



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 Assessment (E TEA), and measured perception by caregivers of ET participant embarrassment using a modified version of the E TEA. 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.

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

Abbreviations: CESD-10, Center of Epidemiological Studies Depression Scale Short Form; CDR, Clinical Dementia Rating; ET, Essential Tremor; E TEA, Essential Tremor Embarrassment Assessment; GDS, Geriatric Depression Scale; MoCA, Montreal Cognitive Assessment

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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 \geq 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 h 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 \geq 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 (E TEA), 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. E TEA 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 min long and included the collection of demographic data, a CDR interview, and the following measures:

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