# Negative/positive home-based caregiving appraisals by informal carers of the elderly in Japan

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Aim: This study aimed to determine factors associated with negative/positive homebased caregiving appraisals by informal carers of older people in Japan to consider which family carers' community health nurses should focus on. Background: Because of the increasing older population in Japan, those needing a high level of care have become more dependent on informal carers. Carers' health is an important aspect of caregiving. Community health nurses play an important role in assessing carers' health, and carer appraisals, that is, how carers perceive their caregiving work, may help them better understand the health state of carers. **Methods:** This quantitative study examined 192 primary carers of the elderly (care level > 3) who used home-visiting nursing services in both rural and urban Japanese communities. The Japanese version of the Zarit scale (22 items) was used for negative appraisal and a positive caregiving appraisal scale (14 items) for positive appraisal. Participants with above-median scores (care burden, 30.0; positive caregiving appraisal, 39.0) were categorized as having a high care burden and high positive appraisal. To determine factors associated with appraisals, multinomial regression analysis was performed. Negative/positive appraisals were separately set as a dependent variable, and 17 items relating to carer characteristics, carerecipient characteristics, and external variables were set as independent variables. This was followed by stepwise regression and backward elimination. Findings: With respect to care burden, positively associated factors were sekentei or social pressure [odds ratio (OR) 4.25, 95% confidence interval (CI) 1.39–13.04], caregiving obligation (OR 3.11, 95% CI 1.43–6.77), spouse carer (OR 2.58, 95% CI 1.05-6.35), daughter-in-law carer (OR 3.68, 95% CI 1.31-10.34), and depression (OR 50.58, 95% CI 13.85-184.67). With respect to positive appraisal, negatively associated factors were caregiving obligation (OR 0.29, 95% CI 0.15-0.53), male carer (OR 0.44, 95% CI 0.21-0.92), and daughter-in-law carer (OR 0.29, 95% CI 0.12-0.74).

**Key words:** community health nurse; elderly care recipients; high care needs; home-based caregiving appraisal; informal carers health

Received 2 July 2012; revised 1 June 2013; accepted 2 July 2014; first published online 7 August 2014

## **Background**

The percentage of the Japanese population aged ≥65 years is the highest in the world (23.3% in 2011) and estimated to rise further in the future

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(Health and Welfare Statistics Association, 2012). An increase in healthcare needs is expected to accompany this rise. The long-term care insurance system was introduced in 2000 to enable older citizens to live at home, rather than in a facility. Indeed, about 60% of the Japanese population desire to receive care at home in the comfort of their community (Health and Welfare Statistics Association, 2012). Community support allows for

elderly care recipients to continue their homebased life, particularly for those with extensive care needs whose informal carers are engaged in all-day care (Cabinet Office, 2011). Providing allday care to older people with high care needs can affect informal carers' health as such older people become increasingly dependent on their carers. This underscores the need to place focus on and provide community support for informal carers.

The need to focus on and support informal carers of older people in long-term home-based care is not an issue unique to Japan. In fact, the proportion of the international population aged  $\geqslant 65$  years is increasing, leading to increased interest in and awareness of long-term home-based care world-wide (Genet *et al.*, 2011). Thus, studies on community support for informal carers of older people with care needs have global significance.

Informal carers are supported by professional carers and services in a community providing care of older people everyday; however, there are gaps in support and provision between health policy and actual clinical situations (Imaiso et al., 2009). Community health nurses play an advocate role in seeking appropriate legislation related to caregiving issues (Faison et al., 1999), and must listen to the experiences and beliefs of informal carers (Imaiso and Sasaki, 2010). Indeed, community health nurses share a close relationship with care recipients and informal carers as partners in the community and have a good understanding of the daily life of carers. The role of community health nurses is to assess carers' health and support them and care recipients, based on information available to them. The carers' appraisal, which assesses how informal carers perceive their daily caregiving life, is an important source of such information. Community health nurses (eg, home-visiting nurses and public health nurses), rather than social workers or GPs, are particularly suited to assessing and applying information obtained from carers' appraisals. This is because community health nurses are capable of assessing the health status of informal carers, as well as that of care recipients, while also considering the community environment, such as the support system.

