

KEY POINTS

- There is a paucity of observational studies of the impact of home care services on burden or other aspects of the caregiver's experience.
- This study examined whether the use of care services was associated with lower feelings of burden among family caregivers in a town in the north in Japan.
- After controlling for the effects of severity of impairments, the use of home care services was associated with lower feelings of burden among family caregivers.
- The findings suggest that home care services have been successfully reducing burden among family caregivers in the study area.

The limitation of the present study is its small sample size, which precluded the use of variables that had been previously reported to be related to caregiver burden, e.g. the kinship of the caregiver (Pinquart and Sørensen, 2003). Given the cross-sectional nature of the data, we also do not know how much of the differences in burden were due to service use or to pre-existing characteristics. Nonetheless, one of the strengths of the present study is that we obtained the sample from the list of people using services, and not from volunteers or clinical populations. In addition, this is the first observational (cross-sectional) study to clearly show the effect of the use of care services on the reduction of caregiver burden in a community setting.

ACKNOWLEDGEMENTS

The authors wish to thank the participants of this study, which was in part supported by research grants provided by the Ministry of Health, Labor and Welfare (Grant No. H11-C036, H15-C025, H17-C029), the Ministry of Education, Culture, Sports, Science and Technology, Japan (Grant No. 14570375) and the Uehara Memorial Foundation.

REFERENCES

- Arai Y. 2001. Japan's new long-term care insurance. *Lancet* **357**(9269): 1713.
- Arai Y, Kudo K, Hosokawa T, Washio M, Miura H, Hisamichi S. 1997. Reliability and validity of the Japanese version of Zarit Caregiver Burden. *Psychiatry Clin Neurosci* **51**(5): 281–287.
- Arai Y, Miura H, Washio M, Kudo K. 1998. Depression among caregivers of the elderly in need of care and their service utilization: a pilot study. *Psychiatry Clin Neurosci* **52**: 463–465.
- Arai Y, Sugiura M, Miura H, Washio M, Kudo K. 2000. Undue concern for others' opinions deters caregivers of impaired elderly from using public services in rural Japan. *Int J Geriatr Psychiatry* **15**: 961–968.
- Arai Y, Washio M, Miura H, Kudo K. 1998. Dementia Care in Japan: insurance for long-term care legislation in Japan. *Int J Geriatr Psychiatry* **13**: 568–574.
- Arai Y, Zarit S, Kumamoto K, Takeda A. 2003. Are there inequities in the assessment of dementia under Japan's LTC insurance system? *Int J Geriatr Psychiatry* **18**: 346–352.
- Arai Y, Zarit SH, Sugiura M, Washio M. 2002. Patterns of outcome of caregiving for the impaired elderly: a longitudinal study in rural Japan. *Aging Ment Health* **6**: 39–46.
- Arbuckle J. 1995. *AMOS: Analysis of Moment Structures User's Guide*. Small Waters: Chicago, IL.
- Asada T, Kinoshita T, Morikawa S, Motonaga T, Kakuma T. 1999. A prospective five-year follow-up study on the behavioral disturbances of community-dwelling elderly people with Alzheimer disease. *Alzheimer Dis Assoc Disord* **13**: 202–208.
- Asada T, Yoshioka M, Morikawa S, et al. 1994. Development of a Troublesome Behavior Scale (TBS) for the elderly patients with dementia. *Jpn J Public Health* **41**: 518–527 (in Japanese).
- Bass DM, Noelker LS, Rechlin LR. 1996. The moderating influence of service use on negative caregiving consequences. *J Gerontol B-Psychol* **51B**: S121–S131.
- Bentler P. 1990. Comparative fit indices in structural models. *Psychologic Bull* **107**: 238–246.
- Browne M, Cudeck R. 1993. Alternative ways of assessing model fit. In *Testing Structural Equation Models*. Bollen KA, Long JS (eds). SAGE Publications: Newbury Park, CA; 137–162.
- Caserta M, Lund D, Wright S, Redburn P. 1987. Caregivers to dementia patients: use of community services. *Gerontologist* **27**: 209–213.
- Collins C, Stommel M, King S, Given CW. 1991. Assessment of the attitudes of family caregivers toward community services. *Gerontologist* **31**(6): 756–761.
- Donaldson C, Tarrier N, Burns A. 1997. The impact of the symptoms of dementia on caregivers. *Br J Psychiatry* **170**: 62–68.
- Draper BM, Poulos CJ, Cole AM, Poulos RG, Ehrlich F. 1992. A comparison of caregivers for elderly stroke and dementia victims. *J Am Geriatr Soc* **40**: 896–901.
- Eto F. 2002. Assessments of physical function. In *Textbook of Geriatric Medicine*, Revised Japan Geriatric Society (eds). Medical View: Tokyo; 164–169 (in Japanese).
- Harper S, Lund DA. 1990. Wives, husbands and daughters caring for institutionalized dementia patients: toward a model of caregiver burden. *Int J Aging Hum Dev* **30**: 241–262.
- Kosloski K, Montgomery RJV. 1995. The impact of respite use on nursing home placement. *Gerontologist* **35**(1): 67–74.
- Koss E, Paterson MB, Ownby R, Stuckey JC, Whitehouse PJ. 1993. Memory evaluation in Alzheimer's disease: caregivers' appraisals and objective testing. *Arch Neurol* **50**: 92–97.
- Lawton MP, Brody EM, Saperstein AR. 1989. A controlled study of respite service for caregivers of Alzheimer's patients. *Gerontologist* **29**(1): 8–16.
- LoGiudice D, Woltrawicz W, McKenzie S. 1995. Prevalence of dementia among patients referred to an aged care assessment team and associated stress in their careers. *Aust J Public Health* **19**: 275–279.
- Maki N, Ikeda M, Hokoishi K, et al. 1998. Japanese version of the Short-Memory Questionnaire: memory evaluation in Alzheimer's disease. *Brain Nerve* **50**: 415–418 (in Japanese).

- Miller B, Townsend A, Carpenter E, Montgomery RVJ, Stull D, Young RS. 2001. Social support and caregiver distress: a replication analysis. *J Gerontol B-Psychol* **56B**: S249–S256.
- Ministry of Health and Welfare. 1996. *White Paper on Welfare (Kousei Hakusho)*. Gyousei, Tokyo (in Japanese).
- Montgomery RJV, Gonyea JG, Hooymann NR. 1985. Caregiving and experience of subjective and objective burden. *Fam Relations* **34**: 19–26.
- Office of Management and Coordination Agency. 1997. *Attitude Towards Service Use. Statistics on Aging Society*. Publication Office for the Ministry of Finance: Tokyo; 153.
- Pearlin LI, Aneshensel CS, Mullan JT, Whitlatch CJ. 1995. Caregiving and its social support. In *Handbook on Aging and the Social Sciences*, George LK, Binstock RH (eds). Academic Press: New York; 283–302.
- Pinquart M, Sörensen S. 2003. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *Gerontol B-Psychol* **58B**: P112–P128.
- Pot AM, Zarit SH., Twisk JWR, Townsend AL. 2005. Transitions in caregivers' use of paid home help: associations with stress appraisals and well-being. *Psychology and Aging* **20**(2): 211–219.
- Schulz R, O'Brien A, Czaja S, et al. 2002. Dementia caregiver intervention research: in search of clinical significance. *Gerontologist* **42**(5): 589–602.
- Shadish WR, Cook TD, Campbell DT. 2001. *Experimental and Quasi-Experimental Designs For Generalized Causal Inference*. Houghton Mifflin: Boston, MA.
- Sörensen S, Pinquart M, Duberstein P. 2002. How effective are interventions with caregivers? *Gerontologist* **42**(3): 356–372.
- Vitaliano P, Russo J, Young HM, et al. 1991. The screen for caregiver burden. *Gerontologist* **31**: 76–83.
- Wade DT, Collins C. 1998. The Barthel ADL Index: a standard measure of physical disability? *Int Disabil Stud* **10**: 64–67.
- Watts J. 1998. Caring for Japan's elderly mission impossible? *Lancet* **352**: 798.
- Zarit SH, Femia EE, Stephens MAP. 2003. The validities of research findings: The case of interventions with caregivers. *Alzheimer's Care Quart* **4**: 216–228.
- Zarit SH, Reever KE, Bach-Peterson J. 1980. Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist* **20**: 649–655.
- Zarit SH, Tood PA, Zarit SM. 1986. Subjective burden of husbands and wives as caregivers. *Gerontologist* **26**(3): 260–265.
- Zarit SH, Zarit JM. 1990. *The Memory and Behavior Problems Checklist 1987R and the Burden Interview*. Pennsylvania State University Gerontology Center: University Park, PA.

Factors related to potentially harmful behaviors towards disabled older people by family caregivers in Japan

Megumi Sasaki, Yumiko Arai*, Keigo Kumamoto, Koji Abe, Asuna Arai and Yoko Mizuno

Department of Gerontological Policy, National Institute for Longevity Sciences (NILS), National Center for Geriatrics and Gerontology (NCGG), Obu-shi, Aichi, Japan

SUMMARY

Objective The purpose of the present study was to examine factors related to potentially harmful behaviors (PHB) by family caregivers towards their older family members.

Methods Four hundred and twelve pairs of disabled older adults and their family caregivers participated in the study. All of these disabled older adults were users of visiting nursing services under the public Long-Term Care insurance system, who resided in one of the eight catchment areas of visiting nursing services in Kyoto Prefecture, Japan. The caregivers were asked to complete questionnaires in relation to their PHB towards their older family members, caregiver burden, patient-caregiver kinship, behavioral disturbances of their older adult, age and sex. Visiting nurses obtained the following information regarding the older adults: the severity of dementia; the severity of physical impairment; age and sex.

Results More than 30% of the caregivers admitted PHB towards their older family members. The most frequently reported PHB included verbal aggression (16.8%) and ignoring (13.6%). A logistic regression analysis revealed that adult children (OR = 2.69, 95%CI = 1.23–5.89, $p = 0.013$) and caregivers of disabled older people with behavioral disturbances (OR = 3.61, 95%CI = 1.65–7.90, $p < 0.01$) were more likely to show PHB.

