

Research Article

Experiences of Close Relatives of Older Adults in Need of a Nursing Home: It Is We Who Manage Their Fragile Daily Life

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Home-based care is expanding, and we need to know more about what kind of support older adults need and how such support should be designed. One way to gain more knowledge is to study the experiences that underlie a nursing home application. However, older adults in need of nursing homes are often too weak to participate in research. Thus, this study aimed to describe the experiences of close relatives of the daily life of older adults in need of a nursing home. A qualitative approach was used, where fifteen relatives of nursing home applicants in central Sweden were interviewed using a study-specific interview guide. The interviews were analysed using thematic analysis. The findings are presented in one main theme “*Being the person who manages a fragile life situation*” with three underlying themes: *Balancing and fulfilling expectations, striving to achieve a status quo, experiencing a breaking point, a change is inevitable, and waiting and moving into a nursing home, a period of tension*. The main theme describes how the participants contributed to managing the older adults’ life situation and acted as a representative in contacts with health and social care. They tried to offer support in their daily life but over time experienced a breaking point when ageing in place was no longer sustainable, resulting in a nursing home application. The rationale for a nursing home application was often a combination of the older adult’s own wishes and the fact that their relatives felt there was a combined need for extensive care and physical proximity to staff, which cannot be provided in ordinary housing. Sometimes the decision to apply was also based on relatives no longer having the capacity to continue managing an older adult’s fragile situation.

1. Introduction

The question of where older adults should live and receive care is a recurring societal topic [1, 2]. Should they age in place, meaning in their ordinary housing or in a nursing home? To identify why some older adults prefer a nursing home to ageing in place is important knowledge for all societies in which the majority of older adults are supposed to be supported to age in place. One way to deepen the understanding of why older adults have different needs regarding where to live and receive care is to study older adults who do not wish to continue ageing in place.

Research on ageing in place shows that most older adults prefer to continue living in their ordinary housings with the option to receive home-based care [3]. Vanleerberghe et al., [5].

said that the opportunity to continue ageing in place with support from health and social care is offered by most societies [1, 2, 5]. However, with increased age and multiple diseases, the need for care becomes increasingly complex, and not all societies have the ability to deliver extensive care in an older adult’s ordinary housing [2]. Instead, different kinds of housing, e.g., nursing homes, are offered. A nursing home offers 24-hour support and care, in a home-like environment, to people with complex health needs, meaning that assistance with ADLs is required [6]. Previous research on predicting the need for nursing home admission has shown that dementia is a crucial factor [7, 8]. Furthermore, predicting factors for older adults with somatic needs, without a diagnosis of dementia, have been shown to be increased age, living alone, depression [9], deterioration in daily activities, and mobility impairment

[10]. This illustrates the diversity of the factors that affect the ability and willingness of older adults to continue ageing in place. In Sweden, the number of places in nursing homes was reduced during the 2000s [11]. Older adults with dementia are now prioritised when places are allocated. Thus, the reduced number of places primarily concerns persons with solely somatic needs [12], and an increasing number of older adults with somatic needs are ageing in place. Their care needs are considered possible to meet through home-based care, and therefore, it is harder for them to receive a place in a nursing home. Consequently, it is important to further study how these adults are best supported. Like in many countries, older adults with complex somatic needs partly depend on their relatives to cope with daily life [13, 14]. Supporting an older adult in the family is often a voluntary task that requires a relative to use much of their spare time [15]. Relatives have described this as being a huge responsibility, including a sense of being overwhelmed, feeling lost, or being perceived as a burden in their own daily lives [16–18]. However, for relatives with strong family bonds, it can also be perceived as a commitment based on loyalty and love [19]. Given the burden and other psychological perspectives of relatives as caregivers, it is important to illuminate their experiences.