In carer appraisals, both negative and positive aspects should be considered by nurses when supporting family carers (Hunt, 2003). Imaiso *et al.* (2012) found that higher care burden is significantly associated with lower positive appraisal,

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and a lower care burden with a higher positive appraisal. Cohen et al. (1994) suggested that the relationship between positive and negative aspects of care is necessarily a complex one and although some positive aspects act as buffers to reduce the intensity of the burden experienced or mitigate the impact of caregiving stress on health, positive aspects might not be directly correlated with burden. Negative aspects do not necessarily equate with less positive aspects. Of concern are the highly negative and minimally positive aspects of caregiving. In addition, as the health of informal carers worsens, there is the possibility that their care recipients would no longer be able to live at home. Thus, support to reduce negative and promote positive aspects should be considered. Any factors that are negatively or positively associated with positive or negative aspects, respectively, should be examined so that informal carers who are often providing the most intense levels of care are able to maintain a healthy state of physical and mental well-being.

Several studies have focused on the negative aspects of care appraisal, such as care burden, care fatigue, and care stress. Faison *et al.* (1999) suggested that nurses need to understand gender differences related to perceived burden. According to Lee *et al.* (2010), to reduce carer burden, nurses need to better understand the values of individual carers regarding quality of life in diverse cultures. Moreover, del-Pino-Casado *et al.* (2011) suggested that balanced reciprocity is useful for the early prevention and early intervention to mitigate subjective burden and must be included in nursing care plans for carers.

On the other hand, several nursing studies have also focused on the positive aspects, such as carer's satisfaction, carer mastery, and enjoyment or pleasure from caregiving. To support these positive aspects, Worcester and Quayhagen (1983) suggested that nurses need to handle psychological and behavioral problems in the home setting, to communicate with physicians when a client is hospitalized, and to train volunteers or healthcare aids with whom carers could leave the client in order to prevent social isolation of the carer and encourage carer satisfaction. In another study, Carruth et al. (1997) suggested that increasing carers' awareness of the reciprocal nature of their relationships with all family members may be an effective strategy to help them appreciate their

contribution to the well-being of their parents and help in achieving caregiving satisfaction.

Bedard et al. (2004) suggested that three determinants (ie, the characteristics of the carer, the characteristics of the care recipient, and external variables that cannot be controlled by carers themselves) must be considered as part of the carer appraisal. Five characteristics identified in appraisals of carers have been found to be significant: age (Worcester and Quayhagen, 1983; Kurasawa et al., 2007); gender (Faison et al., 1999); relationship (del-Pino-Casado et al., 2011); health state (Cohen et al., 1994; Faison et al., 1999; Tsukasaki et al., 2008); and caregiving-related situations (Faison et al., 1999; Saito et al., 2001; Tsukasaki et al., 2008; Lee et al., 2010). In relation to the care recipient, three characteristics have been found to be significant for the care relationship: age (Worcester and Quayhagen, 1983; Lee et al., 2010); gender (Cohen et al., 1994); and extent of care needs (Worcester and Quayhagen, 1983; Faison *et al.*, 1999).

Considering external variables, that is, the third determinant mentioned by Bedard et al. (2004), as well as the aforementioned studies demonstrating an association between carer and care-recipient characteristics, it was hypothesized that high care burden and low positive caregiving appraisal are influenced by different independent factors. To this end, we studied factors associated with homebased negative/positive caregiving appraisals of informal carers of older people with high care needs and considered which family carers' community health nurses should focus on, particularly when attempting to reduce the negative aspects and promote the positive aspects of caregiving.

#### Methods

## Research design

This study was quantitative and designed to examine correlations. The study protocol was approved by the Medical Ethics Committee at Kanazawa University (27 January 2010/No. 246). All participant involvement was voluntary.

#### Definition of terms

Informal carer

Informal carer refers to primary family carers who live with care recipients and perform daily home-based care.

## Community support

Community support refers to both formal home care services related to long-term care insurance in Japan and informal support provided by individuals other than care-recipient family members.

