Hospice in Assisted Living: Promoting Good Quality Care at End of Life

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Purpose: The purpose of this study was to describe good quality care at the end of life (EOL) for hospice-enrolled residents in assisted living facilities (ALFs). Design and Methods: A qualitative descriptive design was used to obtain detailed descriptions of EOL care provided by ALF medication aides, caregivers, nurses, and hospice nurses in urban and rural settings. A semistructured interview guide facilitated interviews where 38 participants described specific examples of care that “went well.” Results: Findings indicated that the quality and nature of resident–staff and assisted living–hospice staff relationships are critical in promoting good care at EOL for ALF residents on hospice. Length of the resident’s stay in the facility and how well staff knew the resident were associated with the quality of the resident–staff relationship. Respectful collaboration, clear communication, use of complementary knowledge and skills of staff, and shared expectations about the care were associated with positive staff relationships. Also important was ALF administrator support for residents’ dying in place with hospice services. Implications: ALFs choosing to support residents dying in place with hospice services. Key Words: Residential care, Hospice, End-of-life care

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intensive and can take time away from the needs of other residents. Some staff members have little experience with death and are unsure about what to expect or do when a resident is dying (Cartwright & Kayser-Jones). Hospice staff report difficulty in communicating with ALF care providers who do not understand disease processes and symptom management (Dixon et al., 2002). Lack of ALF staff knowledge regarding end-of-life (EOL) care has been reported as has hospice RNs’ frustration with the lack of documentation of symptoms between hospice RN visits (Cartwright & Kayser-Jones; Zimmerman et al., 2003). Families identify problems with coordination of services between hospices and ALFs, and confusion regarding limitations in available services at the ALF (Cartwright, Hickman, Perrin, & Tilden, 2006). Residents express concerns about pain management, availability of staff to check on them, and staff competencies to help with personal care (Cartwright & Kayser-Jones). Yet, Dixon and colleagues report that ALF and hospice administrators believe that the opportunities for adapting hospice care to ALFs are important enough to work through the challenges.

In Oregon, where the modern concept of assisted living was developed and the first ALF built over 25 years ago, ALFs have become an important component of hospice caseloads. In 2006, more than 27% of hospice patients in Oregon died in residential care settings, which includes ALFs (Oregon Hospice Association, 2006). Both ALFs and hospices have had to develop systems and procedures for caring for this population and for delineating the responsibilities of each respective organization. The learning curve has been steep, and much has been discovered through trial and error. Despite the challenges identified previously, anecdotal reports suggest that care of dying ALF residents with hospice support can result in good quality dying experiences for all involved—the dying person, family members, ALF staff, and hospice staff. Missing is a systematic exploration of the systems, procedures, and working relationships that promote a high-quality dying experience. Such information would inform the conversation about aging in place, as well as the conditions necessary to achieve the highly valued goal of many ALF residents to die in their ALF home.

Recognizing that fragmented systems of care are both common and problematic at EOL (Lorenz et al., 2004), the National Consensus Panel (NCP) for Quality Palliative Care developed quality practice guidelines for care at EOL (Ferrell et al., 2007). Significantly, these guidelines are designed for use with a wide range of terminal conditions and care settings (Ferrell et al.). The goals of the NCP guidelines related to comfort and symptom management, communication, and continuity of care provide a framework for examining how staff from two different organizations provide EOL care in ALF.

We conducted a study of EOL care delivery for ALF residents who were enrolled in a hospice program by interviewing ALF staff and hospice RNs about their experiences when the care “went well.” We focused on these caregivers (CGs) because they are most likely to know about the actual practices, activities, and interactions that happen when care is provided to hospice-enrolled residents in the ALF setting. This paper presents the themes developed from these interviews and describes factors that ALF and hospice care providers consider important for providing good EOL care.

