

Physical and Cognitive Factors Associated with Self-Perceived Burden in Patients with Advanced Cancer

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ABSTRACT

Self-perceived burden (SPB) is the perception of burden on caregivers felt by patients who require long-term care. The purpose of this study was to investigate the impact of physical function, pain, and recognition of equity-inequity on SPB among patients with advanced cancer. We administered the Self-Perceived Burden Scale (SPBS) to evaluate SPB in 100 patients with advanced cancer. We analysed the data using multiple regression analysis with SPBS score as the dependent variable and patient age, caregiver age, duration of nursing care, performance status, pain, and recognition of equity-inequity as independent variables. The response rate was 62% (62 patients). Recognition of equity-inequity ($\beta = 0.464$, $p < 0.001$) and performance status ($\beta = 0.248$, $p = 0.038$) were significantly associated with SPBS score. The explanatory power of the model was 34.4%. These results suggest that future investigations should focus on recognition of equity-inequity and performance status as factors that can reduce SPB.

Key words: *Self-perceived burden, Advanced cancer, Home medical care*

As the population ages, the number of patients with cancer and cancer-related deaths continue to increase steadily, paving the way to a society in which deaths from cancer are frequent and pervasive. From the perspective of reducing duration of hospitalization and considering the needs and quality of life (QOL) of Japanese citizens, home care assistance is being promoted for patients with cancer. However, many patients are worried about the burden that nursing care at home imposes on their families.

Self-perceived burden (SPB) refers to the perception of a care recipient that he or she is placing a burden on the caregiver when nursing care is required. SPB is defined as 'empathic concern engendered from the impact of one's illness and care needs on others, resulting in guilt, distress, feelings of responsibility, and a diminished sense of self'¹¹. SPB is a major source of concern among patients with advanced cancer¹; 39% of patients with advanced cancer experience a weak to moderate level of SPB and 38% experience an upper-moderate to strong level of SPB¹⁹. SPB has been examined in patients with stroke, chronic pain, and amyotrophic lateral sclerosis^{3,7,13} as well as in patients with advanced cancer. SPB is thus perceived as a sense of burden that is typical among care recipients.

Currently, the only reliable and valid measure of SPB is the Self-Perceived Burden Scale (SPBS)⁴. In studies using this scale, patients with

a high score for SPB may have worse QOL and psychological health, as well as depression^{3,4,8,13,15,16,17}. Physical factors that impact SPB include physical function^{4,8,12,13,15} and pain^{8,12,13}. In addition, patients' recognition of the equity-inequity between caregivers and themselves has been shown to be a factor affecting SPB¹¹. Finally, SPB was found to be higher in patients who believe they over-benefit (i.e., the amount of support that they receive from caregivers is greater than the support they can provide for themselves) compared to those who believe that they under-benefit (the amount of support that they receive from caregivers is less than the support they can provide for themselves), or benefit equally (receive equitable treatment) from the support¹³.

Several previous studies have shown that physical factors and recognition of equity-inequity affect SPB. However, physical factors and recognition of equity-inequity were examined separately in these studies, and the causal relationships between SPB, physical factors, and recognition of equity-inequity have not been investigated. In order to reduce SPB, the impact of factors associated with it must be clarified before focusing on interventions that address these factors. Thus, we investigated the impact of physical function, pain, and recognition of equity-inequity on SPB in patients with advanced cancer.

MATERIALS AND METHODS

Participants and procedures

A questionnaire study was conducted with 100 patients with advanced cancer. The participants were people with advanced cancer who were outpatients at a palliative care clinic or inpatients admitted to a palliative care ward in five facilities within the Kanto, Chugoku, and Kyushu regions during the research period from July 2014 to March 2016.

Eligibility criteria included the lack of serious physical and psychological dysfunction or cognitive impairment, in addition to the following: (1) being aware of one's cancer diagnosis, (2) being over 20 years of age, (3) receiving some type of daily care from family members at home, and (4) performance status (PS) greater than 1. We obtained consent from 100 participants from the participating research institutions.

Demographic and medical variables

Demographic variables included patient age, patient gender, caregiver gender, caregiver age, family structure, and duration of nursing care. The medical variable was cancer type.

