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ORIGINAL ARTICLE

Length of home hospice care, family-perceived timing of referrals, perceived quality of care, and quality of death and dying in terminally ill cancer patients who died at home

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Abstract
Purpose This study aims to clarify the length of home hospice care, family-perceived timing of referrals, and their effects on the family-perceived quality of care and quality of death and dying of terminally ill cancer patients who died at home and identify the determinants of perceived late referrals.
Methods A multicenter questionnaire survey was conducted involving 1,052 family members of cancer patients who died at home supported by 15 home-based hospice services throughout Japan.
Results A total of 693 responses were analyzed (effective response rate, 66 %). Patients received home-based hospice care for a median of 35.0 days, and 8.0 % received home hospice care for less than 1 week. While 1.5 % of the families reported the timing of referrals as early, 42 % reported the timing as late or too late. The families of patients with a length of care of less than 4 weeks were more likely to regard the timing of referrals as late or too late. The patients of family members who regarded the timing of referrals as late or too late had a significantly lower perceived quality of care (effect size, 0.18; P=0.039) and lower quality of death and dying (effect size, 0.15, P=0.063). Independent determinants of higher likelihoods of perceived late referrals included: frequent visits to emergency departments, patient being unprepared for worsening condition, and patient having concerns about relationship with new doctor. Discharge nurse availability was independently associated with lower likelihoods of perceived late referrals.
Conclusions A significant number of bereaved families regarded the timing of referrals to home hospices as late, and

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the perceived timing was associated with the family-perceived quality of care and quality of death and dying. Systematic strategies to overcome the barriers related to perceived late referrals are necessary.

Keywords Hospice · Referral · Length of stay · Quality of death and dying · Quality of care

Introduction

Several studies have revealed that hospice care contributes to increased opportunities to die at home, a reduced frequency of emergency department visits, and improved satisfaction of both patients and their families [1–3]. Multiple surveys from several countries, however, have consistently shown that physicians referred patients to hospice care services at the very latest stage of cancer: the median interval from referral to patient death ranged from 2 to 6 weeks and about 15 to 35 % of the patients died within a week after referral [4–11]. Some studies demonstrated that a shorter length of hospice enrollment was associated with an increased risk of major depressive disorder in family caregivers, less satisfaction with hospice care of family caregivers, and inadequate symptom management [9, 12–16]. Another recent study clarified that patients who received less than a week of hospice care had the same quality of life as patients who did not receive hospice care at all [17].

On the other hand, some studies identified that the family-perceived timing of referrals, not the length of receiving hospice care itself, was significantly correlated with the family-perceived quality of care [4, 6]. Many studies stressed the importance of appropriate referral to a hospice and/or palliative care service to identify unmet needs early, alleviate pain and suffering appropriately, and strengthen emotional connections between patients and their families [18–21]. Recent studies revealed that early hospice and/or palliative care referral improves patients' understanding of the prognosis over time, which may improve end-of-life decision-making [22, 23].

The factors contributing to late referrals are associated with patients, families, physicians, and health care systems [24–28]. To date, empirical studies on healthcare providers have identified multiple barriers to appropriate referrals: patients'/families' unwillingness to receive hospice care, patients'/families' misconceptions about hospices, physicians' unwillingness to discuss end-of-life care, and a lack of hospice care services available [24–28]. Although these findings provide useful information to understand why physicians do not refer patients to hospice care services at an earlier stage of cancer, only small numbers of systematic studies have still been performed to directly collect the views of terminally ill patients with cancer or their families. A recent qualitative study in the USA clarified that the reasons for family-perceived late referrals were centered on concerns with the healthcare providers' role in decision-making, with the main concerns being inadequate with communication physicians and not recognizing that the patient is dying [29]. On the other hand, to our best knowledge, no quantitative empirical studies have investigated factors influencing the perceived timing of hospice referral in terms of the actual experiences of families of cancer patients who received home hospice care and died at home.

