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Family Perspectives on the Hospice Experience in Adult Family Homes

Karla T. Washington,

Kent School of Social Work, University of Louisville, Louisville, Kentucky, USA

Debra Parker Oliver,

Curtis W. and Ann H. Long Department of Family and Community Medicine, University of Missouri, Columbia, Missouri, USA

George Demiris,

Department of Biobehavioral Nursing and Health Systems, School of Nursing & Biomedical and Health Informatics, School of Medicine, University of Washington, Seattle, Washington, USA

Elaine Wittenberg-Lyles, and

Department of Communication Studies, University of North Texas, Denton, Texas, USA

Sara Shaunfield

Department of Communication Studies, University of North Texas, Denton, Texas, USA

Abstract

Growing numbers of terminally ill older adults receive hospice services in adult family homes (AFHs); however, little is known about the provision and receipt of end-of-life care in such environments. This paper reports findings from a qualitative exploration of family members' perspectives of the hospice experience in AFHs. Analysis of data obtained during interviews of fifteen residents' family members exposed significant challenges associated with transition to an AFH, highlighted the importance of AFH and hospice staff in family members' assessment of overall quality of care, and emphasized the critical nature of communication in AFH settings.

Keywords

hospices; long-term care; adult family home; family

In recent decades the segment of the population aged 85 and greater has experienced dramatic growth. Demographers predict this trend will continue, resulting in nearly 21 million older adults in this age group by the year 2050. These individuals are more likely than other older adults to have multiple health problems and physical limitations and, therefore, be in need of long-term care (Hooyma & Kiyak, 2008). In the minds of many older adults and their family members, this is equated with the need to transition to a traditional nursing home; other options for frail elders are largely “invisible” (Prosper, 2006).

Despite their relatively low visibility, an increasing number of long-term residential care options exist in communities across the nation. Perhaps the best known are assisted living facilities which provide housing and some personal care services to adults who do not

require 24-hour skilled medical support (Hooymann & Kiyak, 2011). While assisted living facilities vary in size and form, most have between 25 and 120 units and provide living space ranging from a shared single room to a full apartment (Assisted Living Federation of America, n.d.; Zimmerman, Munn, & Koenig, 2006).

Community-based long-term care can also be provided on a smaller scale in private homes. These residences are referred to by a variety of different terms such as adult family homes, adult foster care homes, board and care homes, and group homes (Hendrick et al., 2003; Hooymann & Kiyak, 2011; Prosper, 2006). While facility characteristics and licensing requirements vary state-by-state, these residences are characterized by their efforts to maintain a “family-like” environment for the older adults they serve (Blanchette, 1997). They are typically licensed to provide care to no more than five or six residents at a time (Hooymann & Kiyak, 2011). Adult family homes or similar residences are located in at least thirty states and serve in excess of 64,000 individuals across the country (Mollica et al., 2009).

The state of Washington has the capacity to care for more individuals in adult family homes than any other state in the nation (Mollica et al., 2009). In the 1990’s Washington state lawmakers passed legislation that created a program to promote residential care settings as an alternative to nursing home care. The program’s goal was to create opportunities for individuals to live in settings less restrictive than traditional nursing facilities and to decrease public expenditures on long-term care for older and disabled adults (Berens, 2010; Curtis, Kiyak, & Hendrick, 2000). As a result, the number of publicly-funded nursing home residents decreased nearly 13% in less than two years, while the use of residential care options such as adult family homes (AFHs) increased dramatically (Curtis, et al., 2000).

Washington state law defines an adult family home as “a residential home in which a person or an entity is licensed to provide personal care, special care, room, and board to more than one but not more than six adults who are not related by blood or marriage to a licensed operator, resident manager, or caregiver, who resides in the home” (Washington Administrative Code Section 388-76-10000). Although AFHs are significantly less regulated than nursing home facilities, state minimum licensing requirements indicate that all AFH providers must “have the understanding, ability, emotional stability and physical health necessary” to meet the needs of vulnerable adults (Washington Administrative Code Section 388-76-10020). As of January 2010, there were 2,843 AFHs licensed in the state of Washington providing services to approximately 11,200 residents (Berens, 2010). To emphasize the significant presence of AFHs, a recent report noted that AFHs had become “more plentiful than Starbucks” in the Seattle area (Berens, 2010).

