Survey of bereavement care at home-visit nursing stations in Japan

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Abstract

Background

With a rapidly aging population, the importance of promoting end-of-life care at home has been pointed out. Home-visit nurses play an important role as professionals in charge of home care, and pre- and post-bereavement care for bereaved families is included in home-visit nursing services. However, bereaved families are not always provided with care after bereavement in Japan. This present study aims to investigate the relationship between the provision rates of pre- and post-bereavement care for the patient family and the demographics of home-visit nurses through a survey of home-visit nurses, and to clarify the details of post-bereavement care and the reasons why the care is employed, exploratorily through a survey of the managers of home-visit nursing stations.

Methods

A self-rating anonymous questionnaire survey was conducted with 2,400 facilities (including 2,200 facilities randomly selected from among the members of Home-Visit Nursing Stations of the National Nursing Business Association). For the analysis, simple aggregation was used and the statistical processing employed SPSS ver21.0.

Results

A total of 680 valid responses were analyzed. The mean length of home-visit nursing experience was 10.6 years and that of hospital nursing experience was 15.2 years. The provision rate of post-bereavement care was 90% or higher in most of the identified items, excluding “Provided continued support/life planning until the family fully recovers social life”. For the provision of post-bereavement care, most items exceeded 70%, but excluding “Provided continued support until the family fully recovers social life”, and “Involved in building a life after bereavement”.

Compared to the participants with less than 5 years of home-visit nursing experience, those with 10 years or longer experience had statistically significantly higher rates of providing post-bereavement care in more than half of the identified items. Home-visit nursing facilities with 24-hour services had statistically significantly higher rates of providing care in more than half of the items of both of pre- and post-bereavement care, compared to the facilities without 24-hour services. About 70% of the managers think that bereaved families need follow-up, and visited the families as a post-bereavement care.

Background

With a rapidly aging population, the importance of promoting end-of-life care at home has been pointed out. Home-visit nurses play an important role as professionals in charge of home care, and pre- and post-bereavement care for bereaved families is included in home-visit nursing services [1]. However, bereaved families are not always provided with care after bereavement as a previous study reported that 37.4% of

home-visit nurses always provide post-bereavement care, and 46.2% provide this depending on the case [2].

Currently, Japan has no established system that covers the bereaved family after the death of a family member. Basically, medical service fees for the bereaved family are not covered by the national insurance program in Japan, and eligibility for medical insurance starts only after symptoms such as depression appear in the bereaved family and it is diagnosed as a disease. Because regular home-visit nursing is prioritized over bereavement care that is not covered by the medical insurance, and because of ambiguities in the role of home-visit nurses due to lack of knowledge of such care for bereaved families, basic efforts to address morbid grief sufficiently have not been made.

Among studies on grief and bereavement care published outside Japan, Stroebe, et al. reported that as situational factors related to grief, 42% of people with spousal loss suffer moderate or more serious depression 4 to 7 months after the death of the spouse [3]. Futterman, et al. reported the importance of bereavement care, pointing out that other than depression, psychiatric illnesses due to increased antipsychotic drug intake and increased alcohol intake are related to higher death rates are related to higher death rates [4]. In the United States, where grief support is substantial, there are a variety of services that meet the needs of bereaved families, making it simple to be provided with such support. The United States has addressed bereavement risks of bereaved families so that appropriate services are available for families after the death of a beloved family member by assessing the family acceptance levels of patient illnesses as death approaches for the patients [5].

These differences in bereaved family care between the United States and Japan show the need to establish details of bereavement care in Japan, including risk management based on skills gained through care experience and a clarification of reasons for evaluations in situations where support is particularly important. A previous study that conducted a questionnaire survey targeting bereaved families with beloved family members who died in hospice or palliative wards in Japan reported that about 40% of those affected experienced poor health conditions after the bereavement, and about 50% of people complaining of physical illness/symptoms assumed their symptom or progression of the symptoms to be due to the bereavement [6]. As situational factors related to grief decrease one year after a bereavement [7], it is necessary to provide continued support after bereavements, in particular for the older people who show more physical reactions than younger people in the grief reactions [8].

