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# Grief Reactions in Family Caregivers of Advanced Cancer Patients in Taiwan

## Relationship to Place of Death

### KEY WORDS

Bereavement  
Grief  
Place of death

Home death has a special cultural meaning for Taiwanese patients who are dying and their family members. However, very limited evidence has been presented on the impact of home death on caregiver bereavement outcomes. The purpose of this study was to explore the preference for place of death by Taiwanese patients dying of cancer and the actual place of death and to investigate the relationship between place of death of a patient and grief reactions of the family caregivers. This study consisted of 46 dying patients and 46 matched family caregivers ( $N = 92$ ). The grief reaction was measured using the Texas Revised Inventory of Grief. Statistical analyses included descriptive statistics, *t* tests, logistic regression, and multiple regression. Most of the patients (74%) preferred to die at home; however, only 33% of family caregivers preferred the patient to die at home, and only 17% of patients actually died at home. Of these patients, 43% of their preferences were congruent with the actual place of death, whereas 79% of the family caregivers' preferences were congruent with the patients' actual place of death. Finally, the place of death was not a significant predictor of caregivers' grief reactions immediately after the loss of a loved one or at 1 month after the death occurred. This study provides important implications for future studies and clinical practice.

Despite increasing cure rates, cancer remains the leading cause of death in Taiwan.<sup>1</sup> The death of a loved one is possibly the most distressing lifetime event one can encounter.<sup>2</sup> The loss of a family member can be one of

the most difficult types of bereavement to deal with,<sup>3</sup> which has been related to an increased risk of mental and physical diseases<sup>4</sup> and even mortality.<sup>5</sup> The goal of palliative care is to maintain the quality of life, to meet patient and family wishes,

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and to care for the bereaved and help them cope with grief.<sup>6</sup> Enabling death at home, if this is the patient's wish, is often seen as ensuring the quality of care for a dying patient.<sup>7</sup> In particular, home death has a special cultural meaning for Taiwanese patients who are dying as well as for their family members.<sup>8</sup> However, very limited evidence has demonstrated the impact of home death on caregiver grief reactions. No study has investigated to what extent the place of death impacts caregiver grief reactions in Taiwan. Therefore, the purpose of this study was to explore the preference for place of death among Taiwanese patients dying of cancer and the actual place of death and to investigate the relationship between the place of death of a patient and the grief reactions of the family caregiver.

In Taiwan, various types of palliative care services, such as inpatient care, outpatient care, and home care, are available for cancer patients at end of life. In Taiwan, once diagnosed with cancer, approximately 92% of cancer patients preferred being told the truth about their diagnosis.<sup>9</sup> However, the practice of nondisclosure of prognosis and detailed disease-related information by healthcare professionals is common in Taiwan. Cancer patients in Taiwan expressed a strong preference for healthcare professionals to inform them of disease-related information before disclosing information to their family members.<sup>10</sup> It has been evidenced that, in Taiwan, 79% of patients had been informed that the diagnosis was cancer, and for the majority (89%), the disclosure of cancer had been made by their physicians.<sup>11</sup> There are several family-related barriers to diagnostic disclosure in Taiwanese terminal cancer patients, including families not knowing how to tell the truth and families believing that it is unnecessary to tell aged patients the truth and that patients can be happier without knowing the truth.<sup>12</sup> As the disease approaches to the terminal stage, approximately 77% of Taiwanese physicians would inform a terminal cancer patient or the family member about the possibility of Do Not Resuscitate and ask them to consider signing a consent form.<sup>13</sup>

Bereavement often results in emotional and physical health consequences that occur with the death of a loved one. Research has shown that bereavement is related to anxiety,<sup>14</sup> depression,<sup>15</sup> decreased immune functioning,<sup>16</sup> physical health problems,<sup>17</sup> and increased mortality rates.<sup>5</sup> Efforts to improve grief reactions and to identify and target individuals at high risk of pathological grief have mainly been the focus of palliative care. Provision of quality end-of-life care, including caregivers' satisfaction with the care and the place of death, has the potential to affect bereavement outcomes.<sup>7</sup> A large cohort study<sup>18</sup> demonstrated that, after the death of a spouse, excess mortality among the bereaved was high from accidental, violent, and alcohol-related causes, moderate from chronic ischemic heart disease and lung cancer, and small from other causes. There have been several causal mechanisms proposed for the path from bereavement to poor health and mortality, including emotional stress and grief caused by the death of a loved one, loss of social support, and loss of material support.<sup>18, 19</sup>

