



# The Hospice Information System and its association with the congruence between the preferred and actual place of death

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## ABSTRACT

**Objective:** A Hospice Information System (HIS) developed in eastern Taiwan in 2012 aimed to improve the quality of hospice care through an integrated system that provided telemetry-based vital sign records, online 24/7 consultations, online video interviews, and online health educations. The purpose of this study was to explore the congruence between the preferred and actual place of death (POD) among patients who received HIS services. **Materials and Methods:** A retrospective study was performed from January 2012 to August 2016. Data from patients enrolled in the HIS who died during this period were included. Data on basic characteristics and the actual and preferred POD were obtained from the HIS database. The primary outcome was the congruence between the preferred and actual POD. Secondary outcomes were comparisons between patients who did and did not achieve their preferred POD. Further comparisons between patients who did and did not achieve home death were also performed. **Results:** In total, we enrolled 481 patients who received HIS services and died. Of them, 444 (92.3%) died at their preferred POD. Patients who preferred an inpatient hospice as their POD had higher achievement rate than those who wanted a home death. High-intensity HIS utilization was associated with a higher likelihood of home death than low-intensity HIS utilization. Patients living in areas distant from the medical center had lower achievement of home death than those living in local areas. **Conclusions:** This study suggested that patients enrolled in the HIS had high congruence between the actual and preferred POD.

**KEYWORDS:** Home care, Hospice care, Palliative care, Patient preference

## INTRODUCTION

The aim of hospice care is to provide a good quality of life, rather than trying to prolong life. It ensures medical care and support to patients with a life-limiting illness. Most of these patients are homebound, elderly, frail people with multiple chronic illnesses that have resulted in cognitive impairment and functional limitations [1]. Most people who are approaching their end of life prefer home as the place for care and death, with inpatient hospice care as a second choice [2,3]. Previous studies showed that congruence between the preferred and actual place of death (POD) ranged from 30% to 90% [4-7]. Specialized home care increased the rate of death at the preferred place from 59% to 91% [8,9].

The core value of hospice care is to enable people to choose their end-of-life care and POD. Thus, how to meet patients' preferences remains the major concern for high-quality hospice care. Physician support, palliative care involvement, and family support improve congruence [8,10]. The use of 24/7 services increased the chance of dying at a preferred place by 2.1 times [11]. The services of home-based end-of-life care, as

part of palliative care programs, increased the probability of care and dying at home [12].

In Taiwan, home is the preferred POD (66.5%). Patients' preference for receiving end-of-life care at home increased from 24.1% to 60.6% if home care services were available [13]. Currently, palliative care is offered as inpatient hospice care, hospital-based shared care, and hospice home care. Most care is provided by urban hospitals, which offer services through specialist healthcare professionals. However, hospice home care, which is mainly provided by a hospital-based outreach team, is insufficient to meet the needs of care and home death for end-of-life patients, especially in rural areas [13]. This uneven distribution of home care is even more significant in eastern Taiwan, an agriculture-based community. Most services are provided through centrally located medical resources and cover a vast territory.


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In 2012, integrated hospice care with a “Hospice Information System (HIS)” was developed to resolve such challenges. This system implemented four interventions to augment traditional hospice care: (1) telemetry-based vital sign records, (2) online 24/7 consultations, (3) online video interviews, and (4) online health educations. A specialist palliative care team is totally dedicated to support and coordination of patient care.

The HIS aims to improve the quality of hospice care, the quality of life for terminally ill patients, and congruence of the preferred POD. It also aims to reduce the burden of care on caregivers and the economic stress of hospitalization. The purpose of this study was to explore the congruence between the preferred and actual POD for patients receiving HIS services.

## MATERIALS AND METHODS

### Design

Palliative care programs, including inpatient hospice care, hospital-based shared care, and hospice home care, are delivered when end-of-life patients are enrolled. Patients with inpatient hospice care or hospice home care can assess and register with the HIS after providing detailed information. A retrospective study was performed from January 2012 to August 2016. Data were collected during HIS services for daily care and research purposes.