Conclusions In the present study, PHB towards the older people by family caregivers was associated with patients' behavioral disturbances and patient-caregiver kinship, i.e. an adult child as a caregiver. These findings should be taken into account when planning strategies to prevent PHB by family members. Copyright © 2006 John Wiley & Sons, Ltd.

KEY WORDS—potentially harmful behaviors; behavioral disturbances; patient-caregiver kinship; adult child; caregiver burden

INTRODUCTION

Recently, concern about elder abuse or mistreatment by informal family caregivers has been increasing (Lachs *et al.*, 1998; Mosqueda *et al.*, 2004). Lachs and Pillemer (2004) reviewed reports on elder abuse and indicated that it is regularly encountered in daily clinical practice. Moreover, elder mistreatment was found to be associated with shorter survival in the elderly (Lachs *et al.*, 1998). In order to prevent elder abuse, in the United States, provision for prevention of

abuse, neglect and exploitation was established in the amended Older Americans Act in 1992. Also in the United Kingdom, the Protection of Vulnerable Adults scheme, as set out in the Care Standards Act 2000, has been implemented since 2004. Moreover, in Japan, the Protection of Vulnerable Adults Law was passed in the diet and took force in April of 2006. Indeed, the prevention of elder abuse is a world-wide issue.

Various kinds of risk factors have been investigated regarding elder abuse. As for patient factors, Bredthauer *et al.* (2005) showed that patients with low cognitive status, serious mobility impairments, and inability to perform ADL activities were at very high risk of being physically restrained. It was also indicated that greater care recipient ADL/IADL needs were a predictor of potentially harmful behaviors (Beach *et al.*, 2005) and that cognitive impairment

*Correspondence to: Dr Y. Arai, Departmental Head, Department of Gerontological Policy, National Institute for Longevity Sciences (NILS), National Center for Geriatrics and Gerontology (NCGG), 36-3 Gengo Morioka-cho, Obu-shi, Aichi, 474-8522, Japan.
E-mail: yarai@nils.go.jp

(Lachs *et al.*, 1997) was a predictor of abuse and neglect by family caregivers. From these findings, severity of patient impairment seems to be one of the important risk factors for potentially harmful behaviors, abuse, and neglect by family caregivers. In addition, behavioral disturbance has been found as a predictor of patient institutionalization (Asada *et al.*, 2000) and elder abuse (Compton *et al.*, 1997; Bredthauer *et al.*, 2005). Coen *et al.* (1997) and Arai *et al.* (1999, 2004) also indicated that behavioral disturbance is one of the predictors of caregiver burden. These findings have suggested that behavioral disturbance in disabled older people may be an important risk factor for burden and abuse in caregivers.

As for caregiver factors, Steinmetz (1988) suggested that caregivers with more burden tend to abuse. Moreover, the patient-caregiver kinship was examined as a possible predictor of potentially harmful behaviors. Beach *et al.* (2005) suggested that spouse caregivers were more prone to conduct potentially harmful behaviors, while Coen *et al.* (1997) found that daughters were especially prone to burden. On the other hand, Fulmer *et al.* (2005) showed that patient-caregiver kinship was not associated with elder neglect. Since the above-mentioned findings are inconsistent, it is necessary to examine whether there is a specific patient-caregiver kinship in which elder abuse is likely to occur.

In Japan, the proportion of adult child as caregiver is as high as that of spouse as caregiver and daughter-in-law as caregiver (i.e. approximately 20% according to the Ministry of Health, Labour and Welfare, 2004). Thus, the various kinship relations between patients and their caregivers should be taken into account in investigations on elder abuse in Japan.

In previous studies, diverse terms such as abuse, mistreatment, and potentially harmful behaviors were employed to imply abusive behaviors. Among them, Williamson *et al.* (2001) and Beach *et al.* (2005) focused on potentially harmful behaviors by family caregivers, which were defined as behaviors detrimental to the physical and psychological well-being in disabled older people but not necessarily severely abusive. Williamson *et al.* (2001) included the following five physically-related items of potentially harmful behaviors: withholding food; hitting or slapping; shaking; handling roughly in other ways; and making them afraid of being hit or hurt. The following five items were included as the psychological items: screaming and yelling; threatening with nursing home placement; threatening to use physical

force or threatening to abandon; using a harsh tone of voice; insulting; calling names; and swearing at him/her. Beach *et al.* (2005) regarded potentially harmful behaviors as an 'early warning sign' to full-blown elder abuse and suggested that its assessment may be amenable to preventive intervention efforts. Following Williamson *et al.* (2001) and Beach *et al.* (2005), we take the term 'potentially harmful behaviors' to mean potential detrimental behaviors by a family caregiver including physical and psychological components. In a preventive perspective, the detection of potentially harmful behaviors will provide valuable information as a warning sign of more serious elder abuse.

Because of lack of comprehensive investigations on risk factors including patient-caregiver kinship for harmful behaviors, the present study examined the patient factors (e.g. behavioral disturbance and physical or cognitive function), caregiver factors (e.g. caregiver burden), patient-caregiver kinship, and other demographic variables to identify factors related to potentially harmful behaviors on the part of family caregivers.

METHODS

Subjects

The present study was conducted in one of eight catchment areas of visiting nursing services in Kyoto Prefecture, Japan. There are 14 visiting nursing service agencies in this catchment (population, approximately 300,000), which covers Uji City, Jyoyou City, and Kumiyama Town. All of these 14 visiting nursing service agencies agreed to participate in the study and identified all 589 older adults, who used visiting nursing services under the public Long-Term Care insurance system. Subsequently, a principle family caregiver of each older adult was identified. This survey was conducted on these 589 pairs of older adults and his/her caregivers. Among these caregivers, 412 caregivers (70.0%) participated in the study and responded to a set of self-administered questionnaires. The inclusion criteria of the caregivers were: (1) principle caregiver of an older adult; (2) family caregiver of the older adult; and (3) living together with the older adult. Three hundred and ninety-eight pairs of disabled older people and caregivers (67.6%) met these criteria, and data from these pairs were subjected to further analyses. Written informed consent was obtained from all subjects. This study was endorsed by the ethical committee of the National Institute for Longevity Sciences.

Measures

In the present study, the following variables were assessed.

For the older people, the frequency of behavioral disturbances and severity of cognitive impairment were assessed by the caregivers. The frequency of behavioral disturbances observed by the primary caregiver was assessed using the Troublesome Behavior Scale (TBS; Asada *et al.*, 1994, 1999), which is designed to quantify the specific observable behavior usually associated with dementia. This scale consists of 14 items and the scoring range is 0–56 points. Cronbach's α coefficient of the scale in this study was 0.80. Cognitive impairment of the elderly was assessed with the Japanese version of the Short Memory Questionnaire (SMQ; Maki *et al.*, 1998, 2000), which was developed as an objective tool for the assessment of memory difficulties of dementia in a Japanese population. The SMQ consists of 14 items concerning everyday memory problems; the scoring range is 4–46 points. A score of less than 40 is suggestive of dementia. Cronbach's α coefficient of the scale in this study was 0.90.

The severity of dementia, the severity of physical impairment, problems in hearing, and problems in vision of the older people were assessed by the visiting nurses. The severity of dementia was assessed by the nurses using the following criteria developed by the Ministry of Health and Welfare (MHW) (1993); the severity of dementia was rated from I (very mild) to IV (very severe), and M was defined as 'very severe with extremely behavior disturbance'. The MHW suggested that those who were rated I or II were relatively easy to care for at home, albeit having dementia, and hence we used this classification [not severe (I and II) vs severe (III, IV, and M)] for the statistical analyses in the present study. The severity of physical impairment was assessed by the nurses using the following criteria developed by the MHW (1991); rating the severity of physical impairment from J (very mild) to C (very severe). The Ministry criteria suggested that those rated J or A were relatively easy to care for at home, and hence we used this classification [not severe (J and A) vs severe (B and C)] for the statistical analyses. These indexes developed by the MHW are often used by home care professionals in Japan. In addition, the hearing and vision problems of the older people were assessed by the visiting nurses.

For the caregivers, the relationship to the disabled older people was assessed; spouse as caregiver, adult child as caregiver, and daughter-in-law as caregiver.

The Japanese version of the Zarit Burden Interview (J-ZBI; Arai *et al.*, 1997) was also included to assess caregiver burden. This questionnaire is a 22-item self-report inventory that has been widely used in Japan. The original version of the ZBI is one of the most common scales used in North America and European countries for assessing the burden of caregiving (Zarit and Zarit, 1990). A short version of the J-ZBI (J-ZBI_8) has recently been released (Arai *et al.*, 2003; Kumamoto and Arai, 2004; Kumamoto *et al.*, 2004). Cronbach's α coefficient of J-ZBI in this study was 0.93.

The potentially harmful behaviors by the family caregivers were assessed using a checklist developed by Ueda (2000). This checklist was similar to the one developed by Williamson and Shaffer (2001). The caregivers' self-report checklist includes nine items; ignoring, leaving alone, verbal aggression, neglecting to care, slapping or pinching, restriction to their bedroom, physical restriction, deprivation of health services, and deprivation of money. Caregivers were asked to indicate how many kinds of behavior listed in the checklist (see Table 2) they had engaged in during the previous six months.

Caregivers were also asked to indicate how many hours per day they provided care for their older family members as well as how many years they had cared for him or her. They were also asked to estimate the number of hours per day they were able to be temporarily relieved of their duties or to leave the side of their older family members to go out.

Analyses

First, pairs of disabled older adults and caregivers were divided into two groups; caregivers who had engaged in at least one of the potentially harmful behaviors and those who had not.

Second, continuous variables except for behavioral disturbance (TBS) and cognitive impairment (SMQ) were dichotomized based on the median. The variable of behavioral disturbance (TBS) was dichotomized based on a score of zero or more than 1, while for cognitive impairment (SMQ), a score of less than 40 was used since it is suggestive of dementia for the dichotomization. The details of the dichotomization for all variables were presented in Table 3. Then, a χ^2 test was conducted to determine differences between the two groups.

