

Development of a home-visit nursing scale for helping spousal caregivers of terminal cancer patients develop positive perspectives of their caregiving experiences: A cross-sectional study

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ABSTRACT

Objective

Home visit nurses play a key role in supporting the spouses of terminal cancer patients and encouraging positive perspectives of the caregiving experience. This study aimed to develop a scale to support nurses in self-assessing their practice around this important role.

Design

Cross-sectional questionnaire study.

Setting

The HNS-HSC questionnaire for self-assessment of home visit nursing to spouses was developed based on interviews with spouses and literature reviews.

Participants

Overall, 1,500 home-visit nurses nationwide who had experience in supporting spousal caregivers and their patients in the pre- and post-death periods were approached for participation.

Main outcome measure

Planned exploratory and confirmatory factor analyses were used to assess the underlying dimensions of the HNS-HSC; Cronbach's α was used to determine the reliability. The Japanese version of Frommelt Attitude Toward Care of the Dying Scale Form B (FATCOD-B-J) and Grief Care scale were administered to assess convergent and discriminant validity.

Results

Exploratory and confirmatory factor analyses identified 26 items on five factors: "helping spouses plan their futures," "helping caregivers alleviate any regrets regarding their care," "understanding the bond between a couple," "providing support for anticipatory grief," and "addressing spousal caregivers' emotions after their spouses' deaths." The final model showed acceptable goodness-of-fit indices. The Cronbach's α for the entire scale was 0.949 and exceeded 0.822 for each factor. The correlation coefficient with the FATCOD-B-J, which served as an external validation, was 0.35. The correlation coefficients for the three grief care scales were 0.64, 0.45, and 0.72 respectively.

Conclusions

This scale is a reliable and valid tool for visiting nurses to self-assess their knowledge, skills and practice around helping spousal caregivers. By using this scale, it is expected to change nursing

practice in pursuit of improving quality of life of spouses.

KEYWORDS: Home-visit nurses; spousal caregivers; terminal cancer; HNS-HSC questionnaire

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This is the first quantitative study for self-assessment of visiting nurses' practices for terminal cancer patients' spousal caregivers.
- This scale was tested with a total sample of 1,500 visiting nurses practicing Japanese palliative care.
- We examined the reliability and validity of a questionnaire providing a quantitative method for nurses to self-evaluate assisting spousal caregivers of terminal cancer patients to adopt positive perspectives of their caregiving experiences.
- Scale items were selected from a limited number of survivors and literature reviews, so they may not cover all cancer patients and their families; thus, it is necessary to use this scale carefully.
- This scale was tested only by visiting nurses providing palliative care in Japan, so further validation in other countries in the future is necessary.

INTRODUCTION

The population of Japan is aging rapidly, and this is expected to lead to an increase in the number of cancer patients.[1] Consequently, securing locations for such patients to recuperate is an urgent issue. In addition, 47% of Japanese citizens answered that they would like to be treated at home if they were diagnosed with terminal cancer.[2] Based on these facts, the improvement of home palliative care services is indispensable for terminal cancer patients. Japan's Ministry of Health, Labour and Welfare [3] is promoting palliative care and end-of-life medical care in the home by creating incentives for home deaths through medical insurance and long-term care insurance. However, in Japan, the death rate at home for cancer patients is still as low as 11%,[4] and it is assumed that the support system for terminal cancer patients and their families at home is insufficient.

Among families caring for end-stage cancer patients, 72% had a high risk of anxiety, and over 60% had a risk of distress and depression. [5] Additionally, in a domestic study, 79% of such families experienced sleeplessness and 57% experienced a depressed mood. For this reason, it has been reported that family caregivers feel helpless and guilty because they have an inability to do anything for the patient and cannot accept the rapid deterioration of the patient's condition. [6] It has also been reported that the high AG score, which measures anticipatory grief, is associated with high levels of post-loss avoidance [7] and complicated grief [8-9] in caregiving families of end-stage cancer patients. More than 50% of families of cancer patients who have received hospice home care have clinically significant depressive symptoms one year after bereavement.[10] In particular, the death of a spouse has been reported to cause depressive symptoms.[11-12]

Apart from these negative psychological states, the existence of positive psychological states has been suggested. In the West, bereaved coping strategies include "continuous bonds," [13-14] "meaning," [15-16] and "emotional disclosure." [17] However, due to differences in bereavement-related religious/cultural factors in each country, there is no consensus on which coping strategies will contribute to the survivor's psychological state. In Japan, it is believed that the patient's soul lives forever and gives encouragement to the bereaved family.[18] Examining family caregivers, it has become clear that 60 to 70% of caregivers have a positive perception of the caregiving experience.[19-20] Lee et al.[21] report that the caregiving effort for cancer patients and the experience of spending the last hours with the patient is important for the bereaved family caregiver. Some previous studies have shown that bereaved families who cared for cancer patients can address their grief by adopting a positive outlook of their experience regarding caregiving for their loved one up to their death.[22-24] Thus, enhancing caregivers' positive feelings about the care they provide is an important element of grief support.

Several previous studies have examined the palliative care needs of family caregivers and home-care nurses, as well as the nursing practices and attitudes for effective palliative care.[25-30] Home palliative care services in Japan provide a wide range of support, including symptom management, patient and family mental care, and coordination with family and people involved in care.[31] Additionally, bereavement care practiced by nurses is structured.[29] However, in Japan, grief care

after bereavement is not implemented properly because there is no institutional remuneration and the care is left up to each visiting nursing station. In fact, about 33-49% of visiting nurses felt difficulty communicating with terminal patients and their families. [32] This may be due to a lack of palliative care experience or expertise. Healthcare professionals also mentioned insufficient time and lack of knowledge of bereaved care.[33] According to previous research,[34] lack of personal achievement is pointed out as one of the factors associated with burnout. If visiting nurses practicing palliative care have difficulty supporting their patients and their families and are unable to cope with them, they seem more prone to develop burnout.

