

ONLINE EXCLUSIVE

Family Satisfaction With Perception of and Barriers to Terminal Care in Japan

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Purpose/Objectives: To examine how families of patients with cancer perceive and are satisfied with terminal care given in a university hospital and to identify barriers to the best care for patients and proper support for their families.

Design: Quantitative, descriptive.

Setting: A Japanese national university hospital.

Sample: Convenience sample of 73 family members of deceased patients with cancer (response rate was 55%).

Methods: Completion of a questionnaire comprised of 23 items, including multiple-choice and open-ended questions.

Main Research Variables: Satisfaction with terminal care, misunderstanding of narcotics use, recognition of disease signs and symptoms, and expectations for terminal care.

Findings: Ninety percent of respondents were satisfied with nursing care. Eighty percent were satisfied with the information they received at admission, 70% were satisfied at the critical phase, and 63% were satisfied at the end of life. The main expected types of desirable terminal care were pain management and spiritual care. The bereaved had difficulty dealing with patients' pain, dyspnea, and appetite loss. Forty-four patients were treated with narcotics. Fifty-seven percent of the family members of these patients found pain to be the most difficult symptom to deal with. Fifty-eight percent of the respondents believed that if narcotics were used, patients would soon die.

Conclusions: Terminal cancer care given in Japanese university hospitals does not appear to be adequate in terms of patients' and families' quality of life. The findings indicate that insufficient current information is given throughout the terminal stage of cancer and patients and their families misunderstand the use of narcotics.

Implications for Nursing: Oncology nurses need to consider different cultural backgrounds when offering specific care to patients with terminal cancer. Patients and their families must be educated about the efficacy of narcotics in the care of terminally ill patients with cancer.

Key Points . . .

- Family members of patients with terminal cancer have difficulty dealing with patients' pain, dyspnea, and appetite loss.
- Nurses need to be aware of different cultural backgrounds when offering specific care to patients with terminal cancer and their families.
- To relieve pain adequately, thorough education about the effects of narcotics is required for patients with cancer and their families.

lives (Aoki et al., 1997), but only 20% of bereaved Japanese families reported that patients had been informed of the cancer diagnosis (Katoh et al., 1998).

Pain management and palliative cancer care seem to be inadequate in Japanese general hospitals as compared with treatment given at cancer hospitals, even though the World Health Organization promotes cancer pain relief. The amount of narcotics used in medical care in Japan is only one-seventh of that used in Western countries (International Narcotics Control Board, 2001), suggesting that pain control is inadequate when compared to other countries. The emotional distress seen in patients with terminal-stage cancer likely is related to inadequate pain control. Nurses may find themselves in a dilemma because families have negative attitudes toward narcotics use even though patients complain about pain (Kume, Ogasawara, Baba, Yamanaka, & Andou, 1999). The reasons that narcotics are not used for patients with terminal cancer need to be clarified.

The support of family members is indispensable if terminal care is to be provided in a manner that improves meaningful life for patients (Lobchuk & Stymeist, 1999). The

Since 1986, cancer has been the leading cause of death in Japan. Of the 290,000 people who died from cancer in 1998, 90% died in medical facilities and less than 10% died at home (Statistics and Information Department, Minister's Secretariat, Ministry of Health, Labor, and Welfare, 1999). Hospitals, especially those that are university affiliated, attach primary importance to active treatment based on the latest techniques and often do not provide adequate care for patients in the terminal stage of cancer (Yagihashi, Hamaya, Ozawa, Sakata, & Satoh, 1995). Telling patients with terminal cancer the truth about the diagnosis, pathology, and prognosis has a significant positive effect on the quality of their

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supportive behavior of family members who visit a patient daily and provide bedside care depends on how they perceive the patient's illness experience through the terminal stage. For medical providers to be able to support these family members, the extent to which family members are aware of the patient's condition and the circumstances of his or her care must be known. A number of studies have been published related to how bereaved family members should be treated at hospices and cancer hospitals (Knappe & DelCampo, 1995; Wyatt, Friedman, Given, & Given, 1999). However, few studies have been published that address how and to what extent a patient's terminal stage of cancer, as managed at general hospitals, is understood by his or her family members (Tsunoda et al., 1997).

One purpose of this research was to identify how bereaved family members perceived their relative's condition and the terminal care presently given in Japanese university hospitals where patients with cancer often live out their final days. Another was to investigate the types of care that families expected from doctors and nurses. The main purpose was to identify existing barriers so that the best care for patients with terminal cancer and proper support for their families can be provided based on the findings.

