AHRQ Grant Final Progress Report

Title of Project: Patient Safety in Hospice Care

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Patient Safety in Home Hospice Care

Final Progress Report: Structured Abstract

Purpose: To explore the types and characteristics of patient safety incidents in home hospice care from the experiences of hospice interdisciplinary team members.

Scope: Hospice provides a full range of services for patients near the end of life, providing palliative care to patients and their families, often in the patient's own home. There are no published studies regarding patient safety in home hospice care.

Methods: We purposively sampled hospices identified through a national hospice research network and identified 65 hospice workers from 17 hospices in 13 states to participate. Semi-structured telephone interviews of hospice nurses, physicians, social workers, chaplains, home health aides, and hospice administrators were recorded, transcribed, and entered into qualitative data analysis software. Additional telephone interviews were completed with 18 hospice experts to corroborate findings from initial qualitative interviews. Three researchers used an editing technique to identify common themes from all interviews.

Results: The most prominent patient safety themes centered on risks or safety incidents related to debilitated patients living alone, poor living conditions, lack of capability or understanding among family caregivers, and medication dosing or handling errors by patients and family members. Interviewees often characterized such risks or incidents as being outside of their control to prevent or mitigate. Even when prompted for specific types of patient safety incidents related to the process of home hospice care, only a few interviewees recalled any incidents or harm related to errors or missed opportunities by nurses or other hospice team members.

Key Words: Hospice, Patient Safety

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Purpose

This study explored the types and characteristics of patient safety incidents in home hospice care from the experiences of hospice interdisciplinary team members and identified potential opportunities for future interventions to improve patient safety. We accomplished these goals by completing the following four specific aims:

Aim 1: Summarize and categorize the types, characteristics, and contributing factors of patient safety incidents that occur in home hospice care, from the experience of hospice care professionals.

Aim 2: Describe the range of patient outcomes and potential harms resulting from patient safety incidents in home hospice care, both for patients and their caregivers.

Aim 3: Identify opportunities for preventing patient safety incidents or for detecting them early to mitigate the potential for harm to patients and caregivers.

Aim 4: Determine whether a subset of patient safety incidents in home hospice care have the characteristics (readily identifiable, preventable, and severe potential for harm) used to define "never events" that occur in hospitals and other healthcare settings.

Scope

Where Most Patient Safety Research Has Occurred: Over the past decade, there has been a flurry of activity and publicity surrounding medical errors and patient safety in the United States. Initial patient safety studies reported hospital data, which, when extrapolated to the entire country, estimated that between 44,000 and 98,000 people die each year in hospitals due to medical errors. But hospital data tell only part of the story – missing in these initial patient safety reports were data from the front lines of medicine where the majority of visits take place: in primary care practices and other community-based healthcare services.

Almost no effort has been given to understanding the prevention of patient safety incidents in the growing segment of community-based healthcare for patients near the end of life – care provided by interdisciplinary hospice teams. Although there is a body of literature exploring patient satisfaction with hospice and palliative care, there is a lack of published research that describes patient safety incidents in hospice care.

Unique Aspects of Patient Safety in Home Hospice: *This initial qualitative study describes patient safety incidents specifically within the context of hospice care provided in patients' homes – within "home hospice care."*

The following characteristics and contexts of home hospice care suggest unique types and patterns of patient safety incidents that may occur in this setting. Some of these factors include the following:

- Hospice care provided in a patient's home creates a unique care situation, frequent interactions with informal caregivers, stressful family dynamics, and other factors that influence communication and care patterns by the interdisciplinary hospice team.
- The goals of care within home hospice, primarily focused on palliation and comfort, differ from the goals of restorative care in most other care settings where patient safety issues have been studied most often.
- Goals and care plans set by the home hospice team not only are directed toward the patient but also include specific goals for family caregivers in the patient's home.
- In home hospice care settings, there is often a rapid introduction and dose titration of powerful, potentially dangerous medications to be either self-administered by the patient or given by the patient's caregiver.
- A number of communication issues between nurses, home health aides, other team members, hospice physicians, and private practice physicians in the community pose unique risks for patient safety incidents.
- Home hospice care patients are generally in a vulnerable state, experiencing many life losses during the weeks or months of hospice care, emotionally preparing for death, with caregivers and loved ones who are also experiencing sadness and often increased general stress of care giving and potential loss.
- Pain crises or other needs for sudden changes in care plans frequently occur during home hospice care. Because most communication occurs by telephone or by fax between primary care physician offices, team members, pharmacies, and others responding to acute care needs at home, patients may not be able to receive a timely or immediate answer to questions regarding a sudden increase in pain or other symptoms.

