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The End of Life Experience in Long-Term Care: Five Themes Identified by Focus Groups with Residents, Family Members and Staff

J.C. Munn, D. Dobbs, A. Meier, C.S. Williams, H. Biola, and S. Zimmerman

Abstract

Purpose—This study was designed to examine the end-of-life (EOL) experience in long-term care (LTC) based on input from key stakeholders.

Design and Methods—The study consisted of ten homogeneous focus groups drawn from a purposive sample of LTC residents (2 groups; total n = 11); family caregivers (2 groups; total n = 19); paraprofessional staff (3 groups; total n = 20); and licensed/registered staff (3 groups; total n = 15) from five nursing homes (NHs) and eight residential care/assisted living (RC/AL) communities in North Carolina. Data were analyzed using grounded theory techniques to elicit manifest and latent themes.

Results—Five overarching themes emerged: (1) components of a good death in LTC; (2) normalcy of dying in LTC; (3) the role of relationships in the provision and receipt of care; (4) Hospice contributions to care at the EOL in LTC; and (5) stakeholder recommendations for enhancing EOL care in these settings. Underlying these themes is one central category, “closeness,” based on physical proximity and frequency of contact.

Implications—Findings suggest that promoting collaborative relationships among the four stakeholder groups, increasing social worker involvement, and removing barriers to Hospice may enhance the EOL experience in LTC.

Introduction

Almost one quarter (24%) of older adults in the United States die in long-term care (LTC) settings (Temkin-Greener & Mukamel, 2002). Mortality ranges from 14–22% annually in residential care/assisted living (RC/AL) facilities (Golant, 2004; Zimmerman, et al., 2005) to 34% during the first year of residence in nursing homes (NHs) and 24% thereafter (Kiely & Flacker, 2003). Unfortunately, despite the frequency of death in LTC, the end-of-life (EOL) experience has been studied less there than in other sites of death (Thompson & Chochinov, 2006) and much existing research has focused on deficits in care such as inadequate pain management, the absence of emotional and spiritual support (Kayser-Jones, 2002), and advance directives (Lambert et al., 2005; Teno, Gruneir, Schwartz, Nanda & Wetle, 2007).

Notably few LTC studies (Goodrich, Bond, Cameron & McKean, 2005; Munn & Zimmerman, 2006; Touhy, Brown & Smith, 2005) and some studies conducted in other settings (Patrick, Engelberg & Curtis, 2001; Singer, Martin, & Keller, 1999; Steinhauser, et

Corresponding Author: Jean C. Munn, Ph.D., Assistant Professor, College of Social Work, The Florida State University, C2511 University Center, Tallahassee, Florida 32306-2570, jmunm@mailers.fsu.edu, Phone: 850-644-9748; Fax: 850-644-8995. Alternate Corresponding Author: Sheryl Zimmerman, Ph.D., Professor of Social Work, Co-Director, Program on Aging, Disability and Long-Term Care, Cecil G. Sheps Center for Health Services Research, The University of North Carolina at Chapel Hill, 725 Martin Luther King Boulevard, Campus Box 7590, Chapel Hill, NC 27599-7590, Sheryl_Zimmerman@unc.edu, Phone: 919-962-6417; Fax: 919-966-1634.

al., 2000; Tong, et al., 2003), have used qualitative methods to understand what is important at the EOL. Areas that have emerged include pain and symptom management, alleviating burden placed on loved ones, social relationships and support, spirituality, being treated as a whole person, and avoiding prolongation of the dying process.

However, the qualitative studies specific to death in LTC were limited in scope (e.g. including only one type of respondent or extremely small sample sizes) and only one non-LTC study (Singer, Martin & Keller, 1999) included LTC residents among respondents. This is an important omission as the setting of care influences many aspects of the dying experience including care philosophy, available services, relationships with caregivers, and caregiver training and knowledge (Mezey, Dubler, Mitty & Brody, 2002). Further, multiple perspectives such as those from families, staff, and residents, allow for triangulation of sources and lend authenticity to the data (Padgett, 1998). Therefore, qualitative research specific to LTC and conducted with multiple respondent groups is appropriate in order to establish a knowledge base and to understand the EOL experience in LTC. Researchers have recommended that such studies explore issues beyond medical care and symptom management (Kayser-Jones, 2002) and seek population-level information on the quality of EOL care from residents, staff, or their families (Clark, 2003; Singer & Wolfson, 2003; Teno, 1999).