**Methods**

We used a qualitative descriptive design to obtain detailed contextual descriptions of EOL care for ALF residents who had been referred to hospice. Following Institutional Board approval for the study from the Oregon Health & Science University, participants were recruited from five ALFs and five hospice programs throughout Oregon. We used a purposive sampling strategy to locate ALF registered staff representing different roles and hospice RNs who had at least three prior experiences providing EOL care to ALF residents. Participants included ALF registered nurses (ALF RNs), ALF medication aides (MAs) and CG, and hospice RNs. In-person interviews were conducted at a time and in a private place of convenience for the participant following signed informed consent for participation.

**Research Setting**

The study was conducted in Oregon, where half of the licensed ALFs are in rural settings and the majority are for profit. Thirty-nine percent of residents receive Medicaid waiver funding (Berkobien, 2006). ALF staff were recruited from five ALFs, two in rural settings and three in urban areas. These settings were representative of Oregon’s 186 ALFs in terms of urban versus rural locations, payment mechanism, ownership, and profit status. Four facilities were for profit and managed by regional or national companies. Three ALFs accepted
residents with Medicaid waiver funds and two accepted only private-pay residents. Capacities ranged from 52 to 159 beds. Hospice RNs were recruited from one or more hospices in the same geographical areas as the ALFs. All the hospices provided services to at least one of the ALFs, and were nonprofit agencies, reflecting the majority of Oregon’s 59 hospice programs. Daily censuses ranged from 35 to 260 patients.

Data Collection
A semistructured interview guide started with broad questions asking the participants to discuss a specific example of a time when the EOL care “went well.” Increasingly, specific questions were used to elicit detailed descriptions of the care; how staff from two organizations communicate and work together; and specific information about decision making, resident monitoring, symptom management, comfort care, and family involvement. Participants were asked to identify ways that the care for ALF hospice residents could be improved. Recruitment was discontinued when no new themes about the care experiences were identified. The interviews were audiotaped and ranged in length from 1 to 2 hr.

Data Management and Analysis
Interviews were transcribed verbatim and entered into NVivo Version 7.0 software to facilitate analysis. Using open-coding and constant comparative analysis, two investigators and a doctoral student research assistant read and compared the interview transcripts and associated field notes for common themes and unique variations. The data were analyzed using qualitative content description that focused on the nature of care provided and by whom; how the care was delivered; and how participants interacted with the resident, family members, other paid care staff, and with each other. Regularly scheduled discussions and exchanges of meeting notes and theoretical memos enabled the team to achieve consensus on what were considered good and not good care experiences, associated factors, and exemplar cases.

Verification that the analysis represents the data occurred via (a) audiotaping the interviews; (b) individually reviewing and coding of all transcripts by each member of the investigative team; and (c) ongoing investigator meetings to discuss the analyses, debate differences in interpretations, and reach consensus regarding the findings. Field notes, meeting minutes, a codebook with definitions, ongoing conceptual and theoretical memos, and exemplar cases document the descriptive findings.

Sample
Participants included 18 hospice RNs, 6 ALF RNs, 9 MAs, and 5 CGs who provided personal care to residents. All had numerous experiences with hospice deaths in an ALF. The participants’ ages, tenure in their work, and ethnicity by role are provided in Table 1.

Findings
Examples of high-quality dying experiences included situations where the dying process was relatively brief and also those that occurred over extended periods of time. Two themes were consistently associated with care that went well: high ALF staff commitment to the resident dying in the ALF and respectful collaboration among multiple care providers. Factors associated with these conditions included (a) administrator support for hospice and for residents dying in the ALF setting, (b) high levels of knowledge and positive beliefs about providing EOL care in ALF, and (c) consistent staffing patterns for hospice RNs and ALF staff. Outcomes of the care experiences encompassed beliefs that the resident was comfortable at the EOL and their wishes were honored, and feeling good about how self and others had participated in the care. The findings reported subsequently represent the combined perceptions of the ALF and hospice participants in describing how care went well.

