

Second, as the intervention was performed by one facilitator (the second author) and at a single institution, the generalizability might be limited. This shortcoming should be overcome in the next study by using different instructors and a multicenter design. Third, the intervention effects might be nonspecific effects, such as the supportive environment of a group session. We believe, however, that this possibility is low because specific outcomes, not only general burnout, significantly changed.

In conclusion, this educational intervention had a significant and clear beneficial effect on nurse-perceived confidence, practice, and attitudes in providing care for patients feeling meaninglessness, in addition to their levels of burnout and spiritual well-being. Further intervention trials with patient-oriented end points using trained instructors are promising.

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Appendix

Members of the Japanese Spiritual Care Task Force

Tatsuya Morita, MD, Palliative Care Physician, Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka

Yosuke Uchitomi, MD, PhD, Psychiatrist, Research Center for Innovative Oncology, National Cancer Center Hospital East, Kashiwa City, Chiba

Terukazu Akazawa, Medical Social Worker, Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka

Michiyo Ando, RN, PhD, Nursing Psychologist, St. Mary College, Kurume City, Fukuoka

Chizuru Imura, RN, Certified Nurse (palliative care nursing), Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka

Takuya Okamoto, MD, Palliative Care Physician, Eikoh Hospital, Fukuoka

Masako Kawa, RN, PhD, Nurse, The University of Tokyo, Tokyo

Yukie Kurihara, LMSW, LMT, Clinical Social Worker, Shizuoka Cancer Center, Shizuoka

Hirobumi Takenouchi, PhD, Philosopher, Shizuoka University, Shizuoka

Shimon Tashiro, PhD, Sociologist, Tohoku University, Sendai City, Miyagi

Kei Hirai, PhD, Psychologist, Osaka University

Yasuhiro Hirako, Buddhist Priest, Soto Institute for Buddhist Studies, Osaka

Hisayuki Murata, MA, Philosopher, Kyoto Notre Dame University, Kyoto

Tatsuo Akechi, MD, PhD, Psychiatrist, Nagoya City University Medical School, Nagoya, Aichi

Nobuya Akizuki, MD, PhD, Psychiatrist, Research Center for Innovative Oncology, National Cancer Center Hospital East, Kashiwa City, Chiba

Eisuke Matsushima, MD, PhD, Psychiatrist, Graduate School of Tokyo Medical and Dental University, Tokyo

Kazunari Abe, Occupational Therapist, Chiba Cancer Center, Chiba

Masayuki Ikenaga, MD, Palliative Care Physician, Yodogawa Christian Hospital, Osaka

Taketoshi Ozawa, MD, Palliative Care Physician, Yokohama Kosei Hospital, Yokohama, Kanagawa

Jun Kataoka, RN, Nurse, Aichi Prefectural College of Nursing and Health, Aichi

Akihiko Suga, MD, Palliative Care Physician, Shizuoka General Hospital, Shizuoka

Chizuko Takigawa, MD, Palliative Care Physician, Keiyukai Sapporo Hospital, Sapporo, Hokkaido

Keiko Tamura, Certified Nurse (oncology), Yodogawa Christian Hospital, Osaka

Wataru Noguchi, MD, Psychiatrist, Graduate School of Tokyo Medical and Dental University, Tokyo

Etsuko Maeyama, RN, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo

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.

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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