In Japan, home care is provided by three types of medical facility in collaboration with home-visiting nurses: physicians working at clinics, clinics with a home hospice function (focusing on delivering home care rather than outpatient care), and home care divisions of hospitals [30]. Eligible criteria for home care service are patients who cannot visit outpatient medical facilities and principally terminally ill patients. Typically, if a patient's condition is relatively stable, a physician visits the patient's home weekly and home-visiting nurses visit the home one to three times per week. For imminently dying patients or patients with marked symptoms, physicians and nurses visit every day when needed, and 24-h 7-day call-out is available. Common medical procedures, such as subcutaneous infusion and home parenteral nutrition using an implantable central venous access device, are available. When discharged from hospital, a discharge nurse arranges services at home required for the patient. Daily life at home is assisted by home helpers covered by the national long-term care insurance, in addition to family caregivers. Respite care is provided by nursing homes, palliative care units, or hospitals. If patients want to be admitted to hospitals, admission is generally possible. Very recently, the government has been trying to develop more efficient home care services through modifying laws, healthcare systems, and multiple educational or cooperative projects. Nevertheless, investigations of referrals to home hospices with a focus on the length and timing among terminally ill Japanese patients with cancer in a home hospice setting have yet to be performed.

The primary aims of this study were: (1) to clarify the length of home hospice care, family-perceived timing of referrals, and their associations in terminally ill cancer patients who died at home, (2) explore the effects of the length of home hospice care and family-perceived timing of referrals on perceived quality of care and quality of death and dying, and (3) identify the determinants of perceived late referrals. The ultimate aim was to identify ways to promote appropriate referrals to home hospice care for patients with advanced cancer.

Subjects and methods

This is a part of a large nationwide survey of bereaved family members of cancer patients (Japan Hospice and Palliative care

Evaluation study: J-HOPEII [31], and a multicenter questionnaire survey was conducted involving bereaved family members of cancer patients who died at home. We mailed questionnaires to bereaved families in June 2007 and again in August 2007 to nonresponding families. The return of the completed questionnaire was regarded as consent to participate in this study. Ethical and scientific validity was confirmed by the institutional review boards of all participating institutions.

Settings and subjects

Participating institutions were recruited from home-based hospice services belonging to the Japan Hospice Association. Among all 37 home-based hospice services belonging to the Association, a total of 15 agreed to participate in this survey.

Primary responsible physicians identified potential participants following the inclusion criteria: (1) bereaved family members of an adult cancer patient (one family member was selected for each patient), (2) aged 20 or older, (3) capable of replying to a self-reported questionnaire, and (4) aware of the diagnosis of malignancy. Exclusion criteria included: (1) inability to complete the questionnaire (dementia, cognitive failure, psychiatric illness, language difficulty, or visual loss), (2) severe emotional distress of the family, as determined by the primary responsible physicians, (3) treatment-associated death or death from comorbidity, (4) death in intensive care units, and (5) no family member unavailable. The second criterion was, as in our previous studies [32–35], adopted on the assumption that primary responsible physicians could identify families who may suffer a serious psychological impact due to the present study, and no formal criteria or psychiatric screening was applied. Families were surveyed 6 to 12 months after the patients' deaths.

Questionnaire

The questionnaire was developed by the authors on the basis of a literature review [5, 8, 9, 12–21, 24–29], interviews, and focus groups involving healthcare professionals and 28 bereaved family members.

Length of care and family-perceived timing of referrals

The primary end-points were the length of home hospice care and family-perceived appropriateness of the timing of physicians' referrals of patients to home hospice services. The former data were obtained from each hospice service. The latter were measured using the same methods as in previous studies [5, 8]. The level of the family-perceived appropriateness was rated on a 5-point scale: "should have been referred much later (very early)," "should have been referred a little later (early)," "referred at the appropriate time," "should have been referred a little earlier (late)," and "should have been referred much earlier (too late)."

Family-perceived quality of care

The family members were asked to rate their perceived quality of palliative care of responsible facilities when the patient died. Family-perceived quality of care was measured using the Care Evaluation Scale, a well-validated and the most commonly used measurement tool to quantify user-perceived quality of palliative care in Japan [36]. This consists of eight subdomains: (1) physical care provided by physicians, (2) physical care provided by nurses, (3) psycho-existential care, (4) help with decision-making, (5) coordination/consistency of care, (6) environment, (7) cost, and (8) availability. Each subscale had two or three items graded with a 6-point Likert-type scale, from "1: improvement is markedly necessary" to "6: improvement is not necessary at all," and the total score of the Care Evaluation Scale was defined as the mean of all subdomain scores. Higher values indicated a lower perceived necessity of improvement, with a range of 1 to 6.

