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Settings of Care within Hospice: New Options and Questions about Dying “At Home”

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Abstract

Although place of death has been routinely studied in end-of-life (EOL) care, more analysis on place of death within hospice is needed because of the recent, dramatic rise in the number of hospice patients dying in inpatient settings. Using a case study to illustrate the complexity of determinants of place of death within hospice, this article highlights important known factors and elucidate gaps for further research. Individual and system level factors, sociocultural meanings, caregiving and preferences are shown to have important implications. Additionally, the unique components of home hospice, inpatient hospice and transitions between these settings may have a fundamental role in the future of quality EOL care. Further research on determinants of hospice settings of care is essential to the care of older adults at the end of life.

Keywords

hospice; place of death; inpatient hospice; caregiving

Introduction

Almost fifty years ago, hospice emerged as a model of care partly in response to the “medicalization” of death. One of its primary goals was to move the dying process out of hospitals and into the home. In the past few decades, dying at home with hospice has become the ‘gold standard’ for end-of-life (EOL) care. The Medicare Hospice Benefit (MHB) was enacted in 1982, providing end-of-life care in patients' homes. Nursing homes

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were included in the MHB as a place for routine home care in 1989.¹ In 2010, hospice served 1.58 million patients; 82.7% of which were 65 years or older.²

As a result of the exponential growth of hospice care, there has been a shift in the site of U.S. deaths from 1989 to 2007, when the percentage of deaths at home increased from 15.9% to 25.4%.³ Research has demonstrated that dying at home with hospice care is associated with better symptom management and overall satisfaction with care compared to dying in an institution or with traditional home care.⁴ Hospice care can be provided in many settings including private residences, hospitals, nursing homes, assisted living facilities, and hospice-owned facilities. Within these settings hospice agencies provide different levels of care. The four levels of care covered under the MHB are general inpatient, routine, respite, and continuous care. These levels have separate eligibility requirements and are reimbursed at different rates. A desired outcome of hospice care is dying in the patient's preferred place of death, which is most often listed as home.⁵

Strong patient preference for dying at home has been well documented; however, a critical examination of home care at the end of life has revealed a thread of romanticism about this ideal.^{6,7} Dying at home in a familiar, nurturing environment, without burdensome symptoms, and surrounded by loved ones is commonly considered the best scenario for end-of-life care. However, the reality of dying at home is often more complicated.⁸ Family caregivers are often stressed and sometimes unavailable; the physical environment may be small, chaotic and even unsafe; symptoms may be inadequately managed; and even basic care such as bathing and grooming may be an insurmountable challenge for patients and caregivers. Further, some patients and families may prefer acute level (or inpatient) care for end of life.⁹

These realities may partially account for the recent increase in inpatient hospice, nursing home, and hospital deaths, with a concomitant decrease in the number of hospice patients dying in their private residences.² While dying at home may have initially been introduced as a response to misguided and poor care of dying patients in hospitals, the more recent shift in place of death suggests that dying at home is a concept needing re-clarification and evaluation nearly thirty years after the beginning of formal hospice care in the United States.

Using the following case study and a review of the literature spanning the past 25 years, this article will illustrate the complexity of dying at home with hospice and elucidate gaps for further research. Although death at home by MHB regulations is the person's private residence (and therefore could include nursing homes, assisted livings, group homes, etc.) the focus in this paper is on those living in private residences outside of facilities. Particular attention will be paid to older adults, as hospice primarily serves that population with 82.7% of patients in 2010 being over the age of 65.²

Case

Rose is an 85 year old woman with end-stage Congestive Heart Failure (CHF), renal insufficiency, and low back pain secondary to osteoporosis. She is on furosemide (Lasix®), Bumex®, Vasotec®, atenolol, aspirin, timed release oxycodone, and immediate release prn oxycodone. She also is receiving oxygen therapy. Her husband of 42 years has Alzheimer's disease and needs to be monitored constantly. Three months ago, when it became clear that Rose could no longer care for her husband alone, Rose and her husband moved in with their only daughter, Jan, and her husband. Rose was hospitalized two weeks ago for dyspnea, lightheadedness, and extreme fatigue. She spent 7 days at the hospital and returned to her daughter's home, stating, "I'm never going back there again!" Subsequently, she was admitted to hospice with Jan as her primary caregiver.

Upon admission Rose reported that she felt “pretty good” most of the time, but she had dyspnea with minimal exertion, difficulty sleeping, and significant lower extremity edema which made it difficult to ambulate. She was able to transfer and feed herself, but needed help with her medications. Rose took care of her own parents in her home until they died and had many times expressed to her daughter that she wanted—“to die in my own bed.” Rose also expressed that she was nervous about dying at home because of her husband’s reaction (given his illness). She also was concerned about how much time her daughter could take off from work “when the time comes.” Jan was insistent that she could handle the situation and would do whatever it took.

