Family Caregivers' Perspectives for the Effect of Social Support on their Care Burden and Quality of Life: A Mixed-Method Study in Rural and Sub-Urban Central Japan

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Japan has adopted community-based integrated long-term care, which has shifted the burden of care from institutions to the home. However, family caregivers have received less attention compared with care recipients. Many family caregivers are also older adults, and it is important that caregivers receive appropriate support to alleviate the burden of care. In rural and sub-urban area with limited resources compared to urban area, it is necessary to know which support to be prioritized. Therefore, this study aimed to understand family caregivers' perceptions of social support, the type and source of support which were considered important, and how it affected their caregiving burden and quality of life (QOL). We conducted a convergent mixed-method study with 174 primary family caregivers of older adults receiving home care in rural and suburb area of Central Japan. The mixed-method approach enabled qualitative data to complement quantitative results. Strong family support and higher education had positive effects on QOL, while higher caregiving burden and longer duration of care had negative effects on QOL. Provision of tangible support from family and healthcare professionals was central in reducing caregiving burden and improving caregivers' QOL. Support from distant relatives or neighbors, which was deemed inappropriate by caregivers, had a negative effect on caregivers' emotional status. In conclusion, family caregivers perceived support positively, but the effects depended on who provided support. While tangible support from close family and professionals was perceived positively, support from neighbors or distant relatives should consider caregivers' needs and condition to avoid a negative impact.

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Introduction

In 2000, Japan implemented a long-term care insurance system with the slogan "from care by family to care by society." Because of the high-cost long-term care in institutions, Japan's government promoted the use of homeand community-based services in 2005. In addition to cost containment, the community-based service initiative aimed to enable older adults to live at home as long as possible. A nationwide survey conducted by Fukui et al. (2011) found that many people wished to have their end-of-life care at home or in a nursing home, but less than 20% of Japanese people died at home or in nursing homes (MHLW, Ministry of Health, Labour and Welfare Japan 2016a). Since then, "community-based integrated care" has become the basis of Japan's long-term care system. It is a comprehensive care integrating various resources in the community through coordination between health, welfare, and medical specialists, and also includes informal or mutual activities by residents (Morikawa 2014; MHLW 2016b).

However, shifting care from health facilities to home also shifts the caregiving burden. As primary caregivers, family members must bear the burden of caregiving for older adults at home. Previous studies showed that family caregivers have many health risks and lower quality of life (QOL) compared with the non-caregiver group (Pinquart and Sörensen 2007; Ho et al. 2009; Roth et al. 2015). To make it possible for older adults to live in the community, it

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is necessary to alleviate the burden on caregivers. Previous studies showed that community involvement had potential positive effects for both patients and family caregivers in long-term care (Barber 2013; Kelley et al. 2017).

One such positive effect was social support, refers to psychological and material resources available to individuals through their interpersonal relationships (Rodriguez and Cohen 1998). It is proposed to have buffering effect on stress and thereby reduce the psychological burden on family caregivers (Chiou et al. 2009; Anjos et al. 2015). Under the community-based integrated care system, social support is considered an important informal care resource, and is expected to improve and compliment formal long-term care services (Morikawa 2014).

Compared to urban areas, sub-urban and rural area of Japan have less medical and long-term care services (Arai et al. 2015; Hara et al. 2017; Nagaya and Alipio 2017). In limited resources, we must prioritize providing support that is considered beneficial by caregivers. Therefore, it is necessary to understand the support needed and how it will benefit caregivers, to ensure appropriate support is provided. Because social support is a multi-faceted concept which may be different depending on the context, it is difficult to cover in single measurement. Addition of qualitative measurement can cover the value that cannot be measured quantitatively. Therefore, this study aimed to understand family caregivers' perceptions of social support, and how this affects their QOL and caregiving burden, using combined quantitative and qualitative data in a mixedmethod approach.

Design

Methods

We used a convergent mixed method design for this study, with a cross-sectional quantitative method and phenomenological qualitative approach. Integration and mixing occurred in the data collection and discussion parts of the study.

Participants

Study participants were primary family caregivers for older adults who received home care in sub-urban and rural areas of central Japan. Eligibility criteria for this study were:

- 1. Adult (aged \geq 20 years)
- 2. The primary caregiver of a patient that was:
- a. Aged \geq 65 years,
- Receiving home care (eligible to receive long-term care services, classified as Japan's Government Certified Disability Index level 1 to 5).
- 3. The capability to make independent decisions and complete the questionnaires
- 4. Willing to participate in this study.

