

Conversations about End of Life: Perspectives of Nursing Home Residents, Family, and Staff

Gail L. Towsley, PhD, NHA,¹ Karen B. Hirschman, PhD, MSW,² and Connie Madden, RN, MS¹

Abstract

Background: Care in nursing homes (NHs) often overlooks individual values and preferences. Residents' voices are critical to discussions about preferences, yet there remains limited research on conversations about the end of life (EOL) from the perspective of older adults who reside in NHs.

Objective: The aim of this study was to describe the communication, content and process, related to EOL conversations among residents, family, and staff.

Methods: We used semistructured interviews in this qualitative, descriptive study to describe conversations about EOL preferences. We examined participants' conversation, when it occurred, and what was discussed. We queried about barriers to and facilitators in discussing EOL care in the NH setting. We interviewed residents ($n = 16$), family ($n = 12$), and interdisciplinary staff ($n = 10$) from four NHs.

Results: The overarching theme—missed conversations—describes EOL-related communication. Residents, families, and staff rarely talked about EOL care preferences, nor did they pass along information about preferences or initiate conversations about EOL care with each other. Three categories explained missed conversations: inquiry (“No one asked”); assumptions (presence of an advance directive [AD], “They know me”); and conveying (lack of conveying information or wishes). Existing barriers and lacking facilitators resulted in missed opportunities to hold conversations about EOL preferences.

Conclusions: Not all residents wanted to have conversations, but many wanted to be asked about their preferences. Missed conversations may adversely affect the quality of EOL care. Conversations with residents can be initiated by asking residents who they would like involved in the conversation and drawing upon the experience of others.

Introduction

ABOUT 1.4 MILLION ADULTS age 65 and older reside in nursing homes (NHs),¹ and an increase in the percentage of people who die in NHs is anticipated.² NHs are unique settings; they serve as places of both residence and care. Residents often have multiple chronic conditions, need assistance with activities of daily living, and the NH is often the last place they receive care.^{3–5} Knowing resident preferences is essential to providing high-quality care. Palliative care, specifically, is a person-centered model that integrates individualized physical and psychosocial care to enhance quality of life for individuals and families.^{6,7}

Person-centered care is fundamental in palliative care and includes heightened exchange of information about the

health care system, symptom experience, and both current and end-of-life (EOL) care preferences, yet rarely happens in depth. Even when advanced care planning was emphasized, protocols for discussions about when a patient's health care wishes should be planned for or recorded were nonexistent.⁸ When wishes were recorded, documents often were not in agreement with the resident's verbal wishes.⁹ Fosse and colleagues (2014)¹⁰ found in their review of EOL experiences that residents wanted to be involved in EOL related choices, but family and staff did not always recognize resident preferences or ability to consent to preferences.¹⁰

Research indicates quality of care in NHs is suboptimal, with deficits in staff training, symptom management, treating residents with dignity and respect, and communication.^{11–13} Few NHs have systematic approaches to elicit and

¹University of Utah College of Nursing, Salt Lake City, Utah.

²University of Pennsylvania School of Nursing, Philadelphia, Pennsylvania.

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communicate information about resident preferences;¹⁴ therefore staff may be unaware of resident preferences for EOL care. During care preference discussions, surrogate decision makers' perspectives often overshadowed residents' perspectives.¹⁵ Research has primarily relied on family and staff reports and resident perspectives are generally unrepresented.

Approximately 19%–40% of residents have completed a living will or health care power of attorney.^{16–18} Upon NH admission, residents and/or families are notified of facility policy regarding advance directives (ADs),^{19,20} however, we know little about conversations regarding EOL preferences. Conversations may be unlikely to occur when residents' physical or mental conditions are stable.¹⁹ Research has generally focused on completion of an AD, with data derived from chart reviews, family informants, and hospitalized or community-dwelling older adults. Including family members, who are often the decision makers for NH residents unable to make decisions for themselves due to impairment, is essential. Moreover, understanding providers' perspectives on coordinating and providing care is also important to communication. Most importantly, residents' voices are critical to discussions about preferences. Advance care planning and EOL experiences have been explored with NH residents.^{21,22} Yet there remains limited research on these conversations from the perspective of older adults who reside in NHs. Therefore, the purpose of this study was to describe the communication, content and process, related to EOL conversations among residents, family, and staff. We examined participants' conversation, when it occurred, and what was discussed. We queried about barriers to and facilitators for discussing EOL care in the NH setting.