Methods

This descriptive survey study was performed after obtaining permission from the department of nursing, the supervisors on each ward, and the chief doctor. The study was conducted at a university hospital (a full-service hospital with 1,076 beds) located in a suburban area in the Kansai, Japan, region. Completed questionnaires were returned by mail in one month.

Sample

The convenience sample consisted of 133 family members who had cared for patients with terminal-stage cancer treated at the university hospital between April 1996 and October 1998. Family caregivers who often visited the patients and provided bedside care were asked to complete the survey questionnaire.

Instrument

The investigators generated a 23-item questionnaire, the **Family Satisfaction With Terminal Care Questionnaire**. The survey was divided into four parts: satisfaction with nursing and terminal care (seven items), understanding of narcotic use (five items), recognition of disease signs and symptoms (two items), and expectations for terminal care service (nine items). These items were selected based on information gained in interviews with two bereaved families and from published research findings (Tsunoda et al., 1997; Yamamuro, 1997).

A five-point scale that rated satisfaction with nursing and terminal care, including medical treatment, was used. In addition, respondents evaluated the adequacy of the information that they received about the treatment given and the prognosis at the times of admission, following exacerbation of the patient's condition, and when the patient was dying. These areas were evaluated according to whether they were satisfied, not satisfied, or not sure. The five items addressed understanding about narcotics, and respondents could agree or disagree with a statement or answer. Respondents were asked to select three signs and symptoms shown by patients that they considered difficult and three kinds of support to relieve distress. Regarding expecta-

tations for terminal care, respondents were asked whether they would have used a hospice unit if the university hospital had one. They also were asked to indicate whether they would have wanted homecare services if such services had been available. Those who answered that they would not have used homecare services were asked to select from the following reasons: (a) working outside the home, (b) lack information about details of available local services, (c) crowded home space, (d) difficulty in obtaining a death certificate, or (e) other. Respondents also were asked whether they could talk about the cancer and the prognosis with the patients.

The last three items were open-ended questions. Respondents were asked to state their expectations of doctors and nurses, as well as what changes they thought should be made in the present care of patients with terminal cancer.

Reliability of the scales was assessed by means of Cronbach's alpha coefficient. The internal consistency reliability for the Family Satisfaction With Terminal Care Questionnaire was $\alpha = 0.712$, satisfaction with nursing and terminal care was $\alpha = 0.817$, and understanding of narcotics was $\alpha = 0.834$. Content validity was confirmed by three oncology nurse specialists, the supervisor of an oncology unit, and the authors.

Procedure

The participants were referred by oncology physicians. Postcards were sent to the main family caregivers. The purpose of the survey and method of research were explained in the questionnaire, and assurance was given that the families' privacy would be protected.

Data Analysis

Descriptive statistics (percentile, means, and standard deviation) were used to analyze the data on the families' perceptions of signs and symptoms and understanding of narcotics use. Spearman's rank correlation coefficients were calculated to evaluate the relationships among satisfaction with medical treatment, nursing, and information received about the illness. Fisher's direct calculation method was used to evaluate differences in perceptions of the narcotic use. The Mann-Whitney U test was used to evaluate differences in satisfaction with medical treatment, nursing, and information received about patients' prognoses during the terminal stage. Written responses to questions about expectations of doctors and nurses, as well as the terminal care they provided, were content analyzed by the members of the research team to identify categories of similar items.

Results

Sample Characteristics

Seventy-three family members responded to the questionnaire, a response rate of 55%. Respondents' ages ranged from 28–85 years ($\bar{X} = 56.1$, $SD = 11.6$), and 43% were men. Relationships to the patient with cancer were wife (44%), husband (25%), child (18%), sibling (6%), parent (6%), and no response given (3%).

Table 1 shows the demographic characteristics of the patients with cancer. The average patient age was 56.1 years ($SD = 11.6$, range = 26–87 years). Average days of hospitalization immediately prior to death was 95.7 ($SD = 69.3$). Fifty-nine percent of the patients had metastases, and 60% had received an opiate such as morphine or long-acting morphine tablets.

Table 1. Sample Demographics

Characteristic	n	%
Age (years)		
\bar{X} = 56.1	—	—
Range = 26–87	—	—
SD = 11.6	—	—
Type of cancer		
Lung	18	25
Breast	14	19
Leukemia, myeloma, Hodgkin's disease	12	16
Esophagus, stomach, rectum	12	16
Thyroid	6	8
Pancreas, liver	4	6
Other	7	10
Treatment		
Chemotherapy	20	28
Chemotherapy plus radiation	12	16
Chemotherapy, radiation, and surgery	12	16
Chemotherapy plus surgery	9	12
Only symptom management	6	8
Surgery	5	7
Radiation	4	6
Surgery plus radiation	3	4
Missing	2	3
Gender		
Male	40	55
Female	31	43
Missing	2	3
Metastasis		
Yes	43	59
No	28	38
Missing	2	3
Narcotic usage		
Yes	44	60
No	27	37
Missing	2	3

N = 73

Note. Because of rounding, not all percentages total 100.

