

Validation of a new Assessment of the Burden on Caregivers (ABC-16)

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Abstract

Aims: The aim of this study is to evaluate the validation of a newly developed self-administered assessment of the burden on caregivers (ABC-16).

Methods: The subjects were 51 family caregivers (mean age 63 ± 11 years) for the first trial and 31 family caregivers (mean age 58 ± 14 years) for the second trial. The ABC-16 consists of 16 items and is designed to cover 4 dimensions (the care receiver's burden, burden on social life, financial burden, and burden on health).

Results: In the first trial, the mean and standard deviation of the total score of the ABC-16 was 14.98 ± 7.52. The first trial showed high reliability; the internal consistency was $\alpha = 0.821$ and significant correlations among the four dimensions were found ($P < 0.05$). A multiple regression analysis showed strong correlations between the ABC-16 and the QOL of the caregivers ($P = 0.034$), and the caregiving during the night ($P = 0.001$).

The second trial showed findings similar to those in the first trial, which suggested the good cross validation of the ABC-16.

Conclusions: It is suggested that the ABC-16 is an excellent tool for assessing the care burden with high validity.

Key words: Care burden, In-home care, Self-administered questionnaire, Family caregiver, QOL

抄 録

目的:本研究の目的は、新たに作成された自己記入式介護負担評価尺度(ABC-16)の妥当性を検討することである。

方法:対象者は、第1群では51名(平均年齢63±11歳)、第2群では31名(平均年齢58±14歳)の家族介護者である。

結果:第1群におけるABC-16総計の平均点は14.98±7.52であった。第1群では高い妥当性(内的整合性、 $\alpha = 0.821$)を示し、かつ4つの領域間に有意の相関が得られた($P < 0.05$)。重回帰分析によりABC-16と介護者のQOL($P = 0.034$)および夜間介護($P = 0.001$)とにおいて強い関連が見られた。第2群は第1群の結果とほぼ同様の結果が得られ、ABC-16の交差妥当性のあることが示唆された。

結論:ABC-16は高い妥当性を有する大変優れた介護負担評価尺度であることが示された。

キーワード: 介護負担、在宅ケア、自己記入式質問表、家族介護者、QOL

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I. Introduction

Recent survey by Japanese Health, Labor and Welfare (2001) showed 64.4% out of the in-home caregivers has been suffering from some psychological distress and 68.3% among those who have experienced bearing hatred toward their care receivers.

Kosberg (1988) reported same results that excessive social, economic, and psychological burden on caregivers and caregiver in experience have been found to be antecedents to abuse of elderly.

It is widely accepted that the burden experienced by caregivers is not a single entity, but is multi-dimensional, including physical, psychological, emotional, social, and financial burden (George and Gwyther, 1986).

Fenger and Goodrich (1979) referred to call the family caregivers as the hidden patients.

However, we have not yet arrived at a golden standard for measuring the burden on caregivers.

The aim of this study is to evaluate the validation of a newly developed self-administered assessment of the burden on caregivers (ABC-16, Table1).

II. Methods

The results of examinations performed in April 2002 using 51 in-home family caregivers (16 males and 35 females, mean age 63 ± 11 years) at urban district in Kobe were cross-sectionally analyzed for the first trial.

In order to evaluate the cross validation of the ABC-16, the second trial was performed in July 2002 in another 31 family in-home caregivers (5 males and 26 females, mean age 58 ± 14 years) at urban district in Northern Osaka .

The following data were collected:

- (1) Age, sex, family relationship and caregiver's quality of life (QOL) .
- (2) The QOL questionnaire has three items including for refreshment, for satisfaction and for well being and a 3-point Likert scale (always I agree=2, Sometimes I agree=1, No, I don't agree=0) was used for measuring.
- (3) Age, sex, and severity of behavioral psychological symptoms of the care receivers.
- (4) Information concerning the care including duration of in-home care, time length for providing the care in a day and necessity of providing care during night.