Therefore, the development of a scale for nurses to self-evaluate home-visit nursing that affirms the spousal caregiver is meaningful for both patients, their families, and nurses. In this study, we aimed to develop and validate a home-visit nursing scale (the “Home Nursing Scale to Help Spousal Caregivers” [HNS-HSC]) that can guide nurses in helping spousal caregivers of terminal cancer patients adopt positive perspectives of their caregiving experiences.

METHODS

The HNS-HSC was developed by: 1) creating an item pool, 2) evaluating the content and face validity to generate the initial scale, 3) sending the initial scale to a sample of home-visit nurses, 4) conducting item analysis on the questionnaire results, 5) conducting factor analyses, 6) determining the scale’s reliability, and 7) determining the scale’s validity.

Developing the initial scale

We previously conducted interviews from August to November 2013 to explore the caregiving experience of 13 spouses whose patient had died at home in the previous 6 to 24 months.[22] The interviews were conducted within this time frame after the bereavement to ensure that the most intense period of grief had passed and to allow the caregiver to reflect on the time of care.[35] We subsequently conducted a second, semi-structured interview with five spouses who had reported a positive view of their first caring experience two years after the first interview. The interviewer raised topics such as (1) what the research participants felt when providing care to the patient, and (2) their awareness of the significance and value of that experience when reflecting upon their home caregiving. We then performed qualitative content analysis using interview data, supervised by two researchers in regional and home nursing science. Particular focus was placed on elements of nursing support that could enhance spousal caregivers’ positive feelings when providing caregiving. Based on the types of support we identified, as well as others identified through a literature review, [36-46] we generated a scale of 115 items, which were classified into three time periods: from the beginning of home care to the end of the patient’s stable condition, the dying period, and the post-death period. The content and face validity of the 115 items were then checked by six home hospice care experts and two researchers in home nursing.

The content and face validity of the 115item pool were confirmed by six home hospice care experts

for the purpose of selecting questions, and similar items were summarized. At that time, items judged inappropriate by more than two experts, items spanning multiple factors, and items that were ambiguous in terms of expression were corrected or deleted. Afterward, we heard opinions from two home nursing researchers for the purpose of examining content validity. Following this process, we preliminarily selected 38 items across nine domains to comprise the initial HNS-HSC. This process is displayed in Online Supplementary Appendix 1. The nine domains across the three time periods were as follows.

A) Support for home care while the patient is in stable condition:

- 1) support in daily life, based on a consciousness that the couple's time together is ending,
- 2) promotion of nursing care that includes family members,
- 3) support of end-of-life decision-making,
- 4) support for promoting positive emotions concerning patient's caregiving,
- 5) providing information regarding signs that the patient's death is near.

B) Support for the dying period:

- 6) support during the dying period to help ensure the patient has a peaceful death.

C) Support for the post-death period:

- 7) listening to the bereaved caregiver's expression of feelings and perceptions regarding experiencing the death,
- 8) helping the bereaved caregiver develop relationships with other people,
- 9) helping the bereaved caregiver plan his/her future.

Validating the initial HNS-HSC

The initial 38-item HNS-HSC was sent to a sample of home-visit nurses across Japan as part of a questionnaire.

Participants

The number of nurses used to validate this tool was calculated based on an item to participant ratio of 1:5 to 1:10. [47-48] The sample size was determined with reference to the collection rate of mail surveys for visiting nurses in Japan. [49-50] We targeted 1,500 home-visit nurses from 500 randomly selected visiting-nursing stations, which were randomly selected from the 7,189 stations listed in the nursing care insurance system information database. All stations supported 24-hour visits, care for severely ill patients, and at-home death. All targeted nurses had experience in providing pre- and post-death nursing support for spousal caregivers of terminal cancer patients who died at home.

Procedure

We sent a research request letter and copies of the questionnaire to the manager of each of the 500 selected nursing stations, asking them to distribute the questionnaire to three of the station's visiting nurses who satisfied the criteria. We asked the nurses to voluntarily answer the questionnaire and then

mail it to the researchers. The survey was conducted between March and September 2018.

Measures

The basic data investigated in the questionnaire on participant's attributes and visiting care-related variables are shown in Table 1. We then asked participants to rate how often they practiced each of the 38 items in the initial HNS-HSC by using a Likert-type scale ranging from 1 ("I do not practice at all") to 5 ("I definitely practice"). Additionally, (1) the Japanese version of the Frommelt Attitude Toward Care of the Dying Scale Form B (FAT-COD-Form B-J), [51] (2) the grief care from the beginning of home care to the terminal period (GCBT), (3) the grief care at the patient's deathbed (GCDB), and (4) the grief care after the patient's death (GCAD)[29] were used. These scales are displayed in Online Supplementary Appendix 2. The FAT-COD-Form B-J is based on Frommelt's original FATCOD, [26-27] having been translated into Japanese and validated by Nakai et al. [51] Following established conventions, [51] we presented two factors from the FATCOD-Form B-J scale: "positive attitude toward caring for the dying patient," and "perception of patient- and family-centered care." Cronbach's α coefficient on this scale was 0.85. The Grief Care Provided by Nurses comprises three scales: (1) GCBT, (2) GCDB, and (3) GCAD. [29] The GCBT scale has three subscales: (1) promotion of acceptance of death and explanation of the death attendance system, (2) support of continuation of the family's care with respect to their intent, and (3) sympathy for the family's feelings. The GCDB scale contains one factor with five items. The GCAD scale has three subscales: (1) sharing and support of the family's experience of the patient's death, (2) psychosocial support for rebuilding life, and (3) grasping of state for resuming social activities. The Cronbach's α coefficient of each scale was 0.93, 0.66, and 0.93, respectively. Although the Cronbach's α coefficient of GCDB was low, the number of items of this scale was five. If the number of items is less than 10 items, Cronbach's $\alpha > 0.50$ is considered acceptable, [52] indicating internal consistency.

