

## Research Article

# Care Convoys and Solitary Vessels: Navigating Family Care for Older Adults Living With Dementia in Arctic Norway

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Received 25 May 2024; Accepted 3 December 2024

Academic Editor: Nan Lu

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Drawing on the metaphor of “care convoys,” this study explores the experiences and strategies of family caregivers of older adults with dementia in rural areas of Northern Norway. The study is part of a broader project that investigates how these older adults and their caregivers use or do not use municipal health and care services. We conducted qualitative in-depth interviews with 11 family caregivers in rural municipalities. The thematic analysis of the interview data yielded three main themes: Delaying the transition to long-term care amid evolving needs, facilitating knowledge transition, and navigating divergent expectations about involvement. In addition, a fourth theme, caregiving in the rural Arctic, was identified as cross-cutting, reflecting the unique rural Arctic context that was a backdrop across all themes. In navigating the caregiving journey, family caregivers assume various roles within care convoys. They may act as solitary vessels, as an integral part of a larger care convoy, or as the main ship guiding the convoy. At times, family caregivers serve as vessels called upon by the convoy when needed. Difficulties in assembling an adequate or robust care convoy were exacerbated by the context of the Arctic North, which represents treacherous waters for the convoy to navigate, primarily due to two factors: first, many of the smaller ships (other family members) were not present or had to travel great distances to join the convoy and second, the lengthy journeys (long travel distances), and particularly in the winter time, made the convoys susceptible to losing ships along the way.

## 1. Introduction

This article draws inspiration from Moen and DePasquale’s [1] appeal for “scholarly enquiry to promote understanding of the changing nature of family care in the 21<sup>st</sup> century.” In particular, we address their invitation for research “capturing individuals’ and families’ adaptive strategies and cycle of control during the caregiving process,” as well as studies “attending to the subjective meanings of care.” Moen and DePasquale [1] identified four key trends that they believe are central to what they describe as “the contemporary crisis of care for older members of society.” The first points to an increase in informal family caregiving due to the extended lifespans of family members. The second observes that many

family caregivers in Western countries are balancing paid employment with the responsibilities of care for older family members. The third highlights a reduction in public care provision for older adults, which is paired with increased reliance on family caregivers. Lastly, the fourth pertains to the burgeoning use of technology to facilitate communication between families and professional caregivers. In summary, the trends indicate a shift toward unpaid and informal care, which is characterized by increasing complexity.

These trends are also evident in Norway. However, the provision of care for older adults is distinctly influenced by Norway’s unique yet varied geographical, political, and material landscapes. Norway is often recognized as a strong

welfare state, characterized by its comprehensive and decentralized public health and care systems. The delivery of statutory services, such as home-based care, falls under the jurisdiction of relatively small and autonomous municipalities and is financed through taxation. With a relatively modest population of 5.5 million, over 80% of Norwegians reside in urban areas [2]. Furthermore, similar to other European countries, the Norwegian population boasts a high and steadily increasing average life expectancy [3]. The demographic shift associated with the baby boom generation is poised to precipitate an expanding care deficit in the forthcoming years, and the projected population trends indicate a nationwide decline in the family caregiving ratio by 2050 across Norway [4], with the steepest decrease anticipated in smaller, rural municipalities [5]. Norwegian policymakers have consistently emphasized the need to maintain or increase family caregiving contributions in the future [6]. This emphasis comes despite, and perhaps because of, forecasts predicting a decrease in the number of available caregivers and a simultaneous increase in the number of individuals requiring care.

Despite Norway's well-developed and comprehensive public care services for older adults, family caregivers continue to provide substantial care and support. It is estimated that family care contributes the equivalent of 136,000 full-time positions [4]. To put this into perspective, care provided by public municipal health and care services is estimated at 141,000 full-time equivalents [4]. The majority of this familial care is delivered by individuals within the employable age range of 40–69 years (28,000 full-time equivalents) and those aged 70 years and older (28,000 full-time equivalents) [4]. Although the decline in access to formal long-term care services for frail older adults is more comprehensive in other parts of the world [7–9], and Norwegian public expenditures in the public care services for the older adult population are high compared to most OECD countries [3, 10, 11], family caregivers still take on substantial care responsibilities due to a decrease in institutional long-term care services relative to the size of the older adult population [12]. These caregivers offer a range of support to older adults, encompassing both hands-on care and indirect assistance, such as helping to navigate the health and care system and advocating for public health and support [13]. Although it is commonly perceived that juggling family caregiving with paid employment constitutes a dual burden, research within the Norwegian setting indicates that women who engage in extensive family care while being only marginally employed experience care as the most burdening [14]. Research indicates that informal caregivers in Norway face significantly fewer missed formal employment opportunities compared to those in non-Nordic welfare states [15]. This can be attributed to both the universal and comprehensive public care services available and the strong employee rights and arrangements in place [14]. Furthermore, resources of family caregivers (partner and children), including employment, higher education, income, and nonuse of long-term care, are linked to the likelihood of older adults transitioning to institutional

long-term care [13]. Specifically, older adults with partners and children who have more resources are less likely to transition into long-term care. Surprisingly, the cited study also found that the geographical proximity of adult children has a minimal impact on the use of long-term care by older adults.

