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Feature Article

Talking about end-of-life care: Perspectives of nursing home residents

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ABSTRACT

The purpose of the paper is to describe how residents express preferences for end-of-life (EOL) care. For this qualitative study, we conducted semi-structured interviews and completed conventional content analysis to describe how residents' expressed their preferences for care at the end of life. Sixteen residents from four nursing homes (NH) in southeastern Pennsylvania participated in this study. Residents were on average 88 years old, primarily non White, and widowed. Three key domains emerged from the analyses: *Preferences for Today, Anticipating the End of My Life, and Preferences for Final Days*. Residents linked their everyday living and EOL preferences by using 'if and then' logic to convey anticipation and readiness related to EOL. These findings suggest new strategies to start discussions of EOL care preferences with NH residents.

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Introduction

Quality end-of-life (EOL) care in nursing homes (NH) is often problematic and conversations about what residents want rarely occur.^{1,2} NHs are complex environments balancing 24-h care for individuals with multiple disabilities and health needs and a place of residence. In this context, advance care planning (ACP) refers to an ongoing process of communication about care preferences (including EOL preferences) between NH residents, health care providers (HCP; care conference team, nurse manager, physician), and family members. The goal of ACP is to allow individuals to convey their care goals (current and future), values, and beliefs—which are all influenced by an individual's hopes and fears as well as their understanding of their health care conditions and available choices. However, ACP has largely focused on developing written advance directives and decreasing resource use—with varied results.^{3,4} Because ACP often focuses on completing advance directives, other important aspects of EOL conversations may be minimized or simply not discussed.

Identified barriers to engaging in EOL conversations include the HCP feeling uncomfortable, unprepared, concerned about causing

distress, and conversation timing (e.g., balancing too early with too late).^{5,6} An additional barrier may be HCP concerns about decisional capacity of an older adult with dementia. However, even though there is a high prevalence of cognitive impairment among the NH resident population,⁴ persons with mild to moderate dementia can accurately express their preferences for care.^{7–9} Finally, people residing in NHs often have multiple life limiting chronic conditions but they may not be at the end of their life, thus planning for uncertainty is challenging.¹⁰

Little is known about *how* NH residents want to have conversations about EOL, yet knowing how to approach EOL conversations may better engage residents and result in care that is better aligned with those preferences. The purpose of this study was to 1) describe the structure and content of conversations related to EOL that take place between staff, family members and NH residents² and 2) elicit EOL preferences of NH residents and describe how they express those preferences. In this paper we focus on EOL preferences of NH residents and describe *how* NH residents express those preferences.

Methods

We used a qualitative design to elicit and describe EOL preferences of NH residents and how they express those preferences. A convenience sample was selected from older adults residing in four NHs (three urban, one suburban; two were for-profit, two nonprofit) located in southeastern Pennsylvania. NH residents were

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Table 1
Nursing home resident preferences: Questions and probes.

Questions	Probes
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?	Values: 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)
What is important for those who are caring for you in the nursing home to know?	Location of death: Where would you prefer to die?
What is important for family members and friends who care for you to know?	Comfort: Who would you like to spend time with in your final days? (family, friend, clergy, pet, caregiver)
	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)

eligible to participate if they spoke English, were 60 years or older, and were anticipating a long-term stay (e.g., months, years), spoke English, 60 years or older, and were able to have a conversation about their preferences. The social worker in participating NHs identified residents who were able to have a conversation about their preferences for care and made initial contact with potential participants. The investigator (GLT) introduced the study and obtained informed consent. The Polisher Research Institute and the University of Pennsylvania Institutional Review Boards reviewed and approved the study.

Measures

A semi-structured interview guide (see Table 1) with the opportunity to probe questions was used to guide interviews. Examples of questions included in these analyses are, “What is it like to live here [in NH]?” “What would you like your final days to be like?” “What is important for those who care for you in the NH to know?” In addition, a brief chart NH record review of the Minimum Data Set was completed and the following data extracted on each NH resident: age, race, gender, cognitive assessment (e.g., cognitive performance scale¹¹ or Brief Interview for Mental Status¹²).

With permission from the participant, interviews were audio recorded (except one per request), and lasted on average 41 min (range: 20–73). Detailed notes of responses were taken throughout the one unrecorded interview (as close to verbatim as possible) and during and immediately following all interviews to document contextual information (e.g., emotional responses such as laughing or tearing up, and length of interview). Audio recordings were transcribed verbatim; transcripts were compared to the audio recording to confirm accuracy of transcription.

Analysis

Conventional content analysis¹³ was employed. Interview text was reviewed and organized using open and directed coding procedures. Open coding uses an inductive process which allowed for identifying how NH residents talked about EOL.¹⁴ The principal investigator (GLT) coded five transcripts to originate an initial coding scheme. Research team members independently reviewed two different transcripts (n = 4) to verify the coding scheme. Words and phrases highlighted in these four transcripts were compared to the initial coding scheme, discrepancies were discussed, and a final coding scheme was formulated to code all transcripts. Analytic notes were used to delineate and describe the most robust codes and categories and illustrate the domains.

Data management and rigor

An audit trail was used to ensure rigor by documenting analytic decisions such as adding, deleting, or reworking code names, and

synthesizing categories.¹⁵ The audit trail also included memos delineating analytic deliberation and peer review by a qualitative analysis group independent of the research team to explore and provide feedback on analytic processes (e.g. codes, categories, analytic decisions) taken by the investigative team.

Results

Sixteen of the 24 residents approached consented to the study and completed interviews (16/24, 66%). One resident was ineligible and seven declined to participate. On average, residents were 88 years old (range: 64–100), 10 non-White (62.5%) and 13 widowed (81.3%). Eight (50.1%) had 12 years of education or less and six (37.5%) graduated from college or were postgraduate. The mean cognitive performance scale (CPS)¹⁴ score (0.93, median 1, range 0–6, n = 13) or the mean Brief Interview for Mental Status (BIMS)¹⁵ score (15, n = 1) indicating that resident's cognitive function was borderline intact. Two cognitive assessments were missing. On average residents had lived in the NH just over two years (range: 0.3–5.8 years).

How do NH residents talk about EOL preferences?

Nursing home residents in this sample expressed responses to questions about EOL preferences that fit into three domains: *Preferences for Today*, *Anticipating the End of My Life*, and *Preferences for Final Days*. Routinely, residents sequenced their responses by first discussing preferences for today (here and now), next anticipating the end of my life (if and then), and finally preferences for final days (when and how).

Preferences for today

Residents talked about EOL in relation to everyday living and being “in the present” when asked about preferences for their final days. Often, they responded with current preferences of activities they are engaged in and desired approaches to care. Residents responded to questions about their final days by clearly stating they were *still living*. Residents described preferences for current routines, which included participating in activities (e.g. religious services) and engaging with family members in activities that occurred at the NH or in the surrounding community. Examples of statements reflecting participants' thoughts on “still living”:

Well, I don't think about the final one so far, I'm still living.

That's what I think is you have to keep on getting up and living.

And I can talk with people. That's a very important thing for me. I love to talk.

Within the domain of preferences for today, residents also discussed *desired caregiver approaches* which focused on wanting to be treated like a person by NH staff (e.g., care that was dignified,

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