Goals of Care or Goals of Trust? How Family Members Perceive Goals for Dying Nursing Home Residents

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Abstract

Purpose of Study: Dementia affects more than 5 million Americans, and is a leading cause of death. Family members of nursing home (NH) residents with advanced dementia report difficulty making decisions about care toward the end of life. As part of a randomized trial testing an intervention to improve decision making, this qualitative study aimed to understand how family decision makers experienced goal-based decision making in advance of the death of their relative.

Design and Methods: This qualitative study was conducted as part of the goals of care clinical trial. Study participants ($n=16$) were family decision makers in North Carolina whose relative with advanced dementia died after participating in the goals of care intervention. Semi-structured interviews were analyzed using a qualitative description approach.

Results: Family members' experience of decision making and death differed based on the presence or absence of trusting relationships with NH staff. Family members who reported trust described a positive end-of-life experience and less need for prescribed goals of care discussions. In the absence of trust, family members reported that goals of care discussions were ignored by staff or created confusion.

Implications: Among family members of persons who recently died from dementia in NHs, expressions of trust in staff were strongly related to perceptions of decision making about goals of care. Although goals of care discussions may potentially promote communication to earn trust, the presence of pre-existing trust ultimately influenced the decision making and end-of-life experiences of residents and families.

Keywords: advance care planning; communication; decision making; dementia; family

Introduction

ALZHEIMER'S DISEASE and other progressive dementias affect more than 5 million Americans.¹ These diseases are progressive and incurable, and increasingly a cause of death in the United States.² Most individuals with late-stage dementia reside in nursing homes (NHs), and two-thirds of dementia deaths occur in this setting.³ Late-stage dementia is characterized by medical complications such as infections, injuries, and nutritional decline, and thus, persons with dementia experience high rates of medical interventions near death.⁴⁻⁶ To ensure that medical interventions are aligned with family and resident preferences, communication between NH providers and family decision makers acting on behalf of their relative is essential.

Despite widespread improvement in quality of care in U.S. NHs, including reduction in physical restraint use, pressure ulcers, and uncontrolled pain, poor communication between NH staff and residents and their family members persists.^{7,8} When communication is poor, care practices are likely to be out of sync with resident and family preferences, resulting in outcomes such as undesired hospitalizations and feeding tube use.⁹ Advance directives and portable medical orders have been promoted to document treatment preferences, especially toward the end of life.¹⁰

Unfortunately, documentation of preferences does not guarantee improved communication for shared decision making about care. Specifically, the treatment-oriented approach of traditional advance directives has been criticized for asking about treatment options without considering overall goals of

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care as context for choices.^{11–15} Furthermore, advance directives may be difficult for residents and their families to understand.^{16,17}

Goal-based discussions address whether prolonging life is the most important medical goal, or whether goals such as maintaining function or promoting comfort should take priority. Once goals are prioritized, treatments can be matched to overarching goals.¹⁸ For example, hospitalization might be considered as a treatment that prolongs life, whereas pain management promotes comfort. Studies of the goals of care approach have shown it to be feasible and acceptable for NH residents with and without dementia.^{19,20} What is not known, however, is how family decision makers perceive goals of care decisions after their relative has died.

This study was conducted as part of a cluster randomized clinical trial of a goals of care decision-aid intervention. Conducted in 22 North Carolina NHs, the parent trial tested a video decision-aid about goals of care viewed by family members of NH residents with dementia, followed by their participation in a care plan discussion with NH staff. The goal of the trial was to determine the effects of the goals of care approach on the quality of communication and care for residents with advanced dementia.²¹ For this analysis, we focused on the unique subset of families who participated in the goals of care intervention and whose relative with advanced dementia died shortly thereafter. The purpose of these after-death interviews was to understand family members' experiences using goals of care decision making in advance of their relatives' death from advanced dementia.

Design and Methods

Participants

Family decision makers in the goals of care intervention sites were eligible to participate after the death of their relative with advanced dementia. To be eligible, NH residents had to have a diagnosis of dementia, be older than 65 years of age, score 5–7 on the Global Deterioration Scale (consistent with moderate to severe impairment),²² and have an English-speaking family decision maker. The family decision maker had to be the resident's legally authorized representative.