Ethical considerations

A request document was attached to each questionnaire, stating: "For research purposes, questionnaires should remain unsigned; return of a completed questionnaire signals your consent to participate and agreement to publication of the results." This research was conducted with the approval of the Epidemiological Research Ethics Review Committee of Hiroshima University (No.E-1127).

Patient and public involvement

Key stakeholders (home-visit nurses) were involved in this study as described above. Patients and the general public were not involved.

Statistical analysis

Two separate factor analyses were performed. Total samples ($n=453$) were randomly divided into two

halves for cross validation: group 1 ($n=226$) for performing exploratory factor analysis and group 2 ($n = 227$) for performing confirmatory factor analysis. To examine the reliability and validity of the initial 38-item HNS-HSC, we used descriptive statistics. After checking the mean Likert-scale score, standard deviation (SD), missing value frequency, kurtosis and skewness of each item, and ceiling and floor effects ($\text{mean} \pm \text{SD}$) were confirmed, and item-total correlation (I-T) was calculated ($\gamma < 0.30$). We assumed that the elements of home-visiting nursing who contribute to the positive feelings of spousal caregivers are related, so factor analysis was performed using the least squares method and promax rotation. A factor loading of 0.40 was taken as the cut-off value for item selection. The number of factors was determined by the initial solution, using eigenvalues of > 1.0 and a scree plot. The fitness of the model obtained through exploratory factor analysis was subsequently confirmed with confirmatory factor analysis. To determine the fitness of the model, we used the chi-square test, comparative fit index (CFI), root mean square error of approximation (RMSEA), and the Tucker-Lewis index (TLI). CFI and TLI values of 0.90 and above indicate that the model is acceptable. [53] Meanwhile, a RMSEA of < 0.05 is considered to represent a good model fit, 0.05 to 0.08 an acceptable fit. [54] To determine reliability, Cronbach's α coefficient was calculated, with values of 0.7 or more indicating good internal consistency.[55] In a previous study,[56] there was no correlation between nurse attitudes towards palliative care and terminal care experience. Therefore, to examine the discriminant validity, it was assumed that there was almost no correlation between the HNS-HSC, which evaluates nursing practice, and FATCOD-B-J, which measures nurses' terminal care attitude. GCBT, GCDB, and GCAD are scales used to evaluate the frequency of grief care practiced by visiting nurses for family caregivers. Therefore, convergent validity was verified on the assumption that there was a correlation with the HNS-HSC. To determine this validity, we used the Spearman correlation coefficient because the data did not follow the normal distribution. For all statistical analyses, IBM SPSS Statistics 21.0 and IBM Amos 24.0 were used.

RESULTS

Respondents' characteristics

From the research request sent to 500 facilities, 604 visiting nurses from 255 facilities consented to participate. We consequently received 529 surveys (response rate: 87.6%). After the exclusion of questionnaires with missing scale responses, 453 participants (valid response rate: 85.6%) were included in the study sample for further analysis. The attributes of the participants are described below (Table 1).

Table 1: Demographic characteristics of participants

Characteristics		<i>n</i>	%
Gender	Female	436	96.2
	Male	17	3.8

Age	46.57 (8.29)*		
Position	Staff nurse	285	62.9
	Chief	37	8.2
	Administrator	122	26.9
	Other	6	1.3
	Missing data	3	0.7
Number of years of experience as home-visit nurse	1-5	186	41.1
	6-10	103	22.7
	11-15	74	16.3
	15-20	60	13.2
	>20	30	6.6
Number of cases involving home hospice care	1-2	37	8.2
	3-5	75	16.6
	6-9	62	13.7
	>9	271	59.8
	Missing data	8	1.7
Number of visits after the patient's death	Once	309	68.2
	2-3 times	58	12.8
	>3	21	4.6
	Others	12	2.6
	Missing data	53	11.7
Visiting time after patient's death(Multiple answers possible)	< 2 weeks	115	25.4
	2 weeks to less than 1 month	236	52.1
	One month to less than six months	158	34.9
	6 months to less than 12 months	18	4

	>12months	13	2.9
Learning Experiences of home-based palliative care	Yes	391	86.3
	No	62	13.7
Degree of motivation for home-based palliative care	Yes	379	83.7
	A little	65	14.3
	Not much	5	1.1
	No	4	0.9

*Mean (SD).

Factor analysis and the naming of factors

For each question item, descriptive statistics, ceiling and floor effects were calculated (Table 2). The score distribution of these items is displayed in Online Supplementary Appendix 3. Items showing a ceiling effect were deleted after consulting the histogram. There were no items with an I-T correlation of 0.30 or less (Table 2). An exploratory factor analysis was performed on the remaining 30 items.

Table 2: Item analysis of the initial home nursing scale to help spousal caregivers (Initial HNS-HSC)

n = 453

Item		Mean		Kurtosis	Skewness	Floor	Ceiling	Item-total	exclusion
		Likert	SD			effect	effect	correlation	
		score				M-SD	M+SD	§ (<i>r</i>)	
1	I understand the couple's daily relationship.	4.20	0.76	0.02	-0.63	3.47	4.96	0.591**	
2	I understand the spouse's feelings for his/her patient.	4.22	0.72	0.11	-0.65	3.50	4.94	0.616**	
3	Since the patient and spouse are conscious of the patient's impending death, I confirm that neither is feeling an undue burden as a result.	4.19	0.76	0.35	-0.71	3.44	4.94	0.671**	
4	I confirm that the spouse and patient can continue to perform their usual lifestyle habits.	3.82	0.86	-0.31	-0.33	2.97	4.67	0.649**	
5	I encourage the spouse and the patient to think about how they would like to spend the terminal part of the patient's life together.	4.00	0.82	-0.57	-0.38	3.16	4.80	0.637**	
6	I coordinate their intentions on how the spouse and relatives should spend their remaining time with the terminal patient.	4.15	0.85	-0.19	-0.74	3.31	5.01	0.579**	×

