

Experience of temporary discharge from the inpatient palliative care unit: A nationwide post-bereavement survey for end-of-life cancer patients

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Research Article

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Abstract

Background: Some patients admitted to an inpatient palliative care unit (PCU), and who were discharged temporarily to home, later died at the PCU. The experiences of these patients and their families during temporary discharge are unclear.

Methods: This study was part of a nationwide post-bereavement survey, the Japan Hospice and Palliative Care Evaluation 3 study. We sent questionnaires to the bereaved relatives of cancer patients who died in a PCU in 2018.

Results: Of the 968 questionnaires sent, 571 (59%) were analyzed. Sixteen percent of the patients experienced temporary discharge from the PCU. Seventy-two percent of the bereaved family reported that the patients said, "I am happy to be discharged to home." Between 22% and 37% of the patients reported an improvement in their condition after discharge. Family caregivers' recognition of the better quality of the patient's life at home and hospital doctors' assurances of re-hospitalization whenever necessary, were significantly associated with positive experiences of temporary discharge.

Conclusion: Bereaved family members recognized temporary discharge as a positive experience for both the patient and the family. Appropriate home palliative care and discharge planning contribute to positive experiences after discharge.

Introduction

Japanese specialized palliative care commenced with the incorporation of inpatient palliative care units (PCUs) into the national medical insurance system [1]. In 2014, 13% of all cancer deaths occurred in the PCU [2]. A Japanese PCU has two roles: as a place of death and for symptom control [3]. In the latter case, patients who had relief from distressing symptoms were discharged to home or were transferred to another facility. In fact, 16% of the patients who were admitted to a PCU were discharged alive [2]; however, this has been estimated to be lower than that reported by acute palliative care units in the US and Canada [4, 5]. A previous nationwide survey showed that 72% of patients who were discharged from PCU were cared for at home, 12% in an acute hospital, and 6% in a care facility; while 39% died at home, 39% in a PCU and 15% in an acute hospital [6]. These results suggest that 39% of the discharges were temporary, and that they needed to be re-admitted to a PCU again because of worsened symptoms or an increased care burden at home.

However, many Japanese prefer staying at home in the terminal phase [7, 8], with both patients and families preferring home care despite the possibility of readmission because of worsened symptoms or care burden. Therefore, the Japanese health authority founded the PCUs to ensure a coordinated discharge, cooperation with community-based medical institutions which deliver home care, and to accept emergency re-admission of the patients from home care [9].

Although home was found to be the most commonly preferred place of care for terminal patients worldwide [10], positive and negative effects and benefits of home care have been reported [11, 12]. Several post-bereavement surveys have reported that home deaths resulted in good deaths being achieved in Japan [13, 14]. However, most of these findings were limited to home deaths; experiences of patients who were discharged temporarily from a PCU and re-admitted and who then subsequently died in a PCU have not been reported. Although clinicians have felt the benefits of temporary discharge empirically, there has been no evidence supporting these benefits.

Therefore, in this study, we aimed to explore the experience of patients who were discharged temporarily from a PCU, from the perspective of the bereaved family members.

Methods

This study was part of a nationwide survey of bereaved family members of cancer patients that aimed at evaluating the quality of end-of-life care in Japan (the Japan Hospice and Palliative Care Evaluation Study 3 (J-HOPE3) conducted in 2018 [15]. The J-HOPE3 study was a multicenter questionnaire survey of bereaved family members of cancer patients who died in a PCU. Ethical approval for the study was granted by the Institutional Review Boards of the Tohoku University (No. 2013-1-334) and all the participating institutions.

Participants and procedures

The participants of this study were 968 bereaved family members of cancer patients who died in a PCU. The inclusion criteria were as follows: 1) the patient died of cancer, 2) the patient was aged 20 years or older, 3) the bereaved family member was aged 20 years or older, and 4) the duration of the last hospitalization was three days or more. The exclusion criteria were as follows: 1) the bereaved family members could not be identified; 2) death was associated with the treatment; 3) the participant experienced serious psychological distress, as determined by the primary physician, and 4) the participant was incapable of completing the self-reported questionnaire because of health issues such as cognitive impairment or visual disability.

The PCUs where the patients were hospitalized and then died sent the questionnaire to bereaved family members between May and July 2014.

Questionnaires

Experience of discharge by what the patient had said

We asked the bereaved family members about the experience of discharge by what the patient had said; whether the patient had said “I am happy to be discharged to home,” “I regret being discharged to home,” or “both.”