Third, Spearman's rank correlation tests were conducted on the variables found to be statistically significant in the univariate analysis.

Finally, a multiple logistic regression analysis was employed to determine which of the explanatory

FACTORS RELATED TO POTENTIALLY HARMFUL BEHAVIORS

Table 1. Characteristics of subjects ($n = 398$)

	n (%)	Mean (SD)
Patients		
Sex		
Male	159 (39.9)	
Female	239 (60.1)	
Age		80.5 (9.2)
Behavioral disturbance (TBS) ($n = 327$)		3.2 (5.4)
Severity of dementia ($n = 386$)		
No problem	89 (23.1)	
I	98 (25.4)	
II	94 (24.4)	
III	51 (13.2)	
IV	42 (10.9)	
M	12 (3.1)	
Severity of physical impairment ($n = 387$)		
No problem	4 (1.0)	
J	29 (7.5)	
A	143 (37.0)	
B	118 (30.5)	
C	93 (24.0)	
Cognitive impairment (SMQ) ($n = 261$)		15.06 (13.92)
Hearing problems ($n = 373$)	108 (29.0)	
Vision problems ($n = 371$)	91 (24.5)	
Caregivers		
Sex		
Male	86 (21.6)	
Female	312 (78.4)	
Age ($n = 396$)		63.4 (11.4)
Hours of caregiving/day ($n = 326$)		9.40 (7.69)
Duration of caregiving (year) ($n = 384$)		5.58 (5.54)
Hours caregivers can be relieved/day ($n = 362$)		2.90 (2.90)
Spouse as caregiver	176 (44.2)	
Adult child as caregiver	134 (33.7)	
Daughter-in-law as caregiver	77 (19.3)	
Caregiver burden ($n = 329$)		31.36 (17.03)
Potentially harmful behaviors ($n = 341$)		
Caregivers with at least a kind of potentially harmful behavior	119 (34.9)	
Caregivers with no potentially harmful behavior	222 (65.1)	

variables was significantly related to the caregivers' experience of the potentially harmful behaviors to their older family member. The odds ratio (OR) and the 95% confidence interval (CI) were calculated for each factor.

The criterion for statistical significance was a p -value less than 0.05 for all analyses.

The Statistical Package for Social Science for Windows (version 12.0J, SPSS, Inc.) was used for the above analyses.

RESULTS

Characteristics of subjects

Table 1 shows the characteristics of the subjects in the present study. The mean age of the disabled older

people was 80.5 (SD 9.2) years, and 60.1% were female. The mean age of the caregivers was 63.4 (SD 11.4) years, and 78.4% were female.

Among caregivers who responded to the question concerning the potentially harmful behaviors, 119 (34.9%) reported that they had engaged in at least one of the potentially harmful behaviors in the checklist. Table 2 presented the percentage of each potentially harmful behavior by family caregivers. The most frequently reported behaviors were verbal aggression (16.8%) and ignoring (13.6%). Of 119 caregivers who reported that they had mistreated the elderly, 81 (68.1%) had engaged in one such behavior, 29 (24.4%) in two behaviors, eight (6.7%) in three behaviors, and one (0.8%) in four behaviors.

Table 3 compares the following two groups regarding the variables concerned; those who had

Table 2. Potentially harmful behavior by family caregivers

	<i>n</i> (%)
Ignoring	54 (13.6)
Leaving alone	13 (3.3)
Verbal aggression	67 (16.8)
Neglecting to care	11 (2.8)
Slapping, pinching, or kicking	18 (4.5)
Restricted to bedroom	2 (0.5)
Physical restriction	0 (0.0)
Deprivation of health services	1 (0.3)
Deprivation of money	1 (0.3)

engaged in at least one type of potentially harmful behavior and those who had not. The following five variables were significantly different between the two groups: the proportion of the disabled older people who had behavioral disturbance; the proportion of those with more severe (level B or C) physical impairment; the proportion of those with hearing problems; the proportion of adult child caregivers; and the proportion of caregivers who felt highly burdened.

Table 4 presents the Spearman's rank correlations between the above four variables. First, the existence of potentially harmful behaviors was correlated with the older people having behavioral disturbances ($\rho = 0.30$, $p < 0.01$), the severity of physical impairment ($\rho = -0.13$, $p < 0.05$), hearing problems ($\rho = 0.12$, $p < 0.05$), adult child as caregiver ($\rho = 0.11$, $p < 0.05$), and caregiver burden ($\rho = 0.20$,

$p < 0.01$). Since the correlation between those with hearing problems and adult child as caregiver was significant but too weak to cause multicollinearity, these variables were also included in the following analysis.

A logistic regression analysis was employed to determine which of the following five variables were significantly related to the potentially harmful behaviors: behavioral disturbance (0 vs 1); severity of physical impairment (no problem, J, A vs B, C); problems in hearing (0 vs 1); adult child as caregiver (no vs yes); and caregiver burden (J-ZBI score 27 and less vs 28 and more). As shown in Table 5, two of these variables proved to be significant factors related to the potentially harmful behaviors: behavioral disturbance and adult child as caregiver. Family caregivers who looked after their older family members with behavioral disturbances were more likely to show potentially harmful behaviors towards them (OR = 3.61, 95% CI = 1.65–7.90, $p < 0.01$). Adult child as caregiver also tended to engage in them (OR = 2.69, 95% CI = 1.23–5.89, $p = 0.013$).

DISCUSSION

The present study showed that 34.9% of the caregivers had engaged in potentially harmful behaviors towards their older family members. Similar results were obtained in the previous studies using the same checklist, 32.4% in Ueda's (2000) study and 34.9% in

Table 3. Comparisons between caregivers with at least one type of potentially harmful behavior and those with none

	Caregivers with no potentially harmful behavior	Caregivers with at least one type of potentially harmful behavior	χ^2	<i>p</i>
Patients				
Sex (Female vs Male)	134 vs 88 <i>n</i> = 222	74 vs 45 <i>n</i> = 119	0.11	0.816
Age (Years) (-80 vs 81+)	112 vs 110 <i>n</i> = 222	54 vs 65 <i>n</i> = 119	0.80	0.426
Behavioral disturbance (0 vs 1+)	127 vs 35 <i>n</i> = 162	27 vs 30 <i>n</i> = 57	19.45	<0.001
Severity of dementia (no problem, I, II vs III, IV, M)	159 vs 60 <i>n</i> = 219	82 vs 29 <i>n</i> = 111	0.06	0.896
Severity of physical impairment (no problem, J, A vs B, C)	89 vs 130 <i>n</i> = 219	61 vs 51 <i>n</i> = 112	5.72	0.020
Cognitive impairment (SMQ) (-39 vs 40+)	130 vs 17 <i>n</i> = 147	78 vs 4 <i>n</i> = 82	2.83	0.101
Hearing problems (0 vs 1)	155 vs 54 <i>n</i> = 209	69 vs 41 <i>n</i> = 110	4.51	0.039
Vision problems (0 vs 1)	161 vs 45 <i>n</i> = 206	81 vs 30 <i>n</i> = 111	1.07	0.333
Caregivers				
Sex (Female vs Male)	174 vs 48 <i>n</i> = 222	92 vs 27 <i>n</i> = 119	0.05	0.891
Age (Years) (-62 vs 63+)	117 vs 104 <i>n</i> = 221	59 vs 60 <i>n</i> = 119	0.35	0.571
Hours of caregiving/day (-5.9 vs 6+)	84 vs 103 <i>n</i> = 187	45 vs 52 <i>n</i> = 97	0.06	0.900
Duration of caregiving/year (-3.9 vs 4+)	110 vs 108 <i>n</i> = 218	59 vs 56 <i>n</i> = 115	0.02	0.909
Hours caregivers can be relieved/day (-1.9 vs 2+)	78 vs 122 <i>n</i> = 200	36 vs 78 <i>n</i> = 114	1.73	0.223
Spouse as caregiver (no vs yes)	126 vs 96 <i>n</i> = 222	71 vs 48 <i>n</i> = 119	0.27	0.646
Adult child as caregiver (no vs yes)	154 vs 68 <i>n</i> = 222	69 vs 50 <i>n</i> = 119	4.44	0.042
Daughter-in-law as caregiver (no vs yes)	171 vs 51 <i>n</i> = 222	101 vs 18 <i>n</i> = 119	2.96	0.091
Caregiver burden (-27 vs 28+)	105 vs 92 <i>n</i> = 197	31 vs 66 <i>n</i> = 97	11.91	0.001

FACTORS RELATED TO POTENTIALLY HARMFUL BEHAVIORS

Table 4. Correlations between potentially harmful behaviors, behavioral disturbances, severity of impairment, hearing problems, adult child as caregiver, and caregiver burden

	Potentially harmful behaviors	Behavioral disturbances	Severity of physical impairment	Hearing problems	Adult child as caregiver
Behavioral disturbances	0.30**				
Severity of physical impairment	-0.13*	-0.11			
Hearing problems	0.12*	0.10	-0.07		
Adult child as caregiver	0.11*	0.07	-0.04	0.11*	
Caregiver burden	0.20**	0.10	0.05	0.05	-0.07

* $p < 0.05$.

** $p < 0.01$.

a study conducted by Kumamoto *et al.* (2004) in Japan. As indicated in Table 2, ignoring and verbal aggression were frequent. It would be difficult for home care professionals to detect the above-mentioned behaviors such as ignoring and verbal aggression on their visits for the following two reasons. First, unlike physical abuse, ignoring and verbal aggression would not leave any traces of abuse on the abused older people. Second, such behavior is often covert. Therefore, self-reports either by the older people or family caregivers may provide more information than observations by home care professionals on their visits. However, self-reports by the older people may not be reliable if they suffer from severe dementia. In the present study, we used self-reports by family caregivers, which may have more reliable and detailed information on potentially harmful behaviors, even if their self-reports may have a response bias regarding more implicit behaviors such as ignoring and verbal aggression. Thus, health professionals should routinely assess potentially harmful behaviors through self-reports by caregivers in order to detect the person and kind of potentially harmful behavior for preventive intervention.