Norwegian health authorities estimate that over 100,000 people in Norway are living with dementia, with two-thirds residing in their own homes [16]. The country's health and care policies strongly support aging in place [17, 18], even for those with significant care needs, including persons living with dementia [19, 20]. Consequently, older adults and those living with dementia are staying in their homes longer. This shift requires increased support from both formal and informal caregivers. Informal caregivers, in particular, provide the majority of care for those living with dementia [21]. Caring for persons with dementia is notably more demanding than many other types of caregiving [22]. Previous research has shown that although family caregivers have positive experiences of caring for persons living with dementia, they also face an increased risk of stress and health complications [23, 24].

In this article, drawing inspiration from Moen and DePasquale [1], we explore the nature of family care and family caregivers' adaptive strategies and cycles of control within the unique geographical and demographic context of rural Northern Norway. Using Moen and DePasquale's metaphor of "care convoys," "convoy" generally defined as a group of ships sailing together for mutual protection and support [25], we explore the experiences and strategies of family caregivers of older adults living with dementia in these rural areas.

*1.1. Dynamics of Formal and Informal Care and Care Convoys.* The interplay between formal and informal care, in this case, understood as care provided by the health and care services and care provided by family members, has been described as a dynamic of crowding-in versus crowding-out [26]. Crowding-out occurs when high levels of public service provision correspond with low levels of family care. In contrast, crowding-in refers to a scenario where both the public service level and the levels of family care are high. Kröger [27] introduced the concept of reversed substitution, which occurs when public care services are reduced, resulting in a heightened reliance on informal care. However, as Kröger [27] pointed out, the most salient question is not simply whether substitution occurs but rather how formal and informal care interplay. This is because, as Kröger observed, "[i]n most families that receive formal services, informal care is still needed." While the distinction between formal and informal care can be useful, Moen and DePasquale [1] point out that "the two sources of care work increasingly intersect in complex ways" indicating that the lines between the two are increasingly blurred. Moving beyond this dichotomy, they introduce the concept of "care convoys" to describe the networks of individuals "who are personally connected to care recipients and manage or oversee their daily care, provide them with instrumental and

emotional support, and advocate for high-quality medical care.”

## 2. Methods

**2.1. Study Design and Context.** Less than 500,000 people, or about 10% of Norway’s population, live in Northern Norway [28], which accounts for roughly 35% of the country’s geographical area. Rural communities in this region are marked by dispersed settlements and significant geographical distances to municipal centers, which typically host health and care services. There is a notable trend of younger people relocating from rural to more urban areas [29], as well as migrating from the north to the south of the country [30]. As a result, the average age of the population in rural Northern Norway is comparatively high. This demographic shift impacts both the availability of family care and the accessibility of health and care professionals within the health and care services.

This study is part of a broader research initiative aimed at exploring the utilization and nonutilization of municipal health and care services by home-dwelling older adults living with dementia and their family caregivers in this specific region of Norway. The research initiative encompasses a survey of 430 family caregivers across a sample of 32 municipalities, focus group discussions with professionals in municipal home-based health and care services from five municipalities, and individual interviews with family caregivers of persons with dementia in five different municipalities. The interviews were conducted in municipalities categorized as Category 6 (the least central) according to the centrality index of Statistics Norway [31], which is determined by travel distance to workplaces and service functions. The selected municipalities are characterized by their small populations, declining population growth, extensive geographical distances, and dispersed settlements. The population sizes of these municipalities range from 800 to 3800.

**2.2. Participants and Recruitment.** This study is based on individual qualitative in-depth interviews with 11 family caregivers conducted in the project. To recruit family caregivers, we distributed written information along with consent forms to those survey participants who had previously expressed a willingness to engage in a follow-up qualitative interview.

The family caregivers in this study provided support to older adults who either resided in their own homes ( $n = 7$ ) or had transitioned into assisted living facilities recently ( $n = 4$ ). In Norway, assisted living facilities are regarded as the resident’s legal home. Most of these facilities receive services from home care services, which are outlined in service agreements similar to those for standard home care services. The demographics and other characteristics of the family caregivers are detailed in Table 1.