Family member's perceptions of the experiences of temporary discharge

We asked the bereaved family members about their perceptions of the temporary discharge, patients' circumstances compared to being hospitalized, and family circumstances compared to the patient being hospitalized. We developed 17 questions based on a literature review, interviews with 10 bereaved family members, and discussions among researchers. Responses were rated on a 5-point Likert scale (1 = disagree, 2 = somewhat disagree, 3 = unsure, 4 = somewhat agree, 5 = agree).

Circumstances of the patient and family caregiver before and after temporary discharge.

We asked the bereaved family members about the circumstances of the patients and family caregivers before and after the temporary discharge; for example, the preferences of the patients and family members on discharging to home; the physical, mental, and social status of the patients and families before discharge; and the consultation and support by health care professionals before and after discharge. We developed 26 questions based on a literature review, interviews with 10 bereaved family members, and discussions among researchers. We asked the participants to respond to either 1: agree or 2: disagree.

Participant characteristics

We extracted the patient's age, sex, primary cancer sites, and duration of the last hospital stay from the medical records. Using the questionnaire, we obtained the bereaved family member's age, gender, relationships with the patient, frequencies of visits to the patient during the last hospitalization, their health status during the last hospitalization, and end-of-life discussions with the physician and the patient.

Statistical analysis

First, we compared the characteristics of the patients and bereaved family members between the discharged and non-discharged groups using the Chi-squared test. Second, for the patients who were discharged to home temporarily, we used descriptive statistics to analyze their experiences after the temporary discharge as well as the circumstances of the patients and family caregivers before and after the temporary discharge. Lastly, we explored associations between having positive experiences of discharge by what the patient had said, namely, "I am happy to be discharged to home," the experience after the temporary discharge and the circumstances of the patients and family caregivers before and after temporary discharge using the Chi-square test or Fisher's exact test, as appropriate. All statistical tests were two-tailed with a significance level of 0.05, and all analyses were conducted using SPSS Statistics for Windows, version 25.0 (IBM Corp., Tokyo, Japan).

Results

Of the 968 questionnaires mailed to bereaved family members of cancer patients, 711 were returned. Of these, 74 refused to answer, 25 were excluded because of violation of the inclusion criteria, and 41 did not

provide answers about the presence or absence of temporary discharge from the PCU. Therefore, 571 questionnaires were analyzed (59%).

Of the 571 respondents, 90 (15.8%) answered that they had experienced temporary discharge from a PCU. Durations from discharge to home to re-admission to a PCU were as follows; 25 patients (25.6%) stayed at home for less than 3 days, 9 (10.0%) for 4–6 days, 11 (12.2%) for 7–13 days, 16 (17.8%) for 1–29 days, and 29 (32.2%) for more than 30 days.

Table 1 shows the participants' characteristics according to whether they were in the discharged or non-discharged groups. Sex (male: $P=0.05$), longer disease duration of cancer ($P=0.004$), better mental health status of caregivers during the last hospitalization ($P=0.04$), and frequent attendance of family members during the last hospitalization ($P=0.01$) were associated with discharge.

With regard to the experience of discharge by what the patient had said, 72% of the patients reported: "I am happy to be discharged to home," 1% reported, "I regret being discharged to home," 4% reported, "both," and 20% did not say anything about the experience of discharge.

The family members' perceptions of the experiences of temporary discharge are shown in Table 2. Seventy-eight percent answered: "both patient and family felt happy by staying at home together; followed by "patient and family members were able to spend time together peacefully (71%)," "the time spent together at home was precious (68%)," "family members were able to spend more time with the patient (66%)," "family members were satisfied that they were able to take care of the patient at home (60%)." Between 22% to 37% of the participants reported improvement in the patients' circumstances and between 15% to 66% reported improvements in the families' circumstances compared to those reported for patients that were hospitalized.

The circumstances of the patients and family caregivers before and after temporary discharge are shown in Table 3. Regarding the circumstances of the patients and the families before temporary discharge, 88% of the participants answered: "the family wanted to spend time with the patient." As for the preparation for temporary discharge, 87% answered "the hospital doctor promised that the patient could be re-hospitalized if necessary." As for medical support after discharge, 91% answered, "the patient was able to be re-hospitalized on the patient's or family's request."