## **Study participants**

Professional home care facilities (total, 767; 355 rural and 412 urban) provided from home-visiting nursing stations were selected from the Welfare and Services Network System (WAM Net) in order to cover facilities in all rural communities in 45 prefectures and all urban communities in 15 prefectures in Japan. The research protocol and participant selection process were initially proposed to the facilities by mail. Facilities that agreed to participate were considered 'approved' facilities. Approved facilities were also asked about the number of carers known by their facilities that they considered were eligible to participate. Each facility was provided with a written explanation of the carers' selection criteria: primary informal carer who used the home-visiting nursing services and lived in rural or urban Japanese regions with elderly recipients (aged ≥65 years) who required care above level 3. 'Care above level 3' refers to care levels determined by the long-term insurance system in Japan, with levels 3 to 5 being the highest. Level 3 care involves care for 70 min or greater but < 90 min, level 4 care for 90 min or greater but < 110 min, and level 5 care for 110 min and greater per day (Health and Welfare Statistics Association, 2012). Carers who met the selection criteria were recognized as eligible for recruitment in the study. From these eligible carers those who were selected by professional carers, such as home-visiting nurses at the approved facilities, participated in the present study.

Of the 398 facilities (response rate, 51.9%) that responded, 91 (22.9%) were approved, including 46 rural facilities (approval rate, 26.0% of 177 rural facilities) in 21 of 45 prefectures, and 45 urban facilities (approval rate, 20.4% of 221 urban facilities) in 14 of 15 prefectures. A total of one to five questionnaires with written explanations of the study were sent to each approved facility (total, 365; rural, 196; urban, 169) based on the number of carers each facility considered eligible to participate.

Completed questionnaires were sent directly from the carers to the researcher by mail. Of the 365 eligible carers (196 rural and 169 urban), 219 responded (60.0%). Of these, 123 (62.8%) were in rural and 96 (56.8%) were in urban communities. Carers who responded with incomplete or inappropriate answers to questions were excluded. A total of 192 (87.7%) eligible carers [103 (83.7%) rural and 89 (92.7%) urban] adequately answered all questions and were included in the study. Data were collected from April 2010 to February 2011.

# Survey with appraisal of home-based caregiving

The questionnaire was confidential and selfadministered. Survey items were based on the three determinants suggested by Bedard et al. (2004): carer characteristics, care recipients' characteristic, and external variables carers cannot control. After a pretest was conducted and the questionnaire revised, the survey was finalized for participant use. Participants took about 30 min to complete the survey, which consisted of the following categories: carer characteristics (attributes, health state, situations related to caring); carerecipient characteristics; external variables (residential communities, support system for caregiving); and a home-based informal caregiving appraisal (care burden, positive caregiving appraisal). To assess depression in carers, the Center for Epidemiologic Studies Depression Scale with 20 questions was used. Scores ranged from 0 to 60, with higher scores indicating greater depression; scores ≥16 are considered indicative of depression (McDowell and Newell, 1996).

With respect to the home-based caregiving appraisal, Zarit et al. (1980) provide an operational definition of caregiving burden as follows: the extent to which carers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relatives. The Japanese version of the Zarit Caregiver Burden Interview, a subjective scale, with 22 items was used. For each item, carers are asked to indicate how often they felt a particular way in a specific situation: never, rarely, sometimes, quite frequently, or nearly always. Scores for each item ranged from 0 (never) to 4 (almost always). Total scores ranged from 0 to 88, with a higher score indicating greater burden (Zarit et al., 1980; Arai et al., 1997; Arai, 2002). To assess positive

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caregiving, a positive appraisal scale with 14 items (Sakurai, 1999) based on the Caregiving Satisfaction Scale (Lawton *et al.*, 1989) and Self-Gain Scale (Skaff and Pealin, 1992) was used. Scores ranged from 1 to 56, with a higher score indicating more positive caregiving (Sakurai, 1999). For each item, carers were asked to indicate how often they felt a particular way in a specific situation: never, rarely, a little, very much. Scores for each item ranged from 1 (never) to 4 (very much).