- (5) Relationships with other rating scales such as the rating scale for providing the care (severity of disorders) by care insurance, index of independence for frail elderly by the ministry of health, labor and welfare, and degree of incompetence by guardianship for adults.

Table 1 Assessment of the Burden on Caregivers (ABC-16)

Care receiver's Burden (troubles with care receivers)

Dependence on Caregiver:	My Care receiver completely depends on me. My Care receiver never does whatever she or he can.
Demands to Caregiver:	My Care receiver is obnoxious and demands too much. My Care receiver does not show concern for me.

Burden on Social Life

Influence on daily life:	Because of caregiving, I cannot finish my work. My schedule has changed because of care giving.
Influence on relationships:	Care giving interferes with my relationships with friends and neighbors. I have nothing for support received in my care giving.

Financial Burden

Influence on present life:	Savings are decreasing. Although expense increase, I cannot afford to buy necessities.
Anxiety concerning the future:	I feel anxious, as there are no savings for the future. I cannot just afford emergency expenses.

Burden on Health

Physical Burden:	I'm exhausted. I'm not in good conditions of health.
Psychological Burden:	I'm irritated and short-tempered. I'm depressed.

The ABC-16 consists of 16 items and is designed to cover 4 dimensions including the care receiver's burden (troubles with care receivers), burden on social life, financial burden, and burden on health.

Each dimension has two subscales, that is,

- (1) Care receiver's burden: dependence on caregiver and demands to caregiver,
- (2) Burden on social life: influence on daily life and influence on relationships with others,

(3) Financial burden: influence on present life and anxiety concerning the future,

(4) Burden on health: physical burden and psychological burden.

The ABC-16 uses a 3-point Likert scale (always I agree=2, Sometimes I agree=1, No, I don't agree=0), and total score of the ABC-16 can theoretically range from a low of 0 to a high of 32.

The results of the ABC-16 were statistically analyzed using t-test, ANOVA, the chi-square test, and the correlation coefficient, and a multiple regression analysis, and a factorial analysis for multivariate analysis.

A value of probability less than 0.05 was considered as significant. The internal consistency was calculated using Cronbach's α coefficient.

III. Results

1. The demographic features of the care receivers

The demographic features of the care receivers in the first trial were drawn in Table 2.

The age distribution of fifty-one in-home care receivers (males 16, females 35) were ranged between 58 and 95 years (mean $77.8 \pm SD9.1$).

The majority of care receivers (72.5%: 37/51) have been provided in-home caring more than 3 years.

Among our 51 care receivers, those who needed the care during night were distributed in 25.5% (13) for always, 11.8% (6) for frequent, 39, 2% (20) for sometimes.

The duration time for providing the care in a day was distributed 47.1 % (24/51) for more than half a day, 21.6 % (11) for 7-12 hours, 15.7% (8) for 3-6 hours, and 15.7 % (8) within 2 hours.

Results of assessments by other criteria including the Rating scale for providing the care (severity of disorders) by Care insurance, Index of Independence for frail elderly by the Ministry of Health, Labor and Welfare, and Degree of Incompetence by Guardianship for Adults were shown in Table 2.

Our 31 subjects in the second trial showed significant different distribution in the scale for providing the care (severity of disorders) by legal care insurance ($\chi^2=30.525$, d.f.=7, $P=0.000076$), Index of Independence for frail elderly by the Ministry of Health, Labor and Welfare ($\chi^2=38.478$, d.f.=3, $P=0.0000$), and Degree of Incompetence by Guardianship for

Adults ($\chi^2=29.377$, d.f.=3, $P=0.000002$), compared with those of 51 care receivers in the first trial (Table 2).