Patient Safety Incidents Conceptual Framework: For our study, we used the conceptual framework from the resulting International Classification for Patient Safety (ICPS), and organized our data collection on common definitions from the framework:

1. A ***patient safety incident*** is an event or circumstance that could have resulted, or did result, in unnecessary harm to a patient.
2. ***Contributing factors/hazards*** are circumstances, actions, or influences that are thought to have played a part in the origin or development of an incident or to increase the risk of an incident.
3. ***Patient and caregiver characteristics:*** In the ICPS conceptual framework, only *patient* characteristics are described as selected attributes in this definition. However, within home hospice care, we also explored attributes of the family caregiver characteristics and the caregiving environment in patients' homes that may contribute to our understanding of patient safety incidents.
4. ***Incident characteristics:*** These are selected attributes of the incident itself. These include aspects of who was involved, the series of events leading to the patient safety incident, the agents and activities related to the incident, timing, place, and other basic attributes.

5. ***Patient outcome*** is the impact upon a patient that is wholly or partially attributable to the incident. We will also explore the impact of patient safety incidents on the patients' family caregivers.

Methods

Summary of Methods: Because there are no published studies that describe patient safety incidents in home hospice care, we used an exploratory, qualitative research approach. We sampled 17 hospices in 13 states from the Population-based Palliative Care Research Network (PoPCRN). We completed semi-structured individual telephone interviews with a total of 65 interdisciplinary hospice team members from the participating hospices, including interviews with hospice physicians, nurses, social workers, chaplains, home health aides, and hospice managers. The interviews were designed to elicit stories of patient safety incidents from the care experiences of members of home hospice teams. Interviews were recorded and transcribed, and we used qualitative analysis methods to summarize and describe themes and patterns within the data.

Interview Methodology: Interviews were designed to elicit stories of patient safety incidents from the care experiences of members of interdisciplinary home hospice teams. Interviews and data analysis proceeded in a parallel fashion during the study, and the team edited and adjusted the interview guide as needed to further clarify and expand themes and concepts that emerged during analysis of initial interviews. The interview guide included the following elements to gather data related to the four specific aims.

(Specific Aim 1: Types, characteristics, contributing factors)

1. Opening question: We used an opening question adapted from similar published patient safety studies in primary care settings to initiate each patient safety incident description: *"From your experience in home hospice care, please describe something that has happened in your hospice practice that should not have happened, that was not anticipated, and that made you say, 'that should not happen in hospice care and I don't want to have it happen again'."* From this opening prompt, the interviewer facilitated a general description of the respondent's story.

2. Clarify incident type: Additional prompts were used as needed to clarify the type or general category each patient safety incident fit within.

3. Characteristics and contributing factors: Once the respondent completed a general description of the incident, the interview guide included prompts to fill in details regarding

characteristics of the patient, caregivers, and home setting that are necessary to understand the setting and course of the incident, and the "circumstances, actions, or influences which are thought to have played a part in the origin or development of the incident, or to increase the risk of the incident" (contributing factors) – questions that clarified the "who, what, when, where, and how" details of the participant's story.

(Specific Aim 2: Outcomes and harms)

4. Description of actual and potential harms: The interviewer then expanded and clarified the participant's description of real and potential harms related to the patient safety incident with prompts to describe not only physical harms but also the potential for psychological or emotional harms from the incident – for both the patient and the family caregivers.

5. Severity of harms: The interviewer then asked the participant to describe the most significant harms that could have occurred from the patient safety incident that had been described. This clarification led to the next section, describing factors that may either prevent or alter the level of harm from each incident described.

(Specific Aim 3: Opportunities for prevention)

6. Description of detection/prevention/mitigating factors: What are the "actions or circumstances" within the course of this incident that could result in "the discovery of the incident" (detection) at an earlier stage or "prevent or moderate the progression of the incident toward harming the patient" (mitigating factors)? The interview guide included prompts to explore possible detection, mitigation, and prevention opportunities.

After step 6 in this cycle, the interviewer returned to step 1, the Opening Question, with the goal of completing at least three full incident description cycles in each interview. After additional descriptions had been completed, the interview moved to the final Specific Aim interview items to summarize and conclude the interview.

(Specific Aim 4: Identifying "never events")

7. Review/summary and assessment of "never-event" characteristics: The interviewer briefly summarized the patient safety incident descriptions completed during the interview and asked if the participant would like to add any other comments. The interviewer then introduced characteristics of "never events" (easily identifiable, preventable, with significant potential for severe or costly outcomes) and explored whether any of the participant's incidents included similar characteristics.

Data Analysis

Interviews were fully transcribed and entered into NVivo 8 software (QSR International; Melbourne, Australia; http:\\www.qsrinternational.com) in order to categorize, store, and retrieve data, maintain the analytic codes and notes of the interpreters, and form linkages within the data. Data collection and analysis proceeded together, so ongoing analyses could guide future interviews as needed. Initial transcriptions were read, along with interviewer notes, in an "editing" style to augment an initial codebook template developed from the interview guide and from the ICPS conceptual model. This method of analyzing narrative data acknowledges that there are preconceived coding categories that exist going into the coding sessions, based on the researchers' previous knowledge of the subject and existing research from patient safety studies in other healthcare settings. However, while coding proceeds in this method, the codebook is modified based on the interviews themselves.

