Global Qualitative Nursing Research
Volume 12: 1–12
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DOI: 10.1177/23333936251335539
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"It's Akin to Standing Alone on the Platform": A Qualitative Analysis of Family Caregivers' Perceived Benefits of Conversations with Professional Dementia Caregivers

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Abstract

Family caregivers often face challenges in navigating care decisions and maintaining involvement after their relatives transition to long-term care facilities. This study explores family caregivers' perspectives on the benefits of engaging in conversations with professional caregivers in long-term dementia care. Semi-structured interviews were conducted with 17 family caregivers in Denmark. Using thematic and template analysis, five core themes were constructed, highlighting both emotional and practical motivations for communicating with healthcare professionals: (1) feeling disconnected and uninformed about their loved one's care, (2) managing emotional challenges while seeking reassurance, (3) leveraging professional expertise for guidance, (4) fostering collaboration through openness, and (5) achieving mutual understanding and perspective shifts. The findings underscore the critical role of open and ongoing communication among family and professional caregivers in building trust, addressing family caregivers' emotional and informational needs, and supporting them in navigating the shared caregiving roles of long-term dementia care. In addition, the findings point to the potential benefits of structured dialogues to promote family involvement and person-centered care in long-term dementia settings.

Keywords

family caregivers, dementia care, long-term residential care, communication, conversations, Denmark

Received: November 6, 2024; revised: March 28, 2025; accepted: April 1, 2025

Introduction

With the global population aging and dementia prevalence rising, the number of family caregivers is also growing. Dementia presents unique challenges that make communication between family and professional caregivers particularly important. Since dementia is characterized by progressive cognitive decline, including memory loss (Irish, 2023), impaired decision-making (Hegde & Ellajosyula, 2016), and reduced ability to communicate effectively (Stanyon et al., 2016), people with dementia increasingly become reliant on others in making decisions and providing care (Mattos et al., 2023). Here, family caregivers play a critical role in care for people with dementia and in ensuring their quality of life throughout the disease (Brodaty & Donkin, 2009). Even after transitioning to long-term care, people with dementia continue to rely on family caregivers. Many studies have highlighted that the critical role of family caregivers continues long after admission into long-term care, both in nursing homes in general (Puurveen et al., 2019; Ryan & McKenna, 2015) and in dementia care in specific (Bolt et al., 2019; Brodaty & Donkin, 2009; Zmora et al., 2021). The Nuffield Council on Bioethics (2009) emphasizes that partnerships between professionals and family caregivers should be grounded in trust and mutual respect for each other's role and expertise (Nuffield Council on Bioethics, 2009). This highlights the importance of fostering strong relationships and open communication between family and professional caregivers to ensure person-centered care and effective decision-making.

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Family involvement in long-term care is a multidimensional domain, which often ranges from day-to-day care, coordination of care, as well as care decisions or financing (Hovenga et al., 2024; Zmora et al., 2021). For instance, family involvement in care often includes practical tasks, such as taking their loved ones out to dinner, church, or medical appointments (Butcher et al., 2001). However, families often serve as proxy decision-makers for complex, emotionally challenging choices, including end-of-life decisions (Hirschman et al., 2006). Whether their involvement concerns practical or complex decisions, the unique relationship family caregivers have with people with dementia, along with their often privileged insight into care preferences, makes their role essential for delivering person-centered care for people with dementia (Reid & Chappell, 2017). In addition, studies have shown that family involvement in long-term care is hugely beneficial and positively impacts the quality of care and quality of life of people living in long-term care (Barken & Lowndes, 2018; Hayward et al., 2022; Hovenga et al., 2022; Powell et al., 2018). Therefore, promoting strong care relationships and cooperation between family members and professional caregivers is crucial for fostering high-quality long-term care environments for people with dementia (Zmora et al., 2021).

However, the shared caregiving role in long-term care is often complicated for family caregivers due to the need to develop relationships with nursing home staff and negotiate new roles in care (Hennings & Froggatt, 2016; Moyle et al., 2002), and family caregivers often report increased levels of strain and burden of care (Gaugler, 2005). For instance, negotiating how their relatives' care should be managed with professional caregivers and the administration of long-term care facilities often presents significant challenges for family caregivers (Baumbusch & Phinney, 2014). Family caregivers report feeling neglected and insignificant when excluded from discussions about how to organize care (Graneheim et al., 2014). Moreover, family caregivers also often struggle to communicate their concerns to professional caregivers when the residential care falls short of their expectations (Hertzberg & Ekman, 2000).

Family caregivers of people with dementia face multiple unmet needs, including emotional support, changing relationships, and evolving responsibilities after their relatives transition to long-term residential care (Lee et al., 2022). Additionally, research highlights the need for more communicative relationships with professional caregivers (Bramble et al., 2009), suggesting that family caregivers perceive engaging in conversations with professional caregivers as beneficial.

