Development and Validity of the Nursing Care Scale and Nurse's Difficulty Scale in Caring for Dying Patients With Cancer and Their Families in General Hospitals in Japan

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This study develops and examines the validity and reliability of 2 scales, respectively, for evaluating nursing care and the experience of difficulties providing nursing care for dying patients with cancer and their families.

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A cross-sectional anonymous questionnaire was administered to nursing staff caring for dying patients with cancer and their families in 4 general hospitals and a university hospital in Japan. The instruments assessed were the Nursing Care Scale for Dying Patients and Their Families (NCD) and the Nurse's Difficulty Scale for Dying Patients and Their Families (NDD). Of the 497 questionnaires sent to nurses, 401 responses (80%) were analyzed. Factor analyses revealed that the NCD and NDD consisted of 12 items with 4 subscales: ''symptom management,'' ''reassessment of current treatment and nursing care,'' ''explanation to family,'' and ''respect for the patient and family's dignity before and after death.'' These scales had sufficient convergent and discriminative validity, sufficient internal consistency (α of subscales: NCD, 0.71-0.87; NDD, 0.74-0.93), and sufficient test-retest reliability (intraclass correlation coefficient of subscales: NCD, 0.59-0.81; NDD, 0.67-0.82) to be used as self-assessments and evaluation tools in education programs to improve the quality of nursing care for the dying patients and their families.

KEY WORDS

care for the dying, difficulty, neoplasms, nursing care, questionnaires

Excellent palliative care for dying patients with cancer and their families should be provided in all care settings. However, patients dying in hospitals often have unrelieved and poorly treated physical, emotional, and spiritual distress.[1-3] In addition, family members often do not receive the desired support and effective communication either before or after the patient's death.[3-5]

Nursing care at this stage requires a comprehensive approach for both patients and their families, including consideration of the burden of caregiving, grief over loss of the loved one, decision making, and other concerns.[6,7] Beckstrand et al[8] found that many nurses felt conflicted in their role and have an awareness that care of dying patients and their families is insufficient. The reasons for

this conflict included nurses' difficulties stemming not only from the insufficient care in general but also from a lack of communication skills and insufficient care.[9-12] Nurses' difficulties providing care to dying patients may lead to distress and burnout.[13] Burnout is associated with various stresses and can result in decreased job performance and commitment among health care professionals, including those working with patients with cancer.[14-16] Therefore, to improve the quality of practice, it is an important need to decrease difficulties experienced by nurses in providing care for dying patients and their families.

Some instruments evaluating the quality of end-of-life care from the nurse's perspective already exist, such as the Palliative Care Quiz for Nursing,[17] which assesses knowledge; the Frommelt Attitudes Towards Care of the Dying Scale,[18] which assesses attitudes; and the Nursing Older People–Competence Evaluation tool,[19] which assesses competence. These nursing instruments evaluate end-of-life care, rather than the processes of dying and death. Curtis and colleagues[20] developed the Quality of Dying and Death questionnaire and confirmed its validity and reliability. The Quality of Dying and Death questionnaire evaluates nursing care of dying patients and their families mainly in intensive care units, rather than general wards and palliative care units.

Therefore, this study developed and examined the reliability and validity of 2 instruments that could evaluate nursing care and nurse self-reported difficulties in providing care for dying patients and working with their families in general wards and palliative care units.

METHODS

A development and validation phase was conducted for both questionnaires.

Development Phase

Two questionnaires were developed to evaluate nursing care and difficulties experienced by nurses in caring and providing for dying patients and their families. First was a semistructured interview with eight registered nurses who had cared for at least 10 dying patients with or without cancer (with other terminal conditions) and their families. Participants were asked to describe how they provided such care and the difficulties they had experienced. On the basis of findings extracted from a literature review[2,6,18,20] and a content analysis,[21] two draft questionnaires were created aiming to evaluate nursing care and the difficulties experienced by nurses in providing care for dying patients and their families. Next, 2 certified nurse specialists in cancer nursing were interviewed to ensure face and content validity—wording and format of the draft instruments. Third, a pilot study was conducted with 20 nurses to determine potential causes of missing data and questions that might be difficult to answer. This process was repeated

with experts in end-of-life care to evaluate the appropriateness of each item, and 27 potential attributes were selected to be assessed in each questionnaire.