Participants were recruited using convenience sampling, who fulfilled eligibility criteria from data collection facilities within July 2015 to July 2016.

Measurements

The main outcome (caregivers' QOL) was measured with the Short Form 8 (SF-8) Health Survey (Tokuda et al. 2009). Responses to this 8-item questionnaire are on Likert scales from 1-5 (or 1-6), which gives a total score from 0-100. A higher score indicates better self-reported QOL. As well as the total score, the SF-8 yields a Physical Component Summary (PCS) score and a Mental Component Summary (MCS) score.

The first primary predictor in this study (social support) was measured using the Japanese Multidimensional Scale of Perceived Social Support (MSPSS), which is a short version of the tool (Iwasa et al. 2007). This scale comprises 12 items with responses on a Likert scale from 1-7. It has 3 sub-scales that represent different sources of support; family, friends, and significant others. Significant other is defined as "special person" who can refer to a number of different individuals (e.g., girlfriend or boyfriend, spouse, etc.) (Zimet et al. 1990). An average score is calculated for each subscale, with a higher score indicating stronger support. The second primary predictor was caregiving burden. The Zarit Burden Index Japanese short version (J-ZBI 8) was used to measure caregivers' burden level. The scale includes eight items with responses on a Likert scale from 0-4 (Kumamoto and Arai 2004). A higher score indicates a higher level of burden. All questionnaires have previously been translated into Japanese and tested for validity and reliability (Kumamoto and Arai 2004; Iwasa et al. 2007; Tokuda et al. 2009).

The questionnaires also collected sociodemographic characteristics for participants (age, sex, educational background, work status, annual income, marital status, cohabitating status with care recipient, relationship with care recipient, duration of care) and care recipients (age, sex, level of dependence, and diseases). The category for care recipients' level of dependence was adapted from the Government Certified Disability Index (MHLW 2016c). Qualitative data about caregivers' experiences of caregiving were obtained using open-ended questions, including:

- 1. What do you perceive as "social support" that you have been receiving while giving care?
- 2. What do you think about the support you receive? Is there other support you wish to receive?
- 3. How does the support you receive affect caregiving? And how do you think it affects your quality of life?
- 4. Can you tell us about your family and the neighborhood you live in? Is there any activity that you can participate in, or support related to caregiving?

Data collection

A set of questionnaires was used to obtain quantitative and qualitative data, thereby quantitative and qualitative data were obtained from the same participants. The research team asked for cooperation from clinics and hospitals that provided home care, in which our department had network with. The team explained the research purpose and questionnaire manual to physicians/nurses who were willing to cooperate. The physicians/nurses then briefly explained the study to family caregivers who met the study eligibility criteria, and gave them a study explanation sheet. Informed consent was obtained from family caregivers who agreed to participante. Physicians/nurses distributed the questionnaires to participants, and collected completed questionnaires in the next home visit.

To comply with ethics guidelines and protect confidentiality and reduce biased answers from interviews, we used self-administered paper-based questionnaires. Completed questionnaires were returned in sealed envelope to keep the confidentiality.

Analysis

Participants' sociodemographic characteristics and mean SF-8, MSPSS, and J-ZBI 8 scores are presented descriptively. Multiple linear regression analyses were conducted with SF-8 total, PCS, and MCS scores as the main outcomes. Predictor variables were: age, gender, work status, education background, marital status, annual income, relationship with care recipient, cohabitating with care recipient, length of care, average daily duration of care, care recipient's dependency level, MSPSS subscale scores (family, significant others, friends), and J-ZBI 8 score. SF-8 scores, J-ZBI 8 score, MSPSS score, age, length of care, and average daily duration of care were treated as numeric variables, while the other variables were considered categorical variables. All variables were checked for collinearity, and those with a variance inflation factor more than 10 were omitted from the model. The MSPSS total score strongly correlated with its subscales and showed high collinearity; therefore, this variable was omitted from the model. To see whether social support has moderation effect on caregiving burden effect toward QOL, we inputted J-ZBI 8 score interaction with MSPSS subscale scores. Next, backward stepwise regression was conducted using Akaike information criterion as the criterion for variable selection. Statistical analysis was conducted with R version 3.4.4 (R Foundation for Statistical Computing, Vienna, Austria). The readxl (Wickham and Bryan 2018), psych (Revelle 2018), tidyverse (Wickham 2017), Hmisc (Harrell 2018), plyr (Wickham 2016), DAAG (Maindonald and Braun 2015), and rockchalk (Johnson 2019) packages were used in the analyses.

