

Original Article

Unique Correlates of Heart Failure and Cancer Caregiver Satisfaction With Hospice Care

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Abstract

Context. Heart failure patients, along with their informal caregivers are increasingly enrolling in hospice care. Caregiver satisfaction with hospice care is a key quality indicator. The role that diagnosis plays in shaping satisfaction is unclear.

Objectives. Our aim was to identify unique correlates of caregiver satisfaction in heart failure and cancer caregivers and explore whether the identified correlates differ between the two diagnosis groups.

Methods. This was a retrospective cohort study of national data collected in 2011 by the National Hospice and Palliative Care Organization using the 61-item Family Evaluation of Hospice Care survey. We used complete Family Evaluation of Hospice Care responses of adult heart failure ($n = 7324$) and cancer ($n = 23,871$) caregivers. Multiple logistic regression was used to examine the relationship between possible correlates and caregiver satisfaction. Correlates examined included caregiver and patient demographics, patient clinical characteristics, and hospice characteristics.

Results. Caregiver-reported patient dyspnea was associated with global and symptom management satisfaction in the heart failure cohort, whereas caregiver race was associated with global and symptom management satisfaction in the cancer cohort. Nursing home placement was associated with lower satisfaction odds in both cancer and heart failure cohorts, but heart failure patients were twice as likely as cancer patients to receive care in a nursing home.

Conclusion. This study generated hypotheses about unique factors related to caregiver satisfaction among two diagnosis cohorts that require further study, particularly the impact of race on satisfaction in the cancer cohort and the management of dyspnea in heart failure hospice patients. *J Pain Symptom Manage* 2016;51:71–78. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Heart failure, cancer, end of life, hospice, caregiver

Introduction

Caregiver satisfaction with hospice care is a key quality indicator. Caregivers are the “survivors” of hospice care and face lasting effects based on their satisfaction. Although previous literature has demonstrated that higher quality of care results in greater caregiver satisfaction, little is known about the impact of patient and caregiver characteristics on satisfaction. Importantly, most studies on caregiver satisfaction have been done in the cancer population, and no studies

have compared correlates of satisfaction in the non-cancer population to those in the cancer population. This is a critical issue given the rise in noncancer admissions to hospice; particularly in the heart failure population.

From 2000 to 2007, hospice enrollment among heart failure patients more than tripled; almost 40% of Medicare recipients who died of heart failure in 2007 enrolled in hospice before death.¹ End-stage heart failure patients have symptom profiles similar

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Accepted for publication: September 3, 2015.

to those of advanced cancer, making them ideal candidates for hospice enrollment.² Yet patterns of hospice enrollment, hospice length of stay, and demographic characteristics (age, gender, place of care) differ between heart failure and cancer patients.^{3–5} This raises the question of whether characteristics associated with caregiver satisfaction are similar or different between the two populations.

Understanding correlates of satisfaction is important as caregiver *dissatisfaction* with hospice care has been linked with an increased likelihood of patient hospitalization or nursing home admission, additional resource use, and worse health outcomes for the caregiver.^{6–8} Dissatisfied caregivers are more likely to suffer depression, complicated grief, and suicidal ideation after patient death, whereas satisfied caregivers are more likely to complete advanced directives and plan for their own death.^{9–11}

Several previous studies have examined correlates of caregiver satisfaction in the hospice population generally and whether diagnosis is associated with caregivers' global satisfaction with hospice care.^{5,12–15} But studies have not yet compared correlates of satisfaction between heart failure and cancer caregivers, particularly in regards to the subdomains of satisfaction, such as satisfaction with symptom management and satisfaction with the emotional support provided.

This hypothesis-generating study sought to answer the question: Do correlates of caregiver satisfaction with hospice care, both global and subdomains, differ between heart failure and cancer caregivers? Our aim was to identify the correlates of satisfaction separately for heart failure and cancer caregivers in hospice care. We hypothesized that significant correlates of caregiver satisfaction would include patient and caregiver demographic characteristics (age, gender, caregiver relationship, race and ethnicity, and educational attainment), patient clinical characteristics (length of stay, place of care, symptoms experienced), and hospice organizational characteristics (hospice agency size, ownership). However, in the absence of previous comparative data, we were unable to hypothesize which correlates would be most salient to each cohort.

Methods

This was a retrospective cohort study of national hospice data obtained from the National Hospice and Palliative Care Organization (NHPCO) using the Family Evaluation of Hospice Care (FEHC) survey in 2011. The NHPCO aggregates data from approximately two-thirds of its member hospices, which span the U.S. Approval was obtained from the University of Pennsylvania Institutional Review Board before study onset.

Sample

Included in the study were caregivers of adult (21+ years of age) hospice patients who 1) reported that their care recipient received hospice care primarily for heart failure or cancer, 2) answered the FEHC in English, and 3) answered the demographics section of the FEHC completely. Although the NHPCO collects data on patients with all diagnosis types, for this study, we only used the data from heart failure and cancer caregivers. After inclusion/exclusion criteria were met, we stratified the database into heart failure and cancer cohorts.

Instrument

The FEHC is a 61-item questionnaire sent out 1–3 months after patient death that asks informal caregivers of hospice decedents to assess the end-of-life care provided.¹⁶ The FEHC has four subdomains, which examine caregiver satisfaction with 1) symptom management, 2) emotional support provided, 3) caregiver teaching provided by the hospice, and 4) coordination of care. The FEHC includes one additional question about global caregiver satisfaction with the hospice care provided. Caregivers are asked to rate the hospice care received on a 1 (excellent) to 5 (poor) scale. Internal reliability of each subdomain has been established by Cronbach alpha of 0.71–0.87.^{17,18}

Each question on the FEHC has multiple answer choices, one of which is designated by the NHPCO to be the “desirable” answer; all others are considered “negative” answers. In each domain, the percentage of negative responses is calculated as a domain score. For example, the first domain (caregiver satisfaction with symptom management) contains four items. If one negative response is given, the domain score is 0.25 (25%). It is important to note that higher numbers indicate a lower quality outcome of care. A domain score of greater than 0.20 or a response of anything other than 1 (excellent) on the question measuring global satisfaction is considered an opportunity to improve care.¹⁸

Dependent Variables

The four satisfaction domain scores and the question on global satisfaction served as our outcomes. Because domain scores of less than 0.20 or a response of excellent on the global satisfaction question are considered indicators of satisfaction, we choose to dichotomize the outcomes as satisfied (domain score <0.20 or global satisfaction score of 1) or dissatisfied (domain score \geq 0.20, global satisfaction >1).

Independent Variables

We obtained caregiver and patient demographic data (age, sex, race, ethnicity, education, and

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