## **Analysis**

Care burden does not necessarily correspond to less positive caregiving appraisal. For example, there may be instances in which care burden is high, but positive caregiving appraisal is also high, and instances in which care burden is low, but positive caregiving appraisal is also low. Therefore, negative and positive appraisal scores were analyzed separately. Normal P-P plots in negative/positive homebased caregiving appraisals are shown in Figure 1. Both care burden and positive caregiving appraisal did not show a normal distribution. For care burden, participants who scored >median score (ie, >30.0) were grouped as having high care burden, and those who scored  $\leq$  median score (ie,  $\leq$ 30.0) were grouped as having low care burden. For positive appraisal, participants who scored >median score (ie,  $\geq 39.0$ ) were grouped as having high positive caregiving appraisal, and those who scored <median score (ie, <39.0) were grouped as having low positive caregiving appraisal. The association between high/low groups of care burden and positive caregiving appraisal was determined by binominal regression analysis. Factors that differed between rural and urban communities were examined with the  $\chi^2$ -test.

To determine the positive factors associated with care burden and negative factors associated with positive caregiving appraisal, multinomial regression analysis was performed. High and low informal caregiving appraisals (care burden and positive caregiving appraisal) were set separately as dependent variables, based on confirmed correlations from 25 survey items, and 17 items were set as independent variables (Table 1). Stepwise regression and backward elimination was then performed.

Statistical analysis was conducted using SPSS 17.0 for Windows (Japanese). *P*-values <0.05 were considered significant.

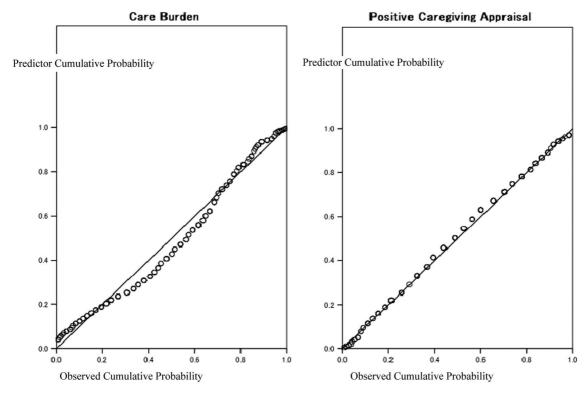


Figure 1 Normal P-P plots in negative/positive home-based caregiving appraisals

#### Results

# **Participant characteristics**

Participant characteristics are shown in Table 1. Of the 192 primary informal carers, 102 (53.1%) were aged  $\geq 65$  years, 146 (76.0%) were female, 83 (43.2%) were spouses, and 34 (17.7%) were daughters-in-law. The mean caregiving duration was  $6.6 \pm 5.9$  years. Of the 192 care recipients, 120 (62.5%) were female.

With respect to external variables, of the 192 primary informal carers, 103 (53.6%) lived in a rural community and 119 (62.0%) had assistant carers in the family. The mean number of formal home care services used was  $2.2 \pm 1.1$ ; 38 (19.8%) received neighborhood support and 33 (17.2%) felt conscious of *sekentei* or social pressure to provide care.

## Home-based caregiving appraisals

Results for home-based caregiving appraisals are summarized in Table 2. The mean care burden score was  $33.3 \pm 18.3$  and the median was 30.0. Of the 192 participants, 95 (49.5%) were in the high care burden group and 97 (50.5%) were in the low care burden group. The mean positive caregiving appraisal score was  $39.0 \pm 9.0$  and the median was 39.0; 102 (53.1%) were in the high positive appraisal group and 90 (46.9%) were in the low positive appraisal group.

High/low care burden groups were negatively associated with high/low positive caregiving appraisal groups. The high care burden group was associated with the low positive caregiving appraisal group, and the low care burden group was associated with the high caregiving appraisal group.

# Factors that differ between rural and urban communities

Factors affecting carers in rural and urban communities are shown in Table 3. Factors that significantly differed between these communities were: relationship, education, assistant carers in

