

Caregiving Consequences Inventory: a measure for evaluating caregiving consequences from the bereaved family member's perspective

Makiko Sanjo^{1*}, Tatsuya Morita², Mitsunori Miyashita¹, Mariko Shiozaki³, Kazuki Sato¹, Kei Hirai^{4,5}, Yasuo Shima⁶ and Yosuke Uchitomi⁷

¹Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan

²Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka, Japan

³Research Fellow of the Japan Society for the Promotion of Sciences and Public Health, Graduate School of Medicine, Osaka University, Osaka, Japan

⁴Center of the Study for Communication Design, Psychology and Behavioral Sciences, Graduate School of Human Sciences, Osaka University, Osaka, Japan

⁵Department of Complementary and Alternative Medicine, Graduate School of Medicine, Osaka University, Osaka, Japan

⁶Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki, Japan

⁷Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba, Japan

*Correspondence to:

Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan. E-mail: shibagaki-ky@umin.ac.jp

Abstract

Objective: The aims of this study were to validate an instrument for measuring bereaved family members' perceptions of caregiving consequences and to examine the association between caregiving consequences and psychological distress.

Methods: Cross-sectional questionnaires were administered to family members of patients who had died in regional cancer centers. We measured the Caregiving Consequences Inventory (CCI), respondent's optimism, overall reward scale, and psychological distress and collected background data. A retest was conducted.

Results: Bereaved families from two regional cancer centers were surveyed ($N = 189$ and 109 ; effective response rate, 57 and 80%). By exploratory and confirmatory factor analyses, we identified four perceived reward domains: 'mastery', 'appreciation for others', 'meaning in life', and 'reprioritization', and one perceived burden domain. Although the four reward domains were highly correlated with each other ($0.47 < r < 0.69$), the 4-domain model was superior. The respondents with less education, strong faith, and less optimism reported fewer perceived rewards, thus demonstrating known group validity. In addition, perceived reward had little or no correlation with psychological distress. The psychometric properties of this scale were good ($\alpha = 0.78$ – 0.93 , ICC = 0.60 – 0.73) and construct validity was supported (GFI = 0.929 ; AGFI = 0.819 ; CFI = 0.749 ; RMSEA = 0.097).

Conclusions: The CCI is valid for measuring caregiving consequences from the bereaved family member's perspective in Japan. Furthermore, it is important to use perceived rewards and burdens as a measure of caregiving consequences for improving the quality of the caregiving and bereavement experience.

Copyright © 2008 John Wiley & Sons, Ltd.

Keywords: caregiver; palliative care; neoplasms; measures; reward; burden

Received: 15 December 2007
Revised: 30 July 2008
Accepted: 3 August 2008

Introduction

The World Health Organization concept of palliative care includes attention to the health and well-being of the family members caring for a patient, and it proposes a support system to help caregivers cope during the patient's illness and their own bereavement [1]. Research has shown that caring for severely ill patients can have a negative impact on the mental, physical, and financial well-being of the caregivers [2–5]. In addition, the caregiver's

burden is associated with family dissatisfaction and regret in received care [6], depression in family members [7,8], and caregiver mortality [9,10] in the course of caregiving and bereavement. Thus, palliative care specialists and researchers have tried to help reduce the caregiver's burden [11–15].

While past research has clearly documented the negative emotions experienced during caregiving and bereavement, recent research has investigated positive consequences of caregiving [16]. Approximately 60–70% of caregivers have reported

that they could recognize positive aspects of the experience [17–19], and psycho-educational interventions have had long-term positive effects on caregiving consequences [20,21]. Although several positive outcomes of caregiving such as appreciation, gratification, mastery, finding meaning and purpose in life, reprioritization, personal growth, and satisfaction [22–26] have been explored, the operational definitions of words used by researchers vary [16] and there is no consensus on what constitutes positive caregiving outcomes.

In Japan, cancer is the leading cause of death. Although enhancement of palliative care for Japanese cancer patients and family caregivers is a priority in Japan, we found only a few studies that investigated in detail caregiving for severely ill cancer patients. To deliver appropriate support for family caregivers, it is important to evaluate both positive and negative caregiving outcomes. There are a few scales that evaluate both positive and negative caregiving outcomes [27,28]. However, in these scales, various positive aspects are measured in 1 domain only, and it is difficult to understand the positive aspects of caregiving in detail. Moreover, surveys of families of patients at the end of life are not culturally appropriate in Japan. Thus, for considering how to provide care to the families, it is necessary to assess caregiving consequences, that is, the positive and negative experiences of the caregivers from the bereaved family's viewpoint. It is difficult to use the scale with many items (more than 20 items) for vulnerable bereaved families in Japan. Today, however, there are a few brief scales.

The aim of this study was to develop a brief measure for evaluating caregiving consequences from the bereaved family member's perspective and to measure the validity and reliability of this new measure in Japan.

Methods

This survey was made up of two cross-sectional anonymous mailed surveys of the bereaved family members of cancer patients in two regional cancer centers in Ibaraki Prefecture (Part 1) and Shizuoka Prefecture (Part 2). Both centers have general wards and inpatient palliative care units (PCU).

Measurements

Caregiving Consequences Inventory (CCI)

To evaluate the consequences of caring for incurable cancer patients from the bereaved family's perspective, we pooled items found through a systematic literature review of studies that described the positive aspects of caregiving [22–25,29–31], caregiver burden [2–5], caregiving-related concepts [16,26,32–38], stress-related growth [39–41], and discussions about the similar-

ity of the concepts. Reviewers were a research nurse specializing in palliative care, a palliative care specialist, and a researcher specializing in clinical psychology. Then, we hypothesized a factor structure prior to psychometric testing of 5 domains of perceived rewards: personal growth, mastery, appreciation for others, meaning in life, and reprioritization, and 1 domain of perceived burden. In Japan and overseas, both a Caregiving Burden Scale with a clear domain structure [42,43] and one without a clear structure [44,45] are used. However, we used 1 domain for the caregiving burden in this survey for the following reasons: (1) the size of the contribution of the first factor is very large compared with the second factor [42] and (2) the caregiving burden in Japan can be assumed to be included in 1 domain [46,47]. We also discussed the content validity for the items using the following selection criteria: (1) easily understood and completed, (2) potentially applicable to both caregiving and bereavement, (3) comprising hypothesized dimensions, and (4) comprising three or more items for each domain. We then selected 19 items as perceived reward domains and 5 items as perceived burden domains. All of the authors were in agreement on these items and factors. This process ensured the content validity of the initial 24-item version of the CCI (available from the authors). These items were rated using a 7-point Likert scale (1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree). We used the initial 24-item version in Part 1 of the survey and the 16-item shortened version in Part 2.

Overall perceived rewards

We asked about overall perceived rewards with the statement: 'It was a good experience for me to care for my family member' using a 7-point Likert scale (1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree). We used this scale to examine the concurrent validity of the CCI in Part 2 of the survey. We did not have scales to examine details of positive aspects of caregiving consequences when the survey was conducted. We therefore used a single item to measure concurrent validity, the best method in such a situation [48].

The Life Orientation Test—Revised (LOT-R)

Research has shown that optimism is associated with positive aspects of difficult situations [18,49]. We hypothesized that the perceived reward domain score is positively correlated with optimism of the respondents. The LOT-R is a 10-item (six target items and four fillers) self-report scale measuring expectations about positive outcomes in general, using a 5-point scale from 0 (strongly disagree) to 4 (strongly agree) [49]. The validity and reliability of

the Japanese version have been confirmed, and Sakamoto proposed a two-factor model consisting of optimism and pessimism [50]. Responses are scored from 0–12 with higher scores on the three optimism items representing greater dispositional optimism, while higher scores on the three pessimism items represent greater dispositional pessimism. We used this scale to examine the known group validity of the CCI in Part 1 of the survey.

The General Health Questionnaire-12-item version (GHQ-12)

The GHQ-12 is a screening instrument covering a range of psychiatric symptoms (e.g. anxiety and depression) as well as somatic symptoms and social dysfunction [51]. We used the GHQ-12 to measure the degree of psychological distress of the respondents and to examine the discriminate validity of the CCI in Part 2 of the survey.

Background data of caregivers and patients

The patient's age, sex, and number of hospital days, time since patient's death, and care settings were extracted from medical databases. The caregiver's background data included the bereaved family member's age, sex, relationship with the patient, and frequency of attending the patient.

In Part 1, we also asked the respondents about health status during the caregiving period, presence of other caregivers, whether the caregiver lived with the patient, and caregiver's faith, education, and household income during the caregiving period. Research has shown that caregivers with less education and strong faith reported fewer perceived rewards [52,53]. Thus, we used these data to examine the known group validity of the CCI.