It has been well documented that most patients prefer to die at home.<sup>20</sup> Studies in different countries have documented that between 60% and 80% of cancer patients would prefer to

die at home.<sup>21-26</sup> Moreover, dying at home has a special cultural meaning for patients and their family members in Taiwan.<sup>8</sup> For Taiwanese, dying at home indicates a form of a good death and, most importantly, that the dead will not become a spirit wanderer. A study found that, among home care patients with cancer in Taiwan, 69% died at home and 31% died in the hospital.<sup>27</sup> Moreover, home care patients with cancer who were never rehospitalized, who received more home care visits, or who were referred to home care services at the greatest functionally dependent status were more likely to die at home.<sup>27</sup> Studies in Taiwan also revealed that 50% to 88% of cancer patients preferred to die at home.<sup>28</sup> Therefore, for Taiwanese, a home death might not only meet the patient's wish but also have potential benefits for the well-being of the caregivers.

The relationship between place of death and grief reaction is controversial. Studies have found that the psychological adjustment of caregivers may be relatively better when patients die at home rather than elsewhere, especially when cultural norms support home death.<sup>29,30</sup> Caregivers have also been found to experience less anxiety, guilt,<sup>2</sup> rumination,<sup>31</sup> and despair and to have more positive feelings about the death<sup>32</sup> when the patient died at home compared with in a hospital. Recent studies have also shown that home deaths are associated with both better bereavement responses and better physical health postbereavement than are inpatient deaths.<sup>7,33</sup> On the other hand, other studies have shown that bereaved caregivers of patients who died at home were more psychologically distressed<sup>34,35</sup> and more likely to have greater tendencies to become socially isolated.<sup>2</sup> However, it has also been shown that the place of death is not related to grief reactions in the bereaved respondents when controlling for other confounding factors.<sup>3</sup>

It is unclear whether place of death has an impact on caregivers' grief reactions in Taiwan given the fact the Taiwanese social norms support home deaths. Results from this study may provide important implications for ensuring the best possible quality of palliative care for advanced cancer patients. Because social support has been shown to affect bereavement outcomes, caregivers' perceived social support was controlled for in this study. Therefore, the specific aims of this study were (1) to study the preferred place of death for dying Taiwanese patients and their primary family caregivers and to document the actual place of death of patients, (2) to examine the congruence of a patient's wish and a family caregiver's wish for place of death with the actual place of death, and (3) to investigate the impact of place of death on the grief reactions of family caregivers after controlling for other confounding variables immediately and 1 month after the death.

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## ■ Methods

### Participants and Settings

This study was conducted in the inpatient palliative care unit of a hospital in the Taipei metropolitan area. A convenience sample was recruited for this study consisting of

inpatients and their primary family caregivers. To be included in the study, patients had to (1) have been diagnosed with advanced cancer, (2) be older than 18 years, (3) have clear consciousness, and (4) be able to communicate in Mandarin Chinese or Taiwanese. For family caregivers to be included in the study, they had to (1) be older than 18 years, (2) be identified by the patient as the individual most involved as a caregiver in their lives, and (3) be able to communicate in Mandarin Chinese or Taiwanese. In total, 46 patients and 46 matched family caregivers were recruited (N = 92). Demographic characteristics of patients and their family caregivers are presented in Table 1.

## Instruments

Instruments consisted of the Texas Revised Inventory of Grief (TRIG), the Interpersonal Support Evaluation List (ISEL), and a demographic questionnaire.

