure, and blushing (15). ET patient embarrassment may be due to the patient’s perception that they have violated social expectations in their display of visible tremor and by a tremor-related abnormal performance of daily tasks such as eating, drinking, or writing (11). In ET, embarrassment is a strong motivator for medication use (10–12), has been linked to depression (16) and may contribute to social phobia (17).

While the motor and cognitive impairments in ET are typically not severe enough to require constant care or paid caregivers, individuals with ET may rely on family members and friends to act as informal caregivers. Relatives and friends may assist individuals with ET with daily activities such as cooking, eating (e.g. cutting food), and dressing. Additionally, individuals with ET may require assistance from relatives or friends with tasks such as writing checks, filling out forms, or using a computer (e.g. pressing correct buttons). Relatives and friends may help individuals with voice tremors in being understood by acting as interpreters. Finally, family members and friends support individuals with ET emotionally and psychologically.

ET caregivers may experience caregiver burden (18), defined as the perceived suffering of emotional or physical health, social life, and financial status as a result of caregiving (19). Caregiver burden has been described in other populations in which affected individuals violate social expectations and therefore face stigma. These populations include children with disabilities (20), Alzheimer’s patients (21), and patients with severe mental illness (22).

Stigma is defined as the labeling, stereotyping, and discrimination against people who deviate from social norms (23). In studies of the above-mentioned populations, caregiver burden increases with caregiver's perception of stigma against the care-recipient. This perception of social distress contributes to caregiver burden independent of physical tasks of caregiving. We hypothesize that in ET populations, there may be a similar effect; caregivers' perception of social distress (in this case, embarrassment) likely contributes to caregiver burden.

To our knowledge, there has been no previous research in this area and none specifically on caregiver perception of ET participant embarrassment. The first aim of this study is to assess caregiver perception of ET participant embarrassment (this caregiver perception is henceforth referred to as "perceived embarrassment"). We hypothesize that perceived embarrassment increases with increased ET participant embarrassment. The second aim of the study is to assess the relationship between perceived embarrassment and caregiver burden. Research linking perceived stigma and caregiver burden suggests that caregiver perception of social distress significantly contributes to caregiver burden. We therefore hypothesize that increased perceived embarrassment is a predictor for increased caregiver burden. An exploratory aim is to determine whether perceived embarrassment is a strong predictor for burden independent of ET participant physical and cognitive impairment. This could have important implications for clinical approaches to alleviating caregiver burden in ET patients as it could inform the focus of counseling for caregivers. Additionally, the relationship between perceived embarrassment and caregiver burden studied here in ET could be important in illuminating the experience of caregivers in other populations in which affected individuals experience embarrassment.

## 2. Methods

### 2.1. Sample

ET participants were enrolled in Clinical Pathological Study of Cognitive Impairment in Essential Tremor (COGNET) (NINDS R01NS086736), a longitudinal study of cognitive function in ET. The institutional review board of Yale University approved this study. ET participants were recruited for COGNET through advertisements on the International Essential Tremor Foundation webpage with the following eligibility criteria: 1. Diagnosis of ET, 2. Age ≥ 55 years, 3. Willingness to be a brain donor and perform study measures, 4. No history of deep brain stimulation surgery for ET. Data collection for the current research on caregiver burden took place between October 2015 and July 2016. The first 57 ET participants and their caregivers who completed the caregiver burden research assessments were considered for the current analyses. Caregivers were identified by each ET participant as someone who knew them well and could give insight into their well-being. Most caregivers (84.2%) were spouses or children of ET participants, 8.8% were friends, and 7.0% had another relationship with the ET participant (niece, girlfriend, daughter in law). A majority of caregivers (60%) lived with the ET participants.