Behavioral disturbance of the older people was identified as a factor related to potentially harmful behaviors. This finding is consistent with a previous study which presented a significant relation between the behavioral disturbance of the older people and abuse by caregivers (Compton *et al.*, 1997). Many

studies revealed that behavioral disturbance correlates to caregiver burden, after other confounding factors are statistically controlled, regardless of the sample characteristics and the place of study (Coen *et al.*, 1997; Arai *et al.*, 1999, 2004). Indeed, coping with behavioral disturbances is one of the most demanding tasks for caregivers, as Coen *et al.* (1997) and Arai *et al.* (2004) also suggested. The present study supports the previous findings.

In order to prevent potentially harmful behaviors of caregivers, it is necessary to provide interventions on behavioral disturbances to both older people and caregivers. As pharmacological interventions for older people with behavioral disturbances, typical/atypical antipsychotic medications or antidepressants is often used in clinical settings. However, typical/atypical antipsychotic medications should be provided with caution due to the fact that these would be expected to increase the risk of death in older people (e.g. Wang *et al.*, 2005). Clinicians may also provide pharmacological interventions to caregivers if necessary (e.g. those depressed because of the behavioral disturbances of older people they look after).

Regarding non-pharmacological interventions, Haupt *et al.* (2000) reported that psychoeducative group intervention with caregivers alleviated agitation and anxiety of demented older people. Moreover, Burgio *et al.* (2003) indicated that African-American caregivers' appraisal of the behavioral disturbances as bothersome was decreased by cognitive-behavioral

Table 5. Factors related to potentially harmful behaviors by family caregivers

Variables	Odds ratio	95% Confidence intervals	p
Behavioral disturbance (0 vs 1+)	3.61	1.65–7.90	0.001
Severity of physical impairment (no problem, J, A vs B, C)	1.11	0.50–2.46	0.794
Hearing problems (0 vs 1)	1.34	0.58–3.11	0.491
Adult child as caregiver (no vs yes)	2.69	1.23–5.89	0.013
Caregiver burden (-27 vs 28+)	1.67	0.76–3.67	0.205

skills training. They also showed that white caregivers' appraisal of the behavioral disturbances as bothersome was decreased by telephone support. These pharmacological and non-pharmacological interventions for behavioral disturbances may lead to the preventions of potentially harmful behaviors by family caregivers.

Another factor related to potentially harmful caregiver behaviors was patient-caregiver kinship, especially adult child as caregiver. Studies in the USA suggested that spouse caregivers were more likely to engage in potentially harmful caregiver behaviors (Beach *et al.*, 2005) or that the patient-caregiver kinship was not associated with neglect (Fulmer *et al.*, 2005). In the present study on Japanese people, adult child as caregiver was identified as a factor related to potentially harmful behaviors. The process in which being an adult child as a caregiver increases the risk for potentially harmful behaviors is still unclear. Strawbridge *et al.* (1991) indicated that relationship quality with the parent had both a direct effect on caregiver burden and an indirect one through family conflict. It would be useful to include the quality of patient-caregiver relationship as well as in future studies in order to clarify the underlying process of potentially harmful behaviors.

A limitation of our study is that we were unable to confirm whether the two factors identified in the present study actually cause potentially harmful behaviors due to the methodological limitation attached to cross-sectional studies.

Nonetheless, our study has the following strengths. It is one of the few studies conducted in a community setting in Japan in order to investigate factors related to potentially harmful behaviors towards the older people by using a self-report by family caregivers.

Second, we investigated various types of patient-caregiver kinship (i.e. spouse, daughter-in-law, and adult child) in order to identify factors related to potentially harmful behaviors. As mentioned in the Introduction, the proportion of each kind of kinship is almost equal among Japanese people (Ministry of Health, Labour and Welfare, 2004). However, adult child as caregiver was the only kinship which was found to be a factor in Japanese family caregivers. It may be useful to include various types of patient-caregiver kinship in the investigation of risk factors of potentially harmful behaviors.

Lastly, this study can be regarded as a comprehensive investigation of the factors related to potentially harmful behaviors including the demographic data of the older people and caregivers, behavioral disturbances and cognitive impairment in the older people,

caregiver burden in the family caregivers, and patient-caregiver kinship. To our knowledge, such a comprehensive investigation has been rarely undertaken.

In conclusion, our study revealed that behavioral disturbances in disabled older people and adult child as caregiver were significant factors related to potentially harmful behaviors by informal family caregivers. These findings should be taken into account when planning preventive strategies for potential harmful behaviors by family members.

ACKNOWLEDGEMENTS

The authors wish to thank the participants of this study, which was in part supported by research grants provided by the Ministry of Health, Labor and Welfare (Grant No. H15-C025, H17-C029). The authors are grateful to Mrs Junko Nitta for her administrative support for this project.

REFERENCES

- Arai Y, Washio M. 1999. Burden felt by family caring for the elderly members needing care in southern Japan. *Aging Ment Health* 3: 158–164.
- Arai Y, Kudo K, Hosokawa T, *et al.* 1997. Reliability and validity of the Japanese version of Zarit Caregiver Burden. *Psychiatry Clin Neurosci* 51: 281–287.
- Arai Y, Tamiya N, Yano E. 2003. The short version of the Zarit Caregiver Burden Interview (J-ZBI_8): its reliability and validity. *Jap J Geriatr* 40: 497–503.
- Arai Y, Kumamoto K, Washio M, *et al.* 2004. Factors related to feelings of burden among caregivers looking after impaired elderly in Japan under the Long-Term Care insurance system. *Psychiatry Clin Neurosci* 58: 396–402.
- Asada T, Yoshioka M, Morikawa S, *et al.* 1994. Development of a Troublesome Behavior Scale (TBS) for the elderly patients with dementia. *Jap J Pub Health* 41: 518–527.
- Asada T, Kinoshita T, Morikawa S, *et al.* 1999. A prospective 5-year follow-up study on the behavioural disturbances of community-dwelling elderly people with Alzheimer disease. *Alzheimer Dis Assoc Disord* 13: 202–208.
- Asada T, Kinoshita T, Kakuma T. 2000. Analysis of behavioral disturbances among community-dwelling elderly with Alzheimer disease. *Alzheimer Dis Assoc Disord* 14: 160–167.
- Beach SR, Schulz R, Williamson GM, *et al.* 2005. Risk factors for potentially harmful informal caregiver. *J Am Geriatr Soc* 53: 255–261.
- Bredthauer D, Becker C, Eichner B, *et al.* 2005. Factors relating to the use of physical restraints in psychogeriatric care: a paradigm for elder abuse. *Z Gerontol Geriatr* 38: 10–18.
- Burgio L, Stevens A, Guy D, *et al.* 2003. Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. *Gerontologist* 43: 568–579.
- Coen R, Swanwick GRJ, O'Boyle CA, Coakley D. 1997. Behaviour disturbance and other predictors of carer burden in alzheimer's disease. *Int J Geriatr Psychiatry* 12: 331–336.
- Compton SA, Flanagan P, Gregg W. 1997. Elder abuse in people with dementia in northern Ireland: prevalence and predictors in

- cases referred to a psychiatry of old age service. *Int J Geriatr Psychiatry* **12**: 632–635.
- Fulmer T, Paveza Z, VandeWeerd C, *et al.* 2005. Dyadic vulnerability and risk profiling for elder neglect. *Gerontologist* **45**: 525–534.
- Haupt M, Karger A, Jänner M. 2000. Improvement of agitation and anxiety in demented patients after psychoeducative group intervention with their caregivers. *Int J Geriatr Psychiatry* **15**: 1125–1129.
- Kumamoto K, Arai Y. 2004. Validation of 'Personal Strain' and 'Role Strain': subscales of the short version of the Japanese version of the Zarit Caregiver Burden Interview (Z-JBI_8). *Psychiatry Clin Neurosci* **58**: 606–610.
- Kumamoto K, Arai Y, Ueda T, Washio M. 2004. Cross-validation of the short version of the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI_8). *Jap J Geriatr* **41**: 204–210.
- Lachs MS, Pillemer K. 2004. Elder abuse. *Lancet* **364**: 1263–1272.
- Lachs MS, Williams CS, O'Brien S, *et al.* 1997. Risk factors for reported elder abuse and neglect: a nine-year observational cohort study. *Gerontologist* **37**: 469–474.
- Lachs MS, Williams CS, O'Brien S, *et al.* 1998. The mortality of elder mistreatment. *JAMA* **280**: 428–432.
- Maki N, Ikeda M, Hokoishi K, *et al.* 1998. Japanese version of the Short-Memory Questionnaire: memory evaluation in Alzheimer's disease. *Brain Nerve* **50**: 415–418.
- Maki N, Ikeda M, Hokoishi K, *et al.* 2000. The validity of the MMSE and SMQ as screening tests for dementia in the elderly general population—a study of one rural community in Japan. *Dement Geriatr Cogn Disord* **11**: 193–196.
- Ministry of Health, Labour and Welfare. 2004. *Comprehensive Survey of Living Conditions of the People on Health and Welfare*. Ministry of Health and Welfare.
- Ministry of Health and Welfare. 1991. *The Criteria of Activity of Daily Living for Impaired Elderly*. Ministry of Health and Welfare.
- Ministry of Health and Welfare. 1993. *The Criteria of Activity of Daily Living for Demented Elderly*. Ministry of Health and Welfare.
- Mosqueda L, Burnight K, Liao S, Kemp B. 2004. Advancing the field of elder mistreatment: a new model for integration of social and medical services. *Gerontologist* **44**: 703–708.
- Steinmetz SK. 1988. *Duty Bound Elder Abuse and Family Care*. Sage Publications: Thousand Oaks, CA.
- Strawbridge WJ, Wallhagen MI. 1991. Impact of family conflict on adult child caregivers. *Gerontologist* **31**: 770–777.
- Ueda T. 2000. Inadequate care by family caregiver of frail elderly living at home. *Jap J Pub Health* **47**: 264–274.
- Wang PS, Schneeweiss S, Avorn J, *et al.* 2005. Risk of death in elderly users of conventional vs atypical antipsychotic medications. *N Engl J Med* **353**: 2335–2341.
- Williamson GM, Shaffer DR, *et al.* 2001. The Family Relationships in Late Life Project 2001. Relationship quality and potentially harmful behaviors by spousal caregivers: how we were then, how we are now. *Psychol Aging* **16**: 217–226.
- Zarit SH, Zarit JM. 1990. The Memory and Behaviors Problems Checklist 1987R and the Burden Interview. State University Gerontology Center: University Park, PA.

