

Original Article

Factors Affecting Research Participation of Bereaved Families of Terminal Cancer Patients: A Prospective Preliminary Study

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Purpose: Little is known regarding the factors associated with the willingness of family caregivers of terminal cancer patients to participate in a bereaved survey. This study aimed to ascertain the pre-loss factors that predict actual participation in a bereaved survey. **Methods:** We conducted a prospective observational study using data from two multi-center surveys at the end-of-life and after loss. In order to identify the pre-loss factors associated with participating in the bereaved survey, we used a step-wise multivariate logistic regression analysis. **Results:** Among 185 bereaved individuals, 30 responded to the survey (response rate: 16.2%). There were differences between the participation group and the non-participation group regarding religion, economic status, and perceived quality of care as assessed by the Quality Care Questionnaire-End of Life. A final multivariate model revealed that bereaved individuals who professed a religion (adjusted odds ratio [aOR]=5.01; P=0.008), had a high income (aOR=4.86, P=0.003), and satisfied with the care for familial relationship (aOR=4.49, P=0.003) were more likely to engage in the bereaved survey. **Conclusion:** Our finding suggests that improving the quality of end-of-life care may promote actual participation in a bereaved survey through easing post-loss distress. More attention should also be paid to those bereaved individuals who are hesitant to participate in a bereaved survey.

Key Words: Bereavement, Neoplasms, Hospice care, Family, Surveys and questionnaires

INTRODUCTION

The loss of a close family member is one of the most

stressful experiences that cause considerable psychological distress (1). Bereaved individuals have a high prevalence of emotional suffering and a decreased quality of life (QOL) (2,3). Understanding bereavement is the first step in increasing the QOL

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of these individuals, necessitating research into bereavement in order to identify areas where intervention may be needed. Although there is concern that bereaved relatives are in a vulnerable and difficult situation for participating in a study (4), a growing body of evidence suggests that such research may actually benefit bereaved populations (5,6).

Response rates in after-death surveys of family members are often low because bereaved individuals are likely to be emotionally upset by engaging in a bereavement study. Identifying the factors associated with participating in bereavement research would be helpful to improve response rates, which leads to clearer and more comprehensive findings (i.e., from sub-group analysis). Empirical studies examined the responses of bereaved individuals to study participation (7-9), but the results were clearly obtained from subjects who agreed to participate in the study. In addition, previous research in this area is limited to specific populations, such as family members of patients in an intensive care unit (ICU) setting (5,10), bereaved siblings (11) or parents (12) in a pediatric oncology setting, or parents who experienced the sudden death of a child (7). Currently, cancer is the leading cause of morbidity and mortality worldwide, and together with spreading palliative care, deaths from cancer have become representative of "expected death." The nature of death and the circumstances surrounding the loss can influence the outcomes for the bereaved (13).

On the cancer trajectory, death of a loved one is frequently preceded by a long and demanding period of informal caregiving which may be a significant predictor for post-loss distress (14,15). Mental health or support resources available to family caregivers (FCs) prior to the patient's death are associated with bereavement adjustment (15), but very little is known of the potentially modifiable pre-loss factors that may affect participation in a bereaved survey. Additionally, cultural variance in end-of-life (EOL) issues such as bereavement experience should be considered because bereavement is greatly influenced by social context (16).

This study aimed to identify the elements of the pre-loss caregiving environment that are associated with actual participation in bereaved surveys among Korean FCs of terminal cancer patients. Examining these elements may influence future research in this area and further define specific family needs. In addition, clinician screening of, and opt out opportunities for, eligible participants may result in increased pro-

tection for potentially distressed individuals.

