Original Article

Does Continuous Hospice Care Help Patients Remain at Home?

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Abstract

Context. In the U. S., hospices sometimes provide high-intensity "continuous care" in patients' homes. However, little is known about the way that continuous care is used or what impact continuous care has on patient outcomes.

Objectives. To describe patients who receive continuous care and determine whether continuous care reduces the likelihood that patients will die in an inpatient unit or hospital.

Methods. Data from 147,137 patients admitted to 11 U.S. hospices between 2008 and 2012 were extracted from the electronic medical records. The hospices are part of a research-focused collaboration. The study used a propensity score-matched cohort design.

Results. A total of 99,687 (67.8%) patients were in a private home or nursing home on the day before death, and of these, 10,140 (10.2%) received continuous care on the day before death. A propensity score-matched sample ($n = 24{,}658$) included 8524 patients who received continuous care and 16,134 patients who received routine care on the day before death. Using the two matched groups, patients who received continuous care on the day before death were significantly less likely to die in an inpatient hospice setting (350/8524 vs. 2030/16,134; 4.1% vs. 12.6%) (odds ratio [OR] 0.29; 95% CI 0.27–0.34; $P < 0.001$). When patients were cared for by a spouse, the use of continuous care was associated with a larger decrease in inpatient deaths (OR 0.12; 95% CI 0.09–0.16; $P < 0.001$) compared with those patients cared for by other family members (OR 0.37; 95% CI 0.32–0.42; $P < 0.001$). It is possible that unmeasured covariates were not included in the propensity score match.

Conclusion. Use of continuous care on the day before death is associated with a significant reduction in the use of inpatient care on the last day of life, particularly when patients are cared for by a spouse. J Pain Symptom Manage 2015;50:297–304. © *2015 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Death, hospice, end of life, nursing

Introduction

Many patients with advanced illness who are nearing the end of life express a desire to spend their final days at home.[1–9] For some patients, this is a private residence, and for others their home is a nursing home or assisted living facility. Although not all patients want to spend their final days at home, this is an important goal for many.

Hospice care is generally focused on providing care in the home, and hospice services are designed to allow patients to remain in their homes as long as possible. Hospice can provide support in two ways.[10] First, at a minimum, hospice provides routine home care, which constitutes the majority of hospice days. This level of care provides the services of a visiting nurse and other disciplines, who typically visit several times per week. The vast majority of hospice days in the U.S. are at this level of care. Second, continuous care provides more intensive staffing, of which at least 50% of care hours must be for a licensed nurse.

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Accepted for publication: April 13, 2015.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2015.04.007

Hospices typically bill approximately $165/day for routine home care and approximately $800/day for continuous care, which is billed hourly.

However, little is known about how continuous care is used or how it affects outcomes. For instance, it is not known which patients are most likely to receive this level of care. Nor is it known whether continuous care is effective in helping patients to remain at home until death. One previous study suggests that the use of continuous care may be associated with a decreased rate of inpatient hospice utilization, but it is not known how much continuous care reduces the rate of inpatient deaths.[11] As well, it is not known whether continuous care is more effective for some patients than it is for others.

Answers to these questions are important because if continuous care can help patients to remain in their homes, then this option should be discussed with all patients at the time of hospice enrollment and offered if they are eligible. In addition, when their patients express a preference for remaining at home, physicians should select a hospice that offers continuous care and should advocate for its use. Therefore, the goals of this study were to describe the utilization of continuous care on the day before death and evaluate its impact on patients' site of death.

Methods

Patient data were extracted from the electronic medical records of 11 hospices in the Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE) network. CHOICE is a research-focused collaborative of hospices that all use Suncoast Solutions Electronic Health Record (EHR) Software and which have agreed to share their data for research purposes. CHOICE projects are defined and approved by a steering committee comprising leaders from all hospices in the network. Participating hospices range in size from 400 to 1700 patients/day and are located in New Mexico, Kentucky, Florida, Pennsylvania, Wisconsin, Michigan, Ohio, Texas (three hospices), and Kansas/Missouri. All are not-for-profit.

CHOICE obtains data from a data warehouse that participating hospices use for tracking, quality measurement, and benchmarking. Warehouse data reside on a secure server that is managed by Suncoast Solutions. Extracted data are then stripped of identifiers to create a Health Insurance Portability and Accountability Act (HIPAA)-compliant limited data set that is transferred as an encrypted file to the University of Pennsylvania for analysis.

Patients were included if they were admitted to a participating hospice between January 1, 2008 and May 15, 2012. We first extracted a data set containing basic demographic variables (age, gender, race) and diagnoses (admitting diagnosis and up to three additional diagnoses). Debility or general decline was an allowable terminal diagnosis during the time frame of this study and was included as a diagnostic category. Extraction also included site of care at the time of enrollment (home, long-term care facility, hospital, hospice inpatient unit). We also included clinical data elements that were markers of the severity of the illness and the complexity of care (e.g., presence of pain, use of oxygen, use of intravenous opioids). These variables are listed in Table 1.

We also included a Palliative Performance Scale (PPS) score for each patient at the time of hospice enrollment. The PPS is an 11-point scale (scored 0−100 in 10-point increments) in which higher numbers indicate better function.[12] We initially described the PPS score as a continuous variable. In subsequent analyses, for ease of interpretation in calculating predicted survivals, we grouped PPS scores into three categories (0−30, 30−40, 50−100) based on previous studies of prognosis in hospice patients.[13,14]

We restricted the analysis to patients who were at home or in a nursing home on the day before death. To examine the impact of care on the day before death, we further restricted the sample to those patients who enrolled in hospice at least two days before death. We then created a propensity score to match patients who did/did not receive continuous care on the day before death.

Propensity score matching is a method of creating two groups that are balanced with respect to key patient characteristics that are specified a priori. This approach is similar to that of multivariable regression analysis but offers several advantages.[15] First, unlike multivariable adjustment, propensity score matching allows for a check of balancing between two groups. Second, as in a randomized controlled trial, propensity score adjustment allows the separation of a study's design (e.g., balancing of groups) from its analysis. Third, propensity score analysis makes it possible to determine when little or no overlap exists in the characteristics of two groups, which in turn suggests that any comparison is likely to be problematic.

To create two matched groups (patients receiving routine home care vs. continuous care on the day before death), first we examined patient characteristics in each of the two groups. We used theory-based logistic regression models to examine bivariate associations and then to identify potential predictors of group assignment. We considered variables that were potentially associated with group assignment and outcome (site of death). Models used robust jackknife standard errors, clustered by hospice, and case-wise deletion of missing data. We then considered variables