**2.3. Data Generation.** The interviews were carried out by the lead author either in the participants’ homes or at their places of work, with each session ranging from 60 to 120 min

TABLE 1: Participants.

Relation to older adult	Spouses $n = 4$ Sons $n = 2$ Daughters $n = 4$ Adult grandchild $n = 1$
Gender	Women $n = 8$ Men $n = 3$
Age span	Mid 30s–early 80s
Employment status	In paid employment $n = 6$ Retired from paid work $n = 5$

in duration. Utilizing a thematic interview guide, the family caregivers were encouraged to openly discuss various topics. These included the daily life and assistance requirements of the individual with dementia, their personal experiences as family caregivers, their participation in caregiving, their interaction and cooperation with the municipal health and care services, as well as their perspectives on future considerations. All interviews were digitally recorded and subsequently transcribed verbatim to ensure a faithful representation of the participants’ accounts.

**2.4. Analysis.** Motivated by Moen and DePasquale’s [1] appeal for research that explores the adaptive strategies and cycle of control of individuals and families throughout the caregiving journey, our analysis was guided by the following questions:

- How do family caregivers adapt to the evolving needs of the older adult during the caregiving process?
- How do family caregivers navigate their involvement in decision-making processes and how does this impact their experiences of caregiving?
- How are the family caregivers’ experiences framed and shaped by the rural Arctic context?

We engaged with the interview data using a thematic analysis approach outlined by Braun and Clarke [32] as “driven by the researcher’s theoretical or analytic interest in the area,” as this provided a suitable approach for “a detailed analysis of some aspect of the data.” The lead author (BHB) meticulously reviewed the interview transcripts multiple times. This was followed by a deliberate examination of each transcript, during which BHB actively searched for and coded text segments that pertained to the experiences of family caregiving, with a special emphasis on the family caregivers’ adaption to change and participation in decision-making. Subsequently, BHB presented the initial codes and corresponding transcript excerpts to the second author (GÅ). The subsequent phase involved both BHB and GÅ collaboratively engaging in the refinement, definition, and (re)naming of themes. This iterative approach allowed for a dynamic interaction with the data, characterized by both deep engagement and reflective distance. Our combined research experience in municipal health and care services, along with our distinct academic backgrounds, BHB in gerontology and GÅ in social sciences, served as valuable assets in the interpretive phase.

The three main themes with subthemes and a fourth cross-cutting theme are presented in Table 2. Main themes 1 and 2, along with their associated subthemes, address Research question 1. Main theme 3 and its subthemes address Research question 2. The cross-cutting theme addresses Research question 3.

**2.5. Ethics.** The study's data management procedures were approved by the Norwegian Center for Research Data (Sikt) (reference number 42469). We have securely stored the anonymized interview transcripts within the Sikt repository. All participants willingly gave informed consent, having been fully apprised of their right to discontinue their involvement in the study at any point without needing to justify their decision. Participants were not reimbursed. We took extra precautions regarding narratives shared by family caregivers that encompassed details about older individuals with dementia, other family members, and health and care services providers who did not consent to be part of the study. In our efforts to maintain confidentiality, we have carefully anonymized any personal information pertaining to individuals with dementia, their family members, and other third parties. In addition, to further protect participant anonymity, especially given the close-knit nature of the communities involved in the study, we have deliberately avoided presenting a combination of the family caregivers' age, gender, and relationship to the person with dementia in Table 1.

### 3. Results

Our data unequivocally show the significant efforts made by family caregivers in providing care and support to older adults with dementia who live at home. Family caregivers play a crucial role in joint efforts to secure adequate and timely care for older adults in their own homes, and thus also in the implementation of governmental policies aimed at supporting aging in place. Nonetheless, the reasons for, the capacity of, and the composition of the partnerships involved in caregiving by family members differ widely.

#### 3.1. Delaying the Transition to Long-Term Care Amidst Evolving Needs

**3.1.1. Managing Gradually Developing and Rapidly Changing Care Needs.** The dedication of family caregivers encompassed both vigilance and flexibility, addressing the needs that gradually evolved and those that shifted swiftly in the day-to-day immediacy, as illustrated in the following narrative:

*I realized that the dementia had. . . that he was sick and needed more care, because he no longer understood what I was saying. I saw that he needed to get out of bed, and I used the lift, and he closed his eyes and fell asleep before his head hit the pillow. After a while, I helped him back up and into the living room. He could sit and watch. . . watch the light outside. He was happy. But he could not sit for long.*

*He was. . . it was the disease that didn't allow. . . He was tired, and he was so skinny that he. . . he couldn't. His body couldn't. So, several times a day, I went back and forth with him. Put him to bed and then into a chair. It was never an option that he should stay full-time in the nursing home. No, I didn't feel. . . I felt I could manage to have him at home (Participant 8, wife).*