Sakaguchi, et al. reported that many nurses experience feelings of sadness, fatigue, and helplessness after the death of patients [9]. Nurses who have little experience in end-of-life care tend to feel “helplessness”, “responsibility”, and “anxiety”, suggesting the necessity to provide support for the mental reactions of nurses including educational support [9]. In bereavement care for families of cancer patients provided by medical institutions in Japan, clinical nurses play the main role, particularly in medical facilities with palliative care units [10]. As some nurses become confused as to how to respond to the families of the patients while performing daily tasks in the clinical setting, educational support for nurses in charge of bereavement care has been found needed [11]. From these reasons, it is necessary to

establish and identify factors related to the implementation of bereavement care to strengthen the support provided for home-visit nurses.

A bereavement care survey of home-visit nursing stations nationwide reported that about 80% of valid responses from 296 home-visit nursing stations provided bereavement care, and 90% visited homes [12]. This study also reported that the support was mainly for the mental aspects and instrumental and informational support accounted for less than 50% [12]. However, as described above, in Japan, it is necessary for nurses in charge of bereavement care to perform risk assessments of symptom appearance also before bereavement and to provide interventions depending on individual needs. Although there are some studies investigating the items addressed in the care before and after bereavement, no studies have systematically focused on home-visit nurses and managers nationwide. This present study aims to investigate the relationship between the provision rates of pre- and post-bereavement care for the patient family and the demographics of home-visit nurses through a survey of home-visit nurses, and to clarify the details of post-bereavement care and the reasons why the care is employed, exploratorily through a survey of the managers of home-visit nursing stations.

Definition of terms

Bereavement care: defined as pre- and post-bereavement care. Pre-bereavement care means sharing information on evaluations and decision making as support for expected family grief at the early stage and mourning, and post-bereavement care involves assisting with a new life, including dealing with the fatigue and health of the family.

Methods

Study population

The study population is drawn from home-visit nurses working at 2,200 facilities randomly selected from the member list of Home-Visit Nursing Stations of the National Nursing Business Association, and facility managers of 2,400 facilities, adding 200 to those included above.

Survey

A cross-sectional survey was conducted using two types of anonymous self-rating questionnaires, administered between September and December of 2014. The questionnaires for home-visit nurses and for facility managers were sent to the 2,200 facilities, and one questionnaire for facility managers at the 200 additional facilities, by post, together with a letter requesting participation with a franked return envelope. Completed questionnaires were forwarded by post. We explained that returning the questionnaire would be regarded as consent to the participation.

Surveyed items

(1) Survey for home-visit nurses

Demographics: length of home-visit nursing experience (in years), length of hospital nursing experience (in years), job title, employment type, type of affiliated organization, presence of extra fees for 24-hours-a-day care, date of death (year) of patients, and the most important method of cooperation between hospitals and community based homecare. Bereavement care: Referring to previous studies[13, 14] and based on the results of discussion with several manages of home-visit nursing stations [14], the authors carefully evaluated the validity of the discussion results and created 8 question items for care before and 10 items for care after bereavement. Participants were requested to answer by recalling one patient they were in charge of. The responses to questions about care frequency were on a 4-point scale: “Always” (4 points), “Sometimes” (3), “Rarely” (2), and “Never” (1).

(2) Survey for managers

Demographics: age, gender, length of home-visit nursing experience (in years); Presence of patient family members needing follow-up care after the death of patients and the reason why the manager thought this to be necessary (free description); Experience of providing post-bereavement care; and Whether there are budgetary provisions for post-bereavement care.

Analysis

Demographics of home-visit nurses and facilities were analyzed by descriptive statistics. If a participant answered “Always” or “Sometimes” to each of the questions regarding the provision of pre- and post-bereavement care, the answer was regarded as “Provided”, the rate of providing this care was calculated by calculating the ratio of the answers that were regarded as “Provided”. The means of provision rates of pre- and post-bereavement care by the demographics of the home-visit nurses and the categories of facility demographics were calculated, and the differences between categories were examined using the Mann-Whitney U test or the Kruskal Wallis test. For the provisions of care for bereaved families and the budget available, the ratio was calculated by simple aggregation. For the statistical processing, SPSS ver21.0 was used, and the significance level was set to 5%. The text of the free description responses was examined by collaboration with several researchers and classified inductively based on similarity of the matters reported. The validity was examined several times by researchers including the home-visit nursing station managers.