One week later, Rose had some difficulty breathing overnight and became very nervous about a recurrence of this dyspnea. The hospice nurse visited and administered an extra dose of subcutaneous Lasix® and morphine with rapid relief of Rose’s symptoms. At this time, Rose asked about being taken to the inpatient hospice house. The nurse explained that as long as her symptoms were under control, she really couldn’t be admitted to the inpatient hospice house, but assured her that if she needed it in the future, it would be an option under her Medicare Hospice Benefit.

Predictors of death at home

Rose is expressing a preference for death at home, although recognizes that certain circumstances may prevent achieving this goal. Measuring congruence between a patient’s preference for place of death and their actual place of death is an important concern in end-of-life care.^{10,11} Giving patients the opportunity to voice their preference and having it be congruent with their actual place of death is a way to emphasize individualized patient care and avoid the assumption of dying at home as the best option for all.

However, many studies have demonstrated several factors other than patient preferences associated with death at home.^{7,11–15} Predictors of place of death include both macro- (e.g., population demographics, regional and cultural differences) and micro-level (e.g., individual, disease specific) characteristics. Macro-level factors associated with death at home include living in a rural area¹² or in a county with low proportions of racial/ethnic minorities.⁷ Dying at home is also more common in communities with higher rates of families living below the poverty line.⁷

Patient and family characteristics have also been considered as predictors for place of death. Gomes and Higginson¹² reported an increased likelihood of dying at home when: patients have a low functional status, both caregiver and patient prefer death at home, and the nurse is aware of this preference. Additionally, age is negatively associated with age; persons over age 65 have a lower rate of dying at home.^{3,16} Interestingly, this difference may not be attributed to differences in symptoms in that Hirakawa and colleagues reported a similar symptom experience of the younger old and older old.¹⁷

The presence of advanced directives, being informed of imminent death and the type of terminal illness are other individual characteristics associated with dying at home. Dying at home with hospice is more likely when a person has completed an advanced directive.¹¹ Additionally, when patients and families were informed that death was imminent, patients were more likely to die in their preferred location.¹⁸ The type of terminal condition is also an important factor. Cancer is associated with a higher likelihood of dying at home, whereas dementia is negatively associated with dying at home.⁷ This may be due to the more predictable illness trajectory of cancer.

Research about predictors of place of death among terminally ill patients usually includes hospice and non-hospice patients. Receiving hospice care is associated with higher rates of

dying at home.⁴ Even within hospice, however, there are different settings of death. In 2011, approximately 66% of hospice patients died at home, which included 41% in a private residence; 25% in a nursing home or residential facility; 11% in an acute care hospital; and 22% in an inpatient hospice facility.² Among hospice patients with cancer, death in an inpatient hospice unit is more likely if the patient received hospice care, lived in a county with an inpatient unit readily available, had a preference to die there and had low functional status.¹⁹ Older data have consistently shown that the availability of inpatient hospice units is an important predictor for death in this setting. Data from the National Hospice Study²⁰, which included 26 hospices across the country, found that organizational characteristics were more significant in predicting place of death than individual factors. For example, patients served by a hospice with inpatient access were three times more likely to die there versus home. A recent study determined that among hospice agencies there are different levels of death in inpatient settings versus home.¹¹

Two studies have examined place of death within hospice using aggregate data from one large multi-state, for-profit hospice.^{21,22} Johnson et al²¹ focused on racial and ethnic differences in place of death within hospice and Miller et al²² explored hospice length of stay and the use of continuous care and inpatient care. Overall, 36% and 34% of patients, respectively, died in an inpatient unit. Johnson et al found that, after adjusting for hospice-use and other demographic variables, Hispanics had lower odds of dying in an inpatient unit than home than Caucasians and African-Americans. Important predictors for dying in an inpatient facility rather than home included: receipt of care from a hospice program with an inpatient unit, residence in the northeast US, Medicaid recipient, non-spousal caregiver,, HMO enrollment, short stay (<8 days), lower income, male, not married, and younger than 85 years old.²¹ Using earlier data from the same large, for profit hospice, Miller et al found that male gender, severe pain, a diagnosis other than cancer or Alzheimer's disease, not living with a caregiver, short hospice stay, and residing in a state with more inpatient beds were significantly associated with inpatient hospice death.²² Caregiver status was measured differently in these studies by either relationship to the patient or whether the patient and caregiver lived together. Both ways of measuring caregiver status impacted inpatient hospice death rates; having a caregiver who was not a spouse²¹ and not living with a caregiver²² were both associated with a higher rate of inpatient hospice death. Although there are consistent associations between dying in an inpatient unit and male gender, access to an inpatient unit, and a diagnosis other than cancer, both studies used data from one large for-profit hospice agency that are now 9–13 years old. Thus, these findings must be interpreted with caution.