Methods

For this qualitative, descriptive study we used semistructured interviews to describe communication (content and process) and barriers to and facilitators for conversations about EOL preferences from the perspective of residents, family, and staff. The University of Pennsylvania institutional review board reviewed and approved this study.

Sample

Residents, family members, and interdisciplinary staff members from four NHs in southeastern Pennsylvania (three urban, one suburban) were eligible if they were English speaking and able to participate in an interview per social worker and interviewer judgment. Family participants included relatives or designated surrogates. The social worker or administrator made initial contact with potential participants and asked if the principal investigator could talk with them about study participation. Upon verbal agreement, met or telephoned participants, set a time, and reviewed the purpose of the study and completed informed consent.

Measures

Semistructured interviews were conducted with residents, family, and staff to elicit information about any conversations they had participated in regarding resident/family member preferences for EOL care. We began by asking residents, "If you were sicker than you are now or at the end of your life, what is important to you?" We then probed what would be important for family and staff to know, as well as what psychosocial and/or physical care would be important. Questions and probes (see Table 1) explored their preferences

TABLE 1. QUESTIONS AND PROBES FROM SEMISTRUCTURED INTERVIEWS

| <i>Questions</i> | <i>Probes</i> |
|--|--|
| <p>If this were the last place you live and when you think about the end of your life, including dying, what is important to you?</p> <p>What is important for those who are caring for you in the nursing home to know?</p> <p>What is important for family members and friends who care for you to know?</p> | <p><i>Values:</i> What do you think will be important to you in your final days? (physical comfort, pain control, presence/no presence of family or friends, not thinking about it, not talking about it)</p> <p><i>Location of death:</i> Where would you prefer to die?</p> <p><i>Comfort:</i> Who would you like to spend time with in your final days? (family, friend, clergy, pet, caregiver)</p> <p>What do you think would support or comfort you in your final days? (being with family, friends, alone, praying or being prayed for, singing, reminiscing, picture, being informed about health state, expressing anger or frustration, music, TV, pet, clergy, reading)</p> |
| <p>What conversations have you had about your final days with family members/friends? How did you feel about having these conversations?</p> | <p>When did the conversation occur? Did an event lead to the conversation?</p> |
| <p>I'm going to ask you to think back to when you were admitted to the nursing home. When you came here, what conversations did you have with [nursing home personnel: SW, nurse, doctor] about what you would like your final days to be like?</p> | <p>What did you think about that conversation? Was it a positive or negative experience for you? Why/why not?</p> <p>Were you asked about your preferences related to your final days?</p> |
| <p>When you came to the nursing home, did nursing home personnel ask you your preferences related to [advance directive]?</p> | <p>[orders for resuscitation, hospitalization, comfort/palliative care]</p> <p>When should conversations like this take place?</p> <p>Who should be involved in these conversations?</p> |
| <p>What do you think are the challenges to talking about one's final days? Facilitators?</p> | |

and the conversational contexts: “Who did you talk to? What did you talk about? When did conversations occur?” Family and staff were asked variations of the same questions and probes. Demographic and clinical information was collected from residents’ medical record; family and staff demographics were collected during the interview.

The interviewer recorded the meeting and took notes during and immediately following interviews to document contextual information, such as emotional responses, interview location, length, and any occurrences (e.g., interruptions). Interviews were conducted face to face in a confidential setting, audiorecorded with permission, and ranged from 20 to 60 minutes; one family member interview lasted almost two hours. Recordings were transcribed verbatim and reviewed and compared to the recording; interview notes were added to the final transcript. Two interviews were not recorded, one due to participant preference and one due to equipment failure. Detailed field notes were taken throughout the interviews and written in transcript format immediately after the interviews. Transcripts were organized and managed using NVivo software version 9 (QSR International, Burlington, MA).