This study aims to explore and understand family caregivers' perceived benefits of engaging in conversations with professional caregivers in long-term care facilities and, in doing so, better understand the motivations behind their need for more communicative relationships with professional caregivers.

Methods

This study draws on qualitative interviews with family caregivers of people with dementia residing in long-term care facilities in Rudersdal Municipality, Denmark. It is part of a larger research project investigating the efficacy and feasibility of the CARE intervention, which aims to strengthen ethical decision-making confidence among family caregivers, individuals living with dementia, and professional caregivers involved in dementia care (Lauridsen et al., 2023). This study employs a qualitative exploratory design, inspired by the approach of narrative inquiry (Clandinin & Connelly, 2000) and aligning with an interpretivist perspective (Schwandt, 1994). A narrative orientation was chosen for its ability to explore the ways family caregivers construct, narrate, and make meaning of their conversations with professional caregivers.

Study Context and Sample

As part of the CARE intervention, family caregivers participated in a 1½ hr workshop alongside professional caregivers from the long-term care facilities where their relatives resided (Lauridsen et al., 2023). A total of 49 participants attended the workshop, including 29 family caregivers and 20 professional caregivers. Professional caregivers included nurses, healthcare assistants, aides, and therapists—all of whom had direct contact with individuals with dementia in long-term care facilities. The workshop facilitated dialogues between family caregivers and healthcare professionals, focusing on collaboration challenges and structured around discussions of ethical dilemmas relevant to dementia care. While the discussions began with the challenging situations depicted in a short fictional or autobiographical story, these stories were designed to be an initial common point of reference, allowing participants to introduce their perspectives and stories. The facilitator ensured that all participants had the opportunity to contribute, particularly focusing on family caregivers addressing challenging situations concerning the care of their relatives.

To recruit family caregivers for subsequent interviews, the workshop facilitator asked if any were willing to participate in an interview about their experience in such discussions between family and professional caregivers.

A total of 17 family caregivers were recruited for the interviews. Participants were mostly female (accounting for 82%), primarily the children of people with dementia (77%), whose ages ranged from 50 to 68, with a smaller proportion being spouses (18%). All spouses in the study were 76 years old. Their caregiver experience ranged from 1 to 13 years, with a mean of 4 years. To ensure anonymity, identifiable information was removed from the data, and participants were assigned fictional names during analysis. See Table 1 for study sample characteristics.

Table 1. Study Sample Characteristics.

Caregiver relationship	Participant names (male/female)
Child	Karen (F), Charlotte (F), Lars (M), Niels (M), Hanne (F), Maria (F), Grethe (F), Lise (F), Mette (F), Eva (F), Lisbeth (F), Marianne (F), Lone (F)
Spouse	Hans (M), Else (F), Jytte (F)
Other	Birgitte (F)

Data Collection

Semi-structured interviews were conducted by a researcher with a background in sociology and extensive experience in qualitative interviews. This researcher was not involved in the design or facilitation of the intervention, ensuring independence in data collection and minimizing potential bias. These interviews were conducted over the telephone and lasted approximately 30 min. The interviews were conducted to explore family caregivers' experiences engaging in dialogues with professional caregivers, both as part of the CARE intervention and in their broader interactions in dementia care settings. The interviews followed an interview guide, which included questions designed to elicit whether family caregivers needed discussions on these topics with professional caregivers (e.g., "Do you feel there is a need for family and professional caregivers to discuss more ethical issues?") and how they experienced the dialogues with professional caregivers (e.g., "How was it to participate in dialogues with professional caregivers?") and whether they believed that such meetings were beneficial preparing family caregivers and formal caregivers for difficult situations that may arise in the care of the person with dementia. During the interviews, participants were invited to elaborate on their experiences in an open-ended manner, inviting extended accounts of their narratives (e.g., "Tell me why that experience stands out?") (Riessman, 2007, p. 25). All interviews were audio-recorded and transcribed verbatim by a student assistant.

Data Analysis

The analysis followed reflective thematic analysis (Braun & Clarke, 2021), adhering to the method of template analysis (King, 2012). Reflective thematic analysis was selected for its flexibility in qualitative research, including its compatibility with narrative inquiry, and its ability to identify patterns within the narratives of family caregivers. Template analysis complemented this by providing a structured yet adaptable coding framework, allowing for iterative refinement of themes while remaining grounded in caregivers' narratives. Together, these approaches facilitated a comprehensive exploration of how family caregivers perceive and experience conversations with professional caregivers.

An initial coding template was developed by [FSJ] based on a subset of the data comprising three interviews. The template was iteratively refined as new themes were constructed during the coding of the data. Two researchers, [FSJ and LMF], applied the template independently to the data and reviewed each other's codes to ensure validity. The analytical process involved iterative steps: familiarization with the data, initial coding, refinement of the template through application, and finalizing themes.