Research suggests that, when compared with similar settings such as assisted living and adult residential care facilities, AFHs serve a significantly more impaired population (Curtis, et al., 2000; Hendrick, Sullivan, Sales, & Gray, 2009). As their illnesses progress and they near the end of life, residents of AFHs are often eligible to receive services from a hospice provider. Unlike models of care designed to cure illness and prolong life, hospice care focuses on controlling pain and discomfort associated with disease and enhancing patients’ and families’ quality of life. As such, hospice providers work to ensure that patients experience a death that is as comfortable as possible and that patients’ family members and friends are supported during and after the dying process (National Hospice and Palliative Care Organization, 2009). As core members of hospice interdisciplinary teams, social workers are integral to efforts to provide this support (Christ & Sormanti, 2000).

In addition to its role in hospice care, gerontological social work has an extensive history of involvement in the provision of long-term care in the United States, including care provided

in residential settings other than traditional nursing homes (Kane, 2006; Prosper, 2006; Zimmerman, et al., 2006). While comprehensive social work services are not commonly provided as a routine part of non-nursing home residential care, advanced social work skills are often required for professionals assisting older adults and their family members grappling with decisions about transitioning to a new residential environment. Further, in some states social workers are employed as care managers responsible for coordinating services for older adults in group residential settings (Kane, 2006).

The majority of all US hospice patients receive care in their place of residence, most in either a private residence (40.7%) or nursing home (22.0%); however, a small but growing number of hospice patients (6.1%) receive services in a residential facility such as an AFH (National Hospice and Palliative Care Organization, 2009). In such cases, residential facility providers retain responsibility for the day-to-day care of the resident, much as a family member or friend would for a terminally ill loved one receiving hospice services in a private residence. Hospice providers conduct regular visits to evaluate the patient, adjust pain and symptom management approaches as needed, and provide support to the resident and his or her caregivers and family members. While a substantial body of research exists with regard to end-of-life care in more traditional long-term care facilities (Casarett et al., 2005; Keay & Schonwetter, 1998; Miller & Mor, 2002; Oliver, Porock, & Zweig, 2004; Teno et al., 2004), very little is known about the provision and receipt of hospice services in AFHs. The purpose of this study was to address that knowledge deficit and provide a greater understanding of the hospice experience in AFHs.

Methods

Background of the Authors and Motivation for the Study

The authors' work was informed by a pilot equivalence clinical trial funded by the National Institute of Nursing Research (NINR) which explored the provision of problem solving therapy to informal hospice caregivers (*i.e.*, family members and friends who provide unpaid support to a hospice patient). Although data collection occurred solely in the Seattle, Washington area, members of the research team were affiliated with academic institutions across the US, including four different states in geographically distinct areas. During regularly scheduled teleconferences concerning the NINR project, researchers from outside of the state of Washington were intrigued by the concept of AFHs since, to the best of their knowledge, such arrangements were unavailable or infrequently utilized in their communities. After a literature search generated remarkably few studies about AFHs and none specifically about the provision of hospice care in AFHs, researchers decided to invite participants in the existing study who had family members in AFHs to discuss their experiences as part of their regularly scheduled exit interview.

Sampling, Data Collection, and Analysis

Purposive sampling was used to select family members of AFH residents from a larger pool of 126 individuals participating in a pilot equivalence clinical trial funded by the National Institute of Nursing Research (R21 NR010744) (Demiris et al., in press). All clinical trial participants who indicated that their family member was receiving hospice services in an AFH were invited to take part in a study specifically exploring family members' perspectives of end-of-life care in AFH settings. Additional inclusion criteria required that participants be at least 18 years old, without functional hearing loss, with limited or no cognitive impairment, and with at least a sixth grade education. All individuals meeting the inclusion criteria, all of whom were already actively participating in the larger clinical trial, agreed to participate in the study of AFHs. Prior to recruitment of study participants, approval of the Institutional Review Board of the principal investigator's university was

granted for the larger clinical trial also covering the analysis of the smaller study described herein.

