Does Palliative Care Improve Quality? A Survey of Bereaved Family Members

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Abstract

Palliative care (PC) is the interdisciplinary specialty that aims to relieve suffering and improve the quality of care for patients with serious illness and their families. Although PC programs are becoming increasingly prevalent in United States hospitals, the impact of hospital PC consultation programs on the quality of care received by family members is not well understood. We conducted prospective quantitative telephonic interviews of family members of patients who died at Mount Sinai Medical Center between April and December 2005 employing the validated "After-Death Bereaved Family Member Interview," to assess quality of medical care at the end-of-life. Multivariable techniques were used to compare family satisfaction of PC patients versus usual care (UC) patients controlling for age, race (white versus non-white), diagnosis (cancer versus non-cancer), socio-economic status (Medicaid versus non-Medicaid) and functional status (number of dependent activities of daily living). One hundred ninety eligible subjects were contacted and successful interviews were completed with 149 (78.4%) family members (54 PC and 95 UC patients). PC showed benefit, with 65% of PC patients' family members reporting that their emotional or spiritual needs were met, as compared to 35% of UC patients' family members (*P*=0.004). Sixty-seven percent of PC patients' family members reported confidence in one or more self-efficacy domains, as compared to 44% of UC patients' family members (*P*=0.03). Our study shows that PC consultation is associated with improved satisfaction with attention to family and enhanced self-efficacy. PC offers a unique approach by integrating the needs of the family into the care of the patient.

Keywords

Palliative medicine; quality of care; bereaved family members; survey

Introduction

Palliative care (PC) is the interdisciplinary specialty that aims to relieve suffering and improve the quality of care for patients with serious illness and their families. Although traditionally

represented by hospice, PC programs are now common in hospitals. Research suggests that seriously ill, hospitalized patients and their families want alleviation of physical distress, some control over their health care decisions, prevention of death-prolonging procedures, improvement in familial relationships, and reduction in caregiver burden.[1, 2] The impact of PC programs on the quality of care received by hospitalized patients is not well understood.[3]

Recently, Teno and colleagues examined the quality of end-of-life care in institutional settings as compared with deaths at home and found that family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience.[4] Teno et al. found that many more people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and treatment perceived as respectful.[5] Data from a few studies with methodological limitations suggest that palliative care programs reduce symptom distress, improve patient and family satisfaction, and reduce hospital length of stay, costs and utilization.[6]

Research examining the effect of hospital PC programs on surviving family members and other loves ones is relatively sparse. The potential harm that can befall family members from caring for a seriously ill family member has been well documented. Prigerson and colleagues found that primary caregivers of terminally ill patients receiving inpatient hospice services frequently witness their loved ones in serious distress and that the frequency of witnessing the patient in distress was associated with psychiatric illness and functional impairment.[7] Additionally, Azoulay et al. found that post-traumatic stress reaction with a high risk of post-traumatic stress disorder was common in family members of ICU patients.[8] Finally, Weiner and Roth hypothesize how to decrease iatrogenic harm near the end-of-life by improving communication.[9] The present study was designed to assess the impact of a hospital PC consultation service on the quality of care received by family members of patients who died at a large New York City academic tertiary hospital.

Methods

We obtained the names, date of death, age and gender of all patients who died at Mount Sinai Medical Center between April 2005 and December 2005 and met our eligibility criteria from hospital administrative databases. Decedent eligibility included patients who 1) had a length of stay greater than ten days and received a PC consultation at least three days prior to the patients' death, or 2) had a length of stay greater than ten days and received usual care (UC). PC patients were identified from the PC program's clinical and billing database, which stores information on all patients receiving PC consultation. UC patients were identified through the hospital's cost accounting system (Transitions Systems Inc.). Three hundred twenty-four patients met our inclusion criteria. The Institutional Review Board approved the study and did not require that we contact the patients' physicians prior to contacting the next of kin or that we contact the next of kin via mail prior to attempting telephone contact.