While the overall focus of the study was shaped by an interest in understanding family caregivers' views on the benefits of engaging in conversations with professional caregivers, the specific themes were not predetermined. Instead, they were developed inductively from the data, ensuring that they reflected the lived experiences and narratives of the family caregivers themselves. Data management, coding, and theme comparison across interviews and coders were facilitated using NVivo 12 software.

Ethical Considerations

Informed consent was obtained from all participants prior to their involvement in the study, ensuring they understood the study's purpose and the use of their responses in research publications. The study adhered to recognized ethical principles for research involving human participants, including respect for autonomy, beneficence, and confidentiality, as outlined in the Declaration of Helsinki (World Medical Association, 2013). Permissions were obtained from the Research Ethics Committee (REC) (Case No. 20/61405) and performed in compliance with the Danish Data Protection Regulation, approved by RIO Legal Services (No. 11.154), of the University of Southern Denmark.

Findings

Although the accounts of each family caregiver varied and their respective experiences of engaging in conversations with professional caregivers were unique, there was considerable commonality across their accounts. Five themes were constructed to capture how family caregivers described these conversations and their perceived benefits (see Table 2).

Losing Touch and Not Knowing What Is Happening

Communication between family caregivers and professional caregivers is essential to addressing the feelings of disconnection that many family caregivers experience after their relatives with dementia transition into care facilities. These

Table 2. Overview of Themes.

Themes	Description	Illustrative quote
Losing touch and not knowing what is happening.	Family caregivers feel disconnected and excluded from their relatives' daily lives after transitioning into long-term care facilities, lacking insights into day-to-day activities.	"you have the feeling that you hand over your parent and then happy-go-lucky hope that it goes well." (Karen)
Navigating emotional challenges and seeking reassurance	Family caregivers often experience emotional challenges, including uncertainty, guilt, and insecurity. Professional caregivers are often essential in providing reassurance, helping caregivers navigate these emotional burdens.	"[. . .]It's the eternal guilty conscience. You can hardly bear all the things you could potentially do. I think the staff have been really good at trying to say 'Well, listen! You're doing well enough.[. . .]" (Hanne)
Guidance through leveraging professional expertise	Family caregivers value the expertise of professional caregivers as essential for navigating the complexities of long-term care.	"It would be really helpful to have a conversation with the staff about where we are and what their experiences are. My sister and I have never been through this before, and we don't have anyone else to turn to for comparison. [. . .]" (Marianne)
Strengthened collaboration through openness	Open and ongoing dialogue was essential for effective collaboration with professional caregivers. Openness, honesty, and a willingness to engage without judgment helped build trust and resolve issues.	"I think the more open you are about things, the easier it is for both me and possibly for others as well. By being open, I might feel encouraged to say things that others might not.[. . .]" "I think the more you put things into words, especially with the staff, the easier it is for everyone with openness and honesty, I believe." (Maria)
Mutual understanding and perspective shifts	Engaging in open dialogue with professional caregivers allowed family caregivers to gain insights into the staff's perspectives and thoughtful considerations.	"You start to see other viewpoints, thinking, 'Well, I can understand that too,' and recognise why they might see it that way. This allows for a dialogue that both they and you can use. [. . .]" (Lone)

feelings often stem from limited insights into their loved ones' daily lives, leaving family caregivers feeling excluded and uncertain about the care being provided. The shift from being the primary caregivers to feeling like peripheral participants in the care team is particularly challenging. As one family caregiver noted:

> As a family caregiver, you kind of lose touch with what it's like when you're no longer in charge. Most of us have probably looked after our sick relatives at home, where you've just been there constantly and had everything completely under control, and then suddenly you can't keep up with what's happening. You come in once a week or something, and you can't really keep up with the progress of the disease and whether it's a bad day or a good day, and so on. (Marianne)

This sense of disconnection was intensified by the limited insight into the day-to-day happenings at the care facility, which exacerbated caregivers' uncertainty and concern. One caregiver described the anxiety of entrusting her parent's care to the facility without knowing what was happening daily: "*You have the feeling that you hand over your parent and then happy-go-lucky hope that it goes well*" (Karen).

Some family caregivers reported that the fact that they are not there constantly, coupled with an experienced lack of regular communication with professional caregivers, they were left uncertain about their relatives' daily activities and overall well-being. Without direct insight into their relatives' involvement in meaningful activities, family caregivers often felt they lacked sufficient information and insight into their relatives' day-to-day care, which contributed to a sense of disconnection from the care process. As one caregiver expressed: "*Because you're not there every day, at least I'm not, I don't know the rhythm*." (Karen).