ALF Staff Commitment to the Resident
In their stories of ALF residents whose dying went well, participants described people with complex dying trajectories (e.g., cardiac disease and
end-stage dementia) and a range of comorbidities, functional abilities, care needs, and levels of family involvement. These factors, however, were not necessarily associated with a positive care experience or whether the dying person could stay in the ALF until death. Rather, if an ALF was committed to providing EOL care to a particular resident, the staff went far above and beyond the usual level of care provided to other residents or described in their policies. The ALFs provided much complex care such as assistance with all activities of daily living, increased monitoring of symptoms, rapid and frequent changes in medications, skin care, mouth care, and emotional support. Two factors, the length of time the resident had lived in the ALF and whether they were well liked by the staff, were consistently associated with whether the ALF would support the resident’s staying in the ALF as levels of care need increased. The more ALF staff knew the resident and liked them, the more likely they were to bend rules or go “above and beyond” in trying to facilitate dying in the ALF.

I don’t know how it happens with some and it doesn’t with others, but with her there were people who bonded with her and they treated her like family... They were willing to step up and they provided really the best care she could possibly get. (ALF RN)

[ALF staff] said “we don’t normally do this level of care, but she has been a resident here so long; we want to keep her here and we will take care of her. We will do that.” (Hospice RN)

Almost all participants recalled experiences where, because of a long-standing relationship, the ALF staff felt close to the dying resident as if they were family. This closeness was an important factor in the level of care provided as well as whether the dying person could remain in the ALF until death.

Respectful Collaboration

Consistently, care that went well reflected respectful collaboration by staff within and between organizations (ALF and hospice) and, when present, the family members. Descriptions of these relationships included “[Hospice RN] respects our views” (MA), “I don’t go in as the boss” (hospice RN). CGs and MAs noted that working together as a team was essential to meet the increasing needs of a dying resident as well as other residents. “You work as a team because if one can’t get there, the other one can... so it’s always a team effort for any of that” (CG). Collaboration strengthened the care:

They were really helpful because they could tell me things that I wouldn’t see just dropping in for a half an hour. That meant we could be really proactive about some things, not let them slide into crisis management. (Hospice RN)

Several hospice and ALF RNs indicated that development of relationships occurred gradually and that the quality of collaboration had improved over time.

Communication was an essential part of collaboration, and participants described the tone of the message as critical.

[ALF staff] didn’t feel like, “you’re questioning our authority or our territory.” It was much more collaborative—a friendly “Hi, what’s going on with Mrs. X today” and we’d sit down and talk about it and it was like, we are a team. (Hospice RN)

Methods for communicating were primarily in person or by phone. However, the ALFs’ routine communication systems including medication records, resident charts, and message boards were consistently used by ALF and hospice staff. Both ALF and hospice RNs noted that communication strategies were facility specific: “It’s just individualizing [communication] per facility, each facility is different” (hospice RN). The effectiveness of seemingly informal communication systems was illustrated by an ALF caregiver:

[Hospice RN] is always good at telling our nurse or the med aide any concerns or anything she’s done to the patient. If we all needed to know, they always post a note on the bulletin board... If the patient needed something in hospice we would always leave a note for [ALF RN] or the med aide... so the word could get around. So, communication with them was pretty good. (CG)

Hospice RNs noted that communication with ALF staff was more frequent and time consuming than in other settings, yet paid off in terms of the quality of the care experience:

At first there were a lot of interruptions to my day when I started working with assisted living... but then I realized these are really quick calls and they need to be affirmed that they’re doing the right thing. (Hospice RN)

Respectful collaboration made use of the complementary knowledge and skills that different providers brought to the care experience. ALF staff contributed insights about resident preferences and
behaviors, and hospice RNs valued this specific knowledge:

They’ll say “she’s getting weaker; it took two of us to transfer her yesterday.” [Caregivers and medication aides] are pretty accurate. She’d been there quite a long time. They were used to her and knew when she was agitated, angry, or moving about in the bed, that she was in pain. (Hospice RN)

The staff abilities to detect subtle and significant changes in behaviors or activity patterns were particularly critical when residents had limited verbal skills or advanced dementia.