ORIGINAL ARTICLE

Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview

A. S. SCHREINER¹, T. MORIMOTO², Y. ARAI³, & S. ZARIT¹

¹The Pennsylvania State University, Pennsylvania, USA, ²Nara Medical University, Japan, and ³National Institute for Longevity Sciences, Japan

(Received 8 December 2004; accepted 3 March 2005)

Abstract

Decades of research have confirmed that being a family caregiver is a stressful role. However, the point at which these stressors constitute a real risk for decreased mental health has not been established. The purpose of the present study was to determine a statistically valid cut-off score for the Zarit Burden Interview (ZBI) in order to identify family caregivers at risk for depression and in need of further assessment and intervention. The ZBI and the Geriatric Depression Scale or the CES-D were administered to three different populations of family caregivers of older adults: stroke caregivers ($n=80$), chronic obstructive pulmonary disease (COPD) caregivers ($n=48$), and general disability caregivers ($n=70$). Using three different statistical methods, a ZBI cut-off score was determined. Next, contingency analysis was used to compare depression scale scores and ZBI cut-offs for the three groups of caregivers. Findings suggest that a cut-off score ranging from 24–26 has significant predictive validity for identifying caregivers at risk for depression. A ZBI cut-off of 24 correctly identified 72% of caregivers with probable depression. The validity of ZBI cut-offs scores warrants further confirmation with larger samples. Valid cut-off scores would enable health care providers to assess family caregivers at risk and provide necessary interventions to improve their quality of life in this important role.

Introduction

Decades of international research have served to confirm that being a family caregiver is a stressful role. Family caregivers have been found to have an increased risk of depression, anxiety, and mortality (Bugge, Alexander, & Hagen, 1999; Carod-Artal et al., 1999; Hughes et al., 1999; Ory et al., 1999; Reese et al., 1998; Scholte op Reimer et al., 1998; Schulz & Beach, 1999; Schulz, Tompkins, & Rau, 1998; Vetter et al., 1999; Wu et al., 1999; Zarit, Todd, & Zarit, 1986). However, despite the magnitude of research in this field we remain uncertain as to exactly how much caregiver stress constitutes a real health risk. There are several ways to measure the stressors of care-giving. The oldest and most often used instrument is the Zarit Burden Interview (ZBI; Zarit & Zarit, 1987), which has been translated and validated in several languages allowing for international comparisons. High burden scores on the ZBI have been significantly related to a decrease in mental and physical health, as well as decreased vitality and social functioning.

The purpose of the present study was to determine a statistically valid cut-off score for the Zarit Burden Interview (ZBI) which can be used to

screen caregivers at risk for depression and in need of further assessment and intervention. The need for valid cut-off scores has been advocated by researchers of family caregivers for some time (Bedard et al., 2001; Hebert et al., 2000; Zarit & Zarit, 1987). One advantage of administering the ZBI over standard depression scales is that it enables caregivers to understand the relationship between their caregiving role and their feelings of stress, as well as gain insight into the magnitude of their own stress which is a necessary prelude to any intervention attempt. In addition, while presumably more objective measures of caregiver stress such as hours of direct care or types of care-giving tasks have not been found to relate to negative caregiver outcomes, subjective measures like the ZBI are strongly related to these negative outcomes.

Methods

Subjects

Family caregivers were defined as co-resident family members who assisted with most, if not all, of the

Correspondence: Andrea S. Schreiner, PhD, Department of Health Policy and Administration, College of Health and Human Development, The Pennsylvania State University, 116 Henderson Building, University Park, PA 18602-6500, USA. Tel: +1 (814) 865-1926. E-mail: axs27@psu.edu

ISSN 1360-7863 print/ISSN 1364-6915 online © 2006 Taylor & Francis
DOI: 10.1080/13607860500312142

patient's daily care needs. Sample inclusion was limited to stroke and chronic obstructive pulmonary disease (COPD) patients and caregivers with no previous psychiatric history. However, it is estimated that 70% of care-recipients in the general disability sample had some form of dementia.

Stroke and COPD caregivers. Following guidelines for ethical use of human subjects, stroke ($n=80$) and COPD ($n=48$) family-caregivers were recruited from private hospitals specializing in either neurological or respiratory disorders, in five metropolitan areas in Western Japan. Seven neurological hospitals (54%) were randomly selected from a total of 13 and all facilities agreed to participate in the study (see Schreiner et al., 2003 for more information on stroke caregiver sampling and protocol). The COPD family caregivers were recruited from a convenience sample of five small hospitals that treated COPD patients on home-oxygen therapy. All co-resident family-caregivers of patients were invited to participate in the study and the participation rate at each facility was 100% for the qualifying caregivers, which reflects the high involvement of the physicians.

General disability caregivers. General disability caregivers were recruited as part of the Matsuyama Caregiver Study (see Arai et al., 2000; Arai et al., 2002 for study details). Similar to stroke and COPD caregivers these subjects were the co-residing principal caregivers of older adults who had been registered as disabled elderly ($n=88$) in a small city (population: 7126) in northern Japan. Disability status was determined on the basis of activities of daily living (ADL) scores and the presence of behavioural disturbances. Seventy surveys were returned for a response rate of 79%. The survey instrument included the ZBI, the Centre for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), and the revised Hasegawa Dementia Rating Scale (HDS-R; scores range from 0–30; scores less than 20 are considered indicative of a possible dementia; Hasegawa et al., 1974; Imai & Hasegawa, 1999), which is the equivalent of the Mini-Mental Exam and widely used in Japan. The mean HDS-R score for care recipients in this sample was 13.8 (SD = 9.2); roughly 70% ($n=70$) scored as having some form of dementia.

Measures

Caregiver burden, was measured with the Zarit Burden Interview (ZBI; Zarit, Todd, & Zarit, 1986; Japanese version Arai et al., 1997) which consists of 22 items, 21 of which are summed to create a total burden score. Higher scores indicate greater burden. The ZBI measures subjective burden in terms of the degree (from 'never = 0' to 'almost always = 4') to which the caregiver experiences physical,

psychological, emotional, social and financial problems as a result of their care-giving role.

Depressed mood among caregivers was measured with the Geriatric Depression Scale (GDS Short Form; translated by Niino, Imaizumi, & Kawakai, 1991) and the Centre for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), which was translated into Japanese and validated by Shima et al. (1985).

The GDS items were summed; higher scores indicate a greater number of depressive symptoms. A cut-off score of six has been determined for Japanese subjects (Schreiner et al., 2003). Subjects with scores >6 (coded 1) were considered to be symptomatic of depression while scores of <5 (coded 0) were considered 'normal'.

The CES-D is a 20-item self-report scale widely used to identify individuals at risk for depression. Total scores range from 0–60. Individuals scoring 16 or more are generally considered to be at risk for clinical depression and we adopted this cut-off for the present study.

After obtaining informed consent, data from stroke and COPD caregivers was collected by interview which lasted approximately 40–60 minutes per subject. Stroke interviews were conducted in a private room at the rehabilitation clinic where care-recipients were patients. The COPD interviews were conducted at the home of the patient and caregiver. Data from the general disability caregivers was collected via mail survey.

Statistical analysis

The purpose of the statistical analysis was to generate a cut-off score for the ZBI which would have a predictive value for assessing the risk of depression. We compared three different statistical methods to identify a cut-off: (1) Tree-based modelling (SAS version 10), which incorporated GDS scores to classify the ZBI; (2) SPSS K-means clustering technique, which looked only at the ZBI scores; and (3) linear regression.

Cut-offs were determined using only stroke and COPD caregivers and excluding the general disability caregivers so they could later be used as an independent reference sample to validate the ZBI cut-off. Tree-based modelling assigned a basic cut-off score of 24.5 to the data from stroke and COPD caregivers. The K-means clustering determined that the value of 25 was an appropriate cut-off point for high and low burden. The regression model predicted a ZBI score of 25 when the GDS was set at the cut-off value of six ($15.02c + (1.807b \times 6) = 25.86$; see Table I). Thus, three unique methods confirmed a ZBI cut-off around the value of 25.

In order to examine the predictive validity of these cut-offs we grouped samples into high and low depression groups based on their depression scores. Next, 2×2 contingency tables were generated

Table I. Linear regression of burden scores on GDS scores.

	Unstandardized coefficients			Sig.
	B	Std. Error	t	
(Constant)	15.02	2.07	7.2	0
GDS Scores	1.807	0.32	5.6	0

Dependent variable: ZBI total burden scores.

Note: Using the GDS cutoff score of 6 results in a burden score of 25.86 ($15.02c + (1.807b \times 6) = 25.86$).

comparing high and low depression groups against high and low burden groups for each sample. We used three different burden cut-offs (24, 25, and 26), which centred around the statistically determined cut-off of 25. Next, we tested the overall validity of the cut-offs with the entire sample of caregivers combined. Finally, the specificity and sensitivity of the most significant contingency table for each subject group was analyzed to reveal how well the 'best' ZBI cut-off for that group compared with a gold standard (the GDS or the CES-D) in predicting caregiver depression (Table III). In our study, the calculated sensitivity describes the ZBI cut-off's ability to correctly identify subjects grouped into probable depression by the GDS or CES-D while specificity reports the ability of the ZBI cut-off to correctly identify non-depressed subjects.

Results

Table II contains descriptive data on the entire sample and all study variables. While both stroke and general caregivers were similar in age they were each significantly younger than COPD caregivers. In terms of sex differences, stroke caregivers had a significantly higher percentage of men than did

COPD caregivers. Stroke caregivers also had significantly higher ZBI and GDS scores than did COPD caregivers.

