

Validation of the Chinese Version of the Zarit Burden Interview

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Abstract

Objective: To validate the Chinese version of the Zarit Burden Interview as an instrument for assessing the stress experienced by carers of elderly patients with dementia.

Patients and Methods: The Zarit Burden Interview was first translated into Chinese and then back-translated into English for comparison. Forty Chinese patients with mild to moderate dementia were recruited from 2 psychiatric clinics in Hong Kong. The Zarit Burden Interview, General Health Questionnaire, and Caregiver Activity Survey were completed by the patients' carers. Two raters rated another 16 carers separately for assessment of inter-rater reliability.

Results: The intraclass correlation coefficient was 0.99 and the split half correlation coefficient was 0.81, suggesting a high inter-rater reliability and internal consistency. The correlation between the Zarit Burden Interview and the General Health Questionnaire was 0.59 ($p < 0.001$), and the correlation between the Zarit Burden Interview and the Caregiver Activity Survey was 0.57 ($p < 0.001$), suggesting high conceptual validity.

Conclusion: The Chinese version of the Zarit Burden Interview is a valid and reliable tool to evaluate the stress experienced by carers of elderly people with dementia in Hong Kong.

Key words: Dementia, Dependency, Stress, psychological

Introduction

Identification of carer stress is as an important issue in caring for patients with dementia. It is becoming increasingly evident that carers have a role in the overall treatment outcome. Most elderly people with dementia live in the community and rely heavily on their relatives for support. Early institutionalisation is undesirable, as this generally imposes a negative effect on disease progression. Patients with dementia show greater impairment in unfamiliar settings, while familiar cues at home can often trigger well-established habits. However, the burden of taking care of an elderly relative with dementia at home can be great. Apart from the demands of physical care, patients with dementia often have psychiatric and behavioural problems that are difficult to deal with in the absence of adequate support.

Having limited knowledge and skills, carers often experience stress when caring for relatives with dementia.

The burden of care is affected by different factors. The illness severity and level of disability could affect the burden for patients and their carers.¹⁻³ Behavioural problems and dependency of patients contribute to, and may be a major cause of, stress.⁴⁻⁹ However, the strengths and coping mechanisms of carers, as well as social support and community resources, could affect the perceived burden.^{3,10-12} The amount of time carers spend with their relative each day also affects the perceived burden.^{9,13} Poor physical and psychiatric health of carers can also affect the perceived level of stress.^{3,8,14,15}

Excessive stress could lead to increased psychiatric morbidity for carers.^{16,17} Gilleard et al found that the prevalence of psychological disturbance was high among carers, as shown by an increased score for the General Health Questionnaire (GHQ).¹⁸ Excessive stress for the carer could also lead to an increased chance of institutionalisation for the patient.^{19,20} There is also evidence to show that carers' stress and maladaptive coping strategies may result in increased behavioural problems of patients with dementia.²¹ These factors would lead to an increase in economic burden.^{22,23}

To better address the stress of carers of patients with dementia, it is desirable to have an instrument to measure their burden in direct relationship to the demand for care. This approach will help clinicians to investigate the factors affecting the level of stress and design appropriate intervention strategies. The Zarit Burden Interview (ZBI)

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has been specifically designed for the assessment of subjective burden of carers, defined as the extent to which carers perceived their emotional or physical health, social life, and financial status to have changed as a result of caring for their relative with dementia.²⁴ The selection of items in this interview was based on clinical experience with carers and prior studies. The ZBI has been used by carers of patients with dementia in different countries with satisfactory reliability and validity.²⁵ The aim of this study was to evaluate the psychometric properties of the Chinese version of the ZBI for measuring the perceived burden of stress in Chinese carers of elderly people with dementia in Hong Kong.

Patients and Methods

Patients with dementia were recruited from 2 psychiatric clinics in Shatin and Tai Po in Hong Kong from December 1999 to August 2000. All patients fulfilled the *Diagnostic and Statistical Manual of Mental Disorders-IV* diagnostic criteria of dementia; severity was mild to moderate according to the Clinical Dementia Rating (CDR) of 1 or 2. Patients were required to have at least 1 primary carer for inclusion into the study. Most of the participants were living with their carers in the community. Informed consent was obtained from the patients with dementia and their carers, and the study was approved by the Clinical Research Ethics Committee of The Chinese University of Hong Kong.

