

Original Paper

Measurement and the Criterion-Related Validity of Care-Related Needs of Family Members Caring for Demented Elderly Patients at Home

Keiko MATSUMOTO*, Kenichi TAKAI**,
Masafumi KIRINO** and Kazuo NAKAJIMA**

(Accepted May 19, 2006)

Key words: cognition, physical function, problematic behavior, demented elderly patients, family needs

Abstract

To develop a scale for measuring the needs of family caregivers of the elderly with dementia, and to determine its reliability and validity, a questionnaire was mailed to 465 family caregivers out of which 237 respondents replied. A secondary structural model consisting of six factors (Information Needs, Other Person Understanding Needs, Family Needs, Health Care Needs, External Activity Needs and Economic Needs) with 23 items was also given. The results were found to be statistically significant and internal consistency of the 23 items showed high reliability (Cronbach's $\alpha = 0.885$). A model was constructed for hypothesizing the arrangement of cognition, physical function and problematic behavior along with their effects on six factors of homecare-related needs. As a result, the degree of fit was $\chi^2(df) = 446.0(290)$, GFI was 0.923, CFI was 0.923 and RMSEA was 0.050. The path coefficient from cognition, physical function, and problematic behavior to needs was -0.26, 0.14 and 0.26 respectively, while the degree of explanation with respect to these three variables was 17.7%. As a result, the aforementioned factor-related model agreed with the data, and statistically significant levels were found for the relationships between cognitive function and homecare-related needs and between problematic behavior and homecare-related needs.

Introduction

The Japanese Ministry of Health, Labor and Welfare estimates that the number of elderly patients with dementia (degree of independence level II or higher) in 2002 totaled roughly 1.5 million, and will increase by roughly 1 million to 2.5 million by 2015 when the baby-boom generation reaches age 65 or older [1]. Caregivers will be essential for these people to be cared for at home. However, the care provided for elderly persons, previously given through cooperation among family members, is now being provided by one family member. Moreover, the age of the caregiver is becoming increasingly higher [2]. In addition, the lack of understanding of dementia among members of the local community, including nursing and care professionals, is ultimately having a negative impact on persons requiring care as well as family caregivers

* Department of Nursing, Faculty of Health and Welfare
Kawasaki University of Medical Welfare
Kurashiki, Okayama 701-0193, Japan
keimatsu@mw.kawasaki-m.ac.jp

** Faculty of Health and Welfare Science, Okayama Prefectural University
Soujya, Okayama 719-1197, Japan

themselves. It is also exacerbating patients' conditions as well as the relationships between elderly persons requiring care and caregivers. Consequently, many family caregivers are experiencing extreme fatigue, sense of burden and burnout [3-6].

Considerable research on the burden felt by these family caregivers was conducted in the US and Europe in the 1980s, and the research findings of Zarit, et al.[7]in particular are known worldwide. Thus, starting in the 1970s, research [8] has been mostly oriented towards the development of a scale for assessing this burden [9], building a support network for family caregivers [10], identification of factors for providing care by family caregivers [11], exploring symptoms appearing in family caregivers [12] and support for ensuring the well-being of family caregivers [13,14]. Also research from the US in the 1980s focused on the positive aspects of caregiving [15]. In Japan, research followed that conducted by the Tokyo Metropolitan Institute of Gerontology in the 1970s [16-18], including psychological responses, caregiver burden, satisfaction [19,20], and relationships and factors among patients and family caregivers [21-25]. However, there has been very little systematic research conducted either in Japan or overseas that focuses on the needs of family caregivers themselves. Thus, determination of the needs of family caregivers providing homecare for patients, who are estimated to reach more than 2.5 million, along with the quantification of their needs, is necessary for measuring the effects of home care as well as selecting appropriate nursing support.

Therefore, the objective of this study was to determine the homecare needs of caregivers and to examine the validity of the course in correlation with a factor model and external criteria.

Methods

Subjects

A survey was conducted at 23 facilities consisting of visiting nurse stations, home care support centers, family groups, special recuperative elderly homes and medical clinics located in four prefectures in the Chugoku region of Japan. The subjects consisted of the main primary family caregivers registered with a facility, receiving support at home from the facility and selected by the supervising physician, public health nurse, care manager or facility director.