Health and social care are investing in providing home-based care for an increasing number of older adults. Thus, there is a need to explore how the support offered to people ageing in place can be improved. A previous study [20] described different reasons for not wanting to continue ageing in place, e.g., physically not being able to cater for family's concerns or wanting to end life in a care facility due to cultural traditions. One group that could provide knowledge about additional aspects of value is nursing home applicants. However, studies have shown that nursing home applicants are a vulnerable group or that they are in a palliative state [21]. This means that they are often too weak to engage in research and share their experiences, and previous research has shown this is a reason to refrain from taking part in research [20, 22]. Relatives are often engaged in an older adult's life, and previous research has shown that they can be engaged to gain in-depth knowledge of a particular life situation such as that of a fragile older adult with a chronic illness [23] or at the end of life [24]. Accordingly, we engaged relatives in this study, which aimed to describe close relatives' experiences of the daily life of older adults in need of a nursing home.

2. Methods

This study adopted a qualitative approach. Data were collected using semistructured interviews [25] and analysed using thematic analysis by Braun and Clark [26]. The study followed the Declaration of Helsinki [27] and was approved by the Swedish Ethical Review Authority (Dnr: 2020-05666). To ascertain comprehensive reporting of the method and findings, the COREQ 32-item checklist was used [28].

2.1. Study Settings. Sweden has a population of around 10 million, of which approximately 20% are over 65 years of age. Most commonly, older adults live in ordinary housing,

and only 4% of older adults over the age of 65 live in nursing homes [29]. Older adults in Sweden can receive home health care for medical needs via the Health and Medical Services Act [30] and subsidised home-based care for support with daily needs such as self-care or household chores via the Social Services Act [31]. Thus, older adults can continue living in their ordinary housing even when they have a significant need for care [11]. It is also possible for older adults to apply for (a) short-term facility care for temporary recovery or rehabilitation and (b) nursing home admission (Act 2001:453). Nursing home residents rent their apartments at a subsidised rate and have access to communal living and dining rooms, as well as 24-hour access to staff. Nursing home residents live in wards designated either for somatic needs or for dementia.

The regulations and the overall organization look the same across the country, but access to nursing homes and thus the queue situation can vary. This study was conducted in a medium-sized municipality in Sweden in both rural and urban areas with relatively close distance to nursing homes regardless of housing conditions. To get a nursing home application approved, the older adult should typically have extensive care needs, have had repeated hospitalisation, and have tried for an extended home-help service. At the time of the study, the waiting time after being assigned a place in a ward for somatic needs was about three months.

2.2. Participants. The inclusion criteria for participation were as follows: (1) Being registered as the closest relative of an older adult with an approved application for a placement in a nursing home aligned for somatic needs means that there was no diagnosis of dementia, but they could have mild cognitive impairments or mental health needs. (2) The older adult should be waiting for admission to a nursing home either at home, in a short-term care facility, or had recently moved into a nursing home, or passed away while waiting for admission. Detailed information about the participants is shown in Table 1.

2.3. Data Collection. Data collection was adapted to Swedish national recommendations during the COVID-19 pandemic. Thus, the interviews were conducted by telephone. The first author (A1), a female researcher, with experience of interviewing, was responsible for data collection. She had no previous relationship with the participants and was presented to them as a female doctoral student in the research field of ageing. The interviews were supported by an interview guide based on broad and open-ended questions to facilitate rich descriptions of the research aim [25]. Examples of questions were as follows: *Tell me about your relationship to the older adult? What kind of daily activities are you engaged in?* As the interviews were performed during the pandemic, additional follow-up questions were added, e.g., *How has the COVID-19 pandemic affected your relation to the older adult?*

Contact information about potential participants fulfilling the inclusion criteria was received from municipality admission coordinators who organised the queues for

TABLE 1: Characteristics of the participants ($n = 15$).