We showed statistically significant associations between having a positive experience of discharge by what the patient had said, the family members' perceptions of the experiences of temporary discharge and the circumstances of the patients and family caregivers before and after temporary discharge (Table 4). The patients who were discharged to home, compared to those who were not, answered "the time spent together at home was precious ($P=0.005$)," "the patient was able to have the time that he/she had wished to spend ($P=0.02$)," "the patient had smiled more ($P=0.02$)," "the patient had slept better ($P=0.05$)," "the patient had an increased appetite ($P=0.05$)," "the family members were able to spend more time with the patient ($P=0.01$)," "the patient showed obvious desire to be discharged to home ($P=0.001$)," "the hospital doctor promised that the patient could be re-hospitalized whenever and if necessary ($P=0.001$),"

“the hospital doctor strongly recommended that the patient be discharged ($P=0.02$),” “the patient and family members had a chance to try staying at home overnight for trial($P=0.02$),” “the patient was able to be re-hospitalized on patient's or family's request ($P=0.008$),” “the home visit doctors, nurses, and care manager were well coordinated during the patient's care ($P=0.04$),” “ and reported more positive experiences.

Discussion

The major findings of this study were as follows: 1) 16% of the patients who died in the PCUs experienced temporary discharge; 2) most of the patients and bereaved family members appreciated their experience of temporary discharge and between 22% and 37% of them reported improvements in the patients' conditions after discharge, 3) the family caregivers' recognition of the better quality of the patient's life at home and the hospital doctors' assurances of re-hospitalization whenever and if necessary were strongly associated with positive experiences by what the patient had said.

With respect to the factors related to the duration of the temporary discharge, significant variables were found to be almost similar to those of a previous study that explored factors related to discharge from a PCU [16–18]. In addition, the results of the circumstances of the patients and family caregivers during the temporary discharge revealed that most patients were in desirable circumstances, which were almost similar to the factors that would contribute to home death [19]. These results suggest that discharge planning for home death can contribute to patients and families' positive experiences at the end of life, regardless of the place of death.

We reported the first nationwide quantitative study on the experience of temporary discharge, although clinicians have felt the benefits of temporary discharge empirically. Although re-admission in the terminal stage is sometimes regarded as one of the negative quality indicators [20]; family caregivers sometimes considered caring for the patients at home as an achievement and that admission or re-admission and dying in the hospital were not considered negatively [12]. These results support our recommendation for temporary discharge even if the patient was expected to stay a long time at home.

Approximately 20% of the patients had improved physical conditions such as pain and appetite. Although several studies have shown that symptom management was better in the institutional hospice setting than in the home setting [21, 22], staying at home may have had a positive impact on the relieve of physical symptoms in some patients [23]. These benefits may have resulted in the better survival in home palliative care settings [5, 24, 25].

In addition, the explanatory analysis of the factors associated with positive experience by what the patient had said and the hospital doctors' assurance of re-hospitalization during discharge counseling, emphasized the importance of providing appropriate home palliative care after discharge.

Limitations

This study had some limitations. First, the response rate was not very high, and we could analyze only 90 questionnaires. Second, the bereaved family members' opinions might not have reflected the patients' experiences. Lastly, we analyzed the patients who died at the PCU, and we excluded patients whose last hospitalization was less than 3 days. We did not analyze the experience of patients and family caregivers who died without having been in a PCU or were readmitted at the very end of life.

Conclusions

Bereaved family members recognized temporary discharge as a positive experience for both the patient and family. Appropriate home palliative care and discharge planning contributed to positive experiences after discharge.

Declarations

Funding:

This study was supported by the Hospice Palliative Care Japan.

Conflicts of interest:

The authors have no conflicts of interest to declare that are relevant to the content of this article.

Ethics approval:

Ethical approval for the study was granted by the Institutional Review Boards of the Tohoku University (No. 2013-1-334) and all the participating institutions.

Consent to participate:

Responses to the questionnaire were regarded as consent.

Consent for publication:

Responses to the questionnaire were regarded as consent.

Availability of data and material:

We can provide the data if needed.

Authors' contributions:

All authors contributed to the study conception and design. Data collection were performed by Go Sekimoto, Maho Aoyama, and Mitsunori Miyashita. Data analysis were performed by Go Sekimoto, Sakiko Aso, and Mitsunori Miyashita. The first draft of the manuscript was written by Go Sekimoto and