Measures

Self-perceived burden scale (SPBS)

The Japanese edition of the SPBS¹⁵⁾ was used to assess SPB. The SPBS is a self-administered SPB evaluation scale developed by Cousineau et al.⁴⁾ Its reliability and validity have been confirmed. The Japanese edition was created following normal translation and back-translation procedures, and its reliability and validity were also confirmed. The questions are composed of nine items that describe how the care recipient feels about receiving nursing care from the caregiver. Responses were on a five-point scale of 'none of the time', 'a little of the time', 'some of the time', 'most of the time', and 'all of the time'. The responses were converted into a score ranging from 1 to 5 points, with higher scores indicating that the care recipient felt more strongly that he or she was placing a burden on the caregiver.

Recognition of equity-inequity

We evaluated the recognition of equity-inequity based on the methods of Buunk et al.²⁾ and the Hatfield Global Measure of Equity-Inequity⁶⁾. Participants were asked to select one of the following answers, with the number of points indicated in parentheses: (a) I am providing much more help and support to my caregiver than I receive in return (-2), (b) I am providing more help and support to my caregiver than I receive in return (-1), (c) We are both providing the same amount of help and support to each another (0), (d) My caregiver is providing more help and sup-

port to me than I provide in return (+1), and (e) My caregiver is providing much more help and support to me than I provide in return(+2).

We considered (a) and (b) to represent recognition of under-benefitting, (c) as recognition of equitable treatment, and (d) and (e) as recognition of over-benefitting. The impact of the recognition of equity-inequity was measured on a five-point scale (from -2 to 2).

Physical function

We used PS to evaluate physical function. PS is an index of the level of bodily functioning in patients with cancer. It is classified into five stages from PS 0 (no restriction to daily life) to PS 4 (cannot function at all) with higher numbers indicating poorer overall bodily functioning⁵⁾.

Pain

The degree of pain was evaluated on a numerical rating scale with values from 0 (no pain) to 10 (severe pain).

Data analyses

Spearman's correlation coefficients were calculated for SPBS score and for each factor. We performed a forced-entry multiple regression analysis using SPBS score as the dependent variable and patient age, caregiver age, duration of nursing care, PS, pain, and recognition of equity-inequity as independent variables. We confirmed kurtosis and skewness of the dependent variable in the multiple regression analysis and determined that there were no extreme biases in the distributions. All analyses were conducted using IBM SPSS Statistics V21.0 (IBM, Tokyo).

Ethical considerations

Potential participants received a verbal explanation and an explanatory document stating the research objectives and confirmation that participation was voluntary, that the participant would not be penalized for participating or not participating, and that individuals would not be identified. For participants who indicated their intention to participate in the survey, an anonymous self-administered questionnaire was distributed. Submission of the questionnaire was considered consent to participate in the study. This research study was conducted after receiving approval from the Ethical Committee of the Department of Etymology, Hiroshima University (Etymology review number: 897) and from the ethical review boards of the facilities participating in the study.

RESULTS

Participant characteristics

There were 62 valid responses (valid response rate: 62%). Participant characteristics are shown

in Table 1. In terms of gender, there were 22 male (35.5%) and 40 female (64.5%) participants with a mean age of 72.5 ± 12.5 years. Regarding family structure, 40 participants (64.5%) lived with only their spouse. The most common types of cancer were breast (9 participants, 14.5%), colorectal (9 participants, 14.5%), and lung (8 participants, 12.9%), in that order. In terms of PS, 24 participants scored PS3 (38.7%) and 15 scored PS4 (24.2%), with a mean pain score of 2.5 ± 2.9 . Caregivers consisted of spouses (29, 46.8%) and children (22, 35.5%). There were 28 male (45.2%) and 34 female (54.8%) caregivers, with a mean age of 59.6 ± 11.3 years. The duration of nursing care was 29.7 ± 49.6 months.

Recognition of equity-inequity

Forty-three participants (69.4%) felt that they

over-benefited from the care they received, while 19 (30.6%) felt that they were equitably treated or under-benefited. The average score for recognition of equity-inequity was 0.9 ± 1.0 .

Factors associated with SPBS score

A significant correlation was observed between SPBS and recognition of equity-inequity ($\rho = 0.499$, $p < 0.001$) and PS ($\rho = 0.337$, $p = 0.007$) (Table 2). The same factors were significantly associated with SPBS according to the multivariate analysis (awareness of equity-inequity: $\beta = 0.464$, $p < 0.001$; PS: $\beta = 0.248$, $p = 0.038$). The R^2 adjusted for the number of degrees of freedom was 0.344 (Table 3). The kurtosis was -1.095 , and the skewness was 0.123, showing no extreme biases in the distribution.