Assessment Tools

The ZBI comprises 22 items. Carers were requested to indicate the level of distress caused by each item, ranging from 'not at all' to 'extremely' distressing, on a scale of 0 to 4. A total burden score was obtained by adding the responses to the individual items. The possible score ranged from 0 to 88; a higher score indicated greater carer distress. The ZBI includes factors most frequently mentioned by carers as problem areas such as carer's health, psychological well being, finances, social life, and the relationships between the carer and the patient with dementia.

The GHQ has been well validated as a screening instrument for psychiatric morbidity in the community, and is used in different languages and cultures. There are 4 different versions available containing 60, 30, 28, or 12 items. Studies have shown that the shorter versions are as good as the longer versions for case detection.²⁶ The 12-item version was used in this study because it is short and easy to administer.

The Caregiver Activity Survey (CAS) is an instrument to measure the amount of time a carer spends looking after a dependent patient in the 24 hours prior to the assessment. The CAS consists of 6 areas of daily living: communicating with the patient, using transportation, eating, dressing, looking after the patient's appearance, and supervising the patient. The total time could be more than 24 hours because of overlap of time used for the different areas.²⁷

The Community Screening Instrument for Dementia (CSI-D) is a well-validated education and culture-screening instrument for dementia.²⁸ The CSI-D consists of 2 parts: cognitive assessment of patients with dementia in 6 domains and a carer's report of the patient's daily functioning and general health. The cognitive function score (CFS) is an item-weighted total score of the cognitive test, with higher scores meaning better cognitive function. The discriminant function score (DFS) is a weighted score combining the cognitive and informant score according to an algorithm that discriminates between patients with and without dementia. A higher score indicates greater cognitive decline.

The CDR is a widely used instrument for staging the severity of dementia. The CDR is obtained via clinical interview with patients and a reliable carer. Impairment in each of 6 cognitive functions (memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care) is rated by a trained professional interviewer on a 5-point scale.²⁹ CDR 0 indicates no dementia and CDR 0.5, 1, 2, and 3 indicate questionable, mild, moderate, and severe dementia, respectively.³⁰ The global CDR was derived from an algorithm based on the information obtained in the clinical interview and its reliability for measuring and staging dementia has been demonstrated.³¹

Methods

The ZBI was first translated into Chinese by a bilingual psychiatrist, and then back-translated to English by an independent bilingual university graduate. The Chinese version was modified until the back-translated version was comparable to the original English version. The translated instrument was then assessed for acceptability and conceptual validity. Focus group discussions were held with health care professionals, community leaders, and carers of patients with dementia. The content and wording were considered clear, with no major modifications required. After obtaining consent, the carers completed the ZBI, GHQ, CAS, and the informant part of CSI-D, while the patients received the CSI-D cognitive test. All of the scales were interviewer-applied instruments and were rated by trained research assistants. Other demographic data were obtained from the carers. Two raters rated a further 16 carers separately for assessment of inter-rater reliability of the ZBI.

Statistical Analysis

The Statistical Package for the Social Sciences version 9.0 and non-parametric methods were used for data analysis. Multi-group comparisons for mean ZBI scores were done using the Kruskal-Wallis H test. Inter-rater reliability was measured by intraclass correlation coefficient, while internal consistency was measured by split half correlation coefficient. Correlations between the ZBI and GHQ, and ZBI and CAS were assessed for conceptual validity. Correlations of ZBI with CFS and DFS were also calculated to evaluate the possible correlation of carer burden with the severity of cognitive impairment.

Results

Forty patients with dementia and their carers were recruited for the study. Twenty one carers (52.5%) were women and 19 (47.5%) were men; the mean age was 51 years. Thirty patients with dementia (75%) were women and 10 (25%) were men; the mean age was 74.9 years. The total mean ZBI score was 24.6. The mean ZBI scores in the carer sub-groups are shown in Table 1. The inter-group differences were not significant.

Table 1. Characteristics and mean Zarit Burden Interview scores of carers of patients with dementia.