Hospice RNs had expertise in symptom management, anticipating situations specific to the cause of death or comorbidities, and obtaining external resources including other personnel (e.g., bath aides) and equipment (e.g., hospital bed). Hospice RNs used their knowledge of commonly encountered symptoms to help ALF staff respond to potential problems. ALF staff praised hospice RNs’ guidance and support:

She’s very nice, easy to talk to and very comforting when you’re having a problem. You can go to her. She will listen to anything you have to say. She explains the process of dying very, very well. (CG)

When the care went well, ALF RNs played a critical role as liaisons for the ALF staff, hospice RN, and families. Hospice RNs reported that the ALF RN knew how to “make things happen” in the ALF: “The main thing that stands out between a good and bad experience is the support and guidance the staff has. They have very little training and they don’t have a lot of experience” [hospice RN].

ALF staff described how the ALF RN helped them understand why and how some treatments (e.g., opioids) were used, acknowledged staff members’ grief after a resident died, and praised the staff for their care:

Our nurse said that when they’re on hospice they’re expected to go at anytime and for us not to feel guilty about anything. They know that we were trying to do our best, that it was okay and just to think of it that she’s in a better world and we did everything we could for her to make her feel better. (CG)

Part of providing good care involved shared expectations by ALF staff, hospice, and family members that situations might arise where the required care exceeded the resources available through the ALF or the hospice. “The facilities that acknowledge their limits have the best scenario” (hospice RN). Although the types of potentially challenging situations varied by ALF, a commonly cited example was if the resident experienced prolonged or severe agitation or repeated attempts to ambulate without assistance. When ALF staff, family members, and hospice RNs understood that the resident’s care needs might be greater than the type and amount of services that could be provided, alternative plans were developed. These plans could include increasing family presence at the bedside, hiring additional services, or relocating to another setting, most commonly a foster home, where staff-to-resident ratios were higher. The critical issue here was that families and providers understood in advance that additional resources might be needed at some point and how this would be handled, should the need arise.

There was considerable variation in how ALFs handled medication orders for symptom management based on the facility’s interpretation of state regulations and their own policies. Most facilities required a physician’s signature before any medication changes (e.g., dosage adjustments) were administered, despite hospice RNs having signed, standing orders for a range of drug and dosage options, and the ability to accept telephone orders. This requirement had the potential to significantly delay order changes as ALFs relied heavily on faxed signatures, which can be time consuming to acquire. In situations where the care went well, strategies were in place for obtaining physician signatures, which facilitated rapid implementation of new orders. These situations reflected hospice RN acknowledgment of the regulatory and organizational limitations on ALF staff and mutual recognition of the need to focus on “what is best for the patient” in terms of problem solving. Thus, shared expectations minimized surprises.

In an ALF, if you’re not troubleshooting [medications], everything is going to blow up. The medication aides are scared because they don’t want to get yelled at [by a physician] at 2:00 am, which they will. . . . The resident’s not getting what they need. Then the family complains. It just blows up because it’s not a nursing home. (ALF RN)

Underlying Factors Associated With Positive Care-Provider Relationships

Several underlying factors facilitated the care-provider relationships that supported a good quality-of-care experience. These included ALF
administrator attitudes, training specific to EOL care, and consistent staffing assignments. Although ALF administrators were not interviewed for this study, their positive attitudes about residents dying in their ALF “home” and the value of hospice services were frequently cited by ALF staff and hospice RNs. Administrator support for residents’ dying in the facility and with hospice clearly influenced the ability of ALF staff to provide increased monitoring and assistance for residents, the sense of collaboration experienced by hospice RNs, and extent of shared understandings around medication management and any boundaries to services available through the ALF. Administrators often led by example. One hospice RN described the administrator’s response when staff became uncomfortable as a resident was dying: “The next thing I knew the administrator was in there reading the Bible to this woman and she would have read whatever would have comforted the patient, but she was reading the Bible and just her presence [was comforting].” With some coaching from the ALF RN and by the administrator’s example, most of the staff chose to eventually sit with the resident before her death.

