Patient Safety Incidents in Home Hospice Care: The Experiences of Hospice Interdisciplinary Team Members

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Abstract

Background: Hospice provides a full range of services for patients near the end of life, often in the patient's own home. There are no published studies that describe patient safety incidents in home hospice care.

Objective: The study objective was to explore the types and characteristics of patient safety incidents in home hospice care from the experiences of hospice interdisciplinary team members.

Methods: The study design is qualitative and descriptive. From a convenience sample of 17 hospices in 13 states we identified 62 participants including hospice nurses, physicians, social workers, chaplains, and home health aides. We interviewed a separate sample of 19 experienced hospice leaders to assess the credibility of primary results. Semistructured telephone interviews were recorded and transcribed. Four researchers used an editing technique to identify common themes from the interviews.

Results: Major themes suggested a definition of patient safety in home hospice that includes concern for unnecessary harm to family caregivers or unnecessary disruption of the natural dying process. The most commonly described categories of patient harm were injuries from falls and inadequate control of symptoms. The most commonly cited contributing factors were related to patients, family caregivers, or the home setting. Few participants recalled incidents or harm related to medical errors by hospice team members.

Conclusions: This is the first study to describe patient safety incidents from the experiences of hospice interdisciplinary team members. Compared with patient safety studies from other health care settings, participants recalled few incidents related to errors in evaluation, treatment, or communication by the hospice team.

Introduction

PATIENTS WHO ENROLL in home hospice receive care from an interdisciplinary team of nurses, physicians, social workers, chaplains, home health aides, and hospice volunteers.^{1,2} Family caregivers are frequently partners in the hospice care plan, providing much of the day-to-day care for patients who are often seriously ill or experiencing difficult symptoms. These contexts and characteristics of care suggest there may be aspects of patient safety that are unique to home hospice.³

Many studies have examined medical errors and patient safety incidents in hospitals and more recently in outpatient primary care practice.⁴⁻⁶ In contrast, very little research is available regarding patient safety when care is provided directly to patients in their own homes, including hospice care. In a recently published review and commentary that called for the development of new safety measures specifically

designed for hospice care, the authors did not cite any original research on patient safety incidents in hospice.³ The purpose of this study was to explore the types and characteristics of patient safety incidents in home hospice care from the experiences of hospice interdisciplinary team members.

Methods

Since no published research studies describe patient safety incidents in home hospice care, we used an exploratory approach, with semistructured individual interviews and qualitative analysis methods to describe themes and patterns within the data.⁷ In phase 1 of the study we completed and analyzed telephone interviews with a hospice interdisciplinary team member from a national sample. In phase 2 we presented a summary of findings from phase 1 to a smaller sample of experienced hospice leaders to assess the credibility of phase 1 findings.

Phase 1 interviews

We invited hospices to participate in phase 1 through e-mail communication with over 200 hospices in the Population-based Palliative Care Research Network (PoPCRN), a national network of hospice and palliative care organizations organized through the University of Colorado School of Medicine. We identified a convenience sample of hospices from across the United States and asked a primary contact at each hospice to identify three to six participants from their interdisciplinary hospice team. A written description of the project and informed consent documents were mailed to each participant, and a telephone interview was scheduled.

The interview guide elicited stories of patient safety incidents from members of interdisciplinary home hospice teams based on definitions from the conceptual framework of patient safety from the International Classification for Patient Safety (ICPS).⁸ The core ICPS definition of a patient safety incident is “an event or circumstance that could have resulted, or did result, in unnecessary harm to a patient.” Interview questions were based on the following outline:

1. Opening question. The opening question was adapted from similar patient safety research in primary care practice by Dovey and colleagues.⁴ *“Have you ever experienced an event with a home hospice patient that made you say, ‘That should not happen in hospice care, and I don’t want it to ever happen again.’”*

2. Characteristics and contributing factors. Once the respondent had described an incident, the interviewer used prompts to understand the setting, contributing factors, and course of the incident.

3. Description of actual and potential harms. The interviewer asked questions regarding the occurrence of real and potential harms related to the patient safety incident.

Phase 1 data analysis

Interviews were recorded, transcribed, and entered into qualitative analysis software⁹ to categorize, store, and retrieve data; organize analytic codes; and form linkages within the data. The data analysis team included a physician researcher with expertise in clinical hospice and palliative medicine (DS), a PhD sociologist with expertise in gerontology (SR), a physician researcher with experience in patient safety qualitative research (NE), and a graduate research assistant with a background in nursing (ED).