Family Satisfaction

Many respondents were satisfied with the medical treatment (74%) and nursing care (90%) given to their relatives during the terminal stage, whereas the satisfaction rate for information received at admission was 80%. This dropped to 70% during the critical phase and 63% at the end. The degree of satisfaction with treatment correlated significantly with the degree of satisfaction with information received concerning patients' conditions and prognoses at admission ($r = 0.342$, $p < 0.01$), after exacerbation of patients' conditions ($r = 0.377$, $p < 0.01$), and immediately before death ($r = 0.276$, $p < 0.05$). The degree of satisfaction with treatment also correlated significantly with the respondents' ages ($r = 0.276$, $p < 0.05$). Whether narcotics were used was not correlated significantly with the degree of satisfaction.

Signs and Symptoms That Families Found Difficult to Deal With

Table 2 shows that 44% of the respondents had a hard time dealing with patients feeling pain, 38% with difficulty breathing, and 35% with loss of appetite. The symptom that husbands selected as most difficult was patients' pain, followed

Table 2. Signs and Symptoms Families Find Difficult

Symptom	n	%
Pain	32	44
Difficulty breathing	28	38
Loss of appetite	26	35
Nausea	16	22
Sleeplessness	16	22
Edema	15	20
Fatigue	14	19
Dry mouth	13	18
Cough	12	16
Constipation	9	12
Itching	1	1

N = 73

Note. Respondents could choose more than one reply.

by anorexia and edema. Wives reported that patients' pain was the most difficult, followed by anorexia and dyspnea. Children reported that patients' pain, dyspnea, and nausea were the most difficult, in that order. Pain was the symptom that all family members found most difficult to deal with, regardless of patients' age, gender, or status of treatment. The presence or absence of symptoms was not correlated with the degree of satisfaction that family members reported with treatment and nursing care.

Use of narcotics had a significant influence on family perception that pain was the most difficult symptom to deal with. Twenty-five (57%) of the families of patients who used narcotics compared to seven (26%) of those who did not use narcotics had a hard time dealing with pain ($\chi^2 [1, n = 71] = 5.3$, $p < 0.05$).

Understanding the Use of Narcotics

Forty-four patients had been treated with narcotics; 32% of the respondents believed that patients' pain was relieved by their use, 57% believed no relief occurred, and 39% did not know whether pain was relieved. Family members were not aware of the use of narcotics for 23% of the patients treated.

Table 3 shows the respondents' understanding of narcotics use: 58% believed that if narcotics were used patients would soon die, 33% believed that frequent use results in addiction, 21% thought that they hasten patient death, and 19% thought that narcotics alter the personality.

Families' Expectations

When asked whether respondents would have used a hospice unit if the university hospital had one, 52% answered yes but 40% did not know. When asked whether they would have accepted homecare services if available, 56% answered yes. The reasons given for "no" answers included working outside the home (42%), lack of information about details of available local services (39%), crowded home space (19%), and difficulty in obtaining a death certificate (10%). When respondents were asked whether they had talked adequately with patients about the cancer or the prognosis, 51% answered that they could not talk adequately, 29% could talk adequately, and 21% were undecided. When asked what they wanted physicians to do if further treatment would be useless, 81% cited the importance of pain relief, 12% wanted active treatment, and 7% gave miscellaneous responses.

Table 4 shows families' expectations about terminal and nursing care. Respondents listed 72 descriptive items that

Table 3. Understanding Narcotic Use

Statement	Agree		Disagree		Do Not Know		Did Not Answer	
	n	%	n	%	n	%	n	%
Use of narcotics means the patient will soon die.	42	58	8	11	18	25	5	7
Frequent use of narcotics results in addiction.	24	33	18	25	21	29	10	14
Use of narcotics hastens patient death.	15	21	14	19	38	52	6	8
Use of narcotics alters the personality.	14	19	22	30	28	38	9	12

N = 73

Note. Because of rounding, not all percentages total 100.

they expected would be involved in terminal care and these were divided into five categories. Respondents expected pain control and symptom management (20 items) (e.g., “want the patient to be free from pain,” “symptom management is the highest priority”). Spiritual care comprised 13 descriptive items, including “preparation for death and dying” and “healing for loneliness.” Concern for the reduction of medical treatment focused only on the cancer consisted of 11 items (e.g., “chemotherapy with side effects”). Desire for support for family members comprised 6 items, including “information about what a patient is able to do in the terminal stage.” The appropriate information about diagnosis and prognosis consisted of 5 items (e.g., “need more consideration about telling the patient in the terminal stage the truth,” “care after the patient is informed of the diagnosis and prognosis”). Seventeen items fell into the “other” category.