### Hospice information system

This HIS was initiated in 2012 for patients receiving palliative care programs at a medical center in eastern Taiwan. This system has four components: (1) Telemetry-based vital sign records and vital sign recorders, including a sphygmomanometer, pulse oximetry, and blood glucose machine, are lent to patients free of charge. The patient’s primary palliative care team and their family can access their vital sign records through a personal computer, computer tablet, or mobile phone. (2) Online 24/7 telephone consultations with a well-trained specialized nurse are available. (3) Online video interviews connect to a specialist palliative care team. (4) Online health educations provided by the HIS website include a wide range of medical information regarding hospice concepts, comfort care, available assistive devices, long-term care resources, commonly used drugs in hospice care, and coping strategies for terminal symptoms. At the same time, traditional hospice care and multidisciplinary consultations are also provided for patients. Therefore, HIS supports the palliative care team in caring for terminally ill patients and their caregivers.

### Participants

All end-of-life patients referred by the medical center for HIS services during the study period were identified and recruited. The life expectancy of end-of-life patients was estimated by prognostic indicators for their terminal disease and by a surprise question: “Would you be surprised if this patient died in the next year? [14-16]” Patients who survived after completion of the study were excluded.

### Outcomes and measurements

The primary outcome was the congruence between the preferred and actual POD. The expressed preferred POD was documented after HIS registration through shared decision-making with the patient and caregivers. A family

conference was arranged, which included the palliative care team, patients, their family, and caregivers. A total care plan, introduction to the HIS, basic information, and preferred POD were fully discussed and documented. Documented categories of the preferred POD included home (including care home), inpatient hospice, or both. Congruence was achieved when the actual location of death, where permanent cessation of the patient’s vital functions occurred, was the same as the documented preferred location of death. Secondary outcomes were comparisons between patients who did and did not achieve their preferred POD. Further comparisons between patients who did and did not achieve home death were also performed. Participants who had no specific preference for POD were excluded from the evaluation of secondary outcomes. Baseline characteristics collected were age, sex, diagnosis (cancer or noncancer), area of residence (local or distant area), duration of HIS services, and HIS use intensity. Local and distant areas were defined as areas within or outside a 20 km radius of the medical center in eastern Taiwan. High HIS use intensity meant all four components of HIS services were provided, and low HIS use intensity indicated components were only partially utilized.

### Statistical analysis

Data were collected from the HIS database. The characteristics of patients who achieved their preferred POD were compared with those who did not. Continuous variables (age) were compared using *t*-tests. Categorical variables were compared using Chi-square tests. Finally, logistic regression models were used to analyze the factors that affected the achievement of the preferred POD, including age, sex, diagnosis, area of residence, duration of HIS services, HIS use intensity, and the preferred POD. Statistical significance was set at  $P < 0.05$ . Statistical analyses were performed using SPSS software, version 17.0 (SPSS Inc., Chicago, IL, USA).

### Ethical approval

The study was conducted in accordance with the Declaration of Helsinki and was approved by the Research Ethics Committee of Hualien Tzu Chi Hospital (IRB105-153-B). Informed written consent was waived because the study was a retrospective data analysis.

## RESULTS

In total, 481 patients who received HIS services and died were enrolled in the study [Table 1]. Patients were predominantly men (60.7%), with a mean age of 70.6 years (standard deviation = 14.3). Most lived in local areas (79.8%), and cancer was the primary diagnosis (70.9%). About half of the patients died within 30 days of HIS enrollment (51.5%). A total of 400 (83.2%) patients had low-intensity HIS utilization.

### Place of death

Table 2 provides an overview of the preferred and actual POD. About half of the patients preferred to die only at home (49.1%) and 5 (1%) patients preferred home or an inpatient hospice. Most participants died at an inpatient hospice (57.2%) followed by at home (42.8%). There were 444 (92.3%) patients who died at their preferred POD if the five patients who preferred either home or inpatient hospice

were included. If these five patients were excluded, 92.2% patients still died in their preferred POD.