Similar to all participants in our study, this wife had been by her husband's side as his illness progressed and his care needs gradually increased over the years. Yet, even when his illness reached a stage where he could no longer comprehend her words and could only sit briefly in their living room, moving him to a nursing home was "never an option." Instead, ever mindful of her husband's needs, she persistently assisted him to and from his bed to his chair by the window throughout the day, allowing him brief periods to enjoy the outdoor light. This account is but one of numerous examples in our data that underscore the profound dedication of family caregivers to postpone the shift to institutional long-term care, and their attentiveness to and attunement with the fluctuating needs of the person with dementia, needs that evolved gradually and needs that altered swiftly.

**3.1.2. Solitary Endeavors and Collective Responsibilities.** In this study, the decision to provide family care at home emerged as a deeply personal choice, often influenced by individual circumstances and life stages. For example, one retired wife expressed her inclination towards caregiving, stating the following:

*We have never said to each other that we will take care of each other at home and live at home for as long as possible. We haven't made a deal. I just want to. After I retired, what else should I do? (Participant 8, wife).*

This sentiment reflects a personal commitment to caregiving but also how this commitment is shaped by retirement. Conversely, other participants highlighted the complexities of balancing caregiving with other life commitments. An adult granddaughter articulated the challenges and her family's collective decision-making process: "We have discussed it, and we will try to do everything we can to have her at home as long as possible. But of course, you have a family, you have a job, and you have. . ." (Participant 11, adult granddaughter).

This statement underscores the interplay between personal commitment and practical constraints, illustrating a common dilemma faced by several of the participants. Some participants, like the retired wife, expressed a sense of individual responsibility, while others, like the granddaughter, emphasized a collaborative approach within the family. This distinction highlights the varying dynamics within family caregiving, from solitary efforts to collective endeavors.

In addition, the presence of potential support networks played a crucial role for some caregivers. For some, the interaction with home care services was a source of

TABLE 2: Themes.

Main theme	Delaying the transition to long-term care amidst evolving care needs	Facilitating knowledge transition	Navigating divergent expectations about involvement
Subtheme	Managing gradually developing and rapidly changing care needs	Facilitating patient safety, continuity of care, and patient-centered care	Balancing expectations and bridging gaps
	Solitary endeavors and collective responsibilities	Sustaining social networks through knowledge transition	Retaining, reframing, and refraining decision-making authority
	Moral duty and concerns for the long-term viability of family care		
Cross-cutting theme: Caregiving in the rural Arctic	Delaying transition to long-term care in the rural Arctic context	Facilitating knowledge transition in the rural Arctic context	Navigating involvement in the rural Arctic context

reassurance, allowing them to continue caregiving independently as long as possible: *“They (the home care services) came and talked with me. (. . .) I said no, I don’t need a conversation yet. But it is good that they knew”* (Participant 8, wife). This statement illustrates how the awareness of available support, other ships prepared to join in a convoy, may provide the strength to persist in caring for family members at home as solitary vessels. However, not all participants had access to such support networks. For some, the absence of external help positioned them as the primary caregiver, driven by necessity rather than choice: *“Why I provide care? He needs help, so I have to. There is no one else around”* (Participant 5, wife). This statement reflects a scenario where caregiving becomes an obligatory role due to the lack of alternatives.

Overall, this subtheme demonstrates the diverse motivations and circumstances surrounding family caregiving, ranging from personal commitment and family dynamics to the availability of support systems. These circumstances collectively shape the caregiving experience, influencing both the approach to and the sustainability of family care.

**3.1.3. Moral Duty and Concerns for the Long-Term Viability of Family Care.** Our results demonstrate that many participants continued their roles as family caregivers, thereby delaying the older adults’ transition to institutional long-term care, often motivated by what they perceived as the preferences of the older adult. For example, one daughter mentioned, *“Going to a nursing home would kill him”* (Participant 9, daughter), indicating a belief that home care aligns with her father’s desires. In contrast, other participants viewed their caregiving role as a moral obligation, as illustrated by another daughter’s comment: *“My mother’s friends said: “You should just drive him to the health center and tell them to take him, that they must find a place for him.” But she didn’t. She felt it was too brutal”* (Participant 4, daughter). This sense of duty often led caregivers to continue providing care despite external suggestions to consider institutional options. Furthermore, some family caregivers expressed that ceasing to provide care would be tantamount to personal failure. One daughter articulated this sentiment, saying, *“You feel that you expose yourself when you tell someone that you can’t cope with more, without implying that you don’t care about your parents”* (Participant 2, daughter).

