Why Do Home Hospice Patients Return to the Hospital? A Study of Hospice Provider Perspectives

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Abstract

Background: Hospice provides an opportunity for patients to receive care at home at the end of life (EOL); however, approximately 25% of patients who disenroll from hospice are hospitalized. Hospitalization can lead to poor care transitions and result in unwarranted care and adverse patient outcomes. Research examining reasons for hospitalization in this patient population is limited.

Objective: The objective was to understand the reasons for hospitalization among home hospice patients through the perspectives of hospice interdisciplinary team (IDT) members.

Methods: This was a qualitative study using a grounded theory approach. Seven semistructured focus group were conducted to solicit reasons for hospitalization among home hospice patients. Participants consisted of 73 home hospice IDT members from a not-for-profit hospice agency in New York City. Focus group recordings were transcribed and analyzed using content analysis.

Results: Eight major themes were identified: (1) not fully understanding hospice, (2) lack of clarity about disease prognosis, (3) desire to continue receiving care from nonhospice physicians and hospital, (4) caregiver burden, (5) distressing/difficult-to-manage signs and symptoms, (6) caregivers' reluctance to administer morphine, (7) 911's faster response time compared to hospice, and (8) families' difficulty accepting patients' mortality.

Conclusions: Reasons for hospitalization in home hospice patients are multifactorial and complex. Our study highlights barriers and challenges that patients, families, physicians, and hospices face around home hospice care and hospitalization. More research is needed to elucidate these issues and develop viable strategies to address them.

Introduction

HOSPICE CARE AIMS to provide comprehensive medical care and support for patients and families at the end of life (EOL). In the United States, hospice has been shown to improve quality of care and satisfaction among patients and caregivers.^{1–3} While a majority of hospice patients are treated successfully at home, there are situations when home hospice may be insufficient and patients opt for hospitalization.⁴ In these situations hospice organizations can provide continuous home care (CHC) or general inpatient (GIP) care as an alternative to regular home hospice care. These interventions deliver a higher level of care that can help address acute medical crises, provide more intensive palliation, and maintain continuity while avoiding poor care transitions. However, a report by the Department of Health and Human Services found that 21.1% of hospices did not provide GIP care to their beneficiaries who were discharged in 2012, and a

small percentage of hospice days (0.4%) were billed as CHC.⁵ The authors of the report expressed concerns regarding the lack of GIP utilization and further suggested that this outcome indicates that some patients are not receiving sufficient access to the level of care that they need.

In regards to hospital utilization by hospice patients, a study by Teno et al. found that approximately one out of every five hospice patients disenrolls from the program, and a quarter of disenrollments results in a hospitalization.⁶ Similarly, a report on Medicare Hospice Payment Reform in 2014 revealed that 6.7% of all hospice admissions result in an emergency room (ER) visit, observational stay (OS), or inpatient visit (IV), which amounts to over 100,000 affected patients annually.⁷

Hospitalization can be detrimental to home hospice patients and their family members. Hospitalization and ER visits increase risk for adverse events, which include injury, disability, or death.^{8,9} Furthermore, ER physicians may not

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be adept or comfortable providing palliative care and are often unaware of patients' prior goals of care discussions.¹⁰ The lack of continuity can lead to a breakdown in communication and undesirable outcomes such as unwanted resuscitation. Given that the majority of hospice patients who become hospitalized reenroll back into the program, these care transitions can be burdensome for patients and families and lead to poor patient outcomes.^{6,11}

Studies examining reasons for hospitalizations among hospice or palliative care patients are few. One study examined caregivers' reasons for transferring home hospice patients to an inpatient facility, defined as an inpatient hospice unit, acute care hospital, or nursing home. The authors found that an acute medical event, uncontrolled symptoms, imminent death, or the inability to provide needed care safely were important reasons prompting transfer.¹² Another study retrospectively analyzed factors associated with hospitalization in hospice patients with lung or colorectal cancer from 1988 to 1998 in the United States. This investigation found that the characteristics most often associated with hospitalization were those who were younger, black, or male.¹³

Accordingly, our study sought to determine reasons for hospitalization among home hospice patients through the perspective of the interdisciplinary team (IDT) members caring for them. IDT members include physicians, team managers, nurses, social workers, spiritual care counselors, and home health aides. Each member plays an important role in delivering care to home hospice patients and families.

Methods

Design

This was a qualitative, cross-sectional study using a grounded theory approach from data collected in seven focus groups.

Study sites

Visiting Nurse Service of New York Hospice and Palliative Care (VNSNYHPC) is a nonprofit hospice organization serving people in New York City. As part of their hospice service, VNSNYHPC offers GIP care to their patients at the VNSNY Haven Hospice Specialty Care Unit located in Manhattan.