7	I discuss with the spouse and relatives whether they can fulfill the patient's wishes.	3.39	1.07	-0.80	-0.12	2.31	4.46	0.593**	
8	I check with the spouse whether the cancer patient has experienced any physical or mental changes.	4.33	0.74	-0.03	-0.82	3.59	5.07	0.574**	×
9	I confirm that the spouse is continuing to perform their usual roles in the family and in society.	3.72	0.90	-0.50	-0.27	2.83	4.62	0.609**	
10	I inform the spouse that spousal caregiving is desired by the patient.	4.07	0.86	-0.08	-0.65	3.21	4.92	0.632**	
11	I inform the spouse that unreasonable caregiving will cause fatigue on the part of both the spouse and the patient.	4.06	0.90	-0.40	-0.62	3.15	4.94	0.596**	
12	I urge the spousal caregiver and the other relatives to adjust their caregiving.	3.93	0.89	0.02	-0.61	3.07	4.82	0.683**	
13	I suggest a method of care that prioritizes the spouse's life.	4.18	0.78	0.53	-0.75	3.41	4.93	0.606**	
14	I create opportunities for the spouse to express their feelings regarding changes in the patient's condition.	4.01	0.85	0.58	-0.74	3.16	4.84	0.650**	
15	I resolve the spouse's anxieties and concerns regarding the patient's death.	4.19	0.73	-0.17	-0.54	3.46	4.91	0.663**	
16	I share various emotions with the spouse, such as the spouse's feelings of sorrow, conflict, satisfaction, and joy.	4.20	0.75	0.23	-0.67	3.43	4.94	0.636**	
17	I think about what the spouse can do to support the patient.	3.96	0.83	-0.14	-0.50	3.12	4.79	0.667**	
18	I confirm the spouse's opinion regarding cessation of the patient's medical treatment.	3.82	0.95	-0.10	-0.56	2.87	4.77	0.683**	
19	I inform the patient's doctor of the patient's and his/her relatives' intentions regarding the patient's death.	4.28	0.85	0.46	-1.03	3.44	5.14	0.656**	×
20	I arrange for the spouse and doctor to discuss the patient's present condition and the patient's final days.	3.95	0.95	-0.48	-0.52	2.99	4.89	0.671**	
21	I provide the spouse with an explanation each time the condition of the patient changes.	4.28	0.75	0.08	-0.78	3.52	5.02	0.629**	×
22	I inform the spouse that anticipatory grief is a natural emotion.	3.89	1.02	-0.24	-0.67	2.86	4.90	.696**	

23	I ensure that the spouse talks about the patient's death and the post-death period.	4.06	0.90	0.60	-0.89	3.17	4.94	0.664**	
24	I encourage the spouse to consider things they can do for the patient up to the point just before the patient's death.	3.96	0.93	-0.03	-0.66	3.02	4.88	0.731**	
25	At patient's death, I advise the spouse and the relatives to have no regrets regarding the patient's passing.	4.20	0.88	0.84	-1.04	3.32	5.06	0.699**	×
26	I base the times of my home visits on the spouse's status during the pre- and post-death periods.	3.51	1.20	-0.79	-0.41	2.26	4.69	0.626**	
27	I carefully listen to the spouse, so that he/she can release his/her emotions.	3.98	1.00	0.45	-0.92	2.95	4.95	0.683**	
28	I share memories of the deceased patient with the spouse.	4.04	0.98	0.58	-0.97	3.02	5.01	0.723**	×
29	I listen to the spouse's thoughts regarding caregiving for terminal cancer patients.	4.13	0.94	1.17	-1.13	3.16	5.05	0.745**	×
30	I commend the spouse for helping the deceased patient die as he/she wished.	4.26	0.91	1.95	-1.40	3.34	5.16	0.705**	×
31	I help the spouse evaluate their emotions.	3.72	1.01	-0.18	-0.59	2.69	4.71	0.752**	
32	I confirm that the spouse maintains a connection with relatives who were with the spouse during the patient's terminal days.	3.36	1.13	-0.57	-0.35	2.22	4.47	0.737**	
33	I confirm that the spouse continues to interact with his/her community.	3.28	1.09	-0.54	-0.23	2.17	4.35	0.709**	
34	I provide information on social resources, such as grief-support groups, if necessary.	2.47	1.13	-0.51	0.44	1.31	3.56	0.478**	
35	I confirm the mental and physical status of the spouse during the grief process.	3.28	1.12	-0.68	-0.21	2.14	4.39	0.681**	
36	I explain to the spouse the general mental and physical reactions that occur during the grieving process.	3.01	1.15	-0.80	0.00	1.85	4.14	0.692**	
37	I check the spouse's perception of life after the patient's death.	3.06	1.10	-0.70	-0.02	1.94	4.16	0.675**	
38	I assess the necessity of continuing support.	2.86	1.21	-0.87	0.15	1.63	4.07	0.599**	

Mean Likert-scale scores range from 1= "I do not practice at all" to 5= "I definitely practice".

§Correlation coefficient between the item and the total score of all the items (but with exception of the item) : less than 0.3.

** $p < 0.01$.

×Ceiling effect were excluded.

Four items that had factor loadings of <0.40 were deleted, leaving 26 items loaded across five factors as displayed in Table 3. This 26-item scale was adopted as the final version of the HNS-HSC.