Ethical considerations

The study was conducted with the approval of the Ethics Committee of Nayoro city university and in conformity to the research guidelines of the first author university belong to (approval number 13-012).

Authors explained the data management methods, anonymity, and privacy protections of the participants throughout the entire process of the study in writing. It was also explained that there would be no advantages or disadvantages whether participating or not participating, or discontinuing participation, and that the study results would be provided in the feedback, the returning of the questionnaire would be regarded as consent to the participation.

Results

Of the 2,200 questionnaires distributed, 688 responses were collected (collection rate 31.0%). After excluding 8 responses where more than 50% of the question items were left blank, 680 valid responses (31.0%) were analyzed.

Demographics and background of characteristics of participants

The most frequently mentioned position was as managers (71.3%): 656 females, 18 males, mean age 48.7 years (SD ± 7.9), mean length of home-visit nursing experience 10.6 years (SD ± 6.8), mean length of hospital nursing experience 15.2 years (SD ± 9.3) (Table 1). The mean numbers of cases where end-of-life care had been provided at the patient home were 15.9 cancer patients and 14.0 non-cancer patients. The mean length after the death of patients (years) recalled at the time of the bereavement care survey was 1.2 years (SD ± 1.4), and the most important cooperative measure between hospitals and community-based homecare activities was at the pre-discharge joint conference at 70.4%.

Table 1 Demographic and background characteristics of participants N = 680

		No.	%
Position	Manager	481	71.3%
	Chief	62	9.1%
	Staff	130	19.0%
	Not noted	7	0.6%
Sex	Female	656	96.5%
	Male	18	3.0%
	Not noted	7	0.6%
Type of organization affiliated to	Medical corporation	257	37.8%
	Private hospital	170	25.0%
	Nursing association	25	3.8%
	NPO	8	1.2%
	Medical association	40	6.0%
	Medical co-op	41	6.0%
	Municipality hospital	26	3.9%
	Other	102	15.6%
	Not noted	11	0.7%
Employment type	Fulltime	651	95.7%
	Part time	21	3.1%
	Not noted	8	1.2%
24-hour services	Yes	637	93.7%
	No	35	5.1%
	Not noted	8	1.2%
Age	Mean ± SD	48.7	± 7.9.
	Min - Max	28- 72	
Years of experience in visiting nursing	Mean ± SD	10.6	± 6.8
	Min - Max	0 - 50	
Mean length of hospital nursing experience	Mean ± SD	15.2	± 9.3
Years of experience in clinical nursing	Min - Max	0 - 47	
Years of experience in end-of-life care at home			
Cancer patient	Mean ± SD	15.9	± 24.1
	Min - Max	0 - 250	
Non-cancer patient	Mean ± SD	14.0	± 23.0
	Min - Max	0 - 250	

Table 1 Demographic and background characteristics of participants (Continued) N = 680

		No.	%
Years since bereavement	Mean ± SD	1.20	± 1.4
Important cooperative measures between hospitals and community-based homecare		Multiple answers (%)	
	Discharge summary	55	8.0%
	Pre-discharge joint conference	479	70.4%
	Care service staff meeting	231	33.9%
	Other	23	3.4%

Bereavement care for patient family: Provision rates of pre- and post-bereavement care

Provision rate of pre-bereavement care was 90% or higher in most items, with “Provided continued support/life planning until family fully recovers social life” below half, 40.5%. For provision of post-bereavement care, most items exceeded 70%, but two items were below 30%: “Provided continued support until family fully recovers social life”, 28.1%, and “Involved in building a life after bereavement”, 13.2% (Table 2).

