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Proximal Discourses in Residential Facility Care Providers' Sense-Making of Their Communication with Family Members of a Loved One with Alzheimer's Disease

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ABSTRACT

Families often stay involved in the care of a loved one with Alzheimer's disease even after relocation to a residential care facility, and through this transition, communication between the residential care providers and families becomes integral to keeping family informed and providing good care to the patient. However, care providers of people with Alzheimer's living in residential facilities find themselves overwhelmed by expectations related to their caregiving role and struggle with making sense of their experiences. Fifteen care providers of people with Alzheimer's disease living in a residential facility participated in qualitative, semi-structured interviews. Using relational dialectics theory as the framework through which to examine how residential facility care providers make sense of their communication with families of patients with Alzheimer's, analysis revealed three sets of competing proximal discourses: family inclusion and exclusion, reality and positivity, and expert and layperson provision of care. We address conclusions for scholars, implications for care providers and facilities, limitations, and suggestions for future research.

More than six million Americans aged 65 and over have Alzheimer's disease (AD) (National Institute of Aging, 2021), a "type of dementia that affects memory, thinking and behavior" (Alzheimer's Association, 2023b). Individuals first show mild signs of memory loss, then symptoms progress and worsen over the years. In the later stages of AD, people experience a breakdown of physical, cognitive, and communicative functions. A person with Alzheimer's lives, on average, 4 to 8 years after their diagnosis but can live as long as 20 years (Alzheimer's Association, 2023b). To date, there is no cure for AD; however, recent medical developments have provided some hope that medications (e.g., Aducanumab, Lecanemab) can address the underlying biology of the disease to reduce speed of decline.

People with AD may continue to live in their homes; however, logistics of staying at home prove challenging if not impossible because of their deteriorating health (Gold et al., 1995). Also, not everyone with AD has loved ones or hired caretakers who can live at or come into their home to provide care and companionship (Cooper & Pitts, 2022). Further, adult children and spouse caretakers experience caregiver burden from the stress of the caretaking role that is often quite overwhelming (Chappell et al., 2014). As a result, the person with AD may move into a long-term residential facility that can include retirement housing, assisted living, nursing homes, and memory care units (Alzheimer's Association, 2023a). In addition to having access to onsite medical care, people with Alzheimer's may benefit from the social interactions that come with living around others (Arai et al., 2021).

There are many people involved in the system of care for someone with AD living in a residential facility. Members of this care system are often interdependent and exert mutual influence as they work to support the person with AD (Miller-Ott et al., 2022). Thus, it is important to examine how residential facility care providers perceive and make sense of communication with patients' families, particularly in light of how relationships with family members may impact quality of care (Gaugler et al., 2014). People engage in sense-making – an interpretative process of trying to understand their experiences – particularly when faced with difficult situations (e.g., Horstman, 2019). Sense-making occurs through "language, talk, and communication" (Weick et al., 2005, p. 409) that helps people assign meaning to an occurrence. It may be particularly challenging for residential care providers to make sense of their roles as care providers as they struggle with stress and burnout (Åhlin et al., 2022) and experience understaffing and high turnover rates that can exacerbate care providers' distress (Gaugler et al., 2014). They also struggle with being pulled in multiple directions and have limited time to provide the care that their patients need or family members expect (Åhlin et al., 2022). How they make sense of their communication with families may impact their feelings of burnout and the provision of quality of care. For this study, we were interested in investigating how care providers in residential facilities make sense of their communication with families of someone with AD under their care. We chose to use relational dialectics theory (RDT) as the framework through which to examine their sense-making, as people often reflect on and try to make

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sense of their lives through competing needs, demands, and/or expectations (Baxter, 2011).

Literature review

Family interactions with non-familial care providers

Once older adults experience significant health declines (Baltes & Smith, 2003), they may relocate to a residential care facility (Gill & Morgan, 2011), a turning point that is often difficult for the person and their families to navigate. Living in a residential facility, around others who may be in far worse health than the individual, is a constant reminder of mortality, health issues, and death (Gill & Morgan, 2011). However, benefits of relocation include decreased risks of living alone and increased companionship (Gill & Morgan, 2011). Moving a loved one into a residential facility involves talking to the family member about the move, discussing their care once moved, and talking with those providing residential care (Shue et al., 2005).