A total of eight home hospice teams serve patients in New York City's five boroughs. Focus groups were conducted at five VNSNYHPC regional offices located in Manhattan, Brooklyn, Queens, Bronx, and Staten Island. These offices housed weekly meetings attended by home hospice IDT members to review patient care needs. The institutional review boards of Weill Cornell Medical College and VNSNY approved this study.

Study participants

In August 2014, two authors (VP, BS) contacted seven of eight VNSNYHPC IDT managers to schedule a focus group meeting with their respective interdisciplinary teams. IDT members were informed by their managers about the purpose of the voluntary meeting prior to meeting with the authors. During these meetings the authors explained the study, invited attendees to participate, and obtained written consent. IDT home hospice members were eligible candidates for the

study. All members present during the focus group sessions were allowed to take part and no one refused participation.

Focus group methodology

Two authors (VP, BS) led each focus group. The investigator (VP) introduced the study's purpose, objectives, and the focus group process and moderated the discussions using a semistructured interview guide with follow-up probes developed from a theoretical perspective. Interviews were led by a topic guide and new topics were introduced based on participants' responses. Participants were initially asked to state their role in the home hospice program and the numbers of years of experience in hospice care. Afterwards, the authors asked the group to share their experiences on reasons home hospice patients and/or their caregivers seek hospitalization. We defined hospitalization as either a stay in the ER or an inpatient hospital admission. Outpatient visits and inpatient hospice stays were not included in the definition of hospitalization.

Analysis

All focus groups were audiotaped, transcribed, and analyzed using content analysis. Two investigators (BS, VP) independently reviewed focus group transcripts and extracted a preliminary set of themes. Qualitative analysis software was not utilized. The investigators (BS, VP) then met to discuss their findings and reconcile any differing themes until there was an agreement on a common set of themes. Data saturation was achieved after the sixth focus group and confirmed after the seventh. The investigators returned and shared these findings with IDT members after the analysis was performed. These members, who had participated in the focus groups, agreed that the identified themes captured their thoughts and feelings shared at the time of their participation in a focus group, suggesting that the investigators' interpretation of the findings was credible.

Results

Table 1 reveals the characteristics of participants based on hospice role and years of experience in palliative/hospice care. Analysis of the transcripts yielded eight major themes, which are presented below and summarized in Table 2. Responses did not vary by type of provider or years of experience.

Not fully understanding hospice

Participants described patients' and families' poor understanding of hospice as a reason often leading to hospitalization.

TABLE 1. RESPONDENT CHARACTERISTICS

Home hospice provider	Number of respondents (%) (n = 73)	Median years of experience in palliative care
Team manager	6 (8.2%)	8.5
Physician	4 (5.5%)	13.0
Nurse	26 (35.6%)	5.0
Social worker	21 (28.8%)	7.0
Spiritual care counselor	14 (19.2%)	6.0
Home health aide	2 (2.7%)	6.0

TABLE 2. REASONS FOR HOSPITALIZATION AMONG HOME HOSPICE PATIENTS

<i>Major themes</i>	<i>Percentage of focus groups that mentioned the theme (%)</i>	<i>Number of times the theme was mentioned in conversation (n)</i>
Not fully understanding hospice	100%	26
Lack of clarity about disease prognosis	86%	16
Desire to continue receiving care from nonhospice physicians and hospital	86%	10
Caregiver burden	100%	17
Distressing/difficult to manage signs and symptoms	100%	39
Caregivers' reluctance to administer morphine	100%	15
911's faster response time compared to hospice	100%	23
Families' difficulty accepting patients' mortality	86%	24

Many IDT members felt that primary, nonhospice physicians played a critical role in discussing hospice philosophy and care with patients and families prior to a patient's enrollment into hospice. Some participants felt that patients' and families' poor understanding of hospice were tied to these physician-patient/family conversations. For instance, one nurse expressed that some physicians who referred patients to hospice may focus on the resources that are provided rather than fully discussing whether the philosophy of hospice coincides with their goals of care. The nurse said:

"Physicians...may emphasize you get a home health aide, you get care at home, but will [not] emphasize that this is it—[that] there's really no more treatment: you can come back for A, B, and C [but] not for treatment. And I don't think that's always reinforced."

Not fully understanding the philosophy of hospice and what is provided can result in a mismatch of care needs. When patients' and families' expectations and understanding of hospice differ from the philosophy and services that home hospice care provides, hospitalization is an option that patients and families may seek.

