

Experiences of Being Significant Others to Older Adults with Frailty Living Alone in Rural Arctic Norway: A Qualitative Study

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Purpose: Our aim in this study was to explore how significant others experience being “significant” to older adults living alone with frailty in rural Arctic areas in northern Norway. The proportion of older adults in the population is larger and growing faster in rural than in urban areas. Due to out-migration of the younger generations, many significant others live far from the older adults.

Methods: Our results are based on a thematic analysis of semistructured interviews with ten persons identified as significant others by older adults in rural Arctic Norway.

Results: The analysis resulted in two main themes and five subthemes: 1. Restoring and maintaining balance in the older adult’s life with the following three subthemes: 1.1. balancing between the older adult’s capacity and the physical environment; 1.2. emotional support; and 1.3. balancing between the older adult’s need for help and the services offered; and 2. Maintaining balance in one’s own life with the following two subthemes: 2.1. family and working life; and 2.2. tensions between family members. The rural Arctic context in which the older adult lived was relevant to varying degrees in all themes.

Conclusion: Our results showed that experiences of being the significant other involve a continuous balancing act affected by the older adult’s life situation, the significant other’s own life and the rural Arctic context in which the older adult lives. Our study adds to previous conceptualizations of frailty as both a bodily and a relational phenomenon framed by materialities, the understanding of frailty as also a situated phenomenon.

Keywords: aging in place, family caregivers, community care, interview

Introduction

In most parts of the world, the proportion of older adults is increasing. Compared to urban areas, the relative proportion of older adults in the population is larger and is growing faster in rural areas.^{1–4} Policies promote “aging in place”; that is, older adults are being encouraged to continue to live in their own homes and communities.^{4–7}

The goal of the Norwegian care model is a division of labor and a close collaboration between health and care services and the significant others of older adults.⁸ Many older adults in need of help receive care from significant others in addition to health and care services.⁹ Medical advances, shorter hospital stays and treatment of chronic illnesses at home have led to long-term care responsibilities for significant others.¹⁰ Moreover, significant others can contribute to improving older adults’ quality of life both because they are an important part of older adults’ social network and because they often provide practical help and informal care.¹¹ Health and care policies are encouraging families, social networks, and local communities to provide more help and support for older adults in the years to come.^{6,8}

Committed significant others can be an important resource in making “aging in place” possible. Help and support from significant others have been referred to as invisible care.¹² Norwegian public statistics estimate that family caregivers and health and care services contribute equal amounts of help and support to home-dwelling older adults

over the age of 80.¹³ A national health and care policy ambition is that health and care services should supplement family care and provide family caregivers with the necessary support to avoid caregiver strain and burden.^{6,14}

Several studies have shown that significant others are the invisible backbone of care for older adults, especially in rural and remote areas with limited access to services.^{12,15} Graffigna et al¹² argued that family caregivers in rural areas fill the gaps that exist due to the fragmentation of the welfare system. Munkejord et al¹⁶ demonstrated that older adults in rural areas were dependent on extensive assistance from health and care services and significant others to continue living in their own home, and informal caregivers contributed practical help, security, and social contact.

Being the significant other for an older adult living alone in rural Arctic areas may present challenges. Many rural communities are characterized by long geographical distances from other communities and municipal centers, out-migration of the younger generations, and insufficient staffing of health and care services.¹⁷ Moreover, Arctic communities are characterized by a harsh climate involving long, dark winters. Due to out-migration of the younger generations, many significant others do not live close by. This may make it challenging to maintain contact and provide help and support in their everyday lives. In addition, older adults' other social networks may be reduced, and they may have less capacity to maintain social relationships,⁴ which may make them even more dependent on help and support from their significant others. Dang et al¹⁸ argued that better access to specialized services in rural areas may reduce family caregiver burden. Gibson et al¹⁹ and Morgan et al²⁰ identified unmet needs among family caregivers in rural areas due to limited access to supportive resources and services. A Swedish study²¹ demonstrated that older adults who cared for spouses in rural areas separated by long distances with limited services were tied to the home and felt isolated. Aure²² demonstrated that the roles of relatives are challenging when the geographical distance between the place of residence of the older adult and the relative is large.