Much of what we know about communication surrounding an aging loved one's relocation to a residential facility or nursing home is focused on internal family dynamics. Relocating a family member with AD to a care facility is stress- and grief- inducing for family (Meuser & Marwit, 2001), particularly for older family members who live far away, who have not provided care before the relocation, and who have low expectations for the type of residential care their loved one will receive (Tornatore & Grant, 2002). Often, the person with AD cannot comprehend the move, and at times, family members may deceive the person by saying that the relocation is temporary (Shue et al., 2005). Families often struggle with accepting the relocation when the loved one continues to demonstrate some independence (Shue et al., 2005).

Working in a residential care facility and providing care to patients with AD is very taxing – emotionally, mentally, and physically. Even after a patient is relocated to a residential facility, family members can still be involved in and communicate about care, to the point of being disruptive to the provision of care (Planalp & Trost, 2008). Families often have high, and sometimes unrealistic, expectations of residential facilities. Gaugler et al. (2014) found that people's perceptions of *optimal* care in nursing homes includes: "proper staffing, regular and thorough assessments, care planning, appropriate management of symptoms, and environments that are conducive to the changing abilities of those living with AD" (p. 651). However, residential care providers often cannot provide the quality of care that family members expect.

Because the person with AD is often unable to communicate their needs to their family, families come to rely on the residential care provider to communicate their loved one's experiences for them (Planalp & Trost, 2008). While including family in the ongoing care of someone with AD can improve the quality of life for the care providers and the quality of care for the person with AD (Linsk et al., 1988), families can experience conflict with providers which makes them less likely to approach them for support or questions, thus complicating care. For instance, hospice workers in Planalp and Trost's (2008) study described complicated relationships with family members that included internal family conflicts, families not wanting to talk about impending death, and some members trying to exclude other family members. They also recalled struggling to facilitate difficult conversations among family members. Care providers are tasked with advocating for the patient's acute and chronic health issues, promoting mental health and well-being, keeping family informed about their health, and tracking health needs (Reckrey et al., 2019). While fulfilling these tasks, they may experience a conflict between the care they are required to provide and care they believe is moral (Midtbust et al., 2022). As nursing assistants working in a long-term care dementia facility explained, numerous factors can influence care providers' quality of life, including the perceived ability to create relationships with their patients and confidence in their own training (Winzelberg et al., 2005). Overall, as Spenceley et al. (2017) asserted, providing care for someone with dementia-related illnesses can be emotionally and physically taxing, related to the caregiving tasks but also navigating various relationships within the care system. Care providers in residential facilities are pulled in multiple directions, tasked with fulfilling various roles and responsibilities simultaneously.

Tensions in the sense-making of caring for a patient with AD

Navigating work as residential care providers for patients with AD is complex. As cited, extant research indicates that care providers in residential facilities face numerous challenges that make their job more taxing and stressful. These include, but are not limited to, limited resources, family members' unrealistic expectations, balancing the needs of the patient with those of the family, and job turnover and burnout. When faced with challenging situations, people tend to engage in sense-making to understand their social worlds (Horstman, 2019). As Taylor and Van Every (2000) explain, "sensemaking, to the extent that it involves communication, takes place in interactive talk and draws on the resources of language in order to formulate and exchange through talk symbolically encoded representations of these circumstances" (Communication as co-orientation section, para. 2). Relational dialectics theory (RDT) 2.0 offers a useful lens through which to understand one's sense-making in difficult times. In their study of women's sense-making when experiencing dissatisfaction during the transition to motherhood, researchers used an RDT lens to determine that women's talk about this transition reflected the contradiction between motherhood as innately desired and motherhood as learned (Cronin-Fisher & Parcell, 2019).