However, the decision to continue caregiving at home was accompanied by concerns about the long-term sustainability of such arrangements. Family caregivers were not only worried about the increasing needs of the person with dementia but also about their own health and circumstances. One wife captured this ambivalence by stating, *“I feel I manage. I do. As long as I’m as healthy as I am now. But I do think every now and then: What if something happens to me?”* (Participant 6, wife). This statement underscores the uncertainty faced by family caregivers about their ability to continue in their role, especially in the absence of a robust support network, that is, other ships in the convoy that could take the lead if the main ship falls behind.

Overall, this subtheme highlights the complex interplay of personal beliefs, moral considerations, and practical concerns that shape the experiences of family caregivers. These factors collectively influence decisions regarding the continuation of family care versus the transition to institutional care settings, reflecting a nuanced understanding of the dynamics of family care.

**3.1.4. Delaying Transition to Long-Term Care in the Rural Arctic Context.** The participants’ experiences of providing family care were significantly influenced by the rural Arctic context. The vast distances to municipality centers reinforced family caregivers’ determination to maintain family care at home: *“If he must go to the health and care center in (the municipality center), respite care is out of the question! His illness is not that. . . he is not there yet. . .”* (Participant 6, wife). These long distances in the rural Arctic also posed difficulties in obtaining respite and support from other family members: *“I have a sister who lives 160 km from here. (. . .) Other than that, the rest (of the family) is in the south”* (Participant 5, wife). The out-migration of younger generations further exacerbated the situation, leaving many family caregivers to shoulder caregiving responsibilities on their own. A husband noted, *“We have always coped without help from others. And our kids live in the south. We have contact with them, but they are almost never here”* (Participant 3, husband). However, occasional visits from family members residing in the south provided some family caregivers with temporary relief and support: *“But when they come here, we can relax. We can leave the responsibility to them”* (Participant 11, granddaughter).

Overall, this subtheme demonstrates that the rural Arctic context significantly shapes the caregiving experience, with vast geographical distances and out-migration influencing both the practical aspects of care and the availability of multiple ships to form care convoys.

**3.2. Facilitating Knowledge Transition.** In our study, we found that family caregivers not only provided direct care but also served as vital conduits for information. The caregivers were the linchpin, coordinating the exchange of information necessary for safe and comprehensive care. They ensured that critical information was communicated between healthcare providers, the older adult, home care services, and the individual’s social network. Moreover, the family caregivers helped the older adults comprehend their situation amidst their own challenges.

**3.2.1. Facilitating Patient Safety, Continuity of Care, and Patient-Centered Care.** The family caregivers were crucial in assisting older adults as their dementia progressed. They played a crucial role in helping the person living with dementia retain an understanding of medical information provided by healthcare professionals. For instance, family caregivers often accompanied the older adult to medical consultations to ensure comprehension and retention of information, as one caregiver noted, *“When he is called in for*

*consultations, I go with him to be sure. . . If the doctor says something he cannot remember” (Participant 6, wife).*

Moreover, family caregivers were instrumental in conveying vital information about the older adult to health and care services, which is essential for ensuring patient safety and maintaining continuity of care. They often took meticulous steps to document daily care instructions for home care staff, detailing everything from medication schedules to the location of meals. One caregiver explained,

*We write, from month to month, what should be done [by the home care services]. In the mornings: “Make sure he takes his medication, give him the nutrition drink, give him eye drops. . .” And we have written where everything is placed (Participant 9, daughter).*

This detailed communication reflects a broader concern among the family caregivers about the home care service providers’ ability to independently recognize and address the needs of the older adult. Many felt the need to actively inform and sometimes push the service providers to ensure proper care, as expressed by another participant: *“They are a little slow, picking up on. . . They are a little slow to recognize. . . As a family caregiver you must push. . . notify them” (Participant 10, son).*

Beyond the specific needs and requirements, the family caregivers also provided valuable insights into the personality and preferences of the older person living with dementia. This deeper understanding is crucial not only for ensuring patient safety and continuity of care but also for enabling person-centered care. Highlighting the importance of this, one participant suggested, *“There should be a clear understanding. . . an agreement between the family and the care personnel that you should write a story about. . . tell about who your parents are” (Participant 1, son).*

Overall, this subtheme demonstrates the pivotal role of family caregivers in bridging the gap between professional health and care services and the individual needs of older adults living with dementia, ensuring that care is safe, effective, and person-centered.

**3.2.2. Sustaining Social Networks Through Knowledge Transition.** The family caregivers extended their efforts beyond interacting with formal caregivers, striving to maintain the older adults’ social connections. They provided friends and acquaintances with guidance on how to interact with the person living with dementia, despite facing challenges such as hesitancy and uncertainty from these social contacts, as described by one participant,

*His friends are unsure about how to handle. . . afraid of dropping by for a visit. I have told them to come. I said to one of them, “Just come for a visit!” And he came. Because they wonder—is he completely gone, right? I believe people are just concerned with how to tackle. . . (Participant 9, daughter).*

This highlights the proactive steps taken to reassure friends and facilitate social interactions.