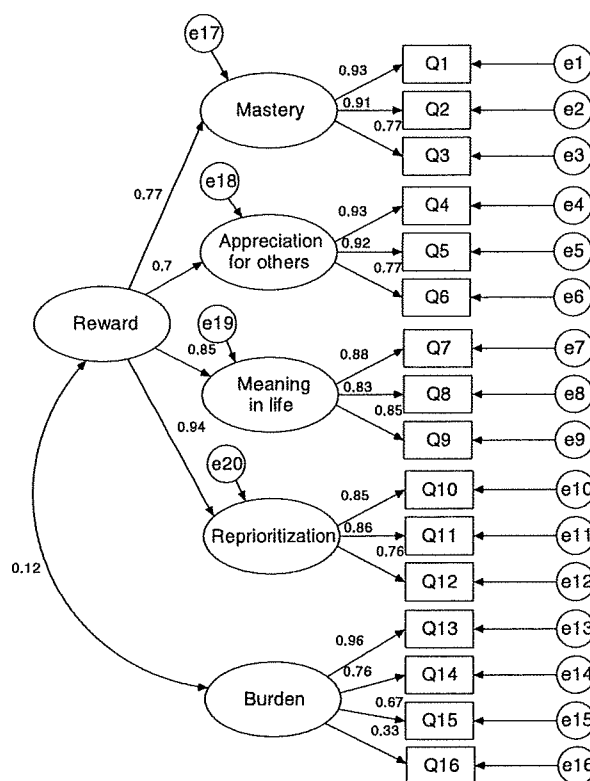
CCI and the one-item overall perceived reward was moderate and ranged from $r = 0.30$ to 0.43.

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	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.

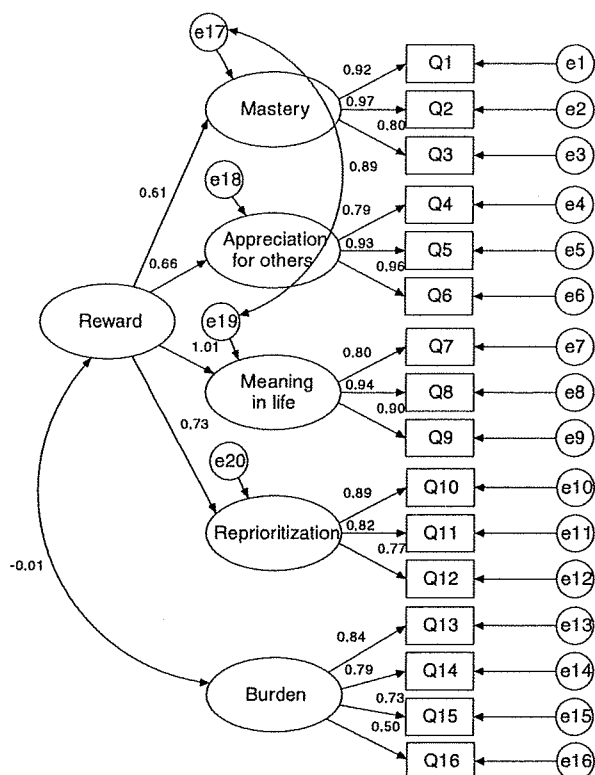


Figure 2. Confirmatory factor analysis of Caregiving Consequence Inventory (Part 2). χ^2 191.6 (DF = 98), $P < 0.001$; GFI = 0.929; AGFI = 0.819; CFI = 0.749; RMSEA = 0.097

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.

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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.

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Original Article

Artificial Hydration Therapy for Terminally Ill Cancer Patients: A Nurse-Education Intervention

Akemi Yamagishi, RN, PhD, Fukuko Tanaka, MD, PhD, and Tatsuya Morita, MD
Department of Adult Nursing/Palliative Care Nursing (A.Y.), School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo; International University of Health and Welfare (F.T.), Ohtawara; and Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka, Japan