Table 2 Provision rates of pre- and post-bereavement care among home-visit nurses

	N	Not provided	Provided[1)]
		N (%)	N (%)
Pre-bereavement care			
1. Attempted assessment of the significance of care unique to home-visit nursing	667	30 (4.5)	637 (95.5)
2. Enabled families to express their emotions in words	675	18 (2.7)	657 (97.3)
3. Approval of the care that the family has provided	675	3 (0.4)	672 (99.6)
4. Provided support to improve the health of the family	668	41 (6.1)	627 (93.9)
5. Explained what would likely occur	675	9 (1.3)	666 (98.7)
6. Communicated the physical changes of the patient	675	6 (0.9)	669 (99.1)
7. Involvement in the care together with the family and listening to their thoughts	675	5 (0.7)	670 (99.3)
8. Provided continued support/life planning until the family fully recovers social life	654	389 (59.5)	265 (40.5)
Post-bereavement care			
1. Attempted assessment of the significance of care unique to home-visit nursing	668	86 (12.9)	582 (87.1)
2. Enabled families to express their emotions in words	673	42 (6.2)	631 (93.8)
3. Approval of the care that the family has provided	672	21 (3.1)	651 (96.9)
4. Provided support to improve the health of the family	671	113 (16.8)	558 (83.2)
5. Explained the physical changes of the patient after death and their reasons	663	153 (23.1)	510 (76.9)
6. Involvement in the care together with the family and listening to their thoughts	672	21 (3.1)	651 (96.9)
7. Learned about the regrets of the family, accepted their thoughts, and showed acceptance	670	65 (9.7)	605 (90.3)
8. Tried to convince the family that the care they had provided was good	672	24 (3.6)	648 (96.4)
9. Provided continued support until the family fully recovers social life	669	481 (71.9)	188 (28.1)
10. Involvement in reestablishing daily life after bereavement	668	580 (86.8)	88 (13.2)

[1)]"Always" or "Sometimes" to each of the questions was regarded as "Provided".

Differences in provision degrees of bereavement care

The mean scores of providing each of the items of bereavement care were calculated. The scores of pre-bereavement care was 3.49 or higher for most items. The lowest scoring item was “Provided continued support/life planning until the family fully recovers social life”. Among the pre-bereavement care items there were no statistically significant differences in the positions. Compared to the participants with less than 5 years of home-visit nursing experience, those with 15 years or longer experience showed statistically significantly higher scores in the following items: “Attempted assessment of the significance of care unique to home-visit nursing”, “Enabled families to express their emotions in words”, and “Provided support to improve the health of the family”. For the employment type, full-time nurses had statistically significantly higher score than part-time nurses in “Provided continued support/life planning until the family fully recovers social life” ($p = .004$). Compared to the participants working in home-visit nursing stations without 24-hour services, those providing 24-hour services had statistically significantly higher p-values in more than half of the items (Table 3).

Table 3 Differences in provision degrees of pre-bereavement care by demographic characteristics

Demographics		Attempted assessment of the significance of care unique to home-visit nursing		Enabled families to express their emotions in words		Approval of the care that the family has provided		Provided support to improve the health of the family		Explained what would likely occur		Communicated the physical changes of the patient		Involvement in the care together with the family and listening to their thoughts		Provided continued support/life planning until the family fully recovers social life	
	N	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Total	680	3.54	.59	3.64	.59	3.90	.32	3.49	.63	3.79	.45	3.82	.41	3.83	.40	2.42	.83
Home-visit nursing experience (years)																	
5 <	157	3.44	.63	3.50	.62	3.86	.40	3.32	.72	3.70	.55	3.76	.50	3.78	.48	2.28	.87
5 ≥, 10 <	136	3.50	.61	3.61	.53	3.93	.26	3.51	.57	3.83	.42	3.80	.42	3.86	.37	2.46	.79
10 ≥, 15 <	179	3.58	.57	3.67	.51	3.89	.34	3.54	.61	3.79	.42	3.84	.38	3.82	.40	2.50	.81
15 ≥	193	3.62	.53	3.72	.47	3.92	.27	3.59	.57	3.82	.40	3.87	.36	3.87	.34	2.43	.83
p		**0.035**		**0.003**		.318		**0.002**		0.10		.120		.309		.065	
Employment type																	
Fulltime	651	3.53	.59	3.63	.54	3.90	.33	3.50	.63	3.79	.44	3.82	.41	3.83	.40	2.43	.83
Part-time	21	3.67	.48	3.67	.66	3.90	.30	3.33	.80	3.71	.46	3.76	.44	3.90	.30	1.95	.62
p		0.229		0.795		0.937		0.366		0.471		0.541		0.278		**0.004**	
24-hour services																	
Yes	637	3.56	.57	3.64	.52	3.91	.29	3.50	.62	3.81	.41	3.83*	.39	3.85	.37	2.44	.82
No	35	3.13	.75	3.35	.85	3.71	.68	3.33	.78	3.38	.78	3.59	.74	3.58	.75	1.84	.77
p		**<0.001**		**0.058**		**0.010**		0.278		**<0.001**		**0.031**		**0.012**		**<0.001**	

