Patient Preferences versus Family Physicians' Perceptions Regarding the Place of End-of-Life Care and Death: A Nationwide Study in Taiwan

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Abstract

Background: Enabling people to die in their preferred place is important for providing high-quality end-of-life care.

Objective: The study objective was to explore patients' preferences regarding the place of end-of-life care and death and to compare these preferences with the perceptions of their family physicians.

Methods: This cross-sectional study used stratified random sampling, surveying 400 registered patients and 200 of their family physicians nationwide, with a five-part, structured, self-report questionnaire.

Results: Of the selected population, 310 patients (response rate 77.5%) and 169 physicians (response rate 84.5%) responded. Regarding the preferred place for end-of-life care, most of the patients would choose to receive care at home (60.6%) if home care services were available. Additionally, home was the most frequently preferred (66.5%) place of death. The family physicians' survey showed that a higher proportion of physicians selected home as the preferred place for end-of-life care and death (71.6% and 87.2%, respectively). The results of logistic regression analysis showed that patients younger than 50 years of age who believed in Chinese folk religion and who resided in a rural area were more likely to prefer to die at home.

Conclusions: The most commonly preferred place for end-of-life care and death is the patient's home. Establishing a community-based palliative care system should be encouraged to allow more individuals to die in their preferred locations. There were discrepancies in the preferred place of end-of-life care and death between the patients' preferences and their family physicians' perceptions. More effective physician-patient communication regarding end-of-life care is needed.

Introduction

ENABLING INDIVIDUALS TO DIE in their preferred place is important to delivering high-quality end-of-life care.^{1–3} Additionally, the World Health Organization recommends that planning for care at the end of life should be responsive to the patient's choices regarding the place of care and death.⁴ Cancer patients who die in a hospital or an intensive care unit have worse quality of life than those who die at home,⁵ and their bereaved caregivers are more likely to develop psychiatric illnesses.⁶ Dying at home allows individuals to have greater control over their environments, increases autonomy and privacy, and allows for a sense of normalcy.⁷ However, most people do not die at home, although home is the preferred place for care and for death for the majority of people.

A previous study in Europe showed that the majority (51%–84%) of terminal cancer patients would choose to die at home;⁸ however, most people do not accomplish this goal.⁹ In surveys, most Americans express a preference to die at home,¹⁰ yet in 2007 only one-quarter of individuals died at home.¹¹ The difference between the preferred and actual place of death is prominent in Asia. Approximately 44% of the general population in Japan preferred end-of-life care at home. However, fewer than one in five people actually die at home.¹²

In Taiwan, the most recent nationwide study showed that more than one-half of terminally ill cancer patients expressed a preference to die at home.¹³ The overall home death rate, according to death registrations, was approximately 43.2% in 2013.¹⁴ In the traditional Chinese belief system, a good death is commonly recognized as one of the Five Blessings

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(longevity, wealth, health, love of virtue, a good death). Death at home is believed to be a major aspect of a good death. Moreover, the spirit of a dead person cannot return home if that person dies far from his or her hometown. Thus, due to the fear of becoming a “gu hun ye gui” (wandering soul and wild ghost), many patients who were registered as dying at home were discharged from the hospital when death was imminent or had occurred. Therefore, the actual home death rate in Taiwan might be lower than the rate in the national death registration database.

Previous studies have determined that the use and intensity of home care are determinants of home death.^{15,16} In Taiwan, palliative care is offered as inpatient care, hospital-based shared care, and home care. Most palliative care is provided in urban hospitals, because the patient volumes at these institutions are sufficiently large to allow staff members to specialize in palliative medicine. Additionally, palliative home care is provided by hospital-based outreach teams. There are 68 palliative home care teams in Taiwan, with a ratio of approximately one service team for every 340,000 inhabitants, which is much lower than the level of one service team per 100,000 inhabitants recommended by the European Association for Palliative Care (EAPC).¹⁷ The number of palliative home care teams is insufficient to meet the needs of terminally ill patients who are cared for at home, particularly in rural areas. Therefore, building increased capacity to provide community-based palliative care has begun in Taiwan.

Involving family physicians in their patients' palliative home care is an important strategy for increasing access to palliative care. Previous studies have indicated that family physicians play a key role in exploring and honoring patient preferences regarding the place of death.¹⁸ The participation of family physicians in palliative care facilitates dying at home for their patients.^{15,19} Because many patients are unable to make decisions at the end of life, timely communication between the family physician and the patient is of particular importance.^{20,21} However, there has been only limited research investigating family physicians' perceptions of their patients' preferences for the location for receiving end-of-life care and dying.

The first aim of this study was to explore patients' preferences for the place of end-of-life care and death. The second aim was to compare the patients' preferences with their family physicians' perceptions. Our third aim was to examine the factors that influenced patient preferences regarding home death.

