

# Factors Influencing Decision-Making of Terminally Ill Cancer Patients and Their Families Regarding Where to Stay and Receive Final-Month Care: A Preliminary Study

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## Short report

**Keywords:** place for end-of-life care, place for final-month care, end of life, terminal cancer, caregiver burden, palliative care ward

**Posted Date:** August 3rd, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-754311/v1>

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# Abstract

## Background:

Advance care planning is essential for a better terminal phase, although many patients do not make a choice regarding the place of receiving terminal care even one month before the expected end of life. This study explores the factors that influence patients with a life-expectancy of less than one month when they are admitted to the palliative care ward or other terminal care institutions.

## Methods:

Self-administered questionnaire surveys were completed by patients and caregiver questionnaire surveys were completed by patients and caregivers. We assessed patient symptoms using Support Team Assessment Schedule-Japan (STAS-J), and all patients' families answered the self-reported questionnaire, Caregiver Reaction Assessment-Japan (CRA-J).

## Results:

The family care burden score for "Impact on schedule" was significantly higher for the palliative care ward inpatient group than for the non-inpatient group ( $21.0 \pm 1.5$  vs.  $17.6 \pm 1.8$ ;  $p < 0.01$ ).

## Conclusions:

Family burden might influence the choice of facility when patients with a survival prognosis of less than one month are admitted to the palliative care ward for reducing the burden of long-term care. Nurses should take care of family caregiver's physical and psychosocial health, especially before the patient's admission to the palliative care ward. The results of this study show that caregiver support is needed to reduce the feeling of family burden related to impact on schedule, enabling them to choose the best place for terminal care.

# Introduction

Developments in medicine mean that it is now possible to continue anticancer treatment even after recurrence and metastasis. However, as treatment becomes difficult, the issue of the end-of-life (EOL) care place arises [1]. As terminally ill cancer patients develop cancer-specific physical symptoms, such as pain and fatigue, caregivers develop symptoms due to the psychological and physical burden of care, and the burden of medical expenses [2–5].

A survey of cancer patients' intent regarding medical treatment and place of death revealed that patients in Europe and the United States prefer to die at home, while patients in Asia, including Japan, tend to prefer the hospital [6]. Although studies have been conducted on factors related to decision-making regarding the place of EOL for the final month, most of them were retrospective surveys of bereaved families of cancer patients [6–8]. Hence, the factors influencing terminally ill cancer patients and their

families in terms of the choice of care place by the families of EOL cancer patients with a life-expectancy of less than one month have not been fully clarified.

We report a preliminary survey regarding the factors affecting terminally ill cancer patients with a life-expectancy of less than one month and their caregivers when it is time to make a decision regarding a place to provide final-month care for EOL cancer patients. Although advance care planning (ACP) is essential for a smoother terminal phase, there are patients who have not made a choice regarding the place of receiving terminal care even one month before death. This preliminary survey was conducted among such cancer patients and their families. The study explores the factors that influence patients with a prognosis of less than one month when they make the decision to be admitted to a palliative care ward or other terminal care facility.

## Methods

### Subjects

Participants consisted of the caregiving family member and each of 14 cancer patients who had a life-expectancy of less than one month as diagnosed by a physician, who consulted with a cancer nursing specialist at the Cancer Nursing Consultation Department of Fujisawa Shounandai Hospital from June to September 2014. Primary physicians identified potential study participants according to the following criteria: (1) terminally ill cancer patients with a life-expectancy of less than one month, (2) age  $\geq$  20 years for both patients and care-giving family members, and (3) cancer patients who had not decided where to stay and receive the final month EOL care. Exclusion criteria were lack of consent and a life-expectancy prognosis of more than one month. Terminally ill cancer patients and their families visited the nurse for a consultation about the impending distress and for decision-making related to the place for receiving final-month care.

### Ethical considerations

This study was approved by the Institutional Review Board of Fujisawa Shounandai Hospital (28 - 004). Written informed consent was obtained from all participants prior to their enrollment in the study.

### Survey method

A self-administered questionnaire survey was conducted.

### Parameters assessed

#### 1) Patient attributes

1. The patients' sex, age, cancer origin, time from first diagnosis (months), performance status (PS), place of medical treatment (outpatient, inpatient), pain management, understanding of medical

condition (disease name, prognosis), mobility care assistance, mental state (anxiety/delirium, clarity) and pain, cognitive decline, insomnia, history of falls, and dementia were assessed.

2. The previously translated and validated Japanese symptom version of the Support Team Assessment Schedule (STAS), developed by Higginson et al., was used to measure the effect of symptoms on the patient [9].
3. The participants were dichotomized based on whether or not they were admitted to a palliative care ward and were classified as “palliative care ward” and “others”.

