

Events Leading to Hospital-Related Disenrollment of Home Hospice Patients: A Study of Primary Caregivers' Perspectives

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Abstract

Background: Approximately 25% of hospice disenrollments in the United States occur as the result of hospitalization, which can lead to burdensome transitions and undesired care. Informal caregivers (e.g., spouses, children) play a critical role in caring for patients on home hospice. Research examining hospital-related disenrollment among these patients is limited.

Objective: To understand the events surrounding the hospitalization of patients discharged from home hospice through the perspective of their informal caregivers.

Design: Thirty-eight semistructured phone interviews with caregivers were conducted, and data regarding the events leading to hospitalization and hospice disenrollment were collected. Study data were analyzed by using qualitative methods.

Setting/Subjects: Subjects included caregivers of 38 patients who received services from one not-for-profit home hospice organization in New York City. Participants were English speaking only.

Measurements: Caregiver recordings were transcribed and analyzed by using content analysis.

Results: Content analysis revealed four major themes contributing to hospitalization: (1) distressing/difficult-to-witness signs and symptoms, (2) needing palliative interventions not deliverable in the home setting, (3) preference to be cared for by nonhospice physicians or at a local hospital, and (4) caregivers not comfortable with the death of their care recipient at home. Over half of all caregivers called 911 before calling hospice.

Conclusions: Our study provides insight into the events leading to hospitalization of home hospice patients from the caregivers' perspective. Further research is needed to quantify the drivers of hospitalization and to develop interventions that reduce utilization, while improving care for home hospice patients and their caregivers.

Keywords: disenrollment; hospice; hospitalization

Introduction

HOSPICE FOCUSES on maximizing quality-of-life while reducing suffering for patients with life-limiting illnesses at the end of life (EoL). In the United States, most hospice care is delivered at home, and informal caregivers (e.g., spouses, children, relatives) play a significant role in providing care to these patients.^{1,2} It is estimated that half a million caregivers provide informal care to their loved ones during the last year of life, which can amount to 66 hours of care each week.^{3,4}

Although hospice interdisciplinary teams and informal caregivers work in tandem to address the needs of patients on

home hospice, approximately one out of every five patients disenrolls and up to 25% of those disenrolled patients return to the hospital within 30 days of discharge.⁵ These care transitions can be detrimental to patients, given the disruption in continuity of care and possibly receiving unwanted care provided by different hospital providers who may be unaware of patients' care preferences.^{6,7} Furthermore, many patients prefer to die at home and especially for those patients who elect hospice care, a hospitalization is a potentially burdensome and costly care transition.^{8,9}

Research examining reasons for hospitalization in this population is limited. One caregiver study revealed that an acute event, uncontrolled symptoms, imminent death, or the

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inability to provide care were reasons for transferring patients to an inpatient facility (e.g., inpatient hospice unit, acute care hospital).¹⁰ Another study examined reasons for hospitalization through the perspective of home hospice providers and found major themes that contributed to this transition include, but not limited to: caregiver burden, distressing/difficult-to-manage signs and symptoms, and families' difficulty in accepting patients' mortality.¹¹

Given the important role that informal caregivers play in providing care for home hospice patients, they can offer invaluable insight into the events leading to a hospital-related disenrollment. Accordingly, our study sought to understand these events from the perspective of the informal caregivers.

Methods

Design

This was a qualitative, cross-sectional study using content analysis to analyze data collected via phone interviews with primary caregivers.

Study setting

We recruited participants from the Visiting Nurse Service of New York Hospice and Palliative Care (VNSNYHPC) in New York City. VNSNYHPC is a nonprofit organization that serves ~850 patients daily. Along with visits provided by an interdisciplinary team, patients receive an emergency medication kit along with a "What Can I Do" guide, which outlines hospice support services and instructions for patients and caregivers to follow in an emergency. A 24/7 phone service is staffed by a dedicated hospice nurse, in which a hospice nurse, nurse practitioner, or physician may be dispatched based on the needs of the patient within the hour. In addition, a physician is on call 24 hours a day/7 days a week.

At enrollment, patients have the option of selecting their hospice physician, whether it be the VNSNYHPC physician on staff or their own internist/specialist. The hospice team also attempts to discuss preference on location of death. In any event, VNSNYHPC providers encourage patients and caregivers to call and notify hospice in the event of an emergency. If patients need general inpatient (GIP) care, VNSNYHPC can transfer patients to one of their inpatient hospice units, which, at most, is 20 miles away from the farthest area served. These inpatient units provide services that include daily physician visits, lab draws, intravenous fluids/medications, blood transfusions, and imaging. If 911 is called and patients are subsequently transferred to an acute care hospital, VNSNYHPC liaisons work closely with hospitals and attempt to meet the patient and family to re-establish goals of care and to discuss reasons for the emergency visit.