Results

In total, 65 in-depth telephone interviews were completed with home hospice interdisciplinary team members from 13 hospices located in 17 states. All major regions of the continental United States were represented within the participating list of hospices (West 16%, East 31%, South 16%, Midwest 37%). Interviews were completed with all professional disciplines represented in home hospice teams (physicians 8%, nurses 39%, social workers 21%, chaplains 16%, and home health aides 16%).

We are preparing detailed results that will be submitted for publication in major hospice and palliative medicine academic journals. The following is a brief summary of primary themes and descriptions of patient safety events from this qualitative study.

Types of patient hazards: The types of hazards for patient safety most commonly described by interviewees were patient factors, caregiver factors, or home living situations. These included:

- Frail or debilitated patients living alone, or being left alone by caregivers;
- Caregiver's physical limitations;
- Patient or caregiver difficulty in understanding care instructions;
- Family or caregiver attitudes or disagreements with hospice care plans;
- Family members overwhelmed with their new, often changing role as caregivers;
- Poor or physically hazardous living conditions.

Descriptions of types of patient harms: The types of harm to patients from the most common patient safety incidents described in our interviews with hospice team members can be summarized in two categories:

A. <u>Injuries from falls</u>: Common contributing factors for falls leading to harm included:
   - Patients living alone/left alone;

- Poor/hazardous living conditions;
- Rapid increases in patient weakness/debility;
- Nonadherence to instructions given by the hospice team;
- Families not accepting short prognosis and "forcing" activity by a dying patient.

B. Inadequate control of symptoms, particularly pain: Common contributing factors leading to poor symptom control included:
   - Patient/caregiver fears regarding medication, particularly opioids;
   - Physician reluctance or delays in prescribing medications;
   - Patient/caregiver poor understanding of dosing instructions;
   - Dosing errors by patients/caregivers;
   - Delays in prescribing/delivering medications to the patient's home;
   - Medication diversion by family members or caregivers.

Lack of reports of medical errors: Published patient safety research in office settings suggests that these interviews would include many descriptions of medical errors or systems issues – contributing factors, such as physician prescribing errors, problems with communication between team members, pharmacy errors, problems with clinical procedures, or hospice infrastructure issues. In our first 20 interviews, there were no incidents that included any medical errors, omissions by the team, or hospice care systems issues. Even after adding specific interview prompts and closed-ended questions for such factors in subsequent interviews, very few interviews revealed important or common contributing factors in these categories.

Patient safety incidents with "never-event" characteristics: In patient safety research in other settings, particularly in hospitals, a short list of serious, preventable incidents that cause significant harm have been designated as "never events" or "serious reportable events." Such designations have led to incentives to identify best practices and policies to prevent "never events" from occurring. Participants described the following events as patient safety incidents that have the following characteristics in common with "never events" in other healthcare settings: rare events, potentially preventable, with the potential or occurrence of significant harm:

A) Burns and fires caused by smoking/sparks/flame near a patient using oxygen at home. Harms ranged from small facial burns to significant structural fires causing death.

B) Patient suicide by violent means while enrolled in hospice care. The harm to the patient is obvious, but emotional harm to family, caregivers, and hospice team members can be severe and long lasting.

C) Multiple shocks from an internal defibrillator during a patient's final dying process. Harms include significant discomfort at the moment of death for the patient and emotional harm to those who witness the patient's death.

D) Unintended overdose of an opioid administered by a family caregiver due to confusion or misunderstanding of how to use concentrated oral opioid liquid preparations. Harm ranged from temporary oversedation to possible hastening of death in an actively dying patient.

Significance This proposed study resulted in the first reported descriptions of adverse events that occur in the course of home hospice care. There are many unique qualities of home hospice care that deserve closer scrutiny as we move toward interventions that will improve the quality of hospice care provided in the United States. This research will provide a foundation for future quality improvement interventions to prevent or mitigate patient safety incidents and adverse and unnecessary harm to patients and caregivers.

List of Publications and Products

The primary results of this study were presented at the annual international meeting of the North American Primary Care Research Group in November 2011 and have been accepted as a research poster presentation at the annual meeting of the American Academy of Hospice and Palliative Medicine to be held in March 2012. We are preparing manuscripts for publication to be submitted to the Journal of Palliative Medicine in early 2012. The following are research presentations related to this study:

Smucker DR, Regan S, Dickhaus E, Elder N. Patient safety in home hospice care: The experiences of interdisciplinary team members. Research poster presentation at: Annual international meeting of the North American Primary Care Research Group; 2011 Nov 12-16; Banff, Alberta, Canada.

Smucker DR, Regan S. Patient safety incidents in home hospice care: A qualitative study of interdisciplinary hospice team members. Research poster presentation (accepted) at: Annual meeting of the American Academy of Hospice and Palliative Medicine; 2012 Mar 7-10; Denver, CO.