### TEXAS REVISED INVENTORY OF GRIEF

The grief reactions of family caregivers were measured using the TRIG.<sup>36</sup> The TRIG, a self-reporting questionnaire, consists of 26 items in 3 parts. The first part (8 items) assesses the respondent's initial reaction at the time of loss, in which caregivers are asked to rate how the death affected their feelings, actions, and relationships immediately after the death. The second part (13 items) measures grieving thoughts and feelings at the present time. The third part consists of 5 items (answered by either true or false) about an assortment of facts related to death. Each item in parts 1 and 2 is answered using a 5-point Likert scale ranging from 1 (completely true) to 5 (completely false). High mean values on the items indicate a low level of grief. Reliability and validity of the TRIG have been established.<sup>3,36</sup> The TRIG was chosen because it has been widely used and has been shown to have good psychometric properties. For this current study, the TRIG was first translated into Chinese and then back-translated into English and compared the 2 English versions. In this study, the internal consistency reliability was 0.87 for part 1 and 0.95 for part 2. The validity was established by a panel of experts. The Index of Content Validity ranged from 0.87 to 1.0, with an average of 0.98. One month after death was chosen as the time to assess caregivers' reactions to loss of a loved one because it has been evidenced that grief reactions from the first to the third month after death remain stable.<sup>37</sup> Therefore, 1 month after death was chosen as the time for short-term reactions of grief.

### INTERPERSONAL SUPPORT EVALUATION LIST

Availability of social support was measured using the ISEL.<sup>38</sup> The ISEL is a true/false questionnaire consisting of 40 items assessing the perceived availability of 4 separate functions of social support that potentially have the ability to facilitate coping with stressful events, including tangible, appraisal, self-esteem, and belonging subscales. The reliability and validity of

**Table 1 • Demographic Characteristics of Patients (n = 46) and Their Family Caregivers (n = 46)**

Patients	n	%
Sex		
Male	27	58.70
Female	19	41.30
Religion		
Buddhism	28	60.86
Christian	3	6.52
Taoism	10	21.71
None	5	10.91
	<b>Mean</b>	<b>SD</b>
Age (y)	70.80	13.37
Education (y)	6.52	5.12
Duration of disease (mo)	24.58	26.02
<b>Family caregivers</b>	<b>n</b>	<b>%</b>
Gender		
Male	20	43.48
Female	26	56.52
Religion		
Buddhism	26	56.52
Christian	2	4.34
Taoism	8	17.40
None	10	21.74
Living with patient		
Yes	42	91.30
No	4	8.70
Bereavement experiences		
Yes	35	76.09
No	11	23.91
Relation to patient		
Parent	29	63.04
Spouse	11	23.92
Other	6	13.04
Work		
Full time	21	45.65
Part time	9	19.56
Unemployed	16	34.79
Decision maker		
Yes	23	50.00
No	23	50.00
Patient perceived to have unfinished business		
Yes	18	39.13
No	28	60.87
	<b>Mean</b>	<b>SD</b>
Age (y)	45.83	14.15
Education (y)	12.13	4.58
Duration of living with patient (y)	32.84	15.27

the ISEL have been established.<sup>39,40</sup> The ISEL was chosen because it has been widely used and it has been shown to have good psychometric properties. For this current study, the ISEL was first translated into Chinese and then back-translated into English and compared the 2 English versions. In this study, the internal consistency reliability was 0.87. The validity was established by a panel of experts.

## DEMOGRAPHIC AND DISEASE INFORMATION

A demographic information sheet covered basic information on patients and their families, including age, sex, education, marital status, religious beliefs, occupation, and relationships of the family caregiver to the patient. For family caregivers, they were asked if they perceived that their patients had unfinished business. The answer was either yes or no. The preferred place of death for the patient and that for the family caregiver were also tabulated. A disease information sheet covered a patient's diagnosis, medications, and treatment status, as well as whether metastasis had occurred.

