

Factors Influencing the Zarit Burden Interview in a Japanese Community: Activities of Daily Living and Depressive State

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Abstract

Objective: Reducing the burden on the caregiver contributes to maintaining or enhancing quality of life of people with disability since caregiver support is indispensable to them.

Methods: The Japanese short version of the Zarit Caregiver Burden Interview (J-ZBI_8) was administered to 167 families of 243 community-dwelling disabled Japanese adults covered by the long-term care insurance system in Japan to clarify the relationship between burden of care and the disability. The status of the disabled adults was evaluated by the Functional Independence Measure (FIM), Frenchay Activity Index (FAI), and Japan Stroke Scale (Depression Scale) (JSS-D). J-ZBI_8 was predicted from the FIM using the classification and regression tree (CART) method.

Results: Rank correlation coefficients between the J-ZBI_8 score and disabled adults' motor and sensory subscores of the FIM, FAI, and JSS-D were -0.205, -0.249, -0.205 and 0.396, respectively. J-ZBI_8 score showed a relatively high relationship to depression. According to the CART method, FIM motor subscore (FIMM) was divided to 3 groups, FIMM less than 20, FIMM from 20 to 79, and FIMM of 80 or more. Scattergram indicated that FIM motor subscore of subjects whose caregiver had a high J-ZBI_8 score ranged at the mid-level of activities of daily living.

Conclusion: Since assisting movement of subjects who need a great deal of help is a harder burden of care than simply moving the subject without considering the subject's desires, the burden of the care of subjects who can perform a few ADL is more severe than the burden of care of completely bedridden subjects.

Keywords: Elderly; Stroke; ADL; Burden of care; Instrumental ADL, Depression

Introduction

The increasing number of elderly people in the population is one of the most serious problems to be addressed in Japan. To manage disabled people in the community, the Japanese government introduced the long-term care insurance (LTCI) system, which provides for all elderly with disability as well as those over the age of 40 having specific diagnoses such as stroke in 2000 [1-4]. Since that time, the population dynamics of people with disability can be followed by LTCI registration.

Caregiver support is indispensable to people with disability in their efforts to maintain the ability to carry out activities of daily living (ADL) at an optimal level in consideration of the disability. Therefore, reducing the burden on the caregiver should contribute to maintaining or enhancing quality of life of people with disability. First, it is important to recognize the factors that influence caregiver burden to reduce such burden. The Zarit Caregiver Burden Interview (ZBI) [5-8], Caregiver Strain Index [9] and Relatives Stress Scale [10] are

commonly used to measure the burden of care [11]. Since the ZBI was translated into Japanese and there have been several reports of its use [12-14], we decided to use it in this study.

There have been some reports on the relationship between results of the ZBI and the ADL status [5,13,15], but these results were controversial and there seems to be no research using the Functional Independence Measure (FIM) [16], which is most frequently used in rehabilitation medicine as a measure of ADL, in relation to the ZBI.

In this study, we planned to clarify the relationship between ZBI and FIM scores, instrumental ADL and the depressive state in those enrolled in the LTCI system in Japan and their caregivers.

Materials and Methods

Subjects were people in the community covered by LTCI in the Shima district in Japan. For this study, 500 insured people were randomly chosen and questioned either by letter or by a visiting care manager whether they were in the community or institutionalized and whether they and their families would agree to participate in this research. Those who agreed to participate were visited by nursing

students who administered the various instruments and collected demographic information with regard to the caregiver and disabled person. Eighty of the contacted subjects were institutionalized, 33 could not meet with the nurse because of absence or other reasons, and 143 had declined to participate. Of the remaining 244 subjects, one person who recently had an acute worsening of the disease was removed from the study. Therefore, 243 people (93 males; 150 females) in the community became candidates for the following evaluations.

The question regarding the etiology of the disability was open-ended; therefore, one subject may have reported two or more diseases. A history of brain disease was reported by 152 subjects, and 124 subjects had an orthopedic problem such as osteoarthritis or hip fracture. Other conditions were related to internal medicine, post-surgery, etc.

Among several versions of the ZBI, the 22-item version [8-12] is most widely used. The short version of the ZBI (J-ZBI_8) devised by Arai [17,18] was used to measure the burden on the caregiver in this study. J-ZBI_8 contains 8 items from the 22-item version: items 6, 12, and 13 to assess role strain and items 4, 5, 9, 18 and 19 to assess personal strain.

The FIM has 18 items that are rated on a 7-point scale, with 7 indicating independence and 1 indicating total dependence. The Japanese version according to the definition of the original manual of version 3 [16] was used. Nursing students were instructed in advance by an experienced doctor on how to rate the FIM. The motor subscore of the FIM (FIMM), which is the sum of the 13 motor items, and the cognitive subscore of the FIM (FIMC), which is the sum of the 5 cognitive items, were calculated.

