Not Quite Seamless: Transitions between Home and Inpatient Hospice

Susan Lysaght Hurley, PhD, GNP-BC, ACHPN,¹ Neville Strumpf, PhD, FAAN,²
Frances K. Barg, PhD, Med,³ and Mary Ersek, PhD, RN, FAAN, FPCN^{1,4}

Abstract

Background: Although most hospice care occurs in the home, a growing number of patients utilize inpatient hospice settings. An inpatient hospice stay requires one or more transitions in care settings, although little is known about these transitions.

Objective/Design: Using ethnographic methods, this study examined the beliefs and practices of older adults, their caregivers, and hospice interdisciplinary team (IDT) members surrounding transitions between home and inpatient hospice.

Setting/Subjects: Data collection took place over 11 months in a large not-for-profit hospice agency in the northeast. Data were collected through 18 observations and 38 semistructured interviews with patients, family caregivers, and hospice IDT members.

Results: Transitions from home to inpatient hospice centered on three processes: developing a plan for future needs, identifying triggers that signaled increased needs for care, and navigating through phases of increased care. Patients, family caregivers, or IDT members identified triggers for more care, and actions were taken to respond in the home care setting. Challenges to these actions occurred in many phases of care and when needs were ultimately unable to be addressed at home, patients were transferred to inpatient hospice.

Conclusions: Understanding how care planning, increased needs, and phases of care influence decisions about transitioning patients to inpatient hospice can guide IDT members in minimizing transitions and providing a more seamless continuum of hospice care.

Introduction

AN INCREASING NUMBER of hospice deaths occur in inpatient hospice facilities. In 2011, over 26% of all U.S. hospice patients died in an inpatient facility.¹ At least one in five hospice agencies now own and operate an inpatient facility, either freestanding or hospital based. Despite the tremendous growth of inpatient hospice, little research exists about decisions regarding admission to inpatient hospice or the role of patient and caregiver preferences in decisions regarding the setting of hospice care.

Jeurkar et al.² reported that although 74% of patients want to die at home, only 53% die there. Upon admission to hospice, only 4.4% of patients stated a preference for dying at an inpatient unit, but 28% died there. The discrepancies between patient preferences and actual site of death have not been fully explored.

Patients who initially prefer to be at home may eventually experience a transition to inpatient care. Three studies examined transitions to an inpatient hospice.^{3–5} In one of these studies, which focused on perceptions of interdisciplinary team (IDT) members, the primary nurse or case manager played a key role in identifying patients whose needs were consistent with inpatient hospice.³ Nevertheless, the decision to transition to an inpatient unit was still based on specific admission criteria, such as symptom control and psychosocial issues/crises. Evans and colleagues⁴ found that family caregivers reported that the most common reasons for transfer were acute medical events (such as an injury or unrelated medical event), uncontrolled symptoms, imminent death, and the inability to provide safe care at home. Although some caregivers wanted a loved one to die at home, preferences changed when difficulties arose, and most expressed satisfaction with inpatient hospice care. In contrast,

¹North Shore Medical Center, Salem, Massachusetts.

²University of Pennsylvania School of Nursing, Philadelphia, Pennsylvania.

³Department of Family Medicine and Community Health, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania.

⁴Center for Health Equity Research and Promotion, Philadelphia VA Medical Center, Philadelphia, Pennsylvania.

Accepted November 1, 2013.

caregivers described both “settled” and “unsettled” experiences after the transition, suggesting mixed reactions to a transfer.⁵ These studies have limitations, as one was conducted in Great Britain where hospice reimbursement and regulations differ from those in the United States,³ and two focused only on the perspectives of family caregivers.^{4,5}

The primary objective of this study was to examine the beliefs and practices of older adults, their caregivers, and hospice interdisciplinary team members regarding transitions between home and inpatient hospice settings. Data were collected as part of a larger exploration of care settings within hospice.

Methods

A focused ethnography⁶ of the practices at one hospice took place over 11 months. The principal investigator (SLH) collected all data using participant observations, interviews, and textual materials (e.g., marketing brochures, templates for documentation, website content) made available by the study site. Appropriate approvals were obtained from the University of Pennsylvania Institutional Review Board and the ethics committee of the hospice agency.