Validation Phase

A cross-sectional questionnaire was completed anonymously by registered nurses who cared for patients with cancer and their families on 3 general wards and 2 inpatient palliative care units in 4 general hospitals and a university hospital in Japan. The most common type of specialized palliative care service in Japan is the palliative care unit.

Participants and Procedures

Potential participants were identified by the institutions involved in the study. The inclusion criteria were nurses who had worked for more than 1 year and who had 1 or more experiences of caring for dying patients with cancer and their families in a general ward or palliative care unit.

The study's secretariat office (Tohoku University) prepared the complete set of questionnaires and sent them to institutions. The collaborator at each institution then sent the questionnaires to the participants in November 2012. The participants returned the completed questionnaires to predetermined boxes in the institutions within 2 weeks. Each institution's coordinator then sent the collected sealed questionnaires to the secretariat's office. Two weeks after sending the first questionnaire, participants who had consented to participate were sent the retest questionnaires. Participants were encouraged not to report individual answers to the institutions. Results were reported to the institutions in an aggregate format.

The ethical and scientific validity of this study was approved by the institutional review boards of the Tohoku University and all participating institutions.

Measurements

Nursing Care and Nurse's Difficulty Scales for Dying Patients and Their Families

Participants were asked about 27 potential attributes of the Nursing Care Scale for Dying Patients and Their Families (NCD) and the Nurse's Difficulty Scale for Dying Patients and Their Families (NDD), using a 5-point Likert-type scale (1, not at all, to 5, always).

The MITORI Care Scale

The authors used the MITORI Care Scale (in Japanese) to examine concurrent validity of the NCD. The MITORI Care Scale consists of 22 representative items that measure nursing care practice throughout the end-of-life phase, not focusing on dying and after death, and has confirmed validity and reliability for patients with cancer.[22]

TABLE 1 Characteristics of Participants (N = 401)		
	n	%
Sex		
Female	372	92.8
Male	28	7.0
Age, y		
≤29	191	47.6
30–39	128	31.9
≥40	81	20.2
Status		
Manager	7	1.7
Submanager	43	10.7
Staff	351	87.5
Qualification		
None	396	98.8
Certified nurse	2	0.5
Certified nurse specialist	1	0.2
Duration of clinical experience, y		
≤4	123	30.7
5-14	175	43.6
≥15	103	25.7
Duration of experience in hospice or palliative care unit, y		
None	336	83.8
1-4	37	9.2
≥5	26	6.5
No. patients with terminal cancer ever cared for		
1-9	118	29.4
10-49	186	46.4
50-99	61	15.2
≥100	36	9.0
Education		
Nursing school	266	66.3

(continues)

TABLE 1 Characteristics of Participants (N = 401), Continued		
	n	%
Junior college	56	14.0
University/higher	77	19.2
Participation frequency in dying care seminars		
At one's own facility		
None	203	70.6
1	84	20.9
≥2	108	26.9
At another facility		
None	282	70.3
1	57	14.2
≥2	57	14.2

Several totals are not 100% because of missing values.

Palliative Care Difficulty Scale

The authors used the Palliative Care Difficulty Scale (PCDS) to examine concurrent validity of the NDD. The PCDS consists of 15 representative items that measure nurses' difficulties in providing palliative care throughout the end-of-life phase, not focusing on dying and after death, and has confirmed validity and reliability for patients with cancer.[23]

Participant Characteristics

Information was collected on sex, age, status, qualification, duration of clinical experience, duration of experience in hospice or palliative care units, number of life-threatening cancer patients cared for, education, and participation frequency in dying care seminars at one's facility and other facilities.

