Original Article

Validity and Reliability of the Zarit Burden Interview in Assessing Caregiving Burden

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Abstract

　Introduction: This study aims to validate the Zarit Burden Interview as an instrument to measure the level of burden experienced by caregivers of patients with dementia (PWD) in Singapore. **Materials and Methods:** Adult family caregivers of PWD were recruited from the ambulatory dementia clinic of a tertiary hospital and the Alzheimer's Disease Association. All subjects completed a battery of questionnaires which consisted of demographic questions and the following instruments: the Zarit Burden Interview (ZBI), Burden Assessment Scale (BAS), General Health Questionnaire (GHQ-28), Dementia Management Strategies Scale (DMSS), and the Revised Memory and Behaviour Problems Checklist (RMBPC). A subgroup of subjects also completed the ZBI for the second time 2 weeks after the first survey. **Results:** A total of 238 subjects completed the survey. As hypothesised, the Zarit burden score was strongly correlated with BAS, GHQ-28, DMSS, and RMBPC scores (Pearson's correlation coefficient: 0.53 to 0.73); caregivers who undertook the major role in caregiving, had spent >1 year in caregiving, or experienced financial problems had higher Zarit burden scores than those who were not main carers, with ≤1 year of caregiving, or reported no/minimal financial problems, respectively. The Cronbach's alpha value for the ZBI items was 0.93; the intra-class correlation coefficient for the test-retest reliability of the Zarit burden score was 0.89 (n = 149). **Conclusion:** The results in this study demonstrated that the Zarit Burden Interview is a valid and reliable instrument for measuring the burden of caregivers of PWD in Singapore.

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Key words: Caregiver, Dementia, Scale, Validation

Introduction

　Dementia is a growing public health issue in the Asia-Pacific region. The number of people with dementia in the Asia-Pacific region will increase from 13.7 million people in 2005 to 64.6 million people in 2050.[1] In Singapore, with the rate of population ageing at 3% per year, 2 to 3 times higher than that of other developed countries,[2] the number of people with dementia will be more than double from 22,000 in 2005 to 52,600 by 2020.[1] As high physical dependency and behavioural problems such as agitation, aggression and delusions are germane to patients with dementia (PWD),[3] the need for caregiving, with its attendant stress and strain, is inevitable.

　Family caregivers form an integral part of holistic dementia management[4] and they often have to contend with the emotional, social, physical and financial strains of caregiving.[5,6] High levels of strain may lead to compromised physical and mental health with a possible increase in psychiatric morbidity and even mortality.[7-10] The burden of caregiving is associated with factors such as severity of dementia, duration of caregiving, coping strategies of caregivers, and degree of social support.[11-13] For these reasons, it is important to assess caregiver burden in a dementia service to identify caregivers with significant levels of burden and provide the necessary interventions to alleviate it.

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Although burden can be assessed qualitatively, it is beneficial to have an easy-to-use and validated instrument to be able to conveniently quantify the degree of burden and provide a means to follow-up objectively. A metric for caregiver burden also enables evaluation of dementia interventions, patient or caregiver focused, for efficacy. Several instruments have been developed for this purpose and have mostly been derived from the experience of caregivers in Caucasian populations.[14-16] There is still no validated instrument to measure caregiver burden in Singapore, an urban country with a multi-ethnic population of 5 million in Southeast Asia.

The Zarit Burden Interview (ZBI), which provides a comprehensive assessment of both objective and subjective burden, is one of the most commonly used burden measures and has been validated in many culturally or ethnically different populations.[16-19] Hence, the purpose of this study is to validate the ZBI by examining its internal consistency, test-retest reliability, and construct validity in family caregivers of PWD in Singapore. We have chosen to validate the English version of the ZBI in the present study because English is the predominant language in the country as well as the primary medium of instruction in schools. The Chinese version of the ZBI is under investigation in a separate study for those who only speak Chinese in Singapore.

Materials and Methods

Study Design

Ethics approval for this study was obtained from the Domain Specific Review Board of the National Healthcare Group (NHG), Singapore.