Setting

The setting was a large, Medicare-certified, not-for-profit hospice agency in the northeast United States. The investigator selected the agency based on its large daily census (approximately 400 patients), catchment of suburban and rural areas, and operation of a 20-bed, freestanding inpatient hospice.

Procedures

After the necessary introductions, consent procedures, and a month for launch and initial field observations, the investigator recruited patients, caregivers, and IDT members to participate in semistructured interviews. She observed team members from all disciplines during all shifts, including nights and weekends, as team members visited patients and families during routine and urgent care home visits. Purposive sampling and maximum variation techniques were used to capture patients who had transferred or were considering a transfer.⁷ The investigator also took extensive fieldnotes and wrote memos based on her reflections.^{8,9}

Interviews were conducted with 38 individuals (Table 1). Every interview adhered to a general guide beginning with, “Tell me about your experience of hospice so far” (for patients and families) or “Tell me about your role in hospice” (for staff members). As the study progressed, probes were added as part of an iterative analysis. Interviews were digitally recorded and professionally transcribed for analysis, and then read and reread for verification. Fieldnotes and interviews were entered into an NVivo 9 database (QSR International Inc., Burlington, MA) for data management.

Analysis

Analysis was iterative and inductive, using constant comparative techniques, beginning with initial observations at the time of entry into the field.⁸ Open coding of fieldnotes occurred first. Categories and themes emerged as data collection progressed and data from ongoing interviews were

TABLE 1. INTERVIEW SAMPLE DEMOGRAPHICS

<i>Role</i>	<i>Number</i>	
Patient (age range 66–95)	4	
Caregiver	10	
Spouse	6	
Child	3	
Grandchild	1	
Staff		
Chaplain	2	
Nurse	7	
Nurse practitioner	1	
Nursing assistant	3	
Physician	2	
Social worker	5	
Administrator	4	
Gender	Male	Female
Patient	3	1
Caregiver	2	8
Staff	1	23
Primary diagnosis of patient		
Cancer	8	
Neurodegenerative disease	2	
End-stage cardiac disease	2	
End-stage pulmonary disease	2	
Time in hospice		
Staff employment (in years)		
< 1	1	
1–2	5	
3–5	2	
6–10	7	
11–15	3	
> 15	1	
Patient enrollment (in weeks)		
< 1	1	
1–2	2	
3–4	6	
5–8	1	
> 8		

added. Meetings occurred monthly with experts in ethnographic methods and palliative care (FB, ME) to review codes and data analysis. The investigator also regularly discussed the emerging codes and themes with a qualitative data analysis group for further feedback.

The investigator also gave specific consideration to trustworthiness and rigor to enhance credibility, transferability, dependability, and confirmability.¹⁰ She conducted a member check with IDT members from the hospice agency (social worker, chaplain, home health aide, two nurse case managers, and two clinical team managers) to confirm the findings.¹¹ Additionally, an external audit group evaluated the coding on 20% of the interviews; differences in coding were discussed to reach consensus and to meet 95% inter-rater reliability.

Findings

Major themes for transitions from home hospice to inpatient hospice included: (1) developing a plan for future needs, (2) identifying triggers that signal increased needs for care, and (3) navigating phases of increased care. Figure 1 is a

FIG. 1. Phases of increased care in home hospice prior to transition to inpatient hospice.

representation of these processes. Shortly after admission, a plan for future needs was developed by the patient, family caregivers, and hospice IDT. This plan was altered or enacted by IDT members and caregivers when triggers for increased care were identified by patients, family caregivers, or IDT. IDT members were attentive to patients' and families' evolving care needs. They directed their clinical actions toward modulating these triggers, although challenges frequently arose. In Figure 1, the stair-step line represents the phases of increased care. Examples of responses to triggers appear above the line, and the possible challenges to ameliorating these needs are described below the line. The final step is a transition to inpatient hospice.

Developing a plan for future needs

The plan for future needs, which addressed the inevitable, increasing debility and dependence at the end of life, began with initial home care visits. Development of the plan was largely directed by IDT members. Important subthemes included: Is the patient dying? What can caregivers "live with?" Who will qualify for inpatient hospice? and Available financial and human resources?