Sex (n)	Female	12
	Male	3
Age (years)	Mean (SD)	59 (10.6)
	Median (range)	59 (38–90)
Relations	Child	13
	Spouse	2

nursing homes and assigned vacancies. An information letter was sent to relatives via post, and about a week later, they were contacted by phone. Thirty-nine relatives were contacted, 24 declined to participate as the older adult had passed away, and they did not want to talk or felt stressed as they had helped their older adult move into a nursing home. A total of 15 interviews were conducted and provided in-depth descriptions of their experiences. Data collection was judged to have reached saturation, meaning no new information emerged in the last interviews. The interviews were audio recorded, and most of them lasted for 2045 minutes (median = 22). One interview was interrupted as the participant became very emotional and had difficulties continuing. A1 and the participant jointly agreed to interrupt the interview after this had been suggested by A1. However, the participant wanted to verbally summarise her experiences and gave consent for them to be included in the data set.

2.4. Analysis. The analysis followed the six phases of thematic analysis by Braun and Clark [26]. Thematic analysis was chosen as it was a well-structured method that still allowed flexibility to highlight the experiences of all participants [32]. An inductive approach was used to enable the analysis to be as close as possible to the experiences and meanings in the interviews. All the authors contributed to the analysis and are experienced researchers in qualitative methods. The first phase, becoming familiarised with the data, started with the data being transcribed by A1. Transcriptions were read by A1 and A4. After transcribing 10 interviews, the second phase, generating initial coding, started. The reason for starting the second phase before all the interviews had been performed was to get a deeper understanding of the data content, thereby making it possible to assess when data collection could end as it had reached saturation. After finalisation of data collection, all the interviews were reread by A1 and A4, who individually noted initial ideas of codes and compared and discussed them to gain a mutual understanding of the data. In phase three, the codes were summarised into tentative themes. In phase four, A1 and A4 searched for patterns of experiences. By discussing what the themes represented and questioning their uniqueness, the themes were reviewed, merged, and abstracted to higher levels of interpretation. In phase five, the themes were given names, and a preliminary report on the findings was written. To verify the consistency of the analysis, A2 and A3 each read three of the transcribed interviews before they read the preliminary theme and findings. In the sixth and final phase, the research group discussed the findings in relation to the research question.

After multiple discussions and further merging and abstraction of the themes, the final findings were formulated. The analysis process is illustrated in Table 2.

3. Findings

The findings comprise one main theme: “*Being the person who manages a fragile life situation*,” with three themes and seven subthemes. These themes are illustrated in Figure 1.

3.1. *Being the Person Who Manages a Fragile Life Situation.*

In the main theme, the participants described how they had to manage a fragile life situation, which points to both their own life and their older adult’s life. Even though they were asked about their views on older adults’ daily lives, they described how their own experiences were sometimes hard to separate from their older adults’ experiences as their lives were intertwined. For the participants, managing meant something bigger and deeper than just providing mental and physical support to their older adults, which meant taking care of, handling, and being the maneuverer of the older adult’s entire everyday life situation and well-being. A fragile life situation arose when their older adult no longer managed to maintain themselves or their daily activities at their usual level. Thus, the participants felt responsible for managing their situation and ensuring that their older adult received the best support possible. This commitment to managing the fragile life situation changed over time and was experienced as a process illustrated by the three themes. In the first theme, “balancing and fulfilling expectations, striving to achieve a status quo,” the participants tried to support their older adults to remain living in their ordinary housing. To achieve this, they had to balance and fulfil the expectations of both themselves and others. In the second theme, “experiencing a breaking point, a change is inevitable,” the participants felt that they had reached a point where remaining at home was no longer an option for their older adults. A reorientation phase then started to identify solutions and take steps to realise a change for the betterment of their older adults. In the third theme, “waiting and moving into a nursing home, a period of tension,” the participants’ situations were still fragile for both themselves and the older adult. This was due to stress for different reasons and the fear of being deprived of what the older adult had been promised, namely, admission to a nursing home.