Participants and procedures

To find potential participants for Part 1 of the survey, we identified from medical records bereaved family members of patients who died from lung or gastrointestinal cancer from September 2004–February 2006 on the general ward in a regional health center in Ibaraki Prefecture and patients who died from all forms of cancer in PCUs in the same regional health center during the same period. We mailed questionnaires to potential respondents in October 2006 and a reminder was sent in November 2006 to those who did not respond. The respondents were asked to report the level of agreement on the initial 24-item CCI and LOT-R and to supply background data. To examine test–retest reliability, we sent the same questionnaire one month later.

For Part 2 of the survey, we identified from medical records bereaved family members of patients who died from April 2005–April 2006 in PCUs of regional cancer centers in Shizuoka

Prefecture. We mailed questionnaires to potential respondents in March 2007 and a reminder was sent in April 2007 to those who did not respond. The respondents were asked to report their level of agreement with the final 16 items of the shortened version of the CCI, their overall perceived rewards, responses to the GHQ-12, and background data.

The inclusion criteria were the same in both surveys and were as follows: (1) patient was aged 20 years or more and (2) patient was hospitalized at least 3 days. The exclusion criteria were the same in both surveys: (1) participant was recruited for another survey for bereaved family members, (2) participant would have suffered serious psychological distress as determined by the primary physician, (3) cause of death was treatment related or due to injury, (4) there was no bereaved family member who was aged 20 years or more, (4) participant was incapable of replying to a self-reported questionnaire, and (5) participant was not aware of the diagnosis of malignancy.

Ethical consideration

The protocols were approved by the institutional review board of each institute. In both Part 1 and Part 2, if the respondents did not want to participate in the survey they were asked to return the questionnaire with 'no participation' indicated, and a reminder was not mailed to them.

Statistical analyses

Scale development

For item reduction, we first deleted items with data missing for 20% or more of the respondents, or highly skewed distributions of the ratings defined as 'mean \pm standard deviation' beyond the scope of the variable. We then used exploratory factor analysis using the maximum likelihood method [54] with a promax rotation for perceived reward domains and perceived burden domains, separately. According to the results of the exploratory factor analysis, attributes with factor loadings less than 0.3 (standardized regression coefficient) were deleted. Among several models tested, we adopted the model that showed sufficient fitness to the factor structure based on the hypothesized concepts and clinical validity based on full agreement of the authors. The items that were finally adopted for the CCI are described in the appendix. The domain score was calculated by summing the items in each domain. The total reward score was calculated by summing the 12 items in all perceived reward domains, although we did not provide the CCI total score, which was calculated by summing the 16 items, including 12 perceived reward items and four burden items.

Scale validation

Validity: To examine concurrent validity, we calculated the Pearson's correlation coefficients between each domain of the CCI and one item overall for perceived rewards using data from Part 2. In addition, to examine construct validity of the final 16 items of the CCI, we calculated the Pearson's correlation coefficients between each domain score of the CCI using data from Part 1, and conducted a confirmatory factor analysis using data from Parts 1 and 2, separately. Known group validity was examined using a *t* test to compare the reward domain scores of respondents who had more faith compared with those with less faith, scores of respondents who had more education compared with those with less education, and scores of respondents who were more optimistic compared with those who were less optimistic.

Faith responses were grouped into a group with less faith (1: none at all and 2: slightly strong) and a group with more faith (3: moderately strong and 4: very strong). In addition, responses about education level were grouped into a group with less education (1: finished junior high school and 2: finished high school) and a group with more education (3: junior college graduate and 4: college graduate). As for optimism and set the threshold value for optimism was established at 6/7.

In addition, to examine discriminate validity, we calculated the Pearson's correlation coefficients between each domain score of the CCI and psychological distress. We used GHQ scoring (0-0-1-1), and set the threshold for psychological distress at 2/3 [55]. We divided the score into binary variables whether the score exceeded a cutoff value or not, and used it as a dependent variable.

Reliability: To examine the reliability of the CCI, we calculated Cronbach's α coefficients (Cronbach's α) and intra-class correlation coefficients (ICC) for test-retest reliability using data for Part 1 of the survey.

All analyses were performed using the statistical package SAS version 9.1 (SAS Institute) and AMOS version 7.0 (SPSS institute). The significance level was set at $P < 0.05$ (two-tailed).

Results

Of 344 and 160 questionnaires sent to bereaved family members in Part 1 and Part 2, respectively, 11 and 23 were undeliverable, and 215 and 121 were returned. Among these, 23 and 12 individuals refused to participate, and 3 and 0 were excluded due to missing data. Thus, 189 and 109 responses were analyzed (effective response rates, 57 and 80%, respectively).

As for follow-up of Part 1, of 175 questionnaires sent to bereaved families who responded during the study period, nine individuals refused to partici-

pate, and two responses were excluded due to missing data. Finally, 112 responses were analyzed (effective response rate, 64%). Table 1 summarizes the background of the respondents.

Item reduction

In accordance with the above-mentioned item reduction procedure, we initially excluded one item

Table 1. Backgrounds of respondents

	Part 1 (N = 189)		Part 2 (N = 109)	
	n	%	n	%
<i>Patients</i>				
Age, y (mean \pm SD)	69 \pm 12		73 \pm 11	
Sex				
Male	108	57	47	43
Female	81	43	62	57
Hospital days (mean \pm SD)	41 \pm 37		56 \pm 74	
Care setting				
General ward	55	29	0	0
Palliative care unit	134	71	109	100
<i>Bereaved family members</i>				
Age, y (mean \pm SD)	57 \pm 12		60 \pm 12	
Sex				
Male	63	33	42	39
Female	122	65	64	59
Time since patient's death: months (mean \pm SD/range)	15 \pm 5 (7-25)		17 \pm 4 (11-24)	
Relationship				
Spouse	87	46	47	43
Child	64	34	42	39
Child-in-law	20	11	8	7
Other	15	9	10	10
Health status				
Good	48	25	—	—
Moderate	106	56	—	—
Fair	28	15	—	—
Poor	5	3	—	—
Presence of other caregivers				
Present	131	69	—	—
Absent	54	29	—	—
Living status				
Living together	157	83	—	—
Not living together	30	16	—	—
Religiousness				
Much	14	7	—	—
Moderate	34	18	—	—
Fair	46	24	—	—
None	85	45	—	—
Education				
Junior high school	34	18	—	—
High school	82	43	—	—
College	40	21	—	—
University	31	16	—	—
Household income (thousand yen)				
000-249 (-2500\$)	31	16	—	—
250-499 (2500-4990\$)	74	39	—	—
500-749 (5000-7490\$)	37	20	—	—
750-999 (7500-9990\$)	21	11	—	—
1000- (10000\$-)	16	8	-	-

Several total percents do not equal 100% due to missing values.

Table 2. Exploratory factor analysis of Caregiving Consequence Inventory

	Standardized regression coefficients				Communality	
	F1	F2	F3	F4		
<i>Perceived reward domain</i>						
1 Mastery (mean = 4.9, SD = 1.2)						
Q1	I feel confident enough to manage future life changes	0.91	0.05	-0.06	0.04	0.86
Q2	I have learned to cope better with my life	0.83	-0.10	0.05	0.18	0.85
Q3	I came to accept some of the changes in my life	0.75	0.11	0.14	-0.18	0.64
2 Appreciation for others (mean = 5.5, SD = 1.0)						
Q4	I came to have more appreciation for others	-0.04	0.96	-0.03	0.04	0.90
Q5	I became more aware of love from other people	0.06	0.84	-0.01	0.07	0.81
Q6	I came to place greater value on relationships	0.06	0.71	0.10	-0.06	0.58
3 Meaning in life (mean = 4.9, SD = 1.2)						
Q7	I came to find purpose and sense of meaning in my life	-0.04	0.04	1.00	-0.06	0.94
Q8	I have a better outlook on my life	0.19	0.00	0.64	0.07	0.66
Q9	I came to believe that there was a meaning in life no matter what happened	0.19	-0.05	0.63	0.15	0.69
4 Reprioritization (mean = 5.6, SD = 1.0)						
Q10	I came to understand of the brevity of life and appreciate each day	-0.02	-0.01	0.01	0.99	0.96
Q11	I came to notice what is really important in my life	0.21	0.17	0.09	0.50	0.66
Q12	I have learned the importance of being alive	-0.09	0.14	0.42	0.43	0.61
<i>Perceived burden domain</i>						
Burden (mean = 3.7, SD = 1.6)						
Q13	I felt a physical burden			0.96		0.58
Q14	I sacrificed my own time and schedule			0.76		0.92
Q15	I felt a mental burden			0.67		0.44
Q16	I felt a financial burden			0.33		0.11

Table 3. Concurrent validity of Caregiving Consequence Inventory

	Overall perceived
<i>Perceived reward domains</i>	
Mastery	0.37***
Appreciation for others	0.30***
Meaning in life	0.39***
Reprioritization	0.43***
Total reward score	0.44***

Figures are Pearson's correlation coefficients. * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

due to skewed responses from the initial CCI. According to the results of the exploratory factor analysis, 12 items for perceived rewards and 4 items for perceived burden were selected. The following 4 domains were extracted as perceived rewards: (1) mastery, (2) appreciation for others, (3) meaning in life, and (4) reprioritization. The result of the exploratory factor analysis of the CCI is shown in Table 2.