## Procedures

Approval for this study was obtained from the Human Subject Committee of the hospital. Patient-family pairs who met the selection criteria were individually approached by the research assistant upon admission to the palliative care unit. The research assistant described the study and obtained informed consent from both patients and their family caregivers. After obtaining informed consent, patients and family caregivers filled out the demographic questionnaire and preferred place of death information. Family caregivers also completed the ISEL. At 1 month after the patient's death, the research assistant visited the primary family caregiver at home or conducted a telephone interview to assess the grief reaction using the TRIG and to obtain information about the actual place of death.


## Statistical Analysis

Descriptive statistics were used to describe the demographic and disease characteristics, preferred and actual places of death, and TRIG scores. *t* Tests were used to examine if caregivers' grief reactions differed according to place of death. Logistic regression was used to determine predictors for a home death. Regression analysis was applied to explore predictors for grief reactions immediately after the loss and those at 1 month postbereavement.

## Results

### Preferred and Actual Place of Death

As shown in Table 2, 74% of patients expressed that they preferred to die at home when they were first admitted to the palliative care unit, whereas 67% of family caregivers expressed that they preferred the patients to die in the hospital. In fact, only 17% of patients died at home, and 83% died in the hospital. The congruence of patients' preferences and family preferences with the actual place of death is presented in Table 3. For most patients (56.62%), the actual place of death was not congruent with their preference; however, for 69.57% of family caregivers, the actual place of the patient's death was congruent with the family's preference. The  $\kappa$  value of the agreement between patient preference and actual place of death was 0.23, indicating low agreement. The  $\kappa$  value of the

 **Table 2 • Preferred Place of Death for Patients (n = 46) and Family Caregivers (n = 46) Versus Patients' Actual Place of Death**

	Patient Preference	Caregiver Preference	Actual Place of Death
Home	34 (74%)	15 (33%)	8 (17%)
Hospital	12 (26%)	31 (67%)	38 (83%)

agreement between family preference and the actual place of death was 0.45, indicating fairly good agreement.

### Predictors of a Patient Dying at Home

To identify factors that predicted a patient dying at home, logistic regression was used. The family caregiver's age, educational level, economic status, work status, preferred place of death, and perceived social support, as well as the patient's age, educational level, and preferred place of death, were entered as predictors in the regression model. It was found that patients with lower levels of education ( $B = 0.72, P = .03$ ) and whose family caregivers had lower levels of education ( $B = 0.88, P = .03$ ), were working full time ( $B = 5.56, P = .03$ ), and had perceived lower social support ( $B = 0.36, P = .03$ ) were more likely to die at home.

### Relationship Between Family Caregivers' Grief Reactions and Place of Death

Texas Revised Inventory of Grief scores of the family caregivers are presented in Table 4. The mean score of the grief reactions diminished from 53.61 (immediately after the loss of a loved one) to 41.80 (at 1 month postbereavement). To examine if the grief reaction differed by actual place of death, *t* tests were used. The results revealed that there was no difference in TRIG scores between family caregivers whose patients died at home versus those who died in the hospital (Table 5).

### Predictors of the Grief Reactions of Family Caregivers

To determine the predictors of the grief reactions of family caregivers, regression analysis was applied. Based on previous studies and clinical observations, the TRIG score was entered as the dependent variable, and the independent variables in the regression model included the actual place of death, relationship to the patient, patient age and educational level, if the place of death was congruent with the patient's wish or the caregiver's preference, caregiver's perceived availability of social support, caregiver's perception that the patient had unfinished business, duration of the diagnosis, and the caregiver's age, sex, and educational level. This model revealed that the selected independent variables accounted for 47% and 46% of the

**Table 3 • Congruence of Patients' and Family Caregivers' Preferred Place With Patient's Actual Place of Death**

		Congruent With Caregiver Preference				Total
		Yes		No		
		n	%	n	%	
Congruent with patient preference	Yes	17	36.96	3	6.52	<b>20 (43.48)</b>
	No	15	32.61	11	23.91	<b>26 (56.62)</b>
	Total	<b>32 (69.57)</b>		<b>14 (30.43)</b>		46 (100)

variance in the TRIG score at the initial reaction and 1 month postbereavement, respectively. The significant predictor for the TRIG score of the initial reaction after loss of a loved one was the family caregiver's educational level (Table 6). The significant predictors for the TRIG score at 1 month postbereavement were the patient's age and the perception that the patient had unfinished business (Table 7).