3.2. *Balancing and Fulfilling Expectations: Striving to Achieve a Status Quo.*

This theme describes how the participants felt about the fragile situation during the time prior to the nursing home application, with their older adults living in ordinary housing with or without home-based care. During this period, the older adult’s health typically deteriorated, leading to recurring urgent medical needs and older adults spending longer periods in a hospital or at a short-term care facility. In order to support their older adults’ daily lives, the participants felt that they had to fulfil their own expectations, as well as the expectations of their older adults and healthcare providers.

TABLE 2: Illustration of the analysis process, from the code to the main theme.

Examples of codes	Tentative analysis of content in themes	Subtheme	Theme	Main theme
<p>(i) Feeling great responsibility, both as company and to secure the health care due to mistrust toward home-based care</p> <p>(ii) Daily contact, but is seldom seen due to long distance</p> <p>(iii) Don't want to complain but cannot handle the whole situation alone</p> <p>(iv) Great frustration to be relative to someone in need of care</p>	<p>(i) Feel and take responsibility</p> <p>(ii) Close relationships</p> <p>(iii) Have to step in when the care fails to meet needs</p>	Internal expectations		
<p>(i) Buying groceries, after the mother's own write shopping lists</p> <p>(ii) It's also about being able to have a reason to be in contact</p> <p>(iii) Wants daily visits, but relatives are unable to fulfil the expectation</p> <p>(iv) She called so often that I started to get angry</p> <p>(v) He calls about everything, such as changing batteries in the remote control</p>	<p>(i) Expect involvement of relatives</p> <p>(ii) The older adults' requirements</p> <p>(iii) Have to be accessible</p> <p>(iv) Be distraction from loneliness</p>	Perceived expectations of the older adult	Balancing and fulfilling expectations: striving to achieve a status quo	
<p>(i) Home health nurse determines our daily routines</p> <p>(ii) More home-based care, means even more times to adjust my life to</p> <p>(iii) The days are spent waiting for staff to arrive without knowing who will come</p> <p>(iv) The hospital staff don't ask dad; they call me first</p> <p>(i) Dad lost his ability to walk and needed help with all mobility</p>	<p>(i) Try to collaborate</p> <p>(ii) Being available</p> <p>(iii) Adapt everyday life after health care</p>	Perceived expectations of healthcare providers		Being the person who manages a fragile life situation
<p>(ii) She is denied more urgent visits because she has home-based care</p> <p>(iii) The majority of the staff should not be allowed working with vulnerable people</p> <p>(iv) He never received any rehabilitation during the pandemic</p>	<p>(i) New insights into different needs</p> <p>(ii) Undignified care with no positive changes in sight</p>	Experiencing a need for change	Experiencing a breaking point: change is inevitable	
<p>(i) During the pandemic there was no support such as relatives' centers</p> <p>(ii) Lack of information meant a lot of research by themselves</p> <p>(iii) Want to be involved so that the older adult don't get tricked or misled</p>	<p>(i) Navigating in the health care system: a lonely work</p> <p>(ii) Involvement in application</p>	Taking steps to realise change		
<p>(i) Quick decisions meant no time to prepare</p> <p>(ii) Have to pay for short-term facility in addition to the regular rent bill</p> <p>(iii) She breaks down from all responsibility</p>	<p>(i) Adapt an entire household to a small area at the nursing home</p> <p>(ii) A stressful event with tight time limit</p>	The emotional process of organising a move		Waiting and moving into a nursing home: a period of tension
<p>(i) Expected to feel at ease while waiting for admission</p> <p>(ii) Why can't they just be allowed to not feel anxiety at the end of their lives?</p> <p>(iii) He was worried about not being allowed to stay at the short-term facility and no one informed him if he was</p>	<p>(i) Stressful information</p> <p>(ii) Anxiety about being re-examined</p> <p>(iii) Frustration at feeling anxious after an application</p>	The fear of a reappraised application		