Scale validation

Validity

Table 3 shows the concurrent validity. The correlation of each reward domain of the

CCI and the one-item overall perceived reward was moderate and ranged from $r = 0.30$ to 0.43.

Table 4 shows the known group validity and demonstrates significant differences in each reward domain of the CCI according to the hypothesized respondent's characteristics (i.e. the respondent's faith, education, and optimism).

Figure 1 shows the result of confirmatory factor analysis using data from Part 1 of the survey. This solution has the most interpretable factors and showed sufficient fitness to the factor structure, consistency with the hypothesized concepts, and clinical validity. Although we hypothesized a model with five perceived rewards including a personal growth domain at first, exploratory factor analysis revealed that the three items we hypothesized as personal growth were due to an improper solution and no convergence could be attained. Therefore, we adopted 12 items for four perceived reward domains and 4 items for the burden domain. The fit indices for this final model were acceptable (χ^2 262.333 [df = 99], $P < 0.001$; GFI = 0.919; AGFI = 0.848; CFI = 0.792; RMSEA = 0.094) (see Figure 1). The confirmatory factor analysis using Part 2 data reproduced acceptable fit indices with one correlated error term (χ^2 191.6 [df = 98], $P < 0.001$; GFI = 0.929; AGFI = 0.819; CFI = 0.749; RMSEA = 0.097) (see Figure 2).

Table 4. Known-group validity of Caregiving Consequence Inventory

	Faith				P-value	Education				P-value	Optimism				P-value
	Less faith		More faith			Less educated		More educated			Less optimistic		More optimistic		
	Means	SD	Means	SD		Means	SD	Means	SD		Means	SD	Means	SD	
<i>Perceived reward domains</i>															
Mastery	4.8	1.2	5.2	1.0	0.02*	5.1	1.1	4.6	1.3	0.01*	4.8	1.1	5.2	1.2	0.03*
Appreciation for others	5.5	1.1	5.6	1.0	0.63	5.6	1.0	5.4	1.2	0.32	5.5	1.0	5.7	1.1	0.15
Meaning in life	4.8	1.2	5.4	0.9	<0.001***	5.2	1.0	4.6	1.3	0.001**	4.9	1.1	5.1	1.3	0.13
Reprioritization	5.4	1.1	5.8	0.8	0.03*	5.7	0.9	5.4	1.2	0.06	5.4	1.0	5.9	1.1	0.003**
Total reward score	5.1	1.0	5.5	0.7	0.01*	5.4	0.8	5.0	1.0	0.01*	5.1	0.9	5.5	1.0	0.03*

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

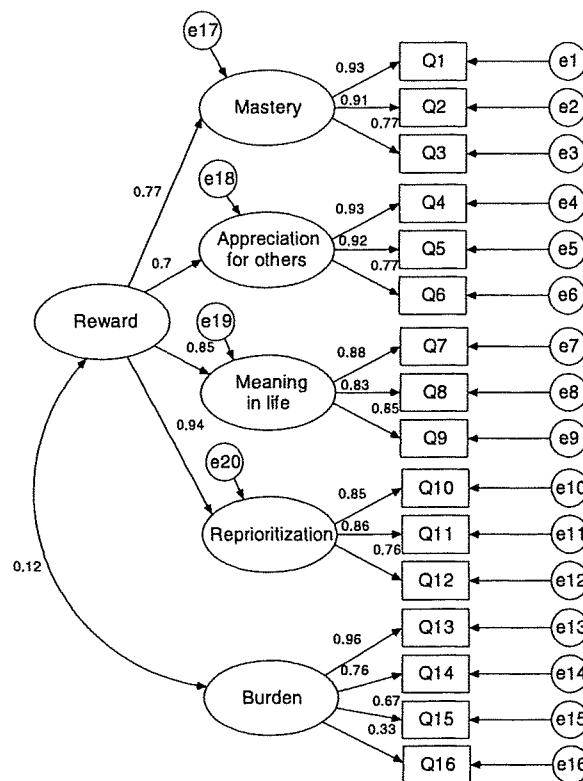


Figure 1. Confirmatory factor analysis of Caregiving Consequence Inventory (Part 1). $\chi^2 262.333$ (DF = 99), $P < 0.001$; GFI = 0.919; AGFI = 0.848; CFI = 0.792; RMSEA = 0.094

The four reward domain scores were highly correlated with each other ($0.47 < r < 0.69$) (Table 5). We tested the factor structure of reward further by conducting confirmatory factory analyses, comparing the 4-reward domain and 1-reward domain approaches. The analysis revealed that the 4-reward domain model fit the data significantly better than the 1-reward domain model ($\chi^2 699.4$ [df = 103], $P < 0.001$; GFI = 0.692; AGFI = 0.652; CFI = 0.541; RMSEA = 0.186).

Table 6 shows the known group validity and shows that no significant correlation exists between each domain score and psychological distress,

except for a slight correlation with mastery ($r = -0.19$, $P = 0.05$) and burden ($r = 0.24$, $P = 0.01$).

Reliability

Table 7 shows the internal consistency and test-retest reliability. Cronbach's α ranged from 0.78 to 0.93. The Cronbach's α coefficient of the total reward domain was 0.93 and of the burden domain was 0.78. The ICC ranged from 0.60 to 0.73. The ICC of the total reward domain was 0.73 and of the burden domain was 0.60.

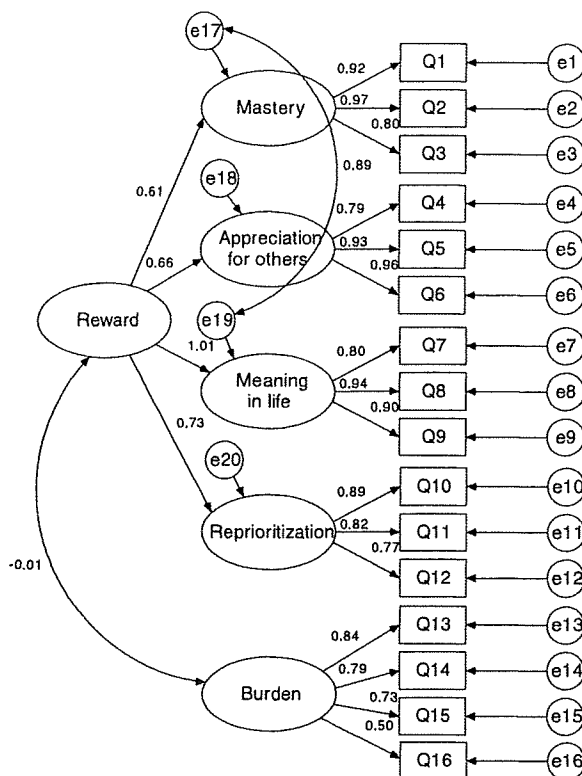


Figure 2. Confirmatory factor analysis of Caregiving Consequence Inventory (Part 2). $\chi^2 191.6$ (DF = 98), $P < 0.001$; GFI = 0.929; AGFI = 0.819; CFI = 0.749; RMSEA = 0.097

Table 5. The association with each other domain score of CCI

	Mastery	Appreciation for others	Meaning in life	Reprioritization
Mastery	1.00			
Appreciation for others	0.47***	1.00		
Meaning in life	0.63***	0.49***	1.00	
Reprioritization	0.60***	0.60***	0.69***	1.00
Burden	0.07	0.06	0.12	0.07

Figures are Pearson's correlation coefficients. * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

Table 6. The association between caregiving consequence and psychological distress

	Psychological distress
<i>Perceived reward domains</i>	
Mastery	-0.19*
Appreciation for others	0.11
Meaning in life	-0.13
Reprioritization	-0.01
Total reward score	-0.07
<i>Perceived burden domain</i>	
Burden	0.24*

Figures are Pearson's correlation coefficients. * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

Discussion

The most important result of this study was the development of an instrument to measure the bereaved family's perceptions about the caregiving experience in Japan. The instrument showed good

internal consistency and test-retest reliability, and known group validity was also consistent with a previous study [52,53]. The CCI is 16 items and takes less than 10 min to complete. Plain terms are used for these items, so the deficit rate is low 2% or less. Thus, we believe that this scale can assess caregiving consequences with few demands placed on the bereaved family.

Exploratory factor analysis and confirmatory factor analysis revealed 5 domains consisting of 4 sub-domains of perceived rewards and 1 domain of perceived burden: mastery, appreciation for others, meaning in life, reprioritization, and burden. The themes of the domains are consistent with our prior hypothesized concepts.