As relational dialectics theorist Baxter (2011) posited, people understand their social worlds through contradictions and tensions they experience. Although dialectical tensions are inherently opposite, it is their interdependent nature that makes them understandable. In other words, tensions are opposites at the same time that they are unified (Baxter & Erbert, 1999), and because of that, Baxter and Montgomery (1996) characterize opposing tensions not as "either/or" but instead as "both/and." For instance, in their study of tensions inherent in the communicative construction of retirement, Anderson and Guo (2018) argued that "tensions are a powerful concept as they highlight a both/and perspective that allows for the examination of how seemingly conflicting ideas/principles/actions can exist simultaneously" (p. 199). Illustrating this both/and perspective in their data, they found that retirees continue to work through bridge employment that allows them to maintain aspects of their past identity and at the same time create new identity postretirement. Further, bridge employment helps them to make sense of their futures as uncertain in both positive and negative terms.

In RDT 2.0, the most recent iteration of the theory, Baxter (2011) argues that in order to understand the role of competing tensions in our social worlds, we must look at sense-making at four levels or sites that acknowledges messages and meanings at the cultural and relational levels. Cultural-level meaning (e.g., societal expectations and evaluations) is reflected at the *distal level*. For instance, considering how Americans perceive, talk about, and provide care for aging family members and how residential care providers fit into that process can be evaluated as the distal level. The relational- or interpersonal-level meaning, termed the *proximal level*, is created by past conversations and anticipated responses by relational partners; for this study, relational partners are the residential care providers and the families of the person with AD. Proximal-level meaning that is *not-yet-spoken* is the anticipation of upcoming utterances (for instance, participants may consider how the family will respond when they share particular information about their loved one's health). *Already-spoken* utterances at the proximal site are reflective of interactions in the past (for instance, participants may be concerned with how family members responded to information they shared in the past). In a recent study of family communication about daughters' social media use, Miller-Ott et al. (2023) found that parents make sense of their intended roles as "good parents" by looking at how they handled past interactions with daughters about social media and anticipating future interactions with daughters about social media.

Sense-making is often tied to relational dialectics theory because as people aim to make sense of their experiences, they recognize competing needs or discourses evident on cultural (i.e., distal) and interpersonal (i.e., proximal) levels that influence their ways of reflecting on and making sense of their lives. There are a few studies examining sense-making of aging through tensions. For instance, scholars who study families' experiences of their loved ones' aging found that families struggle with certainty that the end of life is approaching but uncertainty about the unexpected final days (Egbert et al., 2017). Families' sense-making also includes tensions between the desire to extend their loved ones' lives through medical intervention and sustain their loved ones' personal dignity and quality of life. Complex sense-making was exhibited by wives of husband with AD who understood their husbands as being physically presence and emotionally/cognitively absent (Baxter et al., 2002).

In one of the few studies of professional caregivers' interactions within a residential facility, Blok et al. (2022) uncovered three sets of opposite *dilemmas* that complicate attempts by participants to engage their older adult residents in activities: autonomy versus dependence, personal experiences versus privacy, and happiness versus honesty. According to participants, residents perceive that they have less autonomy than caregivers think they do. Also, residents want privacy but also individualized attention from caregivers and want to focus on the positive parts of their lives but also know they need to recognize and admit pain and sadness.

For this study, we chose to focus our analysis on the proximal level of the theory to investigate tensions that residential facility care providers may experience when making sense of their communication with family members of someone with AD, which is important for communication scholars to understand because their quality of communication with families is tied to the quality of life and care for themselves and the person with AD. We chose to use RDT to understand whether and if so how, their sense-making of communication with family members reflect competing proximal tensions with which they struggle and try to navigate. Thus, the research question guiding this study was:

> What, if any, proximal level dialectical tensions do residential facility care providers report as they make sense of their communication with family members of people with Alzheimer's disease?

Method

Participants

Fifteen care providers working in a residential facility participated in this university IRB-approved study. Of the 15, 12 identified as female and 3 male. Regarding race, six identified as White, five as Black or African American, two as Asian, one as White and Hispanic, and one did not provide an answer. All participants worked in some form of long-term care unit (nursing homes, assisted living, or memory care facilities). Participants' ages ranged from 18 to 32 with the mean of 23.87 ($SD = 4.98$) and the median of 21. All reported having regular interactions and tasks related to caring for people with Alzheimer's disease. Please refer to Table 1 for participant demographics and job information.