Quality of death and dying

The family members were asked to rate the quality of death and dying over the last month of the patient's life. The quality of death and dying was measured using the Good Death Inventory, a measure of the quality of death and dying of patients with advanced cancer [37]. The full version of this scale was used, consisting of ten domains: (1) physical and psychological comfort, (2) living in one's favorite place, (3) maintaining hope and pleasure, (4) having a good relationship with medical staff, (5) not feeling a burden to others, (6) having a good relationship with the family, (7) having independence, (8) living in a comfortable environment, (9) being respected as an individual, and (10) a feeling of fulfillment at life's completion. Each item was assessed using a 7-point Likert-type scale, from "1: strongly disagree" to "7: strongly agree," and the total score was defined as the mean of all subdomain scores. Higher values indicated a higher perceived quality of death and dying, with a range of 1 to 7.

Factors contributing to perceived timing of referrals

Family members were asked to rate the level of agreement with nine statements (yes or no) and six statements (strongly disagree, 1 to strongly agree, 5) as potential factors contributing to their perceived timing of referrals (Table 4). In addition, negative perceptions of home hospices were examined using the mean level of agreement for seven statements: symptoms cannot be sufficiently alleviated at home, home care cannot adequately respond to sudden changes out of hours, home-visit doctors are unavailable, home care causes a heavy family burden, staying at home is expensive, hospital beds are unavailable even if necessary, and patients cannot receive better treatment at home than at hospitals. Each item was rated on a 4-point Likert-type scale, from strongly disagree (1) to strongly agree (4), and the score was calculated as the mean score for each item. A higher score thus indicates a more negative perception of home care, with a range of 1 to 4. Cronbach' alpha was 0.81, and factor analysis identified one factor.

Analyses

We initially calculated the frequency with 95 % confidence intervals for the length of home hospice care and family-perceived timing of referrals. Then, the percentages of the respondents who reported that referrals were late or too late were calculated with 95 % confidence intervals for five groups with a different length of care (<1 week, 1 week to less than 2 weeks, 2 weeks to less than 4 weeks, 4 weeks to less than 8 weeks, and 8 weeks or longer). Secondly, we compared the scores for the perceived quality of care and quality of death and dying between the patients with a length of care of less than 2 vs. 2 weeks or longer, patients with a length of care of less than 4 vs. 4 weeks or longer, and patients with family-perceived late or too late referrals vs. appropriate; the respondents with early and too early perceived timings of referrals were excluded from further analysis. Comparisons were performed using Student's *t* test. We calculated Hedges' g to estimate the effect size, and effect sizes of 0.2, 0.5, and 0.8 were regarded as small, moderate, and large effects, respectively [38, 39]. Thirdly, we compared demographic data and factors contributing to the perceived timing of referrals using univariate logistic regression analysis to screen, followed by multivariate logistic regression analysis. All variables with *P* values of 0.10 or less were entered into the model, and a step-forward elimination method was adopted. The *P* value regarded as significant was 0.050. All analyses were performed using the Statistical Package for the Social Sciences (ver. 11.0).

Results

A total of 1,120 family members met the inclusion criteria, and 68 of them were excluded according to the exclusion criteria. We thus sent our 1,052 questionnaires, and 723 (70 %) were returned, with 24 returned due to the wrong address. Of those, 25 refused to reply. Therefore, we obtained a total of 698 responses. For the present study, as five responses were excluded due to missing data on the length of care, we finally analyzed 693 (66 %) responses. Background characteristics are summarized in Table 1.

Length of care and family-perceived timing of referrals

Patients received home-based hospice care for a median of 35.0 days (range, 3 to 1,307 days). A total of 8.0 % of the patients received home hospice care for less than 1 week, and 21 % received it for less than 2 weeks (Table 2). While the number of family members who reported that the timing of referrals was early or too early was very small, being 1.5 %, 42 % reported that the timing was late or too late, and the remaining 56 % of the family members reported that the timing was appropriate, (Table 2).