Aging is a dynamic process greatly influenced by physical, social, and cultural spaces.¹² Increasing age is associated with an increased risk for illness, disabilities, and the need for help and support.^{23,24} The concept of frailty may be conceptualized as an imbalance between the older adult's physical and psychological condition and his or her physical and social surroundings.²⁵ In this study, we considered frailty to be something that older adults experience themselves that is affected by the older adults' relations and the environments in which they live.²⁶ Given our acknowledgment of the interplay between older persons' physical and psychological conditions and their material and social surroundings, we suspect that significant others' experiences of being "significant" to older adults living with frailty are also shaped by the rural Arctic environments in which the older adults live.

Although there is an extensive body of research reporting the experiences of older adults' significant others, this study explores how significant others experience being "significant" for an older adult identified as frail and living in a rural Arctic environment, and how the significant others' experiences are framed and shaped by the rural Arctic context in which the older adult lives.

Method

Approximately 20% of the Norwegian population resides in rural areas,²⁷ and less than 500,000 of the total population of 5.4 million resides in the two northernmost counties.²⁸ The context for this study was two rural municipalities in the northernmost county of Norway. The two municipalities had populations of 2000 and 6000, respectively. Both municipalities are classified among the least central municipalities in Norway according to Statistics Norway's centrality index based on the number of inhabitants, proximity to services, and access to jobs.²⁹

Participants and Recruitment

The participants were identified as significant others by older adults (80+) living alone and assessed as frail by the home care service. The first author contacted the persons identified as significant and presented the study. The participants received an information letter with an attached declaration of consent and a stamped envelope for the return of signed consent. All participants invited, eight adult children, one grandchild, and one not next of kin, agreed to participate. They were women (5) and men (5), aged between 30 and 70. Because not all were family, we use the term significant others instead of family caregivers. The frequency of contact between the participants and the older adults to whom they were

significant others varied. Some participants met the older adults daily, whereas others could only spend time with the older adults during weekends and holidays. Most participants described frequent telephone contact with the older adults.

Interviews and Data Collection

The first author conducted eight individual interviews and one interview with two participants (participants 9 and 10). The interviews were conducted at locations chosen by the participants or by telephone. The interviews lasted from 15 to 50 minutes (in total, approximately four hours) and were digitally audio recorded. The significant others were invited to talk about their own experiences of being “significant” to the older adults and how they experienced the older adults’ situation. The thematic interview guide was revised during the interview process as the interviewer’s understanding of the topic developed.

Analysis

The first author transcribed and anonymized the interviews. An inductive thematic analysis in six steps, as described by Braun and Clarke,³⁰ was conducted. The first author performed the initial analysis, and the transcribed texts were read several times. The coauthors read the interviews and contributed to further analysis and refinement of the themes. The first author examined each interview individually in a process that involved targeted search for and coding of text that was relevant to the study aims. Then, patterns and contradictions were searched for in the transcribed texts, involving a recurring movement back and forth between the texts and the coded parts.³¹ The codes were grouped into suggested themes and subthemes. To shed light on differences and similarities, themes were identified across the interviews. The themes were named and revised through discussions involving all coauthors.

The preliminary results were presented and discussed with a user group consisting of two older adults, a family caregiver and a nurse from municipal health and care services. The user group provided important input for subsequent analyses. Their feedback regarding the comprehensibility of the themes and the relevance of selected quotes led to another revision of the naming of the themes. The theme headings were finalized during the writing process.

Ethics

The study was pre-assessed by the Regional committees for medical and health research ethics (REK) and was considered to fall outside the Health Research Act. The Norwegian Center for Research Data (Sikt) provided the necessary approval for the study [reference number 508120]. The participants received written and oral information about the overall purpose of the study and were assured of confidentiality. They were informed about their right to withdraw without stating a reason, and that it would have no consequences for themselves or the older adult if they chose to withdraw. All participants gave written informed consent to participate in the study and to include their anonymized responses in future publications based on the interviews. The municipal health and care services had no information about who participated. Information not relevant, such as details about the participants’ own or the older adult’s health conditions and names of family members or places, was omitted in the transcribed material to safeguard the anonymity of the participants and third parties and thus ensure that no individuals could be recognized in the text material. By pointing out who should be invited to participate in the study, the older adults consented to their “significant other” participating in an interview that would also involve a discussion of their life situation.