p: Significance level by Kruskal Wallis test or Mann-Whitney U test

Bold figures show statistically significant results.

Where care was provided to families also after bereavement, the mean score was 3.13 or above in eight items, suggesting that most of the bereavement care items were provided. The lowest scoring item was “Involvement in reestablishing daily life after bereavement” followed by “Provided continued support until the family fully recovers social life”. In the relation between the demographics of home-visit nurses and the provision degrees of post-bereavement care, participants employed as chief nurses had a statistically significantly higher score in “Learned about the regrets of the family, accepted their thoughts, and showed acceptance” than the scores of respondents in the staff nurse category (p = .023).

Compared to the participants with less than 5 years of home-visit nursing experience, those with 10 years or longer experience had statistically significantly higher p-values in more than half of the items, specifically in the following items: “Tried to assess the significance of care unique to home-visit nursing”, Explained the physical changes of the patient after death and their reasons”, and “Learned about the regrets of the family, accepted their thoughts, and showed acceptance” (p = .001). Compared to the participants working in the home-visit nursing station without 24-hour services, those with 24-hour services had statistically significantly higher p-values in more than half of the items (Table 4).

Table 4 Differences in provision degrees of post-bereavement care by demographic characteristics

Demographics		Attempted assessment of the significance of care unique to home-visit nursing		Enabled families to express their emotions in words		Approval of the care that the family has provided		Provided support to improve the health of the family		Explained the physical changes of the patient after death and their reasons		Involvement in the care together with the family and listening to their thoughts		Learned about the regrets of the family, accepted their thoughts, and showed acceptance		Tried to convince the family that the care they had provided was good		Provided continued support until the family fully recovers social life		Involvement in reestablishing daily life after bereavement	
	n	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Total	680	3.34	.77	3.53	.66	3.74	.55	3.25	.80	3.13	.92	3.67	.57	3.43	.72	3.77	.54	2.13	.85	1.68	.76
Position																					
Manager	481	3.35	.78	3.53	.67	3.74	.55	3.26	.80	3.17	.90	3.68	.55	3.46	.70	3.77	.54	2.17	.86	1.72	.70
Chief	62	3.34	.68	3.54	.62	3.77	.53	3.41	.74	3.00	.98	3.63	.71	3.52	.70	3.82	.50	2.15	.81	1.61	.70
Staff	130	3.26	.79	3.52	.66	3.72	.56	3.13	.85	3.06	.93	3.67	.58	3.26	.82	3.73	.57	1.98	.81	1.55	.82
p		0.357		0.988		0.766		0.084		0.229		1.000		**0.023**		0.464		0.098		0.074	
Home-visit nursing experience (years)																					
5 <	157	3.12	.88	3.40	.74	3.68	.64	3.10	.90	2.92	1.0	3.61	.68	3.22	0.9	3.69	.64	1.96	.81	1.51	.64
5 ≥, 10 <	136	3.25	.81	3.46	.75	3.72	.63	3.14	.82	3.12	.91	3.63	.61	3.40	0.7	3.75	.58	2.15	.90	1.68	.79
10 ≥, 15 <	179	3.47	.66	3.58	.57	3.76	.48	3.36	.77	3.12	.92	3.71	.50	3.56	0.6	3.80	.50	2.26	.84	1.75	.76
15 ≥	193	3.46	.69	3.63	.57	3.78	.47	3.36	.72	3.33	.81	3.73	.49	3.52	0.7	3.81	.45	2.17	.84	1.77	.82
p		**<0.001**		**0.013**		.695		**0.003**		**0.001**		.380		**0.001**		.317		**0.016**		**0.013**	
24-hour services																					
Yes	637	3.35	.75	3.54	.64	3.76	.52	3.27	.79	3.17	.89	3.69	.53	3.44	0.7	3.78	.50	2.15	.86	1.70	.77
No	35	3.00	1.0	3.18	.97	3.44	.93	2.88	.98	2.39	1.2	3.41	1.0	3.15	1.0	3.50	1.0	1.79	.69	1.35	.49
p		0.061		**0.026**		**0.030**		**0.017**		**<0.001**		0.498		0.142		0.295		**0.021**		**0.013**	