### 2.2. ET Participant Data Collection

ET participants were evaluated in their homes by trained study personnel (SK, SM, KC, BR). Assessments were 4–6 hours long and measured motor, neuropsychiatric and neuropsychological characteristics. Demographic data were obtained and the following measures were collected:

**2.2.1. Tremor severity—**ET participants underwent a videotaped neurological examination that was reviewed by a neurologist specializing in movement disorders (EDL). The Washington Heights-Inwood Genetic Study of ET clinical rating scale, a reliable (24) and valid (25) scale was used to confirm ET diagnoses and rate tremor severity. One postural tremor test (scale 0–3) and five kinetic tremor tests (scale 0–3) were scored in each arm, resulting in a total tremor score (range 0–36; higher scores indicate greater tremor severity). Diagnostic criteria required moderate or greater amplitude kinetic tremor (rating ≥ 2) during three or more tests or a head tremor in the absence of Parkinson's disease, dystonia, or other known causes (26).

**2.2.2. Tremor disability—**Participants completed a 10-item reliable and valid self-reported disability questionnaire for ET (range 0–20; higher scores indicate greater disability) (27). Participants reported difficulty completing various activities of daily living (e.g. "signing your name," "using a spoon to eat soup") (0=no difficulty, 1=need to modify, 2=disability).

**2.2.3. Cognitive ability—**Participants were administered the Montreal Cognitive Assessment (MoCA), a test of global cognition used to detect mild cognitive impairment (range 0–30; lower scores indicate greater cognitive impairment; scores below 26 indicate abnormal cognition) (28). Additionally, Clinical Dementia Ratings (CDR) (29) were assigned to each participant based on interviews with caregivers focused on functional ability and the examiner's impressions of the participant.

**2.2.4. Depressive symptoms—**Participants completed the Geriatric Depression Scale (GDS; range 0–30; higher scores indicate greater risk for depression), a valid and reliable 13-item scale used to measure depressive symptoms in geriatric patients (30). Participants were asked to answer yes or no to questions such as "Do you feel that your situation is hopeless" and "Do you frequently feel like crying."

**2.2.5. Embarrassment—**Participants were administered the Essential Tremor Embarrassment Assessment (ETEA), a reliable and valid 14-item assessment used to measure tremor-related embarrassment (range 0–70; higher scores indicate greater embarrassment) (11). Participants were asked to rate (0–5) the extent to which they agreed with statements of embarrassment (e.g., "I am embarrassed by my tremor when I try to eat or drink in public," "I am embarrassed by my tremor because other people might think I am drunk or on drugs"). The 14 items assessed embarrassment in various situations, as well as embarrassment's role in the participant's desire to take medication. ETEA scores showed high internal consistency (Cronbach's alpha = 0.94).

### 2.3. Caregiver Data Collection

Caregiver interviews were conducted by telephone by trained study personnel (SK, SM, KC, BR, FM) between one week and three months after the in-person assessment of ET participants. Interviews were 30 minutes long and included the collection of demographic data, a CDR interview, and the following measures:

**2.3.1. Depressive symptoms—**Caregivers completed the 10-item Center of Epidemiological Studies Depression Scale (CESD-10; range 0–30; higher scores indicate greater risk for depression) (31), a reliable and valid (32) scale used to measure risk for depression. Caregivers were asked to endorse statements such as “I felt hopeful about the future” and “I felt lonely.” CESD-10 scores showed internal consistency (Cronbach’s alpha =0.75).

**2.3.2. Perceived embarrassment of ET participant—**Caregivers were assessed with a modified version of the ETEA to measure the caregiver’s perceived embarrassment felt by ET participants. Caregivers were asked to evaluate the extent to which they believed the ET participant agreed with each of the 14 statements using the same scoring system (see above). Perceived embarrassment scores showed high internal consistency (Cronbach’s alpha =0.92).

**2.3.3. Caregiver burden—**Caregivers were administered the Zarit Burden Inventory Short Form (ZBI-12; range 0–48; higher scores indicated greater burden), a reliable and valid short form (33) of the Zarit Burden Inventory, designed to measure burden in caregivers for elderly or disabled patients (34). Caregivers reported the frequency of experiencing various feelings (e.g., “Do you feel stressed between caring for your relative and trying to meet other responsibilities?”, “Do you feel that your health has suffered because of your involvement with your relative?“) (0=never, 1=rarely, 2=sometimes, 3=quite frequently, 4=nearly always). ZBI-12 scores showed high internal consistency (Cronbach’s alpha =0.90).