**Comparison between patients did and did not die at their place of death**

Univariate analysis showed that congruence between the actual and preferred POD was significantly associated with the initial preferred POD ( $P < 0.001$ ). Patients who wanted to die as a hospice inpatient had higher achievement of congruence compared with those who wanted to die at home. Age, sex, diagnosis, area of residence, duration of HIS services, and HIS use intensity showed no significant associations [Table 3].

Multivariate logistic regression showed that the achievement of congruence was significantly higher when the initial preferred POD was the inpatient hospice compared with home death (odds ratio [OR] 17.37, 95% confidence interval [CI] = 5.13–58.82;  $P < 0.001$ ). High-intensity HIS utilization was significantly associated with higher achievement of POD in multivariate logistic regression (OR 3.85, 95% CI = 1.19–12.40;  $P = 0.024$ ) compared with low-intensity HIS utilization although no significant association was noted in univariate analysis (OR 1.70, 95% CI = 0.59–4.94;  $P = 0.330$ ).

**Comparison between patients achieving and not achieving home death**

Of the 236 patients who wanted to die at home, factors associated with achieving congruence were the area of residence and HIS use intensity [Table 4]. The chance of dying at home was significantly lower in patients living in distant areas ( $P = 0.015$ ) compared with patients living in local areas. High-intensity use of HIS services was associated with a higher chance of dying at home compared with low-intensity utilization ( $P = 0.025$ ).

Multivariate logistic regression showed that patients living in distant areas had significantly lower achievement of home death compared with those living in local areas (OR 0.39, 95% CI = 0.17–0.93;  $P = 0.033$ ). High-intensity HIS use was associated with a higher likelihood of dying at home compared with low-intensity utilization (OR 5.53, 95% CI = 1.45–21.11;  $P = 0.012$ ).

**DISCUSSION**

To the best of our knowledge, this study is among the first in Taiwan to explore the achievement of preferred dying place with an integrated hospice care system in a palliative care program. During the study period, the congruence between the actual and preferred POD was achieved by 92.3% of the 481 patients who received HIS services and expressed their preferred location of death. Patients who initially preferred the inpatient hospice as their POD had higher achievement rate than those who preferred home death. High-intensity HIS use was associated with a higher likelihood of home death than low-intensity utilization; however, patients living in distant areas had lower achievement of dying at home than those living in local areas. This study showed that terminally ill patients in the HIS had high congruence between their actual and preferred POD.

A core value of hospice care is the opportunity for terminally ill patients to make choices about their end-of-life care

**Table 1: Clinical characteristics of participants (n=481)**

Characteristics	Achieved preferred POD		Total, n (%)	P
	Yes, n (%)	No, n (%)		
N	444 (92.3)	37 (7.7)	481 (100.0)	
Age at death				
Mean±SD	70.6±14.4	71.2±13.4	70.6±14.3	0.795
Age at death				
<65	157 (35.4)	13 (35.1)	170 (35.3)	0.978
≥65	287 (64.6)	24 (64.9)	311 (64.7)	
Sex				
Male	268 (60.4)	24 (64.9)	292 (60.7)	0.590
Female	176 (39.6)	13 (35.1)	189 (39.3)	
Days of HIS service				
0-2	50 (11.3)	6 (16.2)	56 (11.6)	0.460
3-14	105 (23.6)	6 (16.2)	111 (23.1)	
15-30	77 (17.3)	4 (10.8)	81 (16.8)	
31-60	78 (17.6)	6 (16.2)	84 (17.5)	
>60	134 (30.2)	15 (40.5)	149 (31.0)	
Diagnosis				
Cancer	315 (70.9)	26 (70.3)	341 (70.9)	0.931
Noncancer	129 (29.1)	11 (29.7)	140 (29.1)	
Area of residence				
Local areas <sup>a</sup>	358 (80.6)	26 (70.3)	384 (79.8)	0.131
Distant areas <sup>a</sup>	86 (19.4)	11 (29.7)	97 (20.2)	
HIS use				
Low-intensity use <sup>b</sup>	367 (82.7)	33 (89.2)	400 (83.2)	0.308
High-intensity use <sup>b</sup>	77 (17.3)	4 (10.8)	81 (16.8)	