Abstract

The Japanese Society of Palliative Medicine has developed a clinical guideline to minimize the large variation in clinical practice of artificial hydration therapy for terminally ill cancer patients. The primary aim of this preliminary study was to explore the effects of a five-hour interactive workshop based on the guideline of nurses' knowledge, confidence, self-reported practice, and nurse-perceived usefulness. The study was designed as a pre-post anonymous questionnaire survey. The nurses attended a five-hour interactive workshop based on the guideline and were asked to complete a questionnaire before and after the workshop. The outcome measures were: nurses' knowledge (13 items; the total number of correct answers was defined as the Knowledge score), confidence in caring for terminally ill cancer patients with reduced oral intake (a single Likert-type scale from 1 = "not confident at all" to 7 = "very confident"), and self-reported practice (nine items assessing the degree to which nurses think they would perform more frequently recommended practices described in the guideline after the workshop). Of the 81 nurses who participated in this workshop, we obtained consent from 76 to complete the questionnaire. The Knowledge score significantly increased after the intervention from 7.7 ± 2.3 to 11 ± 1.4 ($P < 0.001$), and the Confidence score significantly increased from 3.1 ± 1.2 to 3.8 ± 1.1 ($P < 0.001$). More than 80% of the nurses reported they would perform six of nine recommended practices after the workshop. The percentages of nurses who evaluated this workshop as "useful" or "very useful" were: 84% (to know the medical indications of artificial hydration therapy), 89% (to know the effects of artificial hydration therapy on patient quality of life and survival), 71% (to know the physiology of appetite loss and cancer cachexia), 83% (to know how to provide nursing care), and 91% (to know ethical principles). Based on these results, it is possible that a five-hour interactive workshop on artificial hydration therapy, based on the clinical guideline of the Japanese Society of Palliative Medicine, improves nurses' knowledge, confidence, and self-reported practices. The workshop was generally perceived as useful for nurses. Nationwide dissemination of the guideline with interactive workshop education for nurses, in combination with physicians, is a promising method for

Address correspondence to: Tatsuya Morita, MD, Department of Palliative and Supportive Care, Seirei Mikatahara Hospital, 3453 Mikatahara-cho, Hamamatsu,

Shizuoka 433-8558, Japan. E-mail: tmorita@sis.seirei.or.jp

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Key Words

Artificial hydration therapy, nutrition, hydration, education, interactive workshop, neoplasms, guideline

Introduction

Recent literature reveals a large variation in physician practice pertaining to artificial hydration therapy for terminally ill cancer patients.¹ This means that patients may suffer unnecessarily because of over- or underhydration. The establishment of a clinical guideline can contribute to patient well-being by clarifying the best practice from empirical evidence and available expert experience. In addition to several general clinical practice guidelines,^{2–7} the Japanese Society of Palliative Medicine recently published a clinical guideline for artificial hydration therapy for terminally ill cancer patients using evidence-based and formal consensus-building methods.⁸ The primary aim of the guideline is to help clinicians make a clinical decision about artificial hydration therapy to ensure a better quality of care for terminally ill cancer patients. The target population is adult cancer patients with incurable cancer who have inadequate oral intake refractory to appropriate palliative treatments and who are likely to die within one to two months. The targeted users are all health care professionals who treat the target population.

The guideline assumes that the determinants of quality of life and the processes of dying and death vary among individuals, and that individual assessment is essential to define what is important for each patient. Palliation of physical distress, peace of mind, having a good family relationship, not being a burden to others, completion of life, fighting against cancer, maintaining hope, and not being aware of death are good death elements that could be related to the decision-making process for artificial hydration therapy for Japanese patients.⁸ The guideline strongly recommends that clinicians respect patient and family values; individualize the treatment for each patient; and assess the situation comprehensively from a medical, practical,

psychosocial, ethical, and legal point of view. On the basis of this conceptual framework, clinicians should first clarify the general treatment goal consistent with patient and family values. Second, clinicians should comprehensively assess the situation, especially the potential effects of artificial hydration therapy on patient physical symptoms, survival, daily activities, psycho-existential well-being, and ethical and legal issues. Third, clinicians should decide on a treatment plan after discussion with patients and families. Finally, clinicians should periodically reevaluate the treatment efficacy at planned intervals, and adjust the treatment suitable for each patient.

During this whole process, nurses play an important role in supporting the decision-making process of patients and families, providing emotional support and planning nursing assistance for artificial hydration therapy. Thus, we believe that educating nurses about artificial hydration therapy is of great importance, and a useful education program can assist in the successful implement of the guideline.

Although simple dissemination of printed guidelines has minimum effect on the actual behaviors of clinicians, an interactive workshop could contribute toward improving clinical practice.^{9–12} As the first step of dissemination efforts to promote the guideline, the primary aim of this preliminary study was to explore the effects of a five-hour interactive workshop on nurses' knowledge, confidence, self-reported practice, and nurse-perceived usefulness of this workshop.