We used thematic analysis for the large qualitative dataset (Nowell et al. 2017). The initial keyword extraction and coding were performed using NVivo 10 software (QSR International Pty Ltd., Melbourne, Australia). Next, we re-visited the data to check coding, categorized codes into themes, and then clustered the themes. Themes, subthemes, and quotes are presented in table form to promote better understanding of the phenomenon. Mixing of quantitative and qualitative data is presented at the discussion part.

Ethical clearance

This study complies with Mie University's ethic guideline on medical research targeting human, which is formulated based on Japan's Ministry of Health, Labour and Welfare Clinical Research guidelines, Declaration of Helsinki, and International Conference on Harmonization of Good Clinical Practice. All participants received an explanation regarding the study, and verbal informed consent was obtained from those who were willing to participate in this study. Ethical clearance was obtained from Mie University School of Medicine Research Ethics' Committee (No. 1501).

Results

Quantitative results

During the data collection period, physicians from 15 clinics and hospitals agreed to cooperate. From 316 potential participants, 174 family caregivers participated in this study (response rate 55%). The majority of participants were older adults (mean age 65 years) and female. Most participants were high school graduates, married, not work-

ing, and had an annual income lower than 4 million yen. Half of the participants had a parental relationship with care recipients, one-third were spouses, and the remainder included various relationship such as in-laws or grandparent-grandchild. Only one-tenth of participants lived separately from their care recipient, while the remainder lived together. The majority of caregivers had been providing care for a long period. The average duration of care was approximately 12 years, with a daily average of 12 hours of care. The average age of the care recipients was 85 years, with more females than males. More than half of the care recipients had multiple diseases and were certified as care levels 4 and 5, which showed a high level of dependency and needs. Details are presented in Table 1 and Table 2.

The mean SF-8 total score was 60 ± 18.1 , and the mean PCS score was higher than the mean MCS score. Among the three MSPSS subscales, support from friends scored the lowest. The mean J-ZBI_8 score was 12.1, from a maximum score of 31 (Table 3). The distributions of all responses were normal, which confirmed that multiple linear regression analyses were appropriate.

Significant regression equations were found in all three multiple linear regression analyses: SF-8 total (F(15, 158) = 7.56, p = 0.000); SF-8 PCS (F(16, 157) = 5.84, p = 0.000); and SF-8 MCS (F(19, 154) = 6.03, p = 0.000). As shown in Table 3, the SF-8 total and MCS scores had the same predictors, except for care recipient's age and parental relationship. Higher J-ZBI_8 score (higher caregiving burden), longer duration of care, and higher annual income (more than 7 million yen) were significantly associated with lower QOL. Social support from significant others, support from friends, female sex, and parental relationship were also negatively related to QOL, even though the relationship was not statistically significant. Support from family, higher education, being married, and living with the care recipient were associated with higher QOL.

In the model for SF-8 PCS, fewer variables explained the variance. Higher burden, longer duration of care, caregiver's age, and support from significant others negatively affected caregivers' QOL. Support from family, support from friends, and higher education showed positive effects on the physical aspect of caregivers' QOL (PCS), with support from family and higher education as the significant positive predictors (see Table 3 for details).

Social support from family can improve caregivers' overall QOL (total, physical, and mental aspect). Social support from significant others had negative on overall QOL, while social support from friends had positive effect on total and physical score and negative effect on mental score, but statistically not significant. However, from the interaction analysis, support from significant others can improve total and mental score in people who have low caregiving burden (Fig. 1). While higher support from family decrease the MCS in people who have low caregiving burden.

