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Original Article

## The relationship between care burdens and subjective well-being in primary caregivers of community-dwelling cancer survivor

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**Abstract.** [Purpose] The purpose of this study was to examine the relationship among care burden and subjective well-being of primary caregivers with the functional status of cancer survivor in primary caregivers of community-dwelling cancer survivor. [Subjects and Methods] Participants were 18 community-dwelling cancer survivors [10 males and 8 females, aged  $82.6 \pm 12.2$  years (mean  $\pm$  SD)] who received home medical care and 18 caregivers [3 male and 15 female, aged  $65.2 \pm 9.1$  years (mean  $\pm$  SD)]. Care burden and subjective well-being of primary caregivers was evaluated using a 100-mm Visual Analog Scale and Philadelphia Geriatric Center Morale Scale, respectively. The functional status of community-dwelling cancer survivors was evaluated using the Karnofsky Performance Status Scale. [Results] Significant correlations were observed between scores for care burden of transferring and Philadelphia Geriatric Center Morale Scale. [Conclusion] These results suggest that care burden is significantly related to the subjective well-being of primary caregivers of community-dwelling cancer survivors.

Key Words: cancer survivors, caregivers, subjective well-being

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### 1. INTRODUCTION

In recent years, the average life span of Japanese people has greatly increased worldwide. On one hand, secondary obstacles caused by increased care burden of primary caregivers are concern in home medical care, such as depression<sup>1)</sup>, decreased quality of life (QOL)<sup>2)</sup>, and increased risk of abuse<sup>3)</sup>. In particular, the increased care burden of primary caregivers of community-dwelling cancer survivors has been studied<sup>4,5)</sup> and was found to be related to physical and psychological health status<sup>4)</sup>, functional status, and activities of daily living (ADL) among cancer survivors<sup>5)</sup>. However, previous studies did not evaluate the care burden of basic and self-care activities or relationship among care burdens of those basic activities and subjective well-being of primary caregivers with the functional status of cancer survivor in primary caregivers of community-dwelling cancer survivor.

The purpose of this study was to determine the care burden of basic and self-care activities and to examine the relationships between care burden and subjective well-being of primary caregivers and the functional status of cancer survivor in primary caregivers of community-dwelling cancer survivor.

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## 2. SUBJECTS AND METHODS

Study participants included 18 community-dwelling cancer survivors [10 males and 8 females, aged  $82.6 \pm 12.2$  years (mean  $\pm$  SD)] who received home medical care, and 18 caregivers [3 males and 15 females, aged  $65.2 \pm 9.1$  years (mean  $\pm$  SD)] (Tables 1 and 2). Descriptive characteristics of cancer survivors and primary caregivers were collected from electronic medical records of the Itabashi Kuyakusyomae Clinic. Additionally, cancer survivors were classified into the following three groups based on their treatment status: radical period ( $>5$  years after treatment), maintenance period (within 5 years after treatment), and terminal stage. The purpose of this study was explained to patients before they gave voluntarily consent to participate. The Ethics Committee of the Itabashi Kuyakusyomae Clinic approved this study.

A cross-sectional observational study design was used, which included a survey of care burden and subjective well-being of primary caregivers, and functional status of cancer survivors. The care burden of each basic and self-care activity was assessed by a self-report questionnaire completed by primary caregivers and was evaluated using a 100 mm Visual Analog Scale (VAS) <sup>6</sup>. A higher VAS score represents a more severe care burden. Basic activities evaluated by VAS were rolling over, getting up, sitting, standing up and standing, transferring, moving by wheelchair, gait, and stair climbing; self-care activities evaluated by VAS were meals, cosmetics, dressing, bathing, and excretion. Subjective well-being was evaluated using the Philadelphia Geriatric Center (PGC) Morale Scale <sup>7</sup>. Scores on the PGC Morale Scale range from 0 to 17 with a higher score representing better well-being. Items on the PGC Morale Scale are classified into the following three subscales: agitation, attitude toward own aging, and lonely dissatisfaction.

The functional status of cancer survivors was evaluated by an attending physician during their first visit after the study began using the Karnofsky Performance Status (KPS) Scale <sup>8</sup>.

