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Quality Hospice Care in Adult Family Homes: Barriers and Facilitators

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Abstract

Objectives—Older adults in need of residential services are increasingly spending their final days in small, domestic-style care settings such as adult family homes. In this study, we sought to identify processes that facilitated the provision of quality hospice care to seriously ill residents of adult family homes and their family members.

Design—We conducted a secondary analysis of qualitative data collected as part of a randomized clinical trial of a problem-solving intervention for family members of hospice patients.

Setting—The original trial was conducted in partnership with two large, community-based hospice agencies in the state of Washington.

Participants—Data from 73 family members of residents of adult family homes receiving hospice services were included in the analysis.

Measurements—Data were collected via semi-structured individual interviews, which were audio-recorded and transcribed prior to analysis.

Results—Family members described quality hospice care in the adult family home as care that is consistent with residents and families' values and that results in comfort and social connectedness for residents while promoting peace of mind and decreasing burden for residents' families. They identified numerous processes that facilitated the provision of quality care including personalizing care, sharing information and expertise, working together to resolve conflicts, and prioritizing residents and families' values over existing or competing philosophies of care.

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Conclusion—The AFH setting can amplify both the benefits and challenges associated with receipt of hospice. When choosing an AFH, older adults and their families should strongly consider selecting a home with a track record of positive collaborations with hospice agencies if the need for end-of-life care is anticipated.

Keywords

adult family home; hospice; end-of-life care; long-term care; family

Introduction

The proliferation of residential alternatives to traditional nursing homes is changing the landscape of modern-day long-term care.[1] In many parts of the United States, older adults in need of custodial care are increasingly opting to live in residential care settings referred to by a variety of different names such as adult family homes, adult care homes, board-and-care homes, group homes, and adult foster homes. These homes are designed to emphasize normalized living in a homelike environment where a relatively small number of older adults live and receive care.[2] There are nearly twice as many residential care settings as nursing homes in the United States; however, because residential care settings are typically much smaller than nursing homes, nursing homes serve more individual residents.[3]

In the state of Washington, the most common type of residential care setting is an adult family home (AFH). Washington AFHs are licensed by the state's Department of Social and Health Services to provide custodial care for up to six non-related residents at any given time.[4] In addition to serving fewer residents, AFHs differ from traditional nursing homes in that they resemble single-family homes and are located in residential neighborhoods. Furthermore, while AFH caregiving staff are required to receive training covering topics such as communication skills, fall prevention, and supporting activities of daily living, AFHs are not licensed as skilled nursing facilities. Therefore, they are not required to ensure on-site availability of licensed nursing services.[4] Costs vary widely; however, AFHs are usually considerably less expensive than nursing homes and assisted living facilities.[5] Potential AFH payment sources include private pay and, in some cases, long-term care insurance policies. In addition, as is true in a limited number of other states, Washington AFHs have the option of contracting with the state to accept residents whose care is covered by Medicaid.[3]

Nationally, just under 9% of all hospice patients reside in residential facilities such as AFHs.[6] For these individuals, the facility's care is supplemented by an interdisciplinary team of healthcare professionals including a hospice medical director and other physicians, nurses and nursing aides, social workers, chaplains, and other care providers who work to meet the biopsychosocial and spiritual needs of care recipients and their families.[7] Routine hospice care typically consists of periodic home visits while the majority of round-the-clock, hands-on care for AFH residents is provided by AFH staff. More intensive hospice staffing arrangements are available during acute medical crises.[8]

Decidedly little is known about the provision of hospice care in AFHs. One small study of 15 residents' family members highlighted the numerous challenges associated with transitioning to the AFH, ensuring quality end-of-care was being provided, and coordinating communication among the AFH, hospice, and the family.[9] Missing from the literature is an in-depth exploration of the processes that result in quality hospice care in the AFH setting. To address this gap, we conducted a study in which we explored the provision of hospice care in AFHs from the perspective of residents' family members, posing the following research question: *How is quality hospice care achieved in the AFH*?