### 2.4. Statistical Analysis

Statistical analyses were performed using SPSS software (version 24). Descriptive statistics are presented for ET participants and caregivers (Table 1). Means and standard deviations of ETEA score, perceived embarrassment score, and caregiver burden score (ZBI-12 score) are presented (Table 2). Endorsements (response>0) of individual items in the ETEA and perceived embarrassment assessment were counted (Table 3). Differences in endorsements of each item by ET participants and caregivers were evaluated with chi square tests (Table 3). Clinical correlates of embarrassment, perceived embarrassment, and caregiver burden were assessed with Spearman’s rank correlations because of non-normality of ETEA score, perceived embarrassment score, and ZBI-12 score (Tables 4, 5).

In two linear regression models, we examined the relationship between perceived embarrassment and caregiver burden (Table 6). The first model was adjusted for confounding variables that were correlated at the $p<0.05$ level with both the dependent variable (ZBI-12 score) and the independent variable (perceived embarrassment score). The second model was adjusted for measures of physical and cognitive impairment (total tremor score, tremor disability score, MoCA score, CDR). Perceived embarrassment score and ZBI-12 score were transformed by square-root to meet linear regression model assumptions.

## 3. Results

### 3.1. Demographics and tremor characteristics

Complete assessments were obtained for 57 dyads of ET participants and their caregivers. ET participants had a mean age of 77.2 ± 10.2 (range= 56–97) years (Table 1). The mean age of tremor onset was 40.9 ± 22.0 (range=5–78) years and the mean total tremor score was 23.1 ± 5.6 (range=10–36). Caregivers had a mean age of 66.6 ± 12.7 (range=41–89) years and mean duration of care in years of 6.8 ± 11.8 (range=0–63) (Table 1).

### 3.2. Caregiver perception of ET participant embarrassment and its correlates

The mean ETEA score was 17.5 ± 17.0 (range = 0–59) and the mean perceived embarrassment score was 11.6 ± 13.7 (range = 0–61) (Table 2). Higher perceived embarrassment score was correlated with higher ET participant ETEA score ($r_s$=0.32, $p<0.05$) (Table 4). ET participants and caregivers similarly endorsed 8 of the 14 embarrassment items (chi square $p>0.05$) and differently endorsed 6 of the 14 embarrassment items (chi square $p<0.05$), with greater ET participant endorsement than caregiver endorsement (Table 3).

ET participant characteristics associated with higher perceived embarrassment score were higher total tremor score, higher tremor disability score, higher CDR and lower MoCA score (Table 4). Caregiver characteristics associated with higher perceived embarrassment score were younger caregiver age, greater hours/week providing care, and longer duration of care (Table 4).

### 3.3. Association between perceived embarrassment and caregiver burden

The mean ZBI-12 score was 6.4 ± 8.4 (range =0–30) (Table 2). ET participant characteristics associated with higher ZBI-12 score were higher GDS score, higher CDR, and lower MoCA score (Table 5). ETEA score was not associated with ZBI-12 score. Caregiver characteristics associated with higher ZBI-12 score were greater hours/week providing care, longer duration providing care, higher caregiver CES-D score, and higher perceived embarrassment score (Table 5). In a linear regression model controlling for confounding variables, higher square root transformed perceived embarrassment score was associated with higher square root transformed ZBI-12 score (Table 6).

### 3.4. Perceived embarrassment as a predictor of caregiver burden controlling for measures of ET participant physical and cognitive impairment

In a linear regression model that considered the effects of physical and cognitive impairment (total tremor score, tremor disability score, MoCA score, CDR) higher square root transformed perceived embarrassment score was associated with higher square root transformed ZBI-12 score. In this model, perceived embarrassment was the strongest predictor for increased caregiver burden (Table 6).

### 3.5. Additional analyses

We performed additional analyses to address the possibility of self-report bias in ET participants with dementia. When we repeated our main analyses only including ET participants without dementia (CDR <1, n=53), our results remained largely the same. All correlations that were significant in the complete sample remained significant, and no correlations that were not significant in the complete sample became significant. In the repeated linear regression model correcting for clinical correlates, perceived embarrassment was no longer a significant predictor for caregiver burden, but the trend remained consistent with that of the previous model (beta=0.27, p=0.07). In the repeated linear regression model including measures of physical and cognitive impairment, perceived embarrassment remained the strongest predictor of burden (beta=0.33, p=0.03).