Study subjects

VNSNYHPC generated a weekly list of patients who were disenrolled and flagged as having been hospitalized in an acute care hospital. This list contained the patient's name and the primary caregiver's name, address, and phone number. In addition, patient demographic data were abstracted from the medical record, which included: age, gender, primary hospice diagnosis, race/ethnicity, length of stay in hospice, and whether there was a nursing visit one day before discharge.

Letters were mailed to the caregivers of patients who were disenrolled from hospice and hospitalized. The letter, which was mailed within one week of obtaining the list, described the aims of the study and informed caregivers that they would be contacted by phone within two to four weeks. The letter provided a number for prospective participants to call if they did not want to be contacted. No one called to opt out of the study. Phone calls were made to the caregivers by one investigator (V.P.) who described the aims of the study and obtained verbal consent. Participants were eligible if they were listed as the primary caregiver of the patient, were 18 years of age and older, and had a care recipient who was documented by VNSNYHPC to have been discharged from home hospice due to a hospitalization. Participants who were not fluent in English were excluded from the study. Phone calls were made on two separate attempts to reach each caregiver; those who failed to respond to the two attempts were deemed unreachable. Calls were conducted in the afternoon during working hours. There was no preexisting relationship between the interviewer and the caregiver.

Subjects were recruited from August 1, 2014 to February 1, 2015. The institutional review boards of both Weill Cornell Medical College and VNSNYHPC approved the study protocol.

Phone interview methodology

One investigator (V.P.) interviewed subjects by using a semistructured interview guide with follow-up probes and introduced new topics based on the participant's responses. Caregivers were asked about their relationship to the patient; factors leading to or triggering the transition to the hospital; whether 911 and/or hospice was called and which was called first; and whether they were present with the patient at the time leading to the hospitalization. Follow-up questions focused on: events leading to the patients' hospitalization, challenges in home hospice care that may have contributed to hospitalization, and reasons why 911 was initially called. Interviews lasted between 5 and 15 minutes, with an average interview time of 8 minutes.

Analysis

Audiotaped interviews were transcribed and analyzed by using content analysis.¹² Two investigators (S.P. and V.P.) trained in qualitative research methods independently reviewed phone interview transcripts and systematically organized data into a structured format. Codes, categories, and themes were constructed individually and continually revised and re-formulated after reviewing each new transcript. No categories or themes were predetermined beforehand. The two investigators then met to compare and discuss their findings and reconciled any differing themes until there was an agreement on a framework of themes and their definition. The final agreed-on framework was subsequently reapplied to each transcript. Qualitative analysis software was not utilized. Thematic saturation was reached after 31 interviews, and a total of 38 phone interviews were completed for the study.

Results

One hundred six caregivers were telephoned, and 63 (59%) were not reachable after two phone calls. Of the 43 caregivers who were successfully reached by phone, 38 (88%) agreed to

TABLE 1. DEMOGRAPHICS OF HOME HOSPICE PATIENTS

	<i>Patients of caregivers interviewed (N=38), n (%)</i>
Age (years)	
Mean	77
Median	80
Gender	
Female	25 (66)
Ethnicity	
White	14 (37)
Black	9 (23)
Hispanic	14 (37)
Asian	1 (3)
Other	0 (0)
Length of stay in home hospice (days)	
Mean	75
Median	42
Primary hospice diagnosis	
Cancer	23 (60)
Noncancer	15 (40)

participate. The caregiver's relationship to the patient was as follows: adult child (55%), nonimmediate relative (18%), spouse (16%), friend (8%), and parent (3%). Twenty-three caregivers (60%) were present during the events leading to hospitalization. Table 1 provides demographic data on the 38 home hospice patients whose caregivers were interviewed. Out of the 38 caregivers, 23 (61%) had a nursing visit within one day before hospitalization and 12 (32%) mentioned that they spoke with a hospice staff before going to the hospital.

Table 2 lists the identified themes that contributed to a hospital-related disenrollment. These include: distressing/difficult-to-witness signs and symptoms ($N=44$), needing palliative interventions not deliverable in the home setting ($N=11$), preference to be cared for by nonhospice physicians

TABLE 2. FACTORS CONTRIBUTING TO HOSPITALIZATION

	$N=44^a$
Distressing/difficult-to-witness signs and symptoms	
Breathing difficulties	10
Pain	8
Lethargy/change in mental status	6
Edema	4
Fall	4
Lack of appetite	3
Bleeding	3
Nausea/vomiting	2
Hypoglycemia	2
Seizure	2
Needing workup/interventions not deliverable in the home setting	11
Preference to be cared for by nonhospice physicians or at local hospital	6
Caregivers not comfortable with death of their care recipient at home	4

^aSome caregivers mentioned multiple signs or symptoms as a contributing factor to hospitalization.

and at local hospitals ($N=6$), and caregivers not comfortable with death of their care recipient at home ($N=4$). Our analysis did not detect differences in responses between caregivers of cancer and noncancer patients or different racial groups.