In response to these recommendations and existing gaps in our knowledge, this study conducted ten focus groups and is unique in including four stakeholder groups: residents, family, paraprofessional care providers and licensed/registered staff (in homogenous groups). By using focus groups rather than individual interviews, respondents could interact and respond to ideas and comments of others (Krueger & Casey, 2000). Initially, the study aimed to determine the components of a good death in LTC based on input from all four groups and to compare findings with components identified as important in other settings. However, as the study progressed, focus group participants provided depth and insight on a variety of issues that were related to EOL yet beyond an understanding of a good death. Therefore, the study aims were expanded to include an examination of the EOL experience in LTC.

Method and Design

Ten focus groups were conducted that were homogeneous in composition (i.e., the focus groups of the four respondent categories were conducted separately) and comprised of LTC residents (two groups); family caregivers of decedents who died in LTC (two groups); LTC paraprofessional staff caregivers (three groups); and licensed/registered LTC staff caregivers (three groups).

At the beginning of each focus group, the project coordinator reviewed the consent form and procedure (e.g., voluntary nature of participation, confidentiality of the focus group discussion, \$25 payment for participation) and each participant signed a confidentiality agreement and consent form. As an incentive to participate and to allow for uninhibited discussion away from the LTC setting, all groups were conducted over dinner in restaurants with handicapped accessible, private dining rooms.. Each group was audiotaped and notes recorded. Following the theoretical sampling model (Glaser, 1994), one of each type of group was conducted, the transcript reviewed, and modifications made to the interview guide before conducting the next group(s) of that type. Group sizes ranged from three to 12 participants. All procedures were approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Setting

Subjects were drawn from a total of five NHs and eight RC/AL facilities in two areas (one urban and one rural) of North Carolina. For this study, RC/AL facilities were defined as non-medical, community-based living arrangements that are not licensed as nursing homes; house two or more unrelated adults; provide shelter (room), food (board), and 24-hour supervision or protective oversight and personal care services in activities of daily living; and can respond to unscheduled needs for assistance.

Subjects

Participants were a purposive sample (n = 65) of residents (n = 11); family members of decedents (n = 19); paraprofessional staff (n = 20), and licensed staff (n = 15), drawn from a total of 13 North Carolina facilities (five NHs and eight RC/ALs) that participated in the NIH-funded Collaborative Study of Long-Term Care parent study, *End of Life in Nursing Homes and Assisted Living Facilities* (Sheryl Zimmerman, PI). In the parent study, staff and family provided data on the EOL experience of decedents. In the focus group study, it was desirable to examine themes related to a good death and to allow new themes to emerge.

Prior to contacting potential participants, the project coordinator sent each facility administrator a letter describing the focus group study and then called the administrator, requesting permission to contact staff and families who had participated in the parent study. All facility administrators agreed that the research team could contact prospective subjects.

Staff—The project coordinator contacted first by letter and then by telephone all staff who had participated in the parent study and were still employed by the facility (n = 25). However, there were too few such individuals to compose groups within geographic areas; hence, to assure sufficient numbers of staff participants, additional snowball sampling was employed. Staff were asked to identify others who might be interested in participating. After the referring person had received permission from the potential snowball participant, the project coordinator telephoned potential participants to elicit their participation.

Family Members—Upon obtaining facility consent, the project coordinator sent a letter describing the study to a sample of family members who had participated in the parent project and lived within the Triangle area of North Carolina (n = 40). Family caregivers were defined as the person most involved in care decisions for the deceased LTC resident during the last month of life and who visited the resident or spoke with the staff on the LTC resident's behalf at least once during the last month of life. The project coordinator then called each family member to describe the project and solicit participation.

Residents—The project coordinator asked administrators from three of the 13 participating facilities (one NH and two RC/AL facilities) for names of residents who might participate in a focus group on the EOL experience. Criteria for participation included: the ability to transfer to and from a specially equipped van necessary for transport to the focus group location; verbally participate in a focus group conducted in English; and discuss a sensitive subject without undue stress. The study coordinator then met with each resident candidate, described the study and obtained informed consent in advance of transporting him/her to the focus group destination.