Table 1 Participant characteristics

Primary informal carer characteristics	Total (n = 192; %)	Care-recipient characteristics	Total (n = 192; %)	
Attribute		Gender		
Age (mean ± SD: years)	$65.7 \pm 9.8$	Male	72 (37.5)	
≽65 years	102 (53.1)	Female	120 (62.5)	
<65 years	90 (46.9)	Care level	, ,	
Gender		Level 3	27 (14.1)	
Male	46 (24.0)	Level 4	58 (30.2)	
Female	146 (76.0)	Level 5	107 (55.7)	
Relationship	. , ,	Cognitive disability	,	
Spouse	83 (43.2)	Yes	106 (55.2)	
Daughter-in-law	34 (17.7)	No	86 (44.8)	
Other (child, etc.)	75 (39.1)	External variable		
Education		Residential community		
Neither university nor postgraduate school	159 (82.8)	Rural	103 (53.6)	
University or postgraduate school	33 (17.2)	Urban	89 (46.4)	
Health state	00 ()	Assistant carers <sup>1</sup>	00 ( 101 1)	
Physical health issues		Yes	119 (62.0)	
Yes	104 (54.2)	No	73 (38.0)	
No	88 (45.8)	Number of formal home care	2.2 ± 1.1	
		services <sup>2</sup>		
Depression Scale (CES-D)	$12.2 \pm 8.7$	≥3 services	71 (37.0)	
•		<3 services	121 (63.0)	
Depression (CES-D; ≥16)	57 (29.7)			
No depression (CES-D; <16)	135 (70.3)	Support by neighborhood		
•		Yes	38 (19.8)	
Situations related to caregiving		No	154 (80.2)	
Duration of caregiving (mean ± SD: years)	$6.6 \pm 5.9$			
≥7 years	78 (40.6)	Sekentei or social pressure		
<7 years	114 (59.4)	Pay attention .	33 (17.2)	
Night care	, ,	Pay no attention	159 (82.8)	
Yes	132 (68.8)	,	(,	
No	60 (31.3)			
Caregiving obligation	( /			
Yes	88 (45.8)			
No	104 (54.2)			

CES-D = Center for Epidemiologic Studies Depression Scale.

Table 2 Home-based caregiving appraisals

	Mean ± SD		High group (%)	Low group (%)	Logistic regression analysis			
		(minimum– maximum)			В	SD	Wald	<i>P</i> -value
Care burden	33.3 ± 18.3	30.0 (1–81)	95 (49.5)	97 (50.5)	Dependent variable			
Positive caregiving appraisal	$39.0 \pm 9.0$	39.0 (14–56)	102 (53.1)	90 (46.9)	-0.64	0.29	4.71	0.030*

B= unstandardized  $\beta$  coefficient; SD = standard deviation.

<sup>&</sup>lt;sup>1</sup>Refers to supporters of primary carers in families.

<sup>&</sup>lt;sup>2</sup> Refers to the number of six possible formal home care services used: home-visit caregiving, home-visit rehabilitation, day services, day care, home-visit bath, or short stay.

n = 192.

<sup>\*</sup>P<0.05.