all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Tables

Table 1. Participant Characteristics							
		Total	No discharge		Discharged		
		N=571	N=481		N=90		
		n	n	%	n	%	P value
Patient							
Age(years), Mean±SD			73.7±11.3		74.5±10.6		0.54
Sex							
	Male	320	278	59.5	43	48.3	0.05
	Female	234	189	40.5	46	51.7	
Primary cancer site							
	Lung	147	128	26.7	19	21.1	0.92
	Stomach	66	54	11.3	12	13.3	
	Colorectum/rectum	64	52	10.8	12	13.3	
	Pancreas	58	48	10.0	11	12.2	
	Urinary	41	35	7.3	6	6.7	
	Liver	28	26	5.4	2	2.2	
	Gynecological	29	24	5.0	5	5.6	
	Breast	26	22	4.6	4	4.4	
	Gall bladder/bile duct	26	21	4.4	5	5.6	
	Other	83	70	14.6	14	15.6	
Marital status							
	Married	351	294	62.3	59	68.6	0.71
	Divorced/widowed	176	152	32.2	24	27.9	
	Not married	29	26	5.5	3	3.5	
Duration of cancer							
	≤3 months	74	73	15.2	1	1.1	0.004
	≥3 months, ≤1 year	157	130	27.1	29	32.6	
	≥1 year, ≤3 years	175	146	30.5	29	32.6	
	≥3 years	160	130	27.1	30	33.7	
Duration of the last PCU stay (days), Mean±SD			40.75±53.31		34.72±32.46		0.96
Preference about place of death (patient)							
	Home	221	183	38.6	39	43.3	0.47
	PCU	212	177	37.3	35	38.9	
	Hospital	25	20	4.2	6	6.7	
	Other	3	3	0.6	0	0.0	
	No preference	19	17	3.6	2	2.2	
	Unsure	82	74	15.6	8	8.9	
Bereaved family member							
Age (years), Mean±SD			60.84±12.08		62.2±11.5		0.66
Gender							
	Male	174	141	29.9	35	39.3	0.08
	Female	385	331	70.1	54	60.7	
Relationship with patients							
	Spouse	258	217	45.5	43	47.8	0.22
	Child	216	178	37.3	38	42.2	
	Others	91	82	17.191	9	10.0	
Physical status during the last hospitalization							
	Good	113	87	18.2	26	29.2	0.12
	Moderate	315	272	57.0	44	49.4	
	Bad	119	104	21.8	16	18.0	
	Very bad	17	14	2.9	3	3.4	
Mental status during the last hospitalization							
	Good	47	35	7.4	12	13.3	0.04
	Moderate	277	227	47.9	51	56.7	
	Bad	207	185	39.0	23	25.6	
	Very bad	31	27	5.7	4	4.4	
Frequency attending the patient (days/week)							

Everyday	369	322	67.1	48	53.3	0.01
4-6	77	60	12.5	17	18.9	
1-3	86	70	14.6	16	17.8	
01	36	28	5.8	9	10.0	
Preference about place of death (family)						
Home	129	103	21.8	26	29.5	0.62
PCU	370	314	66.4	56	63.6	
Hospital	25	22	4.7	3	3.4	
Other	2	2	0.4	0	0.0	
No preference	17	15	3.2	2	2.3	
Unsure	18	17	3.6	1	1.1	

SD, standard deviation; PUC: inpatient palliative care unit

	Agree, somewhat agree (%)	Unsure (%)	Somewhat disagree, disagree (%)
Family's perceptions about temporary discharge			
Both the patient and the family felt happy by staying at home together. (N=87)	78	15	7
The patient and the family were able to spend time together peacefully. (N=87)	71	18	10
The time spent together at home was precious. (N=87)	68	24	8
Family were satisfied about taking care of the patient at home. (N=87)	60	32	8
Time spent together at home had strengthened their family bonding. (N=86)	53	34	13
Family regretted that the patient left home and was re-hospitalized. (N=87)	26	40	33
Family felt that the patient was forced to be discharged. (N=86)	13	14	73
Patient's condition compared to being hospitalized			
Patient was able to have the time he/she had wished to spend. (N=87)	37	31	32
Patient had smiled more. (N=87)	36	41	23
Patient had slept better. (N=86)	23	41	36
Patient had increased appetite. (N=86)	22	29	49
Patient expressed less pain. (N=85)	22	29	48
Family condition compared to patient being hospitalized			
Family were able to spend more time with the patient. (N=87)	66	14	21
Family felt more burden to care the patient. (N=87)	46	31	23
Family felt peaceful. (N=87)	28	39	33
Family was able to have more free time. (N=87)	15	45	40
Family had slept better. (N=87)	15	39	46