Analysis

Content analysis (conventional approach)²³ was employed to describe communication about EOL among residents, family, and staff. Following coding procedures outlined by Miles and Huberman, data chunks (words, phrases) were organized using directed and open coding.²⁴ To understand the content and process of communication we conducted directed coding focused on key concepts (e.g., who, what, when) from our research questions. We examined aspects of conversations based on when the conversation occurred and the content of the conversation. Open and selective coding was conducted to organize categories and conceptualize dimensions and linkages of key concepts.^{23,25} Research team members independently reviewed two different transcripts to verify the coding scheme and cross-checked codes and categories. Team members discussed coding differences until consensus was obtained. A final coding scheme guided the analysis. Codes were collapsed into categories; analytic notes delineated and described the most robust codes and categories. Categories were refined to develop themes.²⁶

Data management and rigor

Rigor of analysis was ensured with an audit trail documenting analytic decisions such as adding, deleting, or reworking code names and synthesizing categories and themes.²⁷ Members of a qualitative analysis group external to the research team provided feedback on preliminary codes, categories, and analytic decisions.²⁸ Memos reflected analytic deliberation and peer review (e.g., answering the question, “What is this about?”)²⁶ to dissect and confirm or redirect analytic processes taken by the investigative team.

Results

Twenty-four residents were invited to participate: seven declined, one was ineligible; 16 agreed and provided written consent. Fifteen family members were invited; three declined. Ten staff members were invited; none declined. Table 2

TABLE 2. SAMPLE CHARACTERISTICS OF NURSING HOME RESIDENTS (N = 16), FAMILY (N = 12), AND STAFF (N = 10)

| <i>Characteristic</i> | <i>Mean (SD) or percentage</i> |
|--|--------------------------------|
| <i>Residents</i> | |
| Age, years (range 64–100) | 88.4 (8.0) |
| Gender | |
| Female (n = 10) | 62.5% |
| Male (n = 6) | 37.5% |
| Race | |
| African American (n = 9) | 56.3% |
| More than one race (n = 1) | 6.3% |
| White (n = 6) | 37.5% |
| Marital status | |
| Widowed (n = 13) | 81.3% |
| Education | |
| < 12 years (n = 3) | 18.8% |
| High school graduate (n = 5) | 31.3% |
| Some college or trade school (n = 2) | 12.6% |
| College graduate (n = 4) | 25.0% |
| Postgraduate (n = 2) | 12.5% |
| Days in the NH ^a (range 118–2115) | 803.19 (616.35) |
| Cognitive Performance Scale Score (n = 14) (range 0–5) | 0.93 (1.33) |
| <i>Family</i> | |
| Age, years (range 52–79) | 61.3 (8.5) |
| Gender | |
| Female (n = 11) | 91.6% |
| Male (n = 1) | 0.08% |
| Race | |
| African American (n = 5) | 41.6% |
| White (n = 7) | 58.3% |
| Marital status | |
| Married (n = 8) | 66.0% |
| Education | |
| High school graduate (n = 3) | 25.0% |
| Some college or trade school (n = 2) | 16.6% |
| College graduate (n = 2) | 16.6% |
| Postgraduate (n = 4) | 33.3% |
| Relationship to NH resident | |
| Spouse (n = 1) | |
| Child (n = 7) | |
| Sibling (n = 2) | |
| Niece/nephew (n = 2) | |
| <i>Staff</i> | |
| Age, years (range 43–73) | 56.4 (11.9) |
| Gender | |
| Female (n = 9) | 90.0% |
| Male (n = 1) | 10.0% |
| Race | |
| African American (n = 3?) | 30.0% |
| White (n = 3) | 30.0% |
| Marital status | |
| Married (n = 7) | 70.0% |
| Education | |
| High school graduate (n = 1) | 10.0% |
| Some college or trade school (n = 1) | 10.0% |
| College graduate (n = 4) | 40.0% |
| Postgraduate (n = 4) | 40.0% |
| Staff position | |
| Chaplain (n = 2) | |
| Nurse (n = 2) | |
| Social worker (n = 2) | |
| Admissions coordinator (n = 1) | |
| Recreation therapist/activities (n = 2) | |
| Psychologist (n = 1) | |
| Years worked in NH setting (range 5–45) | 14.6 (13.3) |

