Palliative Medicine 2003; **17:** 520–526

Difficulties encountered by nurses in the care of terminally ill cancer patients in general hospitals in Japan

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Abstract: The aim of this study was to investigate the difficulties encountered by nurses who have cared for terminally ill cancer patients at general hospitals. To collect data, a survey by questionnaire was self-administered. The respondents were 375 nurses and the response rate was 70.2%. Factor analysis was conducted on 80 items related to the difficulties encountered by nurses who have cared for terminally ill cancer patients to allow reasonable item reduction and to explore better domains. Two items were excluded and the results revealed eight underlying domains: '*Communication with patients and families*', '*Knowledge and skill of nurses*', '*Treatment and informed consent (IC)*', '*Personal issues*', '*Collaboration as a team including patients and families*', '*Environment and system*', '*Collaboration among nurses*', and '*Near-death issues*'. Cronbach's alpha coefficients for each domain ranged from 0.77 to 0.93. The results showed that nurses working at general hospitals have experienced a high degree of difficulty overall while caring for the dying, particularly with communication with patients and families. It was concluded that this study was useful in determining the specific areas where nursing education and research should be focused. *Palliative Medicine* 2003; **17:** 520–526

Key words: cancer; general hospital; nurse's difficulties; palliative care; terminally ill

Introduction

In Japan, cancer has been the leading cause of death since 1981 and the number of deaths attributable to cancer is continuing to increase.[1] In the last 10 years there has been a rapid increase in the number of hospices and palliative care units (PCUs) providing care for the dying, mainly for those dying from cancer. Hospices and PCUs, however, currently cater for only 2.5% of all patients facing death from cancer (which is a small number compared to its counterpart in western countries[2,3]), while most cancer deaths still occur at general hospitals.[4] Therefore, the quality of care provided to terminally ill cancer patients at general hospitals is a very important issue.[5]

Some studies indicate that health care professionals are sometimes ill prepared to manage the symptoms of these patients,[6,7] there is often a lack of teamwork among health care professionals[8,9] and a lack of a designated palliative care service,[10] all of which could lead to the physical and psychological distress of terminally ill cancer patients in general hospitals.[11,12]

In caring for the terminally ill, nurses play a very important role because the focus of care shifts from treatment to support of the daily needs of the patient, in which nurses have a major part to play.[13] However, it has been reported that more than 90% of nurses working at teaching hospitals face problems or difficulties in the care of terminally ill patients.[14,15] A few studies have been conducted to investigate these difficulties. Copp[16] undertook a qualitative study to investigate the difficulties most frequently encountered by nurses taking care of the dying in three different settings: a hospice, a community care setting and an acute care setting. Yuasa *et al.*[17] reported on the difficulties encountered by nurses caring for aged patients at teaching hospitals; and Sakai *et al.*[18] described the difficulties perceived by nurses in coping with the care of cancer patients in both outpatient and short-term care inpatient units. There have been few studies on the specific aspects of the care of terminally ill cancer patients that might pose the greatest difficulties for nurses working in general hospitals.

The aim of this study, therefore, was to identify the content and degree of the difficulties encountered by nurses in caring for terminally ill cancer patients in general hospitals in this country.

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10.1191/0269216303pm802oa

Methods

Pilot study

A pilot study was undertaken to formulate the most appropriate questionnaire. First, we pooled expressions that represented the difficulties encountered by nurses caring for terminally ill cancer patients, based on a review of the literature[14–16,19–28] and from an earlier small study conducted at one of the hospitals, which was ultimately selected for the final survey. A total of 83 items were extracted.

Secondly, these items were predefined by 11 hypothesized domains. Two nurses (a head nurse and a staff nurse), each of whom had more than 10 years of clinical experience and who were working at a general ward, checked the questionnaire and, based on their views, we added modifications to some items.