p: Significance level by Kruskal Wallis test or Mann-Whitney U test

Bold figures show statistically significant results.

Results of the survey for facility managers

We sent out 2,400 questionnaires created for facility managers, and of these 660 responses were collected. Excluding 5 responses where more than 50% of the question items were left blank, 655 responses (valid response rate 28%) were analyzed. Details of demographics are as follows: 633 females, 22 males, mean age 49.5 years (SD ± 7.5), and mean length of home-visit nursing experience 10.5 years (SD ± 6.0). For the presence of patient family members needing follow-up care after the death of patients, 479 managers (73.1%) answered “Yes” and 156 (23.8%) answered “No”. For the experience of providing after bereavement care, 472 (72.1%) managers answered “Yes”, and 167 (25.5%) answered “No”. As to the budgetary provisions for post-bereavement care, 252 (38.5%) managers answered “Yes”, 334 (51.0%) “No”, and 59 (9.0%) reported that they receive no compensation (Table 5).

Table 5 Results of survey using a questionnaire created for facility managers

N = 655

Question	Answer	N	(%)
Do you have experience of involvement in patient family members needing follow-up care after the death of patients?	Yes	479	(73.1%)
	No	156	(23.8%)
	Not noted	20	(3.1%)
Have you provided post-bereavement care?	Yes	472	(72.1%)
	No	167	(25.5%)
	Not noted	16	(2.4%)
Does your facility budget for post-bereavement care?	Yes	252	(38.5%)
	No	334	(51.0%)
	Receive no compensation	59	(9.0%)
	Not noted	10	(1.5%)

Of the 472 managers who answered that there were families who need follow-up after bereavement, 344 provided the reasons for this in a free description response section. The reasons were organized into the following three categories: <Living alone after bereavement>, <Health and economic problems>, and < Death of a child or young family member>. From the < Living alone after bereavement>, one subcategory, 'Living alone after the death of spouse or after the death of an elderly family member the bereaved elderly person provided care' was identified. <Health and economic problems > includes three subcategories: 'Apparent symptoms of mental illness and grief', 'Concerned about the physical problems of the bereaved family', and 'Concerned about the financial problems of the bereaved family'. <Death of a child or young family member > includes two subcategories: 'Loss of a child' and 'Death of a young family member'. The reasons for thinking that follow-up was necessary after the death of patient were organized from 359 codes shown in the free descriptions of the 344 managers (Table 6).

Table 6 Reasons for thinking that follow-up was necessary after the death of patient

n = 344

Category	Subcategory	Code (extracted from 359 in total)
Living alone after bereavement (78)	Living alone after the death of spouse or after the death of an elderly family member the bereaved elderly person provided care (78)	Living alone after the death of wife and having no relatives
		The bereaved elderly person became alone after providing care for an elderly family member.
		The bereaved person is over 80 years old, has lost a son, and will be alone.
		Because the person will be alone.
Health and economic problems (249)	Apparent symptoms of mental illness and grief (222)	The bereaved daughter with autism cannot accept the death of her mother.
		The bereaved person became lethargic and mentally unstable after the death of the family member.
		The bereaved daughter became depressed and was treated at a hospital.
		Because the bereaved wife often said that she would die if her husband died while he was still alive.
	Concerned about the physical problems of the bereaved family (10)	The daughter had terminal cancer.
		Caregiver needed nursing
		Both the husband and wife had cancer and were undergoing medical treatment.
	Concerned about the financial problems of the bereaved family (17)	The bereaved family members were a part-time parent and a 5-year old child.
		The family had financial trouble.
Death of a child or young family member (13)	Loss of a child (11)	The daughter died young, in the 30s, her husband and mother were deeply depressed.
	Death of a young family member (2)	The bereaved child needed follow-up care to live alone after the death of the parent.