<sup>a</sup>Local and distant areas were within or outside a 20 km radius of the medical center in eastern Taiwan, <sup>b</sup>High HIS use intensity: All four components of the HIS were utilized; low HIS use intensity: Components of the HIS only partially utilized. HIS: Hospice Information System, POD: Place of death, SD: Standard deviation

**Table 2: Congruence between the preferred and actual place of death (n=481)**

Preferred place of death	Actual place of death		
	Home, n (%)	Inpatient hospice, n (%)	Total, n (%)
Home	202 (85.6)	34 (14.4)	236 (49.1)
Inpatient hospice	3 (1.3)	237 (98.7)	240 (49.9)
Home or inpatient hospice	1 (20.0)	4 (80.0)	5 (1.0)
Total	206 (42.8)	275 (57.2)	481 (100.0)

and POD. The HIS was constructed to resolve challenging situations for patients and caregivers. With telemetry, online, and 24/7 service resources available, it aims to reduce the care burden for HIS service users, especially those who wish to be cared for and die at home. Our study showed 92.3% congruence between the actual and preferred POD, higher than in previous studies (30%–90%), even with specialized home care (59%–91%) [4-9]. When patients who had no specific preference for POD were excluded, 92.2% patients still died at their preferred POD. The congruence of POD in our study was also higher than that in a previous study with advanced cancer patients in Taiwan (43%) [7]. Although meeting the preferred

**Table 3: Logistic regression of factors associated with death at the preferred place of death (n=476)**

	Univariate			Multivariate		
	OR	95% CI	P	OR	95% CI	P
Age at death						
<65		References	NA		References	NA
≥65	0.99	0.49-2.00	0.983	1.22	0.55-2.72	0.620
Sex						
Male		References	NA		References	NA
Female	1.22	0.61-2.47	0.573	1.12	0.53-2.37	0.767
Days of HIS service						
0-2		References	NA		References	NA
3-14	2.06	0.63-6.71	0.230	2.01	0.58-7.03	0.274
15-30	2.31	0.62-8.60	0.212	2.14	0.53-8.71	0.287
31-60	1.54	0.47-5.04	0.476	1.15	0.32-4.19	0.834
>60	1.06	0.39-2.87	0.915	0.70	0.22-2.15	0.529
Diagnosis						
Cancer		References	NA		References	NA
Noncancer	0.94	0.45-1.96	0.871	0.70	0.30-1.64	0.417
Area of residence						
Local areas		References	NA		References	NA
Distant areas	0.56	0.27-1.18	0.126	0.46	0.20-1.05	0.066
HIS use						
Low-intensity use		References	NA		References	NA
High-intensity use	1.70	0.59-4.94	0.330	3.85	1.19-12.40	0.024
Preferred place of death						
Home		References	NA		References	NA
Inpatient hospice	13.30	4.02-43.94	<0.001	17.37	5.13-58.82	<0.001

CI: Confidence interval, HIS: Hospice Information System, OR: Odds ratio, NA: Not available

POD is an essential outcome for high-quality hospice care, its use in practice varies, which inhibits cross-study comparisons, so results should be interpreted with caution [4].

The patients who wanted to die at the inpatient hospice showed higher achievement of preferred POD than the group who wanted to die at home. It is known that as a patient approaches death, institutional settings such as an inpatient hospice make them feel safer as a place that can provide the best care at a time when death and suffering are feared [17]. The most likely reasons for lower achievement of dying at home were relatively clear, including limited hospice resources, support equipment, and hospice home care services [18,19]. With the use of the HIS to alleviate the above limitations, the achieved preference of home death in the current study (85.6%) was among the upper level of that previously reported although it was lower than the congruence of preferred death at the inpatient hospice [4-9]. Perceived ability of family to help achieve preferred POD was an important factor in increasing congruence in a previous study [20]. In the future, HIS may further evaluate and help caregivers or family in this perceived ability and determine whether they endorse patient preferences for POD.

