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Same Agency, Different Teams: Perspectives From Home and Inpatient Hospice Care

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Abstract

Tremendous growth in hospice over the past 30 years in the United States has increased the number of terminally ill patients dying at home. Recently, however, more hospice patients are dying at inpatient facilities. To understand the varying perceptions about care in the home and inpatient hospice, we conducted semistructured interviews with 24 interdisciplinary team (IDT) members and analyzed the data using the constant comparative method. Core interdisciplinary tasks, including identifying the focus of energy, tailoring family caregiver involvement, acknowledging who is in charge, and knowing both sides differed in the home and inpatient settings. Despite the overarching umbrella of hospice care, home and inpatient hospice settings create different foci for IDT members, burdens and privileges for family caregivers, and control of the care plan. Key differences between home and inpatient hospice processes of care highlight the complexity of patient-centered end-of-life care in the United States.

Keywords

death and dying; end-of-life issues; health care professionals; nursing; palliative care; palliative care

In the United States, the number of terminally ill patients dying with the support of hospice care has increased significantly in the past 30 years (National Hospice and Palliative Care Organization [NHPCO], 2013). The term *hospice* refers to a philosophy of care, and can also mean a specific place for end-of-life care. In the United States, hospice has predominantly referred to a philosophy of care and the insurance mechanism for providing that care. Hospice patients in the United States are cared for most commonly in their homes, but increasingly, they are dying in hospice inpatient facilities.

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Authors' Note

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The setting where end-of-life care occurs is associated with family satisfaction (Teno et al., 2004) and is an important component of quality care (National Consensus Project for Quality Palliative Care, 2009; Stewart, Teno, Patrick, & Lynn, 1999). In 2012, 27.4% of hospice patients died in inpatient hospice care (NHPCO, 2013), as compared with 4.1% in 2002 (Evans, Cutson, Steinhauer, & Tulskey, 2006). Research about hospice care in the United States rarely addresses the differences or similarities between care offered in the home and care offered in the inpatient setting (Martens, 2009), despite differences in regulations, costs, and patient and family experiences. De Sousa et al. (2010) conducted the only such study we could identify in the literature, a comparison of inpatient and home hospice for veterans. These researchers discovered that families of patients who died in inpatient hospice units were more satisfied and gave higher ratings of quality of care than families of those who died at home.

United States Hospice Services: Levels and Settings for Care

The Medicare hospice benefit began in 1983 and is largely responsible for the tremendous growth in United States hospice services. Nearly 1.6 million Americans received hospice services in 2012 (NHPCO, 2013). The Medicare hospice benefit allows for four levels of care: routine care, continuous care, inpatient respite care, and general inpatient care (Centers for Medicare and Medicaid Services [CMS], n.d.). Patients receive hospice care in private residences, nursing homes, assisted living facilities, or hospitals. Routine hospice covers medications related to the terminal illness, interdisciplinary visits, and medical equipment in private residences, nursing homes, and assisted living facilities. Continuous care, provided in the home setting, includes 24-hour nursing support. Designed for short-term caregiver relief, contracted facilities provide inpatient respite care for a period of 5 days per hospice certification period (i.e., every 60–90 days).

General inpatient hospice care provides short-term, acute symptom management and includes room and board charges. This level of care occurs in hospitals, nursing homes, or hospice-owned freestanding facilities, and must meet certain requirements for reimbursement. Continued inpatient hospice care requires ongoing, active symptom issues, medication titration, or other documented needs for acute care.

Dying at home with hospice care often is seen as the “gold standard” (Teno et al., 2004); nevertheless, given the limits for offering end-of-life care at home, health care practitioners and scholars have challenged this idealized scenario (Lysaght & Ersek, 2013). Home hospice involves significant patient and family resources that are not universally available. When hospice home care becomes untenable, a transition to inpatient hospice becomes necessary (Hurley, Strumpf, Barg, & Ersek, 2014). Although one in five hospice agencies in the United States now operates an inpatient facility (either freestanding or as a unit within a hospital or nursing home), few researchers have explored the nature of care delivery in settings other than the home (NHPCO, 2013).