Measures

The facilitator used a semi-structured interview guide with four primary questions: (a) "Some people have talked about the differences between a 'good death' and a 'bad death' in LTC. What does this mean to you, based on your experience?"; (b) "If you could change (or control) only one thing at the EOL, what would it be?"; (c) "What other aspects of residents'

deaths do you feel are particularly important?"; and (d) "Is there anything you would like to add?" Further, the facilitator elicited and probed new areas mentioned by participants, in accordance with standard focus group conduct allowing naturally occurring themes to emerge. Demographic data (age, gender, race) were obtained for each participant.

Data Entry and Analysis

The research team transcribed focus group recordings verbatim and entered the data into Atlas/ti (Scientific Software, Berlin). Initially, two coders (DD and JM) reviewed each transcript independently and assigned preliminary codes to the different content they found in participants' comments (a process known as manifest coding). The codes were developed using an "open coding" strategy (i.e., not imposing pre-established categories on the data), and each represented distinct information (Strauss & Corbin, 1990); if appropriate, any given passage was assigned more than one code. Examples of preliminary manifest codes are staff/family conflict and miscommunication. Atlas/ti, the qualitative data analysis program, was used to enter the codes, after which time the coders met, compared codes, and resolved ambiguities and discrepancies related to code definitions and assignment. Based on coding one transcript from each of the patient, caregiver and staff groups, the coders compiled a master list of 107 codes (the "original code list") for use in coding the remaining transcripts, although additional codes were still created as necessary.

Then, as patterns emerged, related codes were clustered (axial coding) and axial codes added to the coding list to capture the conceptual relationships between the manifest codes (Strauss & Corbin, 1998). For example, during axial coding it became evident that staff/family conflict and miscommunication occurred together and in specific circumstances (such as related to the actual death of the resident) and that such miscommunication seemed to result in staff/family relationships becoming adversarial. In this way, adversarial relationships became an axial code, reflected a sub-category related to the open codes. In the final analyses, an open or axial code needed to be noted at least three times in a transcript to be included.

After completing the manifest and axial coding, three members of the research team (JM, CW, SZ) analyzed the transcripts for latent themes (i.e., implicit themes or messages "behind" the text). They read one of each type of transcript identifying themes as they emerged. In so doing, they examined co-occurrence among codes and themes. Further, they examined central characteristics and ranges of variations for each code and theme. In this way they developed a theme list for coding all transcripts. Themes found in all ten groups were identified as overarching themes.

Results

Twelve residents were approached to participate; 11 (92%) agreed (Table 1). Forty family caregivers were approached to participate, 23 agreed but only 19 (48%) attended a focus group. Regarding staff, only eight paraprofessional staff who had participated in the parent study were still employed at the selected facilities. Using snowball sampling, a total of 20 paraprofessional staff were identified and participated in the focus group study. Seventeen licensed or registered nurses were approached for participation; 13 agreed to participate, but only eight attended a focus group. Therefore, snowball sampling was employed to increase the sample to 15 licensed/registered staff.

Five overarching themes emerged in all groups (Table 2). Some resulted from the questions posed by the facilitator (e.g., the components of a good death); others evolved naturally (e.g., Hospice and the normalcy of death). Each of these themes applied to all four respondent groups.

Theme 1: Components of a Good Death in Long-Term Care

Respondent groups provided similar definitions of a good death as one of comfort, dignity, and closure. Within this context, there were sub-themes of physical symptom management (e.g., “being kept comfortable”); circumstances of death (e.g., short in duration, not “hanging on and hanging on;” “not hooked up to machines;” and “surrounded by family”); preparation (e.g., “having things in order”); closure (e.g., acceptance of death and giving permission to die); spirituality (e.g., “God here I am. Go ahead and do what you need to do”); dignity (e.g., attentiveness to issues of incontinence); and lack of family burden (e.g., relieving family burden was a motivation for initially moving into LTC) as important at the EOL. This theme and related sub-themes are similar to those found in studies conducted in other settings.

Theme 2: Normalcy of Dying in LTC

The normalcy of death in LTC was a naturally evolving theme among respondents who consistently and frequently spent time in the facility. Those who did view death as normal had socially constructed definitions of normalcy based on experience and expectation related to the frequency of death and physical proximity to other residents who were dying. For most, but not all, death was an expected outcome after moving into LTC. However, few family members expressed a sense of normalcy regarding dying in LTC. Those who did had prior experience with death in other settings or with deaths of other family members in LTC.