Methods

Data Source and Analysis

We conducted a secondary analysis of qualitative data collected as part of a randomized clinical trial of a problem-solving intervention for family members of hospice patients in the state of Washington (R01NR012213; Principal Investigator: Demiris). The clinical trial protocol included one in-depth exit interview with all participating family members. During these interviews, which were conducted via telephone and digitally audio-recorded in their entirety, participants were asked to describe the challenges they faced as family members of hospice patients and how they addressed them. To provide context necessary for understanding their experiences, study participants were asked to describe the setting in which their family member received care and to discuss how, if at all, they thought the care setting affected the services they or their family member received (additional details of the original trial are provided elsewhere[10]). The richness of the data provided by family members in these interviews allowed us to conduct a secondary analysis in which we explored the provision of hospice care in AFHs. To be included in this secondary analysis, data must have been obtained from interviews of adult (i.e., age 18 or older) family members of individuals receiving hospice services in an AFH for 48 hours or more. “Family” included anyone designated as such by the care recipient; a legal or biological relationship was not required.

All research activities conducted as part of the original trial were approved by the Institutional Review Board of the Principal Investigator's academic institution. Written consent was obtained from all study participants. Prior to analysis, interviews were transcribed verbatim (minus “filler” words, e.g., “hmm,” “like,” “you know”) by a professional transcription service.

Two members of our research team (KTW, GP) analyzed the data using a template approach to qualitative analysis. Central to this approach, outlined in detail by Crabtree and Miller,[11] is generation of a coding template that is initially based on a subset of the data but is later revised and refined as more data are reviewed. First, we independently reviewed 25% of the dataset, highlighting all passages related to the study's research question and labeling them with a preliminary descriptive code such as “hospice is an extra set of eyes,” “hospice helps AFH staff understand medications,” or “AFH staff have prior hospice experience.” Next, we met together to discuss and compare our preliminary codes and develop an initial template that organized our codes into broader themes. We repeated this process three times, analyzing an additional 25% of the dataset each time, then meeting afterward to refine the template on an ongoing basis. Although we reached saturation (i.e., the point after which additional analysis is unlikely to result in greater understanding of the phenomenon under investigation[12]) after analyzing approximately 75% of the dataset, we included all available data in our analysis to allow for additional testing of the validity of our themes. Additional strategies to enhance study rigor included holding weekly peer debriefing sessions and maintaining a clear audit trail, detailing the multiple iterations of our template and noting our justification for any changes.[13]

In developing our final template, we identified themes that described quality hospice care and its barriers and facilitators. Often, however, barriers were described as the absence of facilitators and vice versa. Thus, to avoid redundancies, we constructed the template around facilitative processes and outcomes, capturing data that described both their presence and their absence.

Results

Data provided by 73 family members of AFH residents met the study inclusion criteria and were included in our final analytic sample. A summary of study participants' demographic information is provided in Table 1, along with selected information regarding their family member/AFH resident.

Below, our study findings are organized around five themes that summarized family members' descriptions of quality hospice care in the AFH and its outcomes: 1) *Care enhances residents' comfort*, 2) *Care facilitates residents' connectedness*, 3) *Care provides families with peace of mind*, 4) *Care decreases families' burden*, and 5) *Care is consistent with residents and families' values*. These themes are summarized in Table 2 and described in detail below, along with a discussion of the processes by which they were achieved. Participant quotations are provided when helpful in illustrating specific concepts. Longer quotations and participant narratives are labeled with participants' study numbers, which are used in lieu of other identifiers to ensure confidentiality.

Care Enhances Residents' Comfort

Study participants repeatedly emphasized the importance of residents' comfort at end of life. They reported that residents experienced comfort when AFH and hospice staff personalized their approach to pain and symptom management. Families described how the small, home-like environment of the AFH allowed staff to really know and understand residents' goals of care and respond accordingly. This was often contrasted with larger nursing facilities that family members believed were typically less conducive to personalized care. Family members suggested that the small, "family-like" environment of the AFH supported a personalized versus institutional approach to comfort-promoting care.

While the AFH environment and staff created a setting conducive to residents' comfort, family members perceived that the hospice staff brought valuable expertise with regard to symptom management. This was particularly true with regard to residents' physical pain. Participant #12014, who described managing her mother's pain as "tricky," explained: "With the help of the [hospice] nurse, we were able to get a better handle on [my mother's] medication …. to … [ensure she wasn't getting] too much [or] too little." Also important to residents' comfort were the equipment and supplies (e.g., wheelchairs, mattress, etc.)

provided by hospice, which were often regarded as being of higher quality than those available to the resident before hospice services were initiated.