All participants reported that most ALF staff had little or no training in caring for dying people or personal experiences with death. ALF staff primarily learned on the job, either from a more experienced caregiver or through small group or one-on-one interactions between the staff and the ALF RN or hospice RN.

I would say, “this is what we’re looking for” because [staff] don’t understand that it’s not necessary for a person to gurgle when they’re dying. There’s things we can do to treat those symptoms and that’s when I try a one-on-one [teaching], and . . . word of mouth is starting to get around. (Hospice RN)

Participants provided other descriptions of care experiences that were initially challenging and were also learning opportunities that influenced subsequent as well as current EOL care. At the same time, all desired more training on EOL care for ALF staff. Hospice RNs also often desired more information for themselves about rules and policies that regulate operations in ALFs.

Consistency in staffing assignments for both ALF staff and hospice RNs was critical to developing respectful and effective relationships. Participants recognized that working with the same people over time facilitated good care as care providers began to know and trust each other.

I have about four or five patients in the building. . . . You’re there and you see a lot of things and can answer a lot of questions or help them or just get to know the staff. It works beautiful as far as relationships are concerned. (Hospice RN)

The salience of low rates of staff turnover in facilitating consistent assignments was recognized: “[ALF] must be a good place to work because the turnover is low” (hospice RN).

Outcomes of High-Quality Care

Positive outcomes focused on benefits for residents and families, as well as for care providers in being able to accommodate the resident’s wishes. Benefits for the resident and their family were reflected in this comment: “With her family surrounding her and really good support from the staff, she died really peacefully and comfortably” (MA). When the care went well, the resident was able to avoid moving to a nursing home or other setting, which participants considered very stressful for the resident. “They [staff and residents] get attached—so the people that really care about you, [residents] recognize their voices and their faces. That’s the best thing probably . . . being around people that you’re comfortable with” (hospice RN).

ALF staff felt good about their contributions to the care of a dying resident. One caregiver summarized frequently expressed ideas:

Making a difference in someone’s life. At the end of mine, I’m going to want somebody doing the same thing that I’m doing. Somebody who will be there holding my hand, and still teasing me and talking with me—knowing I still have a soul and I’m still a person even though I can’t talk and communicate. That’s the reward. (MA)

ALF and hospice RNs often described a sense of pride for the good care that ALF staff provided: “It’s the feeling of having been a team that made it all happen for the family, but also for the facility staff because they become attached. So them seeing the team work—that they worked smoothly” (hospice RN).

Discussion

This study differs from prior research on EOL care in assisted living in that it examined care
situations that “went well” and focused on the perspectives of the ALF and hospice staff that are directly involved in the care. Although there was great variation in dying experiences and care processes, we identified several important factors that characterize good care for ALF residents on hospice. Our findings suggest that the relationships between the resident and the ALF staff, and among care providers, are critical in promoting good quality EOL care. Important features of care-provider relationships included strong teamwork, good communication, use of multiple sources of knowledge in providing care, and shared expectations about managing potential problems. When these aspects of EOL care were in place, ALF staff and hospice RNs reported feelings of accomplishment through their contributions to the resident’s goal to die “at home” and in comfort.

Can ALF Residents Remain in Their ALF Home Until Death?

Central questions exist about whether residents can remain in an ALF until death and how the care needs of residents at EOL should be met. Using a representative national sample of nearly 1,500 ALFs, Hawes and colleagues (2000) concluded that the average consumer could not age in place if it meant living in an ALF to the end of his or her life, regardless of changes in health or limitations in physical and cognitive functioning. In our prior studies describing resident and family perspectives on EOL care in ALFs, we reported that dying residents considered the ALF their home, desired to die at home, and were supported by their families (Cartwright & Kayser-Jones, 2003; Cartwright et al., 2006). Furthermore, families worried that relocation would result in the resident spending their final days in a strange setting and cared for by strangers. Yet, concerns existed about inadequate communication and coordination of care between hospice and ALF, that staff sometimes lacked knowledge about basic care skills and symptom management and that both hospice RNs and ALF staff sometimes did not visit or monitor the resident as often as families believed was appropriate (Cartwright & Kayser-Jones; Cartwright et al.). The findings reported here are not meant to minimize these challenges and concerns. In describing good EOL care in ALFs, this study identifies how some of these issues can be successfully addressed.