Factors contributing to hospital-related disenrollment

Distressing/difficult-to-witness signs and symptoms. The majority of caregivers mentioned that distressing/difficult-to-witness signs and symptoms were the reason for hospitalization (Table 2). Breathing difficulties, pain, and lethargy/change in mental status were the most commonly reported signs and symptoms. In one scenario, a caregiver panicked when she saw her mother seizing, prompting her to call 911. She stated:

“When I came [home] and saw [she was having a seizure], I said we have to call 911. I mean it was horrific, so we called 911.”

Needing workup/interventions not deliverable in the home setting. In some cases, patients required a workup and/or intervention that was not easily feasible to be performed at home. One caregiver discussed that her mother had fallen at home and needed to be assessed. She stated:

“She fell, it was at night. She was between the bed and the dresser and was trying to go to the bathroom. She broke her hip.”

A preference to be cared for by nonhospice physicians or at local hospital. Despite hospices being able to offer services such as continuous home care (CHC) or GIP care for patients who require more intensive care, several caregivers voiced a preference to get more intensive care from the patients' nonhospice physicians and hospital. The caregivers' reasons for this preference included a higher comfort level in interacting with known physicians with whom they have established relationships with, as well as convenience. In one scenario, the caregiver decided to hospitalize her mother because of both familiarity with the hospital staff and the hospital's nearby location. She stated:

“...for so many years she's been going to the hospital, and in any situation where there is a dire situation or not, I need to be in Brooklyn to go and visit her... Because the hospital setting, her primary doctor is there and the people she knows are there and plus people are closer to her home where family members can either walk or travel by car to visit her.”

Caregivers not comfortable with death of their care recipient at home. Some caregivers expressed feeling uneasy witnessing their care recipient actively dying at home, which led them to call 911. In interviews in which caregivers described signs and symptoms of patients who seemed to be actively dying and subsequently died in the hospital, caregivers expressed that they had not been ready for the patient to die, especially at home. In one case, a caregiver stated that her mother stopped breathing and her sister panicked and called 911. She remarked:

“My sister told me she turned blue. [She] panicked, [she] got nervous, and [she] called 911 right away and they called me... I think it's harder when your loved one dies at home. You're right there, you're with the person everyday, just to watch them die it's not a good feeling.”

Utilization of 911

When asked about the utilization of 911, over half of the caregivers (53%) expressed that they called 911 before calling hospice. In cases in which hospice was called initially, half of the respondents reported that they then called 911. Many caregivers in this group shared that they called 911 in the hope of obtaining a faster response time. As one caregiver stated:

“There was no time to waste for an ambulance from hospice or wherever hospice was going to take my mother. So I had to call a regular ambulance right away.”

Hospitalization initiated by caregivers, hospice providers, or community physicians

Over half of the hospitalizations were caregiver driven (60%); however, approximately a quarter of respondents reported that their hospice provider or community physician initiated the transition. Hospice-initiated hospitalizations (13%) typically occurred after an assessment by the hospice nurse. In these cases, patients had had some sort of accident (e.g., fall), which led to a recommendation of hospitalization. For example, one case involved a patient who had fallen from her bed and the hospice provider recommended hospitalization to manage a laceration and potential bone fractures. The caregiver noted:

“She fell out of bed and broke several vertebrae. She also needed stitches. I called the home hospice hotline first and when the nurse arrived, she advised me to call 911.”

An almost equal number of caregivers (11%) reported hospitalizations that were initiated by community physicians. In these cases, caregivers described patients who went to see their community physician and were, subsequently, sent to the hospital. According to one interview, the caregiver and the patient went to a regular doctor’s appointment and transitioned to the hospital after the physician suspected fluid build-up in the patient’s lungs. This caregiver remarked:

“We had a routine appointment to see the cardiologist and he said that he had to keep her, and then sent her directly to the hospital.”

Discussion

Our study examines hospital-related disenrollment of home hospice patients through interviews with primary caregivers. We found reasons for transition to the hospital to be varied, although several common themes emerged from our analysis.

In a majority of phone interviews, distressing/difficult-to-witness signs and symptoms were mentioned as common reasons for a transition to the hospital. Studies have shown that acute symptoms are known to contribute to hospitalization in the hospice population with as many as 90% of patients experiencing symptoms at the EoL.^{13,14} Informal caregivers may often feel uncomfortable or ill equipped to manage patients’ symptoms at home.^{13–16} Given that caregiving and symptom management are likely intertwined components of quality home hospice care, hospitalization may signify the fact that certain caregivers require more support. Research studying symptom management interventions in the home hospice setting is still sparse; however, interventions that incorporate new technologies or empower

caregivers through education have had promising results.^{17–19} Further research is merited to examine effective measures to better identify and reduce symptoms experienced by patients, since reduction of suffering is a cornerstone of quality hospice care.