Table 3. Circumstances of the patient and family caregiver before and after temporary discharge.		
	Agree(%)	Disagree(%)
Circumstances of the patient and family before temporary discharge		
Family wanted to spend time with the patient. (N=86)	88	12
Patient showed obvious desire to be discharged to home. (N=86)	81	19
Family had understood that the patient would not stay long at home. (N=85)	81	19
Pain and other symptoms were controlled. (N=84)	80	20
Family had thought that the patient could be hospitalized in the PCU as long as they wished. (N=85)	65	35
Family wished to take care of the patient at home. (N=81)	54	46
Patient needed medical treatment such as injection and drainage. (N=86)	28	72
There was disagreement among family members about the patient's discharge. (N=86)	6	94
Preparation of temporary discharge		
The hospital doctor promised that the patient could be re-hospitalized whenever if necessary (N=84)	87	13
The hospital doctor informed that the home visit clinics and hospital can provide consultation at any time of the day. (N=81)	85	15
Family could consult with the hospital staffs about the patient's daily life and home care services after being discharged. (N=81)	79	21
The hospital doctor told the family the remaining life expectancy of the patient. (N=85)	59	41
Family had met the home visit doctors and nurses before being discharged. (N=82)	59	41
The hospital doctor strongly recommended that the patient be discharged. (N=82)	44	56
The patient and the family had a chance to try staying at home overnight for trial. (N=82)	40	60
The home visit doctor was familiar with the hospital doctor. (N=75)	39	61
The length of time staying at home was planned in advance. (N=84)	32	68
Medical support after discharge		
The patient was able to be re-hospitalized on the patient's or family's request. (N=78)	91	9
Home visit doctors and nurses gave attention to family as well. (N=75)	84	16
The home visit clinic or PCU provided consultation at any time of day. (N=78)	82	18
Home visit nurses had understanding of the values of the patient and family. (N=72)	81	19
Home visit doctors and nurses worked closely with the PCU staffs regarding patient's care. (N=72)	78	22
Home visit doctors had understanding of the values of the patient and family. (N=71)	76	24
Home visit doctors and nurses were able to relieve pain of the patient. (N=72)	71	29
Home visit doctors, nurses, and care manager were well coordinated during the patient's care. (N=73)	70	30
The patient used respite services, home help services, or volunteer services. (N=76)	33	67

PCU: palliative care unit

Table 4. Associations between the positive experience of discharge by what the patient had said, and family member's perceptions of the experiences of temporary discharge and circumstances of patient and family caregiver before and after temporary discharge.

	patient expressed happiness to be discharged to home	patient expressed regret, neither happiness nor regret, or expressed nothing			
	N=63		N=24		
	□	□	□	□	P value
The time spent together at home was precious.					
Agree; somewhat agree	47	81.0	11	19.0	0.005
Unsure; somewhat disagree; disagree	14	51.9	13	48.1	
The patient was able to have time he/she wished to spend.					
Agree; somewhat agree	27	87.1	4	12.9	0.02
Unsure; somewhat disagree; disagree	34	63.0	20	37.0	
The patient had showed more smile.					
Agree; somewhat agree	26	86.7	4	13.3	0.02
Unsure; somewhat disagree; disagree	35	63.6	20	36.4	
The patient had slept better.					
Agree; somewhat agree	18	90.0	2	10.0	0.05
Unsure; somewhat disagree; disagree	43	67.2	21	32.8	
The patient had increased appetite.					
Agree; somewhat agree	22	88.0	3	12.0	0.05
Unsure; somewhat disagree; disagree	38	66.7	19	33.3	
The family were able to spend more time with the patient.					
Agree; somewhat agree	45	80.4	11	19.6	0.01
Unsure; somewhat disagree; disagree	16	55.2	13	44.8	
The patient showed obvious desire to be discharged to home.					
Agree	56	81.2	13	18.8	0.001
Disagree	5	31.3	11	68.8	
The hospital doctor promised that the patient could be re-hospitalized whenever and if necessary.					
Agree	56	80.0	14	20.0	0.001
Disagree	2	16.7	10	83.3	
The hospital doctor strongly recommended the patient be discharged.					
Agree	30	83.3	6	16.7	0.02
Disagree	27	70.4	18	29.6	
The patient and the family had a chance to try staying at home overnight.					
Agree	27	87.1	4	12.9	0.02
Disagree	31	62.0	19	38.0	

The patient was able to be re-hospitalized on patient's or family's request.					
Agree	53	75.7	17	24.3	0.008
Disagree	2	28.6	5	71.4	
Home visit doctors and nurses and care manager were well coordinated during patient's care.					
Agree	39	70.8	11	29.2	0.04
Disagree	12	54.5	10	45.5	