*The numbers under the categories and subcategories indicate the number of codes derived in the free description.

Discussion

Demographics of the study population

The most frequent job title of the participants was managerial position (71%), and females accounted for more than 90%. The mean age was in the late 40s, and the most frequent type of affiliated organization was medical corporation (38%). These characteristics are similar to those reported in a previous study [15]. With the revision of medical treatment and long-term care fees (insurance mandated), which was considered a major revision to promote the regional comprehensive care system in 2018, the importance placed on flexible services for people with high medical dependence has increased. Home-visit nursing stations are also required to provide medical treatment for those who need 24 hours a day attention, everyday homecare to enable these patients to live at ease in the community. The results of the surveys in this study showed that more than 90% of facilities offer 24-hour services. Further, more than 70% of participants reported that the most important method of cooperation between hospitals and community-based homecare is the pre-discharge joint conference, showing that many participating home-visit nurses were aware of the importance of such cooperation and nursing at the time of discharge. Matsuki reported that medical teams need to share the cases (patients) and execute terminal care plans by acknowledging that each team member has a different perspective as each homecare patient has a different view of life

and death [16]. Matsuki also stated that it is most important for medical teams to share this awareness, and the results of the present surveys support this [16].

Pre- and post-bereavement care provided by home-visit nurses

For pre-bereavement care, compared to the participants with less than 5 years home-visit nursing experience, those with 15 years or longer experience showed statistically significantly higher scores in the following items: “Attempted assessment of the significance of care unique to home-visit nursing”, “Enabled families to express their emotions in words”, and “Provided support to improve the health of the family”.

For post-bereavement care, compared to the participants with less than 5 years home-visit nursing experience, more than half of the items were statistically significantly and more frequently provided by participants with 10 years or longer experience. This suggests that home-visit nurses, who play a part in homecare support, need to have and benefit from a high level of expertise, medical care skills, and communication skills with different professionals. Komatsu, Takiuchi, and Maeda investigated how well home-visit nurses have acquired the knowledge and skills for home-based terminal care, and reported that nurses with longer hospital or home-visit nursing experience have acquired wider knowledge and skills in all four categories covering both the pre- and post-bereavement periods [17]. The reason as stated by Komatsu, et al. was that home-visit nurses acquire knowledge and skills for care in the period near-death or bereavement through the experience of providing terminal care because such knowledge and skills are difficult to acquire in the basic nursing education [17].

These suggest the necessity to provide support for less experienced nurses in this area because accumulation of home-visit nursing care experience in both pre-bereavement care and post-bereavement care leads to high provision degrees of the various types of care.

In Japan, there is no standard for bereavement (end-of-life) care provided by professionals. Therefore, assisting a family with end-of-life care at home is an opportunity where the skills of home-visit nurses become an issue, and presently it is left to the discretion of the nurse in charge of the end-of-life care. Shibata et al. reported “difficulty due to independent visits” and “anxiety and difficulty due to lack of knowledge and skills of home-visit nursing”, giving a sense of the difficulty that home-visit nurses have [18]. Sakashita stated that in terminal care, nurses need mental health care skills to engage in the terminal care with a positive attitude because they are subject to stress every day in the process of dealing with patients, and that it is necessary to create an environment that supports the mental conditions of nurses who feel anxiety and helplessness [19]. Leick focused on aid workers as an at risk group who suffers from a complex grief state, suggesting the necessity for nurses to look at their own psychologically unprocessed losses [20]. It is essential to offer a 24-hour service to deal with end-of-life patients [21]. The results of the present study showed that more than half of the pre-and post-

bereavement care needs were not provided by facilities without a 24-hour service, suggesting the necessity to urgently prepare for and engage in the future progress of a situation where multiple deaths are common in society.