Data collection

We recruited participants through purposive and snowball sampling. We shared a flyer for the study on our social media pages and with personal and professional contacts who may have known people who are residential care providers of people with Alzheimer's. We also sent information about the study to members of a senior support network who likely had contacts in residential Alzheimer's care facilities. We also asked participants to share details of the study with other care providers who might qualify for the study and be interested in participating. The call indicated the following criteria for participation: 1) Be a professional care provider, 2) Have experiences providing care to at least one non-related person with Alzheimer's disease, and 3) Be at least 18 years old. We interviewed all volunteer participants who responded to our call and met these criteria, including those who provided care to patients with AD living at home. However, for this analysis, we chose to focus only on participants working in a residential

Table 1. Participant demographics.

Pseudonym	Age	Race	Gender	Current Care Provider Position
Michelle	21	White & Hispanic	Female	CNA in nursing home
Brianna	30	White	Female	CNA
Erin	18	White	Female	Care provider in LTC memory unit
Maliya	20	White	Female	CNA
Paige	18	White	Female	CNA in nursing home
Nicole	20	Did not provide	Female	CNA
Rebecca	30	Asian	Male	Care provider in memory care nursing home
Julian	21	White	Male	CNA in rehab & LTC facility
Stella	32	Black	Female	Care provider in LTC memory care unit
Leanne	22	African American	Female	CNA in assisted living facility
Corinna	20	White	Female	CNA in nursing home
Victoria	21	Asian	Female	CNA in LTC facility/Alz. unit
Elden	30	African American	Male	Care provider in Alz. residential facility
Marcella	28	Black	Female	Care provider in Alz. residential facility
Bettina	27	Black	Female	Care provider in adult care facility

CNA stands for Certified Nursing Assistant.
LTC stands for Long-Term Care.
Alz. stands for Alzheimer's disease.

facility. We chose this focus because of the possible complex relationships between families who are relocating their loved ones to a residential facility and the care providers. Further, as previously cited, there is a high degree of burnout and turnover in residential facilities, which may make sense-making of difficult situations more salient for the care providers.

People interested in participating emailed the first author to confirm their eligibility and to schedule the interview, at which time she sent an Informed Consent to the participant and asked them to read it ahead of the interview. We both conducted individual Zoom interviews with participants. Interviews lasted from 20 to 60 minutes. Each participant received a $20 digital Target gift card via e-mail after they completed their interview. We stopped interviewing at the point of data saturation, in which interviews were no longer yielding new information (Saunders et al., 2018).

Interview questions centered on four main topics. First, we asked participants to provide background information including their demographics, care provider job, positive and challenging aspects of providing to care to someone with AD, background knowledge and training on AD, and the extent to which their job includes working and talking with family members of the person with AD. The second set of questions focused on family involvement in care. We asked them, among other questions, level of involvement in care they think families should have and why, benefits and challenges of family involvement, and any support they provide to families. Third, we asked them to describe specific instances of communication with family members. In this section, sample questions were: What are the types of information you share with families about their loved ones and about the care they receive? How do you decide which types of information to share with family members and which to possibly not share or limit? What are the most common communication issues or dilemmas you have encountered with the family members? What, if anything, have you done to try to overcome these issues or make them better? Please be as specific as possible. The questions in the last section focused on stress, coping, and problems with care. We asked them, for instance, to explain ways that they think the care they provide increases and/or decreases the stress the family feels, to describe times when the participant and family were not on the same page about care or the family did not agree with or understand the care their loved one was receiving, to provide suggestions for family members to work more collaboratively and positively with care providers, and to provide suggestions for other care providers to work more collaboratively and positively with family members.

We audio recorded and later transcribed each interview using the online program Descript, which yielded 201 single spaced pages of text. We changed all identifying information, including but not limited to participants' names, patients' names, and care providing location, to protect confidentiality.