Analysis

The authors examined the percentage of missing data (cut-off: missing more than 1% of data) and the ceiling and floor effects for items on each scale and excluded items (cutoff: >90% of responses were 1 or 5 on the 5-point Likert-type scale) for item selection. Explanatory factor analysis was conducted using the principal method with a promax rotation due to correlated factors and to allow a clear-cut interpretation.[24] Standard regression coefficients were taken as the minimum of 0.4. For the convergent and discriminant validity, multitrait scaling analysis[24] was used; for concurrent and discriminant validity, Pearson correlation coefficients were used; for internal consistency and test-retest reliability, Cronbach α coefficients and intraclass correlation coefficients

were used; and, finally, for known-groups validity, an unpaired *t* test was used to compare between general wards and palliative care units. All analyses were performed using SPSS version 18 (SPSS Institute, Chicago, IL).

RESULTS

There were 497 questionnaires returned, of which 79 were excluded. Of the remaining 418 responses, a further 17 were excluded because of missing data (>50% of items) or because the respondent had a lack of experience caring

for dying patients. Thus, 401 responses were analyzed (effective response rate, 80%).

As for the retest, of 57 questionnaires sent to nurses who agreed to participate, 36 were returned, of which 2 responses were excluded because of missing data (ie, >50%). Thus, 34 responses were analyzed (effective response rate, 60%). Participants' characteristics are shown in Table 1.

Factor Validity

For the NCD, the authors initially excluded 2 items because of missing data and 4 items because of skewed

TABLE 2 Factor Analysis of the Nursing Care Scale for Dying Patients and Their Families

Subscales and Items	Standard Regression Coefficients				Communality
	Factor 1	Factor 2	Factor 3	Factor 4	
I. Symptom management (mean [SD], 11.6 [2.6]; α = .87; ICC, 0.71)					
1. I regularly assess for dyspnea and confirm its presence in order to treat it quickly.	**0.96**	−0.04	0.04	−0.11	0.86
2. I regularly assess for delirium/agitation and confirm its presence in order to treat it quickly.	**0.88**	−0.02	0.09	−0.07	0.79
3. I regularly assess for pain and confirm its presence in order to treat it quickly.	**0.83**	0.07	−0.13	0.13	0.76
II. Reassessment of current treatment and nursing care (mean [SD], 9.8 [2.8]; α = 0.80; ICC, 0.66)					
4. I reassess treatment using examinations in the dying phase.	−0.09	**0.92**	0.05	−0.08	0.79
5. I reassess current treatment in the dying phase.	−0.01	**0.88**	0.05	0.01	0.81
6. I reassess current nursing care in the dying phase.	0.23	**0.63**	−0.03	0.15	0.62
III. Explanation to family (mean [SD], 11.2 [2.4]; α = 0.74; ICC, 0.81)					
7. I provide an explanation to family members about the patient's suddenly worsening condition.	−0.14	0.12	**0.84**	−0.03	0.70
8. I provide an explanation to family members about the patient's present condition and probable condition in the future.	0.04	0.04	**0.83**	0.01	0.75
9. I provide an explanation to family members about family care such as mouth care.	0.13	−0.05	**0.70**	−0.01	0.54
IV. Respect for patient and family's dignity before and after death (mean [SD], 13.1 [1.8]; α = 0.71; ICC, 0.59)					
10. I respect the patient as a person before and after death.	−0.03	0.06	−0.17	**0.92**	0.73
11. I make time for the family's grief after death.	−0.07	0.02	0.07	**0.76**	0.61
12. I am concerned about the family's physical and psychological fatigue.	0.06	−0.18	0.33	**0.62**	0.67
Total score (mean [SD], 45.6 [6.9]; α = 0.84; ICC, 0.72)					

Abbreviation: ICC, intraclass correlation coefficient.
Cumulative proportion, 71.9%.
Bold data indicates discrimination of other factors.

responses in 90% or more respondents. For the NDD, the authors initially excluded 3 items because of missing data, and 3 items were excluded because of skewed responses in 90% or more respondents. The results of the factor analysis are shown in Tables 2 and 3. The following 4 domains for the NCD and NDD were identified: "symptom management," "reassessment of current treatment and nursing care," "explanation to the family," and "respect for the patient and family's dignity before and after death."