Methods

Participants and procedures

This study was designed as a cross-sectional survey and was conducted in April 2011. The study was approved by the institutional review board of the National Taiwan University Hospital (IRB number 201006082R). A structured questionnaire was mailed to family physicians who were participants in the Family Physician Integrated Delivery System project, which was implemented by the government in 2003. In this system, 5–10 family physicians practicing in the community, whose training background could include different specialties, established a “community medical team” (CMT). The individuals registered in the system were “registered patients” of each CMT family physician, and people did not need to have a specific diagnosis to be a registered

patient. According to the regulations of the project, each family physician could accept up to 1000 registered patients. Currently, there are 360 CMTs in all of the regions in Taiwan. The CMTs offer family-oriented integrated medical care, including preventive medicine, health promotion, a 24-hour on-call service, and end-of-life care. They are covered by designated community hospitals, and they share their patients' medical information with one another.

Using the stratified random sampling technique, 200 physicians in 150 CMTs were selected for the study. For each physician, two registered patients were selected by the convenience sampling method. A five-part, structured, self-report questionnaire was mailed to the participants, including physicians and their registered patients. Three weeks after the questionnaire was mailed, nonresponders were contacted again, and the questionnaire was resent. Nonresponders were sent the questionnaire up to three times. The participant selection and study design were approved by the National Science Council of Taiwan. All of the enrolled participants provided written informed consent.

Measurements

The potential influencing factors surveyed in this study were selected on the basis of the literature review and the opinions of clinical experts.^{15,22} A questionnaire consisting of five parts was used to gather information from the registered patients on demographic characteristics, including the ability to provide end-of-life care at home, the preferred place of end-of-life care and death (home/not home), the challenges to receiving end-of-life care and dying at home, and knowledge related to end-of-life care and services. Preferences for the place of end-of-life care and death were evaluated based on the participants' original responses and reconsideration of whether physician or nurse home care services were available. The family physicians were asked to consider the preferences of their primary care populations regarding the above questions. The definition of end-of-life care in this study refers to the Natural Death Act in Taiwan, which legalized citizens' right to give advance directives in medical decisions regarding the withholding of cardiopulmonary resuscitation (CPR) and the withholding or withdrawing of life-sustaining treatments (LSTs) in the final stage of life. With two physicians agreeing that the terminally ill patient is irreversibly dying, the attending physician must respect the patient's or the family member's willingness to withhold or withdraw CPR and LST.

To gather information about the respondents' backgrounds, we assessed demographic characteristics using a questionnaire, including sex (male/female); age (<35, 35–50, >50 years old); educational level ($\leq$ high school, >high school); marriage status (yes/no); area of residence (city, town, rural); religion (folk/Buddhist/Taoist/I-Kuan, Christian, or none); self-rated health status (good, fair, poor); experience of families facing terminal illness (yes/no); experience of families receiving palliative care (yes/no); and the ability to provide end-of-life care at home (yes/no). The entire five-part questionnaire was tested for content validity by all of the authors.

Statistical analysis

Data management and statistical analysis were performed using SPSS 12.0 (IBM, Armonk, NY). Frequency distributions were used to describe the demographic data and the

distribution of each variable. Potentially significant predictors of the preferred place for end-of-life care and death were identified by univariate analyses using the chi-square test ($P < 0.05$). Finally, to examine the factors that affected patient preferences regarding end-of-life care and dying at home, we performed a multivariate logistic regression analysis using all of the potentially significant predictors identified earlier by the univariate analyses. A P -value less than 0.05 was considered significant.

Results

A total of 310 registered patients and 169 family physicians responded. The response rates were 77.5% and 84.5%, respectively. The characteristics of the study sample are presented in Table 3. Among the registered patients, the respondents were predominantly female (83.2%), with a mean age of 41.3 years old ($SD = 12.2$). Most of the respondents had a high educational level ($>$ high school, 73.2%) and believed in traditional Chinese religion (63.5%). Almost one-half of the respondents had a poor self-rated health status (43.9%). Most of the respondents (86.8%) reported family experience with palliative care.

Place of end-of-life care

Among the patients, the original preference rate for receiving end-of-life care at home was low (24.1%). However, the patients' preference for receiving end-of-life care at home increased to 60.6% under the hypothetical condition that physicians or home nursing care services were available (see Table 1). Regarding obstacles to receiving end-of-life care at home, the need for family members to work was the most common reason given by the patients (87.4%), followed by raising children at home (39.7%) and an inability to manage a medical emergency (36.7%) (see Table 2).