Analysis was iterative and ongoing with data collection. Initial transcriptions were read in an “editing” style⁷ to augment an initial codebook developed from the interview guide and patient safety definitions.⁸ Transcripts were independently coded by two members of the research team. The research team then met to discuss and corroborate their coding. As data analysis progressed, the team made changes to the interview guide to probe for additional types of patient safety incidents, contributing factors, or harms. The team met regularly to identify common themes and patterns in the data.

Phase 2 data review panel

After completing phase 1 analysis we identified a smaller convenience sample of experienced hospice leaders through a second e-mailed invitation to POPCrN members and asked them to assess the credibility of phase 1 results. Each phase 2 participant had at least 10 years of experience in hospice care, held a senior leadership position in hospice, and had additional professional activities consistent with advanced professional experience. They read a written summary of phase 1 findings and then they completed brief written comments and individual telephone interviews.¹⁰ Phase 2 written comments and transcribed interviews were analyzed by the research team to identify and summarize major themes.

Results

Participants

In Phase 1 we completed telephone interviews with 62 hospice workers (85% female) from 17 hospices in 13 states (West 16%, East 31%, South 16%, Midwest 37%). While interviews were completed with all team disciplines, hospice nurses represented the greatest number of participants (nurse 39%, social worker 21%, chaplain 16%, home health aide 16%, physician 8%). In phase 2 we collected written comments and completed telephone interviews with 19 experienced hospice leaders from 15 states.

Major themes from phase 1 resulted in a definition of the scope of patient safety in home hospice care, descriptions of the most common types of harm and contributing factors from patient safety incidents, and a list of less common but serious patient safety harms.

The scope of patient safety in hospice care

Themes emerged that described two types of harm from patient safety incidents that may be specific to home hospice care. First, participants expressed concern not only for the safety of patients during the course of home hospice, but also for unnecessary physical or emotional harm to family caregivers.

I think some of the most common stuff for caregivers is that they’re all of a sudden in a world they’re not familiar with.... They’re being asked to change dressings and clean people up and do those kinds of personal care, so that can be very, very difficult for caregivers.... They’re dealing with the emotions of the person changing and declining but also they’re taking on a nursing role.

Second, hospice team members often referred to an unnecessary disruption of the natural dying process as a type of patient safety harm. Such disruptions could be as dramatic as a last-minute 911 call by a family member or as simple as “family bickering” described by one participant:

A good death to me is where their needs are met, they are pain and symptom free...the family has been educated in knowing what to do for any and all symptoms that she may have...safe in their bed...with family around, no bickering. That is another safety issue, I think, is if they are bickering around the bed. I always tell them, ‘Take it outside.’

We summarized these two themes in a proposed definition of the scope of patient safety in home hospice care that added these two types of harm to the standard definition of patient

safety incidents:⁸ “A patient safety incident in hospice care is an event or circumstance that could have resulted, or did result, in unnecessary harm to a patient, unnecessary harm to a family member or informal caregiver, or unnecessary disruption of the natural dying process for a patient with a terminal illness.”

We asked phase 2 participants to comment on the appropriateness of this expanded definition. All agreed in principle that concern for the two added categories of harm fit within the scope of home hospice care. Sixteen phase 2 participants agreed that the definition was appropriate as presented. Three participants had concerns about the wording of the definition, including terms such as “disruption” or “natural dying process,” which may be too vague to inform safety metrics or policies.

Most common types of patient harms and contributing factors

From phase 1 interviews the most common types of harm to patients from patient safety incidents were injuries from falls and inadequate control of patient symptoms, particularly pain (see Table 1). Nearly all of the described contributing factors were related to patient characteristics, the patient's home living situation, or family caregiver attitudes and practices. When describing these types of contributing factors, participants often noted their efforts to educate patients and family members in order to improve patient safety.

I had talked to her [a patient's daughter] before about, 'Let's not do this anymore, let's just, she can get clean—and your mom's not that dirty—she can get clean with a sponge bath or a bed bath. We don't need to walk her into the bathroom.' And she would just shake her head no. She was going to force her mother to walk.

More than any other contributing factor, hospice team members described concerns for patients who they thought were unsafe to live alone, or patients left alone frequently by family members, as the most prominent contributors to patient safety incidents:

We have a lot of that, where we suspect or know that patients are being left alone and they're not able to get to a phone, get out of bed, get out of that chair. We had one lady and it was always, "She just left, she just left, she'll be right back, she'll be right back...." It's like this lady had to be put in that chair, had to be put in the bed, was in a basement apartment. Wasn't safe.