Carer characteristic	Number of carers (n = 40)	Mean Zarit Burden Interview score
Age (years)		
≥65	13	26.5
<65	27	23.6
Sex		
Women	21	25.3
Men	19	23.8
Marital status		
Married or cohabiting	35	22.4
Single	2	27.7
Separated or divorced	1	62.0
Widowed	2	54.0
Relationship with patient		
Spouse	14	27.4
Son or daughter	14	29.5
Son-in-law or daughter-in-law	2	44.5
Other	10	32.0
Educational level		
Illiterate	5	18.2
Primary, not finished	5	19.2
Primary, finished	12	25.9
Secondary, finished	9	28.6
Tertiary, finished	9	25.9
Employment status		
Full-time paid employment	13	18.2
Seeking employment	2	41.5
House wife/husband	16	29.4
Part-time employment/retired	9	21.6

Table 2. Correlation of Zarit Burden Interview with other assessment tools.

Assessment tool	Zarit Burden Interview
General Health Questionnaire	0.59*
Caregiver Activity Survey	0.57*
Community Screening Instrument for Dementia — cognitive function score	-0.41†
Community Screening Instrument for Dementia — discriminant function score	-0.41†

* $p = 0.001$.

† $p = 0.05$.

The intraclass correlation coefficient was 0.99. The split half correlation coefficient was 0.81. There was a significant correlation between the ZBI and GHQ (0.59; $p < 0.001$) and between the ZBI and CAS (0.57; $p < 0.001$). Furthermore, there was a significant negative correlation between ZBI, DFS, and CFS, suggesting that a lower level of cognitive ability was associated with greater carer burden (Table 2).

The mean scores for the individual items in the ZBI ranged from 1.16 to 1.82 (Table 3). The highest score was for not enough time for the carer, followed by feeling that the patient was too dependent on the carer. Worry over the patient's future, inadequate privacy, feeling uncertain about what to do, wishing someone else would care for the patient, and finding it difficult to fulfil different responsibilities were also highly scored items.

Discussion

The intraclass correlation coefficient was 0.99 and the split half correlation coefficient was 0.81, suggesting that the

Table 3. Mean score for each item of the Zarit Burden Interview.

Zarit Burden Interview item	Mean Zarit Burden Interview score
Patient asking for too much help	1.39
Not enough time for carer	1.82
Worry about fulfilling different responsibilities	1.63
Embarrassed about patient's behaviour	1.51
Feel angry	1.44
Negative effect on other relationships	1.38
Worry over patient's future	1.70
Patient is too dependent	1.79
Feel strained	1.35
Health affected	1.39
Inadequate privacy	1.67
Social life suffering	1.53
Feel uncomfortable having friends visit because of the patient	1.50
Expected to be the only carer	1.63
Financial stress	1.53
Feel unable to take care of the patient for much longer	1.31
Sense of losing control over life	1.16
Wish somebody would take up the care	1.64
Feel uncertain of what to do	1.67
Feel should do more	1.29
Feel could do better	1.28
Feel burdened	1.55

Chinese version of the ZBI has a satisfactory inter-rater reliability and internal consistency. Assuming that increased subjective burden would lead to increased psychiatric and psychological disturbance, which has been shown in previous studies,^{16,17} the highly significant correlation between ZBI and GHQ supported the conceptual validity of the ZBI. A greater carer burden was expected with increasing time spent on the care of patients with dementia.^{6,13,32} Therefore, the high correlation between the CAS and ZBI also suggested that the ZBI was conceptually valid.

The total mean score of the ZBI in this group of carers was 24.6, which was lower than the mean score of 31.0 in the study by Zarit et al.²⁴ This could reflect a general lower level of perceived stress due to caring for patients with dementia among this group. In the Chinese population, assuming responsibility for the care of elderly relatives is usual — children are expected to care for their parents, and wives are expected to care for their husbands. This concept may reduce the stress experienced by a carer because this role is accepted.^{33,34} However, there is a possibility of under-reporting of stress by the carers. In a culture with a strong emphasis on filial obligation, carers may be reluctant to admit to stressful feelings and discussion of such problems outside the family might be regarded as inappropriate. A study performed in Malaysia showed that Chinese people have a greater carer burden than Malays and Indians.¹³ The authors suggested that, while filial obligation coupled with the societal norm of caring for elderly family members was still intact across all cultures in the Malaysian population, cultural differences might influence how filial obligation and burden were related in the care-giving process. The authors further suggested that filial obligation might be the primary motive for care-giving, explaining the greater burden experienced.