Table 1: Participant characteristics

Variable		n	%
Gender	Male	22	35.5%
	Female	40	64.5%
Age (years)		72.5 ± 12.7	
Family structure	With family	22	35.5%
	With spouse	40	64.5%
Cancer type	Oesophagus	3	4.8%
	Lung	8	12.9%
	Breast	9	14.5%
	Gastric	6	9.7%
	Pancreas	4	6.5%
	Gallbladder	3	4.8%
	Kidney	3	4.8%
	Colorectal	9	14.5%
	Prostate	2	3.2%
	Uterine	6	9.7%
	Other	9	14.5%
Performance status	1	11	17.7%
	2	12	19.4%
	3	24	38.7%
	4	15	24.2%
Pain		2.5 ± 2.9	
Recognition of equity-inequity	Over benefited	43	69.4%
	Equitably treated/ Under benefited	19	30.6%
Caregiver	Spouse	29	46.8%
	Children	22	35.5%
	Other	11	17.7%
Caregiver gender	Male	28	45.2%
	Female	34	54.8%
Caregiver age (years)		59.6 ± 11.3	
Duration of nursing care (months)		29.7 ± 49.6	

Table 2: Spearman's correlation coefficient between SPBS and factors

(n=62)

	SPBS	Age	Performance status	Pain	Recognition of equity-inequity	Caregiver age	Duration of nursing care
SPBS	1.000						
Age	-0.033	1.000					
Performance status	0.337**	0.142	1.000				
Pain	0.152	0.030	0.126	1.000			
Recognition of equity-inequity	0.499**	0.103	0.222	0.134	1.000		
Caregiver age	0.031	0.300*	-0.058	-0.179	-0.010	1.000	
Duration of nursing care	0.129	-0.025	0.145	0.194	-0.031	0.169	1.000

**: $p < 0.01$, *: $p < 0.05$

DISCUSSION

Multiple regression analysis showed that the recognition of equity-inequity and PS were associated with SPB.

PS was a positive influencing factor; participants with worsening PS had stronger SPB. In general, patients with advanced cancer have high physical function during the year before death, which begins to decrease 3 months before death¹⁰. Concomitant with deteriorating physical function, these patients start to require assistance with daily activities, making it difficult for them to fulfil their responsibilities. SPB is thought to become stronger in situations where the amount of care received from family members increases as PS worsens. In addition, SPB becomes stronger as a patient nears death, supporting previous findings^{1,14,18}) that SPB is an important consideration for a good death.

The recognition of equity-inequity had a positive impact on SPB. We found that SPB was stronger in participants who perceived that they over-benefited from the care they received. This factor had the strongest influence in our model; 69.4% of participants believed that the level of support they provided was less than the support they received from caregivers. Given that PS and the recognition of equity-inequity were not significantly correlated with each other, it is possible that patients with advanced cancer feel they over-benefited from the care they receive from family, regardless of PS. However, since PS was associated with SPB, worsening PS in patients who feel they over-benefit from care leads to increased levels of care from family members, which in turn can intensify SPB. Thus, it is important to consider how to manage patients with advanced cancer who feel they over-benefit from the care they receive from family members.

Nurses should assist patients with their attempts at self-care and help them to accept that

Table 3: Factors related to SPBS

(n=62)

	β	p-value
Recognition of equity-inequity	0.464	$p < 0.001$
Performance status	0.248	$p = 0.038$
F-value	10.197	$p < 0.001$
R ²	0.415	
Adjusted R ²	0.344	

Multiple regression analysis: forced entry method

they have done everything they can. In addition, a previous study showed that caregivers recognized a sense of burden when providing care²⁰). On the other hand, there were positive aspects such as satisfaction with the caregiving situation, which alleviates the sense of burden^{8,9}). Providing support to caregivers so that they can have a positive experience during caregiving and providing opportunities for caregivers to inform patients of the benefits of caregiving can enable patients to understand the positive aspects of caregiving.

Open dialogues between patients and family members are not only instrumental in coming to a consensus regarding decisions, but also provide opportunities for communicating gratitude verbally and finding positive meaning. Accordingly, nurses should facilitate such dialogues and ensure that they lead to reduced SPB among patients and reduced caregiving burden among caregivers.

One limitation of this study is the small sample size. Future studies should be conducted with a larger sample size. However, no previous study has addressed the impact of factors associated with SPB. It will be important to accumulate more findings in order to propose effective methods to reduce SPB.

CONCLUSION

Recognition of equity-inequity and PS were associated with SPB; recognition of equity-inequity had a larger impact. To reduce SPB, measures focusing on the recognition of equity-inequity and

PS need to be developed.

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