Items selected for the 'mastery' domain represented the extent to which the respondent felt in control over his or her life [35,36,56]. Although the operationalization of 'meaning' varied widely across studies and sometimes represented overall

Table 7. Reliability of Caregiving Consequence Inventory

	α	ICC
<i>Perceived reward domains</i>		
Mastery	0.90	0.73
Appreciation for others	0.90	0.60
Meaning in life	0.89	0.62
Reprioritization	0.86	0.67
Total reward score	0.93	0.73
<i>Perceived burden domain</i>		
Burden	0.78	0.60

α , Cronbach's alpha coefficient; ICC, intra-class correlation coefficient.

positive aspects of caregiving [34,57], items selected for 'meaning' in life domains assessed the sense of purpose in life and task [57]. The 'appreciation for others' domain included items about gratitude for relationships and compassion [52], and the 'reprioritization' domain assessed changes in values and attitudes about living life to the fullest [23,52]. These 4 reward domains are similar to those identified in other studies of post-traumatic growth [39,40], and the burden domain included the items identified important for assessing caregiver burden [2,3,12,14]. Thus, content validity is assured.

It was not surprising that the 4 reward domain scores were highly correlated with each other because a sense of mastery may occur through the development of new capabilities and finding a sense of meaning or purpose [32]. In addition, caregivers described their deeper appreciation for relationships for one of the changes in values [31]. On examining concurrent validity, each reward domain of the CCI and overall perceived rewards were only moderately correlated, and the comparisons between the 4-domain and 1-domain models of perceived rewards revealed the superiority of the 4-domain model. We thus believe that a comprehensive assessment of rewards by one overall item is difficult and evaluation of every domain is recommended.

As for discriminate validity, almost none of the reward domains correlated with psychological distress. Only mastery and burden showed slight correlation with psychological distress, however these correlations were very weak. Therefore, we believe that mastery and burden were not clinically correlated with psychological distress.

This means that the caregiver considered reward to be an entity distinct from psychological distress, and it is important to use perceived reward as a measure for evaluation of caregiving consequences, as well as the caregiving burden, for improving the quality of the caregiving and bereavement experience.

Although the domains of the CCI demonstrated sufficient internal consistency, reliability measured by ICC was of moderate value [58]. Possible reasons for the moderate reliability are (1) the test-retest period was longer than 1 month and (2)

the family member's assessment of the CCI may have changed over time. However, the sufficient internal consistency as a measure of reliability for a cross-sectional study is appreciated; therefore, these moderate ICCs are not considered critical limitations of the CCI.

Limitations and future perspectives

The limitations of this study are as follows: first, the response rate in Part 1 of the survey was 57%. We think that this was low because the response rate of the bereaved families receiving care on the general wards was low (47% on general wards vs 62% in PCU). We believe, however, that the effect on this study was not crucial because (1) the objective was to validate a scale, not to survey actual conditions and (2) comparing the backgrounds of respondents and non-respondents revealed no differences in age, gender, the length of patient's hospital stay, or time since patient's death. Second, we identified the bereaved family members of patients who died from lung or gastrointestinal cancer on the general wards in Part 1 of the survey. We believe, however, that the effect on this study was not crucial because (1) the proportion of deceased patients on the general wards who died from other types of cancers was only 12% (23/188) in Part 1 and (2) we identified the bereaved family members of patients who died of all types of cancer on the PCU in Parts 1 and 2 of the survey. Third, we were unable to examine concurrent validity sufficiently in this study because we did not have scales to examine the details of positive aspects of caregiving consequences when this survey was conducted. Fourth, we set only one correlation between errors in the confirmatory factor analysis in Part 2 because of insufficient sample size. However, we believe this is not a fatal flaw because the fit indices for this final model in Part 1 were acceptable. We are going to perform further confirmation with a larger sample size in the next step. Fifth, this validation was executed in Japan, a culturally and ethnically homogeneous country. It is necessary to examine whether the structure of CCI can be reproduced in different cultures.

In the future, we would like to conduct a national survey on the actual positive and negative aspects of caregiving consequences in Japan. To decide the focus of the intervention, it is necessary to clarify factors related to positive and negative experience, and to explore the mechanisms that maintain and increase positive experiences, as well as those that decrease negative experiences. This CCI provides a good base for further exploration of these mechanisms. We also would like to conduct a prospective survey to clarify factors related to the change of perceived rewards using this tool, and hope that this effort will lead to the

development of intervention programs that focus on specific aims and examine the effects on caregiver outcomes.

Conclusions

We validated the CCI in Japanese bereaved family members. The CCI was a valid scale having sufficient factor validity, internal consistency, test-retest reliability, and acceptable construct validity. The CCI comprises four perceived reward domains: 'mastery', 'appreciation for others', 'meaning in life', and 'reprioritization', and one perceived burden domain, evaluating both positive and negative aspects of caregiving consequences from the bereaved family member's perspective. As for discriminate validity, reward has little or no correlation with psychological distress. Thus, it is important to use perceived rewards as a measure for evaluation of caregiving consequences, as well as the caregiving burden, for improving the quality of the caregiving and bereavement experience.

Acknowledgements

This research was supported by a Health and Labor Sciences Research Grant for a third term comprehensive control research for cancer.

Appendix

Caregiving Consequences Inventory

How do you feel about your caregiving experience with your family member? Please check the appropriate number. 1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree. Through caring for your family member,

Mastery

I feel confident enough to manage future life changes.
I have learned to cope better with my life.
I came to accept some of the changes in my life.

Appreciation for others

I came to have more appreciation for others.
I became more aware of love from other people.
I came to place greater value on relationships.

Meaning in life

I came to find purpose and sense of meaning in my life.
I have a better outlook on my life.
I came to believe that there was meaning in life no matter what happened.

Reprioritization

I came to understand the brevity of life and appreciate each day.

I came to notice what is really important in my life.
I have learned the importance of being alive.

Burden

I felt a physical burden.
I sacrificed my own time and schedule.
I felt a mental burden.
I felt a financial burden.

References

1. World Health Organization National cancer control programmes. *Policies and Managerial Guidelines*. (2nd edn), 2002.
2. Wolff JL, Dy SM, Frick KD, Kasper JD. End-of-life care: findings from a national survey of informal caregivers. *Arch Intern Med* 2007;167(1):40-46.
3. Tilden VP, Tolle SW, Drach LL, Perrin NA. Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden. *J Am Geriatr Soc* 2004;52(4):532-539.
4. Giorgi Rossi P, Beccaro M, Miccinesi G *et al*. Dying of cancer in Italy: impact on family and caregiver. The Italian survey of dying of cancer. *J Epidemiol Community Health* 2007;61(6):547-554.
5. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Ann Intern Med* 2000;132(6):451-459.
6. Shiozaki M, Morita T, Hirai K, Sakaguchi Y, Tsuneto S, Shima Y. Why are bereaved family members dissatisfied with specialised inpatient palliative care service? A nationwide qualitative study. *Palliat Med* 2005;19(4):319-327.
7. Kris AE, Cherlin EJ, Prigerson H *et al*. Length of hospice enrollment and subsequent depression in family caregivers: 13-month follow-up study. *Am J Geriatr Psychiatry* 2006;14(3):264-269.
8. Beach SR, Schulz R, Williamson GM, Miller LS, Weiner MF, Lance CE. Risk factors for potentially harmful informal caregiver behavior. *J Am Geriatr Soc* 2005;53(2):255-261.
9. Lichtenstein P, Gatz M, Berg S. A twin study of mortality after spousal bereavement. *Psychol Med* 1998;28(3):635-643.
10. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *J Am Assoc* 1999;282(23):2215-2219.
11. Grov EK, Fossa SD, Sorebo O, Dahl AA. Primary caregivers of cancer patients in the palliative phase: a path analysis of variables influencing their burden. *Soc Sci Med* 2006;63(9):2429-2439.
12. Grunfeld E, Coyle D, Whelan T *et al*. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Can Med Assoc J* 2004;170(12):1795-1801.
13. Goldstein NE, Concato J, Fried TR *et al*. Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *J Palliat Care* 2004;20(1):38-43.
14. Yun YH, Rhee YS, Kang IO *et al*. Economic burdens and quality of life of family caregivers of cancer patients. *Oncology* 2005;68(2-3):107-114.
15. McMillan SC, Small BJ, Weitzner M *et al*. Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer* 2006;106(1):214-222.