Data analysis

Independently, we both used open coding in an initial reading of all transcripts to gain an impression of care providers' communication and sense-making experiences. In a meeting to discuss our initial read of transcripts, we both shared observations that care providers experience competing tensions in their communication with family members of people with AD for whom they provide care. At that point, we decided to use RDT to guide our analysis of care providers' sense-making.

We then used Braun and Clarke's (2006) six-step process of thematic analysis to uncover "experiences, meanings, and the reality of participants" (p. 81). We reread transcripts and coded interesting features of the data across the whole set, focusing on participants' talk about contradictions and tensions in their communication with family members of their patient with AD, and searched for potential themes related to specific tensions they were experiencing at the proximal (relational) level. We then compared the themes to the features and the overall data set. We continued to define and name the proximal-level tensions, located excerpts to support the themes, and wrote the final report.

Credibility of analysis

We used crystallization and relied on thick description to establish credibility of our analysis (Tracy, 2013). Tracy (2013) defined crystallization as "making use of multiple data points and researcher points of view" (p. 236) to "construct a multi-faceted, more complicated, and therefore more credible picture of the context" (p. 237). We both read and analyzed data, engaged in ongoing conversations about the data, and worked together to construct the overall picture or story of the data. We used thick descriptions through exemplars to demonstrate tensions that care providers experience in their communication with family members.

Findings

Overall, participants' talk reflected several tensions at the proximal level in their sense-making of communicating with family members of someone with AD under their care. In the following sections, we illuminate the three sets of tensions evident in their sense-making.

Family inclusion and exclusion

In their talk about family involvement in care, the participants framed family members as helpful and want to include them, but also potentially unhelpful and hesitate to include them. Instead of privileging full inclusion or exclusion, participants talked about both being beneficial to a degree to maintain quality of care. As they made sense of families' involvement, some participants described families as an integral part of care. For instance, Abby explained that families, "really dive headfirst into the process from when their loved one first gets admitted all the way up until they pass." Participants voiced benefits of family involvement. As Nicole shared, "My patient had his birthday and his mood drastically improved. It makes them feel better to be around people they know and know well and they enjoy being around. Helps their mood and their sense of self." Maliya explained that:

> The family should take the time that they need to like process . . . . It can be very mentally straining on the family, but I have definitely seen that the family members that stay more in contact with their loved ones that have Alzheimer's, I feel like the progression of the Alzheimer's is a lot slower in a lot of aspects. I think those people are able to hold on to the memories a lot longer.

There is an understanding that this illness is mentally straining on families and that families are sometimes hesitant to get involved, as Maliya explained above. While participants see the benefit of family involvement, they also understand that involvement is hard and that families sometimes exclude themselves from care or contact. Stella recalled that in her experiences:

> Family members like to just, you know, disconnect from them so they don't feel so attached to them when they actually lose them. They just give them up for caregivers to just take care of them till [*sic*] they pass on. So most family members, we don't have interactions with them. We just take care of the people and they [the family members] just live their lives.

Care providers acknowledged that families struggle as the illness progresses and their loved one's health deteriorates. Often this decline includes the person with AD no longer able to identify and relate to their family. Erin explained that:

> It's really hard for them [families] to come into that unit. It can be kind of chaotic. It's really loud, sometimes it can be rather unsettling. The things you hear and see and seeing their loved one in that position is very, really hard.

The cognitive loss by their loved one can be particularly taxing on families. As Michelle said, "It's also hard when families come in and they don't remember them. So it can be really emotional at times. They don't remember you most days, but you remember them."

Participants' talk reflected acknowledgment that family members are often part of the sandwich generation (Lei et al., 2022), tasked with responsibilities of caring for older parents and younger children. Participants used this family identity to justify lower family involvement. Brianna recalled the family members are "children [of the patients] themselves. And then you have a full-time job and your own children and sometimes grandchildren. And so it is a lot of pressure on these kids to take care." Through their sense-making, participants voiced the importance of family involvement but an understanding of families' emotional and practical constraints.

Another layer of sense-making related to family participation was the tension between wanting family involvement but understanding that a certain level of involvement is detrimental to care. For instance, Corinna explained a situation in which family interference with care "really took a toll on him [her patient]." She further described:

> There are some things of being a CNA that they [the family] could do, like get them a straw, help them to the bathroom if they wanted. I mean, obviously we were there to do those things, but some of the family preferred to do that if they were there, but I would say that that family specifically was almost there too often, to where it was getting in the way of his progress.