Table 3: Factor analysis of the 26 items of the HNS-HSC

						<i>n</i> = 453
	Factor I	Factor II	Factor III	Factor IV	Factor V	
Cronbach's α	0.935	0.892	0.860	0.851	0.822	
Item/Factor	Helping spouses plan their futures	Helping caregivers alleviate any regrets regarding their care	Understanding the bond between a couple	Providing support for anticipatory grief	Addressing the spousal caregiver's emotions after their spouse's death	
36	0.944	-0.028	0.051	-0.041	-0.042	
37	0.913	-0.100	0.075	-0.031	0.049	
34	0.910	-0.076	-0.041	0.098	-0.233	
38	0.902	-0.034	-0.066	-0.040	-0.011	
35	0.719	0.014	-0.010	-0.075	0.236	
32	0.586	0.056	-0.045	0.090	0.275	
33	0.539	0.132	-0.098	-0.025	0.360	
17	0.051	0.906	0.003	-0.136	-0.063	
14	-0.137	0.780	-0.150	0.146	0.064	
15	-0.092	0.752	0.093	0.037	0.011	
16	-0.054	0.709	0.126	-0.252	0.217	
13	-0.128	0.660	-0.079	0.099	0.079	
18	0.072	0.653	0.081	0.113	-0.149	
20	0.125	0.487	-0.062	0.272	-0.045	
12	0.063	0.438	0.207	0.087	-0.045	
9	0.203	0.435	0.260	-0.043	-0.192	
2	-0.160	-0.002	0.911	-0.030	0.117	
1	-0.017	-0.099	0.758	0.076	0.080	
3	-0.033	0.028	0.757	0.042	0.065	
4	0.202	0.087	0.630	0.034	-0.154	
23	-0.084	-0.089	0.034	0.870	0.136	
24	0.069	0.094	0.040	0.756	-0.043	
22	0.029	0.087	0.070	0.658	0.015	
27	-0.025	-0.077	0.065	0.047	0.887	

31	0.205	0.124	-0.028	0.099	0.596
26	0.200	0.013	0.096	0.023	0.497
Factor correlation coefficients (<i>r</i>)					
Factor I	1.00				
Factor II	0.562	1.00			
Factor III	0.442	0.672	1.00		
Factor IV	0.533	0.659	0.569	1.00	
Factor V	0.595	0.507	0.367	0.464	1.00

Factor I, “helping spouses plan their futures,” comprised seven items, focusing on assessing the spousal caregiver’s physical and mental state after death and how likely the caregiver is to proceed with his/her own life after the patient’s death. Factor II, “helping caregivers alleviate any regrets regarding their care,” comprised nine items regarding both physical and mental support for spousal caregivers, which encourage spouses and patients to spend their final days satisfactorily. Factor III, “understanding the bond between a couple,” comprised four items, each concerned with ensuring that the couple could spend valuable time together as married partners (rather than as a patient and caregiver) even though the patient is close to death. Factor IV, “providing support for anticipatory grief,” included three items that promote helping the spousal caregiver address any thoughts and fears concerning the imminent death of the patient. Finally, Factor V, “addressing the spousal caregiver’s emotions after their spouse’s death,” included three items that help the spousal caregiver review the care he/she provided and the patient’s feelings. Among the factors, II, III, and IV concern support before the cancer patient’s death, while factors I and V concern support after the patient’s death. The correlation between these five factors ranged from 0.37 to 0.67. In addition, the correlations between factors II, III, and IV and factors I and V were 0.66 ($p < 0.01$).

Confirmatory factor analysis

Confirmatory factor analysis was used to test the goodness of fit of the five factor structures ($\chi^2 = 679.628$, $df = 289$, $CFI = 0.917$, $TLI = 0.907$, $RMSEA = 0.077$) [see Figure 1]. These results indicated that the goodness of fit of the 26-item scale was statistically acceptable.

Reliability

The Cronbach’s α coefficient of the overall HNS-HSC was 0.949, and it was 0.935, 0.892, 0.860, 0.851, 0.822 for factors I to V, respectively. Thus, the internal consistency was confirmed.

Convergent and discriminant validity

Regarding the relation between the total scores of the HNS-HSC factors and of FAT-COD-Form B-J, there was a low correlation, between 0.33 and 0.39 for all factors except factor I, which was 0.19. Regarding the relation between the total scores of the HNS-HSC factors and of the three scales of

grief care provided by nurses, we found correlations of $\rho = 0.64$ for the GCBT, 0.45 for the GCDB, and 0.72 for the GCAD (Table 4).

Table 4: Convergent and discriminant validity of the HNS-HSC

	HNS – HSC					
	Total score	Factor I: Plan future	Factor II: Reduce regret	Factor III: Couple bond	Factor IV: Anticipatory grief	Factor V: Spouse's feelings after death
FAT-COD: Attitudes toward care of the dying	.350**	.185**	.331**	.331**	.386**	.326**
GCBT: Grief care from the beginning of home care to the terminal period	.636**	.437**	.627**	.504**	.601**	.546**
GCDB: Grief care at the patient's deathbed	.452**	.311**	.416**	.403**	.469**	.381**
GCAD: Grief care after the patient's death	.719**	.733**	.519**	.463**	.568**	.641**

** $p < 0.01$.

DISCUSSION

In developing the HNS-HSC, we have created a home-visit nursing scale, for use in the periods before and after cancer patient's death to help nurses encourage positive perspectives of caregiving experiences in spousal caregivers. The HNS-HSC scale comprises 26 items across five factors, organized into a consistent timeline from the home-care period to post-death periods.

How the scale will help caregivers

This scale is intended to improve how nurses support spousal cancer caregivers before, during, and after the patient's end-of-life care by reinforcing the following five nursing behaviors.