Participants often perceived life in the facility as monotonous and unengaging, based on their observations of limited activities or engagement opportunities:

> I came at different times, [. . .] at weekends, or in the evening, early morning, midday, [. . .] And what I found was that the TV is on non-stop in the common room. My mum could either choose that or her own TV. (Karen)

Other caregivers expressed frustration at learning about their relatives' activities second-hand rather than directly through conversations with professional caregivers. This experienced lack of direct, timely communication hindered their ability to engage meaningfully with their loved ones while the activities were still fresh in memory. For instance, one husband of a resident noted:

> Many times, I hear from the second or third person what activities they've done. For example, it could be that someone has been visiting, that they've been singing or something else. Or they've been on a little trip or something. And it would be nice if there was a small notice board in a central location that

> listed the activities that have taken place. Because then you can ask your relatives yourself. Not the day after, because then it's too late and it's forgotten. But maybe if it was in the morning, there's a chance that it will still be remembered. (Hans)

Caregivers emphasized the critical role of communication in staying informed about the care facility's daily events and maintaining a connection with their relatives' experiences. As one caregiver noted, regular communication provided reassurance that their loved ones were well cared for and engaged, especially in situations where it was not obvious: "*OK, they don't have it nearly as bad. They're not that bored at all. There's something going on in their lives, even if you can't see it yourself*" (Hans).

These feelings of disconnection and lack of insight into daily care not only contribute to a sense of losing touch but also likely exacerbate the emotional burden on family caregivers as they navigate their new roles.

Navigating Emotional Challenges and Seeking Reassurance

Numerous family caregivers noted that they often faced significant emotional challenges, such as guilt, uncertainty, and insecurity, as they navigated their new roles following their relatives' transition into long-term care. Conversations with professional caregivers played a critical role in addressing these challenges, providing reassurance and guidance that helped caregivers feel supported in their roles. By fostering a sense of confidence and reducing emotional burdens, these dialogues were essential in helping family caregivers adjust to the complexities of long-term care.

Feelings of uncertainty, guilt, and insecurity were common, making reassurance from both personal reflection and professional support essential. Many caregivers reported feeling unsure about how best to engage in care after their relatives moved into long-term care, frequently questioning their decisions. For instance, Grethe described her doubts, and the complex emotions involved in deciding whether her father should come home for Christmas:

> We're talking about Christmas at the moment and what are we going to do with Dad? There are a lot of emotions involved. [. . .] There's a huge amount of shame, or what can you say, maybe that's the wrong expression, but you know, expectations and non-expectations. Then my one grown-up son comes along and says, 'Isn't grandad coming?', and then I have to explain, 'Oh no, I don't think that would be good for grandad'. But I'm still not completely rooted in that decision. (Grethe)

Similarly, other caregivers highlighted that the transition of their relatives into long-term care was an especially emotionally challenging period. Many felt overwhelmed by the process's complexities and the decision's emotional weight. This challenge was often exacerbated by the perception that they did not receive the necessary support and guidance from care facilities or professionals during this critical time. For instance, Marianne highlighted the overwhelming feeling of being unsupported and lost during the transition of her mother into long-term care:

> I think the whole transition from making the decision that your mum is going to a nursing home, then the practical implementation and now the whole start-up period, I actually think you're a bit lost as a relative. You don't get much counselling, even though you need it so much. You need so much help in all sorts of ways. I think it's been traumatic for us. (Marianne)

The emotional challenges were intensified by overwhelming feelings of guilt and all the things that they, as family caregivers, could do, now that their relatives had moved into long-term care facilities. This guilt often emerged as caregivers compared their current, less involved roles with the more active caregiving they provided in the past. Hanne articulated this sense of guilt and her need for reassurance in her conversations with professional caregivers:

> It's the eternal guilty conscience. You can hardly bear all the things you could potentially do. I think the staff have been really good at trying to say 'Well, listen! You're doing well enough. You should come and visit when you have the energy. You should visit when you can be together in a good way and have a good time together'. I think they've been really good at that. (Hanne)

Such reassurance, achieved through dialogue with professional caregivers, played a crucial role in helping family caregivers manage their emotional burdens. Hanne noted how valuable conversations with staff were in easing her uncertainty about how to communicate with her mother:

> I had a conversation with the staff about this once. One of them advised me, 'You need to carefully consider the value of that information for your mother.' I was worried about telling her that I wouldn't be visiting the next day. The staff member looked at me and said, 'Forget it, it doesn't matter. Your mother can't remember whether you visit once or twice a week.' (Hanne)

The type of conversation between family and professional caregivers played a crucial role in addressing the emotional needs of family caregivers. While daily practical discussions were necessary, many caregivers found that conversations extending beyond routine interactions were crucial in helping them navigate emotional challenges. Open communication was perceived as a key element in creating a supportive environment. Grethe underscored this by highlighting how effective communication fosters trust and openness: "*Simply put: The more and better we talk, the easier it is to address other issues; the more and better we know each other, the easier it is to tackle difficult topics*" (Grethe).