## 2) Family attributes

The previously validated Japanese version of the Caregiver Reaction Assessment [4] scale developed by Given et al. was used to measure the care burden on family caregivers [10]. The caregivers’ sex and age, relationship with the patient, and whether living together or apart was evaluated.

## Analysis

Patients were divided into two groups according to where the patients actually stayed after they consulted the nurses and after the survey. The inpatient group included those admitted to the palliative care ward, and the non-inpatient group included patients who received care elsewhere, and their backgrounds and details of medical treatment were examined and compared. For statistical analysis, one-way analysis of variance and the unpaired t-test were used for continuous and ordinal variables, and Fisher’s exact test was used for nominal variables, with the significance level set at < 5%. All analyses were performed using JMP ver. 15 (SAS Institute).

# Results

## 1) Overview of the patients and caregivers

Table 1 shows an overview of the patients. Consultations regarding medical treatments for terminally ill cancer patients with a survival prognosis of less than 1 month revealed that nine of them decided to receive care in the palliative care ward and were admitted within a week. The other five patients decided to receive care elsewhere, and patients who were hospitalized at the time of the survey were discharged to their homes within 3 days. Ten of the patients were male (71.4%), with an average age of  $75.0 \pm 6.5$  years. Cancer type was gastric in two (14.3%), and lung cancer in three (21.4%) patients, with a PS of 3 or higher in seven patients (50.0%). Opioids were used by eight patients (57.1%). Total STAS-J scores were not significantly different between palliative and non-palliative care ward patients ( $20.3 \pm 9.7$  and  $19.8 \pm 5.2$  respectively,  $p = 0.91$ ).

Table 1  
Patients' attributes

	Overall n = 14	Palliative care ward n = 9	Others n = 5	p-value
Patient sex				0.22
Female	4	4	0	
Male	10	5	5	
Patient age (years)				0.41 <sup>†</sup>
Mean ± standard deviation	75.0 ± 6.47	73.9 ± 7.7	77.0 ± 3.1	
Cancer origin				0.76
Gastric cancer	2	1	1	
Lung cancer	3	1	2	
Colorectal cancer	2	2		
Pancreatic cancer	2	2		
Breast cancer	1	1		
Liver cancer	1	1		
Kidney cancer	1		1	
Prostate cancer	2	1	1	
Time from the first diagnosis (months)				0.54 <sup>†</sup>
Mean ± standard deviation	17.4 ± 17.5	15.1 ± 12.2	21.4 ± 25.8	
PS				0.83
0	1	1		
1	2	1	1	
2	4	2	2	
3	6	4	2	
4	1	1		
Place of medical treatment				1.00
Hospitalization	7	4	3	

	Overall n = 14	Palliative care ward n = 9	Others n = 5	p- value
Outpatient	7	5	2	
Pain treatment				0.58
Opioids	8	6	2	
None	6	3	3	
Understanding of medical condition				0.31
Disease name	11	8	3	
Prognosis	3	1	2	
Mobility assistance				0.27
Assistance needed	7	6	1	
Able to walk	7	3	4	
Mental state				1.00
Anxiety/delirium	8	5	3	
No clarity issues	6	4	2	
Pain				0.51
Yes	11	8	3	
None	3	1	2	
Cognitive decline				0.30
Yes	6	5	1	
None	8	4	4	
Insomnia				1.00
Yes	9	6	3	
None	5	3	2	
History of falls				1.00
Yes	3	2	1	
None	11	7	4	
Dementia				1.00

	Overall n = 14	Palliative care ward n = 9	Others n = 5	p-value
Yes	3	2	1	
None	11	7	4	
Total STAS-J score	20.1 ± 8.2	20.3 ± 9.7	19.8 ± 5.2	0.91 <sup>†</sup>
Fisher's exact test,				
†: Ordinal scale/continuous variables were assessed using one-way ANOVA, with p < 0.05 considered significant.				
PS: performance status				

Table 2 shows data on the caregivers, 10 of whom were women (71.4%), including four wives (28.6%) and five daughters (35.7%). The average caregiver age was 58.6 ± 11.6 years, and nine lived with the patient (64.3%). At the time of the survey, there were seven outpatients and seven inpatients (50.0%).