METHODS

1. Study design and subjects

This study was a sub-investigation from data of two multi-center surveys at the end-of-life and after loss. A first survey was conducted at palliative care units (PCUs) within seven tertiary medical centers in Korea to investigate the QOL among FCs of terminally ill cancer patients at the EOL (17). The primary FC was defined as the person who provided the most informal care and who was ≥ 20 years old, able to complete the questionnaire and communicate with the interviewer, and willing to participate. The second survey—examining the mental health of bereaved families—was conducted within 6~9 months after the patient's death, by self-completion postal questionnaires. We felt that bereaved families should not be contacted within the first few months after loss, and also intended to gain the subjects' homogeneity. The 185 bereaved families (from five institutions) that were included in a previous survey were contacted, the purpose of the second study was explained, and the individuals were asked to participate in the second survey via telephone. Of these FCs, 155 declined to participate due to an uncomfortable feeling, lack of interest, or lack of time. The institutional review board of each center approved this study.

2. Measures

Patient information, such as age and sex, was collected from medical records. The FC survey at the EOL requested the following information: demographics (age, sex, relationship to the patient, marital status, employment status, religion, monthly income, and educational level), emotional distress, QOL, resilience, perceived social support, family function, and perceived quality of care. All instruments used have been validated in Korean populations, as previously described (17).

Emotional distress was assessed using the Hospital Anxiety and Depression Scale, which is composed of 14 items rated on a four-point Likert scale from 0 to 3 (18). Subjects were considered as having "emotional distress" if the total scores were 13 or higher (19). In order to assess the QOL of the FCs, we used the Caregiver QOL Index-Cancer, which consists of 35 items rated on a five-point Likert scale from 0 to 4

(20). A total score was obtained by adding all item scores (range: 0~140), with higher scores reflecting a better QOL. Resilience was assessed with the Connor-Davidson Resilience Scale (21), where items are rated on a five-point Likert scale of 0~4, and higher total scores indicate greater psychological resilience. The Medical Outcome Study Social Support Survey was used to assess the social support system (22), and consists of 19 items rated on a five-point Likert scale from 1 to 5, where a higher score indicates perceived strong social support. Family function was assessed using the family Adaptation, Partnership, Growth, Affection, and Resolve questionnaire (23), which has five items rated on a three-point Likert scale from 0 to 2. The total score was obtained by totaling each item's score, and subjects were categorized into two groups: "dysfunctional" (0~6) or "functional" (7~10). Quality of care (QOC) was measured using the Quality Care Questionnaire-End of Life (QCQ-EOL) (24), which is a brief, self-reported, and cancer-specific measure of QOC. The QCQ-EOL contains 16 items that assess dignity-conserving care, care by healthcare professionals, individualized care, and family relationships. The item is scored on a four-point Likert-type scale, with a higher score indicating a higher perceived quality of care.

3. Statistical analyses

In order to compare the differences between the participation group and the non-participation group, we used the Chi-square test or independent t-test, and to identify the variables associated with participating in a bereaved survey, we used a logistic regression model. Each independent factor that was statistically significant ($P < 0.05$) in the univariate analysis was entered into the final multivariate logistic regression model to calculate adjusted odds ratios (aORs). Using a forward step-wise elimination procedure, we obtained a best-fit step-wise multivariate logistic regression model. In multivariate logistic analyses, we considered P values less than 0.05 generated in two-tailed tests to indicate statistical significance. The data were analyzed using STATA SE 9 (STATA Corp., TX, USA).

RESULTS

1. Subject characteristics

Table 1 presents the characteristics of subjects by participation in a bereaved survey. The participation group had higher

proportions of those professing a religion or with a high income than the non-participation group (both, $P < 0.05$). Among the pre-loss conditions for care, perceived care by professionals was the only factor with a significant difference between groups.

2. Factors associated with participation in the bereaved survey (Table 2)

We identified the factors associated with participation in the survey using univariate analyses. Subjects who professed a religion, had a high income, felt their patient received more professional care, or felt that the familial relationship was enhanced by EOL care, were more likely to participate in the survey. In the step-wise multivariate analysis including the four variables significant in the univariate analysis, those who participated in the survey had aORs of professing a religion, a high income, and satisfactory care for familial relationship of 5.01 ($P = 0.008$), 4.86 ($P = 0.003$), and 4.49 ($P = 0.003$), respectively.