TABLE 3	**Factor Validity of the Nurse's Difficulty Scale for Dying Patients and Their Families**				
	Standard Regression Coefficients				
Subscales and Items	**Factor 1**	**Factor 2**	**Factor 3**	**Factor 4**	**Communality**
I. Explanation to family (mean [SD], 9.1 [2.9]; α = 0.91; ICC, 0.67)					
1. I feel it is difficult to provide an explanation to family members about the patient's suddenly worsening condition.	**0.97**	−0.03	0.02	−0.05	0.88
2. I feel it is difficult to provide an explanation to family members about the patient's present condition and probable condition in the future.	**0.91**	−0.01	0.03	0.02	0.85
3. I feel it is difficult to provide an explanation to family members about family correspondence in case of the patient's worsening condition.	**0.86**	0.06	−0.04	0.01	0.79
II. Symptom management (mean [SD], 10.1 [2.8]; α = 0.93; ICC, 0.82)					
4. I feel I lack proper knowledge and skill to relieve dyspnea.	0.01	**0.97**	−0.01	−0.02	0.92
5. I feel I lack proper knowledge and skill to relieve delirium/agitation.	0.02	**0.93**	−0.01	−0.02	0.86
6. I feel I lack proper knowledge and skill to relieve pain.	−0.02	**0.88**	0.05	0.07	0.84
III. Reassessment of current treatment and nursing care (mean [SD], 7.7 [2.8]; α = 0.82; ICC, 0.70)					
7. I feel it is difficult to communicate with physicians about current examinations for reassessment in the dying phase.	0.05	0.04	**0.95**	−0.15	0.87
8. I feel it is difficult to communicate with physicians about current treatment for reassessment in the dying phase.	0.00	0.00	**0.91**	−0.03	0.82
9. I feel it is difficult to communicate with other nurses about nursing care for reassessment in the dying phase.	−0.08	−0.03	**0.65**	0.32	0.61
IV. Respect for patient and family's dignity before and after death (mean [SD], 8.3 [2.7]; α = 0.74; ICC, 0.81)					
10. I feel it is difficult to make time for sufficient care after death.	−0.12	0.08	−0.07	**0.87**	0.67
11. I feel it is difficult to make time for the family's grief after death.	0.02	−0.08	0.09	**0.82**	0.70
12. I feel it is difficult to improve the family environment in order to relieve the family's physical and psychological fatigue.	0.31	0.02	−0.05	**0.62**	0.66
Total score (mean [SD], 35.1 [8.2]; α = 0.87; ICC, 0.76)					

Abbreviation: ICC, intraclass correlation coefficient.
Cumulative proportion, 79.0%.
Bold data indicates discrimination of other factors.

Convergent Validity and Discriminative Validity

Results for convergent and discriminative validity of the NCD and NDD are shown in Table 4.

Concurrent Validity

Results for concurrent validity of the NCD and NDD are shown in Table 5. Three domains of the NCD were moderately correlated with the MITORI Care Scale, but "respect for the patient and family before and after death" of the NCD was weak.

All domains of the NDD were moderately correlated with the PCDS.

Internal Consistency and Reliability

Results of internal consistency and reliability of the NCD and NDD are shown in Tables 2 and 3.

Known-Groups Validity

Known-groups validity of the NCD and NDD is shown in Table 6. The only domain that did not significantly differ between general wards and palliative care units as assessed by unpaired *t* tests was "respect for the patient

and family's dignity before and after death" on both the NCD and the NDD.