Roles of Interdisciplinary Team Members

Interdisciplinary teams (IDTs) are the cornerstone of hospice and palliative care throughout the world. In the United States, IDTs are mandated by Medicare hospice benefit regulations

(Buck, 2007; CMS, n.d.). Medicare-certified agencies must provide each patient with a physician, nurse, social worker, chaplain, and volunteer. In addition to mandatory bereavement support, some hospices offer art, massage, or pet therapy. Much research on communication and collaboration has demonstrated the complexity of hospice care the IDT provides (Oliver, Tatum, Kapp, & Wallace, 2010; Oliver, Wittenberg-Lyles, & Day, 2006; Wittenberg-Lyles, Oliver, Demiris, Baldwin, & Regehr, 2008; Wittenberg-Lyles, Oliver, Demiris, & Regehr, 2010). To our knowledge, however, no researchers have specifically explored the setting of hospice care in the United States and its influence on IDT roles and care processes.

The rapid rise in the use of inpatient hospice, as well as significant constraints imposed by the reimbursement for such care, makes understanding the challenges faced by the IDT, regardless of setting, an urgent need. Therefore, the aim of our study was to describe the experiences of IDT members providing hospice care to older adults in home and inpatient hospice settings in the United States, and ways in which these settings influence the IDT role.

Methods

Part of a larger ethnographic study (Agar, 1996; Roper & Shapira, 2000; Bernard, 2002) designed to understand how patients, caregivers, and a hospice IDT negotiate settings of care (Hurley et al., 2014), we used data from semistructured interviews with IDT members who worked in an agency providing home and inpatient hospice care. The University of Pennsylvania Institutional Review Board and the ethics committee of the hospice agency granted human subjects approval.

Setting

A large not-for-profit hospice in a metropolitan area of a major city in the northeast United States was the single study site. The hospice agency, one of the largest in the United States (NHPCO, 2013), serves patients in urban, suburban, and rural communities, with a daily census of approximately 400 patients. Its organizational structure includes IDT members, clinical team managers, bereavement teams, and a separate business staff. The IDTs are organized by practice setting: home care, nursing home, assisted living facilities, and a 20-bed inpatient hospice unit. In addition, there are admissions teams, triage nurses, a night on-call team, and a dedicated weekend staff.

Sample

We used purposive sampling to recruit IDT members from the participating agency's home and inpatient hospice settings and continued recruiting until we achieved theoretical saturation (Patton, 2002). Eligibility criteria were full-time employment, membership in an IDT (including, but not limited to, registered nurses, advanced practice nurses, physicians, social workers, chaplains, administrators, and certified nursing aides), age 18 years or older, and the ability to speak and understand English.

Following written consent, the first author conducted interviews in private rooms at the main office of the hospice agency or at the inpatient hospice facility; one staff member requested

an interview in a private room offsite. We developed a semistructured interview guide and began with open-ended questions about the IDT member's experiences working in hospice, and then proceeded to more specific questions about care settings and transitions between settings. All interviews were digitally recorded and professionally transcribed. After the interview, the first author validated the transcription and subsequently destroyed the audio file. We maintained confidentiality through the use of unique pseudonyms for each participant, an encrypted USB flash drive for study files, and a private wireless connection with the ability to remote into the secure research drive at all times.

Analysis

We entered the interview data into NVivo9 computer software for management (QRS International, 2010) and used the constant comparative method for inductive analysis (Glaser & Strauss, 1967). The first author created the initial codes, with additional codes emerging as the analysis continued. We grouped codes with similar meanings together to establish larger categories and themes. The first author met with the second author to discuss the codes during the data collection and analysis phases. A separate data analysis group of peers provided additional support for credibility by reviewing de-identified transcripts and emerging codes and themes. The first author wrote memos to document insights and analytic decisions.

A primary feature of ethnography is the concept of the researcher as an instrument of data collection, namely one who comes to the research with experience, views, and insights about the phenomena under study (Lipson, 1989). The first author (who was also the primary investigator) had 6 years of experience in hospice and palliative care at the time of the study, and therefore attended carefully to reflexivity (Arber, 2006). She discussed introspection and the reflection of personal values, beliefs, and influences with coauthors with experience in geriatric and palliative care nursing and ethnographic methods (Finlay, 2002). In Table 1 we illustrate additional measures used to strengthen trustworthiness, including attention to credibility, transferability, dependability, and confirmability (Guba, 1981).