Table 2 Demographic details(No.1)

	First Trial (N=51)	Second Trial (N=31)	P
Family relationship			
Spouse	25(49.0%)	13(41.9%)	NS
Daughter-in-law	9(17.6%)	4(12.9%)	
Children	16(31.4%)	10(32.3%)	
Others	1(2.0%)	4(12.9%)	
Care receivers			
Age (Mean \pm S D)	77.8 \pm 9.1	74.5 \pm 11.7	NS
Sex (Male: Female)	16 : 35	13 : 18	NS
Duration of Care			
One year or less	6(11.8%)	5(16.1%)	NS
1-2 years	8(15.7%)	5(16.1%)	
3 years or more	37(72.5%)	21(67.8%)	
Care Need during Night			
Always	13(35.5%)	7(22.6%)	NS
Frequent	6(11.8%)	6(19.4%)	
Sometimes	20(39.2%)	10(32.2%)	
Seldom or Absent	12(23.5%)	8(25.8%)	
Time of care providance			
1. 12 hours or more	24(47.0%)	15(48.4%)	NS
2. 7-12 hours	11(21.6%)	6(19.4%)	
3. 3-6 hours	8(15.7%)	2(6.5%)	
4. 2 hours or less	8(15.7%)	8(25.8%)	

Table 2 Demographic details (No.2)

	First Trial (N=51)	Second Trial (N=31)	P	
Long-term care need*				
1. Independence	0(0.0%)	4(12.9%)	0.00008	
2. Helping	2(3.9%)	2(6.5%)		
3. Caring (grade 1)	5(9.8%)	5(16.1%)		
Caring (grade 2)	8(15.7%)	6(19.4%)		
Caring (grade 3)	4(7.1%)	3(9.7%)		
Caring (grade 4)	13(25.5%)	0(0.0%)		
Caring (grade 5)	18(35.3%)	3(9.7%)		
Not certificated	1(2.0%)	8(25.8%)		
* : Caring (grade 1) indicates the necessity of 2 hours or less a day of care, and caring (grade 5) indicates the necessity of more than 12 hours a day of care.				
Index of independence for frail elderly citizens				
Independence	2(3.9%)	13(41.9%)	0.00000	
Walking inside	10(19.6%)	15(48.4%)		
Sitting	24(47.1%)	0(0.0%)		
Bedridden	15(29.4%)	3(9.7%)		
Degree of incompetence by guardianship for adults				
Incompetence	26(51.0%)	1(3.2%)	0.000002	
Severe incompetence	14(27.5%)	10(32.3%)		
Mild incompetence	8(15.7%)	5(16.1%)		
Competence	3(5.9%)	15(48.4%)		

NS : statistically not significant

2. Reliability

The internal consistency of the ABC-16 was $\alpha = 0.821$ which showed high reliability.

Significant correlations among the four dimensions were found ($P < 0.05$, Table 3).

Similarly, high reliability was obtained in the second trial, that was, the internal

consistency of the ABC-16 was $\alpha = 0.917$ and there was strong correlation among the four dimensions ($P < 0.001$).

Table 3 Internal Consistency and Correlation Coefficient among each domain

First trial (N=51)				$\alpha = 0.821$
Correlation coefficient				
	S	F	H	
C	.547	.541	.848	
	.320-.715	.312-.711	.747-.911	
S		.296	.751	
		.023-.529	.600-.851	
F			.739	
			.582-.843	
Second trial (N=31)				$\alpha = 0.918$
Correlation coefficient				
	S	F	H	
C	.662	.431	.656	
	.434-.810	.129-.659	.425-.807	
S		.565	.732	
		.300-.750	.538-.852	
F			.666	
			.444-.814	

C : Care receiver's Burden

S : Burden on Social Life

F : Financial Burden

H : Burden on Health

3. Proportion of Positive Answers among 16 items of the ABC-16 (Table 4)

The proportion of positive answers among 16 items of the ABC-16 was ranging from a low of 37.3% for Item No10 to a high of 80.4% for Item No 1.

The distribution of positive answers in 4 dimensions was 90.2% (46/51) for care receiver's burden, 94.1% (48/51) for burden on social life, 76.5% (39/51) for financial burden, and 90.2% (46) for burden on health, respectively.

In the second trial, the proportion of positive answers among 16 items of the ABC-16 was ranging from 20.0% for Item No10 to 83.9% for Item No1, that was similar to those of the first trial.