16. Kramer BJ. Gain in the caregiving experience: where are we? What next? *Gerontologist* 1997;37(2):218–232.
17. Hudson P. Positive aspects and challenges associated with caring for a dying relative at home. *Int J Palliat Nurs* 2004;10(2):58–65; discussion 65.
18. Davis CG, Nolen-Hoeksema S, Larson J. Making sense of loss and benefiting from the experience: two construals of meaning. *J Pers Soc Psychol* 1998;75(2):561–574.
19. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002;17(2):184–188.
20. Hudson PL, Aranda S, Hayman-White K. A psycho-educational intervention for family caregivers of patients receiving palliative care: a randomized controlled trial. *J Pain Symptom Manage* 2005;30(4):329–341.
21. Manne S, Babb J, Pinover W, Horwitz E, Ebbert J. Psychoeducational group intervention for wives of men with prostate cancer. *Psycho-Oncology* 2004;13(1):37–46.
22. Farran CJ, Miller BH, Kaufman JE, Donner E, Fogg L. Finding meaning through caregiving: development of an instrument for family caregivers of persons with Alzheimer's disease. *J Clin Psychol* 1999;55(9):1107–1125.
23. Rodgers LS. Meaning of bereavement among older African American widows. *Geriatr Nurs* 2004;25(1):10–16.
24. Langner SR. Finding meaning in caring for elderly relatives: loss and personal growth. *Holist Nurs Pract* 1995;9(3):75–84.
25. Mehrotra S, Sukumar P. Sources of strength perceived by females caring for relatives diagnosed with cancer: an exploratory study from India. *Support Care Cancer* 2007.
26. Hunt CK. Concepts in caregiver research. *J Nurs Scholarsh* 2003;35(1):27–32.
27. Grov EK, Fossa SD, Tonnessen A et al. The caregiver reaction assessment: psychometrics, and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. *Psycho-Oncology* 2006;15(6):517–527.
28. Cooper B, Kinsella GJ, Picton C, Cooper B, Kinsella GJ, Picton C. Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psycho-Oncology* 2006;15(7):613–622.
29. Koop PM, Strang VR, Koop PM, Strang VR. The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clin Nurs Res* 2003;12(2):127–144.
30. Hogan NS, Greenfield DB, Schmidt LA. Development and validation of the Hogan Grief Reaction Checklist. *Death Stud* 2001;25(1):1–32.
31. Mok E, Chan F, Chan V et al. Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nurs* 2003;26(4):267–275.
32. Hudson P. A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. *Palliat Support Care* 2003;1(4):353–365.
33. Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. *J Gerontol* 1989;44(3):P61–P71.
34. Noonan AE, Tennstedt SL. Meaning in caregiving and its contribution to caregiver well-being. *Gerontologist* 1997;37(6):785–794.
35. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30(5):583–594.
36. Pearlin LI, Schooler C. The structure of coping. *J Health Soc Behav* 1978;19(1):2–21.
37. Park CL, Cohen LH, Murch RL. Assessment and prediction of stress-related growth. *J Pers* 1996;64(1):71–105.
38. Schumacher KL, Stewart BJ, Archbold PG. Conceptualization and measurement of doing family caregiving well. *Image J Nurs Sch* 1998;30(1):63–69.
39. McMillen JC, Fisher R. The Perceived Benefit Scales: measuring perceived positive life changes after negative events. *Soc Work Res* 1998;22:173–187.
40. Siegel K, Schrimshaw EW. Perceiving benefits in adversity: stress-related growth in women living with HIV/AIDS. *Soc Sci Med* 2000;51(10):1543–1554.
41. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *J Trauma Stress* 1996;9(3):455–471.
42. Chou KR, Jiann-Chyun L, Chu H. The reliability and validity of the Chinese version of the Caregiver Burden Inventory. *Nurs Res* 2002;51(5):324–331.
43. Miyashita M, Yamaguchi A, Kayama M et al. Validation of the Burden Index of Caregivers (BIC), a multidimensional short care burden scale from Japan. *Health Qual Life Outcomes* 2006;4:52.
44. Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol* 1983;38(3):344–348.
45. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20(6):649–655.
46. Arai Y, Hosokawa T. Caregiving burden for elderly patient at home. *Health Cult Res (in Japanese)* 1997:1–6.
47. Ogata Y, Hashimoto M, Otsuka K. Subjective caregiving burden for patient who require nursing care at home. *Jpn J Public Health* 2000;47(4):303–319.
48. Cohen R, Leis AM, Kuhl D, Charbonneau C, Ritvo P, Ashbury FD. QOLLTI-F: measuring family carer quality of life. *Palliat Med* 2006;20(8):755–767.
49. Scheier MF, Carver CS, Bridges MW. Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test. *J Pers Soc Psychol* 1994;67(6):1063–1078.
50. Sakamoto S. A study of the Japanese version of Revised Life Orientation Test. *Jpn J Health Psychol* 2002;15(1):59–63.
51. Goldberg DWP. *A User's Guide to the General Health Questionnaire*. NFER-Nelson Publishing: Windsor, Berkshire, 1988.
52. Kim Y, Schulz R, Carver CS. Benefit-finding in the cancer caregiving experience. *Psychosom Med* 2007;69(3):283–291.
53. Picot SJ, Youngblut J, Zeller R. Development and testing of a measure of perceived caregiver rewards in adults. *J Nurs Meas* 1997;5(1):33–52.
54. Fayers PM, Machin D. Factor analysis. In *Quality of Life: Assessment, Analysis and Interpretation*, Fayers PM, Machin D (eds). Wiley: Chichester, 2000; 91.
55. Goldberg DP, Oldehinkel T, Ormel J. Why GHQ threshold varies from one place to another. *Psychol Med* 1998;28(4):915–921.
56. Aneshensel C. The containment of care-related stressors. In: *Profiles in Caregiving*, Aneshensel C (ed.). Academic Press: California, 1995; 154–157.
57. Park CL, Folkman S. Meaning in the context of stress and coping. *Gen Rev Psychol* 1997;1(2):115–144.
58. Streiner DL, Norman GR. *Health Measurement Scales: A Practical Guide to Their Development and Use* (3rd edn). Oxford University Press: Oxford, 2003.

Self-efficacy, psychological adjustment and decisional-balance regarding decision making for outpatient chemotherapy in Japanese advanced lung cancer

Kei Hirai^{a*}, Hirokazu Arai^{bc}, Akihiro Tokoro^d and Nobuyuki Naka^e

^aCenter for the Study of Communication Design, Department of Psychology and Behavioral Sciences in Graduate School of Human Sciences & Department of Complementary and Alternative Medicine in Graduate School of Medicine, Osaka University, Japan; ^bFaculty of Health Psychology, Osaka University of Human Sciences, Japan; ^cCenter of the Study for Communication Design, Osaka University, Japan; ^dDepartment of Psychosomatic Medicine, National Hospital Organization Kinki-chuo Chest Medical Center, Japan; ^eNational Hospital Organization Toneyama Hospital, Japan

(Received 11 November 2006; final version received 1 July 2007)

This study examined the application of the trans-theoretical model (TTM) for readiness for decision-making of outpatient chemotherapy of Japanese advanced lung cancer patients by a cross sectional questionnaire survey. A questionnaire was conducted with 105 Japanese patients diagnosed with advanced lung cancer receiving chemotherapy. We classified them according to the TTM stages, including 4 in precontemplation, 42 in contemplation, 22 in preparation, and 35 in action. The valid model ($\chi^2(37) = 42.56, p = 0.24$; GFI = 0.93; AGFI = 0.88; CFI = 0.98; RMSEA = 0.04; AIC = 100.56) derived from structural equation modeling (SEM) revealed that stage of outpatient chemotherapy was significantly affected mostly by decisional-balance ($\beta = 0.60, p < 0.001$) and partially by time from the patient's house to the hospital ($\beta = -0.15, p < 0.10$), and that decisional-balance was significantly affected by self-efficacy ($\beta = 0.48, p < 0.001$) and nausea ($\beta = -0.23, p < 0.01$). The findings from our study provided encouraging results for adopting the TTM in decision making for outpatient chemotherapy in Japanese cancer care and several clinical implications were obtained from the results.

Keywords: trans-theoretical model; decisional-balance; self-efficacy; outpatient chemotherapy; lung cancer

Introduction

Advanced lung cancer carries a poor prognosis and requires treatment with chemotherapy. Recently, improvements in the quality-of-life (QOL) of advanced lung cancer patients has become essential for good cancer treatment and care (Bottomley, Efficace, Thomas, Vanvoorden, & Ahmedzai, 2003; Ishihara et al., 1999). Supportive care in cancer treatment at home, especially is important for their QOL (Sakai, 2002; Tsukagoshi, 2002). In western countries, outpatient lung cancer treatments are common, but in Japan most patients receive treatment in hospital (Sakai, 2002). One of the reasons for this difference

*Corresponding author. Email: khirai@grappo.jp

may be the requirement of Japanese national insurance system that chemotherapy is administered in an inpatient setting. Recently, the Ministry of Health decided to allow insurance payments for outpatient chemotherapy for cancer patients (Sakai, 2002). In Addition, Japanese oncologists have recognized the importance of outpatient chemotherapy for lung cancer to improve the patients' QOL and have started to recommend such outpatient services for their patients (Asai, Minami, Komuta, & Kido, 2000; Chohnabayashi, Uchiyama, Nishimura, & Nasu, 2004; Kawasaki et al., 2003) and several cancer centers have started outpatient clinic centers for cancer patients (Kobayashi & Kobayashi, 2000).