Engaging in conversations beyond everyday practicalities allowed caregivers to explore deeper emotional and ethical issues. Niels reflected on the distinct quality of interactions when discussions went beyond day-to-day logistics, emphasizing the significant impact of these more meaningful dialogues:

> Such conversations are of a completely different quality. On a daily basis, we ask practical things like, 'Can you unlock the door for Mary?' because she can't have a key, or 'Is it okay if we sit here and talk with Mary?' [. . .] But in these conversations, we were able to talk more broadly about the care for these people who are really struggling and have regressed to a childlike state. It is a completely different experience. (Niels)

This underscores the importance of open and honest communication in not only providing caregivers with the reassurance they need but also in fostering a more supportive and empathetic environment where difficult conversations can be handled with greater understanding and respect.

Guidance Through Leveraging Professional Expertise

Family caregivers valued professional caregivers' expertise and viewed their knowledge as a critical resource for navigating the complexities of long-term care. Conversations with professional caregivers allowed family caregivers to access essential guidance and expertise for navigating their new role as caregivers. For instance, Grethe shared her experience of receiving valuable professional support when her father still lived at home, illustrating how this support was structured to meet the needs of the entire family:

> When my father still lived at home and my mother was alive, we had a dementia consultant involved. We arranged for my father to attend a day centre to give my mother some respite. During that time, a support group for relatives was facilitated, and my mother and I joined the same group. We were eventually divided into groups for adults and children, which provided us with a much-needed support system. (Grethe)

However, she noted that this type of support often disappeared once the relative moved into a care facility:

> But when my father moved to a care home, all that support just fell away and the support tends to go away when the person moves into a care facility. Everything just stops! And while that's understandable, there's nothing else to replace it. As a relative, you're left alone. If no group has been established for you to connect with, you end up feeling abandoned. It's akin to standing alone on the platform, with only the professional caregivers to cling to, who don't have the time we might sometimes need. (Grethe)

Other caregivers echoed the importance of having access to professional insights to better understand their relatives' conditions and needs. Marianne emphasized how valuable it would have been to have more in-depth conversations with staff:

> It would be really helpful to have a conversation with the staff about where we are and what their experiences are. My sister and I have never been through this before, and we don't have anyone else to turn to for comparison. We have no idea what to expect or what is considered normal. (Marianne)

Caregivers often expressed gratitude for the dedication and expertise of professional staff, which reassured them that their loved ones were in capable hands. Jytte appreciated knowing that caregivers were not just performing their duties but were genuinely invested in her father's well-being:

> It's great to feel that there is someone who is taking over out of interest—not just as a duty because they are employed. They care about him, they know something about him, and they understand how to handle him when he's like that. (Jytte)

Engaging in meaningful dialogue with professional caregivers helped caregivers make informed decisions and understand the nuances of their relatives' conditions. Lise reflected on how these interactions had helped her manage her mother's visits:

> I find the dialogue I have with the staff invaluable. That's where you can learn some things, where they have some experiences that I think are nice for me as a person to know. Something that you can then think about. For example, when my mum comes to my house, she gets tired quickly. She wants to be there for a long time, but she gets incredibly tired. And I think it's good that the staff say 'think about it!'. Because I can have a tendency to keep her at home for too long, but she just gets super tired. And then it becomes difficult for her. It's not good for her needs either. And that's where I think it's good to have that back and forth with the staff, where they also say, 'think about it!' (Lise)

While many family caregivers emphasized the benefits of leveraging the expertise of professional caregivers, others raised a concern that this expertise could potentially lead to judgment rather than support. Hanne expressed her anxiety about being judged by professional caregivers, fearing that their knowledge would lead them to critique her caregiving decisions:

> I'm so afraid that they'll judge me for not being good enough as a family carer, and I also need that confirmation that the things I do are good enough. So, I tell them to let me know if there's anything I'm not doing well enough. (Hanne)

However, while some caregivers, like Hanne, felt a degree of apprehension, worrying that professional expertise could sometimes come across as judgmental rather than supportive, many family caregivers emphasized the advantages of leveraging this expertise. They appreciated the meaningful dialogue and guidance received from professional caregivers, noting that these interactions helped them make informed decisions and boosted their confidence in their caregiving roles.