Family caregivers not only acted as connectors between persons living with dementia and their communities but also sometimes served as information gatekeepers. They carefully managed the information shared with the older adult to avoid causing unnecessary distress. One participant expressed this protective stance as

*I never tell her gossip about bad things in the community or within the family. . . Why should she be left worrying? I’m convinced that even though she might forget the details, the anxiety would linger without her knowing the reason (Participant 7, daughter).*

Despite their crucial role in facilitating understanding and maintaining social networks, family caregivers often face personal challenges. The emotional toll and the need for patience could sometimes be overwhelming, as reflected in the sentiments of one participant: *“It’s not a problem that he forgets things. The challenge is for me to remain patient, and I realize I sometimes lack that” (Participant 6, wife).* The feeling of struggling alone is a common thread among the family caregivers, with another stating, *“This anger. I feel: Will this never end? Will this be my life mission until mother passes away? I simply feel that it is too much” (Participant 2, daughter).*

Overall, this subtheme illustrates the complex dynamics family caregivers navigate as they support older adults living with dementia, balancing the maintenance of social networks, and the emotional strain on both the older adult and themselves.

**3.2.3. Facilitating Knowledge Transition in the Rural Arctic Context.** Facilitating knowledge transition in the rural Arctic context is deeply influenced by the unique characteristics of these environments. Our data suggest that the smaller size of rural communities played a beneficial role for family caregivers in communicating the needs of the older adults to the home care services. One participant noted the advantages of such a setting, stating, *“As the disease progressed, she received more help. That’s how it is. When we asked for help, we got it. That’s perhaps the advantage of smaller communities” (Participant 10, son).* This observation highlights how the compact and close-knit nature of these municipalities can simplify the process of initiating contact with public care services and the sharing of essential information. Another participant reflected on the latter aspect, stating, *“Living in a small place is sort of reassuring because everyone knows. . . You know who the person is, sort of. Those who come (from the care services) are not complete strangers” (Participant 9, daughter).*

In addition, participants noted that local community residents employed in the care services helped lower the barriers to knowledge transfer between families and the care services. As such, healthcare professionals residing in these local communities played a key role in forming care convoys as follows:

...the local community is well-equipped to provide care services because those who work in these services are residents of the community. (...) They are naturally attentive to those who might not (receive formal care services). Due to their role, they also have the opportunity to check in on those who don't necessarily require assistance. (...) So, if a time comes when people still live scattered, but all the care workers reside in the municipality center and don't have a relationship with the local communities, the villages, it will be a big disadvantage (Participant 1, son).

Overall, this subtheme indicates that the familiarity prevalent in smaller, rural communities can significantly ease the burden on family caregivers. This is particularly evident in the way information flows between the older adult, the family caregivers, and the home care services.

**3.3. Navigating Divergent Expectations About Involvement.** As family caregivers, the participants had multifaceted roles that extended beyond providing direct care and facilitating the exchange of knowledge among involved parties. They were also instrumental in decision-making regarding the care of the older adult. In this pivotal role, the family caregivers encountered expectations from both the older adult and the home care services, which did not always align. Navigating this intricate terrain of divergent expectations, the family caregivers had to negotiate the level and nature of their involvement.

**3.3.1. Balancing Expectations and Bridging Gaps.** The family caregivers often found themselves managing expectations from multiple directions. They not only addressed the expectations that home care services had towards them but also the expectations that the older adults held regarding the services. The family caregivers often found themselves stepping in to align the services with what the older adult anticipated, effectively bridging the gap between expected and provided care. This dynamic is evident in the family caregivers' efforts to ensure that the older adult's expectations are met, especially in the home environment where personal preferences and routines play a significant role. One participant expressed this challenge as follows:

*I've noticed that (the home care services) are not able to meet the expectations my parents have. And then I feel a duty to contribute to them having their expectations met. Particularly at home, there are many tasks to be done... rearranging items, making repairs (Participant 1, son).*

This statement highlights the family caregivers' role in not only facilitating care but also in maintaining the older adults' lifestyle and preferences, acknowledging that "Even though my parents have dementia, they still have their opinions about how things should be done" (Participant 1, son).