^aDays in NH = date of admission to NH to date of interview.

TABLE 3. REASONS FOR MISSED CONVERSATIONS^a

| <i>Categories</i> | <i>Definition</i> | <i>Exemplar</i> |
|-------------------|---|---|
| Inquiry | Conversations where residents and family were asked or not asked about preferences related to end of life. Predominantly, “No one asked.” | Regarding staff inquiring about EOL preferences: “They never asked me.” (family) “No, I wasn’t questioned at all.” (resident) |
| Assumptions | Ways residents, family, and staff believed resident preferences were already known (they know and presence of AD). | “They know: Just know her. I haven’t asked her.... I know she didn’t want them to suffer and she wouldn’t want to suffer.” (family) “Presence of advance directive: I know what it means, they [staff] know what it means.” (family) |
| Conveying | How resident preferences related to end of life were conveyed (to others). | “No. No, that’s just confidence. Because who would I pass it on to? I wouldn’t tell her family and that’s confidential.” (staff) |

^aExchanges that did not occur or were not continued between residents, family, and/or staff related to EOL preferences of residents: who residents talked to, what they talked about, and when they talked about it.

presents the demographic and clinical information for 16 NH residents, 12 family members, and 10 staff members. The overarching theme that emerged from the analyses was missed conversations. Barriers to and facilitators for having conversations were identified.

Missed conversations

The overarching theme, missed conversations, described EOL-related communication in this sample. Residents, families, and staff did not routinely, if ever, discuss EOL care preferences, pass along information about preferences, or initiate conversations about preferences with each other. They talked about current food preferences, daily activities, medications/medication changes, or burial plans. Conversations did not commonly include discussion of a living will/AD, preferences for code status or hospitalization, use of hospice, or other care practices that might bring residents comfort. Interviews revealed inconsistencies in the process of discussing EOL treatment preferences in the NH (e.g., discussions held in care conference, at admission, or only if resident was on hospice)—and revealed inconsistencies in staff roles (e.g., “not my job”). Eliciting preferences about EOL was not integrated into care provision.

Reasons for missed conversations

The theme of missed conversations about resident’s EOL preferences weaves through three categories (see Table 3): inquiry, assumptions, and conveying.

Inquiry. Residents and families stated they were not asked by NH staff about preferences related to EOL. “They never asked me. They never asked me questions” (family). Residents also reported not being asked about other EOL-related preferences, such as pain management. “No, I wasn’t questioned at all” (resident). When probed if topics such as code status were discussed, for example, upon admission, some family members stated, “I don’t remember.” A few staff members reported they do not initiate conversations about EOL at admission because they are eliciting resident preferences related to psychosocial activities. “That wouldn’t be with the resident. That would usually be with the respon-

sible party and that’s Social Services. That’s not Nursing” (staff). Other participants conveyed someone in the NH obtains ADs upon resident admission and two staff participants said the directive may be discussed at care conferences.

Assumptions. These included ways residents, family, and staff believed resident preferences were already known by others. Assumptions were based on how a person responded in a previous experience, their relationship with the resident, or knowledge of a document, such as an AD. Two main assumptions were expressed: “They know my preferences” and presence of an AD.