Respondent eligibility included 1) being listed as the next of kin in electronic medical record of a patient who died at Mount Sinai and met the decedent eligibility criteria, 2) being aged 18 or older 3) English-speaking because the survey instrument was only validated in English, 4) reported being one of the people most involved in the patients' care when asked directly by the interviewer and 5) could be contacted between three months and 200 days following the patients' death. As the timing of when to conduct post-death interviews has yet to be examined empirically to our knowledge, we based our interview window on prior studies that suggest that family members appear to be experience minimal distress when interviewed three months after death and on our own pilot data that suggested that family recall of hospital events was still reliable and valid six months following the death of their loved one.[10]

Attempts were made to contact the next of kin of the 324 patients by telephone. The interviewer was not told whether the patient had received a PC consultation. The study was explained to potential subjects and they were asked if they were interested in participating. The potential subjects were informed that participation in the study was completely voluntary and they could withdraw from the study at any time during the telephone interview. In cases in which more than one contact person was listed, each person was contacted and the person who identified themselves as closest to the decedent was invited to participate. Informed consent was completed over the telephone for each participant before the telephonic interview.

Participating subjects were administered the "After-Death Bereaved Family Member Interview" (ABFMI) over the telephone. The ABFMI is an instrument designed to assess quality of medical care at the end of life. It was validated in a retrospective telephone survey of family members of patients who died at a consortium of nursing homes, an outpatient hospice service, and an academic medical center, and were interviewed between three months and six months after the death of a patient.[4,11,12] Several questions on the ABFMI were modified so as to make the instrument relevant to a hospital PC consultation team. The modified telephone survey can be obtained by contacting one of the authors (R.S.M.). Additional patient and family demographic information was obtained via interview and electronic medical record review.

Quantitative data were analyzed using Stata version 9.1. T-tests and Chi-square tests were used to compare mean summary scores for the survey domains. Multivariable techniques, including logistic and linear regression, were used to compare quality of care of PC patients versus UC patients controlling for age, race (white versus non-white), diagnosis (cancer versus non-cancer), socio-economic status (Medicaid versus non-Medicaid) and functional status (number of dependent activities of daily living).

The study protocol was approved by the Institutional Review Board of the Mount Sinai School of Medicine. A HIPAA waiver of authorization was granted to the investigators to release personal health information of decedent subjects for research purposes.

Results

Two hundred forty-three of 324 eligible family members could be contacted. Of these, 190 met our eligibility criteria and 149 interviews were completed (95 family members of usual care patients and 54 family members of palliative care patients) for a response rate of 78.4%. Decedents of participating next of kin did not differ significantly from the decedents whose next of kin declined to participate or were unable to complete the interview in terms of age, sex, length of stay or if they received palliative care or usual care.

Decedent characteristics of participating next of kin are in Table 1. Median age was 68.6 years, 68 (45.6%) were women and 32 (21.5%) had a main diagnosis of cancer. The two groups were well matched, with few significant differences. PC patients had significantly longer lengths of stay (P=0.04) and were more likely to report Catholicism (P=0.03) as their religion than UC patients.

Table 2 describes the participating family members. The mean age of participants was 53.4 years and 68 (45.6%) were female. Fifty-two (34.9%) of the participants were the spouse or the partner of the decedent, 55 (36.9%) were the adult children, 8 (5.4%) were parents, 12 (8.1%) were the siblings and 22 (14.5%) had another relationship to the decedent. Forty (26.8%) of the participants rated their own health as excellent, 86 (57.7%) as very good or good, and 19 (12.8%) as fair or poor. There were no significant differences noted between characteristics of usual care and palliative care family participants.

Table 3 describes the bivariate comparison of the outcomes. Compared to family members of patients who received UC, the family members of PC patients were more likely to report that 1) their religious and spiritual beliefs were addressed (UC 23 [24%] versus PC 25 [46%], $P = 0.004$; 2) they received enough support in dealing with their own feelings (UC 52 [55%] versus PC 39 [73%], $P = 0.04$; and 3) they received a referral for psychosocial support for the family (UC 13 [14%] versus PC 19 [36%], $P = 0.002$. Overall, 61 (65%) of the family members of UC patients reported that no emotional or spiritual needs were met, as compared to 19 (35%) of the family members of PC patients ($P = 0.004$).