Participants also discussed families' misunderstanding of the disease as an obstacle to their helpful involvement. Brianna, who talked in an earlier excerpt about families being children too, said that families want what is best for their family member but "they can sometimes come in the way of their care if they're not quite understanding what's needed." Elden said that families will visit and tell the care provider, "This is what I want to happen, even though what she [the family member] wants is not really what's best for him [her patient]," reflecting an interference with care with family involvement.

In sum, participants see the value of family involvement and appreciate when families check up on and communicate with them about their loved one. They also understand that family involvement can make care providing more challenging and that families really struggle with being involved because of issues with coping with AD.

Reality and positivity

In their sense-making, participants saw the benefits of both being realistic and positive about the family members' loved ones and the disease in interactions with them. As they talked and made sense of their interactions with families during the interview, care providers really questioned the most appropriate ways to talk about the disease when communicating with loved ones. They want to share a realistic picture of

Alzheimer's so that families understand the disease and participants can allay families' unrealistic expectations about the disease or about the help that care providers can give. As Nicole voiced:

> I think sometimes, like especially when it is your parents, you wanna believe that there's a way that'll get better. But I feel like in this situation it was, it's gonna almost get worse. And I think that they know that in a way, but they don't wanna believe that, and so it was a lot of like, "I can't give you an answer." [for what will happen next]

Paige believes that it is important for families to understand the reality of their loved one's illness. She explained that "There'll be times where people are a fall risk and have to stay by this desk because they don't remember to use their walker. And so explaining that to a family member is very hard because once again, they don't want to see that." Corinna expressed similar experiences: "It did get to a point where they [the family] believed that we were not doing enough. We weren't there all day, every day, because there are 25 other people on the floor." She had to explain to the family:

> "There are gonna be times of the day we aren't going to be there." It's going to be hard for a lot of families because especially if they've never had family in a facility, they sometimes they do expect a lot of CNAs, them getting care 24/7 minute to minute. And that is not realistic.

Participants also understand the value of communicating positivity when talking to the families. Elden, who voiced complaints earlier about overinvolved families, also reflected on not wanting to scare them:

> I don't want to get them [the family] scared. Me as a professional caregiver, me as someone who is always with their loved one. We are supposed to be giving them feedback and reports. If I tell them about [impending] death, then I feel like they will get scared. They will be frightened.

Michelle, who earlier talked about families who are scared when their loved one doesn't remember them, explained:

> I have to reassure [the family], just like, "Hey, like I'm really sorry. Like it's just a bad day, it's nothing against you." Things like that. I know how hard it can be on those people. I don't want them to be like too afraid to come back or have it be distasteful to them and not want to come visit their family members again just because they weren't acting like themselves that day or if they had a bad day and they were being mean to them.

It was evident in Michelle's sense-making that she gives a lot of attention to families' emotions as she discloses about their loved one. She acknowledged that families struggle with their loved ones' health. She wants to protect their feelings, and she also wants families to have realistic expectations about their loved one and should continue visiting. These tensions seem to challenge participants' sense-making of their interactions with families.

Participants appeared to use empathy, support, and hinting as conversational moves that allows them to address both tensions in their communication with families. Participants talked about offering support (e.g., "I'll be here if you need me") and acknowledging the sadness of the disease (e.g., "I'm really sorry that this happened") to convey connection and empathy while sharing realistic information about the disease. For instance, Erin shared that "we do like to keep them [the family] very informed, very involved" (i.e., reality). But she explained in more detail that when she shares information about patients' behaviors, "there's a pretty specific way we do as to not worry them, because most of these behaviors are very normal even though they can kind of seem shocking to somebody who's unfamiliar with the disease" (i.e., positivity and hinting). Brianna explained that when communicating to a patient's spouse, "I'm just gonna tell them everything or what's going on" (i.e., reality), but if a patient's child approaches her for information, she will say, "Mom's been good" because "they don't need to know that she had three bowel movements yesterday. That would too much information for them" (i.e., positivity). Michelle said that