However, patients are still reluctant to make a decision to go home and receive inpatient treatment instead. One reason for reluctance of the patients may be the strong psychological influence on their decision making process. To develop support systems for the patients, clarification of this psychological mechanism is needed. Thus, we tried to apply a framework and a theory from psychology to clarify the patients' decision making process in the transition from inpatient treatment to outpatient treatment.

In health psychology and behavioral medicine, several theories and models have been developed to account for health behavior. Among these, the trans-theoretical model (TTM) (Prochaska & DiClemente, 1983) is useful to explain changes and has been adopted in not only health problem settings such as several studies of smoking cessation (Prochaska & DiClemente, 1984), but also various health behaviors. For example, in the area of cancer medicine, TTM has been applied to examine compliance in health screening for colorectal cancer generic testing (Manne et al., 2002), and mammography adoption (Lauver, Henriques, Settersten, & Bumann, 2003; Rakowski, Fulton, & Feldman, 1993). We believe that application of the TTM to examine patients' behavior and the intention to receive chemotherapy after transitioning from inpatient to outpatient status will be very useful to clarify the psychological factors underlying the patient decision making process for outpatient chemotherapy.

In addition, in the TTM, the function of self-efficacy has an important role in the stage of change, and mediates between the intention for behavioral change and actual behavior (Prochaska & DiClemente, 1984). Several studies have pointed out that self-efficacy has a great impact on psychological adjustment, including the anxiety and depression of advanced cancer patients (Beckham, Burker, Lytle, Feldman, & Costakis, 1997; Hirai et al., 2002; Lin, 1998; Merluzzi, Nairn, Hegde, Martinez Sanchez, & Dunn, 2001). It is hypothesized that self-efficacy and psychological adjustment may correspond to the readiness or stage of change for outpatient chemotherapy. Thus, self-efficacy may indicate the possibility to develop psychologically-oriented interventions for patients who would benefit from outpatient chemotherapy.

Thus, this study attempted to examine the readiness for outpatient chemotherapy of advanced lung cancer patients in Japan using TTM. In particular, the attempt was focused on the function of self-efficacy and psychological adjustment in terms of the readiness for the treatment. Finally, we discussed the clinical implications derived from our results.

Methods

Participants

The participants were consecutively recruited from one specialized hospital for chest disease using convenient sampling from March 2003 to July 2003. The sample was

composed of 105 Japanese patients diagnosed with advanced metastatic lung cancer, who were inpatients and outpatients receiving chemotherapy. All patients without dementia or delirium were informed of the aim and methods of this study, and their written consent was obtained.

Measures

We developed a questionnaire with a face sheet and four psychological measurements. The face sheet included questions regarding each participant's background, including age, gender, and knowledge and past experience of outpatient chemotherapy.

In a previous preliminary interview study (Hirai, Tokoro, Naka, Ogawara, & Kawahara, 2005) and preliminary analysis (Arai, Hirai, Tokoro, & Naka, 2006), we developed two psychological scales based on TTM: A single item to measure the stage of readiness and a decisional-balance scale for outpatient chemotherapy in lung cancer patients. A single item to evaluate patients' stage of readiness included four alternatives for stage of readiness: *Precontemplation* ("I have no interest in receiving outpatient chemotherapy."), *contemplation* ("I have been thinking that I might want to receive outpatient chemotherapy."), *preparation* ("I am preparing to receive outpatient chemotherapy."), and *action* ("I have already received outpatient chemotherapy."). This item was proved to have content validity through the content analysis of interview data (Hirai et al., 2005). The decisional-balance scale of outpatient chemotherapy is a 20-item scale with two subscales: Pros and cons. The pros consisted of 10 items: *Freedom of movement; comfortable environment; increased relaxation; increased social support; freedom of time; psychological stability; regarding oneself as an ordinary person; fewer time restrictions; decreased concerns; treated as an ordinary person*. The cons also consisted of 10 items: *Worries about instability of illness; dissatisfaction with consultation time; worries about insufficient treatment; lack of enough nursing; worries about side effects; insufficient facilities for treatment; worries about urgent treatment; lack of information from peers; less communication with medical staff; less medical information*. Each subscale of the decisional-balance scale has been shown to have high reliability (Cronbach alpha = 0.88 for pros and 0.87 for cons) and high structural validity by confirmatory factor analysis ($\chi^2(166) = 223.73$ ($p < 0.001$), GFI = 0.83, CFI = 0.93, RMSEA = 0.06) for the two-factor structure which was hypothesized from the results of our interview study (Arai et al., 2006).

The scale of the Self-Efficacy for Advanced Cancer (SEAC) was designed to assess self-efficacy in terms of the illness behavior of advanced cancer patients (Hirai et al., 2001). It is an 18-item scale with the following three subscales: *Symptom coping efficacy* (SCE; e.g., "I can manage insomnia caused by pain"); *ADL efficacy* (ADE; e.g., "I can enjoy TV or radio programs"); *Affect regulation efficacy* (ARE; e.g., "I can maintain a positive attitude"). The scale is formatted on an 11-point Likert-type scale, ranging from 0 (not at all confident) through 50 (50% confident)–100 (totally confident). Each subscale of SEAC has been shown to have high reliability (Cronbach alpha = 0.73–0.81) and high structural validity (GFI = 0.93–0.96; Hirai et al., 2001). The scale also succeeded in clarifying the significant relationships among physical condition, self-efficacy and psychological adjustment of advanced cancer patients (Hirai et al., 2002).

To assess psychological adjustment, we used the Japanese version (Kitamura, 1993) of the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The final

part of the questionnaire included six items for subjective physical symptoms (appetite, sleep state, fatigue, dyspnea, feeling of numbness, and pain) and a tangible social support scale (Blake & McKay, 1986).

Finally, the physician-in-charge of the participants evaluated their performance status using the criteria of the Eastern Cooperative Oncology Group performance status (ECOG PS). ECOG PS is widely used to measure the level of patient activity using eleven grades (0–4). Also, the physician reported details of each participant's diagnosis, metastasis, chemotherapy regimen, expected prognosis, and other physical symptoms.

Analyses

The descriptive analyses were conducted to summarize the participants' backgrounds and psychological measurement scores. Those with over 30% missing values on the questionnaire were excluded from the statistical analyses. If one or two scores within the subscales of psychological measurements were missing, the averaged scores of the series were substituted into a formula for the total scores of each subscale. Univariate analysis (ANOVA) preliminarily analyzed the factors predicting stage of readiness, and categorical regression analysis was performed using all significant predictor variables ($p < 0.05$). Because categorical regression analysis proved only one significant and very strong predictor for stage of readiness, that is, a decisional-balance score, we performed correlation analysis using the decisional-balance score. SEM was performed to confirm the multiple relationships among the significant variables in the results of categorical regression and correlation analysis. As the categorical regression analysis confirmed a strong linear relationship between stage and decisional-balance, we transformed each participant's ordinal response for stage into numeric scale. To obtain a valid model to account for stage, we compare the Akaike Information Criteria (AIC) index of each model. This measure indicates a better fit when it is smaller. We adopted a model with a parsimonious structure and a smaller AIC index. We conducted all statistical analyses using the SPSS software package (version. 11.0) and AMOS software package (version. 5.0.1).

Results

Characteristics of the participants

The participants consisted of 78 males and 27 females. Table 1 shows their demographic and diagnostic data including mean age, gender, diagnosis, stage at diagnosis, ECOG PS, distribution of TTM stage for outpatient chemotherapy and mean time from patients' houses to their hospitals. In the distribution of TTM stage, there were four participants in precontemplation, 42 in contemplation, 22 in preparation, and 35 in action. Because of insufficient number ($N=4$) of the participants in precontemplation for multivariate analysis, we excluded their data from the following analyses.

Psychosocial factors associated with the outpatient chemotherapy stage

To explore the differences among patients in the three stages of contemplation, preparation, or action, we reported the mean score of the following independent variables: TTM components, self-efficacy, HADS, physical symptoms and social support (Table 2). Participants in the action stage showed a significantly higher score on pros,

Table 1. Demographic characteristics of the participants.