**Table 4: Logistic regression of factors associated with achieved home death (n=236)**

	Univariate			Multivariate		
	OR	95% CI	P	OR	95% CI	P
Age at death						
<65		References	NA		References	NA
≥65	1.66	0.78-3.53	0.193	1.70	0.72-4.00	0.228
Sex						
Male		References	NA		References	NA
Female	1.37	0.63-2.97	0.423	1.29	0.57-2.91	0.544
Days of HIS service						
0-2		References	NA		References	NA
3-14	2.10	0.60-7.33	0.245	2.04	0.56-7.40	0.281
15-30	2.70	0.68-10.71	0.158	1.97	0.47-8.27	0.357
31-60	2.85	0.72-11.29	0.136	1.66	0.39-7.07	0.492
>60	1.41	0.48-4.16	0.529	0.64	0.19-2.09	0.456
Diagnosis						
Cancer		References	NA		References	NA
Noncancer	0.78	0.36-1.71	0.539	0.49	0.20-1.22	0.125
Area of residence						
Local areas		References	NA		References	NA
Distant areas	0.37	0.16-0.83	0.015	0.39	0.17-0.93	0.033
HIS use						
Low-intensity use		References	NA		References	NA
High-intensity use	4.06	1.19-13.82	0.025	5.53	1.45-21.11	0.012

CI: Confidence interval, HIS: Hospice Information System, OR: Odds ratio, NA: Not available

Our study showed that patients with high HIS use intensity had higher congruence of POD (in multivariate logistic regression) and home death compared with the low HIS use intensity group. This supports a previous study in which terminally ill patients with high-intensity home care had higher achievement of home death [21]. When using HIS services to access telemetry-based vital sign records and online interviews, the palliative care team could review the patient's clinical condition and evaluate the severity of disease; further medical instructions can be provided to patients and caregivers. This could avoid unplanned emergency department visits and admissions and may support caregivers by minimizing care burdens.

The area of residence impacts the accessibility and utilization of palliative care resources. In our study, patients using HIS services who lived at a distance from the medical center had less chance of dying at home. In eastern Taiwan, there are only four centrally located hospitals that provide complete palliative care. Due to the vast territory and uneven distribution of medical resources, distance from the hospital may interfere with and decrease the probability of patients being able to die at home. Our HIS aims to minimize this distance barrier and help these patients achieve their preference through telemetry and online services.

This study had some limitations. First, it only included terminally ill patients enrolled in the HIS; this group may not represent all patients who receive palliative care in a medical center or in the community. People who refused HIS intervention or those who only received hospital-based shared care were excluded, and the number of patients who were excluded for these reasons could not be obtained. Second, due

to methodological and ethical challenges in the palliative medicine research area, it is difficult to perform randomization to compare outcomes between HIS users and nonusers. Third, participant data were separated into five groups based on the duration of service periods that were determined *post hoc*. The five groups included approximately proportionate numbers of participants (except for the group beyond 60 days with an open-ended period). Fourth, this study grouped care home death as home death because most participants who lived in a care home considered that as their home, and the number of these patients was small. Finally, due to its observational design, we could not define causality or make solid conclusions.

## CONCLUSIONS

This study suggested that terminally ill patients enrolled in the HIS had high congruence between their actual and preferred POD. The participants who expressed a desire to die at home were less likely to achieve this, especially if they lived in distant areas. However, high-intensity HIS utilization was associated with a higher likelihood of dying at home. Future studies are needed to analyze the most useful services and needs that are not met in the HIS to make this integrated hospice care system more complete and allow more people to die at their preferred places at the end of their life.

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## Conflicts of interest

There are no conflicts of interest.

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