 Table 3
 Factors affecting carers in rural and urban communities

	Rural ( $n = 103,\%$ )	Urban ( <i>n</i> = 89, %)	$\chi^2$ -value	<i>P</i> -value
Primary informal carer characteristics				
Attribute				
Age (mean ± SD: years)				
≽65 years	56 (54.4)	46 (51.7)	1.38	0.410
<65 years	47 (45.6)	43 (48.3)		
Gender				
Male	23 (22.3)	23 (25.8)	0.32	0.344
Female	80 (77.7)	66 (74.2)		
Relationship				
Spouse	48 (46.6)	35 (39.3)		
Daughter-in-law	24 (23.3)	10 (11.2)	9.08	0.011*
Other (child, etc.)	31 (30.1)	44 (49.4)		
Education				
Neither university nor postgraduate school	91 (88.3)	68 (76.4)	4.79	0.023*
University or postgraduate school	12 (11.7)	21 (23.6)		
Health state				
Physical health issues				
Yes	52 (50.5)	52 (58.4)	1.21	0.170
No	51 (49.5)	37 (41.6)		
Depression Scale (CES-D)	( )	. ( ,		
Depression (CES-D; ≥16)	25 (24.3)	32 (36.0)	3.12	0.054
No depression (CES-D; <16)	78 (75.7)	57 (64.0)	0.12	0.00 1
Situations related to caregiving	70 (70.77	07 (01.07		
Duration of caregiving				
≥7 years	41 (39.8)	37 (41.6)		
<7 years	62 (60.2)	52 (58.4)	0.062	0.459
Night care	02 (00.2)	32 (30.4)	0.002	0.433
Yes	72 (69.9)	60 (67.4)	0.137	0.415
No	31 (30.1)	29 (32.6)	0.137	0.415
	31 (30.1)	29 (32.0)		
Caregiving obligation Yes	44 (42.7)	44 (49.4)	0.87	0.216
			0.67	0.216
No	59 (57.3)	45 (50.6)		
Care-recipient characteristics				
Gender				
Male	39 (37.9)	33 (37.1)	0.01	0.515
Female	64 (62.1)	56 (62.9)		
Care level				
Level 3	17 (16.5)	10 (11.2)		
Level 4	29 (28.2)	29 (32.6)	1.26	0.533
Level 5	57 (55.3)	50 (56.2)		
Cognitive disability				
Yes	57 (55.3)	49 (55.1)	0.002	0.542
No	46 (44.7)	40 (44.9)		
Fortament we wind to a	, ,	. ,		
External variables				
Assistant carers	70 (00 0)	40 (55.4)	0.07	0.040*
Yes	70 (68.0)	49 (55.1)	3.37	0.046*
No	33 (32.0)	40 (44.9)		
Number of formal home care services	()	00 (40 0)		
≽3 services	32 (31.1)	39 (43.8)	3.33	0.047*
<3 services	71 (68.9)	50 (56.2)		
Support by neighborhood	a= (a ( a)	40 (44 0)		
Yes	25 (24.3)	13 (14.6)	2.81	0.067
No	78 (75.7)	76 (85.4)		
Sekentei or social pressure				
Pay attention	20 (19.4)	13 (14.6)	0.78	0.246
Pay no attention	83 (80.6)	76 (85.4)		

Table 3 (Continued)

	Rural (n = 103,%)	Urban ( <i>n</i> = 89, %)	$\chi^2$ -value	<i>P</i> -value
Home-based caregiving appraisals				
Care burden				
High group	50 (48.5)	45 (50.6)	0.08	0.447
Low group	53 (51.5)	44 (49.4)		
Positive caregiving appraisal	, ,			
High group	57 (55.3)	45 (50.6)	0.44	0.508
Low group	46 (44.7)	44 (49.4)		

CES-D = Center for Epidemiologic Studies Depression Scale.

Table 4 Factors associated with care burden

Variables	В	SD	Wald	OR	95% CI	<i>P</i> -value
Sekentei or social pressure						
Pay attention .	1.45	0.57	6.40	4.25	1.39-13.04	0.011*
Pay no attention	Reference					
Caregiving obligation						
Yes	1.13	0.40	8.15	3.11	1.43-6.77	0.004**
No	Reference					
Relationship						
Spouse	0.95	0.46	4.23	2.58	1.05-6.35	0.040*
Daughter-in-law	1.30	0.53	6.10	3.68	1.31-10.34	0.014*
Other (child, etc.)	Reference					
Depression Scale						
Depression	3.92	0.66	35.26	50.58	13.85-184.67	0.000***
No depression	Reference					

 $B = \text{unstandardized } \beta$  coefficient; SD = standard deviation; OR = odds ratio; CI = confidence interval. Reference is the low care burden group.

Model  $\chi^2$ -test (likelihood ratio test); *P*-value, 0.000; goodness of fit, 79.7%.

the family, and number of formal home care services. Compared with urban communities, there were more spouse and daughter-in-law carers, carers had less education, there were more assistant carers in the family, and there was less use of formal home care services in rural communities.

# Factors associated with negative/positive homebased caregiving appraisals

Factors associated with care burden are shown in Table 4. Positive significant factors associated with care burden were: *sekentei* or social pressure [odds ratio (OR) = 4.25, 95% confidence interval (CI) = 1.39–13.04], caregiving obligation (OR = 3.11, 95% CI = 1.43–6.77), spouse carer (OR = 2.58, 95% CI = 1.05–6.35), daughter-in-law carer

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(OR = 3.68, 95% CI = 1.31-10.34), and depression (OR = 50.58, 95% CI = 13.85-184.67). Goodness of fit of the model was 79.7%.