Thirdly, the pilot questionnaire was tested in a convenience sample of 40 staff nurses working on general wards in hospitals that were different from the hospitals selected for the final survey. To examine the test–retest reliability of the items and domains, the pilot questionnaire was reissued two weeks after the first was completed. Also, the internal consistency was examined by calculating Cronbach's alpha coefficients. Based on the results of these analyses, three items were modified and three others deleted. Eventually a final questionnaire consisting of 80 items was completed.

Sample

For the final questionnaire survey, three general hospitals were selected. Although those situated close to Tokyo were selected for convenience, they nonetheless had more than 300 beds each and all were qualified to provide clinical training for doctors. None was equipped with an inpatient hospice or PCU. Staff nurses working in the general wards at these hospitals were selected for the survey by questionnaire. Nurses belonging to the paediatric, obstetrical or psychiatric wards, the ICU, or the operating theatres were excluded. It was also decided that responses from nurses who had no prior experience with the death of a patient should be excluded.

Study design and procedure

This was a cross-sectional study, conducted using a self-administered questionnaire. Envelopes containing the questionnaire and a cover letter were given to the nurses by the head nurse in each ward. Completed questionnaires were sealed in an envelope provided with the questionnaire and placed in a box located at each ward within two weeks after being distributed.

Measurement

For each item the respondents were asked about the extent to which they had difficulty or trouble during the care of terminally ill cancer patients. The answers were presented on a four-point Likert-type scale of 1 (very much) to 4 (not at all). All respondents were also asked to fill in a set of sociodemographic characteristics (sex, age, years in clinical practice, etc.).

Data analysis

Having confirmed that there was no institutional bias in the distribution, data from the three hospitals were combined and analysed. For the analysis, all the scores were reversed as 1 (not at all) to 4 (very much); therefore higher scores indicated a greater degree of difficulty.

A descriptive statistical analysis was conducted. Factor analysis with Promax rotation was conducted on 80 items. The aim was to achieve reasonable item reduction and identify the best domains. Taking into consideration factor loading and meaning, the items were assigned to the most appropriate domain. Internal consistency was assessed by Cronbach's alpha and analysis was carried out by using the statistical package, SAS version 6.12. Statistical significance was set at the $P < 0.05$ levels, two-tailed.

Results

Study sample

Of the 534 survey questionnaires delivered, 450 were returned, yielding a response rate of 84.3%. Of these responses, those that had more than 10% incomplete data throughout, or filled out by respondents who had never cared for terminally ill cancer patients before, were excluded. Finally, 375 responses (70.1%) were used for further analysis.

The characteristics of the respondents are summarized in Table 1. Nearly 97% were women and the age ranged from 20 to 56 years (mean = 27.5, SD = 6.4) and 74% were under 30. The duration of clinical experience ranged from 0.5 to 30 years (mean = 5.5, SD = 5.5) and over 40% had been trained for less than two years. Most of the respondents were registered nurses (94.4%).

Areas of difficulty encountered in the care of terminally ill cancer patients

As a result of factor analysis, eight domains finally remained with 78 items. Although two items had factor loadings of < 0.3, they were not deleted because these items seemed reasonable in each domain. Two items were excluded from further analysis because respondents did not show significant difficulties with those items, and the items did not load on any specific factor. These domains roughly corresponded to the hypothesized domains. Each domain was entitled: '*Communication with patients and families*', '*Collaboration as a team including patient and family*', '*Knowledge and skill of nurses*', '*Treatment and*

Table 1 Demographics of the sample ($n = 375$)

		Number	%
Sex	Female	363	96.8
Age	20–29	278	74.1
	30–39	72	19.2
	40–49	20	5.3
	50–	5	1.3
Years in practice	<2 years	153	40.8
	3–4 years	83	22.1
	5–9 years	87	23.2
	10 years+	52	13.9
Education	Nursing school	355	94.7
	Junior college	16	4.3
	University/greater	2	0.5
	Something else	2	0.5
Qualification	RN[a]	354	94.4
	LPN[b]	21	5.6

[a] RN: registered nurse.
[b] LPN: licensed practical nurse.