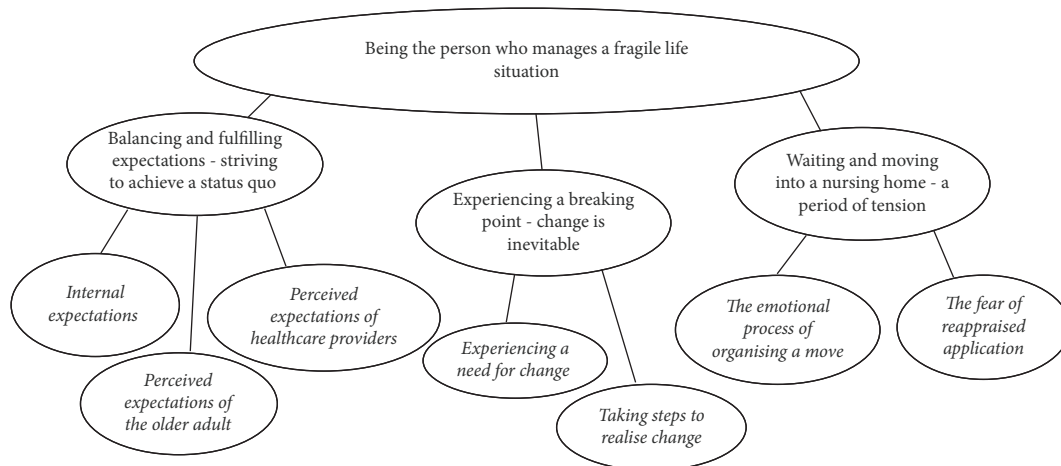


FIGURE 1: Final thematic map.

3.2.1. Internal Expectations. The family structure changed as there was a shift in family roles, which added to their own expectations of themselves to support the older adult through this difficult period of their life. They therefore felt as if they wanted to, or had to, support their older adult. The participants spoke about their grief that their loved ones were in poor health and needed support. Seeing a parent or spouse fade away, in pain, depressed, or in a palliative state, was a life-changing experience. They felt they should give something back.

“I mean, she’s taken care of me all these years, now it’s my turn to take care of her.” (Participant B, son)

3.2.2. Perceived Expectations of the Older Adult. Some of the participants also said that older adults expected the participants to be at their “beck and call” and always be accessible. They also understood that such a behaviour was primarily based on anxiety or loneliness and that making multiple phone calls was a way of seeking companionship or a form of distraction. The participants described how their older adults’ loneliness could manifest as fear and paranoia in which they were scared of doing something, such as using a lift or a mobile phone. Some older adults locked themselves into their homes and would not let their relatives in. The participants also felt that loneliness was a reason for depression, in cases, where their older adults did not leave their beds, stop eating, or perform activities they would usually enjoy. Thus, fulfilling the expectation of always being accessible and reducing the older adults’ loneliness were recurring factors that motivated the participants to continue to provide support.

“He always wants me to be there, but we live two hours away. We phone every day, and I can hear how lonely he is. When my father had suicidal thoughts for the first time I just panicked. I desperately tried to convince him to go to a short-term care facility so he wouldn’t be alone.” (Participant A, daughter)

3.2.3. Perceived Expectations of Healthcare Providers. Descriptions were given on how the participants were expected to be representatives of their older adults and were responsible for having repeated contact with staff at hospitals or short-term facilities. This meant balancing between being both cooperative and acting as a mediator between their older adults and healthcare staff, although not interfering with or interrupting the staff’s work or decisions. The restrictions due to the COVID-19 pandemic were described as an inhibitory factor when trying to fulfil these expectations. Due to the national visiting restrictions established at Swedish care facilities such as hospitals and short-term facilities, it could take weeks or months before the participants were able to visit their older adults, which made it hard to advocate for them.

“They (staff at hospital) expected me to be cooperative and accessible, but they never gave me the latest information, so I never knew what was going on.” (Participant D, daughter)

Another perceived expectation was from the staff who worked in home-based care services. This expectation differed, depending on whether the participant was the child of an older adult or a spouse. They stated how home-based care had its limitations and that a manager of home-based care asked them to help in some daily activities such as shopping for groceries. Spouses stated how home-based care staff expected them to be easy-going and cooperative in adapting their own daily routines and the daily routines of the older adult to the home-based care programme.