First, the "helping spouses plan their futures" domain includes helping spouses to observe their way of life after bereavement with the patient. Confirming how well family caregivers manage after bereavement is an important role in bereavement care. [57] This domain highlighted the importance of helping spouses to be aware of their own life after the patient's death, which can have a positive impact on the work of grief. Second, the items selected in the "helping caregivers alleviate any regrets regarding their care" domain included support for the patient's ability to live and hope. This domain highlighted the importance of helping caregivers be satisfied with their spouse's care, which has been shown to lead to a positive understanding of spousal care after bereavement.[23] It is expected that with the proper nursing support, the spouse will be satisfied with care and can positively assimilate the care experience after bereavement. Third, the items selected in the "understanding the bond

between a couple” domain included support focused on marital relationships. This domain highlighted the importance of encouraging patients and spouses to have a fulfilling end of life in terms of their relationship with each other. In a domestic study, spouses were reassured by “continuing bonds” that helped them recall memories and have inner conversations with their dead loved ones. [58] With this support, the couples’ ties can be connected from before and after bereavement, and the spouse is less prone to develop complicated grief. Fourth, the “providing support for anticipatory grief” domain includes helping spouses accept the death of patients. Low preparedness for the death of cancer patients’ families is associated with complicated grief [59-60] and further depressive symptoms.[61] This domain emphasizes helping spouses share their feelings with nurses and prepare for the patient’s death. Fifth, the “addressing the spousal caregiver’s emotions after their spouse’s death” domain includes helping the spouse sort out the emotional swings caused by bereavement. It is beneficial for the bereaved family caregivers to review and reflect on the caregiving experience.[62] This domain stressed the importance of the spouse’s mental attitude after bereavement. We believe this domain is an important support for positively understanding the spouse’s caregiving experience. Thus, these components should all be essential elements of visiting nurses’ approaches in the pre- and post-death periods to enhance the positive emotions of spousal caregivers of terminal patients.

Examination of convergent and discriminant validity of the HNS-HSC

Several correlations between the HNS-HSC and existing measures validated evidence of convergent and discriminant validity. As expected, the HNS-HSC scale appeared to correlate with GCBT, GCDB, and GCAD. However, when checked by factor, GCDB and factors I and V of the HNS-HSC showed a low correlation. This result seems to be influenced by the fact that GCDB is specialized support for the patient’s near-death period, and is not directly related to post-death support. Moreover, the FATCOD-B-J and HNS-HSC also showed a low correlation. In particular, there was almost no correlation with factor I of the HNS-HSC. Presumably, this result is because the support for a future life and the nurse’s thoughts and feelings about terminal care are different structural concepts. Thus, it seems that the assumption that almost no correlation would be found between the HNS-HSC and FATCOD-B-J, and correlations between GCBT, GCDB, GCAD, and HNS-HSC would be found is confirmed, supporting the validity of convergent/discriminant of the scale.

Practical implications

Utilizing the HNS-HSC is expected to promote the support that nurses lack in their own practice, increase these customs, and raise awareness. Unmet needs of family caregivers such as caregiving and family/social support [5,63-64] have been shown to be related to their psychological morbidity. [5] The HNS-HSC focuses on multiple aspects, and it is expected that the use of this scale will strengthen the fulfillment of spouses’ needs pre-and post-death and improve their quality of life. Additionally, the HNS-HSC is expected to serve as an inventory of training needs for nurses. Further, the HNS-HSC will allow visiting nurses who are not confident in home palliative care to reduce the

difficulty of care and practice with confidence. Furthermore, since nurses have limited time in their home visits, we believe that the HNS-HSC can be partially used to improve nursing support that is determined to be insufficient for spouses.

LIMITATIONS AND FUTURE ISSUES

This study has several limitations. First, the questionnaire collection rate for this study was approximately 35%. This result was slightly lower than a cross-sectional mail survey of domestic visiting nurses. Low response rates can cause bias in survey results, so it is necessary to test the no response effect to maximize the validity of future research. Second, the study selected items based on interviews with a limited number of survivors and literature reviews. However, relationships and communication styles between families are different, so it is not possible to assume that all spouses of cancer patients are represented by the selected items. Third, about 41% of participants in this study had less than five years of visiting nurse experience (Table 1). Similarly to Nonogaki et al. study [65], almost a half of the participants in this study had less than five years of visiting nurse experience, which may be related to the rapid increase in the number of visiting nurses[66] that has accompanied Japan's remarkable aging rate. Further, the percentage of male participants in this study was 3.8% (Table 1), similar to studies of Japanese visiting nurses. [29, 65] These numbers are influenced by the Japanese social/cultural background. Therefore, confirming the HNS-HSC's usefulness in other countries in the future will be useful for international discussions. Fourth, item analysis showed lower average values for items 34 and 38 than other items (Table 2). This study found that many participants visited the bereaved family's home once within six months after bereavement (Table 1). However, the appearance of general grief symptoms peaks for six months after bereavement.[35] Therefore, we speculate that there is a limit to the social and continuous nursing practice that can be accomplished during one visit during this period; thus, we believe that the average score of these two items is low. Fifth, as a result of the item analysis of this study, many items with high average scores were found. Previous study has shown that nurse learning opportunities and motivation have improved nursing practice skills. [67] We surmise that the participants in this study achieved high HNS-HSC scores because over 80% of the participants already had experience of home palliative care learning and motivation (Table 1).

CONCLUSION

The HNS-HSC has 26 items with five domains. The scale was shown to have reliability and relevance, suggesting that the HNS-HSC may be significant in improving the practical ability of visiting nurses. Additionally, it may have a positive impact on the grieving process of a spouse who cares for a terminal cancer patient at home.

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AUTHOR CONTRIBUTIONS

MK and HN contributed to the development of the concept and design of this research. HN was responsible for obtaining the approval of the ethics review committee. MK oversaw data collection and analysis, and was in charge of writing a draft of the manuscript. HN supervised the research and manuscript modification. All authors have read and approved the final manuscript.