During the trial, 27 residents in the intervention group died, making their family decision makers eligible to participate in an interview about end-of-life decisions. When asked whether they would participate in the post-death interview, 16 (59%) agreed. Reasons for refusal included respondent burden and passive refusal.

Interview

The post-death semi-structured interview was designed to understand family members' experiences of decision making about goals of care. The interview included questions such as: How easy or challenging was it to choose a goal of care? Given your choice for goals of care, how did your relative's actual treatment differ from what you expected? Interviews were recorded and transcribed verbatim.

The interview was conducted between one and four months post-death by one investigator (C.R.). Informed consent was obtained in writing and confirmed verbally, and participants received a \$35 gift card upon completion. All

study procedures were approved by the University of North Carolina Institutional Review Board.

Analysis

An inductive, descriptive qualitative approach was taken to capture the perspectives and meanings of the participants' narratives. Qualitative description was done for the purpose of providing a descriptive, nuanced summary of the data.²³ Two research team members, with experience in both qualitative methods and NH care, comprised the primary coding team. As a first step in the data-driven analysis, they applied initial codes and identified similar topics across the transcripts. Eight transcripts were read independently and an initial codebook, comprising topics and definitions, was proposed. The initial codes were subsequently confirmed or refined based on additional coding and ongoing discussion. That is, both individuals applied codes independently for the remaining transcripts, then discussed and reached consensus on all codes, conferring when new codes emerged. Data were coded in ATLAS.ti (v. 7.5.10). After coding was complete, the research team reviewed and discussed the data, looking for patterns across transcripts. This comparative process allowed them to assess the overarching framework presented below.

Results

The 16 enrolled family decision makers represented 9 of the 11 intervention NHs. The majority were white (15/16), female (15/16), and daughters (13/16) of the decedent. Interviews lasted 22–67 minutes. Residents had lived in the NH an average of 5.1 years before death (Table 1).

Experiences with goals of care decision making differed based on whether or not family decision makers expressed trust in NH staff. With 100% agreement, two researchers independently categorized the transcripts based on the presence or absence of expressions of trust. When decision makers expressed trust in the NH, positive relationships with staff were evident, care was based on staff knowledge of the resident as a person, and staff did not appear to be overworked. Conversely, when lack of trust was expressed, decision makers lacked confidence that care was individualized

TABLE 1. SAMPLE CHARACTERISTICS (N=16)

Characteristics	n (%)
Family race	
White	15 (94)
African American	1 (6)
Family gender, female	15 (94)
Family relationship with resident	
Daughter	13 (81)
Spouse	1 (6)
Son	1 (6)
Cousin	1 (6)
Resident length of nursing home stay (mean, range)	5.1 years (10 months–17 years)
Resident time from study enrollment to death (mean, range)	4.6 months (3 weeks–8.5 months)

based on knowledge of the resident, staff seemed pressed for time to complete basic care practices, and staff did not welcome discussions about the resident's care or follow through with care plans. The eight family members who expressed trust in the communications and care practices of NH staff reported positive experiences with goals of care discussions and decision making. The seven who described absence of trust described their discussions about goals of care negatively, or had difficulty remembering whether substantive goals of care discussions happened at all. Finally, one family member described goals of care decisions in positive terms, despite lack of trust in NH staff.

Deciding on goals of care in the presence of trust

Three themes were evident when family members felt their relationships with the staff were based on trust: (1) the end-of-life experience was positive, (2) goals of care were dynamic, and (3) formal goals of care discussions were not always necessary.

The end-of-life experience was positive. All caregivers who discussed having trusting relationships with NH staff also said that the end-of-life experience was positive for the resident and themselves. For example, they talked about the staff being especially present and attentive, believing that good care prolonged their relative's life regardless of whether prolonging life was a goal of care. One daughter noted, "Not prolonged [life] in a negative way, but prolonged in a positive way. Nurses and staff were really attentive to her. They really stayed on top of her [care]." Also, family members who trusted staff reported that they themselves benefitted. Another resident's daughter stated, "We've had so much support. Some of the staff from the NH went to her funeral; and I got calls; and everybody wanted to know if we're doing okay after she passed away. So that made me feel good that they did consider us." Additional sample quotes for this and all themes are given in Table 2.

