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Guilt as an Influencer in End-of-Life Care Decisions for Nursing Home Residents With Advanced Dementia

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Abstract

The concept of guilt has been studied in the context of caregivers of older adults with advanced dementia, usually describing the feelings a person has of placing a loved one in a long-term care facility; however, little research has been done to understand how nursing home staff and proxies for older adults with dementia describe guilt as a decision-influencer in end-of-life care. For the current study, private, semi-structured interviews were conducted with 158 nursing home staff and 44 proxies in 13 nursing homes across four demographic regions in the United States. Interviews were reviewed and analyzed for how the concept of guilt was perceived as a decision-influencer. Nursing home staff described guilt as an important influencer in why proxies make decisions about end-of-life care. Staff noted that proxies who felt guilty about their relationship with their loved one or lack of time spent at end-of-life tended to be more aggressive in care decisions, whereas no proxies mentioned guilt as an influencer in care decisions. Rather, proxies used language of obligation and commitment to describe why they make decisions. Findings highlight the disconnect between nursing home staff and proxies in what motivates proxies to make end-of-

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life decisions for loved ones. Nursing home staff should be aware of misconceptions about proxies and work to understand proxies' true rationale and motivations for making care decisions.

Feelings of guilt are common among family caregivers. Guilt among caregivers of older adults with dementia is a negative feeling resulting from conflict between one's actions and one's internal moral compass (Gallego-Alberto et al., 2020; Losada et al., 2010; Prunty & Foli, 2019). Guilt can be related to feelings family caregivers have regarding care they provide for their loved one, neglecting others, taking time for self, and the decision to place a loved one in a long-term care facility (Davis et al., 2019; Gallego-Alberto et al., 2020; Graneheim et al., 2014; Walmsley & McCormack, 2021); however, less is known about how guilt influences family caregivers who serve as proxy decision makers for those with advanced dementia at end of life.

Many family caregivers of adults with advanced dementia experience guilt. Guilt can come from a variety of sources, including the caregiver's relationship with the person with advanced dementia, the level of perceived care that they provide, and decisions that are made about placing a loved one in a nursing home (Davis et al., 2019; Forbes et al., 2000; Prunty & Foli, 2019). Guilt is closely related to stress or caregiver burden and can amplify feelings of inadequacy (Davis et al., 2019; Prunty & Foli, 2019). Guilt can also result in depression and anxiety for the caregiver (Davis et al., 2019; Prunty & Foli, 2019).

In advanced dementia, many family caregivers serve as proxies and are asked to make difficult end-of-life care decisions. Making end-of-life care decisions for people with advanced dementia can involve challenges and uncertainty for proxies (Caron et al., 2005; Fetherstonhaugh et al., 2019; Lopez & Guarino, 2011; Sellars et al., 2019); however, how guilt plays a role in end-of-life care decisions, such as completing an advance directive, sending someone to the hospital, or inserting a feeding tube, has not been studied. Because these care decisions are significant in that they influence quality of life at end of life, further investigation is warranted into what influences these decisions. Experts have long advocated for a palliative approach to care for people with advanced dementia, including reducing burdensome interventions, such as feeding tubes and hospital transfers; however, some proxies still choose these interventions for their loved ones with advanced dementia (Gieniusz et al., 2018; Mataqi & Aslanpour, 2020; van der Steen et al., 2014).

Nursing home staff and decision-making proxies work closely together in caring for adults with advanced dementia, especially at end of life, when important decisions are made regarding care needs. However, there can be poor communication and discordance between health care providers and family (Falzarano et al., 2020; Sánchez-García et al., 2017). This discordance can lead to lack of trust, barriers to completing advance directives, and poorer quality of care. Sometimes nursing home staff may make assumptions about families' desires without engaging in shared decision making. Understanding the role of guilt as a decision-influencer from nursing home staff and proxy perspectives can provide insight into decision-making processes and the relationship between staff and proxies. In this context, the purpose of the current study was to describe how staff and proxies associate guilt in care decisions at end of life.

METHOD

The current study was approved by the Advarra Institutional Review Board. Verbal informed consent was obtained from all study participants. A qualitative, secondary analysis was conducted of data from the Assessment of Disparities and Variation for Alzheimer's Disease Nursing Home Care at End of Life (ADVANCE) research study. Details of the methodology of the ADVANCE study can be found elsewhere (Lopez et al., 2021). The objective of this parent study was to examine regional and racial variation in end-of-life care for nursing home residents with advanced dementia. In the current study, we focused specifically on developing a deeper understanding of the role of guilt in decision making for residents with advanced dementia. Qualitative descriptive methodology was used to provide a comprehensive understanding of decision making at end-of-life care from multiple perspectives (Sandelowski, 2000).