Table 1 Respondents' characteristics (*n*=683)

	Number	Percent
Patients		
Age (mean, standard deviation)	72 (12)	
Sex		
Male	417	60
Female	266	40
Primary tumor sites		
Lung	154	22
Stomach and esophagus	122	18
Colon and rectum	88	13
Liver, bile duct, and pancreas	149	22
Breast	18	2.6
Prostate, kidney, and bladder	49	7.2
Uterus and ovary	22	3.2
Head and neck and brain	29	4.2
Blood	13	1.9
Others	39	5.7
Bereaved families		
Age (mean, standard deviation)	62 (12)	
Sex		
Male	150	22
Female	524	77
Relationship with patients		
Husband/wife	399	58
Child	200	29
Others	78	12

Some data do not add up to 100 % due to missing values

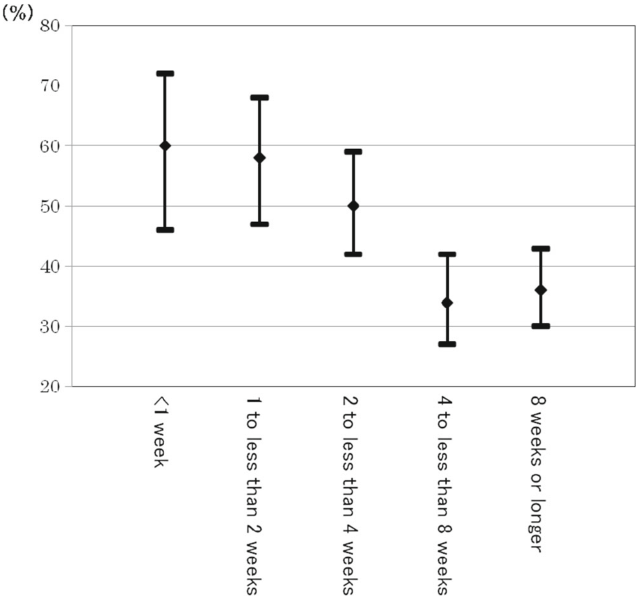
Table 2 Length of care and perceived timing of referrals

	Number	Percent	95 % confidence intervals
Length of care			
<1 week	55	8.0	6, 10
1 week to less than 2 weeks	87	13	10, 15
2 weeks to less than 4 weeks	141	21	18, 24
4 weeks to less than 8 weeks	161	24	20, 27
8 weeks or longer	239	35	31, 39
Family-perceived timing of referral to home hospice[a]			
Too early	6	1.0	0, 2
Early	3	0.5	0, 1
Appropriate	372	56	52, 60
Late	121	18	15, 21
Too late	162	24	21, 28
Missing	19	–	–

[a] Percentages were calculated of the total data available (*n*, 664)

Association between length of care and family-perceived timing of referrals

There were significant differences in the rates of those who reported that the timing was late or too late among the patients with different lengths of care (*P*<0.0001; Fig. 1). The family members of patients with a length of care of less than 4 weeks were more likely to report that the timing of referrals was late or too late compared to those with care of 4 weeks or more. The rates of family members who reported that the timing of referrals was late or too late were: 60 % (<1 week), 58 % (1 week to less than 2 weeks), 50 % (2 weeks to less than 4 weeks), 34 % (4 weeks to less than 8 weeks), and 36 % (8 weeks or longer).



The percentages of families who reported that the timing of referrals was late or too late with 95 % confidence intervals are shown according to the length of care.

Fig. 1 Association between length of care and family-perceived timing of late referrals

Effects of length of care and perceived timing of referrals on family-perceived quality of care and quality of death and dying

There were no significant differences in the family-perceived quality of care and quality of death and dying between the patients with different lengths of care (Table 3). The family members who regarded the timing of referrals as late or too late were significantly more likely to report a lower quality of care (*P*=0.039), and poorer quality of death and dying with marginal significance (*P*=0.063). The effect sizes were 0.18 and 0.15, and the difference was considered as marginal to small.

Determinants of family-perceived timing of referrals

Univariate analyses revealed that the perceived timing of late referrals was significantly correlated with frequent visits to emergency departments, patient being unprepared for worsening condition, and family being unprepared for worsening condition (Table 4). On the other hand, primary tumor sites of the prostate, kidney, and bladder, symptoms adequately relieved, discharge nurse being available, and the patient wanting a hospital doctor was to perform treatment were significantly correlated with lower likelihoods of perceived late referrals (Table 5).

Independent determinants of higher likelihoods of perceived late referrals included frequent visits to emergency departments, patient being unprepared for worsening condition, and patient having concerns about relationship with new doctor. A discharge nurse being available and the patient wanting a hospital doctor to perform treatment were independently associated with lower likelihoods of perceived late referrals. The item of the patient being unprepared for the worsening condition was moderately associated with the item of the family being unprepared (rho=0.43), and, thus, if the former item was excluded from the model then the latter was included.