In addition to managing the older adults' expectations, the family caregivers also had to navigate the expectations of

home care services. One participant described her experience as follows:

*I questioned the home care services, asking, "Where does it say that this is our responsibility?" I also asked, "What if my mother and I had a poor relationship? If you force me into a role I've never had, just because I'm her daughter, who says I should assume that responsibility?" (Participant 2, daughter).*

Overall, this subtheme demonstrates that family caregivers mediate between the expectations of home care services and the personal preferences of the older adult while simultaneously contributing to the older adults' routines and desires.

**3.3.2. Retaining, Reframing, and Refraining Decision-Making Authority.** Some family caregivers emphasized the importance of retaining decision-making authority when interacting with the home care services to ensure that the services provided were tailored to the specific needs and preferences of the person living with dementia. For example, one participant noted the following:

*Right from the start, I made it clear that if we get home care services, it doesn't mean that you can come into our house and decide how to care for him. I will approve the methods you are using. Because I know him - my husband. I have learned how to lift him. It's not just about the lifting. It's about who they are lifting. They lack that understanding (Participant 8, wife).*

This is one of several statements highlighting the family caregivers' commitment to being deeply involved in the care process and ensuring that the care is person-centered. Other participants echoed similar sentiments about the importance of being actively involved in both decision-making and everyday care to maintain their sense of usefulness and connection with the older person. One participant noted, "It is very, very important that the care services don't take over the task you would like to do. You need to feel useful" (Participant 1, son). However, other participants reported feeling overwhelmed by the responsibilities.

Approaches to including the person with dementia in decision-making processes varied widely. Some family caregivers took a more paternalistic approach, making decisions without consulting the person with dementia: "We have accepted the offers [of specific services] on his behalf. There is no point in asking him. We must make decisions for him" (Participant 4, daughter). In contrast, others strived to involve the person with dementia, which they believed lent more legitimacy to their decisions, especially regarding comprehensive care services. For instance, one participant shared, "Eventually, I said that we could start with short respite care stays. And he was clear-minded, and he was on board stating, "I'm doing it for you"" (Participant 8, wife). However, not all family caregivers felt that the person with dementia was agreeable to such decisions. In these cases,



they preferred that home care services take the lead in decision-making, as expressed by a daughter: *“I wish that the home care services entered the field. Because we must take the battle. We see her need for home care, but she’s resistant”* (Participant 2, daughter). This statement suggests that the preferences of the person with dementia can sometimes be a barrier to the formation of robust care convoys. Family caregivers’ desire for home care services to take a leading role in decision-making was particularly evident when considering transitions to long-term institutional care, as noted by one participant:

*They have started to discuss. . . at the nursing home. . . And I, sort of, agree. They said that she should perhaps move there this winter. And I sort of agree because she is getting. . . I don’t know if they have talked to her yet. They should of course prepare her* (Participant 10, son).

Overall, this subtheme demonstrates the complex terrain of decision-making authority, where family caregivers navigate their roles, the expectations of home care services, and the involvement of the person living with dementia in varying and nuanced ways.

**3.3.3. Navigating Involvement in the Rural Arctic Context.** The combination of harsh, lengthy winters and vast geographical distances in rural Arctic Norway can significantly hinder family caregivers’ involvement. One participant described the challenges as follows:

*In summertime, it’s manageable. But come winter, with the unpredictable weather. . . The roads in this municipality are not well-kept. They are in bad condition and slippery. It’s stressful thinking about having to rush there in an emergency* (Participant 9, daughter).

This testimony highlights how seasonal and infrastructural issues limit family caregivers’ ability to be consistently involved in the daily lives of the person living with dementia. In addition, demographic trends in rural Arctic areas, where younger people relocate to cities, increased the burden on the family caregivers who remain to make daily decisions and provide care for the older adults living with dementia. One participant stated, *“I feel responsibility. My sister lives in the city, so she can’t. . . There are limits to how much she can. . .”* (Participant 10, son).

Overall, this subtheme demonstrates how the demographic and geographic realities of rural Arctic Norway constrain family caregivers’ ability to negotiate their level of involvement.

## 4. Discussion

Our study demonstrates the intricate dynamics between formal and informal care, viewed through the lens of family caregivers in rural Arctic Norway. In Norway, and possibly other Nordic countries, the role, function, and contributions of informal caregivers have not received as much attention as

formal care in both policy and research. Formal care, either provided or supervised by public care providers, has been seen as the predominant mode of care in this setting [10, 33]. In the Norwegian healthcare system, formal care has traditionally been the flagship, commanding attention and steering the course of policy and research alike. However, our findings suggest that other vessels, family caregivers, contribute substantially, even though they may be less visible or loud. Family caregivers are not just auxiliary boats, they are crucial to the care convoy, often delaying the transfer of older adults with dementia to institutional care settings. This suggests a potential shift in the care paradigm toward reversed substitution [27] where informal care gains prominence, possibly mirroring broader trends across European countries [34]. Nonetheless, our study provides only a snapshot of the situation and cannot rule out the possibility that these informal care efforts have always existed in certain geographical areas and among some families. As such, it does not necessarily indicate a new care paradigm.