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Characteristic	Frequency (%)	Mean \pm SD (range)
Age		65.5 ± 10.9 (30 to 90)
Sex		
Male	39 (22.4)	
Female	135 (77.6)	
Educational background		
Elementary-Junior high school	29 (16.7)	
High school	94 (54.0)	
College/ University	51 (29.3)	
Working status		
Not working	124 (71.3)	
Working	50 (28.7)	
Household annual income		
< 4 million yen	122 (70.1)	
4 to < 6 million yen	31 (17.8)	
6 to < 7 million yen	8 (4.6)	
7 to < 9 million yen	8 (4.6)	
> 9 million yen	5 (2.9)	
Marital status		
Not married	45 (25.9)	
Married	129 (74.1)	
Relationship with care recipient		
Parent and child	87 (50.0)	
Spouse	60 (34.5)	
Other	27 (15.5)	
Living in the same house with care recipient		
Yes	159 (91.4)	
No	15 (8.6)	
Length of care (months)		131.5 ± 123.1 (3 to 840)
Duration of caregiving in a day (hours)		11.8 ± 7.6 (1.5 to 24)
Quality of life		
SF-8 total score		60.0 \pm 18.1 (9.4 to 100)
SF-8 PCS		62.1 ± 18.9 (10 to 100)
SF-8 MCS		57.9 ± 20.1 (0 to 100)
Social support		
MSPSS total score		4.9 ± 1.3 (1.2 to 7)
MSPSS family		5.3 ± 1.4 (1 to 7)
MSPSS significant other		5.3 ± 1.5 (1 to 7)
MSPSS friend		$4.3 \pm 1.7 (1 \text{ to } 7)$
Caregiving burden (J-ZBI_8 total score)		$12.1 \pm 6.9 (0 \text{ to } 31)$

Table 1. Socio-demographic characteristics of participants (caregivers).

SF-8, short form 8; PCS, physical component score; MCS, mental component score; MSPSS, multidimensional perceived social support; JZBI_8, Zarit Burden Index Japanese short version.

Qualitative Results

Among 174 participants, 124 answered the open-ended questions. A number of themes and subthemes were extracted from these qualitative data (Table 4).

Importance of tangible support as the central theme: The central theme was tangible support. Day care, short stay services, and home visit care were the three most frequent types of services mentioned by participants. Caregivers considered tangible or instrumental support as essential for both received and expected support. Consistent with the tangible support theme, professional services took dominant roles as the main support for family caregivers.

Negative effect of caregiving on caregivers' QOL: Most participants associated caregiving with negative effects, including physical burden, negative emotions, social isolation, reduced private time, financial burden, and insecurity about their future. Complaints such as feeling

Table 2.	Care	recipient's	characteristics

Characteristic	Frequency (%)	Mean \pm SD (range)
Age		84.8 ± 8.9 (66 to 102)
Sex		
Male	80 (46.0)	
Female	94 (54.0)	
GCDI		
Care level 1	19 (10.9)	
Care level 2	35 (20.1)	
Care level 3	30 (17.3)	
Care level 4	32 (18.4)	
Care level 5	58 (33.3)	
Diseases and Illness		
Memory problems (e.g., dementia, Alzheimer)	104 (62.6)	
Cerebrovascular diseases	29 (16.7)	
Heart disease	28 (16.1)	
Liver disease (e.g., chronic hepatitis, cirrhosis)	23 (13.2)	
Cancer	19 (10.9)	
Hypertension	15 (8.6)	
Chronic obstructive pulmonary disease	6 (3.4)	
Kidney failure	6 (3.4)	
Frail	4 (2.3)	
Depression	4 (2.3)	
Other	28 (16.1)	
Average number of diseases and illness		1.2 \pm 0.7 (1 to 4)

GCDI, government certified disability index.

tired, difficulty sleeping, and stress were mentioned in the responses. There was also disappointment about not having time for themselves and to socialize with other people. Because of the high cost of caregiving, caregivers were also burdened financially, and some could not work because of caregiving activities. This resulted in insecurity about the future among family caregivers (e.g., whether they would have sufficient savings to support them when they were old or for their children's expenses).

Role in family and perception of caregiving: Two prominent roles that emerged were those of care recipients' children and female family members. Participants who provided care to their parents felt that it was their duty to their parents, and perceived it as repaying their parents for raising them. Some of these participants also thought that giving their best to care for their parents would prevent them later feeling regret. Female participants (e.g., spouses, children, or daughters-in-law of the care recipient), mentioned that it was the woman's role to provide care in the family. These participants, who perceived caregiving as their natural role, expressed the burden of caregiving. However, at the same time they also expressed acceptance of their "fate" and role in the family as caregiver.

Positive effects of social support: Receiving support was described as having positive effects, such as reducing emotional and physical burden, and resulting in a better social and personal life. The responses reflected that receiving support was perceived as related to emotional support for caregivers as well as reducing physical burden. "Feeling relieved" was the expression mostly used by caregivers. Some also explained that they could take a rest and have time to take care of themselves, including having their health checked at hospital.