DISCUSSION

The NCD and NDD, developed for use in cancer nursing in Japan, will allow review of nursing care and the difficulties experienced by nurses in caring for dying patients with cancer and their families, both in the form of self-assessments and as evaluation tools for education programs. The authors identified the need for easily administrated scales to assess nursing care as part of a multidimensional survey of end of life. In addition, validity and reliability were verified, and the success of scale development and the final product was thus confirmed.

For factor validity, the authors identified 4 possible domains for each scale. Essential components of end-of-life care are reflected across these domains, especially corresponding to the "good death" concept[3,25,26]: sufficient explanations to families, consideration of the caregiver burden, and the relationship with the doctor(s) and nurse(s).[3,4,7] The characteristics of these domains were "respect for the patient

TABLE 4	Convergent and Discriminative Validity of Nursing Care and Nurse's Difficulty Scales for Dying Patients and Their Families			
Subscales	No. Items per Scale	Convergent Validity (Range of Correlations)[a]	Discriminative Validity (Range of Correlations)[b]	Scaling Success (Rate)[c]
The Nursing Care Scale for Dying Patients and Their Families				
I. Symptom management	3	0.87-0.92	0.17-0.43	9/9 (100%)
II. Reassessment of current treatment and nursing care	3	0.78-0.89	0.28-0.38	9/9 (100%)
III. Explanation to family	3	0.76-0.85	0.21-0.49	9/9 (100%)
IV. Respect for patient and family's dignity before and after death	3	0.78-0.81	0.20-0.52	9/9 (100%)
The Nurse's Difficulty Scale for Dying Patients and Their Families				
I. Symptom management	3	0.92-0.96	0.29-0.44	9/9 (100%)
II. Reassessment of current treatment and nursing care	3	0.77-0.91	0.21-0.41	9/9 (100%)
III. Explanation to family	3	0.90-0.94	0.20-0.52	9/9 (100%)
IV. Respect for patient and family's dignity before and after death	3	0.81-0.82	0.26-0.57	9/9 (100%)

[a]Number shows the correlation coefficient of the score of each item and each domain score excluding the item.
[b]Number shows the correlation coefficient of the score of each item and the domain score to which the item did not belong.
[c]Number of convergent correlations significantly higher than discriminant correlations divided by the total number of correlations.

TABLE 5 Concurrent Validity of Nursing Care and Nurse's Difficulty Scales for Dying Patients and Their Families

Subscales	The MITORI Care Scale			The PCDS		
	Assurance of Palliative Care	Supporting Decision Making With Appropriate Information	Arrangement of Available Care	Alleviating Symptoms	Communication in Multidisciplinary Teams	Communication With the Patient and Family
The Nursing Care scale for Dying Patients and Their Families						
I. Symptom management	0.37[a]	0.25[b]	**0.31**[a]	—	—	—
II. Reassessment of current treatment and nursing care	0.26[b]	0.33[a]	**0.34**[a]	—	—	—
III. Explanation to family	**0.31**[a]	**0.44**[a]	**0.31**[a]	—	—	—
IV. Respect for patient and family's dignity before and after death	0.27[b]	0.17[c]	0.23[b]	—	—	—
The Nurse's Difficulty Scale for Dying Patients and Their Families						
I. Symptom management	—	—	—	**0.62**[a]	0.24[b]	0.41[a]
II. Reassessment of current treatment and nursing care	—	—	—	0.21[b]	**0.41**[a]	0.21[b]
III. Explanation to family	—	—	—	0.43[a]	0.20[b]	**0.49**[a]
IV. Respect for patient and family's dignity before and after death	—	—	—	0.34[a]	0.27[b]	**0.44**[a]

Abbreviation: PCDS, Palliative Care Difficulties Scale.
Figures are Pearson correlation coefficients. Boldfaced numbers indicate attributes assumed to correlate with each item of the MITORI Care Scale and the Palliative Care Difficulties Scale.
[a]$P < .001$.
[b]$P < .01$.
[c]$P < .05$.

and family's dignity before and after death" on each scale. Dying patients have distressing symptoms, such as pain, dyspnea, and delirium,[27] and are subjected to distressing treatment and care[28]; conversely, goals of symptom management during the dying phase include comfort and the accomplishment of patient and family desires for good treatment and care.[29] Therefore, "symptom management"

and "reassessment of current treatment and nursing care" should be considered to be specific domains. Existing instruments in Japan, the MITORI Care Scale[22] and PCDS,[23] contain some items regarding respect for the patient and family members. However, those items do not evaluate nursing care or the nurse's difficulty right before and after death.