Methods

This study was designed as a pre-post anonymous questionnaire survey. The nurses voluntarily applied to the workshop across the country by means of announcements in

palliative care specialty journals and the Internet. No inclusion criteria for participation were required. The participants were asked to complete the questionnaire before and just after the workshop. Written consent regarding voluntary participation and confidentiality was obtained, and the questionnaire was collected at the workshop.

Intervention

The workshop was based on the guideline published by the Japanese Society of Palliative Medicine. A task force prepared all materials, including the visual presentation of this workshop, and one member of the task force (T.M.) conducted the workshop. The task force consisted of 32 experts: six palliative care physicians, six surgeons, four anesthesiologists, three medical oncologists, two home care physicians, five nurses, a social worker, two bioethicists, a lawyer, and two epidemiologists. The workshop was designed to be interactive and consisted of a pretest (10 minutes), a lecture about the development process of the guideline (10 minutes), an interactive seminar about recommendations for physical symptoms (60 minutes), recommendations for psychosocial support (60 minutes), recommendations for ethical decisions (60 minutes), an interactive discussion using vignette presentations (60 minutes), free discussion as a group and individual (30 minutes), and a post-test (10 minutes). The number of participants was about 20 per workshop, and four workshops were held. The guideline and materials (in Japanese) are available from the homepage of the Japanese Society of Palliative Medicine (<http://www.jspm.ne.jp/>).

Measurement Instruments

Following the descriptions in the guideline,⁸ we developed instruments to specifically quantify nurses' knowledge, confidence, and self-reported practice about artificial hydration therapy for terminally ill cancer patients. We decided to develop a new questionnaire for this study because of a lack of existing validated measurements. To examine content validity, a multidisciplinary expert panel (two nurses and two palliative care physicians) rated the appropriateness of each item using the Delphi method, and items that achieved 8 or more on a 1–9 scale were selected. We had decided not to

perform formal validity and reliability testing for each measurement instrument, because all items about knowledge and self-reported practice were driven by descriptions from the clinical guideline.

Knowledge. We evaluated nurses' knowledge about artificial hydration therapy using 13 questions (Table 1). We defined a "Knowledge" score as the total number of correct answers ("unsure" responses were regarded as incorrect answers); thus, the "Knowledge" score ranged from 0 to 13 and a higher score indicated a higher level of knowledge.

Confidence. Confidence in caring for terminally ill cancer patients with reduced oral intake was evaluated on a single Likert-type scale from 1 = "not confident at all" to 7 = "very confident." The question was "How confident are you in caring for terminally ill cancer patients with reduced oral intake?"

Self-Reported Practice Scale. We conceptualized self-reported practice as the level of self-reported adherence to recommended clinical practice guidelines about artificial hydration therapy for terminally ill patients. Self-reported practice was evaluated by the degree to which the nurses thought they would perform recommended practices in about nine areas more or much more frequently after the workshop (Table 2). The scale, consisting of nine items, was Likert-type, ranging from 1 = "would perform much less frequently" to 5 = "would perform much more frequently."

Overall Evaluation. We asked the respondents to rate their overall evaluation of the usefulness of this workshop in terms of: 1) understanding the medical indications for artificial hydration therapy, 2) understanding the effects of artificial hydration therapy on patient quality of life and survival, 3) understanding the physiology of appetite loss and cancer cachexia, 4) knowing how to provide nursing care for patients, and 5) understanding ethical principles. The choices were "not useful," "slightly not useful," "slightly useful," "useful," and "very useful."