Negative impact of support from distant relatives or neighbors/friends: The majority of participants lived in a nuclear "older couple" family or as parents with adult children. They said that they had good relationships and received help from other family members, even those living separately. Some participants lived in neighborhoods with few (or no) community activities and organizations, while others resided in active neighborhoods and had good relationships with their neighbors. However, there were also cases in which support from distant relatives and neighbors or friends resulted in negative feelings instead of helping the caregivers. These negative feelings were expressed as feeling uncomfortable or troubled because of "others" poking into family matters and breaching the family's privacy. "Others" in this context included distant relatives (such as sisters-in-law) and neighbors.

Caregivers' self-reliance: Some participants did not expect much support and relied on themselves to provide care. Various reasons were expressed for this self-reliance. First, some accepted their fate and role as a caregiver. Second, long-term experience of caregiving meant they had

Outcome	Predictors	β	95% CI	р	R²	AIC final model	AIC full model
QOL	Caregiving burden (J-ZBI_8 score)	-7.44	–9.82 to –5.06	0.000	43.1	1,439.67	1,463.11
(SF-8 total score)	Social support – family	5.71	2.52 to 8.89	0.000			
	Social support – significant other	-2.74	-6.54 to 1.06	0.156			
	Social support – friend	0.73	-2.26 to 3.73	0.629			
	Education						
	Elementary/Junior high (ref)						
	High school	1.34	-5.02 to 7.69	0.679			
	College/university	10.75	3.52 to 17.97	0.004			
	Annual income						
	< 4 million yen (ref)						
	4 to < 6 million yen	-3.23	-9.52 to 3.06	0.313			
	6 to < 7 million yen	-1.74	-12.51 to 9.03	0.749			
	7 to < 9 million yen	-14.47	–25.23 to –3.71	0.009			
	> 9 million yen	-6.97	-20.54 to 6.60	0.312			
	Married	3.79	-1.52 to 9.10	0.160			
	Cohabitating with care recipient	6.17	-1.95 to 14.29	0.135			
	Average duration of daily care	-0.60	–0.90 to –0.30	0.000			
	Caregiving burden * social support family	-2.74	-5.61 to 0.12	0.060			
	Caregiving burden * social support sig. other	2.83	0.14 to 5.53	0.039			
OOL PCS	Caregiving burden (J-ZBI 8 score)	-7.17	–9.72 to –4.61	0.000	36.3	1.465	1.492
(SF-8 PCS score)	Social support (MSPSS) – family	4.19	0.81 to 7.58	0.015			
	Social support – significant other	-1.63	-5.43 to 2.17	0.398			
	Social support – friend	0.78	-2.42 to 3.90	0.638			
	Caregiver's age	-0.24	-0.49 to 0.01	0.063			
	Education	012 1	0110 10 0101	01000			
	Elementary/Junior high (ref)						
	High school	1.05	-5.97 to 8.07	0.767			
	College/university	10.41	2.49 to 18.33	0.010			
	Annual income	10111	2110 10 20100	01010			
	< 4 million ven (ref)						
	4 to < 6 million ven	-6.45	-13.36 to 0.46	0.067			
	6 to < 7 million yer	-6.25	-18 44 to 5 95	0 313			
	7 to < 9 million yen	-14 49	-26 13 to -2.86	0.015			
	> 9 million ven	_4.12	-19 21 to 10 96	0.589			
	Care recipient with cancer	5.62	-2 12 to 13 36	0.154			
	Average duration of daily care	-0.63	-0.94 to -0.30	0.000			
0.01 MCC		7.00	10.52 +- 5.12	0.000	107	1 401 57	1 502 02
		-1.05	-10.55 to -5.15	0.000	42.1	1,401.57	1,505.92
(SF-8 NICS score)		7.14	3.49 to 10.79	0.000			
	Social support – significant other	-2.75	-7.14 to 1.64	0.217			
	Social support – friend	-0.69	-2.71 to 4.07	0.690			
	Female	-5.76	-12.33 to 0.82	0.086			
	Education						
	Elementary/Junior nign (ref)	0.17	7 26 +- 7 02	0.002			
	High school	-0.17	-7.36 to 7.02	0.963			
		0.74	0.44 10 17.05	0.039			
	Annual Income						
	< 4 million yen (ref)	1.05	0.02 +- 5.02	0.007			
	4 to < 6 million yen	-1.85	-8.93 10 5.23	0.007			
		-1.04	-13.79 to 10.51	0.790			
	$r \cos 2$ million yen	-10.18	-50.19 10 -5.57	0.005			
	> 9 million yen	-14.84	-30.10 to 0.43	0.057			
		5.52	-1.08 to 12.11	0.100			
	Care recipient's age	0.25	-0.07 to 0.57	0.121			
	Parent – children relationship	-4.86	-11.16 to 1.44	0.129			
	Cohabitating with care recipient	7.64	-1.63 to 16.92	0.105			
	Average duration of daily care	-0.56	-0.91 to -0.21	0.002			
	Caregiving burden * social support family	-3.59	-6.84 to -0.35	0.030			
	Caregiving burden * social support sig. other	3.29	0.14 to 6.46	0.041			