Discussion

This is one of large studies investigating the appropriateness of the timing of referrals to home hospice care for terminally

Table 3 Effects of length of care and perceived timing of referrals on quality of death and dying and family-perceived quality of care

	Quality of death and dying	Effect sizes	*P*	Family-perceived quality of care	Effect sizes	*P*
Length of care						
≤2 weeks	5.22 (0.78)	0.01	0.90	4.91 (0.93)	0.0002	0.82
>2 weeks	5.23 (0.76)			4.93 (0.98)		
≤4 weeks	5.19 (0.92)	0.07	0.28	4.93 (0.92)	0.04	0.59
>4 weeks	5.25 (0.73)			4.89 (0.97)		
Family-perceived timing of referrals						
Late or too late	5.17 (0.75)	0.15	0.063	4.84 (1.0)	0.18	0.039
Appropriate	5.28 (0.77)			5.00 (0.89)		

Quality of death and dying measured using the Good Death Inventory, with a range of 1 to 7. Higher scores indicate a higher quality of death and dying. Family-perceived quality of care measured using the Care Evaluation Scale, with a range of 1 to 6. Higher scores indicate higher perceived quality of palliative care. Data are expressed as mean (standard deviation)

ill cancer patients who received palliative care and died at home.

The first important finding of the present study was clarification of the situation regarding the family-perceived timing of referrals to home hospice care. Less than 2 % of families reported that the timing of referrals was early or too early, and 42 % reported that the timing was late or too late. The median length of referral from hospital to death at home was 35 days, and approximately 10 % of the patients died within 1 week. These findings are generally consistent with the existing literature, reporting that patients were referred to home hospice care at a late stage of cancer [4–11]. The fact that over 40 % of family members responded that the timing of referrals was late or too late suggests that the timing of referrals to home hospice care is likely to be delayed, and a strategy needs to be developed to improve this situation.

A novel finding of this study was that, whereas the length of care itself did not significantly influence the family-perceived quality of care or quality of death and dying, the family-perceived timing of a late referral was correlated with family-perceived quality of care, and the quality of death and dying. These findings suggest that it is not the length of receiving hospice care itself but rather the family-perceived timing of referral to home hospice care that should be considered as an indicator of the quality of end-of-life care.

Moreover, this is, to our knowledge, the first study to identify determinants of the family-perceived timing of referrals in terminally ill patients with cancer. Among the five determinants identified for late referral, two of them are within the context of the patient-physician relationship. Especially, concern over the relationship with a new physician was significantly associated with a greater likelihood of perceived late referrals. Because of the lack of a home physician or general practitioner system in Japan, patients generally sever strong ties with hospital physicians over the course of their disease. When patients receive home hospice services, therefore, they have to establish entirely new relationships with home-visiting physicians and nurses. Recently, efforts were made in Japan to increase communication and interactions and nurture relationships among physicians at a regional level, such as through whole-region interdisciplinary conferences [40]. A recent study revealed that a display of social intimacy between a hospital physician and home hospice physician was one of the determinants of a family's evaluation of physicians' communication when patients were referred to a home hospice [41]. Improving regional interaction between hospital physicians and home-visiting physicians may be a promising solution to late referrals to home hospices.

We also identified that discharge nurse availability was a key for decreasing likelihoods of perceived late referrals. Multiple studies have indicated that many patients with life-limiting illnesses were discharged without appropriate proactive management in their homes, and they eventually died in acute care hospitals [42, 43]. Many studies have also stressed the importance of discharge planning and the development of transitional care from a hospital to the home, and so the process of discharge planning is often complex and requires early initiation just after a patient's admission [43, 44]. The findings of this study highlights that discharge nurses play an important role in reducing the risk of delaying the timing of referral to a home hospice.

In addition, as the patients and families who reported frequent visits to emergency rooms and were unprepared for the worsening condition, this population should be a target for improving the timing of referrals to home hospices. A feasible screening system followed by appropriate triage for such a selected population may be of value, although frequent emergency visits could be simply the result of a lack of enrollment in a hospice program.