Family caregivers often navigate complex routes, serving various roles within the care convoy. They act as intermediaries, connecting the formal care providers and sometimes other community members with the older adults. This role is vital in maintaining the cohesion and direction of the convoy, ensuring that it does not disperse or lose its way in the treacherous waters of healthcare needs and personal preferences. The family caregivers’ motivations are multifaceted, ranging from moral obligations to practical necessities due to the scarcity of available options. The notion of family care as a moral duty was particularly predominant in our findings, possibly indicating a preference for traditional family values in these rural areas, or among these particular families. Yet, previous research has also reported obligation as a driver for family care [35]. The reluctance to transition to institutional long-term care might be seen as a critique of the long-term institutional care sector, as observed in other contexts [36]. However, the family caregivers in our study did not cite poor conditions of nursing homes as their primary concern; instead, they expressed a belief that “home is better” for the older adults.

Within care convoys, family caregivers may find themselves in various roles; sometimes as the main ship guiding the convoy, sometimes as the ship uniting the convoy. The possibility to summon additional support, other ships ready to join, enables some family caregivers to continue their caregiving journey. Previous research has also emphasized the importance of respite and support from others [37]. This dynamic is critical in regions such as the rural Arctic, where the sparse population and vast distances make the assembly of a robust convoy challenging. The demographic shifts complicate the forming of effective care networks. On the other hand, the compact and close-knit nature of rural communities might enable the forming of care convoys, as demonstrated in previous research [38]. The family caregivers face challenges in determining their roles and contributions within the convoy. Decisions about how much to involve the person with dementia in decision-making processes, whether as an active participant or merely as cargo, highlight the ongoing tensions within the

convoy. These challenges are exacerbated in rural Arctic Norway, where other vessels (that is, either family members or formal care services) might be distant or unable to join the convoy regularly, making the journey perilous and the convoy prone to dispersion.

**4.1. Limitations and Suggestions for Further Research.** This study was conducted within a specific geographical and demographic context, limiting the universal applicability of our results. The region of our study is undergoing a demographic shift similar to what many other regions will face in the coming years. Therefore, our findings could serve as valuable insights for other communities anticipating similar demographic changes. In addition, this study was conducted within the framework of the robust Norwegian welfare state. In societies with less comprehensive public care services, forming care convoys that include family caregivers, other informal networks, and formal care services might be more challenging. Further research should explore the dynamics of care convoys in various geographical contexts.

Our study involved a limited number of participants, but the sample was diverse in terms of the family caregivers' relationships with the person living with dementia and their ages. Some findings are consistent with those reported in other studies involving family caregivers. The interviews were conducted before the COVID-19 pandemic. While the pandemic may have intensified similar experiences, we believe that the situation in Norwegian rural Arctic communities post-COVID-19 remains similar to prepandemic conditions.

Participants in our study were primarily those who considered themselves the main family caregivers of older adults living with dementia. Future research should also include the perspectives of family members who are less involved in daily care but are still integral to the care convoys. In addition, including professionals from health and care services in the study could provide a more comprehensive picture of the dynamics within care convoys. Most importantly, older adults living with dementia should have an opportunity to contribute their perspectives to studies exploring the functioning of the networks surrounding them.

## 5. Conclusion

The contributions of family caregivers might represent a case of reversed substitution [27], where there is an increased dependence on informal care due to the reduction in public care services, or as a way of shifting responsibility away from the public care sector [6]. While our findings certainly indicate such trends, we are cautious about drawing conclusions regarding their normative implications. These trends may be necessary due to demographic shifts, and they may benefit older adults living with dementia by contributing to more robust and efficient care convoys. However, they may also represent a shift of public responsibility onto individuals, affecting older adults unequally based on their location and the availability of family support. This shift

likely increases the burden of family members who may have to contribute more, whether or not they are prepared to do so. Our study indicates that family members already contribute significantly, which suggests that these care convoys can become less stable. The effectiveness of care convoys may depend not only on the proximity of family members but also on their availability, capacity, and health and on the extent to which formal and informal caregivers manage to navigate in manners that create "crowding-in" rather than "crowding-out" effects.

## Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## Conflicts of Interest

The authors declare no conflicts of interest.

## Funding

This study was funded by the Norwegian Research Council (Norges Forskningsråd) (Grant no 238146).

## Acknowledgments

The authors would like to acknowledge Professor emerita Torunn Hamran for her extensive efforts in the planning and designing of this study and for her valuable inputs in the data generation phase of the study.

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