“They know”. Many residents and families conveyed that residents’ EOL preferences were known because of previous experiences (e.g., witnessing decisions made for another relative) and those decisions would be replicated. “They know all about me” (resident). “Just know her. I haven’t asked her, but from other experiences with friends and my father I know she didn’t want them to suffer and she wouldn’t want to suffer” (family). Some residents stated staff would know certain preferences because of their current routines (e.g., prayer at night). Other than inquiring about psychosocial activities on admission, staff did not discuss ways they knew resident preferences. Two staff members talked about residents being like family. “You just build up a relationship and you know so much about them, like you are part of the family” (staff).

Presence of an advance directive. Residents, family, and staff conveyed different ways resident preferences were known to others (including ADs), which created the notion a conversation might not be needed. “I know what it means; they [staff] know what it means” (family). Residents, family, and some staff stated an AD for a resident was provided to the NH and could be referred to as needed. “They had a guideline” (family). However, the presence of an AD did not guarantee care was provided in the way families expected. One family member believed because a code status form (do-not-resuscitate order) was on file, they would not be approached about intensive treatments, and when they were approached they were surprised.

“She had a Do Not Resuscitate order. And yet the hospital called me and asked me about intubation. I said, well, she doesn’t want to be resuscitated. And they said, ‘Well, intubation is different than resuscitation.’ I was under the impression that Do Not Resuscitate is just let me go” (family).

Another family member felt their relative’s living will was not read or followed because of the intensive approaches to care. “Though he had had the living will, and had it at the nursing home, I think he [doctor] had never read it” (family). A few residents and family reported not having any type of AD (e.g., living will).

Conveying. Another category related to missed conversations was the lack of (mostly) conveying wishes. This category was influenced by the role or expectation of the person receiving information about resident preferences. Staff opinions varied over the confidentiality of information and whether it should be communicated to other staff. For one staff member, the reluctance to convey information was influenced by concern for adhering to regulations (e.g., HIPAA). One staff member in particular shared several encounters where residents told her their wishes, but she did not share the information with other staff. Even if they were part of the interdisciplinary team, the response to residents stating their preferences in an informal way (e.g., in the hallway), was, “You need to put it in writing” or “Have you talked with your [daughter/son]?” (staff). Two staff participants stated they could put information about wishes in the resident’s chart, and two staff explained their referral process for sharing information with other staff if information arose during conversation. Generally, staff did not describe ways they facilitated information sharing about EOL preferences.

Staff had beliefs about their role for querying or conveying resident preferences related to EOL, which influenced whether resident preferences were communicated to or among the interdisciplinary team. Conversing with other staff about informal conversations with residents or specific topics (e.g., a resident receiving hospice) was considered a breach of trust and outside their role. “No. No, that’s just confidence. Because who would I pass it on to? I wouldn’t tell her family and that’s confidential” (staff). However, sharing information was also seen as part of the job. “The team should share a lot of... Just like I know the medical stuff, I think that it’s an obligation of staff to really know the person.... We put notes in the chart, but obviously, I can’t document every interaction” (staff). Care conferences were mentioned by a few staff as a place for clarification of resident wishes.

Barriers and facilitators in EOL conversations

We identified barriers and facilitators in communicating about EOL preferences among residents, family, and staff (see Table 4). Barriers included the difficulty of having a conversation, not having a person to talk to, and not being knowledgeable enough to have a conversation. Two facilitators for conversations about EOL preferences included the experience of others and feeling comfortable with a conversation partner.

Discussion

In this paper we describe missed opportunities for communication about EOL preferences among NH residents,

family, and staff. Missed conversations occurred when (1) no one inquired—residents or families were not asked about their preferences related to EOL; (2) assumptions were made by residents, family, or staff that wishes were known; and (3) conveying resident information lacked a formalized process to converse about or share resident wishes.

Asking what is important to residents corresponds with the nationwide campaign to elicit resident perspectives in support of person-centered care.^{29,30} Despite providing care to many at EOL, NHs largely focus on rehabilitation and restoring function.³¹ Facilitating conversations about EOL contradicts this focus. While a couple of staff members stated certain components of preferences (e.g., AD) were revisited in quarterly care conferences, this was not expressed ubiquitously among staff. Residents and family reported that other EOL preferences (e.g., symptom management, psychosocial preferences) were not discussed. Some residents thought talking about EOL was normal but one described it as “negative.” Perceptions concerning the normalcy of EOL²¹ may influence willingness to have a conversation.