A consecutive sample of study subjects were recruited from two sources, the ambulatory dementia clinic of a tertiary hospital (Alexandra Hospital [AH]) and the local Alzheimer's association (Alzheimer's Disease Association of Singapore [ADA]) from 2 June 2008 to 28 Febuary 2009. At the hospital, family caregivers accompanying their charges to the clinic were invited to participate in the study whereas at the association, the family caregivers were contacted through the clients' registry of the association. The investigator explained the nature and aims of the study, the voluntary nature of participation and the confidentiality of the responses. This information was also provided via an information sheet given to the subjects. Those who agreed to participate signed an informed consent form.

The inclusion criteria were (i) literacy in English and able to complete a survey questionnaire and (ii) family member, aged ≥18 years providing care or assistance to a relative with dementia. Providing care is defined as attending to the needs of the PWD, accompanying him/her to the doctor's appointments, helping with administration of medication, helping with housework, cooking, activities of daily living,

providing emotional support and leisure and recreational activities. We defined main caregivers as family members with the primary responsibility of decision-making and care for the well-being of the PWD. Although main caregivers were the target of the study, some family caregivers who were not the main caregiver were recruited because they were much involved in caring for the PWD. Domestic maids employed to help care for the PWD were excluded as the focus of the study was family caregivers.

The subjects were asked to self-administer a questionnaire that comprised questions assessing demographics and some standardised instruments including the Zarit Burden Interview (ZBI),[19] the Burden Assessment Scale (BAS),[20] the General Health Questionnaire (GHQ-28),[21] the Dementia Management Strategies Scale (DMSS)[4] and the Revised Memory and Behaviour Problems Checklist (RMBPC).[22] Although the questionnaire was designed to be self-administered, the subjects were first given an explanation and run-down on the questionnaire by the investigator before being left to complete the questionnaire. Subjects could complete the questionnaire on-site or off-site. Questionnaires completed off-site were returned by mail. A subgroup of subjects was asked to complete the ZBI a second time, 2 weeks after the first survey, for the assessment of test-retest reliability.

Instruments

The Zarit Burden Interview (ZBI) is a 22-item instrument for measuring the caregiver's perceived burden of providing family care. The 22 items are assessed on a 5-point Likert scale, ranging from 0 = 'never' to 4 = 'nearly always'. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. The questions focus on major areas such as caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the patient.

The General Health Questionnaire (GHQ-28) used in this study is the 28-item version. There are 4 subscales, each with 7 items: subscale A for somatic symptoms, subscale B for anxiety and insomnia, subscale C for social dysfunction and subscale D for severe depression. Out of 28 items, 7 items are formulated in a positive manner and 21 items are formulated in a negative manner. The total possible score ranges from 0 to 84; higher scores indicate worse psychological distress. The GHQ-28 had been used in a previous population-based study in Singapore.[23]

The Burden Assessment Scale (BAS) is a 19-item measure that covers objective and subjective caregiver burden. Out of 19 items, 10 items evaluate objective burden such as financial problems, limitations of personal activity, household disruptions and disrupted social interactions. The remaining 9 items evaluate subjective burden such as

caregiver's feelings, attitudes and emotional experience. Each item has a 4-point response scale ranging from 0 = 'not at all' to 4 = 'a lot'. The responses are summed up with higher scores indicating higher burden. The BAS had been validated in a previous study in Singapore.[24,25]

The Dementia Management Strategies Scale (DMSS) is a 28-item questionnaire, comprising three subscales, of which one is the criticism subscale. Criticism refers to yelling, criticising, threatening and other related behaviours of the caregiver seen as the caregiver's management strategies. This subscale consists of 11 items which are assessed by a 5-point scale ranging from 0 = 'never' to 4 = 'most of the time'.