3.3. Experiencing a Breaking Point: Change Is Inevitable. A recurring experience was that a breaking point was reached. Various reasons were given for why this point had been reached, such as decreasing health, increased loneliness after becoming a widow/widower, or a less active social life due to old age. Another reason was the closure of day centres or social day care due to COVID-19.

3.3.1. Experiencing a Need for Change. The participants often felt that there was a need for a change before their older adults did. This included making the older adults aware of how it was only the participants who were managing their fragile life situations and that this was no longer feasible. Unsatisfactory home-based care was a common reason for experiencing a need for change.

“My mother never complains but she had one demand, she doesn’t want male staff to help her with her personal hygiene. Still, male staff arrived and gave her an ultimatum: Either she would have to accept their help now or she would have to wait. So, she felt like she had no choice. But I knew she was depressed afterwards and felt violated.” (Participant F, son)

A sense of disappointment was mentioned when describing the level of care or support their older adults received in their homes. The participants’ experienced the group of staff as large and varied, which collided with their original expectation. Their expectation was equal to having a personal assistant, whereas home-based care should include care from a smaller group of staff who are available 24/7. Instead, the groups of home-based care staff visited older adults on scheduled times only. The visits were short, and when in need of urgent support outside the schedule, the waiting time for staff from the special response alarm group was 20–60 minutes. This created anxiety, insecurity, and a feeling of poor proximity.

The participants also reported lack of safety routines in relation to COVID-19 such as staff not wearing face masks, which created concerns that the older adult would become infected. These concerns were not always shared by the older adult who could be unaware of safety routines or even of the pandemic itself. Despite having knowledge of the high degree of infected persons in nursing homes, they found an application as preferable to ageing in place.

The participants, who had experiences of hospital care of their older adults during the pandemic, also described how healthcare professionals prioritised COVID-19-related care over rehabilitation. Healthcare staff only made short visits and left older adults alone for most of the time. The participants felt this negatively impacted their older adults’ mental and physical abilities.

“Before he was admitted to hospital, he could stand up using his walker and take a couple of steps, but at the hospital they used a lifting device. At the discharge meeting I asked if he could receive rehabilitation so he could come home again. But the short-term facility practiced the same methods as the hospital, so after two months he couldn’t even stand on his own anymore.” (Participant K, wife)

3.3.2. Taking Steps to Realise Change. A first step to changing the current situation was navigating through the health and social care system, looking for solutions. One navigation strategy was an online search for information or

waiting on the phone. The participants had difficulty describing their older adults’ exact needs, getting right information, or getting in touch with right professionals. Searching for the right information and type of care was described as a demanding task that the participants wanted to relieve their older adults from having to do.

“I asked the municipal service centre which professional I should try and contact to get more help for my parents. [...] I was given a phone number and was convinced that it would be the solution to our problem. However, the phone number was for a physiotherapist who was not on duty. I called the municipality again, which arranged a home call from an occupational therapist. She gave my parents a chair to use in the shower, a chair they didn’t want to use, so I was back to square one.” (Participant B, daughter)

The participants felt that a nursing home was the only solution to their older adults’ life situations as it was the only housing alternative or support that provided access to staff on a 24/7 basis. The participants expressed concern that the older adult would find it difficult to justify their need for a nursing home on their own and perhaps agree to extended home-based care despite their need to move. Therefore, the participants felt a need to be present when their older adults were in touch with social workers. They also expressed that their older adults might have difficulty interpreting information from a social worker and become confused, therefore not being able to express their need for admission to a nursing home.

3.4. Waiting and Moving into a Nursing Home: A Period of Tension. After a nursing home application was approved, the participants described a period of waiting and planning for the move. They had imagined this period to be related to a feeling of relief. However, moving an older adult was described as stressful due to several factors described in the subthemes.