Researchers conducted semi-structured interviews with consenting family members of AFH hospice patients. All interviews were audio-recorded and imported into NVivo 8 qualitative data analysis software. Interviews were transcribed within NVivo 8 by a member of the research team. During this process, all identifying information was eliminated from transcription and a unique pseudonym was assigned to each participant to ensure confidentiality of the study material. Prior to analysis, a second researcher verified the transcription by simultaneously listening to the original audio recordings of the interviews and reading the corresponding transcribed content.

Once interviews were transcribed, researchers met to establish an initial coding frame based on the data's manifest content. Graneheim and Lundman (2004) define *manifest content* as the data's "visible, obvious components" and contrast it with latent content which pertains to the underlying meaning of the data. Afterward, two members of the research team individually coded identical sections of data according to conventional content analysis procedures (Hsieh & Shannon, 2005; Miles & Huberman, 1994). When approximately 20% of the transcribed content had been dually coded, intercoder reliability was calculated and determined to meet or exceed .80 for all established codes. After that point, researchers independently completed initial coding of the remaining data. Related codes were then grouped into core categories.

Findings

The final study sample consisted of 15 family members of patients receiving hospice services in the Greater Seattle area. All had graduated from high school, and over half had earned a bachelor's degree. Participant ages ranged from 36 to 89 years with an average age of 59. Most ($n = 13$) were women. All self-identified as non-Hispanic Caucasian. Participants' family members were receiving hospice services related to a variety of diagnoses including Alzheimer's disease or other dementia ($n = 7$), congestive heart failure ($n = 3$), Parkinson's disease ($n = 2$), and renal failure ($n = 2$). One participant was unsure of her husband's specific diagnosis but noted that he suffered from a number of serious health conditions including quadriplegia. Hospice patients' ages ranged from 66 to 97 years, with an average age of 85. Study participants included hospice patients' adult children ($n = 8$), spouses or partners ($n = 3$), adult grandchildren ($n = 2$), siblings ($n = 1$), and children-in-law ($n = 1$).

Family members' discussions of the hospice experience in AFHs were sorted into three core categories: transitioning to the AFH, quality of care, and communication. A full discussion of these categories is provided below. Where references to specific participants are made, pseudonyms are used in place of actual names.

Transitioning to the AFH

All study participants discussed their family member's move to an AFH, describing it as an emotional transition or the result of practical considerations. A number of participants described AFH care placement as an emotional decision. Many told stories similar to June who struggled with her decision to place her husband in AFH after years spent caring for him at home. Eventually, June was unable to provide the continuous care her husband's advanced dementia required: "It just got too bad. I never thought it could get that bad. I thought I would be able to take care of him until he died." She continued, "I wanted him to go, I needed him to go." Lisa, the daughter of 90 year-old woman with Alzheimer's disease,

also found it emotionally difficult to cope with her loved one's move to an AFH: "I just felt like someone else had total control over her."

Both June and Lisa eventually came to terms with their family member's move. In June's case, her emotional reservations were ultimately replaced by a sense of relief: "In the beginning, I was really ... overwhelmed Now he's up here in that wonderful place, and I don't have to worry at all about it That is the main [reason] for calmness for me." Lisa took a more active role to proceed with her emotional adjustment. She began visiting her mother at the AFH during meal times so she could feed her and, in turn, feel connected to her care: "I ... felt like ... I was just left out, so feeding helps."

Family members also discussed a variety of practical issues that needed to be addressed during their family member's move to an AFH; however, the most frequently cited issues related to the sheer volume of AFHs from which they had to choose. Bill discussed at great length the process of selecting an AFH for his mother, which involved choosing one home out of "several hundred" possibilities. Because he planned to visit his mother frequently, proximity to his home was the first criterion he established for making the selection. He described being surprised to learn that there were "two hundred some within [a] ten mile radius" of his home. Carolyn, the daughter of an 80-year old man with Parkinson's disease, discussed feeling "discouraged" during her search for a home that would meet her father's needs: "You can see all kinds of houses out there, and a lot of them were ... you know, I wouldn't want to put my parent into one of them." She eventually found two she liked after visiting "a dozen, two dozen homes."