> I try to explain what Alzheimer's is [i.e., realistic). But then they'll be like, "Why can't she, why aren't you eating?" They'll get kind of mad at the resident, why they're not doing what they used to be able to do. I don't wanna be the one to tell them, "Oh, she hasn't been able to do this for a long time. That's why she's here." I'm not gonna say that. I'll try to be more kind, like, "Oh, let me cut that for you" and "Oh, let me help you." Sometimes the family members don't really know what's going on with that disease. They get kind of confused on why their family member's acting a certain way, but I don't really like go out and tell them like, "Oh, like that's just the disease," but I'll kind of hint at that.

Expert and layperson caregiving practices

Participants' sense-making seemed to be complicated by families' perceptions of the roles they play in caregiving and how (and whether) to communicate with the participants about their loved one's health. Participants want to be perceived as expert care providers, like nurses, and they struggle to understand why families do *not* see them as such. Participants believed that the fact that they spend a significant amount of time with the person with AD positions them to be the expert in their care. Participants explained that because families do not see the illness every day, they do not fully understand how AD is affecting their family members' day-to-day functioning. Nicole provided the following advice to family members with a loved one with AD:

> Just be aware of what's happening, but give the caregivers a good range of taking care of the patient because usually they do have experience on what could be the right thing to do and what could be helpful or what could be more comfortable, especially with how much time we spend with them.

Participants want the family to be comfortable deferring to them to make decisions about care. As Brianna explained, families will ask questions like, "Why don't they just do this?" Or "Why do they keep on doing this?" … or make comments like, "Oh, no, mom doesn't need that. She could figure it out." I'm like, "No, she can't." At times, participants like Brianna were frustrated by families' challenges because she saw herself as the expert in care. They even refer to themselves as professionals, such as Michelle who said:

> I have one instance where this family member will try to help me put them in the bathroom and help me stand them up and all this stuff. [She will say to the family member] "I promise you she

> cannot [stand up].” You get those family members that won’t take the professional advice and start inhibiting things.

However, their talk in interviews indicated that many of them have limited training in AD or patient care and in some ways, they see themselves as similar to untrained family care providers. Several participants explained that care providers like them who work in residential facilities for people with dementia are often untrained on the disease, especially compared to nurses who work in the same facilities and are often their supervisors. And this plays out in problematic ways when, as Corinna, a CNA in a nursing home recalled, “we’re not medically trained and certified to be discussing those things [with families].” Thus, this tension in sense-making seems to be between expert caregiving (similar to nursing) and lay caregiving (similar to family caregivers). Participants’ sense-making of their interactions with families seem to exist in both of these spaces, and they see the benefit and drawbacks of each role while doing their jobs.

Thus, as they make sense of families’ perceptions of them as care providers, they complain that families don’t trust their expert care, but they also admit that they lack formal training and are less educated on AD and how to interact with families than others in the residential facility. While talking about the desire to be seen as an expert, participants simultaneously voiced the understanding that others are experts because of title (e.g., nurse vs CNA) and the roles and responsibilities that come with that title. For instance, Nicole, a CNA, explained that “I had been asked by [a] daughter and she basically was asking me what she should expect, but it’s preferred for me not to, just because I’m not typically qualified to give that kind of advice or information.” Similarly, Maliya explained that she “takes a backseat” because there are others more qualified to help families in some situations. She said, “I kind of just try to point them in the right direction of those resources.” They see themselves as professional care providers but also acknowledge their similarity to lay care providers.

Discussion

The purpose of this study was to understand care providers’ sense-making through the lens of relational dialectics theory. Specifically, we aimed to understand proximal tensions that emerged as care providers made sense in interviews about their experiences communicating with family members of someone with AD. During our analysis, three sets of competing proximal discourses or tensions emerged: family inclusion and exclusion, reality and positivity, and expert and layperson care provision. We drew several conclusions that provide valuable insights to scholars, care providers, and residential facilities.