Results

Our analyses show that experiences of being the significant other are a continuous balancing act affected by the older adult’s life situation, the significant other’s own life and the rural Arctic context in which the older adult lives.

The analysis resulted in two main themes and five subthemes: 1. Restoring and maintaining balance in the older adult’s life with the following three subthemes: 1.1. balancing between the older adult’s capacity and the physical environment; 1.2. emotional support; and 1.3. balancing between the older adult’s need for help and the services offered; and 2. Maintaining balance in one’s own life with the following two subthemes: 2.1. family and working life; and 2.2. tensions between family members. The rural Arctic context in which the older adult lived became apparent to varying degrees in all themes.

Restoring and Maintaining Balance in the Older Adult's Life

Balancing Between the Older Adult's Capacity and the Physical Environment

The significant others experienced shifts in the balance between the older adults' functional level and the surroundings. Some participants expressed concern for an imbalance between the older adult's capacities and the challenges faced in the physical environment in which the older adult lived. Hence, the participants would prefer the older adults to move to a nursing home or care home, but the older adults themselves wanted to continue to live in their homes. Several participants expressed that although they respected the older adults' wishes, the issue was under continuous consideration.

She would collapse if she was to enter a nursing home. But, of course, if something happens, she will also realize that it is the way to go. [...] You just have to wait and see. [participant 4, daughter]

Changes in the older adults' functional level could appear gradually or suddenly, for example, following illness and hospitalization. The participants also described that one change could lead to several changes. For example, one participant described how his mother, as a consequence of poor health, lost her driver's license and became dependent on others. Although the participants could not do anything to reverse changes in the older adults' functional level, they could help restore and maintain balance between the older adults' capacities and the demands of the physical environment by adapting the latter.

That's the only thing I can help with - make it practically convenient for her ... [participant 5, son]

The participants described extensive efforts to accommodate the older adults' homes. Examples of adaptations included home remodeling and installation of lifts, adaptations for walkers and wheelchairs by replacing doors and doorsteps, upgrading the kitchen and bathroom, and moving the freezer and washing machine from the basement to avoid falls in a steep basement staircase. Many older adults had large outdoor areas with gardens, and several of the participants talked about extensive efforts to take care of properties and outdoor areas. When the older adults were no longer able to take care of this themselves, tasks such as mowing the lawn, gardening and planting became the responsibility of the significant others. Many experienced the accumulation of such tasks.

I think it's a bit heavy now, that it is so much practical outside of her to think about. [participant 4, daughter]

For several of the participants, long distances between their own homes and the older adults' rural residences made it challenging or impossible to integrate help and support for the older adults and the maintenance of houses and properties into their own everyday lives. Several chose to pay for such services. The long Arctic winters with risk for avalanches and closed roads also made daily practical follow-up challenging.

When there has been an avalanche and the road is closed, it is hopeless. A few years ago, they were evacuated and picked up by helicopter. No, winter is the worst. And the winters are becoming more and more unstable, so the roads are closed more often. [participant 1, son]

Emotional Support

Several participants in our study talked about the older adults' need for help and support following changes in the older adults' lives, such as impaired health, hospitalization, and the loss of a spouse or other close relatives.

He says he wants to die, but I told him you can live for another ten years, as fit as you are. [participant 9, son]

The significant others had different strategies for providing emotional support, such as encouraging and being with the older adult but also reprimanding, dismissing, or joking.

She destroyed one of her hips and was just talking about dying. She had no zest for life at all. Then I said, "When it's time, it's time". So, she kind of recovered after she returned home. [participant 7, son]

Due to long geographical distances between their own places of residence and the older adults' homes, several of the participants could only contribute their emotional support via telephone calls and during holidays.

When she was sick, we were there all Easter to keep her company, to help her up. [...] It is about making sure that they maintain the spark of life if you should have them at home. If they lose it, everything breaks down. [participant 5, son]

Most participants described frequent telephone contact with the older adults - for some daily and for others several times a day. The conversations could be about everyday issues. Although phone calls were important for emotional support, phone calls could also be challenging. In particular, communication difficulties following older adults' hearing impairment could cause tension and more emotional strain.