As stated above, based on the statistical analysis we used three different ZBI cut-off scores of 24, 25, and 26 to generate 2×2 contingency tables with the GDS or CES-D cut-off scores for each sample of caregivers (Table III). This range of scores was significant in predicting the risk of depression for all caregivers. Specifically, a cut-off of 25 was most accurate for stroke caregivers, while a cut-off of 24 was most accurate for COPD caregivers, and a cut-off of 26 was most accurate for independent reference sample of general disability caregivers. The results indicated that a ZBI cut-off of 25 correctly identified 77% of high burden stroke caregivers as having further need of assessment for depression. In addition, 72% of stroke caregivers with low risk of depression were in the low burden group. However, only 47% of high burden COPD caregivers were in the probable depression group while 79% of COPD caregivers in the low risk for depression group were also in the low burden group. A ZBI cut-off of 26 identified 64% of general disability caregivers with high burden as being in the probable depression (as measured with the CES-D) group while 59% of caregivers in the low burden group had depression scores below the cut-off. The results for the combined sample of all caregivers were significant at all cut-offs but strongest at a cut-off of 24.

Discussion

The findings suggest that a ZBI cut-off score which ranges from 24–26 would be useful in identifying caregivers in need of further assessment and intervention. A cut-off of 24 for our combined sample of three very different types of caregivers, with

Table II. Sample characteristics by caregiver group.

	Stroke	COPD	General disability
Gender			
Male	28.75% ($n=23$)	8.9% ($n=5$)	22.86% ($n=16$)
Female	71.25% ($n=57$)	91.1% ($n=51$)	77.14% ($n=54$)
Chi-square test sig.	0.013 Stroke vs COPD	0.072 COPD vs General	0.26 Stroke vs General
Mean age (sd)	60.15 (14.04)	65.44 (12.79)	60.19 (12.68)
t-test of significance	-2.28	-2.34	-0.016
df	134	124	148
p	0.024 Stroke vs COPD	0.020 COPD vs General	0.987 Stroke vs General
ZBI mean (sd)	28.32 (12.7)	20.35 (13)	30.34 (17.7)
t-test of significance	3.6	-3.6	-0.81
df	135	125	148
p	0.000 Stroke vs. COPD	0.001 COPD vs General	0.42 Stroke vs General
GDS mean (sd)	6.05 (3.2)	4.54 (3.2)	NA
t-test of significance	2.71		
df	135		
p	0.008		
CES-D mean (sd)	NA	NA	15.7 (9.6)

Table III. Contingency analysis of caregivers by high/low depression and burden groups with sensitivity and specificity of burden cutoff scores.

	High GDS	Low GDS	Total N	Pearson chi-square	df	Continuity correction	Likelihood ratio	Exact sig. (1-sided)
Stroke caregivers								
High burden >25	34	10	44	19.6	1	17.65	20.40	0.00
Low burden <=25	10	26	36					
Sensitivity	77%							
Specificity	72%							
COPD caregivers								
	High GDS	Low GDS	Total	3.80	1	2.66	3.77	0.05
High burden >24	9	6	15					
Low burden <=24	10	23	33					
Sensitivity	47%							
Specificity	79%							
General caregivers								
	High CES-D	Low CES-D	Total	3.82	1	2.93	3.86	0.04
High burden >26	20	16	36					
Low burden <=26	11	23	44					
Sensitivity	64%							
Specificity	59%							
All caregivers combined								
	High score 1	Low score	Total	25.44		24.02	26.09	0.00
High burden >24	68	38	106					
Low burden <=24	26	66	92					
Sensitivity	72%							
Specificity	63%							

Note: High score and low score refer to whether the caregiver was above or below the cutoff for either the GDS or the CES-D.

significant differences in age and sex, had a positive predictive value of 64%, which indicated that 64% of caregivers above the ZBI cut-off were also above the depression cut-off. The negative predictive value, the percentage of caregivers who were below the ZBI cut-off and below the depression cut-off, was 72%. Hence, there were 28% false negatives and 36% false positives.

It is important to note that the cut-off determined with the stroke and COPD samples did have validity with the sample of general disability caregivers although the depression scale used with this group was the CES-D and not the GDS. Therefore, despite the use of a different instrument, as well as a different method (i.e., mail survey versus interview), and in addition to significant differences in age and sex, the cut-off score obtained with stroke and COPD caregivers was significant in predicting the risk of depression in other caregivers.

These findings indicate that caregivers at risk for depression could be identified by administering the ZBI alone rather than a battery of other possibly more threatening tests. Since screening as a false negative (i.e., below the burden cut-off but depressed) was seen as a greater problem than screening as a false positive (i.e., above the burden cut-off but not depressed), we chose cut-off scores that increased the level of sensitivity at the expense of specificity.

The cut-off scores in this study warrant further investigation with larger samples and are intended to serve only as a guideline for practitioners to use to assess their family caregivers and encourage the caregivers themselves to seek supportive services. Future studies may also want to look at the

relationship between ZBI scores and other negative outcomes of care-giving such as moods of anxiety or anger or physical outcomes such as decreased health status in order to expand the relevance of cut-off scores for predicting a broader range of caregiver negative outcomes. Again, we did not look at the influence of moderating variables on burden as our purpose was to determine a cut-off score broad enough to identify risk across a variety of different types of different caregivers.

Conclusion

As the average lifespan continues to increase, so do disability rates from chronic illnesses. Persons with disabilities often require caregivers and family members overwhelmingly assume this role. In fact, family caregivers provide care that is estimated to exceed the combined costs of nursing home and paid home health care (Arno, Levine, & Memmott, 1999). The main reason family caregivers relinquish their role and seek institutional care is from feelings of excessive burden or exhaustion (Narayan et al., 2001). These conditions can be ameliorated with current psycho-educational interventions which focus on improving caregivers' coping skills and their sense of mastery or self-efficacy (Bookwala & Schulz, 1998; Hebert et al., 2003; Ostwald et al., 1999; Pearlin et al., 1990; Yates, Tennstedt, & Chang, 1999). Valid cut-off scores for the ZBI would enable health care professionals to identify family caregivers in need of such interventions to improve their ability to provide quality care in this important role.

Acknowledgements

This study was funded in part by grants from the Japanese Ministry of Health, Labour, and Welfare, (Comprehensive Research on Aging and Health, Grant No. H15-025: Principal Investigator, Y. Arai), from the Japanese Ministry of Education, Culture, Sports Science and Technology (Grant No. 14570375: Principal Investigator, Y. Arai) and from the Japanese Ministry of Education, Scientific Research Foundation, (Grant no. 11672358: Principal Investigator Tomoko Morimoto).

References

- Arai, Y., Kudo, K., Hosokawa, T., Washio, M., & Hisamichi, S. (1977). Reliability and validity of the Japanese version of the Zarit Caregiver Burden Interview. *Psychiatry and Clinical Neuroscience*, *51*, 281-287.
- Arai, Y., Sugiura, M., Miura, H., Washio, M., & Kudo, K. (2000). Undue concern for others' opinions deters caregivers of impaired elderly from using public services in rural Japan. *International Journal of Geriatric Psychiatry*, *15*, 961-968.
- Arai, Y., Zarit, S. H., Sugiura, M., & Washio, M. (2002). Patterns of outcome of caregiving for the impaired elderly: A longitudinal study in rural Japan. *Aging & Mental Health*, *6*(1), 39-46.
- Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs*, *18*(2), 182-188.
- Bedard, M., Molloy, B., Squire, L., Dubois, S., Lever, J., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, *41*(5), 652-657.
- Bookwala, J., & Schulz, R. (1998). The role of neuroticism and mastery in spouse caregivers' assessment of and response to a contextual stressor. *Journal of Gerontology, Psychological Sciences*, *53B*(3), P155-P164.
- Bugge, C., Alexander, H., & Hagen, S. (1999). Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke*, *30*(8), 1517-1523.
- Carod-Artal, F. J., Egidio-Navarro, J. A., Gonzalez-Gutierrez, J.L., & Varela de Seijas, E. (1999). Perception of long-term overload in care-givers of patients who have survived a stroke. *Revista de Neurologia*, *28*, 1130-1138.
- Hasegawa, K., Inoue, K., & Moriya, K. (1974). An investigation of dementia rating scale for the elderly [in Japanese]. *Seishin-igaku*, *16*, 965-969.
- Hebert, R., Bravo, G., & Preville, M. (2000). Reliability, validity, and reference values for the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, *19*(4), 494-507.
- Hebert, R., Levesque, L., Vezina, J., Lavoie, J. P., Ducharme, F., Gendron, C., et al. (2003). Efficacy of a psycho-educative group program for caregivers of demented persons living at home: A randomized controlled trial. *Journal of Gerontology*, *58B*(1), S58-S67.
- Hughes, S. L., Giobbie-Hurder, A., Weaver, F. M., Kubal, J. D., & Henderson, W. (1999). Relationship between caregiver burden and health-related quality of life. *The Gerontologist*, *39*(5), 534-545.
- Imai, Y., & Hasegawa, K. (1999). In A. Burns, B. Lawlor & S. Craig (Eds.), *Revised Hasegawa's dementia scale [HDS-R]. Assessment scales in old age psychiatry* (p. 71). London: Martin Dunitz.
- Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., & Corcoran-Perry, S. (2001). Subjective responses to caregiving for a spouse with dementia. *Journal of Gerontological Nursing*, *March*, 19-28.
- Niino, N., Imaizumi, T., & Kawakami, N. (1991). A Japanese translation of the Geriatric Depression Scale Short-Form. *Clinical Gerontologist*, *1*(10), 85-86.
- Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of care-giving: A detailed comparison between dementia and non-dementia caregivers. *The Gerontologist*, *39*(2), 177-185.
- Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psycho-educational intervention for caregivers of persons with dementia. *The Gerontologist*, *39*(3), 299-309.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Care-giving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583-593.
- Radloff, L. (1977). The CES-D Scale: A self-reported depression scale for research in the general population. *Applied Psychological Measures*, *1*, 385-401.
- Reese, D. R., Gross, A. M., Smalley, D. L., & Messer, S. C. (1998). Caregivers of Alzheimer's disease and stroke patients: Immunological and psychological considerations. *Gerontologist*, *34*(4), 534-540.
- Scholte op Reimer, W. J. M., de Haan, R. J., Rijnders, P. T., Limburg, M., & van den Bos, G. A. M. (1998). The burden of care-giving in partners of long-term stroke survivors. *Stroke*, *29*(8), 1605-1611.
- Schreiner, A. S., Hayakawa, H., Morimoto, T., & Kakuma, T. (2003). Screening for late life depression: Cut-off scores for the Geriatric Depression Scale and the Cornell Scale for depression in dementia among Japanese subjects. *International Journal of Geriatric Psychiatry*, *18*, 498-505.
- Schulz, R., Tompkins, C. A., & Rau, M. T. (1998). A longitudinal study of the psychological impact of stroke on primary support persons. *Psychology & Aging*, *3*, 131-141.
- Schulz, R., & Beach, S. R. (1999). Care-giving as a risk factor for mortality. *Journal of the American Medical Association*, *282*, 2215-2219.
- Shima, S., Shikano, T., Kitamura, T., & Asai, M. (1985). Reliability and validity of CES-D. *Japanese Journal of Psychiatry*, *27*, 717-723.
- Vetter, P. H., Krauss, S., Steiner, O., Kropp, P., Moller, W. D., Moises, H. W., et al. (1999). Vascular dementia versus dementia of the Alzheimer's type: Do they have different effects on caregiver's burden? *Journal of Gerontology*, *54B*(2), S93-S98.
- Wu, H., Wang, H., Cacioppo, J. T., Glaser, R., Kiecolt-Glaser, J. K., & Malarkey, W. B. (1999). Chronic stress associated with spousal care-giving of patients with Alzheimer's dementia is associated with down-regulation of B-lymphocyte GH mRNA. *Journal of Gerontology*, *54A*, M212-M215.
- Yates, M. E., Tennstedt, S., & Chang, B. H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *Journal of Gerontology*, *54B*(1), P12-P22.
- Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, *26*, 260-266.
- Zarit, S.H., & Zarit, J.M. (1987). *Instructions for the Burden Interview*. Technical Document, University Park, PA: Pennsylvania State University.