The matter of frequency was introduced by an 84-year old, male RC/AL resident: “One thing that hasn’t been mentioned, I don’t want to say we are surrounded by death, but for 350 people, elderly people, death is not unusual.” He and other group members went farther in quantifying normalcy: they agreed that three deaths within one month was normal; but the suggestion of more than three deaths in a month prompted a response of “Wow!” Similarly, paraprofessional staff from a different facility expressed distress when that facility experienced six deaths in a three-month period. Thus, within the LTC context, even when death was considered normal, the deviation from some expected frequency was noteworthy.

Another matter related to normalcy derived from living in close proximity to one another; as such, residents became accidental witnesses to the deaths of others and described direct involvement, voluntary or involuntary, in these occurrences. An RC/AL resident described: “I was in an apartment in which the gentleman on the other side of the curtain was at the end of life and three times they came in and asked me if I would not like to move and ... I did say no... I began to realize that I should have [MOVED] when the priest came in and was saying the last rites for the gentleman.”

Also, residents happened upon other residents who were dying and willingly became part of the dying experience. An 87-year old resident with a background in healthcare indicated: “I was with one person at [FACILITY NAME], who died...she had friends in the room with her all the time, morning, noon and night. All the time she was dying, she had friends and I happened to go into the room at the point when she was really dying. And it was so fine that they allowed that, her friends were in the room all the time.”

Resident participants in both groups had observed the removal of deceased residents’ bodies from facilities. In one NH facility, bodies were taken through the main lobby; in another, the morticians came and left by the freight elevator. Residents considered both practices undignified. In other facilities, staff made sure residents did not witness this event by closing doors and removing residents from hallways. Residents saw this practice as representing dignity and respect for the decedent, as did some staff. However, other staff felt that this practice was unnecessary and that residents recognized the normalcy of death more readily when it was openly acknowledged.

Theme 3: The Role of Relationships in the Provision and Receipt of Care

All four respondent groups described relationships as instrumental in the delivery and receipt of EOL care. Residents established relationships with facility staff in order to negotiate care delivery. Some nurtured relationships with direct care staff; others established a relationship with the facility administrator. When things did not go well, they relied on these relationships to help them rectify problems. For example, one 71-year old male resident indicated that he “went straight to the top” with problems. Family members also saw relationships as a method of assuring better quality of care (Table 3). Exploration of the themes and codes identified three sub-themes related to relationships.

Relationships in Long-Term Care are Multifaceted and Ambiguous—The delineation between professional and personal relationships was blurred in the LTC setting. Staff participants, who know residents only through their roles as paid caregivers, still describe relationships with residents as family-like. One licensed nurse said: “...you’re caring for them and you’re making them comfortable and it’s just like a family member because that’s the way I look at it.” Staff also saw themselves as replacement family for residents who did not have family nearby. They sat with dying residents, often on their own, non-work time. Further, staff expressed family-like grief and bereavement after a death.

Both paraprofessional and licensed staff provided emotional and spiritual support to residents in addition to personal and medical care. They indicated that they prayed and sang with and for dying residents, sometimes openly and at other times privately. Some staff saw themselves as responsible for the family members’ emotional and spiritual support as well. However, family members associated with these same facilities did not report receiving emotional and spiritual support from staff.

Paraprofessional staff also provided emotional and spiritual support to one another. As one nursing assistant described: “I know that the two aides that work in the unit with me if somebody was to be dying or anything, they would cover the rest of my residents and theirs ... so we know to cover them and to give them an hour, whatever they need if they want to sit with that resident.”

Relationships Vary in Their Degree of Empathy, Reciprocity, and Trust—Residents demonstrated empathy and reciprocity in relationships with staff, expressing concern for them and their families; one 87-year old female NH resident remarked: “Of course, they’re people. They have their own lives.” Both paraprofessional and licensed/registered staff expressed and demonstrated empathy for residents and their families in spite of unpleasant experiences as a nurse reported: “I even miss the people that I don’t like because ...you become attached to them.” Families were less likely to express empathy for staff, although one daughter indicated: “I wouldn’t do that job for all the tea in China and for minimum wage. I think they do a really good job.”