We tried to call, but she hears so poorly. Then, she hears me shouting and gets angry. [participant 6, daughter]

Balancing Between the Older Adult's Need for Help and the Services Offered

Many participants in our study expressed satisfaction with the local health and care services and did not consider living in a rural area as a disadvantage. Several believed that the quality of the health and care services in rural areas was equal to the quality of services provided in urban areas. However, some participants expressed dissatisfaction with the lack of services that they believed were available in the city. A lack of services could present challenges for significant others, as they had experiences where the need for help for the older adults was not sufficiently met. For example, a lack of night service could cause anxiety and feelings of unsafety among significant others.

You shouldn't have to search and ask and make a fuss. They should ask "what do you need?", and then you should get it. [participant 8, daughter]

Several of the participants described disagreements with the older adults regarding the frequency and extent of help from the home care service.

[...] if they [the home care services] stopped by every other day it would be fine. It is a safety both for us relatives and for herself. [...] She accepted only one visit per week, because she finds it stressful. [participant 1, son]

The participants described several imbalances between the older adults' need for help and the health and care services offered in the communities. Some participants noted that the services were poorly adapted to the rural Arctic areas, the long distances, and the narrow and poorly maintained roads. For example, one participant described how the allocated one and a half hours of support person per week was insufficient when the distances were long. One single trip to the store could exceed the time allocated, and the older adult had to manage without the support person for several of the subsequent weeks. According to the participants in our study, the interplay between local factors, such as distance to place of residence, and individual factors, such as state of health and the older adult's need for help, were not considered in decisions about service allocation.

That's far too little, I think. [...] Yesterday we drove to the store and spent four hours. [participant 2, not family]

Several of the participants described an imbalance between the older adults' need for transport and the transport services offered. The number of kilometers of transport allocated through publicly funded services was not sufficient to meet older adults' needs. In such cases, significant others helped to maintain balance by driving the older adults around themselves.

I usually drive her to the store once a week. She uses taxi occasionally, but the money is limited. And it is very unevenly distributed in the municipalities. An older adult who lives centrally, for example, gets just as much [publicly funded transportation services] as those who live all alone up in the valley, where there is no bus. [participant 1, son]

Significant others experiencing public health and care services as insufficient made efforts to provide the needed help and support, for example, when they suspected the older adult to be lonely and bored.

He's a vital man who likes to talk [...] he needs company. You know, if he lived in the city, there would be more offers. On the countryside, that's missing. So, when I have girlfriends visiting the cabin, I take them to him. Then I bring him the cat, every day, so he can see it. [participant 8, daughter]

Maintaining Balance in One's Own Life

Family and Working Life

Many of the participants' stories dealt with challenges related to the balance between taking care of the older adults' needs and managing obligations in their own lives. They described tension and multiple sources of pressure. The participants experienced that caring for the older adult caused restrictions in their own lives.

Several participants talked about balancing their own family lives and work lives and caring for the older adult. They had family members and children who needed follow-up, and several had full-time work.

We have full-time jobs. I have a teen-age boy who is in critical period. So, we are busy following up on our own lives.

[participant 6, daughter]

For the participants who lived far away from the older adult, it was difficult to find time to provide help and support. This could cause challenges in both their family and work lives. Some significant others managed this balance with their own family and work life by integrating the care into their own everyday lives. For example, those who lived near the older adults could invite them to dinner when the older adult's appetite and nutrition were poor.

Since she eats with us, she gets at least one proper meal a day. [participant 7, son]

The combination of long distances and obligations in one's own family could result in difficult feelings for both the older adult and one's own family.

I have a bad conscience because she's sitting in there, bored, and because I do not have the opportunity to visit. Then, there is a tug-of-war in our house. I want to go to visit her, but the others do not want to go there. So that's a problem. [participant 6, daughter]

Tensions Between Family Members

While the participants talked about tensions in their own families resulting from their obligations for the older adults, they also described tensions among the significant others.