Factors Related to Institutionalization among the Frail Elderly with Home-Visiting Nursing Service in Japan

Asae Oura^a Masakazu Washio^a Jyun-ichi Wada^b Yumiko Arai^c
Mitsuru Mori^a

^aDepartment of Public Health, School of Medicine, Sapporo Medical University, Sapporo; ^bMedical Foundation, Tenshindo Geriatric Health Care Facility, Yokoen, and ^cDepartment of Gerontological Policy (Health Policy for the Aged), National Institute of Longevity Sciences (NILS), Obu, Japan

Key Words

Caregiver · Elderly · In-home care · Japan

Abstract

A dramatic increase in the number of elderly people in Japan has led to a concurrent increase in the number of frail elderly in need of care. It is estimated that the number of frail elderly will reach 3.9 million by the year 2010. Family members are often both physically and mentally burdened with caring for the frail elderly. The present study was conducted to identify the risk factors for institutionalization among the frail elderly receiving in-home care in Japan.

Copyright © 2006 S. Karger AG, Basel

Introduction

The dramatic increase in the number of older people in Japan, which is now well documented [1], has led to a concurrent increase in the number of elderly in need of care (frail elderly). It is estimated that the number of frail elderly will reach 3.9 million in 2010 [2]. Family members are often both physically and mentally burdened with caring for the frail elderly [2].

In former days, the frail elderly were cared for in the traditional Japanese family system because most Japanese elderly, over 60% compared with 20% or less in the West, lived with their children [1]. However, the number of children in each family has dramatically decreased, and the nuclear family has now become more common [3]. Therefore, caregivers often have to take care of the frail elderly without any help because other relatives often live too far away to provide assistance. It has been reported that caring for the frail elderly tends to induce depression in the caregivers [4]. Caregivers' depression is a risk factor for caregivers discontinuing their provision of in-home care [5]. Thus, the present study was conducted to identify the risk factors for institutionalization among the frail elderly receiving in-home care in Japan.

Subjects and Methods

In order to identify the factors related to institutionalization among the frail elderly receiving in-home care, a follow-up study was conducted in Kyushu, south-western Japan, from 1998 to 2003. The participants were 122 pairs of frail elderly and their caregivers. The frail elderly were 52 males and 70 females with a mean age (\pm SD) of 80.7 (\pm 8.5) years at the baseline, while caregivers were 28 males and 94 females with a mean age (\pm SD) of 61.0 (\pm 13.6) years. The kinship status of caregivers were 49 spouses, 51 children,

KARGER

Fax +41 61 306 12 34
E-Mail karger@karger.ch
www.karger.com

© 2006 S. Karger AG, Basel
0304-324X/06/0521-0066\$23.50/0

Accessible online at:
www.karger.com/ger

Asae Oura
Department of Public Health, School of Medicine
Sapporo Medical University, Chuo-ku Minami-1 Nishi-17
Sapporo, Hokkaido 060-8556 (Japan)
Tel. +81 11 6112111, Fax +81 11 6418101, E-Mail aoura@sapmed.ac.jp

21 daughters-in-law, and 1 other. The average (\pm SD) follow-up period was 16.4 (\pm 1.0) months, ranging from 7 to 30 months. Information on the frail elderly was collected from medical records while that of caregivers was obtained from a self-administered questionnaire. Depression was judged according to the Center for Epidemiologic Studies Depression Scale (CES-D) [6]. During the follow-up periods, 16 of the frail elderly were entered into long-term care units and 9 others died at home. Following Japanese tradition, the elderly wanted to stay at home until the end of their life. Therefore, in the present study, dying at home was regarded as successful in-home care and these 9 were therefore excluded from the analysis. This study was approved by the Ethical Boards of Sapporo Medical University.

All statistical analyses were conducted using a Statistical Package for Social Science (SPSS, Version 11.5J). The hazard ratios (HRs) of institutionalization and 95% confidence intervals (CIs) were estimated with Cox's proportional hazard model. The χ^2 test and Fisher's exact test were used to compare the proportions of frail elderly in terms of gender for the various parameters measured. A p value <0.05 was considered to be statistically significant.

Results

Table 1 shows the relative risk of institutionalization. Frail female elderly were revealed to be at significant risk (HR = 5.33, 95% CI; 1.21, 23.45). When the caregiver had time to go out without accompanying the frail elderly, the risk of institutionalization for the latter was reduced compared with their counterparts (HR = 0.27, 95% CI; 0.10, 0.75). After adjusting all the values, frail elderly females were revealed to be at significant risk (HR = 5.01, 95% CI; 1.14, 22.07); data are not shown in table 1. When the caregiver had time to go out without accompanying the frail elderly, the risk of institutionalization for the latter was reduced compared with their counterparts (HR = 0.29, 95% CI; 0.11, 0.81).

Discussion

In our previous study [7], depression was more common in caregivers who could not go out without accompanying the frail elderly than in their counterparts who could. In addition, depressive caregivers were more likely to discontinue caring for the frail elderly at home than non-depressive ones [5]. In the present study, the frail elderly whose caregivers could go out without accompanying them had a lower risk of institutionalization than those whose caregivers could not. The result of the present study is consistent with those of our previous studies.

Table 1. Factors related to institutionalization

	HR (95% CI)
<i>Frail elderly</i>	
Gender (female/male)	5.33 (1.21, 23.45)
Age, years old (80+/-79)	1.58 (0.58, 4.36)
Dementia (+/-)	1.75 (0.64, 4.83)
Dementia with behavioral disturbances (+/-)	2.11 (0.76, 5.81)
<i>Caregiver</i>	
Gender (female/male)	0.64 (0.22, 1.85)
Age, years old (65+/-64)	0.79 (0.29, 2.18)
Depression ¹ (+/-)	1.32 (0.49, 3.56)
Consulted with a doctor about their own health (yes/no)	0.93 (0.34, 2.58)
Spouse (yes/no)	0.45 (0.15, 1.41)
Daughter-in-law (yes/no)	1.25 (0.36, 4.38)
<i>Care setting</i>	
Family member helped with caregiving (yes/no)	0.83 (0.30, 2.30)
Able to go out without accompanying the elderly (yes/no)	0.27 (0.10, 0.75)
HR (95% CI) = hazard ratio (95% CI).	
¹ CES-D (16 and up is 'depression').	

Fitting et al. [8] reported that wives caring for their husbands had more depressive symptoms than husbands caring for their wives. In the present study, frail elderly males receiving care had a lower risk of institutionalization than their female counterparts, which appeared not to concur with our speculation that depression was more common among the former than the latter (57.7 vs. 35.7%; $p = 0.03$). It is possible to partly explain these findings in the following ways. Firstly, this result may be a chance phenomenon, because the number of subjects was small. Another explanation is that spouses tended to continue caring for their partners regardless of the heavy burden, and in particular the percentage of frail elderly males receiving care was higher than for their female counterparts (69.2 vs. 18.6%; $p < 0.01$) in the present study. In our previous study [9], conducted in the same area, frail and elderly whose caregivers were daughters-in-law were at risk of institutionalization. These findings might mirror findings of the study by Colerick and George [10].

Family caregivers hesitate to use social services, because it is Japanese tradition that problems have to be resolved within the family. Thus to seek outside help is deemed as losing face or neglect. We should advocate that family caregivers be allowed to have free time away from

caregiving by attenuating their hesitation to use social services and thereby ease their burden of caregiving.

Certain limitations to our study should be mentioned. The present study is not geographically representative of Japan. Further studies are needed to further clarify the issue of risk of institutionalization among the frail and elderly in Japan. This would facilitate a more informed and comprehensive policy of action by the government to counteract this increasing trend.

Acknowledgements

Our special thanks go to the participants in the present study, which was in part supported by research grants provided by the Ministry of Health, Labor and Welfare, and Sapporo Medical University Foundation for Promotion of Medical Science.