The distribution of positive answers in 4 dimensions was 90.3% for care receiver's burden, 90.3% for burden on social life, 71.0% for financial burden, and 83.9% for burden on health, respectively, which was not different from those of the second trial.

Table 4 Frequency of four Dimensions

	The first trial		The second trial	
	N=	%	N=	%
Care receiver's Burden	46	90.2	28	90.3 ns
Burden on Social Life	48	94.1	28	90.3 ns
Financial Burden	39	76.5	24	77.4 ns
Burden on health	46	90.2	27	87.1 ns

ns : statistically not significant

4. The mean and standard deviation of the scores

The mean and standard deviation of the total score of the ABC-16 was 14.98 ± 7.52 , and 4.02 ± 2.24 for care receiver's burden, 4.53 ± 2.61 for burden on social life, 2.94 ± 2.18 for financial burden, and 3.49 ± 2.18 for burden on health.

Table 5 The Mean and Standard Deviation (SD)

	The first trial (N=51)	The second trial(N=31)
	Mean \pm S D	Mean \pm S D
Care receiver's Burden	4.02 ± 2.24	4.23 ± 2.57
Burden on Social Life	4.53 ± 2.61	3.68 ± 2.26
Financial Burden	2.94 ± 2.56	2.90 ± 2.63
Burden on health	3.49 ± 2.18	3.23 ± 2.56
Total Score	14.98 ± 7.52	14.13 ± 8.52

Statistically not significant

The mean and standard deviation of the total score in the second trial was 14.13 ± 8.52 ,

and 4.23 ± 2.57 for care receiver's burden, 3.68 ± 2.36 for burden on social life, 2.90 ± 2.83 for financial burden, and 3.23 ± 2.56 for burden on health.

The results of the second trial showed nearly same as those of the first trial, which is shown in Table 5.

5. Factorial Validity

Using a factorial analysis, we evaluated whether the results in this study coincided with the ABC-16 model. Then, four latent factors were obtained including the care receiver's burden, burden on social life, financial burden, and burden on health, which nearly corresponded to our model. Significant Correlations among the four dimensions were found ($P < 0.05$).

A multiple regression analysis of the first trial showed the strong correlations between the ABC-16 and the QOL of the caregivers (standardized β coefficient 0.254, $P = 0.034$), the care giving during the night (standardized β coefficient 0.485, $P = 0.001$).

In the second trial, same findings between the ABC-16 and other factors were obtained (Table 6).

Table 6 Correlation with other Factors by Multi-regression Analysis

	First trial(N=51)		Second trial(N=31)	
	β	P	β	P
Length of Care	0.164	NS	0.030	NS
Night care need	0.485	0.001	0.470	0.003
Long-term care need	0.239	NS	0.253	NS
Index of independence	0.317	0.051(NS)	0.049	NS
Degree of incompetence	0.084	NS	0.240	NS
Health	0.145	NS	0.088	NS
Satisfaction	0.162	NS	0.093	NS
Well Being	0.369	0.009	0.478	0.014
	(R-Square 0.578)		(R-Square 0.352)	

NS : statistically not significant

6. QOL of the caregivers

In the first trial, the results of the distribution of the health questionnaire were 29.4% (15/51): strong agreement, and 35.3% (18/51): agreement. The results of the satisfaction questionnaire were 35.3% (18/51): strong agreement, and 37.3% (19/51): agreement. Those of the well being were 5.9% (3/51): strong agreement, and 54.9% (28/51): agreement.

The distribution of the QOL of the caregivers in the second trial was different from that of the health and the satisfaction questionnaire in the first trial, as shown in Table 7.