The Revised Memory and Behaviour Problems Checklist (RMBPC) scale assesses the frequency of problematic behaviours in dementia and its impact on the caregiver. It comprises 3 domains which pertain to memory, disruptive behaviours and depression. Each domain has a separate score. The frequency of problematic behaviours is assessed by a 5-point scale ranging from 0 = 'never occurs' to 4 = 'occurs daily or more often' and the reaction of the caregiver is assessed by another 5-point scale ranging from 0 = 'not at all' to 4 = 'extremely'. The separate domain scores are added up to give a total score that ranges from 0 to 384.

Statistical Analysis

To evaluate convergent construct validity, the correlation between ZBI and other relevant scales were examined by the Pearson's correlation coefficient. We hypothesised that ZBI would be strongly or moderately correlated with the BAS score, GHQ-28 score, RMBPC score and the DMSS criticism subscale score. A correlation coefficient of <0.35, 0.35 to 0.50 and >0.5 was considered weak, moderate and strong, respectively.[26]

The differences in ZBI scores among subgroups of caregivers who differed in the caregiving role, intensity, duration, and degree of financial problems were examined to assess known groups construct validity. These factors were chosen based on extant literature [11,13,27-29] as well as the ground experience of the authors who work with PWD and their families. We hypothesised that main caregivers would have higher ZBI scores compared to those who played a more minor role in caregiving. Similarly, we hypothesised that caregivers who spent a greater proportion of their time in providing care, had longer history of caregiving or reported more financial problems, would have higher ZBI scores than those who spent less time, had been providing care for a shorter period of time, or reported fewer financial problems, respectively. Group differences in ZBI scores were tested with the independent two-sample *t*-test or analysis of variance.

The reliability of the ZBI was evaluated by examining the test-retest reliability and internal consistency. Test-retest reliability refers to the ability of a scale to yield reproducible results when it is used repeatedly on the same person while internal consistency refers to the extent to which the items of a scale are interrelated. Because better correlated items will form a more reliable scale, Cronbach's alpha, which is a widely used internal consistency measure, is also used as a measure for scale reliability.[30] In this study, the internal consistency reliability was assessed using Cronbach's alpha; the test-retest reliability was assessed by the intra-class correlation coefficient (ICC) using the subjects who completed the ZBI at both baseline and 2 weeks later. For both ICC and Cronbach's alpha, a value of ≥0.7 was considered satisfactory.[30]

All statistical tests were 2-tailed with a significance level of 0.05, using SAS version 9.1 (SAS Institute, Cary, NC).

Results

The questionnaire was given out to 321 family caregivers (ADA: 104; AH: 217) among whom 246 (76.6%) returned their questionnaires at the end of the study. After excluding 8 subjects (ADA: 2; AH: 6) with one or more missing responses, the number of respondents who produced valid analysable data was 238 (ADA: 81; AH: 157). Those who did not return the questionnaire cited problems such as poor eyesight, language difficulties, recent death of the relative with dementia, time constraints and lack of interest. Differences between respondents and non-respondents could not be examined.

Characteristics of Subjects and Patients

The final sample of 238 caregivers comprised mainly ethnic Chinese (95.4%), females (68.1%) and children as caregivers (81.5%). The mean age of the caregivers was 50.1 years (standard deviation = 10.5, range, 22 to 84). More than half the caregivers (53.6%) had been caring for a PWD for more than 3 years. The mean age of the patients was 79.3 years (standard deviation = 8.0, range, 54 to 99). The majority of the patients was females (67.5%), on medication for dementia (76.8%), and needed at least some assistance for daily living (75.6%). Detailed characteristics of the subjects are in Table 1.