Faced with an overwhelming number of AFHs from which to choose, some family members worked with an individual whose job it was to help them in their search. While none of the family members in the study provided an official title for this position, data segments describing someone in this position were labeled "broker." Family members described brokers in similar ways. One stated, "It's almost like a real estate agent. You know, you hop in her car, and she drives to six [AFHs]." Jane, whose father was experiencing congestive heart failure, recommended that family members use "people that assist you in finding a place" rather than independently conducting a search. Every family member who had utilized a broker during their search expressed satisfaction with the service. Bill described how his broker helped him find a home that would fit his mother's needs: "She talked to my mother, she sort of thinks about the people that are already [at the AFHs] ... what level of mental functioning they are at." He reported that his broker was able to help him select a home in which his mother's housemates would be "kind of in the same ballpark" as his mother.

Like the majority of study participants, Bill ultimately viewed the transition to an AFH as beneficial for a number of practical reasons. As a full-time employee with numerous work-related demands, he discussed being especially appreciative of the AFH's ability to work with members of the hospice team to handle emergencies: "I just get a call that says 'your mother is this or that and we've called the hospice nurse,' but it doesn't create this whole 'I need to leave [work]' thing." Similarly, Jane expressed her gratitude at having been relieved of providing 24-hour care for her father: "Not having to be there full time is just such a gift, honestly." Maureen, who had previously been responsible for not only her terminally ill father but also other members of her family, discussed the flexibility she gained after her father moved to an AFH.

I told my brother ... "Now that I don't have to always be here for dad, now I can actually drop things and go to the grocery store for you in the middle of the week instead of having to plan everything around doing it one certain time."

For these family members, working through the challenges and stressors they faced early on in their loved one's transition to an AFH proved worth their efforts, as they eventually enjoyed numerous benefits associated with the new arrangement.

Quality of Care

Family members indicated that their loved one was receiving high quality care as a hospice patient in an AFH as a result of good, quality staff. Brenda, whose 97 year-old grandmother was diagnosed with congestive heart failure, succinctly summarized her opinion of her grandmother's AFH: "I know that she's getting good care there." Carolyn felt similarly about her father's home. With regard to the AFH staff, she stated, "They have exceeded my expectations." She continued, "The caregivers I feel that he's got now ... are an extension of my family. They do for him what I would do if I could do it." Jane also had positive things to say about the staff at her father's AFH: "They are phenomenal. I am very, very pleased with them." In one instance a family member voiced dissatisfaction with care, but was still reluctant to move her loved one. She stated, "They're not perfect but, on the other hand, if we took her someplace else ... it might be even worse."

A number of study participants discussed ways they felt hospice enhanced the quality of care their loved one received. For example, Melinda's grandmother had developed pressure ulcers that were being treated by her AFH caregivers. Melinda believed the AFH staff were able to be more responsive as a result of the hospice nurses' direction.

[Hospice nurses] pretty rapidly progressed the type of dressing change they were doing ... and [they were] teaching the people at the home about pressure relief and changing the rules about how long she could be up. So, I felt like it was much more proactive because we had hospice in place.

Melinda also noticed that hospice was able to arrange for her grandmother's medical equipment more readily than she had been able to without their involvement.

All of a sudden she couldn't transfer and her mobility just dramatically dropped and within 24 hours there was a wheelchair in her room ... [Later] her skin breakdown was progressing, and within 24 hours [of the time] they decided it, there was a hospital bed in place.

Melinda also made a comment reflecting an opinion voiced by other participants: "I think having someone on the outside look at [my grandmother] ... every week is a really nice tool." Ruth, whose brother was receiving hospice services in an AFH, had a similar observation. She stated, "[Hospice's involvement] gives me a level of reassurance that he is being check out and that we're doing the best we can." Although she thought her brother was receiving quality care before he began receiving hospice services, she said, "I'm glad hospice is involved because I think it's even better just to have some other eyes to watch."

AFH caregivers were praised for providing high quality care. Satisfaction with quality of care was often voiced by individuals who made comments such as "[Staff members] provide all kinds of stimulation and ... they're forever asking [the resident] 'Who am I?' so [the resident] remembers who the people who care for him are." Another woman stated, "[My mother] loves the staff. Every time they walk by, she wants them to come and hold her hand or kiss her or just give her some attention."