DISCUSSION

Bereaved relatives are a vulnerable group for research purposes (4), and certainly protection strategies should be required (25). Recent qualitative investigations in oncology have suggested that research participation may not be a burden for most bereaved families, many of whom willingly engaged with researchers for altruistic reasons (6,26). However, these results are confined to bereaved family members who agreed to describe their experience. In addition, specific elements of the caregiving experience are known to affect the grieving process (13), which can influence participation in a bereaved study. Here, we identified bereaved families that were hesitant to participate in a bereaved survey, which can inform future research. When providing informed consent to these individuals, particular attention should be paid to thoroughly explaining the purpose of the research and clarifying their understanding of material.

It is noteworthy that the perceived quality of terminal care in a PCU influenced actual participation in the bereaved survey. In an ICU or PCU setting, a low QCQ rating was associated with less of an inclination to participate in a survey (10,27), indicating that further research about EOL care

Table 1. Characteristics of Family Caregivers according to Participation in Bereaved Research.

		Participation (N=30)	Non-participation (N=155)	P value*
Patient information				
Age (year)		66.0±12.8	62.7±13.5	0.224
Male		19 (63.3)	78 (50.3)	0.192
Demographics				
Age (year)		51.9±12.2	48.3±13.5	0.186
Female		21 (72.4)	107 (72.3)	0.990
Spouse to patient		13 (46.3)	49 (33.8)	0.202
Married		26 (86.7)	119 (77.8)	0.272
Employed		15 (51.7)	63 (41.5)	0.306
Religious		24 (85.7)	82 (56.2)	0.003
High income (≥2 million KW)		19 (70.4)	66 (47.1)	0.027
High education (≥College)		13 (43.3)	84 (54.9)	0.246
Pre-loss status at the EOL				
	Range of score			
Emotional distress (HADS)	0~42	17.3±8.2	17.8±7.2	0.731
Quality of life (CQOLC total)	0~140	66.0±16.2	67.4±17.2	0.686
Resilience (CD-RISC)	0~100	64.3±17.1	59.9±15.5	0.162
Social support (MOS-SSS total)	0~100	71.5±12.9	72.4±14.9	0.746
Family function (APGAR)	0~10	6.0±2.4	6.5±2.6	0.338
Quality of care (QCQ-EOL)				
Total	0~48	25.2±8.4	23.3±7.3	0.233
Dignity-conserving care	0~21	8.8±4.3	8.6±3.6	0.837
Care by professionals	0~9	6.0±1.9	5.2±1.9	0.034
Individualized care	0~12	6.5±2.3	6.1±2.2	0.314
Relationship with family	0~6	4.0±1.7	3.4±1.5	0.058

Data are mean±standard deviation or number (%).

KW: Korean Won, EOL: end of life, HADS: Hospital Anxiety and Depression Scale, CQOLC: Caregiver Quality of Life Index-Cancer, CD-RISC: Connor-Davidson Resilience Scale, MOS-SSS: Medical Outcome Study Social Support Survey, APGAR: Adaptation, Partnership, Growth, Affection, and Resolve, QCQ-EOL: Quality Care Questionnaire-End of Life.

*P values were obtained using the t-test or χ^2 test.

Table 2. Factors Associated with Participation in Bereaved Research.

	Univariate			Stepwise multivariate*		
	OR	95% CI	P	Adjusted OR	95% CI	P
Profession of religion	4.68	1.54~14.18	0.006	5.01	1.53~16.48	0.008
High household income	2.67	1.09~6.49	0.031	4.86	1.69~13.98	0.003
Satisfactory EOL care by professionals	3.03	1.29~7.14	0.011			
Satisfactory EOL care for familial relationship	2.85	1.23~6.60	0.015	4.49	1.66~12.15	0.003

OR: odds ratio, CI: confidence interval, EOL: end-of-life.