There were notable variations in empathy and emotional closeness between family members and deceased residents. Within this context, it was not unusual for family members to personalize the death from their perspective, considering it in relation to themselves, rather than to the resident, such as by commenting on how the decedent’s death fit into the flow of the family life. Although one family member expressed empathy for her mother who had been unable to verbalize her needs, there were fewer expressions of empathy toward deceased residents in family groups than staff groups.

Family members and residents described varying levels of trust toward facility staff, with family members expressing the greatest distrust. Further, family members demonstrated their distrust; they described showing up at the facility at different times so staff would not

know when they were coming. They also expressed concerns about retribution toward residents if they expressed complaints too aggressively. Residents were more trusting and expressed trust in the facility to provide appropriate care; however, they also expressed some distrust in the direct care staff whom they accused of stealing.

Relationships Become Adversarial under Predictable Circumstances—Family and staff described circumstances that created conflict and caused family/staff or resident/staff relationships to become adversarial. These circumstances were perceived differently by different stakeholders.

Conflict over EOL Care: Relationships between family and staff became adversarial when staff saw family as consuming time and attention at the EOL. This issue was most pronounced when family had not visited prior to the EOL. One licensed nurse stated: “Families can help or hinder. If the family member has a grudge...I’ve had to assist family members out of rooms. Some of the families never come and visit and they just want to be there at the end, so instead of peaceful time, it becomes very high anxiety.” Another described something akin to sibling rivalry: “You’re there with them 24/7 and you know more than the family member knows. They [the family] don’t like it like that.”

Miscommunication: Relationships also became adversarial when there was miscommunication between facility staff and families, especially regarding medical treatment and the timing and expectation of impending death. Some miscommunication was as simple as word choice. However, all focus groups emphasized a desire for truth in communication and when miscommunication occurred, families consistently perceived this as staff being untruthful. Family members assumed that the staff could accurately predict the time and circumstances of death and expressed great distress if staff had not notified them of an impending death.

Theme 4: Hospice Contributions to Care at the EOL in LTC

The Hospice theme evolved naturally in all focus groups and all four respondent groups indicated that Hospice services made a positive contribution to care at the EOL in LTC. However, each group perceived the function of Hospice differently. Residents, some of whom had been enrolled in Hospice, indicated that Hospice contributed to their personal outlook on dying, saying: “And that’s where Hospice sets in or steps in and helps you understand what death’s about and you have a different outlook on it when someone tells you and you don’t dwell on it every day or every week and you have an understanding with your family.”

Families, on the other hand, primarily saw Hospice as a way of monitoring care as illustrated by this quotation: “So, for me having Hospice was having another set of eyes. If they did nothing else, I could call them and talk to them and say, what did you see?...It was just that sense that at least I knew that there was somebody else that I could rely on to just be there, to just let me know if something was going on.” Licensed/registered staff saw Hospice as experts in pain management and a source of training and bereavement services for staff, in addition to providing services to families. Paraprofessional staff indicated Hospice provided additional care: “Any questions that come up, the Hospice that we deal with is very, they’re very assertive ...when you call them, you get a response.” However, although paraprofessional care providers recognized the value of Hospice, they wished to be more involved in care. One indicated: “The Hospice nurses come in and they talk to the DON [director of nursing] and the ADON [assistant director of nursing] and they figure out what their role’s going to be, what kind of medication they’re going to give them. But they don’t

include us on how we've been taking care of this patient for like two weeks or whatever. I think they should include the CNA."

Theme 5: Stakeholder Recommendations for Improving Care at the End of Life

Focus group participants stated two recommendations regarding improving care at the EOL: the need for more, trained direct care staff and the need for social work involvement. These particular recommendations were not explicitly solicited. Rather, they emerged from general questions regarding how EOL care might be improved. All respondent groups commented on the need for additional staff. One licensed nurse stated what was most important to her was: "Having the staff to provide the care. Everybody knows there is a nursing shortage. When we're at our end of life, there is not going to be anybody to take care of us." A family member indicated: "they need to take that money and pay their staff nurses because I believe they should quit burning out their nurses." Residents also indicated the need for more staff and consistent staffing patterns: "Well, they don't have enough CNAs and they have a great big turnover...you get acquainted with the CNAs and the first thing you know, they're gone."