Although satisfied with their loved one's care and the AFH staff, several family members indicated that staff-resident interactions in AFHs could be complicated by cultural differences between the staff and residents. The most commonly discussed differences pertained to race and ethnicity. One family member described racial/ethnic patterns he observed when searching for his mother's AFH: "A little known fact is north of I-90 they're

almost all Romanian ... south of I-90 [they are] Phillipino.” Ruth’s brother lived in an AFH run by an Ethiopian family. She discussed language barriers she observed between residents and staff members.

When they’re not Americans ... communication is the biggest thing. They’re very nice people, but I know that they just can’t understand [my brother]. Sometimes I’ll listen to [staff members] talking to the other [residents], and I’ll finally just say the word [they’re trying to say] from an American, and then they’ll understand.

Maureen’s father had a similar experience: “[He said], ‘I can’t understand any of those Iranians,’ and I went, ‘They’re Romanians, not Iranians.’” Intercultural interactions were not limited to communication issues but also included cultural differences around day-to-day issues such as cooking. One participant shared her father’s opinion that, “These [staff members] don’t even know how to cook. I can’t get a fried egg for the life of me.”

In addition to racial/ethnic differences, some residents differed from their AFH caregivers with regard to religion and spirituality. While such differences were either not discussed or were mentioned as an aside by most study participants, it was a particularly salient issue for Jane, whose dying father had elected to exercise his rights provided under the recently-enacted Washington Death with Dignity Act (Revised Code of Washington Chapter 70.245), which allows terminally ill adults to request and self-administer lethal medications prescribed by a physician. She discussed her early conversations with the AFH about her father’s wishes.

“I said, ‘Dad’s just determined to go ahead with this death with dignity, and [the AFH caregiver] just kind of looked at me, and she didn’t make any judgment-type things, but she said ‘Is he eligible for that?’ and I said, ‘Yes.’ And she goes, ‘I thought it was for people that had intractable pain,’ and I said ‘His pain isn’t really physical as [much as] it is emotional ...’ She said, ‘Are you and [your family] okay with this?’ and I said, ‘Well, it’s the man’s right and it’s his choice. It wouldn’t be the choice we’d have [made] for him, but we have to respect that.’”

As of the time of her interview, Jane was unsure how her father’s AFH caregivers would feel about her father ending his life in their home: “I don’t know if [Dad’s AFH caregiver] would want ... I mean, her husband’s a minister The option there would be to take Dad to his condo which is right down the street, and he could self-administer there.”

Communication Outside of the AFH

Family members highlighted the importance of formal communication, especially given their involvement in a unique communication triad (family member, AFH, and hospice). Without exception, all family members emphasized the importance of providing and receiving information about their loved one’s care. The most common communication pattern described was one in which the AFH caregivers coordinated care with the hospice agency and were the primary communicators with family members with direct hospice-family communication occurring on a less frequent basis. For example, caregivers made statements such as “the AFH caregiver’s a nurse herself, so she communicates with the hospice and then [she and I] talk back and forth” or “[the AFH caregivers] just call the hospice nurse and I get a call [from the AFH].”

Encountering communication triads was new for both Ruth and Jane who had earlier experiences with hospice in settings other than AFHs. Ruth, who had previously utilized hospice services when caring for both her dying parents in a private home setting, found the AFH experience to be different: “Maybe the difference is that, in the AFH, [hospice] deals with the [AFH] caregiver rather than me with my parents, I was the one that they dealt with it was just a little more personal.” Jane also noticed a difference in

communication when her loved one entered an AFH: “Previously, when [my father] was in the condo, [hospice] spoke directly to me, and they would make it a point to call me. Since he’s gone to the home ... [the AFH caregiver] is right there when the [hospice] nurse comes, and she works with them in regards to anything they do.”

Sheila, the study participant most vocal about needed improvements in the provision of hospice services to AFH residents, discussed problems related to communication triads: “I just hear different things from different people.” To illustrate her point, she described a situation in which the hospice nurse informed her that she would no longer need to purchase topical cream used to protect her mother’s skin from irritation due to wearing adult incontinence briefs. She reported that she later received a receipt from the AFH caregivers seeking reimbursement for the cream they had purchased after being dissatisfied with the brand provided by hospice. Sheila indicated that the AFH caregiver had said, “Oh, no. I talked to [hospice]. That stuff is no good ... it wasn’t the right consistency.” Sheila continued, “So that was ... poor communication. I had a brand new jar at home that I could have used, but nobody contacted me about that.”