3.4.1. The Emotional Process of Organising a Move. Organising a move to a nursing home was described as stressful and emotional. The participants, who were the children of older adults, described how sorting out a household comprising decades of belongings and memories was very emotional both for them and their parents. Spouses spoke about the struggle of making sure that their partners did not feel like they were being kicked out or that they were unwanted.

“I felt terrible telling my partner that they can’t come home. And he didn’t get it at first but with time we both knew it was the only thing to do.” (Participant I, wife)

Another stressful factor was the application-related information given by the social worker, such as information about long waiting times until admission to a nursing home due to long queues or how any request for a specific home

might not be approved. The participants felt this created anxiety for the older adult, which the participants felt they had to manage. Sometimes this information about long waiting times until admission was perceived as incorrect, as an offer for admission was received just days after the application. These experiences created frustration and made the move harder to plan. In addition, the participants stated that the nursing home administration procedures had a negative impact, such as an offer of admission that had to be accepted or declined within a three-day time frame.

3.4.2. The Fear of a Reappraised Application. In connection with the application, the participants and their older adults had been told by the social worker that if the waiting phase was to last for a longer period, a nursing home application that had been approved could be reappraised while waiting for admission. This caused a lot of stress and anxiety for both the older adults and the participants. The participants stated how both they and their older adults had been subject to a long process from older adults living in ordinary housing with or without home-based care to where they were now. Not being able to relax and depend on social care, even after an application had been approved, was disappointing.

These feelings were especially pronounced in the participants with older adults waiting at a short-term facility or in a hospital. These participants expressed fear about their older adults being discharged and obliged to wait for admission in their ordinary housing instead.

“He was so worried at the end. You think a dying man should be left in peace in a short-term care facility with palliative care, but that information made him nervous. And I could tell in the way he acted like he wasn’t objecting to anything. I think that was because he was scared about being discharged and spending his last days at home.” (Participant G, daughter)

4. Discussion

From the perspective of relatives, this study adds knowledge on how ageing in place can become a fragile state and how the need for a nursing home may emerge. When describing the experience of an older adult’s daily life, the participants talked about their own role, life, and older adults’ situation as intertwined. This dyadic experience is consistent with other studies of relatives [33] or caregivers’ perspectives [34]. This study adds to this knowledge base with a rare insight in relatives experiences of daily life of a previously sparsely studied group; older adults in need of a nursing home placement, during the time frame from ageing in place toward an admission. The participants did not focus on specific daily activities but gave descriptions from a holistic perspective, including how the older adult felt and acted. This was described as a process in which their older adults needed more and more support in their daily life. A commonly expressed prerequisite for continuing ageing in place was physical proximity to respectful staff within an acceptable time frame while receiving home-based care. If

home-based staff could not meet these expectations, there was a need to live in an environment that had stable staff. Thus, a nursing home was perceived as the only alternative in this study context. A previous scoping review [35] on the needs of older adults receiving home-based care reported needs such as maintaining autonomy in terms of independence, daily routines, being included in decision-making, and having good relationships with staff. These needs are in line with our results, but the need for physical proximity to staff that we found seems to be an additional factor that needs to be considered when planning interventions to prevent or predict the need for nursing home admission.