The Japanese version [19] of the Frenchay Activities Index (FAI) [20] was used to evaluate the instrumental ADL. The FAI has 15 items and the total score was used in the statistical tabulations.

The Japan Stroke Scale (Depression Scale) (JSS-D), which was developed by the Japan Stroke Society [21], was also rated. Three choices are given for each of the 7 items (mood, guilt feelings, interest, apathy, anxiety, sleeplessness, and expression) to express the status. The total score to denote the degree of depression was calculated according to the proper weight of each choice [21].

Scattergrams showing the relationship between the J-ZBI_8 and the FIMM, FIMC, FAI, JSSD, and age, respectively, were made and Spearman's rank correlation coefficients were calculated. The classification and regression tree (CART) method [22] was utilized to predict the J-ZBI_8 from the FIMM and FIMC. Then subjects were divided into three groups according to cut-off points decided according to the result of the CART (FIMM less than 20, FIMM from 20 to 79, and FIMM of 80 or more). The average of the total score of J-ZBI_8 was compared among these three groups using analysis of variance and the post-hoc analysis of Duncan's multiple comparison. The JMP (SAS Institute Japan, Inc., Tokyo) and Statistica for Mac (StatSoft Japan Inc., Tokyo) were used for statistical calculations.

The ethical committee of the Fujita Health University Nanakuri Sanatorium approved this research and informed consent was obtained from subjects and their caregivers prior to administration of any of the instruments.

Results

After deleting incomplete data, the numbers of usable data were 234 for FIMM, 237 for FIMC, 239 for FAI, and 220 for JSSD. Since some subjects did not have a participating caregiver, in addition to missing data, J-ZBI_8 data were only obtained from 167 subjects.

Table 1 shows the Spearman's rank correlation coefficients among the J-ZBI-8, FIMM, FIMC, FAI, JSS-D, and age. The highest correlation with the J-ZBI-8, was obtained by the JSS-D (0.396). Figure 1 shows scattergrams of the relationship between the J-ZBI-8 and FIMM, FIMC, FAI, JSS-D, and age, respectively. The results of the CART are shown in Figure 2. The average J-ZBI_8 score was 5.44 ± 5.58 in people with an FIMM less than 20, 9.07 ± 7.85 in people with the FIMM from 20 to 79 (middle FIMM group), and 3.98 ± 5.00 in those with an FIMM of 80 or more. The average score on the J-ZBI_8 in middle FIMM group was significantly greater than that for caregivers of other groups, thus, indicating a high burden on caretakers of subjects in this middle FIMM group according to Duncan's post-hoc test. Relationship between the FAI and J-ZBI_8 showed an L-shaped pattern that indicated the absence of a high J-ZBI_8 score in association with a high FAI; however, the caretakers of many subjects had a low ZBI score in spite the subject having a low FAI score.

	FIMM	FIMC	FAI	JSSD	Age
ZBI-8	-0.205	-0.249	-0.205	-0.396 (Eliminate minus)	0.012
FIMM		0.61	0.739	-0.367	-0.036
FIMC			0.639	-0.49	0.099
FAI				-0.351	-0.144
JSSD					-0.045

Table 1: Rank correlation among ZBI, FIMM, FIMC, FAI, and JSSD. ZBI: Zarit Caregiver Burden Interview; ZBI-8: Japanese short version of ZBI; FIM: Functional Independence Measure; FIMM: motor subscore of the FIM; FIMC: cognitive subscore of the FIM; FAI: Frenchay Activities Index; JSSD: Japan Stroke Scale for Depression.

Discussion

The ZBI is frequently used to measure the subjective burden of care. There are several versions of the ZBI, that is, those with 29 items [5], 20 items [6], and 22 items [7,8,12]. In a review, Hébert cited two papers that showed test-retest reliability of 0.71 and 0.89 and Cronbach's alpha of 0.91 and 0.85, respectively [23]. Validity was assured by an association with psychological well-being [24], health-related quality of life [25], frequency and difficulty of caregivers' problems [26], adherence ratings [27], categories of problems of caregivers in relation to various parameters [26], and the Brief Symptoms Inventory or Global Index of Burden [23]. Arai proposed a Japanese version of the ZBI (J-ZBI) through the review process of translation and reverse-translation and established its high reliability and validity [12]. Since it is very time consuming to answer the 22 items on the most frequently used ZBI, Arai made a short version of the Japanese version of the ZBI (J-ZBI_8) [17,18]. The reliability and validity of J-ZBI_8 were as follows. The correlation coefficient between ZBI and J-ZBI_8 was 0.93 among 691 people with disability in a Japanese community [17] and 0.92 among 169 people who used care services in the community [18]. To assess adequately the degree of the

burden of care, the score of the J-ZBI_8 can be converted to the standard ZBI by multiplying by 2.75 (22 divided by 8).