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DISCLAIMER

No funding donors played a role in collecting and analyzing data, making publication decisions, or writing the manuscript.

COMPETING INTERESTS

None declared.

PATIENT CONSENT

Not required.

ETHICS APPROVAL

This study was approved by the Ethical Committee for Epidemiology of Hiroshima University (E-1127). All participants provided their written informed consent. To ensure participant anonymity, the questionnaire contained no identifying details.

PROVENANCE AND PEER REVIEW

Not commissioned; externally peer reviewed.

DATA-SHARING STATEMENT

No additional data available.

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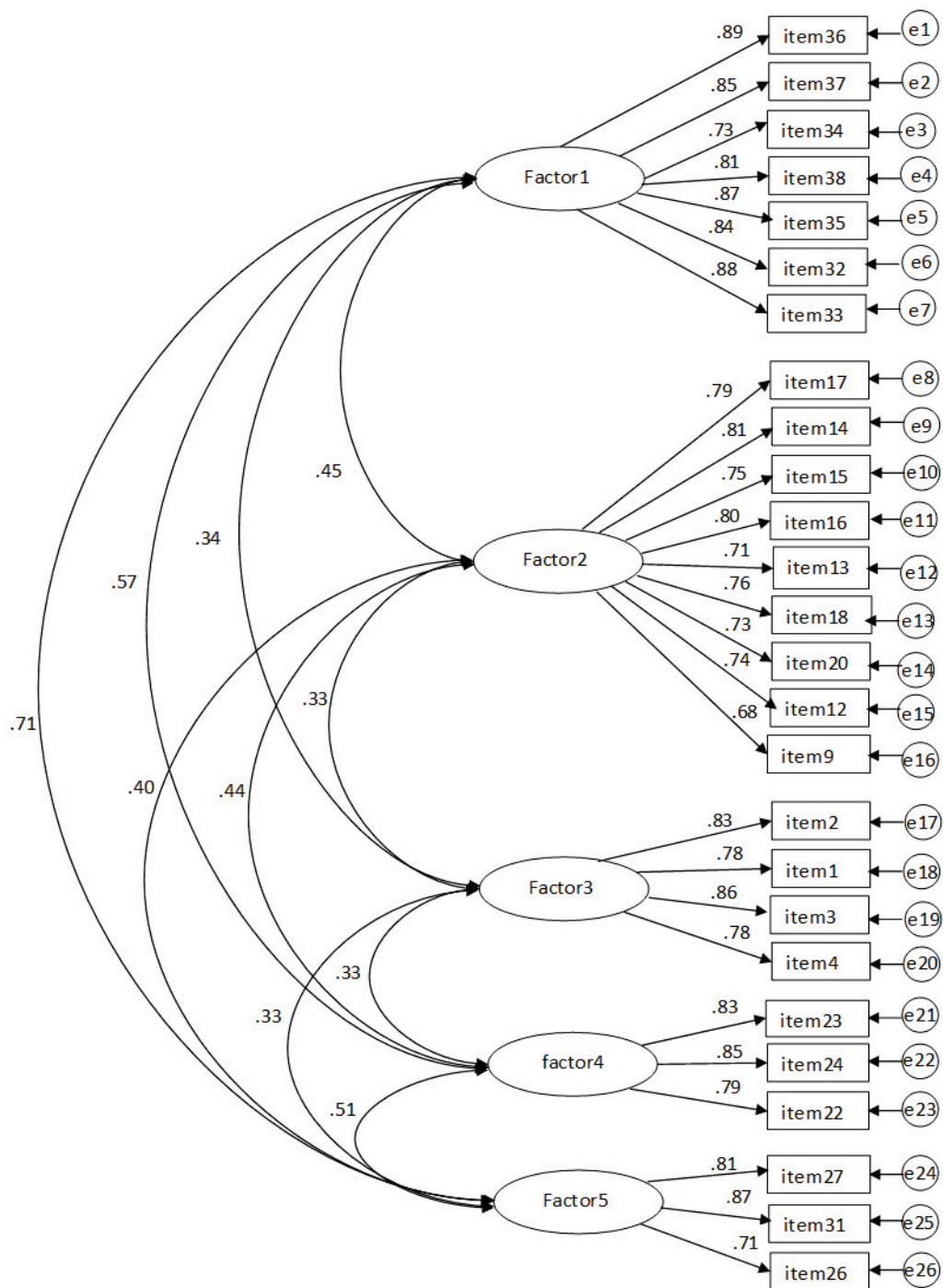
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FIGURE LEGENDS