Participants also indicated a need for more social work involvement or indicated a lack of services generally associated with social services. One licensed nurse stated: "A major problem I see is when somebody is dying or near their end of life, social services is not involved enough. It's very minimal. For them to be involved and help the family ...to be able to deal and cope with a resident dying, what they are going through ...social service are not working with them much and they very rarely see them and they just sort of know hearsay about what is going on." When asked about social support one family member responded: "Are you out of your mind? ... I had to go and find a social worker ... There's no communication. No, I would say there was no spiritual, emotional help." Further, resident groups did not indicate support from social workers for themselves or dying residents as part of the end-of-life experience. While noting the need, staff recognized staffing constraints, such as working in a facility in which there were 380 residents and one trained social worker. Still, staff and families were specific in naming social work as the needed profession.

Central Category: Closeness

Finally, using a grounded theory approach, the themes were examined to determine a central category (a category that is related to all categories; appears frequently in the data; is abstract; grows in depth and power upon further examination) (Strauss & Corbin, 1998). In this study, the central category was "closeness." Closeness emerged as an integrating context for the overarching themes and was based on physical proximity and frequency and regularity of contact among stakeholders. Understandably, persons who were geographically closest and had the most contact were most likely to form relationships. However, closeness also influenced the properties of those relationships (e.g., collaborative or adversarial; degree of reciprocity, empathy and trust); and the sense of normalcy associated with dying, with less closeness associated with less empathy, more miscommunication, adversarial relationships, and differences in expectations for Hospice.

Discussion

This study set out to examine the components of a good death in LTC. However, the use of qualitative methods enabled the research team to move beyond this initial aim and capture other themes that arose during focus group conduct and data analysis. Findings indicated that although focus group participants identified essentially the same components of a good death as studies in other settings (Steinhauser, et al., 2000; Teno, 2002), the EOL experience

additionally reflects unique aspects of living and dying in LTC. For example, unlike other settings, in LTC there was a sense of normalcy associated with death. Further, relationships were noted to be instrumental in the provision and receipt of care, many of which revolved around LTC staff. Previous literature has found both LTC staff objections to Hospice inclusion (Baer & Hanson, 2000; Keay & Schonwetter, 2000; Miller & Mor, 2004) as well as favorable attitudes toward Hospice from the perspective of the administrator (Dobbs, Hanson, Zimmerman, Williams, & Munn, 2006). In this study, Hospice was perceived positively by all respondent groups. Because this study included four types of respondents, we were able to determine that the role of Hospice was conceived differently by each stakeholder group. Also, stakeholders offered specific recommendations for improving care at the EOL. Underlying these themes is one central category, a sense of closeness; that is, residents who live in LTC and the staff who work there are in close physical proximity to one another and have frequent and regular contact. This sense of closeness relates to how LTC residents live their lives and their experiences with death and dying and provides the context for understanding these findings. Family respondents differed from others in three of five thematic areas: for them, death is not normal in LTC; family/resident relationships exhibited less empathy and less reciprocity than staff/resident relationships; and families see the positive contribution of Hospice as monitoring EOL care in their absence.

Frequency of contact and physical proximity are especially pertinent in the theme of normalcy of dying in LTC. For three of the four respondent groups, there was an overall expectation of death as part of the LTC setting. Further, despite higher mortality rates in NHs (Kiely & Flacker, 2003), residents of both RC/AL facilities and NHs saw death as normal. However, residents also wished to focus on living rather than dying, confirming findings in other studies (Engle, Fox-Hill & Graney, 1998). This finding takes on new significance in LTC as residents see death on an almost weekly basis.

Families do not consider death as normal, though, which is an important difference between them and other stakeholders. It has implications for the relationships they have with LTC staff, especially because this study confirmed findings from other studies that developing and maintaining relationships are important in LTC (McGilton, 2002; Zimmerman, Sloane, Hanson, Mitchell, & Shy, 2003). The inclusion of four respondent groups in this study allowed a more nuanced and expansive examination that revealed the complexity of relationships among stakeholders. For example, while it seems counterintuitive that family members would express less empathy for dying and deceased residents than expressed by licensed/registered staff and paraprofessional care providers, this was consistently the case. When examined in the context of normalcy and closeness, this finding becomes more understandable as family members experience the death in a different context, and have less physical proximity and less contact with residents (Port, et al., 2003) than staff. Also, the family members are experiencing the loss of a more personal relationship.