Table 2  
Family caregiver's attributes

	Overall n = 14	Palliative care ward n = 9	Others n = 5	p-value
Caregiver sex				0.22
Female	10	5	5	
Male	4	4	0	
Caregiver age (years)				0.01 <sup>†</sup> *
Mean ± standard deviation	58.6 ± 11.6	64.0 ± 10.9	48.8 ± 3.6	
Caregiver's relationship with patient				0.02*
Wife	4	4		
Husband	2	2		
Son	2	2		
Daughter	5	1	4	
Daughter-in-law	1		1	
Living together or apart				< 0.001*
Together	9	9	0	
Apart	5	0	5	
Fisher's exact test,				
†: Ordinal scale/continuous variables were assessed using one-way ANOVA, with p < 0.05 considered significant.				
PS: performance status				

## 2) Factors associated with family care burden and palliative care ward admission

Table 3 shows the relationship between the choice of care place and the burden on family caregivers. Regarding family care burden, the subject score for "Impact on schedule" was significantly higher in the inpatient than the non-inpatient group ( $21.0 \pm 1.5$  vs.  $17.6 \pm 1.8$ ;  $p < 0.01$ ). No other significant correlations were observed.

Table 3  
Factors associated with family care burden and palliative care ward admission

	<b>Overall n = 14</b>	<b>Palliative care ward n = 9</b>	<b>Others n = 5</b>	<b>p-value</b>
Mean ± standard deviation				
Total CRF score	52.9 ± 8.4	55.6 ± 8.9	48.0 ± 4.9	0.11
Impact on schedule (5–25)	19.9 ± 2.4	21.0 ± 1.5	17.6 ± 1.8	< 0.01*
Caregiver's self-esteem (5–25)	11.0 ± 3.4	10.8 ± 3.8	11.4 ± 3.0	0.76
Lack of family support (4–20)	9.9 ± 3.1	10.6 ± 3.2	8.8 ± 2.9	0.33
Impact on health (2–10)	6.2 ± 2.0	6.9 ± 2.0	5.0 ± 1.4	0.09
Impact on finances (2–10)	6.5 ± 2.3	7.0 ± 2.6	5.6 ± 1.5	0.30
*: p < 0.05 with one-way analysis of variance considered significant				

## Discussion

In this study, we found that terminally ill cancer patients with a life-expectancy of less than one month whose families feel the care interferes with their schedules are more likely to be hospitalized in the palliative care ward. Worsening of symptoms in EOL patients does not affect decision-making regarding the final place of care, because total STAS-J score was not significantly different between palliative care ward admission and non-admission. In this study, the decision regarding admission to a palliative care ward tended to be made by older families and those who were living together. Terminally ill cancer patients develop physical symptoms peculiar to cancer, such as pain and fatigue, and caregivers experience a psychological, physical and financial burden related to medical expenses when providing care [3–5, 11–13]. Nurses should take care of family caregiver's physical and psychosocial health, especially before the patient's admission to a palliative care ward [14]. The results of this study show that support is needed to reduce the sense of family burden related to impact on schedule, which would enable them to choose the best place for terminal care.

The situation where patients have not decided the place for receiving care even at the end of life might be related to the fact that very few explanations about impending death are given to patients in Japan [15]. Few Japanese patients (4.8%) were informed of their impending death. Some studies reported that when elderly people needed discussions for decision making near the end of life, most lacked the capacity to make decisions [15–19]. Health care professionals were viewed as playing an important role in addressing interventions to improve communication, and in discussions about decision-making regarding the goals of EOL care [13, 19–21]. Nurses might need to provide assistance to families and physicians to facilitate EOL discussions for the entire family.

This study has some limitations. The participants were limited to patients with EOL cancer and a less than one-month survival prognosis. Caregiver age correlates significantly with the location of terminal care (younger caregivers prefer non-palliative care ward care). In future, further studies involving larger populations based on multi-facility surveys are necessary.

## **Conclusion**

Family burden might influence the decision regarding whether or not patients with a prognosis of less than one month are admitted to the palliative care ward for reducing the family caregiver's long-term care burden. Nurses should take care of the family caregiver's physical and psychosocial health, especially before the patient's admission to the palliative care ward. The results of this study show that support that reduces the feeling of family burden related to impact on schedule is needed to enable them to choose the best place for terminal care.

## **Declarations**

### **Ethics approval and consent to participate**

This study was approved by the Institutional Review Board of Fujisawa Shounandai Hospital (28-004). All subjects provided written informed consent to participate in the study.

### **Consent for publication**

Written informed consent for publication of this report was obtained from all participants prior to their enrollment in the study.

### **Availability of data and materials**

Detailed data are available from the corresponding author upon reasonable request.

### **Competing interests**

The authors declare that they have no competing interests.

### **Funding**

This research received no specific grant from any funding agency in the commercial or not-for-profit sectors.

### **Authors' contributions**

EH and FF organized the study. Data collection was performed by EH and the institution's physician, who designed the methods and wrote the first draft of the manuscript. HO revised the draft of the manuscript. All authors approved the final version of the manuscript.

## Acknowledgements

The authors would like to thank the patients and their family members.

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