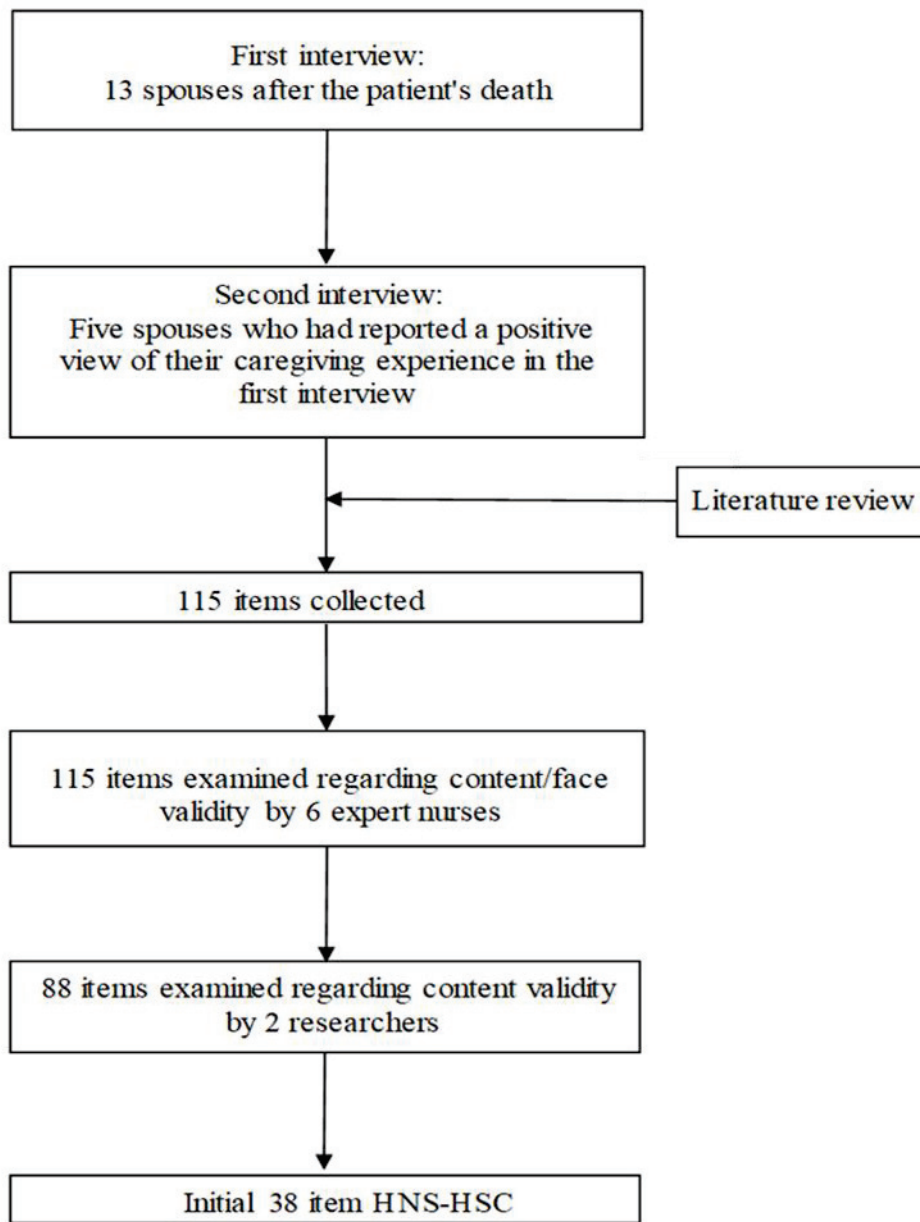
Figure 1: Confirmatory factor analysis for the HNS-HSC, showing the Spearman's rank correlation coefficients between each item and factor.

Item numbers refer to those of the initial, 38-item scale, e-numbers refer to the new order of the items in the final, 26-item scale.



$\chi^2=679.63$, CFI=0.917, TLI=0.907, RMSEA=0.077, $p<0.001$

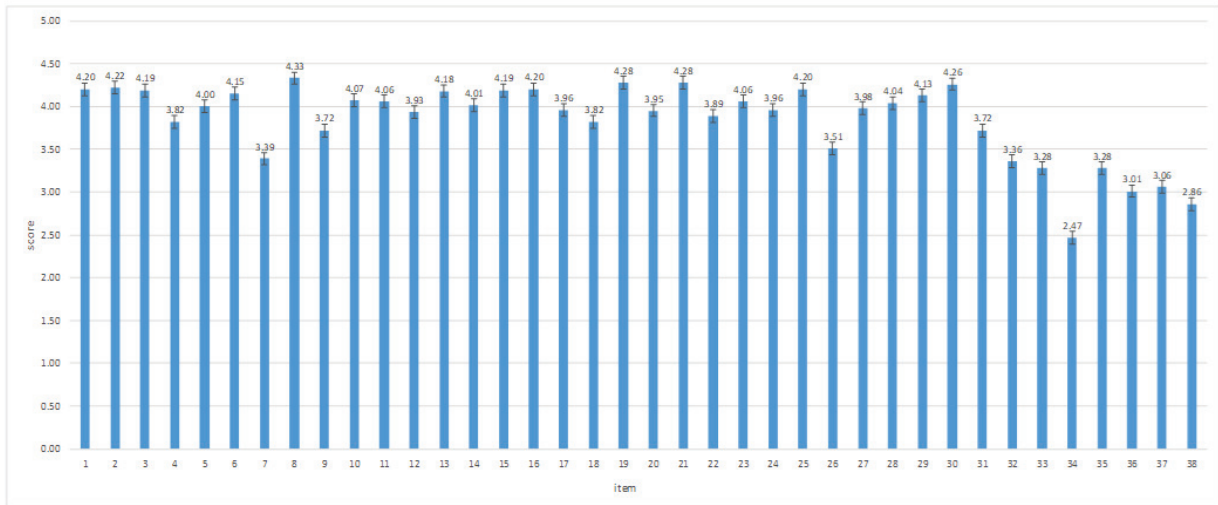
Figure1 .Confirmatory factor analysis for the home-visit nursing scale



Appendix 1: Initial scale development process

Appendix 2: Existing scales for examining criterion-related validity

Scale	Factor
Japanese version of the Frommelt Attitude Toward Care of the Dying Scale Form B (FAT-COD-Form B-J)	Positive attitude toward caring for the dying patient (16 items)
	Perception of patient and family-centered care (13 items)
Grief care from the beginning of home care to the terminal period (GCBT)	Promotion of acceptance of death and explanation of the death attendance system (6 items)
	Support of continuation of the family's care with respect to their intent (7 items)
	Sympathy for the family's feelings (3 items)
Grief care at the patient's deathbed (GCDB)	Grief care at the patient's deathbed (5 items)
Grief care after the patient's death (GCAD)	Sharing and support of the family's experience of the patient's death (9 items)
	Psychosocial support for rebuilding life (9 items)
	Grasping of state for resuming social activities (3 items)



Appendix 3: Distribution of responses for each item