All data were analyzed using IBM SPSS Statistics 24.0 for Windows. Spearman's rank correlation coefficient was used to examine the relationship between VAS, PGC Morale Scale (agitation, attitude toward own aging, lonely dissatisfaction, and total score), and KPS scores. P-values of  $<0.05$  were considered to be significant.

## 3. RESULTS

Data on participant characteristics are shown in Tables 1 and 2. Among community-dwelling cancer survivors, the median KPS score was 50%; this reflects a group of patients for whom nursing and regular medical care are deemed necessary, considering the status of disease. Among primary caregivers, the mean age was younger than 15 older than cancer survivors, approximately 80% were female and approximately than 50% were spouses of cancer survivors. Primary caregivers reported the highest care burdens, which were as follows: moving by wheelchair among the basic activities and excretion among the self-care activities. The median PGC Morale Scale total score was 10 points for primary caregivers. Correlations between the VAS, PGC Morale Scale, and KPS scores are shown in Table 3. Significant positive correlations were found between the VAS (transferring score) and PGC Morale Scale (agitation and total scores) and between the KPS score and VAS (gait and stair climbing scores); significant negative correlations were found between the KPS score and VAS (rolling over, getting up, sitting, and dressing) scores.

Table 1. Community-dwelling cancer survivor characteristics and each parameter

		Cancer survivor n = 18
Age (years)		82.6 ± 12.2
Gender n(%)	Males	10 ( 55.6 )
	Females	8 ( 44.4 )
Site n(%)	Thyroid gland	1 ( 5.6 )
	Lung	1 ( 5.6 )
	Breast	1 ( 5.6 )
	Stomach	4 ( 22.2 )
	Liver	3 ( 16.7 )
	Gallbladder	1 ( 5.6 )
	Colon	7 ( 38.9 )
	Kidney	1 ( 5.6 )
	Uterus	1 ( 5.6 )
	Prostate	4 ( 22.2 )
	Bladder	1 ( 5.6 )
Metastasis n(%)	Thoracic spine	1 ( 5.6 )
	Lumbar spine	2 ( 11.1 )
	Lung	1 ( 5.6 )
	Liver	1 ( 5.6 )
	Peritoneum	1 ( 5.6 )
Treatment status n(%)	Radical period	8 ( 44.4 )
	Maintenance period	5 ( 27.8 )
	Terminal stage	5 ( 27.8 )
Treatment content n(%)	Surgery	14 ( 77.8 )
	Chemotherapy	2 ( 11.1 )
	Untreated	3 ( 16.7 )
Comorbidity n(%)	Pulmonary	2 ( 11.1 )
	Cardiac	3 ( 16.7 )
	Cerebrovascular	10 ( 55.6 )
	Orthopedic	6 ( 33.3 )
	Connective tissue disease	1 ( 5.6 )
	Dementia	2 ( 11.1 )
KPS(%)		50 ( 40, 60 )

KPS; Karnofsky Performance Status

Age is shown as mean ± standard deviation.

KPS is shown as median or 25 and 75percentile.

Other items are presented as percentage or numbers of cases.

Site, metastasis, treatment content has duplicate items.

Table 2. Primary care giver characteristics and each parameter

		Primary care giver n = 18	
Age (years)		65.2 ± 9.1	
Gender n(%)	Males	3 (	16.7 )
	Females	15 (	83.3 )
Relationship n(%)	Spouse	10 (	55.6 )
	Child	6 (	33.3 )
	Other	2 (	11.1 )
Social resources n(%)	Home-visit nursing	12 (	66.7 )
	Home-visit care	1 (	5.6 )
	Home-visit rehabilitation	9 (	50.0 )
	Home-visit massage	1 (	5.6 )
	Day care	1 (	5.6 )
	Short stay	1 (	5.6 )
	Unused	2 (	11.1 )
Care burdens VAS (mm)			
Basic activities	Rolling over	3.5 (	0.0, 90.0 )
	Get up	2.5 (	0.0, 97.0 )
	Sitting	4.5 (	0.0, 97.0 )
	Stand up and Standing	4.0 (	0.0, 68.0 )
	Transfer	19.0 (	0.0, 93.0 )
	Move by wheelchair	23.0 (	0.0, 93.0 )
	Gait	10.0 (	0.0, 72.0 )
	Stair	4.5 (	0.0, 99.0 )
	Self-care	Meals	11.5 (
Cosmesis		6.0 (	0.0, 53.0 )
Dressing		11.5 (	0.0, 70.0 )
Bathing		12.0 (	0.0, 96.0 )
Excretion		22.5 (	0.0, 99.0 )
PGC Morale Scale	Agitation	4.0 (	0.0, 6.0 )
	Attitude toward own aging	3.0 (	0.0, 5.0 )
	Lonely dissatisfaction	3.5 (	1.0, 6.0 )
	Total score	10.0 (	1.0, 16.0 )