During the process described in our results, the participants stated how they became representatives of their older adults and were the main contact with professionals in health and social care. This result clarifies how dependent older adults without relatives might be on professionals in health and social care. This is an important insight that professionals need to be aware of in their interaction with older adults without relatives. Furthermore, the participants described a lack of communication and collaboration between different care facilities, where no one seemed to have the main responsibility for their older adults’ care. They felt that trying to navigate through the health and social care system was a demanding and difficult task. These experiences correspond with the experiences of older adults waiting to be admitted to a nursing home [20], and with patients in primary health care [36, 37]. These studies confirm that there is a lack of communication in Swedish health and social care. This deficiency is not unique to Sweden as other countries have identified similar barriers for the relatives of seniors with complex needs [15] and frail older adults [38, 39]. Furthermore, their experiences were negatively affected by the Swedish restrictions on visitors during COVID-19. The participants felt that the restrictions on visitors contributed to decreased transparency from health care, which excluded the participants from acting as representatives and made their older adults more vulnerable. A lesson from the COVID-19 period might be that, in times of high pressure on health care, transparency and information become even more important. A clinical implication in health care could be to find strategies to ensure the transfer of information to relatives. Being a representative of an older adult has been described in other studies [39]. In palliative care, relatives felt that they had a great responsibility and adjusted their daily life to benefit the older adult [21]. Similar experiences have been found in Norway, where the relatives of nursing home residents describe how they felt unprepared for the transition from ordinary housing (Eika et al., 2013). Our result showed how such a transition can be experienced as a period of tension. Our participants had expected peace after an application had been approved, but different regulations in social care made it hard for them to trust the system with fear of a reappraised application. The previously mentioned research on experiences of being the relative of an older adult with a life-changing situation is similar to our results. However, our results added specific knowledge on older adults in need of

a nursing home and how ageing in place can become a fragile state. In addition, our results showed that lack of physical proximity to staff might be a predictor of nursing home admission.

In this study, several efforts were made to strengthen credibility, e.g., following the COREQ checklist for reporting qualitative research, in order to give as comprehensive reporting as possible [28]. In addition, Braun and Clark's [26] checklist of criteria for good thematic analysis were applied. To achieve confirmability in the results, parts of the analysis were performed individually by two (A1 and A4) out of the four authors. The other two authors (A2 and A3) also read the three transcribed interviews to ensure that the analysis was consistent. In this way, the stability and dependability of the results were tested [41]. As always, when data collection is conducted in one geographic and study-specific setting, the transferability is limited and could only be strengthened by being replicated in other settings. However, efforts have been made to carefully describe the study settings and participants in order to help the reader judge the transferability according to their own setting. Other study limitations were that all participants were from the same municipality and that the distribution of health care and social care differed slightly between Swedish municipalities. Due to the COVID-19 pandemic, all interviews were conducted by phone, and some of them can be considered short. It is possible that they might have been longer if conducted face-to-face, thus providing even richer data. Some potential participants declined participation, referring to a stressful situation, such as moving an older adult within the same period, as the interview was too much to handle, which became obvious in the last, interrupted interview. A potential limitation may be that the relatives with the most stressful situation declined participation, which may affect transferability of the results [32]. However, in the discussion, efforts were made to enhance trustworthiness by confirming and discussing the results with findings in related research areas.

5. Conclusions

This study shows how a lack of physical proximity to respectful staff while receiving home-based care may increase the desire for nursing home admission. It therefore seems important for policymakers to ensure the logistic of physical proximity to staff in different types of housing for older adults. The result also highlights the importance of information to relatives; as in their experiences as representatives of older adults, they described a lack of communication and trust in professionals in health and social care. Although our conclusions should be interpreted with caution, this study contributed to the knowledge base of a scarcely studied group, older adults in need of a nursing home.

Data Availability

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

Additional Points

What is known about this topic: (i) The majority of older adults age in ordinary housings, but an alternative housing for older adults is needed. (ii) Relatives often support older adults' daily life and have great insight into their life situations. (iii) The predictors for not ageing in place in older adults with somatic needs are increased age, living alone, depression, deterioration in daily activities, and mobility impairment. The paper adds as follows: (i) When daily life became fragile and an older adult needed more support, relatives experienced how deficiencies within health and social care systems made it even more unsustainable. (ii) The relatives of older adults in need of a nursing home play an important role in managing an older adult's life situation and acting as representatives. (iii) Additional predictors for ageing in place could be physical proximity to home-based staff and waiting time before receiving support.

Ethical Approval

Ethical approval was obtained from the Swedish Ethical Review Authority (Dnr 2020-05666).

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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