Applying the literature to the case study: Rose is enrolled in hospice, making it more likely for her to die at home. She also has a caregiver who also expressed a preference for the patient dying at home. However, Rose lives near an inpatient hospice unit which may increase her chance of dying in an inpatient unit.

Sociocultural meanings about “Dying at Home”

Although dying at home denotes the place of death, the phrase also represents a more complicated, nuanced concept that reflects patient and family preferences for environmental and situational characteristics at the end of life. In a qualitative study of older adults, Gott, Seymour, Bellamy, Clark, & Ahmedzai²³ found that home connoted the presence of loved ones, familiarity, autonomy, security, and the proximity to personal possessions. Similarly, Melin-Johansson, Odling, Axelsson & Danielson²⁴ found that being at home was a significant component of quality of life for terminally ill elders. Respondents reported several characteristics about home that promoted quality of life. These features included:

feeling safe and secure, being familiar with one's surroundings, remaining close to one's personal belongings, and promoting patient independence.

Although dying at home is frequently desired by patients and families, other studies reveal the challenges of dying in this setting. In Melin-Johansson et al's study, participants expressed many concerns about dying at home, which included "not having an informal carer; not wanting to be a burden to family and friends; believing that quality care cannot be delivered at home; and perceiving professional home care as an intrusion."²⁴(p. 463) Studies of inpatient hospice settings reflect that desired home-like qualities can be created in an institutional setting and the physical environment is important for patients and families.²⁵ Elements such as reflections of nature, cleanliness and ease of access for families are ways in which the inpatient hospice setting became more like a home. Significantly, when inpatient hospice care is offered as an alternative, the preference for hospice home care decreases.²⁶ Acceptability of and preference for inpatient hospice care may reflect the setting's ability to create a sense of "at homeness" as well as patients' and families' priorities for skilled pain and symptom control, safety, and quality of life.²⁷

Applying these concepts to the case study, it is unclear how "at-homeness" influences Rose's preference for dying at home. On one hand, she is living with her daughter in what is likely a familiar environment. However, it is not her home; and therefore may not have the same significance. Additionally, she is aware of the inpatient hospice house and requested to go even though her symptoms are controlled; thus, she may feel some of the anxieties of dying at home that other patients have described. Ultimately, it may depend on the support she is receiving at home and her desire to avoid burdening her daughter and upsetting her husband.

Changes over time in preferred site of dying and death

A small number of studies examined shifts in patients' and caregivers' preferences for place of care over time.^{28,29} Documented preferences for place of care in hospitalized patients indicated that 37% of patients identified a different location over time. Interestingly, patient preference often moved away from home to an inpatient setting (either hospice or hospital).²⁸ In another study, patients receiving palliative care were asked over time about their preferred place of care and similarly found that over time, about one-third of patients changed their minds.²⁹ These studies support a classic nationwide study of patients, bereaved family members, physicians, and other care providers, where dying at home was ranked last among selected attributes of important components of good end-of-life care.³⁰ Very few studies have examined the transition from home to inpatient hospice. Evans, Cutson, Steinhäuser, & Tulsky²⁷ interviewed eighteen caregivers whose family members transferred to a hospital, nursing home, or inpatient hospice setting during a hospice admission. The transfer did not engender feelings of regret among caregivers. Moreover, satisfaction with care was not related to concordance between previously stated preferences and actual site of care and death. These findings suggest that changing patient needs may result in a shift away from home as the desired setting for death and towards the care setting that minimizes physical and psychosocial suffering.²³ Higginson and Sen Gupta³¹ noted that these shifts may occur because the preference for care at home was predicated on ideal home and caregiver circumstances. When actual situations are not ideal, then the preference for dying at home is negated.

In the case study, the dyspnea that Rose experienced may have caused a shift in her preference for dying at home. Her question to the nurse about the inpatient hospice house indicates her willingness to move to avoid unnecessary discomfort.

Caregivers

In most cases, dying at home requires one or more informal caregivers. Caregiver availability and ability is highly important in electing home as a place of death.¹² Having a spouse as a caregiver (vs. other relative) increases one's chances of dying at home.³² This finding suggests important questions to examine such as, "Do widows and widowers have different preferences and expectations about dying at home?" Acknowledging the difficulty in providing care at the end of life, patients who prefer to die at home have expressed concern about being a burden to their loved one and their loved one's ability to provide necessary care.²³ In hospice care, healthcare team members educate and support informal caregivers, who in turn provide much of the actual care.