Lack of clarity about disease prognosis

Several participants described caring for patients and families who did not seem to be informed about their terminal prognosis at the time of enrollment. As a result, patients and families may enter hospice without understanding that they are dying. Whether these conversations were had with their physician, IDT members felt that patients and families who did not understand that the prognosis was terminal were more predisposed to getting hospitalized. One participant remarked:

"I found that I have a lot of patients from a [medical center who] have not been told that they are dying. I find this basi-

cally all the time. So when we get the patients, now we must tell them that there is no more treatment.... So I think if there was better patient education on that end, it would eliminate a lot of [hospitalization]."

Desire to continue receiving care from nonhospice physicians and hospital

Other participants cited that strong ties between patients and their nonhospice physicians and hospital influenced the decision for some patients to seek hospitalization. In situations where patients or families believed that a higher level of care is needed, many participants felt that some patients and families prefer the familiarity of care provided by their nonhospice physicians and in their hospital compared to what hospice may be able to provide through CHC or GIP care. As one participant noted:

"There may also be situations where there is still a strong relationship with the cancer center where [patients] were being treated, and wanting to go back there or feeling more of a connection with them than with the hospice team."

Caregiver burden

Many indicated that the burden of caring for a loved one on home hospice is overwhelming for many caregivers. While hospice provides support, caregivers are expected to provide a majority of the day-to-day care for the patient. Caregivers who are not prepared to manage the needs of their care recipient at home will seek other options of care such as hospitalization. One manager stated:

"Some families really are inept to take care of medical things.... So they get in too deep, too quickly, they're just not capable, and in fear, they send the patient to the hospital."

Distressing/difficult-to-manage signs and symptoms

Participants often mentioned that a "crisis" would trigger a hospitalization. This "crisis" was commonly described as a distressing or difficult-to-manage sign or symptom perceived by the caregiver. Breathing difficulties, pain, bleeding, and change in mental status were described by participants as common reasons that triggered a "crisis" and led caregivers to call 911. One nurse commented:

"It's a breathing problem. That's why [caregivers] call 911—they cannot get the patient comfortable breathing."

Caregivers' reluctance to administer morphine

Although morphine is a medication commonly used in hospice care to help relieve pain and dyspnea, participants described caregivers' reluctance to administer it to manage acute or chronic symptoms. Many cited the stigma that caregivers have about morphine as a medication used to hasten death. As a result, many participants find that caregivers are not confident in administering morphine to patients when they experience distressing signs and symptoms. This leads to poor symptom control and can result in hospitalization. One participant stated:

"So even though you teach [caregivers], when something happens and you tell them, well, you can give them morphine—I can't do it, I need somebody else to do it." And [caregivers] just 9-1-1 it, because that's what they've done their whole life."

911's faster response time compared to hospice

Participants described that when caregivers perceive that the patient is in a “crisis,” many will call 911 regardless of what hospice can offer, because 911 yields a more immediate response. IDT members acknowledged that while they can respond to emergencies within seconds to minutes over the phone, it may take up to one to two hours for a medical professional to reach the patient’s residence. In some cases caregivers will reflexively call 911 knowing that Emergency Medical Services (EMS) will respond within minutes, while other caregivers call hospice first but eventually call 911 because they desire a quicker response. As one participant reported:

“The other part of that is we can’t get there fast enough for them, [families] panic, they want somebody and something done right now. And so they’ll call us and if we don’t respond fast enough they’ll call 911.”

A team manager commented:

“And I think that 911 is a powerful tool—you push the button and [EMS] is there in three minutes. Even if we say confidently, “I will send a nurse over soon,” that’s not the same as [911].”

Families’ difficulty accepting patients’ mortality

Even in cases where families have a clear understanding of the patient’s prognosis and are on board with hospice care, participants acknowledged that hospitalization occurs when families are not ready to accept that the patient is dying. When death is imminent, several IDT members find that families may not be emotionally prepared for the process. As one spiritual care counselor explained:

“They understand [the wish of the patient is to die at home], but at a moment of crisis when they see a loved one [dying], it’s like all bets are off. Sort of like, ‘You know, this is my loved one and I know they don’t [want to go to the ER] but I’m calling 911.’” [Caregivers are] wrestling with the feeling of not doing the right thing for my loved one.”

Discussion

Our study found that factors contributing to hospitalization among home hospice patients are complex, layered, and multifactorial. Our analysis revealed several important areas for future research and intervention.

Improving understanding of hospice and EOL issues

Many participants believed that home hospice patients who did not fully understand their prognosis and/or hospice care were more likely to be hospitalized. One study showed that half of patients had little or no knowledge of hospice until the time of enrollment.¹⁴ Our findings echo these results and add to the literature that insufficient understanding may contribute to hospitalization in the home hospice population.