Respondents’ expectations of nurses covered 68 descriptive items and also fell into five categories. Patient- and family-oriented nursing comprised 16 written items that included “speaking gently to the patient” and “approaches with a smile.” Improvement of nurses’ bedside manner and techniques also consisted of 16 written items (e.g., “comfortable suctioning,” “gentle touching”). Examples of concern for psychological care and support (11 items) included “want nurses to be constantly considerate of the patient’s feelings” and “want nurses to give spiritual care to the patient even if he or she asks the impossible.” Quick response comprised 6 written items that included “want nurse to give medicine and care immediately.” Individualized care according to specific situations (4 items) included

“ease up on hospital rules depending on the patient’s situation.” Fifteen items fell into the “other” category.

Respondents’ expectations of doctors comprised 83 descriptive items grouped into seven categories. They included appropriate informed consent for the family (17 items), psychological support for the patient and family (17 items), desire for satisfactory treatment (11 items), minimal medical tests (10 items), patient-centered treatment (9 items), treatment corresponding to palliative and home care instead of research- and treatment-based care (8 items), appropriate timing of treatment (3 items), and other (8 items).

Discussion

Research findings indicate that truth telling is an essential part of terminal cancer care (Surbone, 1997). In Japan, the number of patients to whom the diagnosis of cancer is disclosed is low but increasing (Uchitomi & Yamawaki, 1997). The number varies markedly with the type of Japanese medical facility: 92% of patients in a cancer hospital were told the true diagnosis, whereas only 29% of those in a general hospital were informed (Watanabe, 1998). In one general hospital, adult patients with curable cancer were told the truth more frequently than those with incurable cancers or those who were elderly (Watanabe). Another report showed that 60% of patients’ families believed that they had not been given information about the cancer diagnosis and pathology (Yokota, Tokashiki, & Ishizu, 1995).

In this research, the satisfaction rate for information received decreased as patients’ conditions deteriorated from admission to the terminal stage. The level of satisfaction was correlated with whether families had been given information about the cancer or prognosis at admission or following exacerbation of the disease. Respondents’ answer that they could have adequate talks with patients when given sufficient information about the possible period of survival indicates that family members’ awareness of the prognosis is a determining factor for smooth communication between patients and families.

The lack of information given by doctors and nurses as patients progress through the terminal stage indicates the need for continuous updating of information. Therefore, the receipt of adequate information appears to be a determining factor in families’ perceptions of the efficacy of terminal care. Nurses should act as mediators between doctors and patients and their families.

Respondents had the hardest time dealing with a family member’s pain. In a survey of families of patients who had died from cancer after being cared for in cancer hospitals and how they dealt with individual symptoms, 57% had difficulty dealing with pain, 47% with fatigue, 38% with dyspnea, 29%

Table 4. Family Expectations

Expectation	n	%
Type of terminal care		
Pain control and symptom management	20	27
Spiritual care	13	18
Reduction of medical treatment of the cancer itself	11	15
Support for family members	6	8
Appropriate information about diagnosis and prognosis	5	7
Other	17	23
Nursing care		
Patient- and family-oriented nursing	16	22
Improvement of bedside manner and techniques	16	22
Concern for psychological care and support	11	15
Quick responses	6	8
Individualized care according to specific situation	4	5
Other	15	21

N = 73

with the inability to move, and 25% with vomiting (Tsunoda et al., 1997). Some research has suggested that family caregivers perceive higher levels of distress from pain than patients do (Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002; Yeager, Miaskowski, Dibble, & Wallhagen, 1995), although one report indicated that cancer pain perceptions between patients and family caregivers are in general agreement (Lin, 2001).

Nurses need to recognize that caregivers may tend to perceive patients' pain as more severe than it actually is and that their sympathy for patients' pain causes caregivers great distress. Psychological support of family caregivers therefore is essential.

In this study, 57% of the respondents listed pain as the symptom most difficult to deal with, even when patients were given narcotics. Only 32% considered that patients' pain had been well relieved. This demonstrates that adequate pain control may not be provided at Japanese university hospitals and pain management and psychological support are priorities in the minds of family caregivers.