Findings

We conducted interviews with 24 IDT members. Most were women with 3 to 10 years of experience in hospice. A variety of disciplines and roles were represented, including chaplains (2), nurses (6), physicians (2), social workers (4), certified nursing assistants (3), administrators (4), nurse practitioners (1), bereavement counselors (1), and admission nurses (1). IDT members worked in home care (10) or inpatient care (4), or rotated between both settings (10). We found through comparative analysis that the experiences and priorities of staff working in home and inpatient care differed. The overarching theme of divergent core IDT tasks emerged from several sub-themes present in home and inpatient hospice, but with different characterizations: identifying the focus of energy, tailoring family caregiver involvement, acknowledging who is in charge, and knowing both sides.

Identifying the Focus of Energy

IDT members providing home care focused their energy on balancing safety with patient and family caregiver preferences, in contrast to the inpatient team, who viewed themselves chiefly as resources for symptom management. Home safety concerns were paramount for home hospice IDT members, patients, and caregivers, including the physical environment (e.g., the ability to exit easily in case of an emergency), risk of falling, problems administering or determining the need for medication (as well as the possibility of the illegal diversion of medications), and the ability of the caregiver to provide care. As one home hospice nurse explained,

[Safety concerns are] around their gait, being unsteady on their feet ... are they forgetful, can they administer their own medications, can they administer their medications safely ... can they get out, if there were a fire, safely and in a timely manner ... do I have concerns about them using the stove or leaving the stove on?

IDT members recognized the conflict when staff determinations of unsafe conditions conflicted with patient and family preferences, as reflected in a home hospice nurse's statement:

[There] is a whole other big thing of ... patient autonomy versus safety. A person has a right to fall if they want to, you know, and they will tell you that: "Get out of my house. I can do what I want." But then, you know, we have an obligation to report something that's blatantly unsafe.

Safety was a key factor in team decisions to care for the patient at home or transfer to either an inpatient hospice or a nursing home. In these cases, IDT members used formal team meetings and engaged in informal conversations with colleagues to weigh concerns about safety against patient and family preferences. Understanding when to fix things (e.g., family discord, furniture arrangement, and meal planning) or when to support patient autonomy was often difficult. A home hospice social worker described this by saying,

I've had some wonderful conversations with the nurses about [patients' home situation] when they're like, "We need to fix this. We need to do this." I'm like, "You don't, you really don't. You gave them the information. This is their choice."

In an effort to balance safety with respect for patient and family preferences, staff regularly devised backup solutions to anticipated problems. For example, they prefilled syringes, confirmed a medical alert system, and recruited additional help from family and neighbors in anticipation of needs to relieve or respond to symptom distress for patients living alone.

By contrast, as symptom-management resources, the inpatient IDT focused on crisis situations. This included crises occurring in the home that led to a transition to inpatient hospice. One inpatient hospice nurse explained:

Well, because when they're going there, they're so symptomatic ... they can give things [subcutaneously], 'cause the meds [medications] are right there.... It's kind of like a hospital setting. It's like sending someone to an emergency room and being admitted. I mean, that's really the benefit of it. Everything is right at hand.

Discrepancies in assessing symptoms between the home and inpatient teams at the time of admission often contributed to friction. A home hospice nurse stated,

Sending your patient to [inpatient hospice] is the equivalent of taking your kid [child] to the doctor. You're always afraid when you take your kid to the doctor that the fever will go down and then they won't be sick. It's a real art and it's a real skill as a nurse here to know [when to transfer a patient].

It was expected that the inpatient hospice team would resolve the most difficult symptom-management cases because an inpatient hospice admission occurred only when the symptoms could not be managed in the home. The inpatient teams were considered to be the ultimate problem solvers, and to view resolution of acute symptoms as their role in making home hospice successful. One inpatient hospice nurse explained:

They'll come in in agony and we titrate them up a little bit, start them on a [infusion pump to provide medications], whatever the doctor does, and they're home in a few days. That's nice.... They're the ones that are saying, "I'm working on my bucket list [a list of things an individual wishes to accomplish before death], so I still have things to do." And it's nice to give them that opportunity.