Goals of care discussions were dynamic. When relationships were based on trust, family decision makers experienced goals of care discussions as a process that was responsive to the resident's condition and nuances of treatment decisions. One daughter stated, "I wouldn't be expecting mom to get up and walk again after she had been there four years. But in the very beginning when she went there the goal was to reestablish as much of her mental and physical abilities as we could, and then gradually it changed."

Formal goals of care discussions were not always necessary. Lastly, in the context of trust, family members reported less need for formal goals of care discussions. Instead, ongoing interactions based on trust allowed for shifts in goals of care to occur gradually over time.

Deciding on goals of care in the absence of trust

Three themes were evident when family members felt their relationships with staff were not trusting: (1) the end-of-life experience was negative, (2) goals of care were ignored by staff, and (3) goals of care discussions created confusion for family decision makers.

The end-of-life experience was negative. Nearly all family members who did not have trusting relationships with staff reported that the end-of-life experience was negative for the resident and themselves. Illustrative quotes include a daughter who said, "I'm just wondering if she lay there and nobody even checked on her. I mean there's a question in my mind. [The nurse] said to me, 'We went in there and she wasn't doing good, so we went and got somebody. She's already gone,' like she just died instantly. But it seemed to me that there was a long period in there for her to have already turned white."

Goals of care discussions were perceived to be ignored. Family members who reported a lack of trust in the staff noted that goals of care discussions seemed to have little impact; in essence, they perceived all residents were treated the same, based on institutionalized care practices. One daughter said, "Now as far as the NH, they never really sat down and discussed anything with me, and I just kept telling them that I wanted her comfortable, and by being comfortable I mean in more ways than one. I didn't want her to be fearful. I didn't want anxiety. I would talk with the staff, but things didn't get filtered down or they would get filtered down wrong."

Goals of care discussions created confusion. In the absence of trust, family members were confused as to the intention of goals of care and their own role as decision makers. The daughter of a resident said, "So when I walked in Mom's mouth was open and she was breathing very hard. I went out to the floor nurse and said, 'Mom seems to be having difficulty breathing.' The supervisor that was there said, 'Oh well do you want us to put her on oxygen?' I've said this kind of stuff to them before. I said, 'Well I don't know, I'm not a doctor, I'm not a nurse. I don't know how to advise you on whether or not she needs oxygen, all I'm saying is that she looks like she's having a hard time breathing'."

Discussion

Making decisions for a family member with advanced dementia living in a NH can be difficult. A goals of care approach is not only feasible, but also has the potential to improve the quality of communication and agreement regarding care.¹²⁻¹⁴ Our interviews with families involved in decision making in advance of the death of a relative found that trust between NH staff and family decision makers is central to experiences with goals of care for dementia; trust may moderate the effectiveness of the goals of care decisions and other efforts to improve decision making.

Although this study focuses on goals of care communication for persons with dementia, the importance of trust in NH care likely extends to families of residents with diverse conditions. Prior research has shown associations between expressed trust in NH providers and better mental and functional outcomes for older patients,²⁴ and acceptance of the NH as the site of end-of-life care.²⁵ Trust is not an innate or static element in relationships; it is earned by both parties through compassion and responsiveness, but eroded by incompetent care, lack of communication and cooperation, or avoidance of family or staff concerns.²⁶⁻²⁹ Suggestions to build trust include sufficient and consistent staffing,

TABLE 2. SAMPLE QUOTES ILLUSTRATING THEMES RELATED TO GOALS OF CARE DECISIONS IN THE PRESENCE AND ABSENCE OF TRUST IN NURSING HOME STAFF