In recognition that ALF residents want to stay and die in their ALF home, and avoid moving to another setting, most states are changing their regulations to allow ALFs to provide more extensive health care services to a fairly impaired resident population and to admit or retain residents who meet criteria for nursing home admission (Mitty, 2004; Mollica, 2006). In this study, we found that some facilities were willing to provide the extra and often complex care that was needed and that hospice support was a critical factor in being able to provide this care. Furthermore, some hospice RNs adapted the traditional hospice model of primarily working with family CGs to work at a systems level with ALF staff.

The quality of the resident–staff relationship at EOL has been identified by families as providing essential social support to dying residents (Cartwright et al., 2006; Munn & Zimmerman, 2006). We found that ALF and hospice RNs also recognized that positive resident–staff relationships increase the likelihood that additional services will be provided by the ALF staff as the resident’s care needs increase. These findings support the intentional development of nurturing relationships between residents and staff, which are promoted through consistency in staffing assignments and opportunities for social interaction, and may be associated with friendship and attachments between care providers and residents (White, 2008).

Positive relationships between care providers have been associated with high-quality care in nursing home settings (Anderson et al., 2005; Miller, Teno, & Mor, 2004; Tarzian & Hoffmann, 2006) and are reflected in a growing movement to person-centered care. This study supports the importance of care-provider relationships, particularly when staff are employed by organizations with different missions and cultures.

There are limitations to this study. The experiences of these care providers may not represent other ALF and hospice staff perceptions of good quality care. How residents and families view the quality of the care experience may differ significantly from the perspectives of the care providers. These experiences may differ from care experiences for nonhospice-enrolled residents. Because the regulations pertaining to ALFs in Oregon are among the broadest in the country, these findings may not be transferable to other states. However, the stories shared by these care providers represent their constructions of events and the significant details, and thus articulate critical issues from the
perspectives of staff closely associated with the care at EOL.

Recommendations

This study identified factors associated with good care at EOL for ALF residents. Many of these are amenable to intervention (e.g., team work, understanding the roles of other care providers, education about care at EOL). Others may be influenced (e.g., consistency in assigning the same hospice RN to a facility), whereas some are fixed (e.g., resident length of stay in a facility prior to dying). ALF administrators need to carefully consider whether their facility can support dying in place and if so, what is needed for this to happen. Facilities will benefit from developing systems that support person-centered care and optimize communication and collaboration among care providers. Prospective residents and their families deserve to know whether the facility supports residents dying in place both philosophically and instrumentally through added services to facilitate EOL care. Hospice and palliative care programs must acknowledge that increasingly, older adults will be assisted by unlicensed, paid care staff, and redesign their services accordingly. Organizational, public policy, and funding structures need to reflect these realities through standards of care, training programs, staffing guidelines and regulations, and reimbursement criteria and rates. Additionally, the nature of staff–resident relationships and their impact on care processes and resident outcomes need more research.

Given the projected growth in demand for community-based residential care, the development and testing of models of care are needed that identify new ways to support older adults dying in ALF. The number of people who will be referred to a hospice will increase as both ALFs and hospices recognize the need for and are successful in providing high-quality care experiences for dying residents. Furthermore, over time, the sheer number of ALF residents who are dying will likely exceed the available placements in nursing homes, in part because the number of nursing homes is declining (Federal Interagency Forum on Aging-Related Statistics, 2004).

Lynn (2002) challenges the health care, funding, and regulatory systems to systematically and empirically identify the services needed to develop systems of care that serve people at EOL in ways that are meaningful, comfortable, and sustainable. This study has illuminated key factors that ALF and hospice staff identify as desirable in order to support ALF residents during this final life transition. These factors have great potential for serving as the basis for models of EOL care for this important and growing population.

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