Care Facilitates Residents’ Connectedness

Many residents’ family members noted the value of relationships with others, highlighting the ways in which residents’ social connectedness with AFH staff, other AFH residents, and hospice providers enhanced care at end of life. Relationships with AFH staff and other residents were often emphasized. Most family members reported holding AFH staff in high regard. AFH staff were described as “caring,” “attentive,” and “loving.” Participant #21110 reported feeling as if her mother had been “incorporated [into the AFH] like family,” and Participant #12033 stated, “I feel like [the AFH staff] actually love my mom.” Family members expressed frustration when they perceived that AFH staff were prioritizing convenience over residents’ connectedness. Participant #12096 described visiting his mother in the early evening and observing the staff getting her ready for bed:

> [The AFH staff member] said, “Well, [she] needs to start getting ready to go to bed” …. [I thought,] it’s 6:00pm and you’re going to put [her] to bed now? …. She would be laying in bed over 12 hours …. I know my mom doesn’t like that. [She] doesn’t like being by herself.

He discussed how, due in part to experiences like this, he assumed the AFH’s suggestion that his mother receive hospice services originated from a desire to “knock her out” to make her care easier to manage. Hospice’s decision to stop her Parkinson’s medication and increase pain medications further supported his perception that the AFH staff viewed hospice as an opportunity to prioritize convenience of care over his mother’s quality of life.

In addition to the more tangible benefits of hospice services, many family members indicated that residents simply enjoyed the time they spent with hospice providers and often looked forward to their visits. One family member praised hospice volunteer services, mentioning that the musician visits through hospice were “an unexpected and delightful benefit …. the entire AFH and all residents could enjoy” (Participant #12090). In terms of factors that detracted from residents’ sense of connectedness, changes in hospice staff due to turnover or reassignment for reasons other than care concerns were cited as problematic and disruptive to emerging relationships between residents and their care team.

Care Provides Families with Peace of Mind

Quality hospice care in the AFH was characterized by residents’ family members as care that resulted in their peace of mind. Many study participants described the anxiety they felt entrusting the care of their seriously ill family member to others. This worry was alleviated in several ways. Study participants were relieved to have hospice staff provide additional oversight and keep “a close eye” on the care their family member was receiving. It was also comforting for study participants to know that hospice provided help with care tasks AFH staff might find challenging, such as when hospice aides assisted AFH staff with bathing residents. In addition, family members considered hospice to be a resource for themselves and the AFH staff when emergencies arose. Hospice was repeatedly described as a “backup” or a “safety net” for challenging situations. Participant #11067 described the hospice nurse as a “lifeline” and described how comforted she felt with “just the additional support of having someone come to the [AFH] and actually follow [my mother] toward the end.” Several study participants commented on hospice services provided directly to them, particularly those designed to provide psychosocial and spiritual support during the intensely emotional experience of a family member’s terminal illness.

Study participants also described feeling at peace when their communication preferences were respected. For the vast majority of study participants, this meant that they were kept very much “in the loop” and well informed by both hospice and the AFH, receiving information about planned hospice visits so they could attend if desired. However, some family members noted that overly frequent communication could result in “a lot of phone calls” and a sense of feeling overwhelmed. While no consistent pattern emerged regarding specific communication preferences, it was uniformly observed that family members wished to be asked about their preferences and to have them honored.

Also contributing to family members’ peace of mind were AFH and hospice staff that were able to collaborate effectively, sharing an understanding of one another’s roles and responsibilities and managing conflicts as they arose without unduly involving residents’ family members. Study participants reported experiencing pronounced stress when AFH and hospice staff were unable to communicate effectively, seemed to be working toward different care goals, or became engaged in power struggles that detracted from resident care. This was the most salient theme in the dataset by a wide margin. When asked what recommendations they would provide to others in similar situations, family members most frequently advised others to find an AFH that had experience with and a collaborative attitude toward working with hospice.