Table 3. Final multiple linear regression models for SF-8 total, PCS and MCS.

Results of multiple linear regression analysis for total QOL and it's subscales.

QOL, quality of life; SF-8, short form 8; PCS, physical component score; MCS, mental component score; MSPSS, multidimensional perceived social support; JZBI_8, Zarit Burden Index Japanese short version; AIC, Akaike information criterion.



Fig. 1. Effect of interaction between social support and caregiving burden toward QOL. Using multiple linear regression, participants' (n = 174, represented by the small circles) social support interaction with caregiving burden and how it affected the QOL were analyzed and plotted into simple slopes. Social support score was categorized into high, moderate, and low support. Caregiving burden is represented by its SD score. The interaction in simple slopes [A] and [C] show that participants with low caregiving burden had better QOL with less support from family. On the contrary, simple slope [B] and [D] show that support from significant other can improve total and mental score of QOL. However, these effects are diminished in the high caregiving burden.

become used to the situation. Third, many felt reluctant to burden other people so they kept the burden themselves. Finally, inadequate information about available support resulted in caregivers not accessing the support they could receive.

Discussion

This study found that strong support from family had positive effects on overall QOL, as well as the PCS and MCS domains. Support from friends had positive effects on overall QOL and the PCS domain, but negative effects for the MCS domain. In caregivers with low caregiving burden, higher support from significant others was associated with higher overall and mental aspect of QOL. Higher caregiving burden and longer duration of care were the main negative predictors of all QOL components. The results from qualitative data showed that tangible support from healthcare professionals and close family members as important support to alleviate caregiving burden. While caregiving had negative impact on caregivers' QOL, positive perception about caregiving and their role in the family might buffer the negative impact. Support from neighbors, friends, or distant relatives might resulted in negative impact on caregivers' mental aspect.

The regression models showed that caregiving burden was a strong negative predictor of caregivers' QOL. The qualitative data supported this finding, and showed that caregiving affected caregivers' physical condition, emotions, social life, and finances. Bodily pain, stress, feeling anxious, insufficient time for self-care and socializing, and financial trouble due to expensive long-term care were some of the negative effects of caregiving mentioned by participants. These findings were consistent with previous studies that found caregivers with higher burden had worse QOL and mental health (Morimoto et al. 2003), worse musculoskeletal symptoms (Darragh et al. 2015), and higher mortality risks (Perkins et al. 2013).

In contrast, we found social support had positive effects on caregivers' QOL. This finding was consistent with several previous studies. Some studies showed that social support had a buffering effect on stress (Cohen et al. 1986), and therefore could reduce emotional burden in caregiving and improve the mental aspect of QOL (Morimoto et al. 2003). A study among Japanese family caregivers conducted by Arai et al. (2008) showed that social support and social networks could predict caregivers' health-related QOL. Another study by Anjos et al. (2015) in Brazil showed that social support for caregivers was important to