## 4. Discussion

Embarrassment has been recognized as an important feature of ET (10–13). However, to our knowledge, no research has examined how embarrassment may affect the experience of caring for someone with ET. This study aimed to understand perceived embarrassment and its relationship to caregiver burden in order to provide more tailored psychological support to ET patients and their family caregivers.

Our first aim was to assess caregiver perception of ET participant embarrassment. We found that caregivers are overall attuned to ET participant embarrassment but are not fully aware of what specific situations ET participants find embarrassing. Higher ET participant embarrassment was associated with higher caregiver perceived embarrassment. Furthermore, 63.2% of ET participants and 66.7% of caregivers (in the perceived embarrassment assessment) endorsed the statement, “my tremor is embarrassing to me.” The two most endorsed specific items by ET participants were “I am embarrassed by my tremor when I try to eat or drink in public,” and “I am embarrassed by my tremor because it makes it difficult for me to write clearly.” These two items were also most endorsed as being perceived to be true by caregivers. Items least agreed upon were “I am embarrassed by my tremor because other people might think that I am nervous” with endorsements by 61.4% of ET participants only 19.3% of caregivers, “I sometimes try to hide my tremor” with endorsements by 50.9% of ET participants only 14.0% of caregivers, “I am embarrassed by my tremor when I have to speak in front of a group” with endorsements by 36.8% of ET participants only 14.0% of caregivers and “one of the reasons I take medication is that I am embarrassed by my tremor” with endorsements by 36.8% of ET participants only 14.0% of caregivers. It seems that caregivers are highly aware of embarrassment caused by inability to properly perform daily tasks, and may be less aware of embarrassment that only arises within social interactions.

Our second aim was to assess the relationship between perceived embarrassment and caregiver burden. We found that perceived embarrassment was a predictor for caregiver burden, independent of caregiver clinical correlates such as duration of providing care and hours/week providing care. Our third aim was to assess whether perceived embarrassment is a predictor for burden independent of ET participant physical and cognitive impairment. Interestingly, perceived embarrassment was a stronger predictor for caregiver burden than measures of physical and cognitive impairment. This is aligned with research in other populations including children with disabilities, Alzheimer's patients, and patients with severe mental illness, that identifies perception of stigma to be a strong predictor for caregiver burden (20–22, 35, 36), in that embarrassment and stigma are both signs of social distress. Our finding supports the idea that the perception of a care-recipient's strained social interaction can be distressing and burdensome for caregivers.

Our finding has important clinical implications, as it suggests that burden due to perception of patient embarrassment is greater than that caused by providing assistance with daily tasks. As such, caregiver burden may not be alleviated by medical or surgical treatment of motor disability in ET patients. Clinicians should additionally provide caregivers and patients with support and counseling that is focused on the psychological effects of patient embarrassment. For example, ET patients and caregivers may benefit when their experiences and perceptions of embarrassment become more aligned, or when caregivers have a better understanding of what situations may be particularly embarrassing for patients. Although the present findings reveal important information that clinicians can directly apply in interacting with ET patients and their families, our findings may also be relevant to caregivers of patients with other visible disorders in which patients experience embarrassment.

This study is limited in that the sample size was small, which may have restricted our ability to detect significant relationships in the data. Despite this, numerous statistically significant associations were detected. The study was strong in inclusion of ET participants with a wide range of tremor severity and cognitive impairment. We were therefore able to assess the effects of perceived embarrassment in people with broad physical and cognitive disability.

In conclusion, we found that caregiver perceived embarrassment was a predictor for caregiver burden independent of other clinical correlates. Additionally, perceived embarrassment was a stronger predictor for caregiver burden than physical and cognitive disability. Clinicians may wish to address patient embarrassment and perceived embarrassment in patient-caregiver pairs in order to better support caregivers of ET patients.