Care Decreases Families’ Burden

Many study participants commented on the decreased burden they experienced as a result of their family member receiving hospice services in the AFH. Data comprising this theme addressed the practical and logistical (versus emotional) aspects of care. Study participants discussed how hospice providers assumed responsibility for coordinating logistics such as the delivery and return of medication, equipment, and supplies. Several noted that hospice involvement meant they no longer had to transport their family member to medical appointments or worry that medical crises would result in trips to the emergency room and subsequent hospitalizations. Others appreciated hospice assuming responsibility for communication with their family member’s primary care physician and other healthcare providers. One woman noted it had been difficult to get in direct touch with her mother’s physician, but that a hospice nurse’s call had been promptly returned. Another family member shared her understanding of the value of hospice in the moments immediately following an AFH resident’s death: “[Without hospice] it sounds like you have to call the police, they do an investigation and all this paperwork and everything, but it’s not like that if you’re on hospice” (Participant #22142).

Care is Consistent with Residents and Families' Values

Study participants described quality hospice care in the AFH as care that was consistent with their values and the values of their family member. When praising the care his mother received after hospice was initiated, one study participant discussed how his mother had previously been taken to the emergency room multiple times, finding the experience distressful. He described how, after an emergency physician recommended hospice, "[hospice was] actually able to switch the care methods to more of what Mom wanted … It made it a lot easier on everybody" (Participant #12127).

Others discussed challenges ensuring that the care their family member received was consistent with his or her values and goals. For example, one family member recounted the following:

> It was like [the AFH staff] were trying to save her, and my mom was literally dying. I mean, she'd stopped eating and everything, and it was almost like they were trying to force feed her …. [Hospice] worked really hard with me to try to get the AFH to try to understand … our goal for comfort (Participant #12100).

When such challenges arose, it was most often the case that family members and hospice staff favored a more palliative approach than the AFH staff were comfortable providing; however, in a few instances, study participants described feeling uncomfortable with suggestions from hospice. For example, one family member reported that hospice "[was] trying to push some things … that we felt weren't appropriate at that point in time. [They were] like, 'Here, why don't you try some morphine? Why don't you try some Ativan?' And they weren't quite listening" (Participant #22111).

At times, conflicting care philosophies were attributed to cultural differences. This was particularly true when AFH staff were of a different ethnicity than the resident and his or her family member, as was frequently the case in this geographic area. Relatedly, family members identified language barriers as potential challenges in communicating more abstract concepts such as values and goals of care to AFH staff.

Discussion

Family members described quality hospice care in the AFH as care that is consistent with residents and families' values and results in comfort and connectedness for residents while promoting peace of mind and decreasing burden for residents' families. In several ways, these findings mirror studies examining family members' experiences with hospice in nursing home settings.[14–17] For example, the literature suggests key elements of successful hospice and nursing home partnerships include effective collaboration between hospice providers and residence staff,[17] clearly delineated roles and responsibilities for the hospice and nursing home,[15,16] and allowing hospice an additional care oversight role to maximize quality.[14]

In other ways, these findings highlight considerations unique to the provision of hospice in the AFH. Many study participants attributed caregivers' ability to personalize symptom management to the smaller, more intimate AFH setting, where a maximum of six residents received care. They found comfort in their belief that AFH staff genuinely cared for their small group of residents and regarded them as family. In addition, they noted that individual caregivers' attitudes toward end-of-life care carried significant weight in a setting in which there were typically few staff members present at any given time. Study participants repeatedly emphasized that AFH staff members' understanding of and commitment to the plan of care was a necessary component of high-quality hospice care in the AFH. Further, although the homes themselves were licensed by state authorities, AFHs were not necessarily staffed with licensed healthcare providers. This provides important context for family members' sense of comfort at having additional hospice oversight and for their perception that the clinical aspects of end-of-life care, particularly as they relate to medications to manage pain and other symptoms, were improved with the addition of hospice.