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Theme	Subthemes	Quotes
Importance of tangible support	 Physical support Financial support Public facilities Professional services 	"Day service, Short Term Admission Daily Life Care for care that is difficult to do at home, such as bathing, etc. In addition, for health management, during short time when alone at home, if the person who received care does not feel well, they can call the hospital so it's helpful for me." (Respondent T01)
Negative impact of caregiving	 Physical burden Psychological burden Social isolation Financial burden Future insecurity 	"Changing diapers in the middle of the night is really hard. I am lacking sleep and get shingles. I am recovering, but my body is worn out." (Respondent T25) "When the person under care can no longer move, I won't be able to go anywhere all day, and that causes a lot of stress" (Respondent A07) "I do not only do care giving, but I also work part time in order to provide the long- term care. My income and future pension will become lower. Because I work part- time, I have worries about my own future economic security." (Respondent Y14)
Role in family and perception on caregiving	 Child's responsibility to take care of parents Women's natural role to give care 	<i>"It's natural that children take care of their parents. If I can't have my own time because of care, the period is several years of my life. I want to do my best so as not to regret about my parents." (Respondent Y16)</i> <i>"Although it's very hard, I take this as my calling and I do my best." (Respondent T70)</i>
Positive effect of support	 Positive physical effect Positive psychological effect Positive social effect Support from peer with similar identify 	"By using the long-term service, I think caregivers can have their own time and thus increases the quality of life. (Reducing the time spent on caregiving)" (Respondent 104) "They make my workload lighter and I can feel the sense of working together with someone else. I feel there is less sense of being alone in nursing… I really feel that there is someone whom I can rely on, and this provides the nurse with mental care." (Respondent G02)
Negative effect of support from neighbor/friends and distant family	 Unwanted intervention from distant family member Feeling uncomfortable from neighbor attention Breach of family privacy 	<i>"My husband's sister comes to visit once a week, but she cleans the rooms without permission and that bothers me" (Respondent A01)</i> <i>"I don't want someone to come to my house and support me. On the contrary, the support may be troublesome for me…" (Respondent T25)</i>
Caregivers self-reliant	 Accepting fate Long-term experience Reluctance to burden others Not knowing source of support 	"Although it's very hard, I take this as my calling and I do my best." (Respondent T70) "I don't want to bother my children now, so I don't consult with them." (Respondent N12) "When my parents needed nursing care, what support and assistance is there? Where can they go? I really had no idea." (Respondent Y34)

prevent health implications, burden, and biopsychosocial stress and allowed greater freedom for daily activities, which then provided favorable conditions for QOL.

Among the three sources of support measured by the MSPSS, social support from family scored the highest. Social support from family can improve caregivers' overall QOL (total, physical, and mental aspect). However, from the interaction analysis (Fig. 1), participants who have low caregiving burden had better QOL with less support from family, and this effect are diminished in the high caregiving burden. It means, when the caregiving burden is high, social support from family only cannot improve caregivers' QOL. The qualitative data showed that support from close

family member was not the main support for caregivers. The caregivers considered professional care as the main support, and family support came as second.

Participants in this study had higher burden compared with participants in a previous study conducted by Hori et al. (2011), and similar perceived social support scores to a study by Iwasa et al. (2007). However, the average PCS and MCS scores in our study were higher compared with previous studies that measured health-related QOL with the SF questionnaire in general (Tokuda et al. 2009) and caregiver populations (Arai et al. 2008; Miyashita et al. 2011). This suggests that factors other than caregiving burden and perceived social support may affect caregivers' QOL. Our qualitative data offered plausible explanations for this phenomenon. First, we found that tangible support was central for family caregivers. Tangible support was mainly provided by professionals, which was not measured with the MSPSS questionnaire. Provision of respite care was especially helpful to alleviate caregivers' physical and psychological burden. Therefore, it may contribute to improving both physical and mental aspects of caregivers' QOL. This finding was consistent with previous findings from Lund et al. (2014) that showed respite services resulted in improved wellbeing among caregivers. In a study with a Japanese-American community, Young et al. (2002) found that family caregivers considered professional services as an extension of family caregiving, rather than an external resource.

Another plausible explanation could relate to the theme "Role in family and perception of caregiving." The feeling of filial duty towards parents and willingness to keep the closeness of family are possible reasons for participants' perceiving caregiving positively (even satisfying) rather than as a burden. Similar to other Asian cultures, the role of caregiving in Japan primarily rests on females in the family, either the spouse or adult child (Park et al. 2013). A review by Miyawaki (2015) showed a similar finding about filial duty among Japanese Americans. In addition, Yamamoto-Mitani et al. (2002, 2004) showed that positive appraisal of care was important in improving mental aspects of caregivers' QOL and willingness to continue caregiving. However, female caregivers in our study had lower overall QOL and MCS scores, although this was not statistically significant. Qualitative findings from female participants showed that while they perceived caregiving as a burden, they accepted it as their "fate" and role as the female in the family. As the main caregiver, females or spouses had higher caregiving burden, which resulted in lower QOL (Helgeson 2003; Anjos et al. 2015).

