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Original Study

Quality Hospice Care in Adult Family Homes: Barriers and Facilitators

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A B S T R A C T

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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 2 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.

Conclusion: The adult family home setting can amplify both the benefits and challenges associated with receipt of hospice. When choosing an adult family home, 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.

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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 6 nonrelated residents at any given time.⁴ In addition to serving fewer residents, AFHs differ from

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traditional nursing homes in that they resemble single-family homes and are located in residential neighborhoods. Furthermore, although 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 health care 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 1 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 elsewhere¹⁰). 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 (K.T.W., G.P.) 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 data set, 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 3 times, analyzing an additional 25% of the data set 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 investigation¹²) after analyzing approximately 75% of the data set, 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 5 themes that summarized family members' descriptions of quality hospice care in

Table 1
Participant Characteristics

Characteristic	No. (%)	
	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)

SD, standard deviation.

^aInformation reflects the resident's primary terminal diagnosis as reported by the family member.

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