Some participants talked about the strength of having several family members contributing collaboratively. However, for many of the participants in the study, this was not possible. The participants described tensions between family members who contributed with help and support to varying degrees. For example, those who lived far away might experience difficult feelings in relation to those who lived closer and provided more help and support, whereas those who lived close might have felt that they contributed more than to those who lived further away. Tensions could also arise between family members if one contributed less help and support due to conditions such as work, family, and their own health.

I'm retired. [...] I often have to be there. My sister works and has a family, so she is not there that much. I'm getting very involved now with my mom. [participant 4, daughter]

Some participants said that they had to help the older adult despite their own illness because other family members could not.

He has only me because my brother cannot help him. I feel like I've had enough myself because I've been so sick. I have stretched as far as I can. I have no more to give. [participant 8, daughter]

The participants who, for various reasons, could not contribute with help and support still considered it a resource to be one of multiple significant others. They considered their own contribution "behind the scenes", as someone who the more involved significant other could talk to and discuss matters with, as valuable.

When my sister complains a little to me, I say "I'm here for you. If there's something, I'll show up". [participant 3, daughter]

Discussion

Our aim in this study was to explore how significant others experience being "significant" to older adults with frailty living alone in rural Arctic areas in northern Norway.

Our results demonstrated that being the significant other for an older adult living with frailty is a continuous balancing act framed and shaped by the older adult's life situation, the significant other's own life and the rural Arctic context in which the older adult lives. Frailty can be understood as a shift in "the balance point between an individual's resource pool and the challenges faced",³² and such shifts in the balance point result from an interplay between age- and health-related changes and contextual challenges.²⁶ Our results showed that the significant others' varied and continuous help and support contributed to restoring and maintaining "the balance point" so that the older adults could continue to age in place. In a previous study,²⁶ we showed that frailty is a dynamic phenomenon and that older adults' experience of frailty varies over time. This study showed that the significant others were aware that the situation of the older adults could change, and therefore, they continuously assessed whether it was safe for the older adult to live at home. Our results showed that, in parallel with significant others' efforts to restore and maintain balance in the older adult's life, they experienced imbalance and tensions in their own family and work lives. The study showed that some significant others "stretched as far as they could and had no more to give". Our results concur with a recent qualitative study³³ demonstrating that next of kin took over tasks that they considered not sufficiently well performed by healthcare professionals. Although they were tired and frustrated, they did not address the issues with the healthcare professionals until they had stretched too far. In another recent study³⁴ some older women caring for a spouse reported that they felt abandoned by the public care services.

According to the European Commission report on "The indirect cost of long-term care",³⁵ psychosocial distress is prevalent among family caregivers. This is especially the case for caregivers of older adults and for those who spend much time on caregiving activities. Psychosocial distress can have negative impacts on both the caregiver and the care recipient.³⁶ This resonates with our results. Several participants in our study reported that they had "stretched too far" and "had nothing more to give". Moreover, our results demonstrate how the combination of long distances and obligations in one's own family and work life may produce extra stress for significant others. Early identification of psychosocial distress is important for the prevention of caregiver strain and burden.^{37,38} Interventions from the care services aiming for the early identification of psychological distress was not reported by the participants in our study. Rather, some of the participants reported experiences of having to "make a fuss" to receive appropriate help from the services.

In our study, the significant others' experiences were framed and shaped by the rural Arctic context in which the older adults lived. This was particularly evident with regard to their concerns for the older adults' access to help and support during long winters with shifting weather conditions and closed roads. Moreover, the influence of the rural Arctic context was evident in the significant others' balancing between the older adults' needs for help and the health and care services offered. Previous research has shown that health and care services in rural areas can be limited and characterized by insufficient staffing,^{12,17} and resources spent on health and care services can vary significantly between municipalities.³⁹ In our study, notably, the lack of night services caused anxiety and feelings of unsafety among the significant others. Moreover, transport services poorly adapted to long geographical distances created an imbalance that the significant others had to deal with. This corresponded with previous research demonstrating that rural family caregivers experienced barriers such as distances and lack of transportation and access issues related to heavily burdened care services and healthcare provider shortages.⁴⁰

The rural Arctic context with out-migration and long distances between the significant others' and the older adults' places of residence made it challenging for significant others to provide help and support in everyday life. Our results concurred with Aure,²² who showed how significant others spent vacations and leisure time together with older adults. When the distances are long and access is limited due to lack of public transport and high travel expenses, the possibility of follow-up becomes even more difficult.²² Notably, previous studies have found no differences in caregiver burden between rural and urban caregivers.^{41,42} Some have pointed to differing cultural values and more family-oriented attitudes as possible explanations for this.^{41,43} Our data did not provide an opportunity to examine differences in caregiver burden and family-oriented values between significant others in rural and urban areas.