The informal nature of AFHs sometimes created challenges when the need arose for formal communication. Carolyn described how problematic family dynamics led to the need for a family member to be denied access to her father. She stated, “My dad’s stepdaughter was constantly coming in, trying to get him to sign papers She came in and supposedly had him sign this thing for Social Security she got his check for about four months.” Because her father’s AFH had no experience with this type of situation, the AFH providers had no formal mechanism in place for establishing who could visit residents: “I had to work with [the AFH owners] to ... create a document ... so that [they had] a basis for denying her access, or access to certain things.” In Bill’s case, documentation from the AFH was needed to formally communicate with other entities about his mother’s care. In particular, he described challenges he faced with an insurance company: “There’s just sort of an ongoing stream of talking to a long-term care insurance [company]. You know, they don’t like the forms that the AFH submitted. They want them somewhat differently, [so] you’ve got to resubmit those.” Although many family members praised AFHs for being unlike institutions, lack of the formal communication mechanisms that would be present in more established organizations created challenges for these two families.

Discussion

Research into the care received by residents of AFHs is scarce, and this is the first study of its kind to specifically explore the intersection of hospice services and AFH care. Consequently, the study findings’ implications for gerontological social workers and other health care professionals are numerous.

With regard to the transition to AFHs, the emotional aspects of family members closely mirror those of individuals pursuing nursing home placement for a loved one. Similar to the participants described above, family members of nursing home residents describe the transition to out-of-home placement as emotionally difficult and often indicate that it was considered an option of last resort (Ryan & Scullion, 2000). Gerontological social workers and other members of health care teams need to be sensitive to such concerns and acknowledge that, although AFHs are often advertised as attractive alternatives to institutional care, family members may be emotionally conflicted about AFH placements. Data suggest that family involvement in the day-to-day activities of the AFH may help counter negative feelings, as was the case for Lisa who viewed feeding her mother as a way to remain emotionally connected. Gerontological social workers can be instrumental in

encouraging family involvement in AFHs and other residential care settings and may be needed to facilitate inclusive opportunities.

From a practical perspective, however, it appears that AFH placements may present unique challenges to family members who feel overwhelmed by the hundreds or thousands of options available to them. Data from this study suggest that the services of individuals who coordinate AFH placements are highly valued by families. Much of what little has been published about senior placement services and the AFH industry, however, has been cautionary. While data collection related to the present study was underway, *The Seattle Times*, the largest daily newspaper in the state of Washington, published a series of articles investigating abuses and exploitation of older adults in Washington's AFHs. One article featured the heading *Placement agencies: Conflicts of interest?* and described scenarios in which senior placement agencies could earn commissions typically ranging "from \$2,000 to \$7,000" per resident (Berens, 2010). The article posed the following question: "Are placement agencies steering people to homes that are the best fit - or instead to the ones that pay the highest referral fees?" The report's author concluded, "There is no way to know for certain." While investigative journalism undoubtedly differs from empirical research, health care providers working with older adults and their families should keep abreast of research concerning AFH placement of older adults. This issue and the obvious ethical considerations surrounding it are of critical importance to gerontological social workers who are often involved in helping older adults and their family members make decisions concerning residential care options (Kane, 2006). Social workers are ethically bound to prioritize service, integrity, and appreciation for human worth over personal gain (National Association of Social Workers, 1999); clearly, participation in inappropriate referrals for financial benefit constitutes unethical social work practice. Related social policy recommendations include regulation of placement providers and agencies, rules governing commissions, and required training for placement coordinators. It must be noted, however, that data resulting from the present study do not indicate that placement coordinators accepted commission for their services or, if they did, that residents' family members were aware of such compensation.

With regard to quality of care, study participants were overwhelmingly positive about the services their family members received. Given that AFH research is in its infancy, it is not possible to compare findings from this study to other, more representative samples. Certainly non-academic reports, such as the aforementioned *Seattle Times* series, suggest that poor quality of care is provided in some AFH settings and call for additional oversight and regulation by state agencies. However, as data from this study illustrates, the informal, homelike atmosphere of AFHs is attractive to individuals seeking alternatives to heavily-regulated traditional nursing homes. Therein lies a common political dilemma: What is the right balance between regulation and support of innovation? Some study participants indicated that establishment of more formalized communication mechanisms would be helpful, although in most instances family members were mostly satisfied with the information they received about their loved one's care.