For the home care physician, key end-of-life management issues will typically occur outside of routine, scheduled visits. Strategically partnering with hospice allows for the hospice nurse to serve as the “eyes and ears” of the physician to deliver the personalized approach to pain and symptom management that families identify as important. However, because family members are often not present during scheduled physician visits and since the AFH staff are the main source of communication about care options when acute issues arise, the home care physician should educate AFH staff about the benefits hospice can provide in the AFH setting and how to communicate the need for hospice enrollment. The physician can also play a key role in creating a culture of collaboration between the AFH and hospice by communicating with both AFH and hospice staff simultaneously and modelling effective teamwork behavior.

Study Limitations

Numerous study limitations warrant attention. First, data analyzed in this study were provided exclusively from the point of view of residents' family members. The perspectives, experiences, and opinions of AFH staff, hospice providers, and residents themselves were not included, precluding a fully comprehensive exploration of how quality hospice care is achieved in the AFH setting. Second, several study participants contrasted the AFH hospice experience with that of other settings, sometimes without direct experience in the other settings. For example, numerous study participants reported a belief that their family member received care in an AFH that was superior to what they would receive in a traditional nursing home setting; however, only a few had actually experienced the death of a family member in a nursing home, and fewer still had had hospice involvement there. Thus, the accuracy of these comparisons is unknown. Third, the study sample was overwhelmingly homogenous in terms of race. Thus, our findings provide very little insight into the experiences of racial and ethnic minorities. Finally, because this study was a secondary analysis of existing data, it was not possible to elicit feedback from study participants regarding the study findings (a process referred to as “member checking”[18]), introducing the possibility that researchers interpreted the data differently than participants themselves would have.

Conclusion

Study findings suggest that the AFH setting amplifies both the benefits and challenges associated with receipt of hospice. Homes that have effective working relationships with hospices enjoy an “extra set of hands,” a “lifeline,” and expertise regarding pain and symptom management. In these homes, the intimate environment provides a backdrop for rich connections, personalized care, and peace of mind for family members. In contrast, initiating hospice services for a resident in an AFH without a joint commitment to palliation or with a territorial versus collaborative approach to end-of-life care can increase stress for families and exacerbate misunderstandings or feelings of mistrust. Physicians and others providing services to older adults should remain mindful of the advice of experienced family members, who emphasized the importance of finding an AFH with a track record of positive collaborations with hospice agencies if the need for end-of-life care is anticipated.

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Table 1

Participant Characteristics

	No. (%)	
Characteristic	**Family Members (*N* = 73)**	**Residents (*N* = 73)**
Female	53 (72.6)	61 (83.6)
Age, mean (*SD*)	60.7 (9.4)	87.8 (9.5)
Race/ethnicity		
White, non-Hispanic	70 (95.9)	70 (95.9)
Asian American	2 (2.7)	2 (2.7)
African American	1 (1.4)	1 (1.4)
Relationship to resident		
Adult Child	56 (76.7)	
Spouse or Partner	6 (8.2)	
Other Relative or Friend	11 (15.1)	
Resident’s Diagnosis[a]		
Dementia or related illness		39 (53.4)
Cardiovascular disease		13 (17.8)
Cancer		10 (13.7)
Other		7 (9.6)
Unknown		4 (5.5)

[a] Information reflects the resident’s primary terminal diagnosis as reported by the family member.

Table 2

Characteristics of Quality Hospice Care in Adult Family Homes and Related Processes

Characteristics of quality hospice care in AFHs	**Processes that facilitate quality hospice care in AFHs**
Care enhances residents' comfort	AFH and hospice work together to provide personalized management of pain and other distressing symptoms
	Hospice provides high-quality equipment and supplies
Care facilitates residents' connectedness	AFH facilitates socialization with staff and other residents
	Hospice visits have social component, are enjoyable
Care provides families with peace of mind	AFH and hospice share oversight of residents
	Hospice helps AFH with challenging care tasks
	Hospice is a resource for AFH and family during emergencies
	Hospice directly comforts family
	AFH and hospice honor families' preferences regarding communication
	AFH and hospice share an understanding of one another's roles and responsibilities
	AFH and hospice manage conflicts among themselves
Care decreases families' burden	Hospice keeps residents' physicians informed
	Hospice coordinates medication, supplies, equipment
	Hospice removes need for travel to appointments or hospital
Care is consistent with residents and families' values	AFH and hospice staff manage their own beliefs, values, and preferences