IC', '*Near-death issues*', '*Environment and system*', '*Collaboration among nurses*' and '*Personal issues*'. Cronbach's alphas for each domain ranged from 0.77 to 0.93 (Table 2), which indicated that the internal consistency was high.

Degree of difficulty encountered in the care of terminally ill cancer patients

Table 2 shows the percentages of each item. The items are presented in order of the high percentage of 'very much' in each domain.

In '*Communication with patients and families*', over 30% of respondents answered 'very much' for all items. On a whole, over 50% of respondents answered 'a little' or 'very much' for most of the items across the domains.

The highest three items were 'Little time to talk to patients' (62%), 'Immaturity of myself as a nurse or person' (56%) and 'Little time to talk to families' (55%). Overall, responses tended to gather 'a little' or 'rare'.

Discussion

Study sample

To begin with, attention should be called to the characteristics of the sample of this study. The proportion of younger nurses was higher in these subjects than in the national average of those who work in general hospitals (under 30 years old, 34%[29]). This is a considerable difference, even though this study included only staff nurses, and therefore, the sample should be represented by younger nurses. This also relates to the fact that the proportion of less experienced nurses was high. In terms of educational level, there was no big difference between this sample and the national figure – the majority of nurses working in general hospitals in Japan are educated at nursing schools rather than at junior college or universities.[29] It was assumed that the age and clinical experience would influence the sense of difficulty, so this unique feature should be taken into consideration in interpreting the results.

Areas of difficulty encountered in the care of terminally ill cancer patients

From the factor analysis, eight domains emerged. These domains are consistent with those reported in previous studies that conducted qualitative analysis or experts' opinions in order to identify problems related to the care of terminally ill cancer patients.[16,22,23] The present study is valuable in terms of identifying specific areas using quantitative analysis.

One area that was identified was '*Communication with patients and their families*'. Although we predefined communication with patients and their families separately, they became one as the results of the factor analysis. This suggested that nurses regarded communication with the patient in the same light as those with their families, which might reflect the interdependent relationships in Japanese society, in sharp contrast to the independence of individuals in western cultures.[30]

As curative treatments become ineffective, the focus of the care shifts to palliation of the patient's distress. For the patient, to accept the fact that there is no treatment option other than palliative care can be totally devastating.[31] The burden of explaining the situation, which can be difficult and stressful, falls on the doctors and nurses. This might be different from the situation encountered in a hospice, where the patient mostly goes after being informed of the fact that no further curative treatment may be available. Furthermore, terminally ill patients and their families have serious and diverse issues to tackle, such as physical, psychological, social and spiritual problems.[32] To resolve these problems, good communication between the patients and nurses is essential. While its importance was recognized, nurses reported open communication to be difficult.

'*Knowledge and skill of nurses*' was identified as one of the difficult areas. One of the core elements in the care of terminally ill patients is symptom management.[13] To provide effective management, nurses have to obtain indepth knowledge and a number of skills from a wide perspective, for example, mechanism of symptoms, drugs used for treatment and assessment of the patient's status. If nurses are unable to reduce the patient's suffering adequately, they may not have confidence in their own knowledge or skills[25] and this might lead to '*Personal issues*'.

Table 2 Percentage of difficulties perceived by nurses ($n = 375$)