The family members of PC patients reported significant benefits in the self-efficacy domain. Self-efficacy can be defined as the competence perceived by family members in participating in the care of the dying person. In comparison to family members of UC patients, family members of PC patients were more likely to report that they were fairly to very confident that they knew what to do when the patient died (UC 64 [71%] versus PC 46 [87%], $P = 0.03$). A trend was observed favoring PC in response to items querying whether families knew what to expect when the patient was dying (68% of UC families felt very confident [n=55] versus 82% of PC families [n=42], $P = 0.07$). Overall, PC showed significant benefit in the self-efficacy domain, with 52 (56%) of family members of UC patients reporting that they were not confident in one or more of the above subdomains, as compared to 18 (33%) family members of PC patients ($P = 0.03$).

Discussion

Hospital PC consultation services are interdisciplinary programs that address patients' pain and other symptoms; patients' and families' emotional, psychological and spiritual needs; and provide comprehensive transition management. Our study shows that hospital PC consultation services improve family-centered outcomes; more specifically, the family members of patients who received PC were more likely to report that their emotional and spiritual needs were attended to, and to have greater confidence in their self-efficacy.

Prior research, including studies from the PC program in this study, has demonstrated that hospital PC programs can significantly improve patients' physical and psychological symptoms. Teno et al. found that bereaved family members of patients with home hospice service, in contrast to those in the hospital or nursing home, reported higher satisfaction, fewer concerns with care, and fewer unmet needs.[13] This provides evidence that family members perceive a benefit from the services offered by the PC and hospice teams.

Previous studies have suggested that involvement of family members in decision making and preparation for what to expect improves bereavement and could offset the increased mortality risks associated with caring for a terminally ill loved one.[14–16] The results of this study provide evidence that hospital PC programs also significantly improve family-centered outcomes, in addition to their perceived satisfaction with care.

Our study had several important limitations. First, it was limited to English-speaking family members and may not be generalizable to non-English speaking families. Second, we were only able to contact families who had next-of-kin listed in the electronic medical record and who had a listed telephone number. Third, the responses of the next of kin were subject to recall bias, which we tried to limit by not interviewing more than 200 days after the death. Fourth, our study was limited to hospital decedents with prolonged lengths of stay and may not reflect the experience of families whose patients with brief length of stay or those who were discharged from the hospital alive. Fifth, this study was undertaken at a single site, a large New York City tertiary care hospital, and the results may not be generalizable to other populations and settings. Sixth, the original cohort was not randomized to PC or UC, which

may contribute to confounding. It is clear, however, that it would not be ethical to randomize patients to PC or UC. Seventh, we adopted a validated telephone survey and we cannot be certain that the responses are reliable and valid without directly testing the modified survey. Finally, our study may have been underpowered to detect significant differences in all outcomes measured. Nevertheless, we observed significant differences in family domains.

Our study shows that PC consultation is associated with improved satisfaction, with attention to family and enhanced self-efficacy. PC offers an approach to integrate the needs of the family into the care of the patient. These results indicate that improvement in hospital end-of-life care and enhanced training of physicians will help address the needs of family members. Further studies should address which aspects of this multi-component intervention reflected these improved family outcomes.

Acknowledgements

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Table 1

Demographic Characteristics of Patients[‡]