Potential benefits and needs of post-bereavement care suggested by survey results in home-visit nursing managers

This study was conducted with the background that there is no agreed upon standard for bereavement care in Japan [22]. However, about 70% of the managers participating in this study think that bereaved families need care also following the bereavement, with the most common reason being the displayed 'Apparent symptoms of mental illness and grief'. About 70% of participating managers visited bereaved families as part of post-bereavement care because it was difficult to resolve problems and other issues through telephone and email consultations due to the clearly apparent symptoms of mental distress and grief.

Ozawa, Uchino, and Takaoka et al. conducted semi-structured interviews with 12 managers of home-visit nursing stations in Japan, and clarified the structure of the bereavement care performed by the managers [14]. Their results showed that the nursing managers assessed their relationship with the family who used home-visit nursing services from the period when the patient was still alive, and estimated the needs for post-bereavement care based on their own experience [14]. However, only one participant (8%) reported that the facility had budget assigned to post-bereavement care [14]. This is similar to the results of the present study in terms of prospects for support of post-bereavement care by managers, implementation of bereavement care, and budget allowances. The present study quantitatively showed that about half of the managers provide this bereavement care as a volunteer activity with no compensation available.

The reason for this is that it is often impossible for home-visit nursing stations to assign full-time staff to educate newly employed home-visit nurses, and that the managers are responsible for the education of the nurses who are in charge of bereavement care. This suggests that it is the managers that are acting in the role of trainer for home-visit nurses. For the details of the support provided by managers of home-visit nursing stations, previous studies suggest that the nurses themselves are [Trying to moderate their own feelings at the death and also those of the bereaved family] by providing an [After-service as post-bereavement care] for the bereaved family and interacting with the bereaved family [23, 24]. As described above, it may be inferred that nurses provide bereavement care as a "support activity for the family" easing the remaining family towards the future life by moderating the feelings of the family as well as their own feelings. However, because bereavement care is not acknowledged as a part of the home care system and because it is a care that is voluntarily provided, "continued support until the family fully recovers social life" and "involvement in building a life after bereavement" were least commonly provided. This suggests the necessity to improve collaboration with and among different professional and care support specialists to enable nurses to visit the patient family repeatedly from early in the period of

involvement, before the bereavement, as it seems to be required by the necessity of the situation. It is also necessary to establish a system incorporating a multi-faceted perspective including the costs involved and preventive care so that care can be provided sufficiently to meet the wishes of the family.

The valid response rate of this study is low at about 30%, and this presents a limitation to a generalization of the results. However, this study focused on home-visit nurses who are dedicated to home medical care in Japan, and yielded valuable information in the results. In further studies, it will be necessary to clarify details of problems home-visit nurses are aware of in supporting bereaved families in the general community to develop and create a bereavement care system that enables nurses to cooperate with the communities they are involved in.

Conclusions

For the care provided after bereavement, compared to the participants with less than 5 years of home-visit nursing experience, those with 10 years or longer experience had statistically significantly higher degrees of providing care in more than half of the items identified. It was found that home-visit nursing facilities with 24-hour services had statistically significantly higher degrees of providing care in more than half of these items both before and after the bereavement, compared to the facilities without 24-hour services. About 70% of the managers think that bereaved families need follow-up, and based on the comments in a free description response section, it was suggested that the most common reason for this is ‘Apparent symptoms of mental illness and grief’. It was also found that about half of the managers provide bereavement care as volunteers because the facilities do not have no budget to assign to post-bereavement care.

Declarations

Ethics approval and consent to participate

This study was conducted with the approval of the Ethical Review Committee of the institution the authors belong to (approval number 13-012). Authors explained the data management methods, anonymity, and privacy protections of the participants throughout the entire process of the study in writing. It was also explained that there would be no advantages or disadvantages whether participating or not participating, or discontinuing participation, and that the study results would be provided in the feedback, the returning of the questionnaire would be regarded as consent to the participation.

Consent for publication

Not applicable

Availability of data and materials

The data that support the findings of this study are shown in Tables 1 – 6.

Competing interests

No competing financial interests exist.

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Authors' contributions

O.M., U.S., and J.S. contributed to the conception and design of this study; O.M. and U.S. performed the statistical analysis and drafted the manuscript; J. S. created Tables; and U.S. and J.S. critically reviewed the manuscript and supervised the whole study process. All authors read and approved the final manuscript.

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