Factors associated with positive caregiving appraisals are shown in Table 5. Negative factors significantly associated with positive caregiving appraisals were: caregiving obligation (OR = 0.29, 95% CI = 0.15–0.53), male carer (OR = 0.44, 95% CI = 0.21–0.92), and daughter-in-law carer (OR = 0.29, 95% CI = 0.12–0.74). Goodness of fit of the model was 66.1%.

Independent associated factors that significantly differed between care burden and caregiving appraisal were *sekentei* or social pressure, spouse carer and depression for high care burden, and male carer for lower positive caregiving appraisal.

<sup>\*</sup>P<0.05.

<sup>\*</sup>P<0.05, \*\*P<0.01, \*\*\*P<0.001.

Table 5 Factors associated with positive caregiving appraisal

Variables	В	SD	Wald	OR	95% CI	<i>P</i> -value
Caregiving obligation						
Yes	- 1.26	0.31	15.95	0.29	0.15-0.53	0.000***
No	Reference					
Carer gender						
Male	- 0.81	0.37	4.73	0.44	0.21-0.92	0.030*
Female	Reference					
Relationship						
Spouse	0.004	0.34	0.00	1.00	0.51-1.97	0.992
Daughter-in-law	-1.22	0.47	6.82	0.29	0.12-0.74	0.009**
Other (child, etc.)	Reference					

 $B = \text{unstandardized } \beta \text{ coefficient; SD} = \text{standard deviation; OR} = \text{odds ratio; CI} = \text{confidence interval.}$ Reference is the low positive caregiving appraisal group. Model  $\chi^2$ -test (likelihood ratio test); *P*-value, 0.000; goodness of fit, 66.1%.

#### Discussion

The physical and mental fitness of informal carers not only permits older care recipients to continue living at home but also enhances quality of life for the carers themselves. Informal carers of older people with care needs above level 3, in particular, should have their health monitored, as caregiving at this level has the greatest impact on their daily lives and the lives of their care recipients. Daily caregiving may lead not only to negative feelings, but positive feelings as well. Thus, both negative and positive aspects of home-based caregiving must be considered. Professional carers involved in home care, particularly community health nurses, have the capacity to assess informal carer's health by considering circumstances surrounding informal carers and care recipients, as well as carer and care-recipient characteristics, in order to reduce negative feelings and promote positive feelings of informal carers. To assist in this, the current study made use of home-based caregiving appraisals, which considered the emotional aspects of caring and searched for associated factors.

## **Home-based caregiving appraisals**

In the current study, the median score in the care burden group was 30.0, and the mean score was  $33.3 \pm 18.3$ . In contrast, the median score in the positive caregiving appraisal group was 39.0, and the mean score was  $39.0 \pm 9.0$ .

A normal distribution was not observed for care burden or positive caregiving appraisal. There may have been bias in selecting carers in the current study. For example, it is possible that carers who had good relationships with home-visiting nurses or home care facilities and who care for older people with a positive attitude were selected and that, as a result, scores for care burden may have been lower and scores for positive caregiving appraisal higher in these carers.

# Factors associated with home-based caregiving appraisals

There was a difference in factors associated with care burden and positive caregiving appraisals. Among factors positively associated with care burden were sekentei or social pressure, spouse carers, and depression. That is, informal carers who felt high care burden were conscious of sekentei or social pressure in their caregiving, were spouses and were depressed. It is possible that spouse carers do not use sufficient formal or informal support resources because they are conscious of sekentei or social pressure and fall into a depressed state, and are thus in the high care burden category. Moreover, it is possible that spouse carers of older care recipients are themselves elderly, and thus their own health could be more significantly affected by the care burden.

Bushy (2000) previously reported that informal carers in rural communities tend to experience social pressure to care for family and resist formal community support. In the current study, although sekentei or social pressure was not a significantly different factor between rural and

<sup>\*</sup>*P*<0.05, \*\**P*<0.01, \*\*\**P*<0.001.

urban communities, it was a positive factor associated with care burden. One possibility is that sekentei or social pressure for caregiving leads carers to avoid using community resources given the mindset that they themselves must perform the care duties, which leads to a higher care burden. The important issue may be what the whole community (ie, rural or urban) understands about home-based informal caregiving work, rather than the views of the actual community that informal carers and care recipients live in. On the other hand, in rural communities, social support, that is, formal home care services, tends to be of lower quality and quantity than that available in urban communities. In the current study, formal home care support was used less in rural communities compared with urban communities. Thus, another important issue is the type of home care support available in the community.