## Discussion

This is the first prospective study to explore the preferred and actual place of death and to investigate the impact of home death on caregivers' grief intensities in Taiwan. In this study, 74% of patients preferred to die at home. This result is consistent with several studies conducted worldwide,<sup>21-26</sup> which documented that approximately 60% to 80% of patients prefer to die at home. Unlike other studies, much fewer family caregivers in this study (33%) expressed a preference for the patient to die at home. In a study conducted with patients referred to a hospice home care program in the United Kingdom, it was found that most caregivers (82%) expressed a preference for their patient to die at home.<sup>25</sup> This difference could have been due to differences in sites of patient recruitment. In the study of Tiernan et al,<sup>25</sup> patients were recruited from a hospice home care program. On the other hand, patients in this study were recruited from an inpatient palliative care program. Therefore, family caregivers in this study may have tended to prefer to keep the patient in the hospital until the patient died. Also, in this study, patients were recruited from an inpatient palliative care unit located in an urban area. Most patients or family members live in apartments, which would present difficulties with handling the body and coffin after the patient had died. As a result, most family caregivers in this study may have been reluctant to care for the dying patient at home.

**Table 4 • Caregiver Scores on the TRIG**

	Mean	SD	Min	Max
Initial reaction	41.80	10.22	19	60
At 1 mo	53.61	16.19	26	85

TRIG indicates Texas Revised Inventory of Grief.

**Table 5 • Determination of Whether Place of Death Affects Grief**

	Home Death	Hospital Death	t	P
Grief at initial reaction	41.58 (9.51)	41.96 (10.88)	-0.12	.90
Grief 1 mo after death occurred	54.58 (15.81)	52.93 (16.72)	0.34	.73

Although in this study most patients preferred to die at home, only 17% of patients actually died at home. It was found that patients with lower levels of education and whose family caregiver had a lower level of education, worked full time, and perceived having lower social support were more likely to die at home. This result is consistent with results from previous studies. One large study in the United Kingdom found that older people and women were less likely to die at home.<sup>20</sup> Another study found that Taiwanese cancer patients receiving home care and home care patients with cancer who were never rehospitalized, who received more home care visits, and who were experiencing pain were more likely to die at home.<sup>27</sup> Inconsistencies among these findings could be due to different recruitment sites of patients and different places of care. More studies are needed to determine the factors predicting the place of death in Taiwan.

In this study, the preferences of 43% of patients were congruent with their actual place of death; however, among family caregivers, 70% of preferences were congruent with the patient's actual place of death. This result supports the notion that the patients' wishes for a preferred place of death are often not met.<sup>20</sup> In Taiwanese culture, family members play a critical role in healthcare, including the roles of decision maker and gatekeeper. For example, a study in Taiwan demonstrated that family caregiver barriers (concerns) significantly contribute to the prediction of inadequate management for cancer pain after controlling for patient and caregiver demographics and disease variables.<sup>41</sup> This finding supports the critical role that family members play in

**Table 6 • Predictors of Grief Reactions Immediately After Loss of a Loved One**

	B	SE	t	P
Constant	-5.55	14.86	-3770	.71
Actual place of death	1.86	2.14	0.87	.39
Relationship to patient	0.41	0.49	0.83	.41
Patient age	0.17	0.14	1.27	.21
Patient educational level	-0.44	0.34	-1.31	.20
Patient had unfinished business	5.94	3.49	1.70	.09
Congruent with patient's wish	-2.56	3.50	-0.73	.47
Congruent with caregiver's wish	4.17	3.44	1.21	.24
Social support	0.14	0.21	0.65	.52
Duration of diagnosis	-0.01	0.05	-0.14	.88
Caregiver age	0.13	0.12	1.05	.30
Caregiver educational level	0.96	0.42	2.29*	.02