Assumptions referred to ways residents, family, and staff believed their wishes were already known. The presence of an AD may have averted conversations and created the assumption that resident EOL preferences were known. However, ADs have limited scope:³² they have not been shown to reduce unmet needs,¹⁸ to facilitate conversations, or to enhance planning for EOL.³³ Staff sentiments suggested they viewed residents like family,¹¹ which may have created assumptions regarding residents’ preferences and confusion between personal and professional relationships.²¹

Existing literature has focused on the completion of an AD;¹⁷ our research has revealed that conversations around the content of ADs was sparse. Similar to the finding of Fosse and colleagues,¹⁰ we found residents wanted to be involved in decision making concerning care. Staff reported residents often conveyed preferences informally, but no process was evident to integrate these wishes into a systematic or formal way of conveying preferences. Furman and colleagues found that systematic processes to elicit goals of care in NHs were lacking.¹⁴ The absence of a process for reporting resident wishes expressed informally may result from limited training, support, or knowledge about person-centered care¹¹ or facilitating such discussions.¹⁴

Our findings illustrate missed formal and informal opportunities for conversations about EOL preferences among residents, family, and staff. However, key elements were identified that could facilitate changing missed conversations into conversations that involve residents, family, and staff and elicit or account for resident preferences. First, the experience of others (see Table 4) was identified as a way to initiate EOL conversations. Older adults residing in NHs are in close proximity to other residents and witness EOL experiences firsthand. Hallway conversations may serve as a cue residents are thinking about their EOL preferences, believe EOL planning is normal,²¹ and want to convey their wishes. For example, staff follow-up with residents after a hallway comment could segue into a formal conversation and prevent a missed conversation.

Second, conversations related to EOL may depend on the persons involved. Residents, family, and staff expressed feeling comfortable with the person or making the person comfortable helps facilitate conversations. Asking residents