We also found that a majority of caregivers called 911 before contacting hospice, despite the fact that VNSNYHPC providers do educate patients and caregivers to call hospice in the event of an emergency. Although many caregivers called 911 because they perceived the need to obtain acute medical attention, we did not assess their knowledge around more intensive medical services (i.e., CHC, GIP care) that are offered by hospices. While it may be difficult to change the “reflex” that many caregivers have of calling 911, efforts focused on reinforcing patients and caregivers to contact hospice first, educating them on services that are offered, and developing new strategies on being more responsive to their needs are important. In our previous work, which examined reasons for hospitalization in home hospice patients, some hospice providers remarked that response times may be quicker when calling 911 compared with hospice, especially in an urban environment where an ambulance can get to a patient within minutes. To address this issue, developing partnerships between hospice and Emergency Medical Services (EMS) may be an important step to assess whether these patients need to be transitioned to the hospital.²⁰

Another contributor to hospitalization in our sample was the desire among patients and caregivers to seek treatment from their care recipients’ physicians and in hospitals that were familiar and convenient. Studies have shown that patients value continuity with their physicians and see their physicians as a valued member of their care, although no

TABLE 3. CHALLENGES AND AREAS FOR FUTURE RESEARCH/INTERVENTION

Distressing/difficult-to-witness signs and symptoms
Finding more effective ways to educate patients, caregivers, and hospice providers about managing common symptoms at the end of life
Implementing telemedicine technology to better track symptoms and notify providers when escalation of symptoms occurs
Developing better predictors to identify patients who may require enhanced symptom management
EMS versus hospice response times
Developing partnerships between hospices and EMS
Utilizing synchronous telemedicine technology to communicate with patients/caregivers at times of crisis
Patients requiring palliative interventions not deliverable at home
Assessing patient and caregiver knowledge in regards to more intensive hospice services (e.g., CHC, GIP)
Earlier identification of patients who need CHC or GIP level of care
Expanding palliative care interventions (e.g., ultrasound) that can be performed at home and studying its impact on hospitalization/quality of care
Desire to seek care from nonhospice physicians and hospital
Incorporating and involving physicians into patients’ hospice care plan

CHC, continuous home care; EMS, Emergency Medical Services; GIP, general inpatient.

studies have looked at situations at the EoL.^{21–24} However, enrolling a patient into hospice can significantly alter the dynamics of the treating physician and patient, given that a majority of the care is provided at home and delivered by a dedicated hospice team. One can imagine that patients and caregivers who have established trusting relationships with their physicians and affiliated hospitals would want to continue to receive care from them under certain circumstances, even after enrollment into hospice. Therefore, understanding what patients and caregivers desire from their regular physicians during this care transition will allow hospices to better integrate physicians into hospice care in a more meaningful way.

The results of this study complement our previous work, which examined reasons for hospitalization from the perspectives of hospice providers (e.g., nurses, social workers, spiritual care counselors).¹¹ Both study groups share some important commonalities. Distressing symptoms were perceived to contribute to hospitalization along with the underlying issue of caregiver burden. We also found that relationships with physicians and hospital systems are important and may influence care transitions at the EoL. Overall, addressing the issue of reducing hospitalization in the home hospice setting involves a multicomponent approach to better educate, prepare, equip, and support patients, caregivers, and hospice teams. Table 3 outlines some of the central themes in our study and lists potential areas for future interventions and research.

This study has several limitations. This was a single-site study and participants were caregivers living in a large urban environment, which may not reflect caregivers' experience in other regions of the country. Recall bias may have played a role in the accuracy of responses, since we interviewed caregivers two to four weeks after the patient was hospitalized and not all caregivers were present during the transition. Furthermore, our patient population does not quite reflect the makeup of home hospice patients nationwide, since a majority of caregivers (60%) we interviewed were caring for a patient with cancer, whereas cancer patients only make up 40% of hospice patients enrolled in the United States.²⁵ In addition, our sample has a more diverse racial distribution and longer length of stay compared with national average. Finally, although we were able to confirm with caregivers about patients' hospitalization and gather data regarding events leading to this transition, we did not have access to patients' hospital medical records that would have provided a more comprehensive picture and verification of what occurred in the hospital and whether the hospitalizations could have been potentially avoidable.

Overall, this study provides insight into the events leading to hospitalization of home hospice patients from the caregivers' perspective. Our results suggest potential avenues for future interventions, including reducing patients' symptom burden, improving caregivers' ability to manage patients' distressing symptoms, improving hospice response times, and better incorporating patients' physicians into hospice care when appropriate.

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