Tailoring Family Caregiver Involvement

Whether patients were at home or in the inpatient unit, family caregivers were integral to their care, although roles differed according to setting. At home, with guidance from the home IDT, the role of the family member in giving direct care was stressed. This arrangement shifted markedly with admission to the inpatient setting, where the IDT assumed all responsibilities for direct care. In the home, the IDT understood the importance of the family caregiver in keeping a patient at home. Thus, support for the caregiver in the provision of safe and adequate care was a central concern for the home IDT. One physician suggested,

I don't know that there's any data to support this, but the Number One criterion for us keeping people in their homes is a competent caregiver.... That's the most important factor ... a competent, committed caregiver.... A caregiver who realizes that the patient is dying and who is able to step up to the plate and provide twenty-four-hour care at the end of life.

Nevertheless, patient preferences and family resources did not always match. One IDT member asserted, "The struggle sometimes, I think, is the patient wants to die at home and wants to be at home with his family, and the family says, 'I can't do it.'" When these conflicts occurred, IDT members offered more frequent visits from all disciplines and facilitated crucial conversations among family members. When a patient began declining, IDT members often encouraged caregivers to accept respite care and additional help from other family and friends, as exemplified by this observation from a home hospice social worker:

You look at who's there to take care of them. A lot of times there's only one person and they say, "Well, I can do it." And you ask them, "Well, when are you going to sleep?" And they're like, "Oh, I'll be fine. I'll be fine. I'll be fine." It's like, "No.

You know, this isn't going to be two days. This could be two weeks, and you need to sleep at some point."

When a patient was transferred to inpatient hospice, caregivers were no longer responsible for direct care and could therefore assist with simple tasks aimed at comfort. Admission to inpatient hospice allowed the caregiver to focus solely on the emotional and personal needs of loved ones. Because of the requirements for reimbursement, symptom management was the driver of inpatient admissions, despite legitimate concerns about stress levels, sleep deprivation, and need for caregiver respite. Respite care was also offered but is time limited. One chaplain said,

[T]hey know that their loved one is going to get changed, and kept clean, and smell good, and look good as much as they can, and all of the pain is going to be taken care of here, so it relieves family of a lot of that burden of caring for them physically.

IDT members were aware that caregivers experienced relief when inpatient staff assumed responsibility for direct care. Another chaplain noted, "I've actually seen people after they come [to inpatient hospice] ... and I mean the calm that seems to come over people with greater support, oftentimes the caregiver just looks different." IDT members indicated that most patients admitted to inpatient hospice also died there, although some patients admitted for symptom management were discharged back to home hospice. Once home, caregivers quickly recognized that the full responsibility for direct care was theirs, and often experienced a great deal of stress. One inpatient hospice social worker elaborated:

For somebody to be transferred back home after [inpatient care], that can be a real challenge, where they pick up on that. "Okay, I need to put that nurse hat back on," or, "I need to be the caregiver again. I need to focus on that. I'm glad to do it. I know I want them to stay home or they wanted to stay home." ... But they have to kind of step up to the challenges again and to feeling the responsibility all on one person's shoulders or a couple people's shoulders.

Acknowledging Who Is In Charge

The setting determined who controlled care. Home IDT members identified as guests in the home, thereby conceding decision making and care to patients and families. In contrast, inpatient staff led and delivered care. As a guest in the patient's home, the team acknowledged the authority of patient and family, allowing them to be in charge. IDT members adhered to patient and family expectations, spoken and unspoken, in several ways. For example, adherence could be as simple as removing one's shoes upon entering the house or sharing tea and cookies. A nurse practitioner stated,

[I]t's a different dynamic. You're a guest in the home. It's their house, their stuff, you know. They're in whatever room they want to be in.... You're invited in. They ask you if you want to sit down. They ask if you want something to drink.

On a more complex level, IDT members also recognized the subtlety of exercising control without appearing too authoritative or overbearing. One home hospice social worker explained:

I think it's a good way to help them feel like they actually are in charge of their care, because we're coming into their environment. They're inviting us into their home and they don't have to, and we're guests. So even though we're the ones making these recommendations and telling them what they should or shouldn't do, I feel like they can still be more comfortable to make their own decisions because they are at home.