The total ZBI score ranged from 0 to 77, with the mean and standard deviation being 35.4 and 15.5, respectively. The mean scores for individual items of ZBI ranged from 0.93 to 2.73 (Table 2). The highest score was patient's dependence on caregiver (mean = 2.73), followed by 'feeling stressed between caring for the patient and meeting other responsibilities for family or work' (mean = 2.27), and feeling of needing to do more for the patient (mean = 2.05). The feeling of 'not having enough time due to the time spent on taking care of the patient' (mean = 1.92) and the fear of the future for the patient (mean = 1.97) also had

Table 1. Caregivers' Characteristics (n = 238)

	n (%)
Age (y)	
Mean (standard deviation)	50.1 (10.5)
Gender	
Male	76 (31.9)
Female	162 (68.1)
Ethnic Group	
Chinese	227 (95.4)
Indian/Eurasian/others	11 (4.6)
Marital status	
Single	83 (34.9)
Married	141 (59.2)
Widowed/divorced/separated	14 (5.9)
Work status	
Working full time	127 (53.4)
Working part time	40 (16.8)
Homemaker/housewife/not working	51 (21.4)
Retired	20 (8.4)
Education	
Primary	4 (1.7)
Secondary	94 (39.5)
Tertiary	140 (58.8)
Relation with patient	
Spouse	18 (7.6)
Child/child-in-law	208 (87.4)
Grandchild/others	12 (5.0)
Living with patient	
Yes	158 (66.4)
No	80 (33.6)
Main caregiver	
Yes	184 (77.3)
No	54 (22.7)
Duration of caregiving	
≤1 year	30 (12.7)
>1 to 3 years	80 (33.8)
>3 years	127 (53.6)
Time contributed	
≤20%	37 (15.5)
21% to 60%	70 (29.4)
61% to 100%	131 (55.1)

Table 2. Mean Scores and Standard Deviations of Individual ZBI Items

Item no.	ZBI item	Mean score (SD)
1	Do you feel that your relative asks for more help than he/she needs?	1.59 (1.02)
2	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	1.92 (1.06)
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	2.27 (1.12)
4	Do you feel embarrassed over your relative's behaviour?	0.95 (0.97)
5	Do you feel angry when you are around your relative?	1.28 (0.96)
6	Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	1.25 (1.16)
7	Are you afraid of what the future holds for your relative?	1.97 (1.18)
8	Do you feel your relative is dependent on you?	2.73 (1.12)
9	Do you feel strained when you are around your relative?	1.68 (1.10)
10	Do you feel your health has suffered because of your involvement with your relative?	1.32 (1.14)
11	Do you feel that you don't have as much privacy as you would like because of your relative	1.45 (1.15)
12	Do you feel that your social life has suffered because you are caring for your relative?	1.6 (1.19)
13	Do you feel uncomfortable about having friends over because of your relative?	0.93 (1.01)
14	Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?	1.87 (1.38)
15	Do you feel that you don't have enough money to care for your relative?	1.63 (1.22)
16	Do you feel that you will be able to take care of your relative much longer?	1.14 (1.07)
17	Do you feel that you have lost control of your life since your relative's illness?	1.18 (1.09)
18	Do you wish you could just leave the care of your relative to someone else?	1.31 (1.13)
19	Do you feel uncertain about what to do about your relative?	1.53 (1.03)
20	Do you feel that you should be doing more for your relative?	2.05 (0.86)
21	Do you feel you could do a better job in caring for your relative?	1.87 (0.92)
22	Overall, how burdened do you feel in caring for your relative?	1.94 (1.08)

high scores.

Construct Validity

The Zarit burden score was highly correlated with the BAS score (correlation coefficient = 0.73, *P* <0.0001) and the GHQ-28 total score (correlation coefficient = 0.62, *P* <0.0001). The Zarit burden score was also strongly correlated with patients' dementia symptoms measured by RMBPC score (correlation coefficient: 0.53, *P* <0.0001). The correlation coefficient between the ZBI and the DMSS

criticism subscale was 0.53 (*P* <0.0001), indicating that caregivers who tended to criticise their patients reported higher level of burden than those who utilised less criticism in their management strategy.

Caregivers who were main caregivers had higher Zarit

burden scores (P = 0.0004). Similarly, caregivers who had spent more than one year in caregiving had higher ZBI scores than those with a shorter period of caregiving (P = 0.0003). Caregivers with fewer financial problems had lower burden levels (P <0.0001). Caregivers who spent ≤20% of their time in caregiving had lower ZBI scores than those who spent >20% of their time, although the differences were not statistically significant. Mean scores for each subgroup of caregivers are displayed in Table 3.