Independent of discussions regarding the ideal degree of government oversight of AFHs, study findings suggest the need for enforcement of existing policies. State regulations require that AFH caregivers be able to communicate with residents in their primary language or make provisions to ensure such communication is possible (Washington Administrative Code Section 388-76-10135). Study participants, such as Ruth and Maureen, provided data indicating that language barriers sometimes prevented effective staff-resident interactions and may have negatively influenced perceptions of care quality.

Findings from the present study indicate that hospice may be a valuable resource for AFHs providing services to terminally ill residents. Unlike AFHs which are, at least at the time of this writing, governed by relatively few external regulations, nearly all hospice services in the US are provided by agencies subject to Medicare Conditions of Participation (United States Department of Health and Human Services, 2008) and other state and federal rules and regulations. Further, hospice agencies are experienced at collaborating with informal caregivers; over 40% of the services they provide are to individuals in private residences being cared for by unpaid family members or friends (National Hospice and Palliative Care Organization, 2009). Study participants discussed this hospice benefit in terms of having “other eyes” to oversee their loved one’s care and described hospice as “a really nice tool” to ensure care quality.

Adding to the potential benefit of hospice for AFH residents is the reality that comprehensive social work services are not routinely provided to individuals living in non-nursing home residential group settings (Kane, 2006). As the data from this study demonstrate, residents of AFHs and their families face many of the same issues as individuals living in nursing homes, such as coping with emotional challenges associated with transitioning to a new environment and ensuring quality of care. If alternative living arrangements such as AFHs are in fact the wave of the future, as some suggest may be the case (Hooyman & Kiyak, 2011; Kane, 2006), many older adults may struggle to access necessary social services in years to come. For terminally ill AFH residents, hospice social workers will be available to meet those needs.

Social workers must remain mindful of the potential challenges associated with communication triads that often arise among hospice providers, AFH caregivers, and family members. They can be instrumental in facilitating discussions in which all involved parties work together to develop a satisfactory communication plan and may be called upon to assist with problem solving around communication issues. Care must be taken to ensure that hospice social workers reach out to family members of AFH residents who may not be physically present at the AFH during hospice visits which occur more frequently during daytime business hours. This, as Ruth indicated during her interview, may lead to family members have a “more personal” connection with the hospice team. This situation is undoubtedly not unique to AFHs. Challenges coordinating effective communication among multiple providers and families are common when individuals receive hospice care in traditional nursing home settings (Oliver, et al., 2004). Innovative strategies may be required to facilitate effective communication with numerous providers and family members. Use of telehealth technologies (*i.e.*, videoconferencing) has been shown to be a promising method to include family members in discussions about their loved one’s hospice care (Parker Oliver, Washington, Wittenberg-Lyles, Demiris, & Porock, 2009). Use of similar technologies to include residential care providers along with family members seems a logical extension of such approaches.

Study strengths and limitations

There are numerous strengths and limitations to the present study that warrant attention. Because very little is known about the hospice experience in AFHs, researchers approached the present study in a purely exploratory manner. Rather than establishing and testing hypotheses as is typically done in quantitative studies, researchers allowed data categories to emerge from participants’ accounts of their own experiences. As such, the goal of the study was not to secure a representative sample. The reader is encouraged to remain mindful of the fact that the experiences of the participants included in the present study may not accurately reflect the experiences of other, or even most, family members of hospice patients in AFHs. Additional research is needed to determine if the categories identified in this study are salient components of the hospice experience in AFHs for a larger, more representative

sample of family members. This is particularly important since family members participating in the present study were limited in their ability to provide a detailed description of the AFH in which their loved one resided. Certain contextual details unknown to family members (*e.g.*, resident and staff characteristics, AFH size, involvement of health professionals, etc.) undoubtedly differ among AFHs in the region and likely impact the hospice experience in such settings. In addition, future research should seek to explore the hospice/AFH intersection from the perspective of other key stakeholders including AFH owners and caregivers, hospice providers, and – perhaps most importantly – residents themselves.

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