Relationships with families are additionally complex and ambiguous because although other studies have reported that staff see themselves as family to residents (Bitzen & Kruzick, 1990), these focus groups go further in describing the tension that develops when staff must move from a family-like role to that of an employee. This occurrence was particularly stressful upon the arrival of distant family who had limited participation in the residents' lives prior to the EOL. However, staff developed close bonds with the residents and had more experience than families in dealing with the dying experience. Thus, they can and do support family during the EOL, a role not yet widely recognized or encouraged.

The issue of trust emerged as particularly salient in describing family/staff relationships. Distrust of staff by families and descriptions of failure to communicate often were associated with not being told that the resident was dying. These findings are congruent with

current literature that describes staff/family relationships as adversarial and characterized by stereotyping, distrust (Krause, Grant, & Long, 1999; Tobin, 1995) and unrealistic expectations (George & Maddox, 1989; Heiselman & Noelker, 1991; Pillemer, Sutor, Henderson, Meador, Schultz, Robison & Hegeman, 2003). However, unique to this study is the finding that some distrust grew out of an unrealistic expectation that staff should know, without error, the timing and trajectory of individual resident deaths. This matter is especially important because “being there” at the time of death is paramount to family members (Munn & Zimmerman, 2006).

The positive perception of Hospice indicates that barriers to the use of Hospice in LTC need to be addressed. For example, given the regulatory climate in NH, administrators fear that they will not be seen by NH surveyors as providing adequate care if they allow a resident’s health and function to decline without curative intervention (Dobbs et al., 2006). Sometimes administrative staff do not see a need for Hospice because they perceive their own staff as doing an adequate job already in the provision of EOL care. Financial barriers limit the provision of Hospice care for NH residents who are receiving Medicare skilled services (Zerzan, Stearns & Hanson, 2000). Such barriers include lower reimbursement rates and delayed reimbursement for dually-eligible Medicaid/Medicare Hospice beneficiaries (Miller & Mor, 2001). Also, NH administrators may discourage Medicare Hospice enrollment for those who qualify for Medicare Skilled Nursing Facility (SNF) coverage and are dually-eligible because Medicare’s SNF benefit has a higher room and board payment rate than the typical Medicaid NH benefit (Gage, et al., 2000). Therefore, policies to provide equal funding for Medicare Hospice beneficiaries are needed. Other studies indicate that physician involvement increases Hospice referrals and the timeliness of those referrals (Casarett, et al., 2005); therefore, increased physician involvement is another area of interest.

Unfortunately, social workers, who are trained in fostering collaboration, mediating adverse relationships and providing support to families, residents and staff, were mentioned as absent or providing inadequate services. There was a suggestion that increased involvement of LTC social workers at the EOL might contribute to collaboration among stakeholders and thereby enhance the EOL experience for dying residents. Currently, social work services are mandated in NHs with at least 120 beds, but no such requirements exist in RC/AL. These findings suggest an expanded role for social workers in both settings.

Limitations

This study had some limitations. As with all qualitative studies, the findings cannot be widely generalized. It is possible that motivated individuals with strong opinions attended the focus groups; thus, the opinions might be considered more extreme than would otherwise be the case. Also, resident attendance was dependent upon certain physical abilities such as hearing and cognitive status. Therefore, participants in these focus groups are not representative of all in LTC. However, the study presents four distinct participant groups from a total of 13 facilities and allows for triangulation of sources. Also, the inclusion of 65 participants in 10 focus groups is robust by qualitative standards.

Another limitation is that the focus groups were not “paired” in the sense that staff respondents were not necessarily reporting on EOL experiences regarding decedents of the family respondents. In addition, resident respondents were drawn from only three of the 13 facilities. Finally, these groups occurred between six months and two years post-death which may have affected the ability of families to recall details accurately.

Implications

Despite these limitations, the study findings suggest avenues to improve the EOL experience in LTC. More recognition of the important and varied role of LTC staff is warranted, as they support both dying residents and their families. Anticipation of the increased stress experienced by those family and staff members closest to residents at the EOL could help to avoid staff/family conflict. Social workers might play an important role in this area, and along with Hospice, improve the EOL experience in LTC.