In their review of types of harm and contributing factors from phase 1 interviews, hospice leaders in phase 2 all agreed that the summary categories of patient harm and contributing factors were also common in their home hospice experience (see Table 1). There was also strong agreement that patients living alone or inappropriately left alone are particularly common contributing factors, but difficult to change due to hospices' goal of respecting patient autonomy.

A lack of reported medical errors

When answering the opening interview question, none of the phase 1 participants described errors by members of the hospice team in evaluation, treatment, or communication. Even when specific questions were added to prompt memories of medical error events, few participants described medical errors, and some thought that errors were rare events in their teams.

As far as safety, I really can't think of anything. We have good teams, everyone cooperates, communication is flowing.

Of the small number of medical errors described in phase 1, most were associated with communication problems, physician reluctance to prescribe medications, or delays in obtaining medications for patient symptoms:

On the weekend, one of the doctors had conflict with one of the nurses.... Communication broke down and there was disagreements between them and I believe that caused distress and problems for one of our patients.... The pain medications were not adjusted quick enough.

Phase 2 participants were not surprised that hospice team members focused primarily on patients, caregivers, and home

TABLE 1. SUMMARY OF COMMON PATIENT SAFETY HARMS AND CONTRIBUTING FACTORS

(1) Most common categories of patient safety incidents leading to harm	
A.	Injuries from falls
B.	Inadequate control of symptoms, particularly pain
(2) Most commonly described hazards and contributing factors for patient safety incidents	
• Frail or debilitated patients living alone, or being left alone by caregivers (the most commonly described contributing factor in phase 1 interviews)	
• Caregiver's physical and/or cognitive limitations	
• Patients' physical and/or cognitive limitations	
• Patient or caregiver difficulty in understanding care instructions	
• Family or caregiver attitudes or disagreements with hospice care plans	
• Nonadherence to instructions given by the hospice team	
• Families not accepting short prognosis and “forcing” activity by a dying patient	
• Family members overwhelmed with their role as caregivers	
• Poor or physically hazardous living conditions	
• Rapid increases in patient weakness/debility	
• Patient/caregiver fears regarding medication, particularly opioids	
• Patient/caregiver poor understanding of dosing instructions	
• Dosing errors by patients/caregivers	
• Medication diversion by family members or caregivers	
• Delays in prescribing/delivering medications to the patient's home	
• Physician reluctance or delays in prescribing medications	

settings as major contributing factors. However, a majority of phase 2 participants thought that medical errors are more common than described in phase 1 and that more research is needed to understand the rate and types of medical errors that occur in hospice care.

Less common but significant harm events

The four types of incidents listed in Table 2 were described by phase 1 participants as uncommon but serious events, associated with potential for severe physical or emotional harm. Participants often described harm from these incidents as not only adversely affecting the dying process of the patient, but also causing potentially significant emotional harm to patients' family members:

It was a family that had just signed in to the program, I believe, and the family ended up calling 911 and she'd actually died, her defibrillator kept going and there was really nothing we could do by the time they called 911.... What it sounded like was that the daughter was pretty horrified because they were so new to hospice, they hadn't even had time to really think, okay let's have this turned off.

Phase 2 participants all agreed that such events (see Table 2) are uncommon but deserve attention in ongoing efforts to improve hospice patient safety due to the potential severity of the associated harms. Every phase 2 participant had experienced one or more of these four types of incidents during their career.

Discussion

In this initial qualitative study we described harms and contributing factors in patient safety incidents in home hospice care from the viewpoint of interdisciplinary hospice team members. The most commonly described types of harm to patients were injuries from falls and inadequate control of patient symptoms. The most commonly cited contributing factors for patient safety incidents were related to patient characteristics and attitudes; the patient's home living situation; or family caregiver characteristic, attitudes, and practices.