Mean age \pm SD	64.52 \pm 9.40
Gender	
Male/Female	78/27
Diagnosis	105
Lung cancer	55
Ad	23
Sq	1
La	18
Sm	8
Stage at diagnosis	
Stage IA	2
Stage IB	1
Stage IIA	5
Stage IIB	13
Stage IIIA	14
Stage IIIB	66
Stage IV	4
Missing	1
Inpatient/Outpatient	37/68
PS (ECOG)	
0	29
1	69
2	6
Missing	1
TTM Stage for outpatient chemotherapy	
PC	4
C	42
PR	22
A	35
Missing	2
Mean time (minutes) from house to hospital \pm SD	46.19 \pm 32.29 [10–240]

PC: precontemplation, C: contemplation, PR: preparation, A: action.

decisional-balance and the three variables of self-efficacy than participants in contemplation. Participants in contemplation had a significantly higher score on cons and dyspnea than participants in action. For HADS-depression, participants in preparation had the highest score among the three groups.

For TTM components, there were significantly negative correlations between pros and cons ($r = -0.37$, $p < 0.001$), and between cons and decisional-balance ($r = -0.83$, $p < 0.001$), and a significantly positive correlation between pros and decisional-balance ($r = 0.82$, $p < 0.001$). In addition, correlations between decisional-balance and both pros and cons were comparatively high ($r = -0.83$, $p < 0.001$; $r = 0.82$, $p < 0.001$, respectively). Therefore, we concluded that using these three variables for the multivariate analyses would not be useful and that only using decisional-balance as a representation of TTM components would be valid.

Categorical regression analysis was preliminary performed on the variables showing a significant relationship with stage differences in ANOVA, and revealed that decisional-balance was the main factor to explain the differences in outpatient chemotherapy stage

Table 2. Descriptive data and ANOVA: Mean comparison of outpatient chemotherapy stages.

Measure	Contemplation		Preparation		Action		Total		<i>F</i> (2, 96)	<i>P</i>
	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
TTM components										
Pros	33.67	8.18	37.71	6.00	40.55	6.08	37.00	7.61	9.28	0.000
Cons	39.46	5.95	35.55	4.85	28.06	6.81	34.56	7.84	34.19	0.000
Decisional-balance	-5.79	10.77	2.16	8.59	12.49	9.87	2.44	12.78	31.87	0.000
Self-efficacy										
ARE	59.39	16.05	64.62	22.69	70.33	16.63	64.42	18.37	3.57	0.032
SCE	49.68	24.73	52.50	22.07	62.94	21.33	54.99	23.54	3.34	0.040
ADE	64.22	17.64	68.94	15.32	79.60	17.45	70.71	18.25	7.88	0.001
HADS										
Anxiety	5.81	4.03	6.10	2.68	5.21	2.95	5.66	3.39	0.52	0.594
Depression	6.12	2.72	7.00	2.86	5.16	2.46	5.98	2.73	3.32	0.040
Total	11.93	5.74	13.10	5.01	10.38	4.54	11.64	5.24	1.98	0.144
Physical symptom										
Pain	27.56	23.11	28.18	25.57	24.00	23.91	26.43	23.78	0.29	0.753
Appetite	1.95	0.74	1.91	0.81	1.60	0.69	1.82	0.75	2.35	0.101
Insomnia	1.83	0.66	2.00	0.53	1.66	0.54	1.81	0.60	2.33	0.103
Nausea	1.45	0.71	1.48	0.81	1.18	0.46	1.36	0.66	2.07	0.132
Fatigue	1.95	0.70	1.86	0.89	1.80	0.68	1.88	0.73	0.41	.662
Dyspnea	1.45	0.63	1.23	0.43	1.17	0.38	1.30	0.52	3.18	0.046
Numbness	1.71	0.77	1.45	0.60	1.86	0.81	1.71	0.76	1.94	0.150
Social support										
Tangible assistance	3.81	2.38	4.50	2.79	4.79	3.32	4.31	2.83	1.21	0.304
Performance status										
ECOG PS	0.79	0.61	0.77	0.43	0.79	0.59	0.79	0.56	0.10	0.991

ARE: affect regulation efficacy; SCE: symptom coping efficacy; ADE: ADL efficacy.

($\beta = 0.58$, $p < 0.001$; $R^2 = 0.45$). There were no significant effects of other demographic, physical or psychological variables: Affect regulation efficacy ($\beta = -0.03$, *n.s.*), symptom coping efficacy ($\beta = -0.01$, *n.s.*), ADL efficacy ($\beta = 0.12$, *n.s.*), HADS-depression ($\beta = 0.00$, *n.s.*), and dyspnea ($\beta = -0.11$, *n.s.*). These findings suggested presence of a model in which decisional-balance mediated between psychological and physical variables and outpatient chemotherapy stage. Therefore, in the next step of the analyses, we tried to identify the variables that accounted for the variance in the decisional-balance score. Prior to the analysis, preliminary correlation analysis was conducted between decisional-balance and demographic variables (time from house to hospital, stage at diagnosis, expected prognosis, and performance status), physical symptom variables (pain, appetite, insomnia, nausea, fatigue, dyspnea, and numbness), and psychological variables (depression, anxiety and self-efficacy subscales) The results of correlation analysis was represented in Table 3. The analysis showed significant correlations, including time from house to hospital ($r = -0.29$, $p < 0.01$), appetite ($r = -0.25$, $p < 0.05$), nausea ($r = -0.32$, $p < 0.01$), dyspnea ($r = -0.21$, $p < 0.05$), HADS-anxiety ($r = -0.23$, $p < 0.05$), HADS-depression ($r = -0.23$, $p < 0.01$), affect regulation efficacy ($r = 0.39$, $p < 0.001$), symptom coping efficacy ($r = 0.35$, $p < 0.001$), and ADL efficacy ($r = 0.52$, $p < 0.001$). Using SEM, we developed a structural model, which regressed the decisional-balance using these nine

Table 3. Intercorrelations among decisional-balance, demographic variables, physical symptom variables, and psychological variables.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Decisional-balance	-																
2. Time from house to hospital	-0.29**	-															
3. Stage at diagnosis	0.01	-0.02	-														
4. Expected prognosis	-0.13	0.07	-0.12	-													
5. Performance status	-0.10	0.20	0.13	-0.30**	-												
6. Pain	-0.14	0.17	0.02	-0.22*	0.25*	-											
7. Appetite	-0.25*	0.13	-0.03	-0.02	0.15	0.31**	-										
8. Insomnia	-0.10	-0.06	-0.03	0.00	0.09	0.25*	0.15	-									
9. Nausea	-0.32**	0.19	-0.09	0.05	-0.02	0.35**	0.31**	0.02	-								
10. Fatigue	-0.15	0.27*	0.03	-0.14	0.12	0.46***	0.47***	0.11	0.40**	-							
11. Dyspnea	-0.21*	0.09	-0.17	0.02	0.15	0.05	0.17	0.22*	0.23*	0.12	-						
12. Numbness	0.10	0.11	0.01	-0.08	0.01	0.17	-0.17	-0.12	0.10	0.08	-0.24*	-					
13. Tangible social support	0.09	-0.14	0.00	-0.04	-0.09	-0.14	-0.01	-0.06	0.02	-0.05	-0.06	-0.02	-				
14. HADS-anxiety	-0.23*	0.12	-0.02	-0.09	0.14	0.40***	0.19	0.21*	0.31**	0.46***	0.32**	0.09	-0.16	-			
15. HADS-depression	-0.23*	0.10	-0.04	-0.10	0.10	0.20*	0.22*	0.08	0.18	0.33**	0.01	0.12	-0.11	0.46***	-		
16. Self-efficacy-ARE	0.39***	-0.15	-0.04	-0.02	-0.05	-0.30**	-0.19	-0.33**	-0.25*	-0.28**	-0.17	0.09	0.23*	-0.42***	-0.42***	-	
17. Self-efficacy-SCE	0.35***	-0.12	-0.06	-0.03	-0.14	-0.18	-0.24*	-0.16	-0.18	-0.16	-0.22*	0.05	0.18	-0.25*	-0.22*	0.53***	-
18. Self-efficacy-ADE	0.52***	-0.24*	0.00	-0.12	-0.10	-0.35***	-0.43***	-0.25*	-0.17	-0.40***	-0.17	0.10	0.29*	-0.47***	-0.43***	0.72***	0.59***

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$. ADE: ADL efficacy; SCE: symptom coping efficacy; ARE: affect regulation efficacy.