**Table 7 • Predictors of Grief Reactions at 1 Month After the Death Occurred**

	B	SE	t	P
(Constant)	-19.52	23.37	-0.84	.41
Actual place of death	2.51	3.36	0.74	.44
Relationship to patient	0.61	0.77	0.78	.44
Patient age	0.39	0.21	1.84*	.04
Patient educational level	-0.09	0.53	-0.17	.87
Patient had unfinished business	12.98	5.49	2.36*	.02
Congruent with patient's wish	-3.26	5.50	-0.59	.56
Congruent with caregiver's wish	7.81	5.42	1.44	.16
Social support	0.04	0.33	0.13	.89
Duration of diagnosis	0.05	0.09	0.57	.57
Caregiver age	-0.06	0.19	-0.30	.77
Caregiver educational level	0.99	0.66	1.50	.14

\* $P < 0.05$ .

healthcare. Because of the integral role family caregivers play in a patient's healthcare in Taiwan, the family's preference may have a great impact on a patient's actual place of death. As a result, the patient's wishes or preferences may often be neglected, which results in an incongruence between patients' wishes and the actual place of death. Therefore, assessing the congruency of preferences between patients and their family members early in the process of palliative care and increasing the congruency could be important in achieving quality palliative care in Taiwan.

Although dying at home is the wish of most Taiwanese terminal patients, contradictory to our expectation, it was found that, in this study, the place of death was not related to the grief reactions of family caregivers. Nevertheless, this result is consistent with other studies.<sup>3,42</sup> Ringdal et al<sup>3</sup> found that the place of death was not associated with grief reactions of bereaved respondents measured by the TRIG when controlling for other confounders. The lack of a relationship between place of death and grief reactions in this study could have been due to the fact that the inpatient palliative care unit provided good quality care and support to patients and their families, which may have resulted in better grief reactions. It has been demonstrated that perceptions of inadequate care and support for dying patients and their family caregivers and high symptom severity were associated with worse caregiver grief reactions.<sup>7</sup> However, the findings of this study do not support other studies which found that home deaths were related to better bereavement responses and better physical and psychological health postbereavement.<sup>7,33</sup> Goodenough et al<sup>33</sup> found that fathers whose children died at home reported significantly lower levels of depression, anxiety, and stress. Moreover, Grande et al<sup>7</sup> found that caregivers whose patients died at home reported a significantly better early bereavement response as measured by the TRIG and better physical health as measured by the physical component of a quality-of-life measure, compared with caregivers of those who died in the hospital. Although a failure to fulfill a patient's wish about the location of death could lead to worse grief reactions, it should be noted that excessive strain may be

placed on the caregiver during home care. Therefore, it may be important for healthcare professionals to provide sufficient home care support for family caregivers when assisting patients with fulfilling the wish for a home death.

There are several limitations in this study. It should be reiterated in this study that the substantial participant attrition among patients and family members should be examined to determine whether it implies a selection bias. However, we do not have information on those participants who refused or dropped out of the study. Moreover, this study was limited by its small sample size. Lastly, the research design in this study is not able to explore the meanings or feelings of the death of a loved one. Therefore, more studies may be needed to replicate this study with a larger sample size to determine the ability to generalize the results from this study. Studies with a qualitative design will provide more detailed information about meanings or feelings of a family caregiver when facing the death of a loved one.

In conclusion, we found that most Taiwanese cancer patients prefer to die at home, which is inconsistent with the family caregivers' preferences. Moreover, the actual place of death was more congruent with that of the family caregiver than the patient. Last, the grief reactions of family caregivers did not differ between patients who died at home versus in the hospital. This study has revealed the need to increase the congruence between patients' and family members' preferences of the place of death and to fulfill patients' wishes concerning the place of death. Contradictory to our expectations, this study revealed that the place of death did not affect family members' grief reactions. Nevertheless, given the fact that a home death has cultural meaning for Taiwanese, more studies are needed to investigate the benefits of home death for family caregivers in Taiwan and the meanings of home death for Taiwanese family members. There is a need for professional education aimed at improving the understanding of the meanings of home deaths for dying patients and their family caregivers. This study provides important implications for future studies, clinical practice, and professional education.

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