The misconceptions about the use of narcotics leading to drug addiction and hastening death shown by this research seem to be related to inadequate explanations about narcotics use. Therefore, as other research (Ferrell, Grant, Chan, Ann, & Ferrell, 1995; Yeager et al., 1995) suggests, reeducation of families about the role of narcotics in cancer treatment is required.

The current study's findings showed general satisfaction with the medical treatment (74%) and nursing care (90%) given. However, when expectations concerning doctors and nurses are considered, the need for patient-centered rather than cancer-centered care clearly was the goal of patients and families. Respondents expected spiritual care, pain management, and reduction of medical treatment focused only on the cancer for patients as well as support for family members. Eighty-one percent of the respondents who were told by physicians that further treatment would be useless desired pain relief for the patient. This is evidence that pain management and palliative care need to be provided to patients with terminal cancer in Japanese university hospitals that, at present, usually give primary importance to active treatment.

In Japan, few general hospitals have palliative care units. Because patients with cancer and their families tend to select general hospitals (especially large ones such as university hospitals) and many patients die there, initiatives for pain relief care should be adopted at general hospitals (Yagihashi et al., 1995). Provision for spiritual care, which families desire, is difficult in the absence of initiatives for pain relief care. The quality of life of patients in the terminal stages of cancer can be improved only if pain management and palliative and spiritual care are provided. A cross-cultural study of patients in Japan and the United States indicates that the barriers to pain management are inadequate knowledge, inadequate assessment of pain and pain relief, and lack of psychological support (Bookbinder & Ogasawara, 1997). Therefore, if a patient's quality of life is important, palliative care units should be established in general hospitals and offer pain management and spiritual care.

This research suggests that Japanese culture influences ways of thinking about terminal care for patients with cancer. Although Japanese families focused on hospice and home care, they attached importance to continuing medical treatment. Unlike practice in Europe and the United States, quality of life in 80% of these Japanese patients included continuing active medical treatment for as long as possible.

The traditional family-centered decision-making system that functions in Japan, Korea, and southeast Asia is a barrier that needs to be considered (Crow, Matheson, & Steed, 2000). When a patient is diagnosed with cancer in Japan, usually the physician first tells the family, who decides whether the patient should be told. The family makes the decisions about care; often, the patient does not even participate in the decisions. In addition, physicians assume a very authoritarian role (Ruhnke et al., 2000). Passivity shown by patients and family members and the paternalism exhibited by physicians is known as *omakase* (Ohmoto, Ooumi, Simabara, & Miyake, 1996; Voltz, Akabayashi, Reese, Ohi, & Sass, 1998).

In this study, the respondents did not want patients to be informed of the cancer diagnosis, but they themselves wanted adequate information. The Japanese family believes that not informing a patient about a cancer diagnosis is the family's prerogative.

Even when a patient and a family were sad and anxious, they acted, in many cases, as if they were not worried at all. Japanese patients who are terminally ill try to show consideration for their families by pretending they do not know of their diagnosis, believing that family harmony is more important. In this way, patients with terminal cancer do not show their distress and tend to accept death calmly (Seo, 1997). This is in contrast to the typical reactions of European and American families.

Limitations

Extrapolation of the findings to medical facilities must be done cautiously because the sample analyzed was from only one university hospital in Japan. In addition, the researcher-developed questionnaire used several types of rating scales. As a result, the reliability and validity of the completed questionnaire could not be confirmed conclusively. A low response rate also may be a limiting factor.

Conclusions

Terminal cancer care in Japanese university hospitals does not appear adequate in terms of patients' and families' quality of life. Family members had difficulty with patients' pain, dyspnea, and appetite loss. The most expected types of terminal care were pain control and symptom management in addition to spiritual care. Two major barriers to terminal care exist—insufficient current information given throughout the terminal stage of cancer and patients' and families' misunderstandings about the use of narcotics. Therefore, patients and their families must be educated about the efficacy of narcotics in the care of patients with terminal cancer. Moreover, the psychological care and support of patients and their families given by nurses was seen as inadequate.

Nurses should be aware of beliefs surrounding patients' cultural backgrounds, such as paternalism and family-centered decision making, when offering specific care to patients with terminal cancer. Doctors' emphasis on offering medical treatment rather than enhancing the quality of life of patients with terminal cancer is also a major issue in Japan, especially in university hospitals, because it tends to lead to inadequate palliative care.

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For more information . . .

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- Cancer Care
www.cancercare.org

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