TABLE 6	Known-Groups Validity of Nursing Care and Nurse's Difficulty Scales for Dying Patients and Their Families				
	General Wards (n = 378)		Palliative Care Units (n = 23)		
Subscales	Mean	SD	Mean	SD	P
The Nursing Care Scale for Dying Patients and Their Families					
I. Symptom management	77.0	16.9	87.5	17.1	<.01
II. Reassessment of current treatment and nursing care	64.8	18.3	77.1	17.2	<.01
III. Explanation to family	73.5	16.0	88.1	10.2	<.01
IV. Respect for patient and family's dignity before and after death	87.1	12.0	90.4	8.0	.20
Total score	75.6	11.5	85.2	10.4	<.01
The Nurse's Difficulty Scale for Dying Patients and Their Families					
I. Symptom management	67.7	18.8	60.0	15.0	.03
II. Reassessment of current treatment and nursing care	51.7	18.8	42.0	14.3	.02
III. Explanation to family	61.3	19.5	54.8	19.1	.12
IV. Respect for patient and family's dignity before and after death	55.9	17.8	45.8	17.2	.01
Total score	58.9	13.8	50.7	10.8	<.01

Numbers show that means and standard deviations are calculated in terms of a total score of 100. P value shows the result of unpaired t test.

As for concurrent and discriminant validity, "respect for the patient and family before and after death" in the NCD was weakly correlated with the MITORI Care Scale. This means that the NCD might accurately evaluate nursing care focusing on dying patients and their families. As for the NDD, all domains were moderately correlated with the PCDS. This means that nurses caring for patients with cancer and their families might experience difficulty throughout the end of life, not focusing on the dying phase. However, all domains in the NDD specify nursing care for dying patients and their families. Taken overall, the NCD and NDD seem to effectively evaluate nursing care and nurses' difficulties in relation to dying patients with cancer and their families as self-assessments and evaluation tools for education programs and might serve to illuminate the dying phase in a multidimensional survey of end of life.

Known-groups validity was also examined. On the NCD, "respect for the patient and family's dignity before and after death" was not significantly different between the general wards and palliative care units. This was interpreted as indicating that respect for the patient and family's dignity is an important component of nursing care in general.[30-33] As for the NDD, "explanation to the family" was not significantly different between the general wards and palliative care units, indicating that evaluating prognostic implications of dying patients and delivering bad news were a common issue for health care providers.[34,35]

This study had several limitations. First, these scales had a small number of items and thus might not evaluate all aspects of nursing care before and after death in detail. However, items were also selected based on literature review and interview for nurses caring for dying patients and their families. Therefore, these scales might evaluate dying care before and after death. Second, participants were nurses caring for patients with cancer in hospitals. This survey was not administered to nurses who work in homes caring for dying patients with nonmalignant conditions, such as heart failure, chronic obstructive pulmonary disease, and dementia; these issues need examinations in the future.

CONCLUSIONS AND IMPLICATIONS FOR NURSING RESEARCH

This study has developed 2 scales, the NDP and NDD, to evaluate practices and difficulties in nursing care of dying

patients and their families. The NDP and NDD had sufficient validity and reliability according to a psychometric analysis. Therefore, these scales should help nurses conduct informative self-assessments of practices and difficulties in nursing care of the dying patients and their families on a regular basis. In addition, these scales may assist in evaluating the effectiveness and reassessing the contents of education programs focusing on the dying phase, helping nurses improve the quality of nursing care for dying patients and their families.

Acknowledgments

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