Conclusions and implications

First, care providers experience ongoing tensions as they provide care to people with AD, navigate interactions with family members, and aim to fulfill multiple roles (Reckrey et al., 2019). The three tensions that emerged in their sense-making appeared to be exhausting and hard to manage, within a job that already experiences high turnover and stress. Care providers want to give families answers but they want to protect their feelings, make sure they keep coming back, and maintain the dignity of their patient. Providers see themselves as experts in care and also understand that they have less training and education than nurses and other hired care providers and often inhabit the role of layperson care provider. Care providers wish for family involvement and are also concerned with family over involvement. They receive challenges from families about care provision and the severity of the illness and understand that others in the residential facility are more qualified. Even when faced with families’ high and often unrealistic expectations for care (Gaugler et al., 2014) that can be taxing emotionally (Spenceley et al., 2017), participants still expressed high concern for family members’ feelings and experiences. They make communication choices in part to protect the family members and demonstrate concern for how some information may exacerbate their distress (Cooper & Pitts, 2022; Miller-Ott et al., 2022). Their sense-making process reflected the act of providing tangible care to patients, but more taxing and problematic was the emotional work for themselves, the families, and their patients (Åhlin et al., 2022) that emerged from interactions with family members.

Second, care providers are part of a care system that often constrains their actions. Participants spoke of not only being perceived as someone with less training than their care counterparts, but that the facility does not require or provide training participants desired to improve their expert status, thus positioning them more as untrained familial care providers. Their lack of training emerged as salient in interactions with family members when they are limited in the medical advice they can provide. They also view themselves as expert care providers because of the sheer amount of time they spend with their patients. Arguably, CNAs and other residential care providers spend a significant time providing daily care to their residents with Alzheimer’s, perhaps even more time than nursing staff. Facilitating regular check-ins and conversations among care providers, nursing staff, and management about particular patients may help lower the structural barriers that care providers believe exist. Participants want to feel empowered (Yeatts & Cready, 2007), and participants struggle in their sense-making as they identify themselves as experts but also acknowledge that in many ways, they are not experts. Mandating and then providing training in Alzheimer’s disease will help increase care providers’ education in this disease and best practices for care provision.

Third, although care provider – family relationships can be complicated and parties can experience conflict with one another (Planalp & Trost, 2008), participants believed that when family members play an active role in their loved one’s care – which includes being physically present – the person with AD experiences improvements in their mental and physical health. Participants reported a lot of work – emotional and communicative – to keep families returning to visit their loved ones. For instance, engaging in supportive communication and enacting indirect communication (hinting) helps care providers be direct but also positive. They also understand that sometimes, it is better to exclude families from care if they are interfering with provision of care.

There is a strong connection among sense-making, tensions, and communication. Although sense-making is a cognitive process, people often rely, at least in part, on their reflection on past and anticipated future interactions with proximal others to understand their lives. Further, tensions that emerge in people's talk (i.e., communication) of these experiences inform meaning they assign to their lives and to their interactions with others. Tensions that emerge through the process of making sense of people's lives can influence their subsequent interactions with others and their understanding of these interactions, thus reflecting the intertwining of these phenomena in people's daily lives.

Limitations and future research

Our sample was comprised of primarily young women, many of whom recently became CNAs and other types of residential care providers. While their input was invaluable in understanding dialectical tensions inherent in communication with families, their limited time in this career may have influenced their sense-making of interactions with families. In future studies, we would aim to interview more men, care providers with more years of experience, and also include nurses, as they are often the official "go to" person when families have medical questions about the progression of the disease. Although we chose to use RDT as the theoretical framework guiding our investigation of sense-making, we do believe that other theories such as facework and concepts like identity work and emotional labor would be fruitful to examine this population and their interactions with families.

Conclusion

Care providers of people with Alzheimer's disease in a residential facility are expected to fulfill needs of multiple members of the care system – their patients, their families, and themselves. Care providers' sense-making reflects competing tensions that illuminate struggles with appropriate family interaction, health disclosures, and perceptions of expertness. The data helped us to provide useful suggestions for scholars and staff in residential care families who continue to aim to understand and provide care for people with Alzheimer's disease.

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