Procedure

A survey request form describing the objective and overview of the survey along with a return envelope were enclosed and sent to the cooperating facilities. The self-administered questionnaire was collected after being sealed by the survey subjects themselves for the purpose of strict confidentiality. In the case of persons who were unable to fill out the questionnaires by themselves, the questionnaires were requested to be filled out by accompanying case managers or other professionals on their behalf while being careful not to influence the responses of the survey subjects. When the surveys were sent to the facilities, managers were requested to allow subjects to decline to answer a questionnaire if they did not desire to do so, and to inform them that their names would not be used. The survey was approved by the ethics committee of Okayama Prefectural University and conducted from December 2003 to April 2004.

The survey contents consisted of gender, age of the patients, as well as the gender, age, relationship and needs of the primary caregiver. Furthermore, cognition was assessed using six cognitive function items, problematic behavior was assessed by measuring the problematic behavior index for elderly persons requiring assistance, and physical function was assessed by using ten items that indicated the cross validity of the construct validity of the Barthel Index (BI). In this study, matters and desires felt by the primary caregiver to be necessary in terms of providing homecare for demented elderly patients were defined as homecare-related needs, and a total of 33 questions were independently arranged by the authors with reference to those factors contained in The Family Needs Survey developed by Bailey & Simeonsson [26].

The questionnaire was administered using a 3-point response category; a reply of “Yes” was assigned a score of 2 points, “Neither yes or no” a score of 1 point, and “No” a score of 0 points.

Content validity was assessed according to the Corrected Item-Total Correlation (CITC) for the purpose of enhancing the internal consistency of the data. The criteria for omission at this time were a CITC of 0.3 or less. Next, those items remaining after the aforementioned analysis were used in principal component analysis, and those items having a load index of the first component of 0.3 or more were extracted. Among these extracted items, those factors able to be interpreted in an exploratory factor analysis were extracted by oblique rotation (Promax Rotation) using the maximum likelihood. At this time, attention was focused on those factors having an eigen value of 1 or more, and their associated items were required to have an absolute value of their factor load index of greater than 0.3.

Next, a confirmatory factor model was hypothesized with the factor load at zero except for subordinate items with a CITC of 0.3 or more, which were extracted. A secondary factor (“homecare-related needs”) was established. Degree of fit was assessed using the Comparative Fit Index (CFI) and Root Mean Square Error of Approximation (RMSEA). An absolute value of 1.96 (level of significance: 5%) was taken to constitute statistical significance. In addition, Cronbach’s α coefficient was determined for internal consistency of the finally selected items.

The distribution of the replies to survey items relating to the homecare needs (23 items) is shown in Table 1. This model was then assessed by structural equation modeling.

The statistical software, “SPSS Version 10.0J for Windows” was used for the analyses, and “AMOS Version 4.0” used for the structural equation modeling.

Table 1 Family Caregiver Needs of Demented Elderly Patients at Home (n = 237)

	Item	Factor loading
X ₂	Desire more information regarding care	0.820
X ₄	Desire knowledge on problematic behavior including ways of coping with it	0.757
X ₃	Desire to know about the quality and level of welfare services	0.742
X ₅	Desire information on the prognosis (what will happen in the future) of the person receiving care	0.724
X ₁	Desire more information on the illness status and degree of impairment of the person receiving care	0.637
X ₁₄	Desire to have the government more effectively inform (enlighten) the public about the illness (dementia)	0.497
X ₁₁	<u>Desire to read a book written by a person in the same situation of providing care</u>	0.425
X ₁₅	Desire to have own relatives understand the actual state of providing care	0.828
X ₁₇	Desire to have own siblings understand the actual state of providing care	0.771
X ₂₀	Desire to have mainly family members not involved in providing care be aware of that care	0.679
X ₁₆	<u>Desire to have own children understand the actual state of providing care</u>	0.426
X ₃₁	Desire for family members to help each other	0.848
X ₃₀	Desire to discuss and resolve problems with family members	0.676
X ₃₂	Desire to have family members decide their roles in the family	0.535
X ₃₃	<u>Desire family members to participate in diversionary activities</u>	0.467
X ₂₁	Desire physicians willing to make house calls to observe and provide health care	0.786
X ₂₂	Desire home nurses to observe and provide health care	0.757
X ₂₃	<u>Desire a dentist to make house calls</u>	0.538
X ₂₈	Desire to have a job and provide care	0.890
X ₁₃	Desire to have a job outside the home	0.727
X ₂₉	Desire to work during the farming season and provide care	0.402
X ₂₇	Desire to know about ways of obtaining economic assistance	0.982
X ₂₆	<u>Desire economic assistance for care expenses</u>	0.609

Results

Patients consisted of 69 men (29.1%) and 168 women (70.9%), with an average age of 83.7 years (SD: 8.5). Subjects consisted of 36 men (15.2%) and 201 women (84.8%), with an average age of 62.7 years (SD: 10.2), and also of 85 daughters-in-law, 71 daughters, 55 spouses and 15 sons, 35.9%, 30.0%, 23.2% and 6.3%, respectively (Table 2).