Strengthened Collaboration Through Openness

Many family caregivers viewed open and ongoing dialogue as essential for fostering practical cooperation between family and professional caregivers. They emphasized that strong collaboration relies on openness, characterized by honest, non-judgmental, and ongoing dialogue, as well and the willingness of professional caregivers to engage in meaningful conversations, that is, professional caregivers' disposition toward engaging in dialogues with families, actively initiating communication. Grethe highlighted how a good relationship and openness made it easier to address issues and collaborate effectively:

> The better we know each other as professional carers and relatives [. . .] if things happen, it's a hell of a lot easier to say 'something went wrong.' If you have a fundamentally good relationship and a good sense of the people around him [her father], then I can go to them and say, 'Hey, what was going on there?' (Grethe)

Conversely, some caregivers noted that a lack of openness could hamper trust. Marianne recounted an instance at a previous care home where she noticed that her mother was not being bathed as expected. When she attempted to discuss this with the staff, their unwillingness to engage led to a breakdown in trust:

> Instead of engaging in that conversation, the staff just sat there and said, 'She gets a bath once a week.' We were like, 'No, we can see that she doesn't.' There was absolutely no dialogue or setting of expectations. This led to us losing trust in them. (Marianne)

Marianne further emphasized the importance of professional caregivers being genuinely curious about the perspectives of family caregivers and interested in collaborating on care, stating:

> That they actually want to work with dementia care. That they want to make themselves better and it's not just storing the residents. You can talk about it, both about what you do and have a professional collaboration and talk about residents with dementia. (Marianne)

Caregivers consistently highlighted that openness and a genuine willingness to engage in dialogue were crucial for fostering stronger relationships and building trust. Many family caregivers noted that open communication, in which both parties engage honestly and without judgment, could significantly improve their ability to handle difficult situations. As Hanne noted, "*For me, openness and communication are key. When you've met and talked with each other, you can also manage the situations that may come up later*." (Hanne) This sentiment was echoed by another family caregiver, Maria, who noted that openness allowed for her to express herself more freely:

> I think the more open you are about things, the easier it is for both me and possibly for others as well. By being open, I might feel encouraged to say things that others might not. [. . .] I think the more you put things into words, especially with the staff, the easier it is for everyone with openness and honesty, I believe. (Maria)

Grete added that openness not only facilitated honest discussions but also prevented feelings of resentment, making it easier to navigate caregiving dynamics. She stressed the importance of approaching conversations without accusations, which helped maintain a positive atmosphere and understanding:

> I make a point of not coming in with accusations if I have an issue. Instead, I present it as a question [. . .] There are many questions like, 'Why do you do it this way? What were you thinking here?' And I am always met with openness and explanations. (Grete)

This emphasis on open, non-confrontational communication was seen as crucial in fostering a collaborative environment where family and professional caregivers could effectively collaborate.

Mutual Understanding and Perspective Shifts

Many family caregivers found that conversations with professional caregivers provided insight into the reasoning behind their decisions and actions. Lars noted that these dialogues aligned his expectations with those of the staff: "*I have learnt that the staff at the facility have some views on how professional caregivers should act in relation to the residents, which very much matches my views*" (Lars).

Birgitte appreciated that these conversations provided a more comprehensive view that went beyond the perspectives of family caregivers alone: "*It gave a sense of wholeness [. . .] a different understanding than the one you get between relatives only*" (Birgitte).

Charlotte shared how valuable it was to be included in the daily considerations of professional caregivers, appreciating the insight into the practical, everyday decisions made by the staff:

> What I found most valuable was hearing about the daily considerations of the care staff. It wasn't about management-level decisions, but their very practical, day-to-day thoughts. [. . .] It's always nice to know that it's not just our family's considerations, but that our relative is now part of that larger family too, with the staff and their considerations. (Charlotte)

Else echoed the value of hearing directly from staff, noting: "*It was good to hear the staff's opinion in words; that is, directly what the staff think about things*." Conversations with professional caregivers not only helped family caregivers understand the rationale behind actions but also encouraged shifts in their own perspectives. Grete observed that professional caregivers thoughtfully considered how they approached care tasks, which fostered a greater appreciation for their role. She concluded: "*They think about how they do things. They think about how they treat, talk, prioritise tasks in relation to the social wellbeing of residents*" (Grete).

Similarly, Mette expressed the view that professional caregivers, through their daily presence, develop insights into residents' needs that family caregivers may not always recognize.

> The conversations give a different understanding that it's not only the relatives who aren't there on a daily basis who should sit and decide how everything should be done [. . .] healthcare professionals also have a daily life and are sometimes actually better at seeing what's right for the resident. (Mette)

This was echoed by others, who highlighted that such understanding of the perspectives of the professional caregivers and the recognition of their expertise allowed caregivers to trust that professional caregivers were making decisions based on sound considerations. For instance, Marianne noted that "*It allows you to let go a bit and trust that the staff are acting based on their assessment of her*" (Marianne).