Place of death

Most patients (66.5%) selected home as their preferred place of death. Concerning the preferred place of end-of-life care and death, family physicians were significantly more likely to prefer end-of-life care and death to occur at home (71.6% and 87.2%, respectively). Concerning obstacles to dying at home, most patients did not want to be a burden to

TABLE 2. OBSTACLES TO RECEIVING END-OF-LIFE CARE AND DYING AT HOME

	Patients' preferences		Family physicians' perceptions	
	Number	%	Number	%
Obstacles to receiving end-of-life care at home				
Total	199		138	
Family members have to work	174	87.4	118	85.5
Raising children at home	79	39.7	73	52.9
Unable to manage medical emergencies	73	36.7	101	73.2
Do not have a suitable home environment	43	21.6	77	55.8
Obstacles to dying at home				
Total	104		21	
Burden to the family	95	91.3	5	23.8
Unable to manage medical emergencies	43	41.3	7	33.3
Do not have a suitable home environment	32	32.1	8	38.1

their families (91.3%). In addition, being unable to manage a medical emergency (41.3%) and not having a suitable home environment (32.1%) were common reasons.

The results of the multivariate logistic regression analysis are summarized in Table 4. Patients who espoused traditional Chinese religious beliefs (OR 2.23, 95% CI 1.04–4.79), were younger than 50 years of age (OR 2.64, 95% CI 1.31–5.32 for age $<$ 35 years old and OR 2.26, 95% CI 1.19–4.28 for age 35–50 years old), and resided in a rural area were more likely to prefer to die at home. However, logistic regression analysis of the determinants of the preference for receiving end-of-life care at home yielded no significant influencing factors.

Discussion

To the best of our knowledge, this study was among the first in Taiwan to compare patient preferences with physician perceptions regarding the location of end-of-life care and death. Our study showed that most patients preferred to die at home, consistent with a previous study.²³ The patients' original preference rate for receiving end-of-life care at home was quite low. However, if home care services were available, most of the patients expressed a preference for receiving end-of-life care at home. The differences between the original preferences for end-of-life care and place of death resulted in the phenomenon in Taiwan of "going home to die" (GHTD).²⁴ GHTD means that hospitalized terminally ill patients are discharged and come back home when death is imminent or even when it has occurred in the hospital. This phenomenon is reflected in the fact that dying at home has a special cultural meaning for Chinese patients and their families.⁷ The old Chinese saying "luo yeh guei gen" (falling leaves return to the ground) expresses the idea that to die at home is as natural as autumn leaves falling to the ground.²⁵

However, caring for terminally ill patients at home without the help of a palliative care team can be psychologically traumatizing for family members who are untrained to handle

TABLE 1. PATIENTS' PREFERENCES AND FAMILY PHYSICIANS' PERCEPTIONS OF THE PREFERRED PLACE OF END-OF-LIFE CARE AND DEATH

	<i>Patients' preference (%)</i>	<i>Family physicians' perceptions (%)</i>	<i>P-value</i>
Place of end-of-life care (original response)			
Home	76 (24.1)	31 (18.3)	0.022
Not home	234 (75.9)	138 (81.7)	
Place of end-of-life care (if home care service available)			
Home	188 (60.6)	121 (71.6)	0.031
Not home	122 (39.4)	48 (28.4)	
Place of death			
Home	206 (66.5)	144 (87.2)	0.000
Not home	104 (33.5)	21 (12.7)	

TABLE 3. CORRELATIONS BETWEEN PATIENTS' DEMOGRAPHIC CHARACTERISTICS AND PREFERRED PLACE OF DEATH BY UNIVARIATE ANALYSIS

	<i>Preferred place of death</i>		<i>P-value</i>
	<i>Home (%)</i>	<i>Not home (%)</i>	
Total	206	104	
Sex			
Male	37 (18.0)	15 (14.4)	0.520
Female	169 (82.0)	89 (85.6)	
Age			
< 35	75 (36.4)	29 (27.9)	0.041
35–50	93 (45.1)	43 (41.3)	
> 50	38 (18.4)	32 (30.8)	
Education			
≤ High school	59 (28.6)	24 (23.1)	0.342
> High school	147 (71.3)	80 (76.9)	
Married			
Yes	136 (66.0)	60 (57.7)	0.171
No	70 (34.0)	44 (42.3)	
Area of residence			
City	78 (37.9)	58 (55.8)	0.005
Town	68 (33.0)	30 (28.8)	
Rural	60 (29.1)	16 (15.4)	
Religion			
None	48 (23.3)	30 (22.8)	0.044
Traditional Chinese religions	140 (68.0)	57 (54.8)	
Christian	18 (8.7)	17 (16.3)	
Self-rated health status			
Good	16 (7.8)	10 (9.6)	0.555
Fair	103 (50.0)	45 (43.3)	
Poor	87 (42.2)	48 (46.2)	
Family experience with terminal illness			
Yes	151 (73.3)	83 (79.8)	0.263
No	55 (26.7)	21 (20.2)	
Family experience with palliative care			
Yes	180 (87.4)	89 (85.6)	0.362
No	22 (10.7)	15 (14.4)	
Able to provide end-of-life care at home			
Yes	78 (37.9)	36 (34.6)	0.619
No	128 (62.1)	68 (65.4)	
Knowledge of end-of-life care (max = 21)			
≤ 15	50 (23.3)	23 (22.1)	0.690
16–18	85 (41.3)	40 (38.5)	
19–21	71 (34.5)	41 (39.4)	

emergency conditions.²⁶ Generally, specialized palliative home care teams in Taiwan are based in large urban hospitals. To serve rural and other underserved areas in Taiwan, community family physicians with basic training in palliative care have been reimbursed since January 2014 by the National Health Insurance for providing palliative home care, enabling more people to die at home.