Despite the strength of the present study regarding the success in obtaining a relatively large sample and the use of

Table 4 Factors contributing to perceived timing of late referrals by univariate logistic regression analysis

	Frequency or mean (SD)	Odds ratio	95 % confidence intervals	*P*
Patient and family characteristics				
Patient age		1.00	0.98, 1.01	0.46
Patient sex (female; male as reference)		0.84	0.61, 1.15	0.28
Primary tumor sites				
Lung		1.0 (reference)		
Stomach and esophagus		0.67	0.33, 1.37	0.28
Colon and rectum		1.21	0.58, 2.49	0.61
Liver, bile duct, and pancreas		0.64	0.30, 1.38	0.26
Breast		0.86	0.42, 1.75	0.68
Prostate, kidney, and bladder		0.21	0.052, 0.85	0.028
Uterus and ovary		0.75	0.32, 1.76	0.51
Head and neck and brain		0.86	0.29, 2.54	0.79
Blood		1.23	0.45, 3.32	0.69
Others		0.21	0.041, 1.09	0.063
Family age		0.99	0.98, 1.01	0.31
Family sex (female; male as reference)		0.97	0.67, 1.41	0.88
Relationship with patients (husband/wife vs. others)		0.95	0.69, 1.30	0.74
Situations when home care was initiated				
Symptoms were adequately relieved	58 % (396)	0.66	0.48, 0.91	0.012
Transportation was difficult	82 % (557)	1.44	0.93, 2.23	0.099
Patient frequently visited emergency departments	23 % (158)	1.59	1.10, 2.29	0.013
Family had health problems	10 % (70)	1.52	0.91, 2.52	0.11
Alternative informal caregiver unavailable	65 % (445)	1.15	0.83, 1.61	0.40
Family had personal experience in caring for terminally ill patient at home	15 % (103)	1.01	0.65, 1.56	0.98
Discharge nurse available	58 % (399)	0.61	0.44, 0.85	0.003
Patient had a home doctor	19 % (128)	1.09	0.73, 1.61	0.70
Hospital physician knew a homecare physician well	52 % (358)	0.93	0.67, 1.29	0.65
Perceptions of patients and families[a]				
Patient's explicit wish to stay at home	82 % (558)	0.93	0.78, 1.12	0.43
Patient wanted hospital doctor to treat	16 % (107)	0.87	0.76, 0.99	0.046
Patient was unprepared for worsening condition	48 % (327)	1.16	1.00, 1.35	0.047
Patient had concerns about relationship with new doctor	17 % (119)	1.13	0.98, 1.31	0.097
Family's explicit wish to stay at home	74 % (504)	0.95	0.81, 1.12	0.56
Family was unprepared for worsening condition	45 % (308)	1.21	1.05, 1.40	0.009
Negative perceptions of home care[b]	2.50 (0.62)	1.09	0.85, 1.40	0.51

SD standard deviations

[a] Strongly disagree (1) to strongly agree (5). Frequencies are the numbers of the respondents who agreed or strongly agreed

[b] Mean score of seven items, ranging from 1 to 4. Higher score indicates higher negative perceptions of home care

validated measurements of perceived quality of care and quality of death and dying, the present study has several limitations. Firstly, home services participating in this study were generally well-organized and belonged to a national association. The findings might not be applicable to other smaller services. Secondly, the study subjects were the families of patients, and so the patients' views might have been different. Thirdly, the questions about factors potentially contributing to the perceived timing of hospice referrals used in this study were ad hoc and did not undergo formal validation testing. Fourthly, the reason why the Care Evaluation Scale and Good Death Inventory did not correlate with the actual timing of hospice referrals may be the ceiling effects of these scales, resulting in limited sensitivity, and/or the exclusion of patients

Table 5 Independent determinants of perceived timing of referrals as late or too late

	Odds ratio	95 % confidence intervals	*P*
Discharge nurse available	0.56	0.39, 0.81	0.002
Patient frequently visited emergency departments	1.53	1.03, 2.29	0.038
Patient wanted hospital doctor to treat	0.80	0.69, 0.94	0.008
Patient unprepared for worsening condition	1.23	1.04, 1.47	0.018
Patient had concerns about relationship with new doctor	1.20	1.02, 1.43	0.033

R^2 =0.071

who died in intensive care units. These limitations should be explored in future studies.

In conclusion, more than 40 % of bereaved Japanese families receiving home hospice care regarded the timing of referrals as late or very late, while less than 2 % reported it as early. Independent determinants of higher likelihoods of perceived late referrals included: frequent emergency department visits, patient being unprepared for worsening condition, and patient having concerns about relationship with new doctor. Systematic strategies to overcome these barriers should be explored to promote appropriate referrals to home hospices.

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