References

- 1 Campbell JC: *How Policies Change: The Japanese Government and the Aging Society*. Princeton, Princeton University Press, 1992.
- 2 Maeda D: *The Outline of New Public Long-Term Care Insurance Program*. Japan Aging Research Center: *Aging in Japan 2003*. Tokyo, Japan Aging Research Center, 2003, pp 188–191.
- 3 Kono S: *Demographic Aspects of Population Ageing in Japan*. Japan Aging Research Center: *Aging in Japan 2003*. Tokyo, Japan Aging Research Center, 2003, pp 7–51.
- 4 Barnes CL, Given BA, Given CW: Caregivers of elderly relatives: spouses and adult children. *Health Soc Work* 1992;17:282–289.
- 5 Arai Y, Sugiura M, Washio M, Miura H, Kudo K: Caregiver depression predicts early discontinuation of care for disabled elderly at home. *Psychiatry Clin Neurosci* 2001;55:379–382.
- 6 Radloff L: The CES-D scale: a self-reported depression scale for research in the general population. *Appl Psychol Measurement* 1977;1:385–401.
- 7 Kuwahara Y, Washio M, Arai Y: Burden among caregivers of the frail elderly in Japan. *Fukuoka Acta Med* 2001;92:326–333.
- 8 Fitting M, Robins P, Lucas MJ, Eastham J: Caregivers for dementia patients. A comparison of husbands and wives. *Gerontologist* 1986;26:248–252.
- 9 Arai Y, Washio M, Kudo K: Factors associated with admission to a geriatric hospital in semi-suburban southern Japan. *Psychiatry Clin Neurosci* 2000;54:213–216.
- 10 Colerick EJ, George LK: Predictors of institutionalization among caregivers of patients with Alzheimer's disease. *J Am Geriatr Soc* 1986;34:493–498.

Caregiver Burden Associated with Behavioral and Psychological Symptoms of Dementia in Elderly People in the Local Community

Naomi Matsumoto^a Manabu Ikeda^{a,b} Ryuji Fukuhara^a Shunichiro Shinagawa^{a,c} Tomohisa Ishikawa^a Takaaki Mori^a Yasutaka Toyota^a Teruhisa Matsumoto^a Hiroyoshi Adachi^{a,d} Nobutsugu Hirono^e Hirotaka Tanabe^a

^aDepartment of Neuropsychiatry, Neuroscience, Ehime University Graduate School of Medicine, Ehime,

^bDepartment of Psychiatry and Neuropathology, Faculty of Medical and Pharmaceutical Sciences, Kumamoto University, Kumamoto, ^cDepartment of Psychiatry, Jikei University School of Medicine, Tokyo, ^dOsaka University Health Care Center, Osaka, and ^eFaculty of Humanities and Science, Department of Human Psychology, Kobe Gakuin University, Kobe, Japan

Key Words

Neuropsychiatric Inventory · Neuropsychiatric Inventory Caregiver Distress Scale · Caregiver's burden · Behavioral and psychological symptoms of dementia · Nakayama study

Abstract

Background: Despite many studies about the association between caregiver burden and behavioral and psychological symptoms of dementia (BPSD), there have been no population-based studies to evaluate caregiver burden associated with each BPSD. **Objective:** To evaluate caregiver burden associated with the individual BPSD in elderly people living in the community. **Methods:** The subjects were 67 participants with dementia living with their caregivers (diagnosed in the third Nakayama study): 51 Alzheimer's disease, 5 vascular dementia and 11 other. The Neuropsychiatric Inventory (NPI) and NPI Caregiver Distress Scale (NPI-D) were used to assess subjects' BPSD and related caregiver distress, respectively. **Results:** In the subjects exhibiting BPSD, aberrant motor behavior had the highest mean NPI score, and depression/dysphoria had the lowest. Agitation/aggression had the highest mean NPI-D score, and euphoria/elation had the lowest. Delusion, agitation/aggression, apathy/indiffer-

ence, irritability/lability and aberrant motor behavior showed a correlation between the NPI and NPI-D scores. **Conclusion:** The burden associated with BPSD is different for each symptom and does not always depend on frequency and severity of BPSD. These findings suggest that some symptoms, such as agitation/aggression and irritability/lability, may affect the caregivers significantly, although their frequency and severity are low.

Copyright © 2007 S. Karger AG, Basel

Introduction

Behavioral and psychological symptoms of dementia (BPSD) are distressing to patients and caregivers [1, 2] and often lead to institutionalization [3–5]. However, appropriate management of BPSD lessens the burden of caregivers [6]. Thus, BPSD have important diagnostic, prognostic and management implications.

Caregiver burden is a multilayered phenomenon involving various factors on both sides (care recipients and caregivers) [7]. The structure of the care recipients' side consists of various factors such as their activities of daily living, severity of dementia, and BPSD. The correlation of caregiver burden with the recipient's activities of daily

KARGER

Fax +41 61 306 12 34
E-Mail karger@karger.ch
www.karger.com

© 2007 S. Karger AG, Basel
1420–8008/07/0234–0219\$23.50/0

Accessible online at:
www.karger.com/dem

Manabu Ikeda, MD, PhD
Department of Neuropsychiatry, Neuroscience
Ehime University Graduate School of Medicine, Shitsukawa To-on City
Ehime 791-0295 (Japan)
Tel. +81 89 960 5315, Fax +81 89 960 5317, E-Mail mikeda@m.ehime-u.ac.jp

Table 1. Subjects' and caregivers' data

Subjects (M:F)	67 (29:38)
Mean age \pm SD, years	80.8 \pm 7.0 (66–97)
Diagnosis (AD/VaD/others)	51/5/11
Mean education \pm SD, years	8.1 \pm 2.5 (0–13)
Mean MMSE score \pm SD	20.1 \pm 5.2 (1–28)
CDR (0.5/1/2/3)	24/22/13/8
Caregivers (M:F)	15:52
Caregivers' mean age \pm SD, years	63.5 \pm 10.9 (39–81)
Caregivers' relationship (spouse/child/child-in-law)	28/13/26
Mean ZBI score \pm SD	19.6 \pm 14.8 (0–66)
Mean NPI score \pm SD	13.3 \pm 13.9 (0–58)
Mean NPI-D score \pm SD	4.6 \pm 5.6 (0–24)

Figures in parentheses are ranges.

living and severity of dementia is still controversial [8]. Meanwhile, numerous studies have claimed that the recipient's BPSD may be the most important care recipient variable in terms of their adverse impact on caregiver burden [9].

Other previous studies have demonstrated a strong association between caregiver burden and the care recipient's BPSD such as wandering, agitation or depression [10–13]. Almost all relevant studies, however, evaluate the correlation between the general burden of caregivers and BPSD. Evaluation of the correlation between caregiver burden and individual BPSD will make clear which symptoms require intervention and will be useful in reducing the burden of the caregiver.

The Neuropsychiatric Inventory Caregiver Distress Scale (NPI-D) [11, 14] is an instrument that provides a quantitative measure of the distress experienced by caregivers in relation to the individual symptom domains assessed by the Neuropsychiatric Inventory (NPI) [15–17], which is a comprehensive instrument of BPSD.

Although there are some studies using the NPI-D [11, 12], these studies have come from clinic-derived samples such as patients in Alzheimer's disease research centers. These sources are subject to referral bias. There are few population-based studies investigating the relationship between BPSD and burden. Pot et al. [18] evaluated caregivers' distress and their stressor. However, they used their original assessment scale for BPSD and burden. To our knowledge, there have been no population-based studies to evaluate caregiver burden associated with each BPSD with comprehensive assessment scales.

The aim of the present investigation is to evaluate caregiver burden associated with each BPSD of elderly patients with dementia living in the Japanese community.

Methods

Subjects

The study was conducted on all people aged 65 years and older residing in Nakayama town [19]. The first study was done in 1997 and the second study in 2001. The third study was carried out among 1,521 residents aged 65 years and older between April 2004 and April 2006. In the present study, we analyzed the data from the third study.

The diagnosis of dementia was established according to DSM-III-R criteria [20]. Alzheimer's disease (AD) was defined according to the NINCDS-ADRDA criteria [21], vascular dementia according to the NINDS-AIREN criteria [22] and other dementia according to the standard criteria of each dementia.

Ninety-two participants fulfilled the diagnostic criteria of dementia. Among these, 67 participants living with a caregiver were selected for this study: 51 probable AD, 5 vascular dementia, and 11 other (2 dementia resulting from normal-pressure hydrocephalus, 2 progressive supranuclear palsy, 1 dementia with Lewy bodies, 1 dementia resulting from subdural hematoma, 1 dementia resulting from alcoholism, 1 Parkinson's disease with dementia, 1 dementia resulting from head trauma, 1 dementia resulting from anoxia and 1 dementia resulting from organic phosphorus toxicosis).

The demographic information of the subjects and caregivers is summarized in table 1.

Written informed consent was obtained from all participants (or relatives when necessary), with a full explanation of the procedures.

General Assessment for Dementia

Senior neuropsychiatrists administered the Mini-Mental State Examination (MMSE) [23], and standard physical and neurological examination to the subjects. The severity of dementia was evaluated using the Clinical Dementia Rating (CDR) [24]. All subjects were asked to undergo a cranial computed tomography (CT), and some of them were checked with a blood test and/or a brain single photon emission computed tomography (SPECT) when necessary.

BPSD and Caregiver Distress Scale

The NPI [15–17] and the NPI-D [11, 14] were used to assess subjects' BPSD and related caregiver distress, respectively. The general caregiver burden was assessed by the Zarit Caregiver Burden Interview (ZBI) [7]. All of these were administered by senior neuropsychiatrists. The NPI is a validated caregiver-based clinical instrument that evaluates 10 domains of neuropsychiatric symptoms: delusion, hallucination, agitation/aggression, depression/dysphoria, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability and aberrant motor behavior. The informant was asked if the behavior represented a change from that shown by the participant before the onset of dementia and had been present during the previous month. If a positive re-