From the quantitative analysis, social support from friends had negative effect on caregivers' mental aspect of QOL, but not statistically significant. However, this phenomenon was also found in the qualitative data, which showed that support from distant relatives, neighbors, or friends could have negative impacts on caregivers' feelings. Park et al. (2013) showed that recipients of social support worried that they might cause trouble for those who offered support. However, participants in this study expressed the feeling of discomfort or trouble because of "others" poking into family matters and breaching family's privacy. Another plausible explanation for this negative effect of support may be the discrepancy between the actual support given by distant relatives or neighbors or friends and the support expected by the caregivers. The type of support needed by caregivers may change depending on the time and situation. Although people do not mean harm by giving support, sometimes the support they offer is not expected or may even have a negative effect for the caregivers (Hupcey 1998; Helgeson 2003). An example of this was captured in a comment by respondent Y11, "The neighbors also help in watching over my father. Although it has good points, there are also annoying points from the neighborhood. Previously they often visit my house, but now I don't ask them for help anymore." Park et al. (2013) also stated that while perceived support is generally more normcongruous in Asian cultures, it can sometimes be troubling. In order to clarify this phenomenon better, it is necessary to conduct quantitative research with more participants, or conduct qualitative research with in-depth interview.

Longer duration of care was negatively correlated with QOL. The more time caregivers spend on caregiving, the higher the caregiving burden they have, which resulted in lower QOL (Anjos et al. 2015). Support from significant others also had a negative effect on QOL, even though this was statistically insignificant. This might be explained by the spousal relationship with the care recipient, who was the source of caregiving burden. Married caregivers had higher QOL scores. This phenomenon was explained by Stanley et al. (1998), who found that married caregivers received higher social support.

Our findings confirmed the results of previous studies, and also revealed phenomenon that was possible to explain using the mixed-method design. First, caregivers in this study preferred to receive support from professionals rather than support from distant relatives or neighbors or friends. This result might have implications for the government's plan to enhance social care under community-based integrated care. Our finding suggests that social care in the form of informal support from neighbors may inconvenience caregivers instead of helping them. Therefore, considering that formal care or formal support was preferred by caregivers, social care in community should be designed or packaged to look like formal services. This may diminish the feelings of reluctance and potential negative feelings of others "breaking into" family matters.

Second, this study found that higher income was significantly correlated to lower overall QOL and MCS scores. This result is contrary to previous studies that reported lower income negatively affected QOL (Zhang et al. 2015; Saito et al. 2018). From qualitative results, we found that most participants felt low burden since the long-term care expenses were covered with care recipients' long-term care insurance. However, in case of caregivers who had reduced time to work and earn income because of caregiving, they expressed financial insecurity. It may also be how the person values money and not the amount of money that affects QOL. For example, Callard (1996) showed that belief about money had a large influence on QOL, rather than money itself. Kahneman and Deaton (2010) showed that emotional wellbeing increased as income increased, but only to certain limit; after passing that limit, there was no change in participants' emotional wellbeing.

This study was limited by the small number of participants. The method of qualitative data collection using an open-ended questionnaire further limited the number of responses that could be obtained. Many participants were older adults who might have had difficulty writing responses, and it may have been better to interview participants. However, our approach using questionnaires guaranteed confidentiality, and therefore enabled respondents to answer frankly. Last, as this study was conducted with participants living in sub-urban and rural areas, generalizations should be made carefully. Caregivers who live in large cities, which have different social constructs and more access to various services, may have different results.

In conclusion, the provision of tangible support from professional and close family member was central to reducing caregiving burden and improving caregivers' QOL. Support provided by distant relatives, friends or neighbors, which was deemed inappropriate by caregivers, resulted in negative effect on caregivers' emotional status. Discrepancies between support offered by distant relatives and friends or neighbors and support expected by caregivers may result in negative effects of social support. Caregiving burden, which affected caregivers' physical condition, emotions, social life, and finances, may be the strongest negative predictor of caregivers' QOL. However, positive perceptions of the caregiving role, including filial duty to parents, may buffer this negative effect. Socioeconomic factors (e.g., being female, older caregiver age, not married, and longer duration of care) also negatively affect caregivers' QOL. Further studies using longitudinal designs with larger sample sizes and better qualitative data collection methods (e.g., in-depth interviews) are necessary for more confident generalizations.

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Conflict of Interest

Authors declare no conflict of interest.

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