Table 1
Knowledge About Artificial Hydration Therapy

Questions	Before the Workshop	After the Workshop
	% (n)	% (n)
Water supplied by artificial hydration therapy is not retained efficiently in the veins when the albumin level is low or inflammation is severe. (T)	80 (61)	93 (71)
Terminally ill cancer patients require more calories than patients with early cancer, because more calories are consumed by the tumor. (F)	68 (52)	87 (66)
Ascites or pleural effusion is not aggravated in patients with a negative calculated water balance. (F)	75 (57)	79 (60)
Fluid infusion is rarely performed in certified palliative care units in Japan. (F)	50 (38)	89 (68)
Fluid infusion is the only treatment for patients with reduced oral intake because of cancer. (F)	68 (52)	95 (72)
Total parenteral nutrition often contributes to improve the quality of life of patients with a good performance status and (who are) incapable of oral nutritional intake because of gastrointestinal obstruction. (T)	58 (44)	80 (61)
Fluid infusion palliates the sensation of thirst in patients expected to die within a few weeks. (F)	55 (42)	95 (72)
If it becomes impossible to establish an IV route in a peripheral vessel, the central vein is the only available route of fluid infusion. (F)	70 (53)	97 (74)
In patients expected to die within several days, no improvement in the general well-being or survival can be obtained by fluid infusion. (T)	64 (49)	88 (67)
Ascites or pleural effusion can be aggravated in patients receiving fluid infusion of 1000 mL/day or more. (T)	71 (54)	86 (65)
Total parenteral nutrition improves the survival and quality of life in lung cancer patients with adequate water intake. (F)	38 (29)	59 (45)
More than 90% of Japanese consider that "Fluid infusion is the minimum standard of care." (F)	16 (12)	64 (49)
If hyperglycemia occurs during total parenteral nutrition for terminally ill cancer patients, the addition of insulin improves the nutritional state and controls the blood glucose level. (F)	37 (28)	63 (48)

T = true; F = false; IV = intravenous.

The percentages of nurses who gave correct answers are shown. The number of nurses who gave the correct answers are shown within brackets.

Results

Of the 81 nurses who participated in this program, we obtained consent from 76 (94%). Their mean age was 33 ± 7.5 years, and 71 were females. Their institutions included general hospitals ($n = 41$), cancer centers or academic hospitals ($n = 13$), specialized palliative care services ($n = 11$), and outpatient clinics or home care settings ($n = 4$). They had a mean clinical experience of 10 ± 5.7 years, and the median number of patients who died of cancer was 20 per year. Five nurses were certified nurses (palliative care, cancer pain, or chemotherapy), and 10 nurses had graduated from a nursing university.

Knowledge

The Knowledge score significantly increased after the intervention from 7.7 ± 2.3 to 11 ± 1.4 ($P < 0.001$). The items for which 80% or more nurses gave correct answers increased from one item before the workshop

(7.7% of 13 items) to nine items (69%) after the workshop (Table 1).

Confidence

The Confidence score significantly increased after the intervention from 3.1 ± 1.2 to 3.8 ± 1.1 ($P < 0.001$). The percentage of nurses who rated their confidence as "not confident at all" or "not confident" decreased from 34% ($n = 25$) to 15% ($n = 11$).

Self-Reported Practice

After the workshop, more than 80% of the nurses reported that they would more or much more frequently perform six of nine recommended practices (Table 2). The percentage of nurses who reported that they would perform three medically-related practices more or much more frequently ranged from 53% to 68%.

Overall Evaluation

The percentages of nurses who evaluated this program as "useful" or "very useful"

Table 2
Self-Reported Practice About Artificial Hydration Therapy

Questions	More Frequently or Much More Frequently Perform	Unchanged
	% (n)	% (n)
I will try to explore what worries the patients may have about not being able to eat.	89 (68)	3.9 (3)
I will try to understand the patients' wishes and values concerning fluid infusion therapy.	91 (69)	3.9 (3)
I will try to explore what worries the patients' families may have about the patients not being able to eat.	91 (69)	3.9 (3)
I will observe the oral area and provide mouth care for thirst.	93 (71)	1.3 (1)
I will ask the patients themselves about pain or how comfortable they are.	89 (68)	3.9 (3)
I will modify the infusion according to the patient's lifestyle (intermittent infusion, etc.).	82 (62)	12 (9)
I will advise physicians to perform subcutaneous administration if the peripheral IV route cannot be established.	53 (40)	29 (22)
I will advise physicians to perform drug therapy that increases oral intake other than fluid infusion.	68 (52)	22 (17)
I will advise physicians to reduce the volume of fluid infusion if ascites or pleural effusion is increased.	67 (51)	24 (18)

were: 84% ($n=64$, to understand the medical indications for artificial hydration therapy), 89% ($n=68$, to understand the effects of artificial hydration therapy on patient quality of life and survival), 71% ($n=54$, to understand physiology of appetite loss and cancer cachexia), 83% ($n=63$, to understand how to provide nursing care for patients), and 91% ($n=69$, to understand ethical principles about hydration).