*Including significant ($P < 0.05$) variables during univariate analysis.

should focus on the response bias toward overestimating QOC, a modifiable healthcare-related factor. High QOC is important not only for the well-being of the patient, but also for the long-term mental health of the bereaved families. From the results of our study, we inferred that enhancing the familial relationship was a critical factor, and it could be by pro-

moting open communication between terminal cancer patients and their FCs at the EOL (28).

Profession of a religion and high economic status were associated with willing participation in the bereaved survey, consistent with previous studies. Regarding bereavement adjustment, religion is considered an enhancer of positive effects as

well as a protectant against negative impacts (29,30). In the Korean population, religion enabled bereaved families to find meaning in life after loss (31), whereas bereaved families with a lower income were at risk for poor mental health (3).

Unexpectedly, the response rate in this study was far lower compared to other bereaved studies (32,33), although it was comparable to one Korean study (20.9%) that surveyed the bereaved (34). We anticipated that a good rapport with the PCU team at the EOL and previous experience with research participation would increase an individual's willingness to engage in the bereaved survey. We inferred that this low response rate may be primarily due to "little motivation." Besides the benefit of helping others in the same situation, bereaved individuals had no incentive to participate in bereaved surveys and may have felt free to express their unwillingness to participate. Korean FCs assume the great burden of caring for a family member with terminal cancer before loss (35), which may lead to their finding research participation intolerable. Further international studies comparing post-loss distress and/or contemplating participation in a bereaved survey in relation to palliative care systems are warranted.

Our study has several limitations. First, sample biases may exist as our sample had previously participated in the FC at the EOL study. However, they may have more positive attitudes toward endorsing the benefits of research participation, which could attenuate the significance of our findings. Second, the results of this study cannot be generalized to other healthcare systems. The outcomes of bereavement may vary by ethnic and/or cultural context (36), and there may be some differences in hospice care between the home and the hospital (37). Third, mental health among the bereaved may vary over time, and is dynamic and gradually abated (38). However, no research yet exists concerning the best time for conducting bereaved research.

Despite these limitations, this preliminary study is valuable in determining the willingness of bereaved families to participate in a survey. Our data suggest that improving quality of EOL care may reduce the view of a survey as a burden and increase participation. In addition, more attention should be paid to those bereaved individuals that are hesitant to participate in surveys. Although the study should be replicated rigorously with a larger sample, our findings may help guide other researchers in studying EOL issues in these vulnerable

populations.

요 약

목적: 말기암환자 가족간병인의 사별가족 연구참여와 관련된 요인에 대해서는 알려진 바가 적다. 본 연구에서는 사별가족 연구에 실제 참여를 예측하는 임종 전 요인에 대해 살펴보고자 한다.

방법: 임종 전과 사별 후에 시행된 다기관 조사연구 자료를 이용하여, 전향적 관찰연구를 진행하였다. 사별가족 연구 참여와 관련된 요인을 추출하기 위해, 단계적 다변량 로지스틱 회귀분석을 이용하였다.

결과: 185명의 사별가족 중, 30명이 사후조사에 참여하였다(응답률: 16.2%). 사후조사 참여군과 비참여군은, 종교, 경제적 상태 그리고 임종 전 인지되었던 돌봄의 질에서 차이를 보였다. 최종 다변량 모델에 의하면, 종교를 가지고 있던 가족(adjusted odds ratio [aOR]=5.01, P=0.008), 높은 경제수준을 가진 가족(aOR=4.86, P=0.003) 그리고 가족 내 관계형성에 대한 돌봄에 만족했던 가족(aOR=4.49, P=0.003)이 그렇지 않은 가족에 비해 더 사후 연구에 참여를 하였다.

결론: 본 연구에 의하면, 임종기 돌봄의 질을 향상시키는 것은 사후 고통을 줄임으로써 사별가족연구에의 참여를 촉진시킨다. 사별가족 연구참여를 망설이는 사별가족들의 특성에 관심을 가질 필요가 있다.

중심단어: 사별, 종양, 호스피스, 가족, 설문조사

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