	Response (%)				α*
	None	Rare	A little	Very much	
1. Communication with patients and families (17 items)					0.93
Little time to talk to patients	0	5	33	62	
Little time to talk to families	1	6	38	55	
To deal with patients who are not well informed their diagnosis or condition	0	5	41	53	
How to react when patients talk about death or dying	1	9	43	47	
To deal with families who are not well informed patients' diagnosis or condition	2	13	39	46	
How to react when patients talk about their prognosis	1	7	48	43	
How to deal with patients who do not express their emotion	1	7	47	43	
Unable to provide support to patients and families after they have been informed their diagnosis or condition	1	6	51	42	
How to talk right after patients are informed their diagnosis or condition	1	10	46	42	
How to deal with families who deny patients' diagnosis or condition	1	13	44	42	
How to deal when patients express their anxiety, anger and concern	1	8	51	41	
How to deal when families express their anxiety, anger and concern	1	12	49	38	
How to talk right after families are informed patients' diagnosis or condition	1	12	49	38	
How to deal with patients who deny their diagnosis or condition	1	15	45	38	
How to react when families talk about death or dying	1	13	49	37	
How to deal with families who do not express their emotion	2	19	47	32	
How to react when families talk about patients' prognosis	1	14	53	31	
2. Knowledge and skill of nurses (10 items)					0.92
Nurses' insufficient knowledge of drugs	1	10	52	38	
Nurses' insufficient basic medical knowledge of disease and pain	0	10	55	34	
Reassessment of pain after intervention is either inadequate or late	1	11	60	28	
Pain assessment is either inadequate or late	1	14	57	28	
Assessment tools are not used effectively	1	16	54	28	
Nurses' insufficient basic knowledge of disease and symptom	1	15	58	27	
Nurses' insufficient knowledge of symptom management	1	13	61	26	
Symptom assessment is either inadequate or late	1	13	65	20	
Reassessment of symptom after intervention is either inadequate or late	1	15	65	19	
To handle the side effects of opioids	1	16	64	18	
3. Treatment and IC (eight items)					0.92
Patients and families are informed without nurses' presence	1	11	44	43	
Doctors do not record discussion with patients and their families	2	18	44	35	
No discussion between patients and health care providers regarding the treatment, or even if there is, it is too late	2	15	50	33	
Patients are not fully informed their condition	1	20	49	30	
Patients are not fully informed their diagnosis	2	19	50	29	
Inappropriate active treatments	2	28	44	25	
Treatment decision without taking account of patients opinion	3	34	42	21	
To liase between patients and families and doctors (e.g., setting for discussion, informing doctors regarding patients' wish)	3	33	50	14	
4. Personal issues (six items)					0.77
Immaturity of myself as a nurse or person	1	7	36	56	
No confidence with the care providing to patients	1	8	53	39	
To care for both dying patients and patients who recover at the same time	7	38	37	18	
To control my own emotions	4	36	46	14	
To have a big sense of loss after patients' death	2	33	53	12	
Unable to confront patients	3	35	50	12	
5. Collaboration as a team including patient and family (14 items)					0.92
Less opportunity to discuss with doctors	1	16	47	35	
No consistent goal for pain management between patients, doctors and nurses	2	20	55	23	
Differences in the perception or assessment of pain between patients, doctors and nurses	2	23	54	21	
No consistent goal for symptom management between patients, doctors and nurses	2	19	58	20	
Poor collaboration between doctors and nurses regarding pain management	2	24	54	20	
Poor communication between doctors and nurses	2	21	58	19	
Differences in the perception or assessment of symptoms between patients, doctors and nurses	2	20	61	18	
Doctors do not seek the help or advice from other professionals	3	34	45	18	
Doctors' insufficient knowledge regarding drug effects	4	31	48	16	
Poor collaboration between doctors and nurses regarding symptom management	3	23	58	15	
Doctors' insufficient knowledge regarding symptom management	3	36	47	15	
Doctors are reluctant to use opioids	6	50	32	12	
Doctors do not have interest in symptom management	7	41	41	11	
Patients or families are reluctant to use opioids	4	46	43	6	

Table 2 (Continued)