	USUAL CARE N=54	PALLIATIVE CARE N=95	P-VALUE
Age, mean (range), y	69.11 (18–101)	67.57 (24–96)	0.60
Female, No. (%)	40 (42)	28 (52)	0.25
Length of stay, mean (range), d	26.82 (11–112)	41.57 (11–291)	0.04
Insurance Status, No. (%)			0.31
Medicare	51 (54)	36 (67)	
Medicaid	12 (12)	4 (7)	
Third Party Payer	32 (34)	14 (26)	
Private Duty Nursing, No. (%)	15 (16)	7 (13)	0.81
Education level, No. (%)[†]			0.30
High school or less	52 (55)	36 (67)	
Greater than high school	42 (44)	18 (33)	
Marital status, No. (%)			0.85
Married/Partnered	50 (53)	28 (52)	
Widowed	18 (19)	12 (22)	
Divorced/Separated	13 (14)	5 (9)	
Never married	14 (15)	9 (17)	
Living alone, No. (%)	22 (23)	13 (24)	0.90
Religion, No. (%)			0.03
Protestant	22 (23)	13 (24)	
Catholic	41 (43)	16 (30)	
Jewish	25 (25)	12 (22)	
Other	7 (7)	13 (24)	
Race, No. (%)			0.10
White	58 (61)	30 (56)	
Black	20 (21)	18 (33)	
Hispanic/Latino	15 (16)	4 (7)	
Other	2 (2)	2 (4)	
Income, No. (%)			0.48
Less than $11,000	20 (21)	16 (30)	
$11K to $50K	35 (37)	19 (35)	
Greater than $50K	24 (25)	14 (26)	
Refused	16 (17)	5 (9)	
ADLs, dependent on 2 or more	37 (39)	22 (41)	0.83
IADL, mean (range)	9.04 (0–16)	8.78 (0–16)	0.77
Diagnosis, No. (%)			0.77
Malignancy	19 (20)	13 (24)	
Infection	15 (16)	9 (17)	
Neurological Disease	2 (2)	4 (7)	
Cardiac Disease	20 (21)	10 (19)	
Liver Disease	5 (5)	2 (4)	
GI Disease	6 (6)	3 (6)	
Pulmonary Disease	6 (6)	5 (9)	
Pneumonia	9 (10)	3 (6)	
Renal Disease	7 (7)	1 (2)	
Other	6 (6)	4 (7)	

[†]
The Education level of patients does not total 100% because one respondent refused to answer.

[‡]
Items may not total 100% because of rounding.

Table 2

Demographic Characteristics of Next of Kin[‡]

CHARACTERISTIC	UC	PC	P-VALUE
Age, mean (range), y	53.77 (25–82)	52.89 (19–89)	0.73
Female, No. (%)	40 (42)	28 (52)	0.25
Education level, No. (%)			0.86
High school or less	39 (41)	23 (43)	
Greater than high school	56 (59)	31 (57)	
Relationship to Patient, No. (%)			0.65
Spouse/Partner	31 (33)	21 (39)	
Child	38 (40)	17 (32)	
Parent	5 (5)	3 (6)	
Sibling	9 (10)	3 (6)	
Other	12 (13)	10 (19)	
Self-rated health, No. (%)			0.48
Excellent	28 (30)	12 (22)	
Very Good/Good	51 (54)	35 (65)	
Fair/Poor	13 (14)	6 (11)	
Refused	3 (3)	1 (2)	
Time between Death and Interview, mean (range), days	131.76 (85–200)	131.39 (98–181)	0.92

[‡] Items may not total 100% because of rounding.

Table 3

Bivariate Comparisons of Outcomes*†*

EMOTIONAL SPIRITUAL NEEDS OF FAMILY	UC	PC	P-VALUE
Religious/spiritual beliefs addressed	23 (24)	25 (46)	.004
Enough support in dealing with own feelings	52 (55)	39 (73)	.04
Feelings after death addressed	14 (15)	13 (24)	.16
Referral to psychosocial support for family	13 (14)	19 (36)	.002
No emotional/spiritual needs met	**61 (65)**	**19 (35)**	**.004**
SELF EFFICACY OF FAMILY			
Fairly-very confident knew what to expect when patient dying	55 (68)	42 (82)	.07
Fairly-very confident knew what to do when patient died	64 (71)	46 (87)	.03
Fairly-very confident knew about medications to treat symptoms	74 (82)	49 (91)	.16
Not confident in one or more domains	**52 (56)**	**18 (33)**	**.03**

*†*Items may not total 100% because individuals refused to answer item.