Discussion

This was a preliminary study to systematically investigate nurses' knowledge, confidence, and self-reported practice about artificial hydration therapy, and to examine the effects of educational intervention on these outcomes. The most important finding was the positive effects of this workshop on nurses' knowledge, confidence, and self-reported practice, and the generally high levels of the nurse-perceived usefulness of this workshop. In fact, after the workshop, nurses' knowledge and confidence significantly increased, and many nurses reported that they would more frequently perform the recommended practices described in the guideline. Moreover, more than 80% of the nurses evaluated the workshop useful or very useful.

As to nurses' knowledge, this study identified six areas in which nurses had generally inappropriate knowledge: availability of artificial

hydration therapy in certified palliative care units, medical indication of hyperalimentation, no beneficial effect of artificial hydration therapy on alleviating the sensation of thirst, the percentage of public belief that artificial hydration therapy is the minimum standard of care, and the role of insulin for hyperglycemia in terminally ill cancer patients. This finding suggests that future educational intervention should particularly focus on these areas.

Of special note was that, despite clinical evidence that artificial hydration has no or minimum beneficial effects in alleviating the sensation of thirst and that nursing oral care is essential for symptom control in dying patients,¹³⁻¹⁵ only half of the nurses had the correct knowledge. After the workshop, however, 95% of the nurses had the correct knowledge and 93% reported that they would perform mouth care more or much more frequently. This result indicates that this educational intervention could contribute to better alleviation of thirst through improving nurses' knowledge and attention to mouth care for terminally ill cancer patients.

In addition, we believe that improvement of knowledge about the availability of artificial hydration therapy in certified palliative care units is of value. Multiple surveys have identified misconceptions about palliative care units in their availability to provide medical treatments as a significant barrier for appropriate referral.^{16,17} Although many palliative care

units actually provide artificial hydration therapy, a considerable number of the general public believe that patients admitted to palliative care units cannot receive artificial hydration therapy. Because the Japanese public and patients generally believe that artificial hydration therapy is the minimum standard of care,¹⁸⁻²⁰ whether or not patients can receive artificial hydration therapy appears to be important in Japanese treatment settings. An educational intervention about the reality of the availability of artificial hydration therapy in certified palliative care units could thus contribute to better understanding and the introduction of palliative care units for patients in general hospitals.

As to nurses' self-reported practice, after the workshop, more than 80% of the nurses reported that they would more frequently ask about patient and family concerns and values specifically related to artificial hydration therapy, and modify administration methods according to the patient's lifestyle. This finding is, we believe, of importance and is clinically relevant because, in our previous study, major determinants of satisfaction with artificial hydration therapy include an adequate decision-making process and practical assistance to reduce disruption in daily activities.²¹ The clinical guideline also stresses the nurses' role in eliciting patient and family wishes and in modifying infusion methods suitable for each patient.⁸ This finding suggests that this workshop has a positive influence on psychosocial and nursing-practical areas of artificial hydration therapy, not only medical aspects, and could contribute to better patient outcomes.²¹

On the other hand, in the remaining three areas, the percentage of nurses who reported that they would perform them more frequently was relatively low, that is, 53%–68%. The interpretation of this finding is that these areas are mainly related to medical decisions, and traditional nurses are unwilling to "override" physician decisions. Nonetheless, the fact that more than half of the nurses reported that they would more frequently recommend that physicians use hypodermoclysis, pharmacological treatment for decreased oral intake and volume reduction for imminently dying patients seems to be encouraging. This finding, however, strongly indicates that to disseminate this guideline, an educational intervention will be

required for both nurses and physicians. Another project, the PEACE program, is now underway to provide adequate education about palliative care to physicians throughout Japan.