One home hospice care team manager expressed that when patients and families were the decision makers, care was negotiated among IDT members, caregivers, and patients:

It's not about us and what you think is the best thing. You know they need a hospital bed. Well they don't want one. But they need it. No, they don't. You don't need a hospital bed to die. It makes it easier to care for them. It makes it easier for them to breathe and to move around, but they don't have to have it. If they want to die in their reclining chair, it's their right to die in their reclining chair. We need to ... figure out how to care for that patient.

Conversely, the on-site availability of all disciplines in inpatient care, especially during the day shift, was a major advantage in achieving comfort and resolving problems. As a physician stated, the inpatient IDT was clearly in charge of the care plan:

And the good thing about the [inpatient team] too, is the whole team is there all the time, which in home care we're all over the place. So they have the whole team present all the time. The social worker is just right there or the chaplain is right there. The home health aide is right there.

The IDT members' ability to provide a rapid response in the inpatient setting contributed immeasurably to addressing problems and maximizing patient comforts. One nurse stated, "[You know] that they are going to get the nursing care that they need, and I also let them know that the doctor's going to be here to adjust medications to get them comfortable quickly." One advanced practice nurse felt that titrating medications was far better in inpatient care than when managed at home by family members.

Knowing Both Sides

Both home and inpatient IDT members noted that familiarity or training in both settings instilled greater confidence in carrying out their respective roles. Although not mandatory, cross training occurred during orientation or position transfers within the organization. After a newly hired nurse spent a month in the inpatient hospice, she felt better equipped to explain its purpose and to judge appropriateness for admission. Rotations among and between settings was uncommon, although it occasionally occurred when the inpatient census was low. Inpatient experience allowed staff to feel more prepared to manage symptoms in the home setting. One inpatient hospice nurse explained:

However, since I've come here, I've seen terminal delirium over and over and over and over. If I go back out in the field, which I have done, I'm better for it because I've dealt with it and practiced it and said, "This is what it is!" So that makes me a better nurse if I go back out ... much more confident when I go out there.

Discussion

Our ethnographic study of one large United States hospice agency, offering both home and inpatient care, illustrates the unique differences in care provided by IDT members depending on the setting. Operating under the umbrella of hospice, the services provided by home and inpatient teams differed significantly. IDT members in both settings were clearly patient centered and supportive, but the perceptions of the team members and the recipients of care differed markedly.

Balancing safety with patient and caregiver preferences emerged as a major theme for IDT members responsible for home hospice care. All home care has safety-specific issues (Lang, Edwards, & Fleiszer, 2008) with parallel concerns, but in the home, infection control (Chilvers, 2009), falls (Gombar, Smith-Stoner, & Mitchell-Mattera, 2011), and staff safety (Sylvester & Reisener, 2002) take on new meaning. Findings from our study underscore the significance of safety in light of patient and family preferences (Casarett, Spence, Clark, Shield, & Teno, 2012). Preferences for safety will always be complicated by the uncertain trajectories occurring at the end of life, notably the physical and cognitive declines that frequently render the home unsafe. Researchers, clinicians, payers, and policy makers must pay greater attention to the complex core task for home hospice providers to meet safety needs.

We found the presence of competent family caregivers essential to home hospice care. This too-often-ignored reality is consistent with the work of others (Funk et al., 2010; Stajduhar et al., 2010; Tang, 2009), who have documented that dying at home (vs. at a hospital or an inpatient hospice facility) is associated with the presence of a spouse or primary caregiver (Jeurkar et al., 2012; Johnson et al., 2005; Miller, Kinzbrunner, Pettit, & Williams, 2003). Nonetheless, symptom management often leads to caregiver burden (Evans et al., 2006).

Unfortunately, United States hospice regulations and reimbursement policies dictate that symptom management, not caregiver breakdown, is necessary for admission to inpatient hospice. The length of stay in inpatient hospice is dependent on continued acute symptom management. Respite care is available, but is limited to only 5 days. The fact that the inpatient team focused almost exclusively on symptom management was not surprising given the insurance requirements for admission. However, a serious unaddressed issue is how to support family members adequately in their efforts to keep their loved ones at home, assuming there is a family member or members able to provide such support.