Setting and Sample

The current study was conducted in 13 nursing homes in four states in the Northeast and Southeast regions of the United States. Using nation-wide Minimum Data Set (MDS) assessments for 2016–2017, we purposefully selected hospital referral regions across the United States and nursing homes within those hospital referral regions as providing either high or low intensity care to nursing home residents with advanced dementia. Residents with advanced dementia were those meeting the following eligibility criteria based on MDS assessment closest to April 1, 2016 (±60 days): nursing home length of stay >100 days, Alzheimer's disease or other dementia, and severe cognitive impairment defined by a Cognitive Function Scale score of 4 (range = 0 to 4, higher score indicates worse impairment) (Thomas et al., 2017). To quantify intensity of care, we used the proportion of residents with advanced dementia with a feeding tube and the number of hospital transfers per resident-year alive. For this study, we included six nursing homes with high intensity care and seven nursing homes with low intensity care.

For staff, inclusion criteria were age >21 years, able to communicate in English, and involved in the care of residents with advanced dementia for ≥2 months. Inclusion criteria for proxies were age >21 years, a decision maker for a resident with advanced dementia, and able to communicate in English. Participants included 158 nursing home staff, including 12 directors of nursing, 35 nurses, 23 nursing assistants, 12 administrators, 16 prescribing providers, 10 dieticians, 11 speech language pathologists, three occupational therapists, 14 social workers, four chaplains, and 18 other staff. Forty-four decision-making proxies of nursing home residents with advanced dementia were also interviewed. Proxies included five spouses, 25 children, 12 other family members, and two legal guardians. Mean age of proxies was 61 years.

Data Collection

Data were collected by trained research assistants using semi-structured interviews either in person in a private location at the nursing home or via telephone. Interviews were digitally recorded and included open-ended questions asking participants about what influences decisions surrounding end-of-life care for residents with advanced dementia, including decisions about advance directives, feeding tubes, and hospital transfers. Examples of questions from the parent study can be found elsewhere (Lopez et al., 2021). Participants were not explicitly asked about guilt as an influencer in end-of-life care decisions.

Data Analysis

Recorded interviews were transcribed verbatim, checked for accuracy, and imported into QSR NVivo 12.0. Qualitative analyses were conducted using NVivo by a team of researchers that included two PhD-prepared researchers (A.R., R.P.L.) and two PhD candidates (A.H.R., M.H.).

Interviews were coded independently by all team members. Staff interviews were reviewed specifically for mentions of perceptions of what influenced proxies' decisions at end of life and proxy interviews were reviewed for mentions of their role as a decision maker. The team then met to review individual coding and consensus on the coding was reached via discussion. The primary author (A.R.) reviewed all interviews coded for "guilt" and developed subthemes, which were then presented to the research team for further discussion and consensus (Morse, 2015).

RESULTS

Although participants were not asked explicitly about guilt as a decision-influencer in end-of-life care decisions, participants mentioned guilt as an important influencer. Analysis revealed a disconnect between the way that nursing home staff and proxies spoke about and perceived proxies' sense of guilt as an influencer in end-of-life care decisions. Nursing home staff described two sources of proxy guilt: (1) proxies' personal relationship with their loved ones, and (2) guilt about lack of time spent with their loved one in the nursing home. Staff also reported that proxies who felt guilty tended to choose more aggressive care; however, no proxies mentioned guilt as an influencing factor in their decision making about end-of-life care. Rather, proxies described their role as decision makers as being difficult, a privilege, and a job. One proxy described feeling guilty about placing her loved one in a nursing home, but not about end-of-life decisions.

Nursing Home Staff

Guilt About Personal Relationship With Resident.—Nursing home staff noted that proxies' guilt was a result of the relationship between the proxy and the nursing home resident, going back long before the resident was in the nursing home or had advanced dementia. Some staff believed that there were issues in the relationship that went beyond what they could deal with as health care providers:

> They'd feel guilt; they want to do whatever they can to prolong life. I think a lot goes into it with the personal relationships that were before-hand…which obviously we're not part of as the health team.
>
> (Staff 1)

Staff expressed a sense that proxies were trying to make amends for past relationships with residents. There may have been some unresolved conflict, or possibly feelings of inadequacy in their role in the relationship: “Guilt. Families feel guilty that they haven’t done enough so they’re making up for it now” (Staff 2). These feelings caused proxies to seek more aggressive care at end of life because they weren’t at peace with their relationship: “My opinion is guilt and selfishness. They haven’t cleared the air about something, they’re not willing to let the person go yet” (Staff 3).