This study is a preliminary study, and thus, has considerable limitations. First, as this study investigated nurse-reported and short-term outcomes, actual changes in nursing practice and/or patient-oriented long-term effects should be explored in a future study. Because of the complexity of clinical practice, improved outcomes in this study should not be directly interpreted as confirmed improvement in patient outcome. Second, cultural differences, especially about the role of artificial hydration therapy in end-of-life care, might limit the generalizability of the findings to other populations. Third, potential selection bias of participants engaged in this program, no formal testing of the reliability and validity of outcome measurements, and the relatively small sample size weaken the study design. Finally, the intervention targeted nurses, not physicians, and thus, the impact on patient quality of life might be relatively small. We believe, however, that educating nurses is at least as important as for physicians, because psychological support for patients with no oral intake ability, quality mouth care to improve dry mouth, and planning a hydration method suitable for the patient's lifestyle are the nurses' chief roles and would contribute to better patient outcome.

In conclusion, this five-hour interactive workshop based on the clinical guideline of the Japanese Society of Palliative Medicine seems to improve nurses' knowledge, confidence, and self-reported practice, and was perceived as useful for nurses. Nationwide dissemination of the guideline with interactive workshop education for nurses, in combination with physicians, is promising to improve clinical practice of artificial hydration therapy for terminally ill cancer patients. A confirmatory study using a larger number of unselected samples and objective outcome measures is needed.

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Original Article

Development of a Standard for Hospital-Based Palliative Care Consultation Teams Using a Modified Delphi Method

Tomoyo Sasahara, RN, PhD, Yoshiyuki Kizawa, MD, Tatsuya Morita, MD, Yuumi Iwamitsu, PhD, Junji Otaki, MD, DMedSc, Hitoshi Okamura, MD, PhD, Mikako Takahashi, RN, MS, Sayaka Takenouchi, RN, MPH, and Seiji Bito, MD
Institute of Nursing Science (T.S.), Institute of Clinical Medicine (Y.K.), Graduate School of Comprehensive Human Sciences, University of Tsukuba, Ibaraki; Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Shizuoka; Department of Medical Psychology (Y.I.), Graduate School of Medical Sciences, Kitasato University, Kanagawa; Department of General Medicine and Primary Care (J.O.), Tokyo Medical University Hospital, Tokyo; Psychosocial Rehabilitation Laboratory (H.O.), Graduate School of Health Sciences, Hiroshima University, Hiroshima; Palliative Care Unit (M.T.), St. Luke's International Hospital, Tokyo; Department of Biomedical Ethics (S.T.), Graduate School of Medicine, Kyoto University, Kyoto; and Division of Clinical Epidemiology (S.B.), National Hospital Organization, Tokyo Medical Center, Tokyo, Japan

Abstract

Although palliative care consultation teams are rapidly being disseminated throughout Japan as a result of government policy, the role of these teams has not been standardized. The aim of this study was to develop a hospital-based palliative care consultation team standard. We adopted a modified Delphi method to develop a standard. Twenty-seven multiprofessional panelists were selected according to two criteria: adequate experience as part of a palliative care consultation team and representative of 16 palliative care-related organizations. Panelists rated the appropriateness of 33 statements in a provisional standard, which was generated by the authors, using a nine-point Likert-type scale in a first-round survey. We set two criteria for agreement: the median value was 8 or more, and the difference between the minimum and maximum was 4 or less. There were 15 disagreements in the first-round survey. Based on discussions through e-mails and a panel meeting, these 15 statements were dealt with as follows: one was rejected, one was combined with another statement, three were unmodified, and 10 underwent minor revisions. Moreover, two statements that generated agreement were divided into two statements each. Consequently, the number of statements was 37. In a second-round survey, three statements engendered disagreement and were modified. At the end of the process, there were 37 statements in four areas: "philosophy and policy," "structure for care provision," "contents of activities," and "quality assurance and care improvements." This standard may be useful as a clinical

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Address correspondence to: Tomoyo Sasahara, RN, PhD, Institute of Nursing Science, Graduate School of

Comprehensive Human Sciences, University of Tsukuba, 1-1-1 Ten-nodai, Tsukuba, Ibaraki 305-8575, Japan. E-mail: tsasahara@md.tsukuba.ac.jp

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