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Table 1

Respondent Demographic Characteristics by Respondent Group

	Residents (n = 11) ^a	Family Caregivers (n = 19) ^a	Paraprofessional Staff Caregivers (N = 20) ^{b,c}	Licensed Staff Caregivers (n = 15) ^b
	N (%)	N (%)	N (%)	N (%)
Female	7 (64)	17 (90)	19 (95)	14 (93)
Ethnicity				
non-Hispanic	11(100)	17 (90)	17 (85)	13 (87)
Race				
White	9 (82)	16 (84)	9 (45)	7 (47)
Black	2 (18)	2 (11)	9 (45)	5 (33)
Other	0 (0)	1 (5)	1 (5)	3 (20)
Education				
< High school	5 (46)	0 (0)	2 (10)	0 (0)
High school	1 (9)	1 (5)	5 (25)	0 (0)
Some college/trade school	1 (9)	4 (21)	8 (40)	11 (73)
College +	4 (36)	14 (74)	2 (10)	4 (27)
Marital status				
Never married	2 (18)	2 (11)	NA	NA
Married	1 (9)	9 (47)	NA	NA
Widowed	5 (46)	3 (16)	NA	NA
Separated	1 (9)	1 (5)	NA	NA
Divorced	2 (18)	3 (16)	NA	NA

^aTwo groups^bThree groups^cSome numbers do not total 20 and percentages do not add to 100 due to missing data.

NA; Not asked

Table 2Overarching Themes ^a

1	The components of a good death.
2	Normalcy of dying in long-term care.
3	The role of relationships in the provision and receipt of care. <ul style="list-style-type: none">a. Relationships in long-term care are multifaceted and ambiguous.b. Relationships vary in the degree of empathy, reciprocity, and trust.c. Relationships become adversarial under predictable circumstances.<ul style="list-style-type: none">i. Conflict occurs between family and staff over end-of-life careii. Miscommunication occurs between family and staff.
4	Hospice makes contributions to care at the end of life.
5	Stakeholder recommendations for improving care at the end of life.

^aThemes that occurred at least once in all ten focus groups, for all respondent groups (residents, family caregivers, paraprofessional staff, licensed staff).

Table 3

Exemplars of Theme: The Role of Relationships in the Provision and Receipt of Care

Speaker	
Family member	I found that having relationships with people was the most important thing. And I worked really hard at that. And it would kill me when people would turn over. The unit nurse was probably the most important person.
Nursing assistant	I'm really attached to our residents. I'm attached to every single one of them. I know what they like; I know what they don't like. Another stated: You can't help but care. If you don't care, there is no way that you can do this job.
<i>Sub-Theme: Multifaceted and Ambiguous</i>	
Licensed nurse	Working at [FACILITY NAME], there are many people who don't have friends and family come visit them. So the staff becomes their family. So even if it is just a staff member who is there at the time of passing, they know that somebody is there for them, somebody who cares about them.
Nursing assistant	They also encourage us to go to the funerals, go to the memorial services that the families are having. If we were really close to a resident we're like family too. We're just family in a different part of their life.
<i>Sub-Theme: Empathy/Reciprocity/Trust</i>	
Nursing assistant	...making them [FAMILY] feel that it's okay; it's okay to cry, it's okay to touch them, it's okay to talk to them because they still hear you. I had a resident's daughter who wanted me to sit next to him and I said: 'You sit here; this is your daddy. Talk to him. Let him know you're here...I'll step out.' ...for us to be there for the family members as much as we possibly can, that's important to me because I've taken care of that loved one and I want to take care of that family member also.
Family member	I was not there when my mother died...we buried her in Ohio, not here. So, I had a lot of other things to take care of here to be able to get her up there and get the funeral things up there too.
<i>Sub-Theme: Conflict over Care at the End of Life</i>	
Licensed staff	(Speaker 1) 'I've had residents that nobody has seen them for ten years but when you called them up and told them something that happened they' (Speaker 2) 'come out the woodwork!' (Speaker 1) 'and they want you to do everything at the last minute.' (Speaker 2) 'They really have to compensate ...And it seems like you know the attention is taken off the resident who the attention should be given to and the family member just consumes all the attention.'
<i>Sub-Theme: Miscommunication</i>	
Family member	The lady told me that my mother-in-law had expired. Well, the only time I had ever heard expired was like your credit card expired. I have never heard you use that term pertaining to a human being.
Family member	I was devastated that I had not been there with her. And I feel that she would have been devastated as well and in all of my life, the one thing she was afraid of was dying alone and she died alone.