Table 2 Attribute Distribution of Family Caregivers (n = 237)

Gender	Men	36 (15.2 %)
	Women	201 (84.8 %)
Average Age		62.7years (SD [†] =10.2) (Range=36–93years)
Gender (Demented elderly patients)	Men	69 (29.1 %)
	Women	168 (70.9 %)
Average Age (Demented elderly patients)		83.7years (SD [†] =8.5) (Range 65–103years)
Relationship with Demented Elderly Patient	Spouse	55 (23.2 %)
	Son	15 (6.3 %)
	Daughter-in-law	85 (35.9 %)
	Daughter	71 (30.0 %)
	Granddaughter	3 (1.3 %)
	Other	8 (3.4 %)

† Standard deviation

The reliability of the Homecare-Related Needs scale was determined on the basis of the analysis results. Cronbach's coefficient for internal consistency was 0.885. The coefficients of each factor were determined for Information Needs, Other Person Understanding Needs, Family Needs, Health Care Needs, External Activity Needs, and Economic Needs at 0.856, 0.786, 0.778, 0.726, 0.691 and 0.774, respectively.

A model was constructed that hypothesized the arrangement of the cognition, physical function and problematic behavior as observed variables along with their effects on the six factors that composed homecare-related needs (Fig. 1).

As a result, the degree of fit was $2(df) = 446.0 (290)$, GFI was 0.923, CFI was 0.923 and RMSEA was 0.050. The path coefficient from cognition, physical function, and problematic behavior to needs was -0.26 , 0.14 and 0.26 , respectively, while the degree of explanation with respect to these three variables was 17.7%. Furthermore, positive correlations between cognition and physical function and between physical function and problematic behavior were 0.50 (C.R. = 6.589, $p < 0.01$) and 0.14 (C.R. = 2.011, $p < 0.01$), respectively, while a negative correlation between cognition and problematic behavior was -0.35 (C.R. = -4.839 , $p < 0.01$).