IDT members expressed the need to improve patients’ and families’ understanding of EOL issues and hospice. These are often difficult conversations to have; however, studies show that patients trust their physicians and desire realistic conversations about these issues.^{15–17} Given the relationships

between patients and their treating physicians, it is important that these discussions take place prior to hospice enrollment in order to better prepare patients and families for this transition. Medicare’s recent plan to reimburse for EOL counseling will hopefully provide the incentive to discuss these issues earlier on with patients.¹⁸ In conjunction, the hospice admission process is another important period when these topics are often reintroduced and discussed. By identifying barriers in communicating EOL issues and hospice care with patients and families at various points in the course of patients’ terminal disease, we may be able to develop targeted strategies and implement incentives aimed at improving understanding, identifying appropriate candidates for hospice care, and reducing disenrollment due to hospitalization.

Creating better transitions into hospice

When patients enroll into hospice, it signifies a shift in philosophy and methodology of care for many patients and families. Some of the transitions when switching from traditional medical care to home hospice care were highlighted as potential contributors to hospitalization.

One particular theme that was commonly mentioned was the response times in situations where caregivers felt urgent care was needed. As a result, faster response time by EMS compared to hospice was seen as a contributing factor to hospitalization. We suspect this is a concern encountered by many if not all hospices. Given the report on Medicare Hospice Payment Reform in 2014 regarding CHC and GIP utilization, perhaps we need to proactively implement these existing options of care to better meet the needs of patients that opt for hospitalization.⁵ Forging collaborations with EMS and finding novel ways to deliver care, such as using synchronous telemedicine technology, have been implemented in other care settings with promising results.^{19–22} These interventions would appear to have significant potential to deliver more timely care to home hospice patients and better equip families during crisis situations.

Another transitional challenge involves patients and families who prefer care provided by their nonhospice physicians and hospital when a crisis occurs. Many patients trust their physicians and highly value that continuity.^{16,23–25} Further research is needed to understand how patients’ and families’ preferences to maintain care with their physicians influences hospitalization patterns. Developing ways to better integrate nonhospice physicians within hospice care may reduce patients’ and families’ desire to be hospitalized when care can be delivered within hospice.

Challenges faced by caregivers

Informal caregivers provide significant amounts of care for home hospice patients at the EOL and for many, it can be an unfamiliar and challenging experience.^{23,24} Therefore, it is not uncommon for many to experience significant anxiety, depression, and stress during the caregiving process.²⁵ Our analysis reveals that caregivers with high burden levels may decide to hospitalize patients because they feel overwhelmed. While hospice care aims to be comprehensive, standard home hospice care may not be sufficient for all patients and caregivers. Therefore, interventions are needed to better identify and intervene with caregivers who are experiencing

significant burden, struggling to provide care, and at risk of relying on hospitals for care.

Many participants expressed that a crisis—frequently described as distressing or difficult-to-manage signs and/or symptoms perceived by the caregiver—to be a trigger for hospitalization. Our findings echo the results from a prior study, which found that shortness of breath and pain were common reasons for palliative care patients to present to an emergency department.²⁶ Although every crisis is unique, it is important to understand how we can better manage commonly experienced crises and develop more effective approaches to assist caregivers and care teams when they arise.

A barrier mentioned by IDT members regarding distressing or difficult-to-manage signs and/or symptoms involved the reluctance caregivers have in administering morphine. This is consistent with a study by Joyce et al., who sampled hospice providers and found that one-third had cases where caregivers experienced problems managing medications.²⁷ Better symptom management through caregiver training can potentially play a significant role in reducing the stigma of morphine use. The Effective Management of Pain: Overcoming Worries to Enable Relief (EMPOWER) study, which implemented an intervention to help lessen the stigma surrounding opiate use and improve knowledge about pain management among caregivers, was found to reduce caregivers' concerns about pain medication and improve patient pain.²⁸ Interventions used in the EMPOWER study have the potential to assist caregivers in better managing symptoms, improving their confidence, and potentially reducing the need for hospitalization.

This study has several limitations. This was a single-site study and practices may differ in other hospice organizations. Our participants care for a diverse patient population in a large urban environment (New York City), which may not accurately represent the patient population served in other regions of the country. In addition, we were not able to correlate participants' responses to the timing of these hospitalization. Furthermore, this study specifically looks at IDT members' perceptions, which may not accurately represent the reason patient and caregivers seek hospitalization. Recall bias may also play a role in the accuracy of our responses.

Conclusion

This study identified several factors that contribute to hospitalization in home hospice patients from the perspective of home hospice IDT members. Based on these results, potential avenues for future interventions include (1) improving understanding of hospice philosophy and EOL care through communication, (2) tackling the challenges that patients and families face when transitioning to home hospice care, (3) identifying and reducing caregiver burden, and (4) improving symptom and crisis management.

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