Acknowledgement of the patient's prognosis heavily influenced the plan for future needs. Some hospice patients and families were either unaware of or avoided discussion about the patient's inevitable decline. Without a shared understanding of the needs for increased care and imminent death, advanced planning was much more difficult. An overriding question—whether implicit or explicit for patients, families, and hospice staff—was "Is the patient dying?" Another factor that influenced the plan was the

length of hospice stay and the trajectory of decline. That is, IDT members found it more difficult to have this conversation if patients had been enrolled in hospice for longer periods and had experienced a gradual decline. In these cases, patients, family, and staff seemed less willing to engage in any discussion of death.

Sometimes it is hard for patient[s] to wrap their mind around that. You know, they're thinking, "But I drive now." And I hate to be a downer, but I think it's important to start planning and I tell them, "I just want to plan now. I just want a plan B." And some people say, "I'm going to die in my sleep." Well, that's a great plan, but if that doesn't happen, I want to discuss other options...because I want to have a plan before that day is here [and] you need more help and we're in crisis. *Nurse*

A second factor that influenced the care plan was concern for how caregivers might experience and remember the death. For this reason, IDT members considered "What can caregivers live with." Following a loved one's death, caregiver memories of the care they provided and decisions about where the patient died might greatly affect grief and bereavement. Patients may recognize the need for a move to inpatient hospice.

I thought about it and I was going to tell [my daughter] the next day and she beat me to it. She said I think you should go into hospice. I said I was going to tell you that today. *Patient*

Alternatively, caregivers providing 24-hour physical care at the very end of life struggled to feel that the care they were giving was "good enough." As one social worker pointed out, allowing a patient to die at home was not always possible because caregivers could no longer manage the burdens of

care. The family must live with that decision, despite the patient's expressed wish to die at home.

Some patients and families accepted the possibility of dying in an inpatient setting and actually preferred it. In these cases, a major factor in planning for future care revolved around Medicare requirements for inpatient hospice admissions. Thus, IDT members struggled with "Who will qualify for inpatient hospice?" Currently, Medicare stipulates that only patients with acute, uncontrolled symptoms qualify for inpatient hospice coverage. For this reason, inpatient hospice was not available for patients whose families felt overwhelmed and exhausted unless the patient experienced severe symptoms that could not be managed at home. The team members often had difficulty acknowledging that inpatient hospice was not always an option for contingency planning.

[Inpatient hospice] is never a "dwindle plan"...I always say to families, "I wish I had the ability to say anybody who wants to die at the [inpatient hospice] can do so, but that doesn't necessarily happen." So what's the plan...[when] they really need a lot of intense care and they might not qualify for [inpatient hospice] care? What's the plan then? *Clinical Team Manager*

A fourth issue that influenced development of a future plan was determining the "available financial and human resources" as the patients' condition declined. For example, if a patient needed more supervision or physical care, some families had the resources for hiring additional private nursing care. Other families were able to reach out to previously uninvolved family members to assist the primary caregiver by covering shifts or running errands.

A plan for future needs came together over time and could take days, weeks, or months to formulate. Patients and family

members gave input to team members during routine home visits, and with this in mind, the team discussed the plan at biweekly team conferences. The IDT evaluated whether plans were solid or fragile based on availability of resources.

Identifying triggers that signaled increased needs for care

A trigger for increased care was a physical, psychosocial, or other care problem that required changes in the management plan. Triggers included worsening symptoms, safety concerns, or a mismatch in the reports between team members and caregivers (Table 2). When patients or caregivers identified triggers, they called the triage phone service (available 24 hours/7 days per week) or brought up concerns during home visits.

IDT members questioned patients and caregivers about "worsening symptoms" (e.g., pain, dyspnea, confusion, and falls) and evaluated the physical and psychosocial environment for safety during every home visit. A symptom, such as pain, was commonly treated with medications, with the dose, frequency, and effects monitored closely by IDT members. Escalating pain became a trigger for a change in medication dose or for visits by an advanced practice provider.