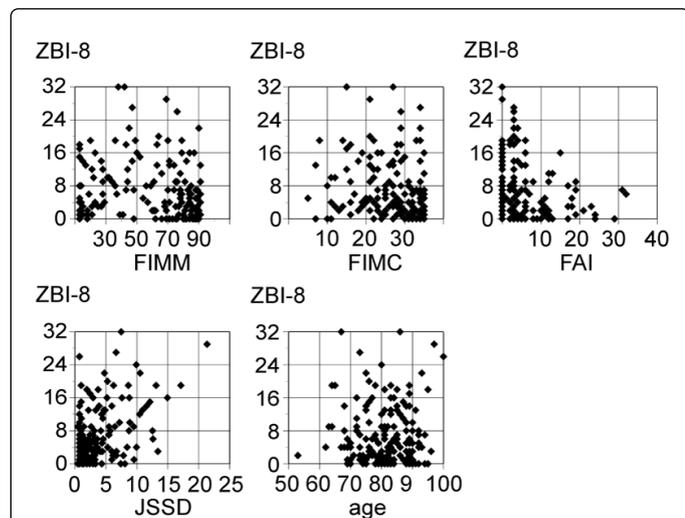


Figure 1: Scattergram in relation to ZBI. To consider the contribution to ZBI, scattergram against ZBI was plotted. ZBI: Zarit Caregiver Burden Interview; FIMM: Motore subscore of the FIM; FIMC: Cognitive subscore of the FIM; FAI: Frenchay activities index; JSSD: Japan Stroke Scale (Depression Scale).

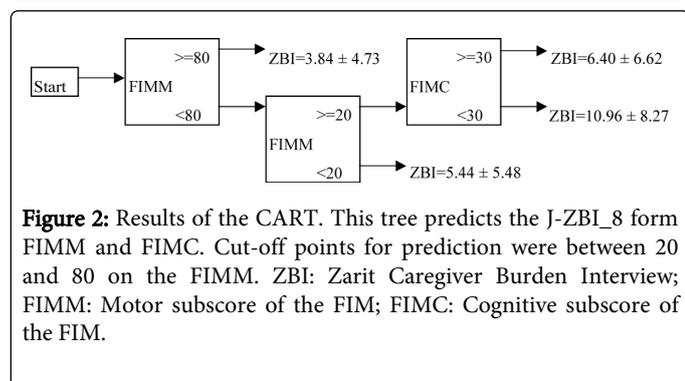


Figure 2: Results of the CART. This tree predicts the J-ZBI_8 form FIMM and FIMC. Cut-off points for prediction were between 20 and 80 on the FIMM. ZBI: Zarit Caregiver Burden Interview; FIMM: Motor subscore of the FIM; FIMC: Cognitive subscore of the FIM.

Factors influencing the burden of the caregiver can be classified into two groups: those related to caregivers and those related to care recipients. Caregivers' emotional factors such as depression would be elicited by factors related to care recipients. The cause-and-effect logic may be complicated; however, factors related to recipients would be first in the chain of events affecting the caregiver. In this study, to avoid confusion, we discussed factors only related to care recipients such as their ADL level, instrumental ADL level and the depressive state. Factors related to impairment, such as paralysis or range of motion, are neglected in this study since the degree of impairment is reflected in the ADL or instrumental ADL in the chronic state.

The factor most related to the ZBI in this study was depression. The JSS-D, which we used, is not popular internationally. The items on the JSS-D were selected from items on 11 existing scales, DSM-IV and ICD-10. Conjoint analysis, which used 18 hypothetical patients and involved 100 specialists belonging to the Japan Stroke Society, was performed to decide the proper weight of each of the selected items [21]. The inter-rater reliability of each item on the JSS-D was expressed by the value of the kappa coefficient ranging from 0.65 to

0.89 and the intra-rater reliability was 0.80 to 0.97 [21]. We chose the JSS-D because of its validity, reliability and ease of use.

With regard to the relationship between the ZBI and depression scales, Arai reported a correlation coefficient of 0.67 between the ZBI and Center for Epidemiologic Studies Depression Scale in 45 Japanese elderly in a rural community [13]. Since a depressive state not only lowers the activities of those with the depression but also makes the caregiver overly careful not to worsen the depression, the burden on the caregiver becomes great.