Our study also confirmed how daunting and stressful it was for family members when patients were discharged from inpatient hospice following a stay for symptom management. The hospice teams asserted that family resources and patient preferences did not always match, thus making it even more challenging to meet patient goals at the end of life. A key next step for research translation and policy, especially if minimization of transfers to inpatient hospice is a desired outcome (whether that should be a goal is a separate issue), is to untangle caregiver burden and the management of acute symptoms at home to achieve a death at home if desired.

IDT members described the role that setting and family partnership played in controlling the care plan. Although home IDT members were guests, this created, at times, too much caution about intervening as situations intensified. The focus of the inpatient hospice setting on medical symptom management relieves families of providing direct care, but at the same time, the family must be included in discussions of the care plan. The United States urgently needs a more effective way to deal with the requirements of reimbursement, the needs of patients and families, and the decisions that inevitably must be made based on these realities.

Our findings must be considered in light of several limitations. All data collection occurred in one hospice agency and might not be generalizable. Also, the participating hospice agency owned a freestanding inpatient hospice unit and therefore did not include the hospital as a site for inpatient hospice. One person, the first author, conducted all data collection and initial analysis, possibly introducing unchecked bias. Measures taken to address this potential limitation included the use of reflexivity, meetings with mentors, debriefing with peers in a qualitative collective, and writing memos.

Another limitation is the inability to translate findings to countries with different models of hospice delivery and financing (Thomson, Osburn, Squires, & Jun, 2013). In the United States, hospice services are largely defined by the Medicare hospice benefit, which requires a robust IDT and varying care levels while limiting the use of inpatient hospice, with the aim of keeping costs in check—especially the high cost of inpatient care. Economic pressures in other countries might result in similar policies (Callaway et al., 2007; “Dying at Home,” 2014). Moreover, our findings about balancing patient safety with patient and family autonomy, the advantages of inpatient hospice for intractable symptom management, and the differing roles of inpatient and home care hospice teams are likely translatable to other countries.

Conclusion

Differing reimbursement and service requirements for home and inpatient hospice care in the United States, and the differing needs of patients and family caregivers present unique challenges to IDT members in each setting. Concerns for safety in home hospice is paramount and needs further exploration to identify how patients, families, and home hospice teams negotiate the balance of patient-centered care and adequate resources to remain at home. Although hospice care is designed to be delivered primarily in the home, increasingly such care is provided along a continuum that includes both the home and inpatient facilities. Current guidelines for reimbursement limit inpatient care, but this is not always well understood by families, and often complicates the safe management of care at home. Our study also underscores the lack of continuity in the care plan, which is handled differently depending on whether care occurs at home or in an inpatient setting. Finally, IDT members valued training in both settings, and the impact of that cross training on care management decisions is worthy of additional exploration.

Hospice care in the United States has been in existence for more than 30 years. It is a dynamic and changing landscape, with significant shifts in the location of care in the past

decade. As our study findings suggest, more examination is needed of the impact on patients and families, costs, and overall outcomes of safety, quality, and satisfaction of a model of hospice care that is now sharply demarcated by the requirements and expectations of home vs. inpatient settings.

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Table 1

Strategies to Enhance Trustworthiness.

Criterion	Definition	Specific Strategy Used to Address Criterion
Credibility	Plausible findings	Prolonged engagement in the study setting (11 months, at least some part of 1 to 2 days/ week) Use of data analysis group (colleagues also conducting qualitative analyses who met regularly and reviewed de-identified transcripts, field notes, and emerging codes)
Transferability	Detailed hypotheses that might be applicable to other contexts	Purposive and maximum variation sampling (targeted patients considering transfer or just transferred between home and inpatient hospice and sought representation from each discipline, balance of home and inpatient teams, every shift [i.e., day, evening, night]) Thick, descriptive data collection (field notes)
Dependability	Ability of other researchers to follow methodological decisions	Audit trail (memos regarding methodological decisions)
Confirmability	Ability of other researchers to follow theoretical decisions	Confirmability audit (memos regarding analytic decisions) Member checking (focus group with IDT members at hospice agency who confirmed findings) Reflexivity (dialogue with experienced coauthors and memos about field experiences)