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## Abbreviations

| | |
|---|---|
| **CESD-10** | Center of Epidemiological Studies Depression Scale Short Form |
| **CDR** | Clinical Dementia Rating |
| **ET** | Essential Tremor |
| **ETEA** | Essential Tremor Embarrassment Assessment |
| **GDS** | Geriatric Depression Scale |
| **MoCA** | Montreal Cognitive Assessment |

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## Research Highlights

- Caregivers are attuned to ET patient embarrassment
- Caregiver perception of ET patient embarrassment is associated with caregiver burden
- Perceived embarrassment better than measures of ET impairment as predictor of burden
- Clinicians should address perceived embarrassment to support caregivers

## Table 1

Characteristics of 57 ET Participants and Caregivers

| Variable | Value |
|---|---|
| **ET Participant Characteristics** | |
| Age (years) | 77.2 ± 10.2 (56–97) |
| Female gender | 36 (63.2) |
| White race | 55 (96.5) |
| Education (years) | 16.5 ± 2.5 (12–21) |
| Age of tremor onset (years) | 40.9 ± 22.0 (5–78) |
| Tremor duration (years) | 36.2 ± 21.6 (2–87) |
| Total tremor score | 23.1 ± 5.6 (10–36) |
| Tremor disability score | 67.6 ± 24.4 (20–100) |
| MoCA score | 24.7 ± 3.9 (13–30) |
| CDR | |
| No dementia (0) | 40 (70.2) |
| Questionable dementia (0.5) | 13 (22.8) |
| Mild dementia (1) | 3 (5.3) |
| Moderate dementia (2) | 1 (1.8) |
| **Caregiver Characteristics** | |
| Age (years) | 66.6 ± 12.7 (41–89) |
| Female gender | 37 (64.9) |
| White race | 52 (91.2) |
| Education (years) | 16.3 ± 2.4 (12–21) |
| Caregiver relationship to ET participant | |
| Spouse | 31 (54.4) |
| Child | 17 (29.8) |
| Friend | 5 (8.8) |
| Other (niece, girlfriend, daughter in law) | 4 (7.0) |
| Caregiver living with ET participant | 34 (59.6) |
| Duration of care (years) | 6.8 ± 11.8 (0–63) |
| Hours per week providing care | 5.2 ± 9.8 (0–40) |
| CESD-10 score | 4.9 ± 4.7 (0–21) |

Values represent number (percentage) or mean ± standard deviation (range).

CDR = Clinical Dementia Rating, CESD-10= Center of Epidemiological Studies Depression Scale Short Form, MoCA = Montreal Cognitive Assessment

## Table 2

Embarrassment and Burden

| Variable | Value |
|---|---|
| ETEA score [a] | 17.5 ± 17.0 (0–59); 12 |
| Perceived embarrassment score [b] | 11.6 ± 13.7 (0–61); 6 |
| ZBI-12 score [b] | 6.4 ± 8.4 (0–30); 3 |

Values represent mean ± standard deviation (range); median.

ETEA = Essential Tremor Embarrassment Assessment, ZBI-12 = Zarit Burden Inventory Short Form

[a] Data on ET participant

[b] Data on caregiver

## Table 3

Embarrassment Item Endorsement by ET Participants and Caregivers

| Items in ETEA | ET Participant Endorsement | Caregiver's Endorsement (item is perceived to be embarrassing to ET participant) | Chi Square p value |
|---|---|---|---|
| My tremor is embarrassing to me | 36 (63.2) | 38 (66.7) | 0.70 |
| One of the reasons I take medication is that I am embarrassed by my tremor | 21 (36.8) | 8 (14.0) | 0.005 |
| Tremor is embarrassing to me because it draws attention to me from strangers | 28 (49.1) | 24 (42.1) | 0.45 |
| I am embarrassed by my tremor when I try to eat or drink in public | 39 (68.4) | 32 (56.1 | 0.18 |
| I am embarrassed by my tremor because it makes it difficult for me to write clearly | 39 (68.4) | 28 (49.1) | 0.04 |
| I am embarrassed by my tremor because other people might think that I am nervous | 35 (61.4) | 11 (19.3) | <0.0001 |
| I am embarrassed by my tremor when I have to speak in front of a group | 21 (36.8) | 8 (14.0) | 0.005 |
| Tremor is embarrassing because I do not like to have to explain it when I meet new people | 21 (36.8) | 13 (22.8) | 0.10 |
| Tremor is embarrassing because I think other people might think that I am disabled or ill | 26 (45.6) | 20 (35.1 | 0.25 |
| I am embarrassed by my tremor because other people might think that I am drunk or on drugs | 17 (29.8) | 8 (14.0) | 0.04 |
| People are hesitant to speak to with me or spend time with me because of my tremor | 10 (17.5) | 5 (8.8) | 0.17 |
| People judge me or treat me differently because of my tremor | 21 (36.8) | 15 (26.3) | 0.23 |
| I avoid social situations because of my tremor | 18 (31.6) | 14 (24.6) | 0.40 |
| I sometime try to hide my tremor | 29 (50.9) | 8 (14.0) | <0.0001 |

