Brief Methodological Report

Assessment of Burden Among Family Caregivers of People With Parkinson's Disease Using the Zarit Burden Interview

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Abstract

Context. Previous studies have supported the psychometric properties of the 22-Item Zarit Burden Interview (ZBI-22) scale among family caregivers of people with various disorders, including Parkinson's disease (PD). However, its short forms have not been psychometrically tested among PD family caregivers, and available psychometric analyses have not accounted for the ordinal nature of item-level data.

Objectives. To assess the psychometric properties of the ZBI-22 and its short forms among family caregivers of people with PD, while taking account for the ordinal nature of data.

Methods. Cross-sectional postal survey ZBI-22 data from 66 family caregiver members (59% women; mean age 69.6 years) of a local Swedish PD society branch were analyzed according to classical test theory methods based on polychoric/polyserial correlations.

Results. Missing item responses were $\leq 5\%$. Corrected item-total correlations were ≥ 0.42 and floor/ceiling effects were <20%, besides for the briefest (4- and 1-item) short forms (20% and 40% floor effects, respectively). Reliability was good for all scales (ordinal alpha 0.89−0.95). External construct validity was in general accordance with a priori expectations. Short forms demonstrated good criterion-related validity (r_s 0.87−0.99) and discriminative ability (area under the curve, 0.91−0.98) relative to the full ZBI-22.

Conclusion. This study provides support for the reliability and validity of the ZBI-22 and its various short forms for use among PD family caregivers. In studies where caregiver burden is a central outcome, either ZBI-22 or ZBI-12 is suggested for use; other short forms can be used when caregiver burden is of less central focus or for clinical screening.   J Pain Symptom Manage 2017;53:272−278. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Introduction

People with long-term progressive neurological disorders such as Parkinson's disease (PD) may be in great need of assistance, and family caregivers often provide practical as well as medical, emotional, and social supports.[1,2] Family caregiver perspectives have therefore been increasingly recognized, and a central caregiver outcome is perceived burden,[3] most commonly assessed using the generic 22-Item Zarit Burden Interview (ZBI-22).[2,4,5] In addition to the original ZBI-22,[6,7] a number of short forms have been proposed as a means of simplifying its use, target the scale to different settings and needs, and to minimize respondent burden.[4,8,9]

A Spanish study assessed the ZBI-22 regarding its basic psychometric performance among family caregivers of people with PD.[10] The ZBI-22 was found to exhibit acceptable psychometric properties with, for example, 90% computable total scores, 3% floor/

ceiling effects, item-total correlations between 0.31 and 0.78, a reliability estimate (coefficient alpha) of 0.93, and correlations between -0.33 and -0.50 with physical and -0.52 to -0.64 with mental health domains of the 36-Item Short Form Health Survey (SF-36).[10] As with most classical test theory (CTT)-based psychometric studies, the core analyses (e.g., item-total correlations and coefficient alpha) were parametric and did therefore not account for the fact that item-level data are ordinal. However, polychoric-based correlation and reliability estimates take the ordinal nature of data into account and diminish the bias associated with applying parametric procedures with ordinal data.[11–14] Furthermore, in the case of the ZBI, psychometric evidence regarding its various short forms is relatively limited[4] and appears absent among PD family caregivers, which is limiting because short forms may provide more feasible clinical tools.

The aim of this study was to reassess the psychometric properties of the ZBI-22 and its short forms among Swedish family caregivers of people with PD using CTT approaches that take the ordinal nature of data into account.

Methods

The study was conducted in accordance with the Declaration of Helsinki and reviewed by the local institutional ethics advisory committee. All participants provided informed consent.

Data were taken from an anonymous cross-sectional postal survey to all 107 registered family caregiver members of a local south Swedish branch of the Swedish PD Society.[15]

Instruments

Zarit Burden Interview

The ZBI-22 (Table 1) consists of 22 items with five ordered frequency-related response categories scored 0 (never) to 4 (nearly always), except for the final item, which has five ordered intensity-related response categories (0 = not at all; 4 = extremely). All 22 items are used to calculate a total score that can range between 0 and 88 (88 = more burden). A total score of 21 has been suggested as a burden cutpoint.[4,16]

In addition, several short forms of the ZBI-22 have been proposed,[4,8,9] including 12-, 8-, 7-, 6-, and 4-item versions and a single-item (ZBI-1) version to be used as a screening tool (Table 1). These are scored according to the same principle as the original ZBI-22, yielding total scores that range between 0 and 48 (ZBI-12), 32 (ZBI-8), 28 (ZBI-7), 24 (ZBI-6), 16 (ZBI-4), and 4 (ZBI-1) with higher scores representing more burden. Here, we used the Swedish version of the ZBI-22 (www.mapi-trust.org) but did also compute scores according to the six short forms, as embedded in the ZBI-22.

Table 1
The Zarit Burden Interview[a]

ZBI-22 Items		Short-Form Items[b]					
No.	Content (Abridged)	ZBI-12	ZBI-8	ZBI-7	ZBI-6	ZBI-4	ZBI-1
1	Relative asks for more help than needed						
2	Not enough time for yourself	X		X	X	X	
3	Stressed between caring and other responsibilities	X		X	X	X	
4	Embarrassed over behaviors		X				
5	Angry when around your relative	X	X				
6	Relative affects your relationship with others	X	X	X	X		
7	Afraid of what the future holds for relative						
8	Your relative is dependent on you						
9	Strained when around your relative	X	X	X	X	X	
10	Your health has suffered because of caring	X		X	X		
11	Insufficient privacy because of your relative	X					
12	Social life has suffered because of caring	X	X				
13	Uncomfortable having friends over because of relative		X				
14	Relative seems to expect you to take care of him or her, as if you were the only one to depend on						
15	Do not have enough money to care for your relative						
16	Not able to take care of your relative much longer						
17	Lost control of your life since your relative's illness	X		X	X		
18	Wish you could leave the care to someone else		X				
19	Uncertain about what to do about relative	X	X			X	
20	You should be doing more for your relative	X					
21	Could do a better job caring for your relative	X					
22	Overall, how burdened do you feel in caring			X			X

ZBI-22 = 22-Item Zarit Burden Interview.
[a]Item response categories: 0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, 4 = nearly always (except Item 22: 0 = not at all, 1 = a little, 2 = moderately, 3 = quite a bit, and 4 = extremely).
[b]Total score ranges (higher = more burden): ZBI-12 = 0–48; ZBI-8 = 0–32; ZBI-7 = 0–28; ZBI-6 = 0–24; ZBI-4 = 0–16; and ZBI-1 = 0–4.