Table 7 QOL of the caregivers

	First trial	Second trial	P
	N (%)	N (%)	
1. Health			
Strongly agree	15(29.4%)	0(0.0%)	0.0003
Agree	18(35.3%)	15(48.4%)	
Disagree	18(35.3%)	16(51.6%)	
2. Satisfaction			
Strongly agree	18(35.3%)	3(9.8%)	0.0024
Agree	19(37.3%)	13(41.9%)	
Disagree	14(27.5%)	15(48.4%)	
3. Well Being			
Strongly agree	3(5.9%)	5(16.1%)	NS
Agree	28(54.9%)	12(38.7%)	
Disagree	20(39.2%)	14(45.2%)	

NS : statistically not significant

IV. Discussion

Families provide 80 percent of all In-home care for frail elderly, and conversely, eighty percent of a frail elderly with In-home care needs depend primarily on their family, and negative effects on the caregiver's health or financial burden cannot be ignored (Silverstone,

1993).

The caring is, in general, the one of the altruistic behaviors which caregivers and care receivers both are mutually able to understand their each QOL and the close bond between the two.

However, our previous study (Kohashi, et al, 1995) showed that the majority of family caregivers were in emotional troubles with their care receivers, mainly because of burden on social life, burden on health, and financial burden. Some families experience a crisis when they can no longer provide the caregiving needed by a frail elderly relative.

The framework of providing the care, in general, consists of both the problems of the part of the care receivers including severity of diseases, worsening of activities of daily life (ADL) and the quality of life (QOL) and the troubles in the part of the caregivers such as worsening of the QOL, restriction of social life, problems on health and financial strain (Fig. 1).

Imprudently to say, the more the capacity of care providing extends, the less the pain of the care receivers is, and the less the capacity of the caring is, the more the QOL of care receivers get worsened.

In order to promote the providing of the care better, it needs the good quality of standard for assessing the care burden and optimal support for the caregiving according to that standard.

Further, we are able to expect that measuring the care burden have advantage to ask caregivers' own reflection and more to notice excessive dependence on caregivers to care receivers.

However, little attention has been paid to assessment and alleviation of the primary caregiver's burden in today's Japan.

To begin with, we made a draft-screening test for assessing care burden on reference to several famous questionnaires including the Care Strain Index, the Cost of Care Index, the Caregiver Burden Inventory, and Japanese version of Zarit Caregiver Burden Interview, by employing kinds of the multivariate analyses.

The CSI was developed by Robinson (1983) as a screening instrument for detecting strain, and consists of 13 items such as feelings of inconvenience, confinement, adjustments, competing demands, upsetting behavior, sleep disturbance, and financial strain and such like, and is scored by summing the no (0) and yes (1) responses for the items.

The CCI, developed by Kosberg and Cairl (1986), consists of 20 items and is designed to cover five dimensions of care giving, namely, personal and social restrictions, physical and emotional health, value items, the care recipient as provocateur, and economic costs. It uses a 4-point Likert scale.

And the CBI by Novak and Guest (1989) includes 24 items and is divided into five factor subscales: time dependence burden, developmental burden, physical burden, social burden, and emotional burden.

Japanese version of Zarit Caregiver Burden Interview (Arai, Y., Kubo, K., Hosakawa, T., et al, 1997) has two factors of personal strain and role strain.

After revision through our own experiences, we developed a new assessment of the burden on caregivers (ABC-16), which consisted of four dimensions including the care receiver's burden, the burden on social life, the financial burden and the burden on health.

In the present study, we evaluated the reliability, the validity, and the repeatability of the ABC-16.

Then, it should be indicated that the ABC-16 is an excellent tool for assessing the care burden because that it has high reliability, and high validity, good repeatability and also has no risk or burden on the examinee during administration.

Clinical implication and limitation

The 16 items in the ABC-16, which are made up after revision by statistical analyses and by clinical experiences of many instruments for assessing the care burden are to be universal ingredients regardless of culture, religious belief, language or life style differences among individuals and ethnic groups. The ABC-16 is designed to cover 4 different dimensions and 8 subscales, therefore are obviously able to clarify the individual need of the care burden. Assessment by the ABC-16 can easily and quickly be carried out by any member without tangled explains.

While, the sample size was smaller for the statistical analyses.

The subjects in both the first- and the second trial are unilaterally urban family member in Japan.

The study was cross-sectionally analyzed and the capacity of the ABC-16 for reflecting the change of care burden by some intervention was not evaluated.

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