While our phase 1 interviews resulted in a variety of patient safety incidents and many descriptions of errors or mistakes made by patients or family caregivers, few involved any descriptions of errors by the hospice care team. This is in contrast with descriptive patient safety studies from hospitals and primary care practice in which a majority of reported contributing factors were related to errors or missed opportunities by physicians or the health care team.⁴⁻⁶ Our study did not examine the reasons for this discrepancy. Possible ex-

planations include that there may in fact be fewer errors in home hospice care due to lower rates of diagnostic testing, less use of complicated health care technology, fewer invasive procedures, and the continuity of care that results from frequent home visits by a single health care team. It may also be that the site of care, in this case a patient's home, influences the patient safety perspectives of hospice team members. Families and home care environments present a particular set of challenges. When a hospice team only provides care within patients' homes, they may preferentially notice problems within the complexities of the home "site of care" (condition of the home environment, capabilities and attitudes of patients and family members, level of patient supervision by the family). In contrast, for health care teams that only provide care in the complex system of an outpatient office,¹¹ their views of the most prominent causes of patient safety incidents focus on problems and errors most visible within that system of care (ordering tests, communicating from office to patient, documenting in office-based charts).⁴

If patient, family caregiver, and the home care environment are indeed the primary contributing factors to patient safety incidents in home hospice care, then systems and education to improve patient safety should focus on improving care interventions that are commonly managed by patients and families at home. This is in agreement with recommendations by Casarett and colleagues who suggest that on the one hand hospices should not be held directly accountable for errors or poor care decisions by informal caregivers, but at the same time should be required to strengthen educational efforts to prevent unnecessary harm.³

Therefore, when patients are in their homes and are receiving care from family members, neighbors, or friends, different standards of accountability should apply. Nevertheless, hospices should still be required to provide family members and other informal caregivers with sufficient education and training to mitigate foreseeable risks and to provide patients with the safest possible environment.

Findings from phase 1 of our study suggested a definition of patient safety incidents specific to home hospice care that would include concern for unnecessary harm to a family member or caregiver or unnecessary disruption of the natural dying process for a patient with a terminal illness. The exact wording of our proposed "hospice-specific" definition deserves more discussion and debate before being considered as a guide for policies or quality improvement efforts. For example, recommendations by Casarett to craft new safety metrics that are specific to hospice care³ suggest that a

TABLE 2. INFREQUENT BUT IMPORTANT PATIENT SAFETY INCIDENTS ASSOCIATED WITH SIGNIFICANT HARM

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(1) Burns and fires caused by smoking/sparks/flame near a patient using oxygen at home (2) Patient suicide by violent means while enrolled in hospice care (3) Multiple shocks from an internal defibrillator during a patient's final dying process (4) Unintended overdose of an opioid administered by a family caregiver	• Harms ranged from small facial burns to significant structural fires causing death • Harm to the patient is obvious, but emotional harm to family, caregivers, and hospice team members described as severe and long lasting • Harms include significant discomfort at the moment of death for the patient, and emotional harm to those who witness the patient's death • Harms ranged from temporary oversedation to possible hastening of death in an actively dying patient, and significant emotional distress for caregivers
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“disruption” of the dying process should only be defined as “unnecessary harm” if it contradicts documented patient preferences:

For instance, hospices should have policies to ensure that patients' preferences to avoid cardiopulmonary resuscitation or hospitalization will be honored and that symptoms are controlled. Similarly, hospices should be held accountable for the frequency with which patients' preferences are discussed and recorded, and the frequency with which patients receive aggressive treatment against their wishes.³

While the exact wording deserves further discussion, the general principle of adding these two categories of unnecessary harm to a hospice-specific patient safety definition is congruent with the National Hospice and Palliative Care Organization's Standards of Practice for Hospice Programs.¹² This guideline states that the “*patient and family is the unit of care*” for hospice teams and that the “*desired outcomes of hospice intervention are safe and comfortable dying, self-determined life closure and effective grieving, all as determined by the patient and family/caregivers.*”¹²

There are limitations to this initial study of patient safety incidents in home hospice care. As an exploratory qualitative study, the results provide insights from hospice team members and suggest hypotheses for further research, but the study does not represent a comprehensive description of patient safety incidents that occur in home hospice care. Our choice of opening question may have prompted descriptions of only the most prominent incidents in participants' memories. Additional research using prospective, active surveillance of safety incidents would be necessary to allow root cause analysis of a wider scope of errors, near misses, and harms, including those associated with day-to-day care processes under direct control of the hospice provider. Despite limitations, this study offers the first description of patient safety incidents from the perspective of home hospice interdisciplinary team members and provides information to guide additional research and interventions to improve the safety of home hospice care for patients and their families.

Author Disclosure Statement

This study was supported by grant funding from the Agency for Healthcare Research and Quality, grant #1R03 HS018245-01.

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