IDT members often noted "safety concerns" at admission and throughout a hospice stay. Safety was a trigger for increased care in the form of additional visits, modification or addition of equipment, and the use or the addition of community resources. Examples of safety concerns were observing that families were unable to transfer patients effectively or identifying that there was no adequate egress from the patient's residence in case of an emergency. Another major concern was improper medication administration,

TABLE 2. SUMMARY OF THEMATIC ANALYSIS

<i>Theme</i>	<i>Definition</i>	<i>Subthemes</i>	<i>Exemplar quotation</i>
Developing of a plan for future needs	Largely directed by IDT members, this plan addressed the patient's inevitable, increased debility and dependence at the end of life.	1) Is the patient dying? 2) What can caregivers "live with?" 3) Who will qualify for inpatient hospice? 4) Available financial and human resources?	"Whenever that first change or symptom pops up, like the first time they're too tired to get out of bed on their own or the first time they do have pain, then it tends to be like, 'OK, you've had this situation happen....What are we gonna [sic] do to keep you comfortable and safe?'" <i>Social Worker</i>
Identifying triggers that signaled increased needs for care	New physical, psychosocial, or other need necessitating a change in care management	1) Increased symptoms 2) Safety concerns 3) Mismatch between team observations and caregiver reports	"But last night he was so fidgety and...he couldn't move his legs. I mean you'd tell him to walk...And his brain just wasn't telling him. And then I'd say to him, sit down...[he] just wouldn't sit." <i>Caregiver</i>
Navigating through phases of increased care	Responses to increased needs of the patient and family	1) Actions 2) Challenges	"You're pulling in all of the resources that you can and then you're also sitting with the family and having them think of their resources, who else can help...meaning can they come over and sit with the patient and provide care for them, and how much care are you willing to do?" <i>Nurse Case Manager</i>

especially when the patient lived alone. Safety also involved uncertainty about caregiver competence or integrity, e.g., diversion of opioids and other medications.

But last night he was so fidgety and...moving around too much that my son put him in the bed and...he couldn't move his legs. I mean you'd tell him to walk...and his brain just wasn't telling him. And then I'd say to him sit down...[he] just wouldn't sit, because he was afraid he was going to fall. *Caregiver*

"Mismatches between team observations and caregiver reports" also caused concern for the IDT. For example, family caregivers might insist that they were able to provide care with minimal guidance from the IDT, whereas the team observed that the patient's hygiene was poor or the family failed to administer medications as recommended.

For instance, if the patient is in pain and the family says "No, they're fine. We're not going to medicate him. They're alright..." Or the other way around, are they overly anxious and any time [the patient] moves [the slightest bit] they're on top of him saying "Do you want this? Do you want that?" *Social Worker*

Navigating through phases of increased care

Phases of increased care occurred as patient and family recognized heightened needs that required new or more intensive interventions. The navigation process was one in which caregivers and IDT members responded to triggers with "actions" such as asking the family to provide more care, making medication changes, and increasing IDT visits. "Challenges" arose as the result of patients' or families' responses to these actions. System problems, such as difficulties with medication delivery or unavailability of an inpatient bed, posed additional challenges (Fig. 1).

If the family and IDT could not address triggers in the home and the patient met the inpatient hospice eligibility requirement, the final phase of care was transfer to inpatient hospice. Barriers to executing the transfer, however, arose when the caregiver felt compelled to honor a promise to keep the patient at home or when there was no inpatient bed available.

It was so hard for me to get through a day and then have him up at night. And I know there's something tugging at your heart, but you have to go beyond the feeling and really face this reality. *Caregiver*

Table 2 provides a summary of the thematic analyses as described above and additional exemplar quotations. Figure 2 illustrates major themes of plan development, new trigger identification, and the need for increased care using a composite patient case.

Discussion

In this ethnographic study of transitions from home to inpatient hospice, three important processes emerged that affected whether patients might be transferred to an inpatient hospice facility: development of a plan for future needs, identification of triggers signaling increased needs for care, and navigation through succeeding phases of care. These processes serve as a guide for addressing patient and family preferences and for managing resources for home hospice.