<i>Theme</i>	<i>Example</i>
In the presence of trust	
The end-of-life experience was positive	<p>Daughter: The [nursing assistants] went above and beyond what was asked of them. I would see them come in the room every 15–20 minutes to see if my mother needed anything, or sometimes they would just come in to sit down and chat. It wasn't like that was required of them to do. [One nursing assistant] offered to bring us coffee, tea. It was just different things that they did that wasn't part of the job description, is what made them stand out in my eyes.</p> <p>Daughter: The other thing is that they were gracious enough to continue to help her get out of bed and into the chair rather than just leaving her in bed all day long, and I think that in itself also prolonged her life.</p> <p>Wife: I came in that door, and there were six or seven of the CNA's (certified nursing assistants) who had worked with him over all this time all lined up on the hall. And then the RN came up and brought me in here and said he had passed away. When I walked out, there were all these girls. One came over and gave me her arm, and one of'em had a box of Kleenex, and they walked me over to the room. I can't tell you how I felt when I saw all of those girls that had worked with him and knew me. It was the kind of support that I would hope anybody in that situation would have because you're not alone then. You feel like there are a whole bunch of people that are gonna hold you up.</p>
Goals of care discussions were dynamic	Daughter: I mean, it was time for changing our minds about how deep or far we would go with making something right for her, because at that point it just reached a point where nothing that was done was going to get her out of the bed and allow her to have that kind of life again. And so that's when we reached a point of just going to pain and comfort measures.
Formal goals of care discussions were not always necessary	Daughter: We had actually not spoken of it [goals of care] in those terms. I knew that they were trying to make her quality of life as good as possible and as functional as possible for as long as they could. And then near the very end, they switched to keeping her comfortable. But we didn't ever really need to have that conversation.
In the absence of trust	
The end-of-life experience was negative	Daughter: I feel very guilty because that night they called me and said that they could not revive her, that I maybe should get up there, and that shocked me. I feel really bad about that because I wish I had spent more time with her that day, but I was tied up with the staff trying to come up with a plan of care for her.
Goals of care discussions were perceived to be ignored	Son: They were more hung up about what they can and can't do, and the rules and regulations, and what you can get into trouble for. They treat everybody pretty much the same. If you're looking after your mom, then you're going to do what you want done for your mom. If somebody else is looking after her, unless you have a really close relationship with them, they're going to follow some kind of practice that they're instructed to do.
Goals of care discussions created confusion	Daughter: And what has always been confusing [about goals of care] is, are we really talking about the end-of-life or are we talking about continual care? Last fall she was up and about doing her thing and she was a functioning person, and that's separate from the end-of-life, which is what she went through in the last 24 hours of her life. And to me that is what the MOST form gets at, so I guess that end-of-life falls into the comfort bucket in terms of goals for care.

person-centered policies and practices, and flexible routines. Specific to communication, providing information to families and changing care based on advance consultation are advised.^{30,31} Of course, family members also have responsibility, such as to seek participation in care planning.

Based on the results of this study, communication and care practices to earn trust might improve the end-of-life experience, help family members feel heard, and avoid confusion when treatment decisions are needed. Future exploration of therapeutic alliances and strong communication networks between healthcare providers and families may be a useful pathway to person-centered care and reduced decisional conflict in the NH context.³²

One matter that merits attention is decision makers' confusion about whether goals of care decisions are applied to daily living or only when death is imminent. For those with advanced dementia, goals of care decisions are intended to guide current care, which may precede death by many months over an irreversible but slow trajectory.³³ In this study of family of decedents, such goals translated to end-of-life decisions by default. Future initiatives would do well to clarify that goals of care relate to both daily living and active dying.

An important consideration in any qualitative study is the extent to which thematic saturation occurs. In this study, thematic saturation was evidenced by 100% agreement across all transcripts about the presence or absence of trust. Furthermore,

with only one exception, the valence between trust and participant's experience of goals of care decision making was the same. It is possible that our study participants agreed to be interviewed because they had especially strong positive or negative opinions about the quality of care in their NH or the care practices around their relatives' death. As such, although thematic saturation did occur, our findings may be most transferable to those who had strong opinions about their experiences in the NH.

In conclusion, among family decision makers of persons who died from dementia in NHs, expressions of trust were strongly related to perceptions of decision making about goals of care. All participants in this study experienced regular NH care augmented by the goals of care decision aid and more in-depth discussion of goals of care. Families reflecting on decision making after death occurred expressed different communication experiences in the presence or absence of trust in the communicators. Although goals of care discussions themselves promote the communication that may help to earn trust, differences in pre-existing trust may ultimately influence the end-of-life experience of residents and families.

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