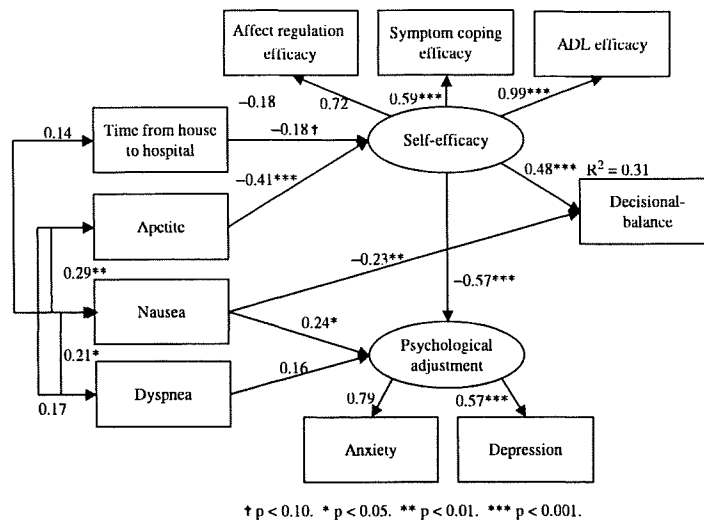


Figure 1. Structural model for decisional-balance of outpatient chemotherapy.

variables set as predictor variables. First, we assumed two latent variables; one was *psychological adjustment*, which explained anxiety and depression of HADS, and the other was self-efficacy, which explained affect regulation efficacy, symptom coping efficacy, and ADL efficacy, because there were significant correlation among these variables. We set environmental and physical symptom variables; time from house to hospital, appetite, nausea, and dyspnea as independent variables in the model, and the latent variables; psychological adjustment and self-efficacy as mediating variables between environmental and physical variables and decisional-balance. Also, we draw a path from self-efficacy to psychological adjustment because our previous research indicated that there was significant relationship between them (Hirai et al., 2002). As we removed no significant paths from full path model (AIC=94.69), which contained all regressed paths to decisional-balance, until the AIC index of model became the least score (AIC=88.53) among the models, we obtained the final model as indicated in Figure 1. The model excellently fit the data ($\chi^2(26) = 36.53$, $p = 0.16$; GFI=0.93; AGFI=0.88; CFI=0.97; RMSEA=0.05; AIC=88.53) and accounted for 31% of total variance in decisional-balance by self-efficacy ($\beta = 0.48$, $p < 0.001$) and nausea ($\beta = -0.23$, $p < 0.01$).

Finally, we added a variable, the stage for outpatient chemotherapy, into the model in Figure 1. As we also tested the AIC index from the full path model (AIC=105.85), which contained all regressed paths to stage, to the model with the least AIC index (AIC=100.56), the final model represented in Figure 2, was obtained. Fit indices for this model were excellent: $\chi^2(37) = 42.56$, $p = 0.24$; GFI=0.93; AGFI=0.88; CFI=0.98; RMSEA=0.04; AIC=100.56. Overall, the final model accounted for 40% of the variance in stage for outpatient chemotherapy by decisional balance ($\beta = 0.60$, $p < 0.001$) and time from house to hospital ($\beta = -0.15$, $p < 0.10$).

Discussion

The findings from our study provided encouragement for adopting the TTM in the decision-making for outpatient chemotherapy in Japanese cancer care, although the applicability is limited. We think that the TTM is a very useful and universal framework

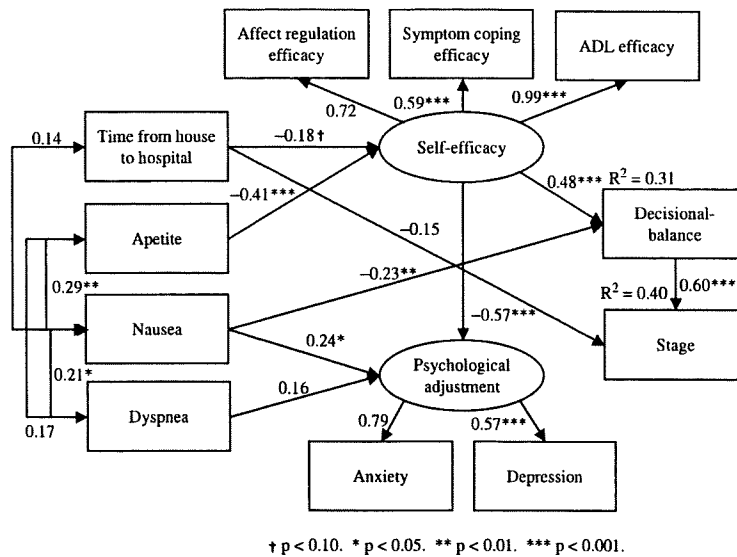


Figure 2. Structural model for stage of outpatient chemotherapy.

for clarifying behavioral problems, even if they are specific to a certain problematic phenomena in one domestic case.

First, the measurement for stage of change succeeded in classifying the participants into three stages: Contemplation, preparation, and action stages, and there were only four patients in the precontemplation stage. In the hospital where our survey was conducted, all lung cancer patients who were eligible for outpatient chemotherapy were informed about the options and availability of treatment by their physicians, and most of them understood that outpatient chemotherapy was one of their choices. This seems to be why only a few patients were in precontemplation. However, a number of patients ($N = 42$ [40%]) were still in contemplation and they were reluctant to choose the treatment as the immediate option, although they knew outpatient chemotherapy was an option for them. Therefore, the TTM indicated that a simple explanation of the treatment is insufficient to motivate patients to choose the option and that other factors influence patient decision making.

Second, we obtained a valid structural model, which explained the 40% of the variance in the advanced stage for outpatient chemotherapy. In our structural model, decisional-balance, which is the difference between the pros and cons, explained most of all the variance in stage progressed from contemplation to action. That is, patients who perceived high pros and low cons reached the action stage, while patients who perceived low pros and high cons remained in contemplation. This pattern of change in decisional-balance was consistent with the pattern indicated in basic assumption of the TTM (Prochaska & DiClemente, 1983), the result of the study of mammography (Rakowski et al., 1997), and that of the colorectal screening study (Manne et al., 2002). Therefore these results indicated that adoption of the TTM for outpatient chemotherapy was valid.

Third, in our structural model, demographic, physical and psychological variables significantly predicted the decisional-balance which mainly explained the stage of outpatient chemotherapy. Thus, decisional-balance mediates between demographic, physical and psychological variables, and the stages of readiness for outpatient chemotherapy. This model is also consistent with the theoretical assumption of the

TTM, in which decisional-balance is a mediating factor between the change of stage and other variables. In our model, the time from each participant's house to their respective hospital was the only demographic parameter to have a direct effect on stage, although it was a small parameter. It also showed that outpatient chemotherapy is an inconvenient option for patients who live far from a hospital, for example, more than 1 h away and the mean time from house to hospital was 46.19 min. Also, the reason nausea was a significant predictor of decisional-balance was explained by the fact that it is a significant side-effect of chemotherapy.

The interesting finding of this study was function of self-efficacy including affect regulation efficacy, symptom coping efficacy and ADL efficacy. Patients in the action stage showed significantly higher self-efficacy, and also the latent variable, self-efficacy was the significantly largest predictor of decisional-balance and psychological adjustment including anxiety and depression, and the mediating factor between environmental and physical variables and these outcome variables. Self-efficacy is one of the key components of the TTM (Prochaska & DiClemente, 1984) which explains stage transition, and previous studies showed that self-efficacy of cancer patients mediated between physical conditions and psychological adjustments (Beckham et al., 1997; Hirai et al., 2002). Our results are consistent with these theoretical assumptions and previous findings. Therefore, we have two possible explanations of the results. One is that patients' high self-efficacy becomes a motivator to make the transition to the action stage for outpatient chemotherapy and the other is that actual experiences in outpatient service and life in their own house enhanced their self-efficacy. In the first case, self-efficacy becomes a target for intervention to facilitate the transition to outpatient chemotherapy. In the latter case, since the transition to outpatient chemotherapy does not necessarily cause severe physical conditions or disability of daily living to the patients, recommendation of actual experiences for treatment reduces patients' cons and enhances self-efficacy.

We predicted that state of psychological adjustment, including anxiety and depression, would influence differences in stages or the decisional balance in the transition to outpatient chemotherapy. Although univariate analysis implied that patients in preparation were significantly more depressed compared to those in the other two stages, we could not obtain a statistically significant direct effect of depression or anxiety in our structural model. These suggest that the relationship between psychological adjustment and stage is not linear and mediated by self-efficacy, and that psychological adjustment was just a psychological outcome variable. They also implied that the severe depression of patients in preparation might be temporary deterioration in psychological adjustment, and that the actual transition to outpatient chemotherapy might not make patients highly anxious or highly depressed. Therefore, we concluded that recommending the transition to outpatient chemotherapy would not have any negative psychological impact on patients.

There are several clinical implications of the results in this study. First, it is beneficial for medical staff to evaluate subjective components, including decisional-balance and self-efficacy, in patients who are eligible for outpatient chemotherapy. To evaluate decisional-balance, individual differences and inpatients' pros and cons allow medical staff to make an individualized care plan and give adequate information to patients. Second, it may be possible to develop an intervention program combining the TTM-based screening with enhanced self-efficacy. TTM-based screening consists of two psychological assessments, including our single item for measuring the stage and our decisional-balance scale for psychological eligibility