This study suggests that patient and caregiver preferences for place of death are negotiated through care planning processes. Meeting emergent patient and family needs while also honoring their preferences often was challenging because inpatient admission often is dictated by insurance reimbursement for acute symptom management needs, a situation that is very difficult to predict.¹² Thus, patients' and family caregivers' preferences for place of death may be seriously compromised. Moreover, these preferences for place of care and death change over time,¹³ and trajectories are unpredictable. Patients and caregivers may prefer inpatient hospice as a place of care, but current requirements prevent hospice facilities from serving solely as a placement for a serious decline or imminent death. The discrepancies between promises and expectations about home hospice services and the reimbursement requirements for inpatient hospice underscore the failure to reconcile patient and caregiver preferences for the setting of end-of-life care and death.

Transitions in care settings are most often made in a response to crisis.⁵ Study findings confirm that overwhelming symptom needs and increased family caregiving burden led to crises that required making decisions about whether to continue home care or transfer the patient to inpatient hospice. This study also reinforces the findings of earlier studies^{4,5} about the complexities associated with decisions to transfer to inpatient hospice. For instance, family caregivers are not always confident that the decision to make a transition to inpatient hospice was the right one. Further investigation of challenges in symptom management, safety issues, and caregiver support could enhance planning for those patients and families desiring a death at home.

Triggers for increased care were points of vulnerability, especially vis-à-vis patient and family preferences, which are more likely to be disregarded whenever unforeseen circumstances occur. Major decision points during this time, can be opportunities for family and IDT members to revisit preferences in determining the next steps in providing care.

A limitation of this study was the use of a single hospice setting for data collection, hindering generalizability of findings, however, focus on a single site allowed rich, thick description of one hospice agency. The study site used very little continuous care (24-hour nursing support provided in the home setting for short-term caregiver or symptom management relief) and variability in the use and outcomes of continuous care among hospices has not been studied. Use of continuous care is probably influenced by availability of an inpatient unit¹⁴ and accessibility of continuous care staff. Further study of the phases of care leading to inpatient hospice versus use of continuous care at home is needed to further ascertain patient preferences as well as compare best utilization of hospice resources in times of crisis.

Planning for the future needs and inevitable decline in health status of a hospice patient is central to providing high-quality care. Numerous questions remain unanswered with regard to the needs of hospice patients and their families. Notable among these questions is how best to manage a rapid decline in condition and the transition from home to inpatient hospice. What influence does the plan for future needs have on the congruence of the preferred and actual place of death for hospice patients, particularly for those with a strong desire to die at home? How is the plan for future needs

Mr. S, an 85 year old man with metastatic esophageal cancer, was discharged from the hospital and admitted to home hospice on a Friday. He lives with his wife in a small, one bedroom apartment. One daughter lives nearby and another resides several hours away. Prior to admission, he had increasing right hip pain and the admission nurse planned a weekend visit on Saturday, the following day. He has not eaten in the past few days. His wife stated that her goal was for her husband to die at home, as she has taken care of him throughout his illness. Her daughter who lives nearby will come to the apartment as necessary and her other daughter will travel if needed.

The weekend nurse found that Mr. S's pain increased when he tried to get out of bed, so she ordered a hospital bed. This significantly reduced his pain. The nurse suggested a visit on Monday, but advised the family to call if any other needs arose. When the nurse case manager met the patient on Monday, he reported increased pain with any movement in bed. The nurse suggested titrating his prn and long-acting opioids. Mrs. S initially declined these changes, stating she was afraid she would give the wrong dose, a challenge to the plan suggested by the nurse. Fortunately, education and pre-filled syringes eased the wife's concerns, and she was able to administer the drugs.

If the pain worsened, the plan was to have a physician or nurse practitioner visit and initiate a subcutaneous infusion. Mr. S had a pain crisis one week later and the weekend staff visited again. The nurse gave multiple doses of short-acting opioids with minimal relief, noting the patient had become increasingly confused and resisted care. The daughter and wife struggled with how to proceed. The nurse explained it would be 6-8 hours until a pain pump could be delivered, but the wife felt very strongly that her husband remain at home. She felt he would never forgive her if he was transferred to inpatient hospice. Eventually, the daughter and nurse persuaded Mr. S's wife to agree to the transfer, as his physical needs could no longer be met at home. The time of decision making was intense and difficult and represented a point of vulnerability, as the preferences of patient and wife were challenged. Nevertheless, concerns for safety and family to care for this patient at home led to a decision to transfer the patient.