Values represent number (percentage);

ETEA = Essential Tremor Embarrassment Assessment

## Table 4

Clinical Correlates of Embarrassment and Perceived Embarrassment

| Variable | ETEA score | Perceived embarrassment score |
|---|---|---|
| **ET Participant** | | |
| Age | −0.19 | 0.20 |
| Total tremor score | 0.25 | 0.45 ** |
| Tremor disability score | 0.39 ** | 0.30 * |
| GDS score | 0.16 | 0.21 |
| CDR | −0.13 | 0.28 * |
| MoCA score | 0.09 | −0.35 ** |
| ETEA score | -- | 0.32 * |
| **Caregiver** | | |
| Age | 0.02 | −0.30 * |
| Hours/week providing care | −0.11 | 0.49 ** |
| Duration of care (years) | 0.03 | 0.31 * |
| CESD-10 score | −0.17 | −0.03 |

Values are Spearman’s rho. 2-tailed;

[*] $p<0.05$;

[**] $p<0.01$;

CESD-10 = Center of Epidemiological Studies Depression Scale Short Form, CDR = Clinical Dementia Rating, ETEA = Essential Tremor Embarrassment Assessment, GDS = Geriatric Depression Scale, MoCA = Montreal Cognitive Assessment

## Table 5

Clinical Correlates of Caregiver Burden

| Variable | ZBI-12 score |
|---|---|
| **ET Participant** | |
| Age | 0.18 |
| Total tremor score | 0.16 |
| Tremor disability score | 0.08 |
| GDS score | 0.33 * |
| CDR | 0.54 ** |
| MoCA score | −0.48 ** |
| ETEA score | −0.08 |
| **Caregiver** | |
| Age | −0.22 |
| Hours/week providing care | 0.55 ** |
| Duration of care (years) | 0.40 * |
| CESD-10 score | 0.35 ** |
| Perceived embarrassment score | 0.39 ** |

Values are Spearman’s rho. 2-tailed;

[*] $p<0.05$;

[**] $p<0.01$;

CESD-10 = Center of Epidemiological Studies Depression Scale Short Form, CDR = Clinical Dementia Rating, ETEA = Essential Tremor Embarrassment Assessment, GDS = Geriatric Depression Scale, MoCA = Montreal Cognitive Assessment

## Table 6

Association Between Caregiver Burden and Perceived Embarrassment in Linear Regression Models

| Variable | Beta Coefficient | Significance |
|---|---|---|
| **Model 1: Perceived embarrassment as predictor for burden, correcting for other clinical correlates** | | |
| Perceived Embarrassment score[b] | 0.30 | 0.02 |
| Hours/week providing care[b] | 0.10 | 0.50 |
| Duration of care (years)[b] | 0.32 | 0.007 |
| MoCA score[a] | −0.04 | 0.82 |
| CDR[a] | 0.30 | 0.14 |
| **Model 2: Perceived embarrassment as predictor for burden, correcting for physical and cognitive impairment** | | |
| Perceived Embarrassment score[b] | 0.34 | 0.02 |
| Total tremor score[a] | −0.02 | 0.87 |
| Tremor disability score[a] | 0.01 | 0.92 |
| MoCA score[a] | −0.09 | 0.66 |
| CDR[a] | 0.33 | 0.09 |

CDR = Clinical Dementia Rating, MoCA = Montreal Cognitive Assessment,

[a] Data on ET participant

[b] Data on caregiver