The fact that conversations between family caregivers and professional caregivers helped facilitate a mutual exchange of perspectives, allowing both sides to gain insights into each other's viewpoints, was nicely summarized by one family caregiver:

> You start to see other viewpoints, thinking, 'Well, I can understand that too,' and recognise why they might see it that way. This allows for a dialogue that both they and you can use. [. . .] It also gives them insight into what we are thinking. (Lone)

Overall, family caregivers highlighted that dialogues not only facilitated practical cooperation but also allowed caregivers to appreciate the professional expertise and thoughtful considerations of the staff.

Discussion

In this study, we examined family caregivers' perceived benefits of engaging in conversations with the professional caregivers of people with dementia in long-term residential care. These findings add to the expanding body of research highlighting the essential role of engaging not only with peers but also with professional caregivers in enhancing the well-being and support of family caregivers in dementia care (Shanley et al., 2011). By highlighting how conversations with professional caregivers address emotional and practical challenges, this study highlights the potential benefits of structured dialogues, such as those facilitated in the CARE intervention, to promote family involvement and person-centered care in long-term dementia settings. Family caregivers often feel disconnected from the daily experiences of their loved ones with dementia, which engenders not only feelings of disconnection or losing touch (Bramble et al., 2009), but may also introduce feelings of guilt (Caputo, 2021; Gallego-Alberto et al., 2022) and isolation (Kovaleva et al., 2018). The fact that family caregivers feel left out of the loop and disconnected from day-to-day practices aligns with other studies documenting how resident care is negotiated among staff and family members in nursing homes, revealing that family members of relatives in nursing homes, in general, often occupy only a "marginal position relative to staff" and are not adequately engaged in dialogues about care decisions and given a seat at the table (Puurveen et al., 2019).

This sense of disconnection, where family caregivers feel they are losing touch and lack insight into their relatives' daily lives, is echoed in broader literature, which points to the importance of initiatives that promote the inclusion of family caregivers of people with dementia, after the person with dementia has transitioned into long-term care settings (Backhaus et al., 2020). We found that family caregivers articulated a strong need to stay involved in the care of their relative with dementia, expressing the desire to keep up with the progress of the disease and daily fluctuations in well-being. This need resonates with findings from other studies, which highlight the need of family caregivers of people with dementia to participate in care (Bramble et al., 2009; Legault & Ducharme, 2009) and the importance of continuity and monitoring in caregiving roles in geriatric care in general (Davies & Nolan, 2006) and dementia care in specific (Graneheim et al., 2014). This perspective may stem, as highlighted elsewhere, from the assumption of family caregivers of people with dementia that professional caregivers might be unable to provide the level of care deemed adequate for their loved ones (MacLeod et al., 2017).

The significance of conversations and effective communication in building trust has been well-documented in the context of nursing home residents with advanced dementia (Boogaard et al., 2017). Likewise, family caregivers in our study emphasized that conversations with professional caregivers helped mitigate these feelings of disconnection, providing reassurance and a sense of involvement despite their physical absence from day-to-day care. In this respect, openness was seen as essential for building trust and ensuring that both family and professional caregivers could work together effectively. Family caregivers' emphasis on the benefits of engaging in open and honest conversations, viewing them as essential for fostering trust, mutual understanding, and a sense of confidence, is consistent with findings elsewhere in the literature. For instance, others highlight the importance of building trust and confidence as a prerequisite for enabling family caregivers of people with dementia to relinquish care responsibilities and partially adjust to their new role (Legault & Ducharme, 2009).

Moreover, given family caregivers' relational ties to individuals with dementia, they often remain actively engaged in the care of their loved ones even after they transition to care facilities (Bolt et al., 2019; Brodaty & Donkin, 2009). This involvement occurs both emotionally and practically, as caregivers support meaningful, person-centered engagement through activities such as attending church together or going out for dinner (Butcher et al., 2001). Such engagement underscores the potential for promoting person-centered care for people with dementia (Kitwood, 1997). The inclusion of family caregivers aligns with theoretical frameworks such as relational autonomy, which emphasizes the interdependence of individuals within caregiving relationships, and shared decision-making, which highlights the collaborative nature of care decisions. These frameworks suggest that actively involving family caregivers in decision-making processes not only facilitates person-centered care but also strengthens the emotional and practical support provided to care recipients. Studies indicate that including family caregivers is a central component in the provision of person-centered care, which has been shown to positively impact care recipients (Powell et al., 2018; Reid & Chappell, 2017).

Our findings also reveal that many family caregivers experience significant emotional challenges, such as guilt, uncertainty, and insecurity, which are exacerbated by the transition of their relatives into long-term care. These emotional burdens are often rooted in the caregivers' perceptions of their roles and responsibilities and their struggle to adjust to the new dynamics of providing care for their relative with dementia from a distance (Crawford et al., 2015). Consistent with previous research, our study shows that professional caregivers play a crucial role in providing the reassurance needed to navigate these emotional challenges, underscoring the importance of support both during the transition into long-term care and continually throughout the placement of their relatives with dementia in residential care (Bramble et al., 2009; Hennings et al., 2010).