The comparison of level of carer burden in different populations cannot be made simply by looking at the ZBI scores without considering the characteristics of the carers such as age, sex, educational level, ethnicity, and cultural values, which could significantly affect carer burden. Therefore, the calculation of a cut-off score for the ZBI to identify carers at high risk for stress may not be useful because different populations with different characteristics may need different cut-off scores.

Studies have shown differences in carer burden among different age groups and sexes, and according to the relationship with the patient.^{10,14,35} This study failed to show such differences. However, this could be due to the small sample size.

The extent of cognitive decline of patients with dementia reflected the severity of the illness, and this aspect affected the subjective burden of the carer.^{1,2} The patients in this study had mild to moderate dementia, and the results suggested that the severity of cognitive impairment may be associated with increased stress experienced by the carers. However, as the severity of the dementia progressed and behavioural problems attenuated, some carers found the patients with severe dementia easier to care for; while the physical demands increased, the psychological demands decreased. Physical demands caused a different type of stress from that

caused by the psychological demands. Mobile and active patients with dementia are more able to act out their thoughts and feelings, making them more difficult to manage.³⁶

The carers in this study had high scores for areas such as fear of what the future held for the patient, which is compatible with other studies.^{15,24} In this study, the patients with dementia were at a relatively early stage in the course of their illness. Therefore, uncertainty about the progression of the disease was understandable. Other high scores were noted for areas such as feeling that the patient was too dependent on the carers and not having enough time for themselves. Lack of time for oneself leaves little time for rejuvenation and increases stress.^{6,9,15} Life balance is important in western cultures and may also be important in a Chinese population.

Stress caused by caring for patients and meeting other responsibilities is common. Approximately one-third of the carers in this study were in full-time employment, and many of them also had different family roles. Therefore, they frequently felt guilty about not fulfilling a role and felt trapped. The desire to leave the care of the patients to another person had a high score. The score suggests that carers were not ready for the role, but felt obliged to take the responsibility. Alternatively, this score may reflect the psychological state of 'burn out' among carers. Generally, the highly scored items in the ZBI were similar those in the study by Zarit et al.²⁴ This finding suggests that the difficulties experienced by carers may be similar in different cultures.

The number of carers enrolled in this study was relatively small, which limited its ability to study factors associated with greater carer burden in addition to the main focus of validation of the Chinese version of ZBI. This may be why age, sex, educational level, and kinship of the carers with the patients were not found to significantly affect the carer burden. Other important factors such as personal coping, physical and psychological well-being, available social support, and prior quality of the relationship of the carers with the patients^{37,38} were also not addressed in this study.

This study investigated the association of cognitive function and the level of carer burden. However, self-care impairment, behavioural and psychotic symptoms, and level of dependency and functional deterioration may be equally, if not more, important for modulating the carer burden. These issues were not explored in this study. Patients with mild to moderate dementia were selected for this study because more severely affected patients often live in institutions and it is more difficult to identify the primary carers. The extent and sources of stress for carers of patients with severe dementia may be different from those of carers of patients with mild or moderate dementia. Therefore, larger studies involving more carers and patients with a wide range of disease severity that address different carer and patient factors may help to provide a more complete picture of the burden of carers of patients with dementia in a Chinese population. Future studies could also focus on the effect of stress on some specific areas of outcome of the patients such as the development and progression of behavioural and mood symptoms.

Carers with high scores in the GHQ and ZBI could be followed up for development of psychiatric illness or change of subjective burden over time as their relative's illness progresses.

This study served the purpose of testing the reliability and validity of the Chinese version of the ZBI for use in future studies, which could lead to a better understanding of carer burden of dementia in Hong Kong. The ZBI is a reliable and valid instrument to assess the subjective burden of carers of patients with dementia in the Chinese population. The subjective burden of carers is high and greater efforts to address this burden will enhance the treatment of patients with dementia. Memory and behavioural impairment are not easily ameliorated, and interventions that focus principally on the control of specific memory or behavioural deficits have a low probability of success. Instead, an approach that includes support for carers to improve their coping mechanisms and provide respite, as well as modifying aspects of the behaviour of patients with dementia will bring better outcomes.

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