	Response (%)				α*
	None	Rare	A little	Very much	
6. Environment and system (eight items)					0.79
Lack of private rooms for patients and their families	1	15	41	42	
Poor home care system	1	19	49	30	
Poor physical facilities for the care of dying patients	1	23	49	26	
No support system for bereavement	8	31	40	19	
Shortage of professionals, such as social workers and counsellors	3	38	41	18	
Insufficient supply of drugs or equipment for symptom management	7	37	42	14	
Insufficient supply of drugs or equipment for pain management	5	34	47	13	
There is no one from who I can seek help when in time of trouble	7	43	38	12	
7. Collaboration among nurses (five items)					0.81
The content of discussion is poor	2	28	55	15	
Few opportunities for discussion among nurses	3	33	49	16	
Unable to share feelings with other nurses	3	38	49	10	
Unable to provide consistent care because of different views of nursing staffs	3	45	43	7	
Poor communication among nurses	3	44	48	5	
8. Near-death issues (10 items)					0.79
How to talk to families immediately before and after death	2	18	50	30	
How to behave immediately before and after patients' death	5	35	42	18	
Nurses or doctors are by patients' side instead of families because of giving procedure	4	34	46	16	
Inadequate application of CPR	6	31	47	15	
Difficult to have families by the patients' side at the time of death because of poor contact or estimation	2	35	46	15	
Patients die in shared rooms	16	33	36	15	
Unable to find time for the families to farewell before washing the deceased	17	46	29	8	
Doctors' unfaithful attitude or behaviour	7	53	32	7	
Unable to go to see when deceased and their family leave the hospital	10	47	38	5	
Nurses' unfaithful attitude or behaviour	14	65	18	2	

* Cronbach's alpha coefficient.

'*Treatment and IC*' was also identified as an area of concern. The cancer notification rate in Japan is not 100%.[33,34] According to the study conducted by Sasaki *et al.*,[33] the rate was about 75.1% in specialized cancer hospitals. The present study was subjected to nonspecialized cancer hospitals and the rate is assumed to be lower than the figure. In addition, the notification rate dose not guarantee that patients are fully informed of their condition. This should be related to a difficulty with communication between patients and nurses. In other words, if informed consent is inadequate, the nurse will find it difficult to communicate with the patient.

In the care of terminally ill cancer patients, pain and other distressing symptoms cannot always be alleviated and the patient's condition continues to deteriorate in spite of the most devoted care by nurses. This might lead to a nurse's sense of helplessness or insecurity. In addition, it is said that health care providers need to confront their own emotions while caring for the dying.[35] Because of these reasons, '*Personal issues*' seemed to emerge as specific area of difficulty encountered by nurses who were caring for dying patients.

Degree of difficulty encountered in the care of terminally ill cancer patients

The results showed that nurses working at general hospitals experienced a high degree of difficulty overall while caring for the dying, particularly with the communication with patients and families.

Respondents demonstrated high difficulty with 'Little time to talk with patients' and 'Little time to talk with families'. It is not easy for hospitals to increase the number of nursing staffs because of financial constraint, even though there is evidence for the need to improve communication with patients and families.[36,37] One of the options to dealing with the issue is the peripatetic palliative care team observed in western countries. There are many reports that this kind of team provides psychological support as well as symptom management, etc.[38,39] In Japan, a palliative care team in a hospital setting was institutionalized within national medical insurance in April 2002[40] and the team is expected to make a major contribution to provide palliative care in hospital.

Respondents also had a lot of difficulty with 'Immaturity of myself as a nurse or person'. According to Copp's study,[16] nurses working at acute care hospitals had more emotional difficulties while caring for dying patients when compared with those working at hospices and in the community. This may be related to the fact that the staff in a hospice can more easily express their emotions and discuss them with their colleagues.[30] However, under the circumstance where most deaths occur in a hospital, it is very important to consider how emotional care can be provided to nurses.[27] Teamwork and raising self-awareness of nurses may be important in this context. This also needs further study.

This study has a limitation. The results cannot be generalized because among the 8000 general hospitals in Japan, the sample was limited to nurses from three hospitals located close to Tokyo.[1] The sample was biased as mentioned earlier and therefore the results should be interpreted with caution. Further study with a larger sample size is needed.

Conclusion

The aim of this study was to identify the areas of and the degree to which nurses encounter difficulties when caring for terminally ill cancer patients in general hospitals in Japan. Eight domains emerged from factor analysis, and the nurses had considerable difficulty with many aspects of this type of care. This result should be useful in terms of planning initiatives in nursing education and research.

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