Guilt About Not Being Present at End of Life.—

Nursing home staff also discussed their perception of proxies’ guilt in relation to proxies’ involvement in end-of-life care in the nursing home. Proxies who were not involved in the resident’s care or did not visit in the nursing home tended to feel guilty about their lack of involvement and therefore sought more aggressive care at end of life:

> It’s the family members that aren’t around that tend to have the problem or maybe haven’t seen mama in 5 years that are more hesitant to make those decisions and I think that’s a guilt kind of thing.
>
> (Staff 4)

Nursing home staff believed that proxies’ tendencies toward more aggressive care at end of life was a result of trying to assuage their feelings of guilt for their lack of involvement:

> I think it comes down to guilt. I think family has a lot of guilt. Like, “Oh you know, I haven’t visited enough, this is my fault, I didn’t do all this stuff.” So, I think it’s kind of why they push some things that, from like a medical point of view, we’re like, “Well, this isn’t really the safest.” But, sometimes family do things because it makes them feel better.
>
> (Staff 5)

Guilt about not being involved was compounded by not being aware of the condition of the resident. Not only did proxies feel guilty about not being at the nursing home, they also did not understand the disease trajectory and the decline experienced by the resident:

> I just think that it’s a guilt thing. You’re not here. You’ve not seen her. So you’re gonna, “No, my mama wouldn’t want that.” But you haven’t been here to see her decline and go through all the stages of dementia and now she’s here and she’s not going to go back up and I just personally think it’s a guilt thing for not being around and then you can’t help that…but you’re holding onto that last little piece that you have.
>
> (Staff 6)

Proxies

Decision Making is Difficult.—

Proxies discussed difficulty in being decision makers. This difficulty may be because they did not know their loved ones’ wishes, but not because they felt guilt about the relationship. They still sought to act with good intent: “It’s very difficult because I don’t know what she wants, but I try to do it with her best interests in mind” (Proxy 1). Not knowing the resident’s wishes also made proxies feel uncomfortable because they were taking on a big responsibility for someone else:

> That's been difficult because it made me decide to go ahead and do a will and a direct living will for myself because I don't see that someone else should have the control over another person as far as their life. I don't feel that I have that right to make the decision for another person, but she had not put that in place, somebody had to step up and make the decision for her. I don't like doing that.
>
> (Proxy 2)

Decision Making is a Privilege.—Despite the difficulty of making decisions, proxies believed that their role as decision maker was a privilege. Rather than viewing this role as something that was driven by guilt, they saw their role as a responsibility, albeit a large responsibility:

> It's a privilege. It's a big responsibility for an adult. It's a big responsibility to honor their wishes and to keep in perspective all the different factors, like quality of life and income and budget and ability to pay for care and all the things.
>
> (Proxy 3)

Some proxies felt honored to make decisions for their loved ones and were intentional about honoring the wishes of their loved ones. Knowing their loved ones and knowing their wishes seemed to make this responsibility more of a privilege than a burden:

> It's an honor to be able to do it for someone. I mean, I take it seriously and I want to be able to provide what it is that she would want, just knowing her as I have over the years.
>
> (Proxy 4)

Decision Making is a Job.—Some proxies were very matter of fact in the way they viewed their decision-making responsibilities. They acknowledged the difficulty and privilege of their role but saw it as a job or something they were "supposed" to do:

> I realized that we are husband and wife and we are supposed to take care of one another so it doesn't bother me. It makes me feel proud that I'm able to do it.
>
> (Proxy 5)

> It's not really been too much of a problem. It's what I do…but she is my mother so obviously I have to take care of her. So it's not a big deal.
>
> (Proxy 6)

Proxies did not mention guilt in reference to their job, even when they felt conflict between their own preferences and the decisions they made for their loved ones. Even though proxies may have had different preferences for themselves, they felt responsible for advocating for what the resident would have wanted:

> It was kind of difficult for me at some points because I personally for my own care tend to be a little more aggressive and she was just so not aggressive that it felt difficult in advocating for her at that level, but that was my job and I knew herself very, very well.

(Proxy 7)

When proxies did not know exactly what the resident wanted, they still felt the need to advocate and speak up for them:

> [It's] something I have to do. I mean it's not easy. Sometimes you don't know if you're making the right decision. You can't know if what you're saying is what he really needs, but I also know the worst is to not say anything, to not advocate for him, defend him because in a nursing home he needs to be defended more and more as time goes by.

(Proxy 8)

Guilt for Placing in Nursing Home.—One proxy mentioned guilt, but not in relation to end-of-life care decisions. She described how hard it was to place her loved one at the nursing home. She experienced conflict with her decisions and about knowing whether it was the right thing to do. She struggled because she wanted to be present for her loved one but did not want to cause her more confusion:

> You feel guilty about leaving them because when I first brought her in the decision was made to leave her and don't come back for a while and I think that…that hurt in a way but I didn't understand because when they first come in, they always trying to get out and when you come to visit, they try to leave with you. All that causes pain and the person not understanding what they're going through at the moment.