FIG. 2. Exemplar case study.

communicated among IDT members and documented in the medical record, particularly in response to a trigger for increased care? What determines an appropriate transition from home to inpatient hospice? Finally, for those patients who want to die in an inpatient facility, what reimbursement structures would accommodate those preferences without need for crisis at home or fear of discharge if symptoms stabilize?

Although preferences for place of care and place of death are two different issues,¹³ the matter of preferences and plans for declining status are critical components of quality of care measurement in hospice. More research concerning transitions among levels of care in hospice is needed to validate the findings of this study. Additionally, future research should address current availability and use of levels of hospice care

along with patient preferences to ensure that transitions within hospice are meeting the needs and wishes of patients and families.

Acknowledgments

S. Lysaght Hurley was supported by a John A. Hartford Building Academic Geriatric Nursing Capacity Scholar Award 2010-2013 and a Ruth L. Kirschstein Individual NRSA Predoctoral Fellowship (1F31NR013103).

The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.

Author Disclosure Statement

No competing financial interests exist.

References

1. National Hospice and Palliative Care Organization: NHPCO Hospice Facts and Figures. www.nhpco.org/files/public/Statistics_Research/2012_Facts_Figures.pdf (Last accessed December 2, 2012).
2. Jeurkar N, Farrington S, Craig TR, Slattery J, Harrold JK, Oldanie B, Teno JM, Casarett DJ: Which hospice patients with cancer are able to die in the setting of their choice? Results of a retrospective cohort study. *J Clin Oncol* 2012; 30:2783–2787.
3. Eagle LM, de Vries K: Exploration of the decision-making process for inpatient hospice admissions. *J Adv Nurs* 2005;52:584–591.
4. Evans WG, Cutson TM, Steinhauer KE, Tulsy JA: Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. *J Palliat Med* 2006;9:100–110.
5. Waldrop DP, Meeker MA: Crisis in caregiving: When home-based end-of-life care is no longer possible. *J Palliat Care* 2011;27:117–125.
6. Agar M: *The Professional Stranger: An Informal Introduction to Ethnography*, 2nd ed. New York: Academic Press, 1996.
7. Patton M. *Qualitative Evaluation and Research Methods*, 3rd ed. Thousand Oaks, CA: Sage Publications, Inc., 2002.
8. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine Publishing Company, 1967.
9. Schatzman L: Dimensional analysis: Notes on an alternative approach to the grounded of theory in qualitative research. In: Maines DR (ed): *Social Organization and Social Process*. New York: Aldine De Gruyter, 1991, pp. 303–314.
10. Guba EG: Criteria for assessing the trustworthiness of naturalistic inquiries. *Educ Commun Tech J* 1981;29:75–91.
11. Goldblatt H, Karnieli-Miller O, Neumann M: Sharing qualitative research findings with participants: Study experiences of methodological and ethical dilemmas. *Patient Educ Couns* 2011;82:389–395.
12. Centers for Medicare and Medicaid Services: Electronic code of federal regulations, title 42: Public health; part 418-hospice care. <http://ecfr.gpoaccess.gov/cgi/t/text/text-idx?c=ecfr&sid=009d7a8f47e1232ab64f843034cf7275&rgn=div5&view=text&node=42:3.0.1.1.5&idno=42#42:3.0.1.1.5.4.5.6>. Updated 2010 (Last accessed September 27, 2010).
13. Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernethy AP: Preference for place of care and place of death in palliative care: Are these different questions? *Palliat Med* 2008;22:787–795.
14. Miller SC, Kinzbrunner B, Pettit P, Williams JR: How does the timing of hospice referral influence hospice care in the last days of life? *J Am Geriatr Soc* 2003;51:798–806.

Address correspondence to:
 Susan Lysaght Hurley, PhD, GNP-BC, ACHPN
 North Shore Medical Center
 81 Highland Avenue
 Salem, MA 01970

E-mail: slysaghthurley@alumni.upenn.edu