Reliability

The Cronbach's alpha value was 0.93. The intra-class correlation for the test-retest reliability, which was examined with a subgroup of 149 subjects, was 0.89.

Discussion

In this study, the ZBI demonstrated good validity and reliability in measuring the burden of caregivers of PWD in Singapore.

We found strong evidence supporting the construct validity of the ZBI. First, a strong correlation was observed between ZBI and GHQ scores in the study. Previous studies have demonstrated a positive relationship between subjective burden and psychiatric and psychological disturbances[9,10] and a strong correlation between ZBI and GHQ scores.[31] Second, as observed in a previous study,[32] the ZBI score was strongly correlated with patients' behavioural symptoms measured by the RMBPC and was significantly higher in caregivers who played a major role compared to caregivers who played a more minor role. Third, the ZBI score was highly correlated with the BAS score, another burden scale, and was significantly associated with the amount of time spent in caregiving and the extent of financial difficulties. All these results are consistent with what we hypothesised about the ZBI score, thus confirming the validity of the ZBI as a valid instrument to measure caregiver burden in dementia in our population.

In terms of reliability, both the intra-class correlation for assessing the test-retest reliability and Cronbach's alpha for evaluating the internal consistency were higher than 0.7, suggesting satisfactory reliability of the ZBI in the study population.

The levels of caregiving burden in our study were similar to those in previous studies in that highest scores were observed for item 8 (Do you feel your relative is dependent on you?) and item 7 (Are you afraid what the future holds for your relative?).[19,31,33,34] However, unlike most previous studies, item 3 (Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?) also garnered a high score in the present study. This may have arisen due to differences in our caregiver samples. More than half of our caregivers

Table 3. ZBI Scores for Subgroups of Caregivers

	n	Mean (SD)	*P* value*
Main caregiver			
Yes	184	37.3 (15.5)	0.0004
No	54	29.0 (13.6)	
Duration of caregiving			
≤1 year	30	26.0 (14.8)	0.0003
>1 year	207	36.9 (15.1)	
Time contributed			
≤20%	64	31.5 (15.4)	0.0552
21% to 60%	84	37.4 (14.3)	
>60%	90	36.5 (16.4)	
Financial problems			
No/minimal	120	33.0 (14.0)	<0.0001
Some	33	44.5 (13.3)	
A lot	16	47.1 (20.8)	

*Two sample t-tests or analysis of variance test.

were in full-time employment and thus more likely to be burdened by the need to juggle between caregiving duties and employment. Possibly for the same reason, a high score was also observed for item 20 (Do you feel that you should be doing more for your relative?). These differences highlight the issues unique to the caregiving situation in Asian societies like Singapore which may thus necessitate a different approach to intervention to reduce caregiver burden.

Some aspects of our study design may have limited the external validity of this study. Firstly, we only studied family caregivers. Thus, our results may not apply to non-family caregivers such as friends or employed domestic maids. Secondly, we recruited subjects only from two sites: an ambulatory dementia clinic and the local Alzheimer's Association. Caregivers from these two sites are generally well supported by the care providers and may possibly experience a lower level of care burden. As a result, our results may not be generalisable to all caregivers of patients with dementia in Singapore as a whole. Thirdly, we allowed some subjects to take the survey forms back home for self-completion. This might have compromised the accuracy of the responses as compared to subjects who were interviewed face-to-face because those subjects who may not fully understand certain questions in the survey questionnaire cannot have their doubts clarified. Last but not least, the English version of the ZBI was investigated in this study. Some caregivers in Singapore, especially spousal caregivers from an earlier generational cohort who had received less education, speak mainly Mandarin or other Chinese dialects. Thus, we are conducting another study to investigate the validity and reliability of the ZBI

in Chinese-speaking caregivers in Singapore.

In conclusion, the results in this study demonstrated that ZBI is a valid and reliable instrument in measuring the burden of caregivers of PWD in Singapore.

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