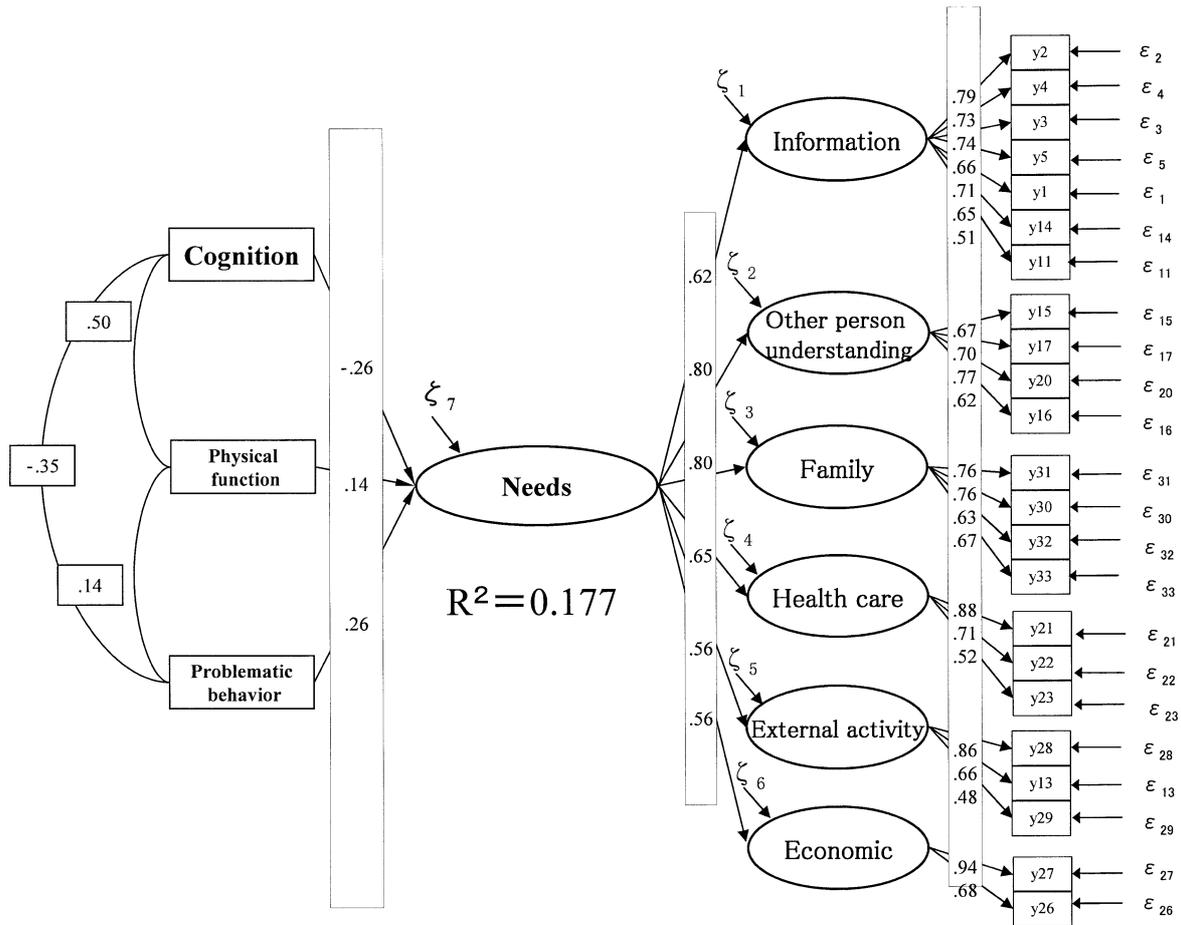


Fig. 1 Relationship Between Cognition, Physical Function and Problematic Behavior of Person Being Cared for and Family Caregiver Needs (Normalized Solution) $n = 218$, $\chi^2(df) = 446.0(290)$, CFI = 0.923, RMSEA = 0.050

Discussion

A secondary factor model was hypothesized using the aforementioned six factors as primary factors and “homecare-related needs” as the secondary factor, and an attempt was then made to analyze the degree of fit to the data by structural equation modeling. As a result, the degree of fit indices of the model to the data satisfied the statistically allowed level, demonstrating the presence of conceptual unidimensionality. This result demonstrates that construct validity is supported in terms of the internal structure (factor model). On the other hand, construct validity is also confirmed by evaluating the aforementioned factor model with respect to its relationship with external criteria. According to a previous report targeting parents of handicapped children [27], the possibility was suggested that needs vary according to the type and degree of the disability. Consequently, in this study, the cognition, physical function and problematic behavior of the elderly person being cared for were positioned as external criteria, and their relationship with homecare-related needs was examined. As a result, the aforementioned factor-related model agreed with the data, and statistically significant levels were satisfied for the relationship between cognitive function and homecare-related needs and the relationship between problematic behavior and homecare-related needs. In particular, it was clearly determined that homecare-related needs increase with a decrease in cognitive function, and that homecare-related needs also increase with an increasing frequency of problematic behavior. These results can be said to support in the broad sense a report which found that problematic behavior relating to uncleanly behavior and wandering was the highest cause of perceiving difficulties in providing care

[28], and the conventional perception that problematic behavior typically increase the sense of burden and symptoms of stress among caregivers and family members [29]. In addition, the results obtained with respect to cognitive function were interpreted as coinciding with a report that signs of cumulative fatigue among family members significantly increase as psychological symptoms become more serious, while also leading to an increase in the desire for institutionalization [30].

In this manner, the advantage of being able to score needs is considered to indicate that this study serves as a reference for providing personalized and comprehensive homecare services by enabling individual differences to be reflected in measurement results, enabling the effects of care to be expressed by a reduction in scores, clarifying the roles of professionals in charge of homecare services, and identifying the unique needs of each individual while being based on the aforementioned scale.

As was reported by Nakajima, et al. [2], although the status of families providing care is clearly weakening, they are also observed to be expanding their own social support networks. This is easily correlated with the elderly care social insurance system enacted in 2000 being responsible for a portion of this. In addition, conflict of needs that occur among not only primary family caregivers but also within families stemming from having to bear the burden of homecare is not only an important issue that confronts family caregivers caring for elderly persons at home, but also is presumed to even cause discord among family members. Moreover, it is also said to be a central phenomenon that explains the changes in the behavior and perceptions of family members as well as the role structure of the family [31]. In view of this, as family members accumulate experience in homecare, even if they fall into a temporary state of difficulty due to conflicting needs, instead of abandoning the homecare they provide, they are presumed to also have the ability to take advantage of the opportunity to change the situation, control conflicting needs and resolve the situation on their own, enabling family members to coexist in harmony while continuing to provide homecare.