Being a male carer was a factor negatively associated with positive caregiving appraisal. Indeed, positive caregiving appraisal was low among male carers. Kramer (1997) suggested that men and women differ across a number of variables such as health, social support, and coping strategies in caregiving appraisals. Faison et al. (1999) reported that male carers may decrease care burden by adapting a more task-oriented and problem-solving approach to caregiving than women. In the current study, however, being a male carer was a negative independent factor in positive caregiving appraisals. This may reflect the possibility that male carers have difficulty promoting the positive aspects and reducing the negative aspects of caregiving.

## **Support by community health nurses**

The findings of this study suggest that community health nurses need to assess informal carers' health by focusing on whether informal carers, particularly spouse carers, avoid getting appropriate formal or informal support services to reduce their high care burden due to being conscious of *sekentei* or social pressure in caregiving. Moreover, community health nurses should understand what male carers feel when providing care and support them in order to increase positive caregiving appraisals.

Community health nurses (eg, home-visiting nurses and public health nurses) should assess the extent to which a community understands home-based

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informal caregiving work; whether informal carers are conscious of *sekentei* or social pressure in their caregiving, and understand community environments (eg, the support systems available) in which informal carers and care recipients, live in order to reduce care burden. Community health nurses also need to understand the types of social resources that are available in communities. If informal carers cannot effectively use community support resources due to social pressure, community health nurses must coordinate with care managers, social workers, care management organizations, and non-professional carers to ensure that such carers receive adequate community support.

# Strengths of the study

There are three strengths of this study. First, the current study analyzed both negative and positive aspects of caregiving appraisals by informal carers. Second, we have provided evidence through data collection in Japan of factors associated with negative/positive home-based caregiving appraisals: the type of residential community (rural/urban) in Japan; community support, and primary informal carer and care-recipient characteristics. Third, the community support that community health nurses should provide to informal carers was clarified.

#### Limitations

This study has some limitations worth noting. First, participants were not recruited from all prefectures with rural or urban communities in Japan. Instead, participants were selected from 21 of 45 prefectures (46.7%) with rural communities and 14 of 15 prefectures (93.3%) with urban communities, that is, from the prefectures that volunteered to participate. Thus, the results may have limited generalizability.

Second, there is a possibility of bias in the selection of carers who had good relationships with home-visiting nurses or home care facilities. Participant selection was based on the use of home-visiting nursing services because the purpose of this study was to consider how nurses should support such carers. Yet, it is possible that home-based caregiving appraisals would have differed if the study selected for participants who did not use or could not use home-visiting nursing services.

Given this possibility, the study population was probably not a representative population of the population of all informal carers.

Third, there is a possibility that respondents exaggerated the burden they perceived in order to receive more support, particularly because the care provider administered the questionnaire to participants.

#### **Conclusions**

This study surveyed 192 Japanese primary informal carers of older people with high care needs to assess the negative and positive aspects of the carers role through use of a home-based caregiving appraisal. Positive significant factors associated with care burden included sekentei or social pressure, caregiving obligation, spouse and daughter-in-law carers, and depression. Negative factors associated with positive caregiving appraisals included caregiving obligation, male carers, and daughter-in-law carers. This study suggests that community health nurses should increase their awareness of informal carers' feelings toward caregiving duties, assess their health to reduce negative aspects and promote positive aspects of caregiving, and prevent deterioration of the physical and mental health of informal carers.

# **Acknowledgements**

This study was a part of a March 2012 doctoral dissertation for the Graduate Course of Nursing Sciences, Division of Health Sciences, in the Graduate School of Medical Science at Kanazawa University, Japan. Part of this article was presented at the 24th International Nursing Research Congress in Prague, Czech Republic, by the Sigma Theta Tau International Honor Society of Nursing from 22 to 26 July 2013. The author is grateful to the family carers for their participation in the study and to the staff at the home-visit nursing stations and other home-care facilities for their cooperation. The author would also like to thank Kanazawa University, particularly Professor Keiko Tsukasaki, DSN, PHN, RN.

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