Our study demonstrated that frailty was not only dependent on bodily impairments but also dependent on relationships and the help and support that was or was not provided. In addition, our study showed that the place the older adult lives is important for access to help and support. Rahman²⁴ previously called for a more comprehensive understanding of aging that takes into account demographic factors in addition to sociocultural, psychological and physiological factors.

Our study showed that even if older adults experience physical functional changes, relationships with significant others and their efforts to maintain balance can contribute to older adults being able to continue living at home, which can have an impact on the experience of frailty. Our study concurred with the body of research demonstrating that “frailty is associated with a range of social, economic and environmental factors”.⁴⁴ Cluley et al⁴⁴ recently argued that the conceptualization of frailty as a bodily attribute should be replaced with a relational understanding of “a frailty assemblage”, in which “materialities establish the on-going “becoming” of the frail body”.⁴⁴ Our study demonstrated that “materialities” in and beyond the older adult’s home, such as geographical distances, weather conditions and transportation services, frame the “becoming” of the frail body and the experiences of significant others. Moreover, our study demonstrated how significant others mitigated the impact of these materialities in older adults’ everyday lives and how their efforts were framed and shaped by the rural Arctic context in which older adults live. As such, our study adds to the conceptualizations of frailty as both a bodily and a relational phenomenon framed by materialities, the understanding of frailty as also a situated phenomenon.

Methodological Considerations

This study involved relatively few significant others and was conducted in a rural Arctic context. Nonetheless, our results may be relevant beyond this specific context. Further research in various geographical contexts is needed to learn more about this topic. A strength of this study is the breadth of our sample in terms of participants’ gender, age, and relationships with older adults. The authors’ different clinical, theoretical, and methodological expertise provided rich opportunities for investigator triangulation to reduce the risk of biased interpretations.⁴⁵

Conclusion

Aging in place is a political goal.^{4,7} Help and support from significant others is a “balancing factor”⁴⁶ significant for achieving this goal. However, aging in place in rural Arctic areas is associated with challenges. Norwegian health and care policies promoting maintained or even increased contributions from family caregivers in the years to come⁶ must take into consideration demographic development, including out-migration of the younger population from rural areas.⁴⁷ Moreover, the rural Arctic context with its long geographical distances, long winters, and harsh weather conditions may present challenges both for older adults living with frailty²⁶ and for significant others, which mutually reinforce the “becoming” of frailty. Hence, planning and individual tailoring of health and care services for home-dwelling older adults in rural Arctic areas must be based on careful assessments of not only the functional capacities of the older adults but also the accommodation of the older adult’s homes and their access to family care. Older adults’ access to help and support from significant others in everyday life may vary due to both long geographical distances and changing weather conditions. Moreover, the imbalances and tensions in significant others’ lives that are associated with being “significant” for an older adult living in a rural Arctic area must also be included in the holistic assessment of older adults’ need for health and care services. Future health policies must consider geographical variation and the opportunities and limitations associated with “the place” in which the older adult “ages”.

Significant others have important functions in maintaining balance in the lives of older adults living with frailty. In parallel, they experience imbalance and tensions in their own lives. Both the significant others’ and the older adults’ life situations are affected by the rural Arctic environment in which the older adult lives. Our study adds to the conceptualizations of frailty as both a bodily and a relational phenomenon framed by materialities, the understanding of frailty as also a situated phenomenon. The planning and individual tailoring of health and care services should involve both older adults and their significant others. Moreover, geographical variation and the opportunities and limitations associated with “the place” in which the older adult “age”, for both the older adults and the significant others, must be taken into consideration.

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Disclosure

The authors report no conflicts of interest in this work.

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