Continuing and prompt examination of these study results in the future is imperative for quickly determining the medical demand for the occurrence of caregiver needs on the basis of a long-term-care perspective, including whether or not care can be provided that focuses on suitable and reliable medical support.

During the course of studies relating to care for demented elderly patients by family members, the burden of care felt by caregivers and the effects on their health have been pointed out [19,32]. As a result of positioning those matters and desires felt to be necessary in terms of providing homecare for demented elderly patients by primary caregivers as needs, this study can be said to support in the broad sense the finding that there is a correlation between the quality of family function and the degree of physical function of elderly persons as a factor related to the positive feelings associated with providing care as reported by Sueyama, et al. [33]. Instilling positive feelings with respect to providing care in caregivers while decreasing negative effects as much as possible is an important issue for nursing personnel, and examination of factors that define the needs of primary caregivers, their relationship with additional related factors and their effects is also considered to be an imperative task. As a premise for this, it is considered to be imperative to promptly proceed with an evaluation of the correlation between the factor model developed in this study and the sense of burden felt by caregivers, their mental health and various other factors.

References

1. Ministry of Health, Labor, Welfare: *White Paper of the Ministry of Health, Labor and Welfare*, 207, Administration, Tokyo, 2004.
2. Nakajima K, Nagata K, Kitagawa F: A Comparative Study on the Caregivers of the Elderly with Dementia

- between 1982 and 1991, *The Japanese Journal of Nursing Research*, 175–187, 1996.
3. Yonehana S, Tanikame M, Igawa Y, Tanaka T: Research on Influential Factors Relating to the Burden on Social Life of Family Members Caring for Persons Using Visitation Nurses, *Tokai University School of Medicine, Home Health Care Science Course*, 2003 Annual Report, 148–174, 2003.
 4. Nariki H, Iida S, Noji Y, Sato R, Yuki M, Hoshino A, Maniwa K : A Study on Reduction in Care Burden of the Family caregiver of the Bedridden and senile elderly — Examination of subjective factors about construction in care burden —, *Bulletin of St. Luke's College of Nursing*, 22:1–13, 1996.
 5. Ishigaki K, Hasegawa K, Muramatsu S, Saitou H, Ohnaka K, Shikimori H: Narrative Study of Caregiver's Experience and Utilization of Social Services Whose Care Recipients Are Waiting to Enter a Nursing Home - With Respect to Family Relationship , Spouse , Daughter - in-law and Adult children- , *Journal of Japan Academy of Gerontological Nursing*, 5:115–123, 2000.
 6. Saito E, Kunisaki C, Kanagawa K: Positive Perceptions Encouraging Continued Caregiving at Home Among Family Caregivers, *Japanese Journal of Public Health*, 48:180–189, 2001.
 7. Zarit SH, Reever KE, Bach-Peterson J: Relatives of the Impaired Elderly - Correlates of Feelings of Burden, *The Gerontologist*, 20:649–655, 1980.
 8. Vitaliano PP, Young HM, Russo J: Burden - A Review of Measures Used Among Caregivers of Individuals with Dementia, *Gerontologist*, 31:67–75, 1991.
 9. Given CW, Given B, Stommel M, Collins C, King S, Franklin S: The Caregiver Reaction Assessment (CRA) for Caregivers to Persons with Chronic Physical and Mental Impairments, *Research in Nursing and Health*, 15:271–283, 1992.
 10. Hibbard J, Neufeld A, Harrison MJ: Gender Differences in the Support Networks of Caregivers, *Journal of Gerontological Nursing*, 22:15–23, 1996.
 11. Shyu YI, Lee HC, Chen ML: Development and Testing Family Caregiving Consequences Inventory for Home Nursing Assessment in Taiwan, *J. Adv. Nurs.*, 30:646–654, 1999.
 12. Zunzunegui MV, Beland F, Llacer A, Keller I: Family, Religion and Depressive Symptoms in Caregivers of Disabled Elderly, *J. Epidemiol. Community Health*, 53:364–369, 1999.
 13. Tebb S: An Aid to Empowerment, *Health & Social Work*, 20:87–92, 1995.
 14. Berg-Weger M, Tebb SS: Caregiver Well-Being: A Strengths-Based Case Management Approach, *Journal of Case Management*, 7:67–73, 1998.
 15. Inoue I: Caregiving Situations of Families Caring for Older People with Cognitive Impairment , *The Japanese Journal of Nursing Research*, 29:189–202, 1996.
 16. Tokyo Metropolitan Institute of Gerontology: Project Research Report, Senile Dementia, *Tokyo Metropolitan Institute of Gerontology*, 1986.
 17. Tokyo Metropolitan Institute of Gerontology: Project Research Report, Fundamental and Clinical Aspects of Senile Dementia, Genetics of Aging and Dementia, *Tokyo Metropolitan Institute of Gerontology*, 1989a.
 18. Tokyo Metropolitan Institute of Gerontology, Project Research Report, Fundamental and Clinical Aspects of Senile Dementia, Neurology of Dementia, Clinical Aspects and Social Science of Dementia, *Tokyo Metropolitan Institute of Gerontology*, 1989b.
 19. Nakatani Y, Tojo M: Burden Applied to Family Caregivers, Measurement of Burden and Factor Analysis, *Social Gerontology*, 29:27–36, 1989.
 20. Arai Y: Application of Japanese Version of Zarit's Burden Scale, *Journal of Clinical and Experimental Medicine*, 186:930–931, 1998.
 21. Yasuda H, Kondo K, Satoh Y: A Study of Factors influencing the Perception of Burden and Subjective Well-being in Japanese family caregivers of the impaired Elderly , *Journal of the Japan Rehabilitation Medicine*, 38:481–489, 2001.