Caregivers choose patient death at home less frequently than patients³³; moreover, caregiver preference is a stronger predictor of site of death than patient preference.³⁴ Caregiver workload increases when the patient is dying at home and can be associated with increased frustration and uncertainty, despite their efforts to maintain a sense of normalcy.³⁵ However, caregivers providing more intense care in the home setting may not necessarily feel more caregiver burden or depression than those whose loved one died in the hospital³⁶ and have been shown to have lower psychiatric illness compared to caregivers of patients who died in the hospital³⁷. The coping mechanisms of family caregivers are influenced by patient and caregiver characteristics: patient's health and symptom status, patient-caregiver interactions, caregivers' sense that their efforts are validated, and lay and professional support system.³⁸

Jan, Rose's daughter, has been a primary caregiver for a short period, but the prognosis for congestive heart failure can be highly unpredictable. During a home visit with the hospice social worker, she describes caring for her mother at home as time-limited. Moreover, Jan stated that she feels it is important to honor her mother's wishes. Jan recognizes that she has the support of the hospice team, but she will be responsible for more and more care as her mother's health status declines.

Policy implications

Dying at home often is considered a "gold standard" for quality end-of-life care⁹ and is commonly defined simply as the patients' private residence. With this limited view, it is difficult to understand the large, growing number of deaths occurring in settings other than a private residence even among hospice patients.⁷ Medicare regulations, however, restrict which patients have access to inpatient hospice and the number of inpatient days a hospice agency can use for their patients. Given the complex nature of place of death even within hospice, it is important to consider this recent trend and attempt to further understand where the needs of terminally ill patients might be best met.

A place of care should be an environment that enhances patients' quality of life and death. The actual place can be a private residence or institution, but must meet certain criteria. The patient and family must feel safe and nurtured, and dying at home must encompass a place of physical, psychosocial and spiritual comfort. Patients' symptoms and physical needs must be met and caregivers must feel supported and competent in meeting patients' needs. Because this definition is consistent with standards of palliative care, high quality care that leads to better patient and caregiver outcomes may be provided in multiple settings. This broader conceptualization of dying at home also fits with palliative care's focus on person-centered care and the acknowledgment of the patient and family as the unit of care.³⁹

Helping patients and families think beyond an actual setting of care also can address unrealistic expectations and allay guilt. If the predominant expectation is that "good deaths" occur in a private residence (most likely the patient's home), then families are under

tremendous pressure to deliver that care. As Cannuscio⁴⁰ pointed out, end-of-life caregiving can be physically exhausting and at times very distressing, even with sufficient financial resources and loving, well-educated family members at the bedside. When the caregiving situation is less than ideal, families may be left with a sense of failure if the death occurs in a non-home setting or if the patient dies at home with unrelieved symptoms or other unmet needs; in other words, they are in a no-win situation unless they are encouraged to think broadly about what it means to “die at home.”

Rose had another episode in the middle of the night with increased dyspnea and new delirium which could not be relieved by the on-call nurse. Jan had been up all night the previous night with her mother and was exhausted. The on-call nurse suggested a transfer to the inpatient hospice house and Jan agreed, with Rose's assent. Rose spent the last five days of her life at the hospice house, dying peacefully with her family by her side.

Future research

The literature around dying at home, particularly in the current hospice context suggests several avenues for future studies. One area in particular that needs further examination is transitions in settings of palliative care. Transitions in care settings are often stressful for older patients and families, and result in poorer patient outcomes and increased costs.⁴¹ However, a transition at end of life may be welcomed and essential under certain circumstances. The recent increase in deaths at inpatient hospice facilities² suggests that transfers from home may actually enhance the quality of dying. Despite this trend, there is scant empirical evidence regarding the factors that predict transfer to inpatient facilities, or the outcomes of inpatient hospice care.

Additionally, Medicare reimburses care provided in inpatient hospice facilities only when there is one or more uncontrolled symptoms needing acute management. The rise in use of inpatient facilities may reflect an increase in unmet needs in the home care setting or patients who are likely to have a heavy symptom burden, rather than a shift from the general perspective that a death at home is superior to a death in an institution. Social considerations including distance caregiving and caregiving options for an older adult when their spouse has died are also important in considering unmet needs in hospice homecare. Other psychosocial considerations such as anxiety, depression and spirituality affecting the setting of care within hospice should be explored. More research is needed to elucidate these complex relationships.

Conclusion

Preferences for place of care and place of death continue to be an important component of quality EOL care. In light of recent trends for increases in the use of inpatient settings within hospice, further exploration of the cost and quality implications for levels of care within hospice is imperative. What do patients and families want and need? When patients transition between settings within hospice, what are the essential components of these transfers? Given the system-level factors and individual-level factors, understanding this complex interplay will hopefully lead to care that meets patient and family needs and preferences in the future.

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