In this study, the ZBI score had little relation to ADL or instrumental ADL. Opinions on such a relationship in previous papers were controversial, with some reports showing no relationship. There was no relation between Physical Self Management of demented patients in an ADL instrument and the total score of Relatives' Stress Scale [10]. Scholte showed a 14% contribution of the FAI to predict results of the Sense of Competence Questionnaire for partners of stroke survivors; however, no contribution of the Barthel Index was found [28]. The fact that more than half of Scholte's patients were independent would contribute to the negative result. Zarit showed a non-significant correlation coefficient of -0.06 between the ZBI and ADL scores and -0.20 between the ZBI and Lawton's instrumental ADL scores [5]. Arai showed no differences in the mean ZBI score of caregivers when caregivers were divided into two groups according to the patients' Barthel Index score (more than 60; 60 or less) [12].

On the other hand, Fitting noted that severe functional impairment was related to the severe burden expressed by the ZBI in spouses of patients with dementia [15]. Although this impairment scale includes both cognitive disturbance and physical disability, this is one proof of the contribution of ADL status to the burden of care. The Katz ADL index showed a small but significant correlation to the ZBI score among caregivers of demented patients [29].

Why did these discrepancies arise? Detection power of evaluation instruments to find small but important differences may change the result. Since the FIM uses a 7-point scale for each item, the use of the FIM can contribute to refining such a relationship. The FIM is the most frequently used ADL instrument in rehabilitation. Its reliability [30-33] and validity [30,34-36] are well established. Only two papers mentioned both the ZBI and the FIM [26,37]; however, these papers separately described the relation between the caregivers' problems and the ZBI score and the relation between the caregivers' problems and the recipients' FIM. Therefore, we employed the FIM in this study.

In previous papers on the burden of caregiving, the most prevalent diagnosis of patients was dementia; however, our subjects included a mixture of physically disabled and demented patients. ADL can be lowered in two ways. In physically disabled patients, the impairment itself, such as paralysis, disturbs independence. Decreased initiative and confusion as to how to perform ADL are reasons for ADL dependency in demented patients. Thus, the proportion of the physical disabilities and intellectual problems will change the interpretation of the relationship between the burden of care and the ADL status.

In the present study population, the relationship between ZBI and FIM scores is rather complex and does not show a linear pattern as can be seen in the scattergram. Arai commented that those who looked after the disabled elderly with partially limited ADL tended to feel a heavier caregiver burden than those caring for the elderly who were totally dependent in ADL [13]. This was reconfirmed in our study by the comparison of the FIMM among 3 groups that were formed according to the FIMM. This phenomenon can be explained as

follows. Assisting movement of subjects who need a great deal of help is a harder burden of care than simply moving the subject without considering the subject's desires. In order that a patient can perform an ADL a little, a caregiver must wait for long periods for the patient to execute the activity. Thus, the burden of the care of subjects who can perform a few ADL is more severe than the burden of care of completely bedridden subjects. On the other hand, the relationship between IADL and ZBI was rather simple. Subjects who performed instrumental ADL place only a slight burden on caregivers. It is because both good physical ability and good cognitive ability are needed to perform instrumental ADL.

The CART was used to find the cut-off point to discuss the above matter. In general, the beneficial points of the CART were the ability to treat non-linear relationships and simple results sufficiently to understand the logic of the result. Since the CART itself discards information on variables that are irrelevant for the purpose, we did not want to use the CART solely as a predictive tool but wanted to use it as a method to determine the cut-off point of the ADL.

Some reports stress the stronger relationship of the behavioral disturbance to the ZBI than the ADL [13,38]. In our study, the cognitive subscore of the FIM can be recognized as a marker of behavioral disturbance because it contains items on social interaction and problem solving. Since the rank correlation coefficient between the ZBI and the cognitive subscore of the FIM is not very high, behavioral problems do not seem to be the main factor in a deteriorated ZBI score. The power of abnormal behavior changes according to the level of ADL. If patients with good physical ability have a behavior problem, they can go anywhere and do what they want. So the anticipated stress of an undesirable event will be large, such as in the case of dementia. If the patient is almost dependent in ADL, the extent of damage by the abnormal behavior will be small because the area where an undesirable event occurs can be predicted. Thus, subjects with lower ADL status will weaken the correlation between the ZBI and FIMC in this study.

The age of people with disability showed low correlation to the J-ZBI_8 score. One reason is the narrow range of age distribution in this study. The average age was 81 with a standard deviation of 8. As a shortcoming of this study, profiles of caregivers were not analyzed. In a follow-up study, Arai found a difference in the change of the burden whether the caregiver was a spouse or a daughter-in-law [14]. Furthermore, Fitting noted that in younger wives and older husbands scores indicating burden were higher with increasing levels of impairment; however, this did not hold true for older wives or younger husbands [15]. The effects of characteristics of caregivers on the degree of burden of care is rather complicated. Although stratification by gender, age, or degree of kinship is needed and a fairly larger sample will be required to clarify the complicated structure, adding many cases is not easy and is an issue for studies in the future.

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