22. Mori F, Kume K: The Burden of Caregiver of Patient with Dementia and the Necessary Role of Outpatient Nursing, *Journal of the Japan Society of Nursing Research*, 22:27–37, 1999.
23. Ichimiya A, Igata R, Ogomori K, Igata T: Care-givers' QOL and the burden of care-giving for demented elderly at home - An analysis using WHO/QOL-26 -, *Japanese Journal of Geriatric Psychiatry*, 12:1159–1166, 2001.
24. Morimoto T: Accident Prevention for Homecare Demented Elderly and Relief of Burden of Family Caregivers - Discussion of a Checklist for Family Caregiver Guidance, *Japanese Journal of Nursing Arts*, 48:734–739, 2002.
25. Murakami M, Okina T, Nagahama Y: Study of the Quantitative Care Burden in Senile Dementia - Zarit's Burden Scale, *Journal of Shiga University Medical Science*, 24:20–22, 2002.
26. Bailey DB Jr., Simeonsson RJ: Assessing Needs of Families with Handicapped Infants, *The Journal of Special Education*, 22:117–127, 1988.
27. Tunall B, Power TG: Creating Satisfaction: A Psychological Perspective on Stress and Coping in Families of Handicapped Children, *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 34:945–957, 1993.
28. Odawara H, Nakayama E: Factor affecting “home care for the aged with dementia” Survey of awareness and actual situation of male - caregivers, Survey of the Awareness of Male Caregivers, *Journal of the Japan Socio-Gerontological Society*, 14:84–90, 1992.
29. Niina R: Burden of Caring for Demented Elderly at Home - Research Issues and Future Outlook, *Japanese Journal of Geriatric Psychiatry*, 2:754–762, 1991a.
30. Yokoyama Y, Shimizu T, Hayakawa K: Relationship between the use of community welfare services of the disabled elderly living at home and cumulative fatigue symptoms of caregivers, *Journal of the Japan Socio-Gerontological Society*, 15:136–149, 1994.
31. Kita M: Home Care Process for the Frail Elderly: The Process of the Competing Needs among Family Members that Arises from the “Shiwayose” of Caregiving at Home, *Journal of the Japan Academy of Nursing Science*, 22:33–43, 2002.
32. Niina R, Yatomi N, Honma A: Moderating effect of social support on the burden of family caregivers of the demented elderly, *Journal of the Japanese Psychogeriatric Society*, 2:655–663, 1991b.
33. Sueyama K, Konno R, Konno Y: Factor Analysis of the Formation of Positive Appraisal of Family Caregivers, *Journal of the Japan Socio-Gerontological Society*, 25:461–470, 2004.