TABLE 4. BARRIERS AND FACILITATORS IN CONVERSATIONS ABOUT END OF LIFE

| Barrier | Exemplar |
|---|--|
| <p><i>Conversations are difficult:</i> Characteristics of conversations are difficult, included encountering differing opinions and denial; concern of being judged; and beliefs about talking, such as talking about EOL is not typical or viewed as negative or unpleasant.</p> | <p>There is this—in a way this discomfort with feeling that because of religious beliefs there is going to be a difference in attitudes of some of the staff members to this. And as I said, I felt this strongly in the [Southern Rose House], that some of the nurses were never the same after they heard that I had asked that he be taken off medication. And I think they looked at this as if I was committing a great sin, that this was God’s work and I should leave it up to God. There was some undercurrent of the disapproval. (family)</p> <p>Some people are very outspoken about it. Some people are scared to talk about it and don’t talk about it, but as human beings we have to face reality and so you talk about it when you have to. (resident)</p> <p>You have to know your own biases and make sure that you’re not imposing them. And you know, people deal with things in different ways, they hear different things. So you need to help them, but also you know it’s always a matter of giving a certain amount of space and allowing things to unfold and supporting that. (staff)</p> |
| <p><i>Conversations require knowledge:</i> characteristics of conversations Requiring knowledge was primarily expressed as a barrier by family and included lack of knowledge about ADs and communication strategies.</p> | <p>General lack of knowledge and people’s discomfort talking about death. General lack of knowledge about what one can or can’t do with ADs and living wills. People aren’t willing to take doctors on, be forceful if needed. Bad communication about this stuff. (family)</p> <p>I need to be knowledgeable to talk to my family. Or at least say to them this is something you need to think about. Or be sensitive to their needs, and have empathy. (family)</p> |
| <p><i>Conversations depend on the people involved:</i> Having a conversation about EOL was primarily identified by residents and depends on who is involved in the conversation.</p> | <p>You want to discuss it with those people closest to you or people that you trust. Like here I like to talk to [Cassie], but I don’t think anybody else. I’ll talk to you because you’re doing a study. (resident)</p> <p>Just that, if I had a nurse that I felt really wanted to hear it. I have the feeling that the nurses are just going from one person to another and they have enough.... So you just don’t have the feeling that they can spend much time with you. (resident)</p> <p>There are only a few people I’d want to share anything with. (resident)</p> |
| <p><i>Facilitators</i></p> | |
| <p><i>Experience of others:</i> The experience of friends, family, residents of having a health problem, dealing with EOL and/or dying was identified by all three groups as a good time to initiate conversation.</p> | <p>Especially when someone else dies you kind of really start talking about it when you lose a friend or another relative or when someone you know dies. Because normally that’s the topic of conversation. (family)</p> <p>If somebody close passes...that makes it easy. It opens the door a little bit. If somebody has an illness, if there is a clergy person around. (family)</p> |
| <p><i>Comfort and support from or with person involved in the conversation:</i> Feeling comfortable and supported serves as a facilitator if individuals feel comfortable and trust the person(s) they are talking to in a conversation about EOL. Staff participants conveyed the importance of taking interest in the resident they are talking to and being present in the conversation.</p> | <p>Being comfortable with the person you are talking to would make it easier. If you don’t like that person why would you confide or talk intimately because to me this is very intimate. You know. So, yeah, being comfortable with the person that you’re talking to. (family)</p> <p>They have to be here and have one person get their confidence, someone they can talk to, be it one of the nurses who some of them are very wonderful. They’ve seen life and they know what life is about. (resident)</p> <p>They [residents] don’t want to talk around their roommate. So I will say, Let’s go to the chapel, or Let’s go downstairs and have a cup of tea. Let’s go to a private place where we can talk. So they appreciate privacy and confidentiality. So that’s an enabler—privacy, confidentiality—and also if they can feel that you’re genuine, like I’m really into you. I am here for you. You have to relate that and if they feel that, then you know, I think that’s half the battle. (staff)</p> |

and family who they would like to involve in a conversation about EOL preferences is one way to include the resident and begin to establish trust.^{14,21} If residents do not identify a member of the interdisciplinary team who can integrate information into the resident care plan, establishing a process to convey information from the conversation will be important. Finding alternative methods for communication, such as video, may be valuable for those unable or reluctant to convey wishes in writing or a group setting, such as care conferences. Moreover, not all staff have access to write or read notes in residents' medical records. Education and training for all staff is critical for developing skills to facilitate EOL conversations, clarifying who to call for a referral, and documenting resident wishes.

Limitations

Interviews were retrospective; we did not observe conversations among residents, family, and staff. The breadth of staff roles meant not all staff (e.g., nursing assistants) were involved in resident and family conversations, potentially limiting the depth of information collected about EOL-related conversations between staff and residents. The social worker did not identify nursing assistants as potential participants—possibly because they may not be included in conversations about EOL. Family participants were identified by the social worker for our study, but not all were surrogate decision makers, which may have limited their engagement in previous conversations about EOL. Finally, EOL care preferences were not always clear between residents, family, and staff, possibly reflecting differences in terminology or reluctance to consider EOL.

Conclusions

Future studies may (1) examine the actual conversations that occur within and among residents, family, and staff around EOL preferences to confirm content of conversations; and (2) develop a structure for conversations and measure the outcomes and conversation quality. Missed conversations resulting in lack of knowledge about resident preferences may adversely affect quality of EOL care.³⁴ Conversations with residents can be initiated by asking residents who they would like involved in the conversation and drawing upon the experience of others. These approaches embrace person-centered care and are attainable for both family and staff.

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Address correspondence to:
Gail L. Towsley, PhD, NHA
University of Utah College of Nursing
10 South 2000 East
Salt Lake City, UT 84112
E-mail: Gail.towsley@nurs.utah.edu