Family caregivers valued conversations where they could leverage the professional expertise of the professional caregivers, valuing their knowledge and insights as critical resources for understanding the complexities of long-term care. However, many caregivers also noted a perceived decline in access to professional guidance once their relatives moved into care facilities, reflecting a gap in support that more structured communication opportunities could address. While this need reflects broader findings in the literature that stress the importance of guidance in addressing the information and knowledge needs of family caregivers of people with dementia (McCabe et al., 2016; Steenfeldt et al., 2021), whether professional caregivers should provide this type of guidance under fiscal constraints in the dementia care context remains open. However, while evaluating optimal resource allocation for care is beyond the scope of this study, existing research indicates that the inclusion of family caregivers in the care process can not only lead to greater satisfaction and enhance dementia family caregivers' own well-being (Backhaus et al., 2020; Cohen et al., 2014), but also help ensure a person-centered approach to caregiving, as family caregiving is often essential for establishing a coordinated approach to dementia care (Wang et al., 2019).

The availability of professional caregivers' time is often limited by their responsibilities toward care recipients, making it difficult to engage in prolonged or frequent conversations with family members. However, the benefits of these conversations for family caregivers are clear. To ensure that these interactions are both productive and feasible within long-term care settings, it is crucial to establish structures that not only foster the willingness of professional caregivers but also allocate the necessary resources to support this task. Without such support, the potential benefits of these conversations may be significantly constrained.

Strengths and Limitations

A notable strength of this study is its in-depth qualitative approach, which allows for a comprehensive understanding of family caregivers' perspectives on the perceived benefits of conversations with professional caregivers. However, several limitations deserve mention. First, this study sought to adopt a narrative orientation in its interpretation of participant accounts However, we recognize that family caregivers' accounts—and their reflections on perceived benefits—were shaped, at least in part, by the context of the research setting and the relational dynamics of the interview process. Although efforts were made to create space for open and reflective accounts by allowing participants to follow their own trails (Riessman, 2007, p. 24), the role of the interviewer and the semi-structured format, which included predetermined domains of interest, may have influenced how experiences were shared and understood. We also acknowledge that our own positioning—particularly our initial interest in the potential benefits of conversations—may have shaped both the development of themes and the interpretation of participants' accounts.

Another limitation is the representation of family caregivers interviewed, as most participants in this study were daughters of people with dementia. This demographic distribution is noteworthy because the predominance of female participants suggests that the insights and themes identified are largely shaped by the experiences of daughters, which may differ from those of other family members, such as sons or spouses. The variation in years of caregiving experience, ranging from 1 to 13 years, presents another limitation, as both the length of caregiving experience and the relationship to the person with dementia likely affect the needs for conversation and support, potentially skewing the interpretation of relevant needs. Future research could investigate these potential variances in needs based on characteristics such as the caregiver's relationship to the person with dementia and their caregiving experience, exploring how different familial roles and caregiving histories might influence communication preferences and perceived support needs. Moreover, this study focuses on the benefits and motivations of family caregivers for engaging in conversations with professional caregivers. While this provides valuable insights into the positive aspects of these interactions, it does not fully capture the potential challenges caregivers might experience in these conversations. Future research could examine both benefits and challenges to provide a more balanced understanding of these dynamics.

Despite these limitations, this study provides new insights into the emotional and practical benefits of conversations between family caregivers and professional caregivers in long-term dementia care. Specifically, it highlights the critical role of open communication in mitigating family caregivers' feelings of disconnection, addressing emotional challenges such as guilt and uncertainty, and fostering collaborative, person-centered care environments. By focusing on family caregivers' perceived benefits, the study offers a unique perspective on how dialogue can strengthen family-professional relationships in dementia care contexts. These findings contribute to the broader understanding of family involvement in long-term care, emphasizing the importance of communication in promoting trust and collaboration

Conclusion

This study highlights that family caregivers of people with dementia in long-term dementia care experience significant benefits from engaging in conversations with professional caregivers. These dialogues address specific needs by helping to reduce feelings of disconnection, mitigating emotional challenges such as guilt and uncertainty, and fostering collaboration through openness and trust. Conversations also provide family caregivers with guidance and reassurance, allowing them to feel more confident and involved in their relatives' care. The findings underscore the critical role of open and ongoing communication among family and professional caregivers in building trust, addressing family caregivers' emotional and informational needs, and supporting them in navigating the shared caregiving roles of long-term dementia care.

Acknowledgments

We thank the research assistant Marie Eva Berg, for assisting us in conducting the interviews for this study.

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Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by The Velux Foundation under Grant Agreement No. 27773

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability

The data supporting this study's findings are available from the corresponding author upon reasonable request.

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