VAS; Visual Analog Scale, PGC Morale Scale; Philadelphia Geriatric Center Morale Scale

Age is shown as mean ± standard deviation.

Care burdens VAS and PGC Morale Scale are presented as median or minimum and maximum value.

Other items are presented as percentage or numbers of cases.

Social resources has duplicate items.

Table 3. Correlation between care burdens and subjective well-being and functional status

Care burdens VAS	Basic activities	PGC Morale Scale					KPS
		Agitation	Attitude toward own aging	Lonely dissatisfaction	Total score		
	Rolling over	0.124	0.337	0.143	0.267	-0.572*	
	Get up	0.167	0.320	0.175	0.297	-0.632**	
	Sitting	0.123	0.317	0.167	0.275	-0.537*	
	Stand up and Standing	0.024	-0.151	-0.283	-0.167	0.268	
	Transfer	0.692**	0.465	0.343	0.626**	-0.244	
	Move by wheelchair	0.369	0.226	0.020	0.272	-0.112	
	Gait	0.203	-0.247	-0.098	-0.086	0.528*	
	Stair	0.310	0.033	0.140	0.123	0.497*	
	Self-care						
	Movals	0.040	0.081	-0.202	0.010	-0.323	
	Cosmesis	0.138	0.378	0.055	0.238	-0.464	
	Dressing	-0.045	0.265	-0.087	0.063	-0.551*	
	Bathing	-0.113	-0.117	-0.269	-0.223	0.303	
	Excretion	0.408	0.220	0.242	0.355	-0.080	

\* p<0.05(Spearman), \*\* p<0.01(spearman), VAS; Visual Analog Scale, PGC Morale Scale, Philadelphia Geriatric Center Morale Scale, KPS; Karnofsky Performance Status



#### **4. DISCUSSION**

This study demonstrated the possibility that subjective well-being increases as the care burden of transferring increases among primary caregivers of cancer survivors. Higher scores on the PGC Morale Scale are interpreted as a higher degree of happiness<sup>7)</sup>. However, results of the present study were in contrast with those of a previous study<sup>2)</sup>. In general, primary caregivers who support elderly people who are disabled are affected in terms of their psychological status and income<sup>9)</sup>. Therefore, the effects of psychological status and income should be considered in the QOL of primary caregivers of community-dwelling cancer survivors. Studies are needed to collect data on and further evaluate these additional factors.

It became evident that the care burden of each basic and self-care activity reported by primary caregivers can change depending on the functional status of the cancer survivor. Previous studies have reported that increased care burden of primary caregivers is related to the functional status and decreased ADLs of cancer survivors<sup>4)</sup>; however, the basic and self-care activities that comprise ADLs have not been verified. Findings show that the physical self-care assistance that is burdensome to the primary caregiver may change depending on the functional status of the cancer survivor; low functional status represents ADL scenes requiring low activity levels (such as floor-based activities and self-care), whereas high functional status represents ADLs with high activity levels (such as walking and stair climbing).

Results of the present study suggest that care burden is related to subjective well-being and changes depending on the patient's functional status among primary caregivers of community-dwelling cancer survivors. A future study is needed to further evaluate the relationship between care burden and these associated factors in this population.

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No funding was provided for this study. The author declares no conflict of interest.

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