According to patients observed in our study, the most common obstacle to receiving end-of-life care at home was the need for family members to work. There are two aspects regarding this result that should be mentioned. First, the long-term care and community support system is still

TABLE 4. DETERMINANTS OF PREFERENCE FOR HOME DEATH AMONG PATIENTS BY LOGISTIC REGRESSION ANALYSIS

	<i>Death at home (reference: not home) OR (95% CI)</i>
Age	
< 35	2.64 (1.31–5.32)*
35–50	2.26 (1.19–4.28)*
> 50	1 (Reference)
Area of residence	
City	0.38 (0.20–0.75)*
Town	0.63 (0.31–1.29)
Rural	1 (Reference)
Religion	
None	1.41 (0.61–3.28)
Traditional Chinese religions	2.23 (1.04–4.79)*
Christian	1 (Reference)

OR, odds ratio; CI, confidence interval.

**p*-value < 0.05.

being developed in Taiwan. Implementing prevocational palliative care training for long-term care workers should be encouraged to increase their involvement in caring for terminally ill patients at home. Second, employees in Taiwan are allowed to take up to seven days of annual unpaid family leave. In contrast, in the United States, the federal Family and Medical Leave Act (FMLA) requires employers to provide employees job protection and unpaid leave for up to 12 weeks. To balance the demands of the workplace with the needs of caring for a terminally ill family member, the family leave policy in Taiwan should be changed to meet the needs of family caregivers.

Our study found that younger patients were more likely to prefer to die at home. However, the preferred place of death should be seen as a dynamic issue, and patient preferences can change over time.²⁷ As patients approach death, they might feel safer in institutional settings, particularly if there is at home a lack of support and resources for the patients or their caregivers.^{16,28}

To allow more people to die in their preferred places, doctor-patient communication during end-of-life care should be enhanced. The National Health Insurance in Taiwan began in December 2012 to allow billing for family meetings for hospitalized terminally ill patients to facilitate communication in advanced care planning. Eliciting patients' preferences for the place of death and fulfilling patients' wishes are complex processes that demand a compassionate and skillful approach.²⁹ Our study revealed that differences remain between patient preferences and the perceptions of their family physicians. Family physicians play a critical role in guiding patients with chronic and life-limiting illnesses through all of the phases of an illness that could eventually be terminal. These physicians are responsible for patient-physician communication and medical decision making. How well physicians perform this communication and decision making has important effects on the experiences of patients as they are dying.^{30,31}

Patients living in cities were less likely to die at home, in agreement with previous studies.^{32,33} Death at home or the passage of a dead body past the living spaces of others could cause some Chinese people to worry about "contamination"

of the home by dead bodies, perhaps causing such dwellings to become unattractive to future buyers or causing the fear of bringing misfortune to family and neighbors. Unlike the situation many years ago in Chinese ancestral villages, homes are no longer retained for generations by one family. It appears that, with deeply held ideas about collective responsibility, one's personal interests (wishing to die at home) are secondary to protecting the well-being of one's family.

This study had some limitations. First, the respondents to the questionnaires were not terminally ill patients, and preferences regarding end-of-life care could change in the face of terminal illness. Second, family physician perceptions of the preferred place for end-of-life care and death were based on the preferences of their primary care populations and not on the preferences of individual patients. Physicians might have tended to select the most common answer. Therefore, the results indicating a high proportion of preferring end-of-life care and dying at home based on the physicians' perceptions might be overestimated. Third, two patients were selected in each CMT by a convenience sampling method, which might not be representative of the entire population.

Conclusions

In this study, home was the most commonly preferred place for end-of-life care and death. The patients were significantly more likely to express a preference for receiving end-of-life care at home if home care services were available. To respond to patient preferences, it is necessary to establish a better palliative home care system. Providing palliative care training for long-term care workers and adjusting family leave policy should be encouraged. In addition, there were discrepancies in patient preferences and family physicians' perceptions regarding end-of-life care and death. Communication between patients and physicians about end-of-life care should be enhanced to ensure that decision making is based on patients' preferences and to allow more individuals to die in their preferred places.

Author Disclosure Statement

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