(Proxy 9)

DISCUSSION

The purpose of the current study was to describe how nursing home staff and proxies of nursing home residents with advanced dementia understand proxy guilt as an influencer for end-of-life care decision making. Our findings indicate a disconnect between staffs' and proxies' perceptions of guilt. Whereas staff repeatedly commented on guilt being an influencer in end-of-life decisions, proxies did not.

Our findings suggest that staff assume proxy guilt influences proxies to make decisions for more aggressive treatment at end of life, including sending residents to the hospital or placing feeding tubes with the hope that these interventions will prolong their lives. This finding is consistent with other studies that have found that nursing home staff perceive guilt as an influencer in decision making for adults with advanced dementia (Brea et al., 2016). Staff assumed that proxies had unresolved conflict with their loved ones or that they were trying to make up for not being present. Staff described assumptions of what drives proxy decision making but did not include actual examples of proxies making decisions based on guilt.

In contrast, proxies did not describe guilt as an influencing factor in making decisions about end-of-life care. These findings differ from other studies that found that health care proxies do experience guilt when caring for individuals with advanced dementia (Davis et al., 2019; Gallego-Alberto et al., 2020; Graneheim et al., 2014); however, guilt is related to negative emotions toward loved ones, their performance as a caregiver, engaging in self-care, and placing their loved ones in a nursing home (Prunty & Foli, 2019). In their concept analysis of guilt experienced by caregivers of individuals with dementia, Prunty and Foli (2019) do not mention guilt as influencing end-of-life care decisions. Similarly, Gallego-Alberto et al. (2020) listed seven categories of guilt in caregiving, none of which include making end-of-life care decisions, which is consistent with our findings. Rather, we found that although proxies acknowledged the difficulty in decision making, they did not experience internal conflict regarding end-of-life care decisions. The one proxy who mentioned guilt felt guilt about placing her family member in the nursing home, which is a common experience among caregivers (Graneheim et al., 2014; Walmsley & McCormack, 2021).

One explanation for the lack of guilt expressed by proxies could be because of previous conversations between proxies and older adults with advanced dementia about end-of-life decisions. Having these conversations and knowing the wishes of loved ones before dementia is in the advanced stage can ease the burden around decision making (Mountford et al., 2020). Lack of guilt could also be attributed to proxies genuinely wanting to provide the best possible care for their loved ones, and therefore not experiencing the internal conflict of going against their loved ones' wishes (Lopez, 2009).

IMPLICATIONS FOR NURSING

Implications of the current study include the need for nursing home staff to have conversations about end-of-life decisions early, ideally upon admission, to mitigate feelings of guilt for proxies. More open communication between providers and proxies about sources of guilt could avoid false assumptions and better address actual sources of guilt rather than assumed sources of guilt. Conversations do not necessarily need to focus on guilt but should involve establishing trust and include education about disease trajectory and honest communication regarding burdensome interventions. Having these conversations can allow time for proxies to reconcile any internal conflicts or feelings of guilt before their loved ones reach the advanced stage of dementia. Nursing home staff, especially nurses, should be provided with training and tools to have these conversations, as these topics are not often addressed in nursing school curricula. Nurses should also prioritize time for conversations with families to increase concordance and engage in shared decision making. In addition, time should be reimbursed by insurance, as poor communication and discordance can lead to poorer quality of care (Roberts & Ishler, 2018).

Furthermore, nursing home staff should be aware of assumptions and biases about proxies' motives for making decisions. If staff assume proxies feel guilt and desire aggressive treatment, they may not be inclined to have important conversations with them about care decisions and engage in shared decision making. Nurses should routinely examine their personal biases and nursing homes should implement systems to document conversations so that conversations are built into the nursing workflow and care processes so these conversations are not dependent upon assumptions or biases.

LIMITATIONS

There were several limitations to the current study. Because participants were not asked directly about the role of guilt in decision making, proxies may not have considered or acknowledged underlying feelings of guilt. For this study, contextual and demographic factors, such as regional and racial differences of participants, were not considered and could possibly influence the perception of guilt as an influencer in end-of-life care decisions. Future research into these factors and how they intersect with decision making is warranted. Furthermore, this study only focused on proxies of older adults who had progressed to late-stage dementia. Additional research is needed in understanding guilt in end-of-life decision making earlier on in the disease process.

CONCLUSION

Guilt is often experienced by proxies for older adults with advanced dementia. These feelings should be recognized by nurses and other health care providers to support proxies in the role they play in caring for their loved ones. However, health care providers should be careful about making assumptions about what influences proxies’ decisions and work collaboratively with proxies to understand their intentions and rationale. Making efforts to understand these intentions can help reduce implicit bias, reach concordance, and allow for nursing home staff and proxies to work collaboratively to provide the best possible care for nursing home residents with advanced dementia.

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