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Older people's experience and related factors while receiving home-based long-term care services: a qualitative study

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Abstract

Background Home-based care may cover anything from 24-hour support for people with a disability, to short-term post-discharge care, or to periodic assistance with simple tasks such as domestic aid for frail older people. The process can be complex and time-consuming and requires coordination between the individual, their family caregivers, and healthcare providers. Receiving care at home can also lead to social isolation as older people may have limited opportunities for social interaction. This study aimed to investigate older people's experience and related factors while receiving home-based long-term care services.

Methods A qualitative study was used. Face-to-face individual interviews were conducted with people who were receiving nursing care in their homes ($N = 17$) and analyzed through thematic analysis.

Results Analysis of interview data resulted in the identification of three major themes that captured participants' personal experiences regarding long-term care in the home: (1) Challenges faced by older people receiving long-term care at home; (2) The impact of home care services on people's social well-being; and (3) Older people's contradictory emotions regarding care delivery.

Conclusions Findings of the study revealed that the most important and challenging factors in home care from the perspective of older people were social well-being, religious needs, and physical needs. They considered the nurses who provided these services as family members and the most significant helpers in their daily activities. Participants expressed a desire for more services in the future.

Keywords Older people, Long-term care, Home-based care, Nursing

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Introduction

Aging and the rapid increase in the number of older people is a global problem driven by low birth rates and rising life expectancy. The World Health Organization (WHO) estimates that by the year 2050 the global population of individuals aged 60 years and above will reach a staggering two billion. Notably, about 80% of this older population is expected to reside in developing countries [1, 2]. These structural changes are increasing the need for long-term care in people's homes. Long-term care services at home are generally more convenient and cost-effective than care provided in healthcare institutions, and they can be as effective [3, 4]. Home care reduces hospital admissions that are financially more costly than home care. And the effectiveness of services can be measured by quality of life, which is considered a main evaluation criterion [4].

The WHO defines home-based care as “any form of care given to ill people in their homes, including physical, psychosocial and palliative activities” [5]. Home-based care may cover anything from 24-hour support for adults with a disability, to short-term post-discharge care, or to periodic assistance with simple tasks such as domestic aid for frail older people [6]. Receiving nursing care at home can provide older people with a greater sense of independence and comfort in a familiar environment; however, this arrangement can also present unique challenges. Some challenges include older people's desire for independence, which can be influenced by their health conditions, frailty, and the need for assistance with limited activities of daily living. Additionally, in an effort to ensure comfort and independence, people often face isolation, losing social contacts as they remain in their own homes. Family members often provide most of the care for older people receiving care at home which can be emotionally and physically challenging, especially if they have other responsibilities such as work or caring for their own families [7]. Many older individuals receiving long-term care at home have one or more chronic health issues. Therefore, informal caregivers providing care at home should be well-prepared to manage these conditions. It is also important for relatives to be aware of respite care or support services that can ease the burden on family caregivers [8]. The process can be complex and time-consuming and requires coordination between the individual, their family caregivers, and healthcare providers [9–11]. Older people receiving care at home may be at risk for falls or other accidents due to physical limitations or cognitive impairment. Ensuring that the home environment is safe and accessible can help prevent accidents and promote independence [12].

These challenges are therefore unique, as they do not arise in long-term care settings because there are staff

and other people around all the time, unlike with home care [7].

To address these challenges, it is important to develop a comprehensive care plan to meet the unique needs of older people and family caregivers as well [13]. Overall, providing high-quality, person-centered care can help older people receiving long-term care at home maintain their independence and quality of life. High-quality care follows a holistic approach, ensuring the basic needs of the person, such as psychological and physical needs, dignity, and autonomy [13]. Patient-centered care emphasizes the involvement of the individual, both in terms of the information provided and in decision-making [14]. Ensuring that these concepts are incorporated in the care will help to preserve a person's autonomy permit them to be involved in their care and make choices, which engenders an improved quality of life.

At the beginning of 2020 there were 556,000 (19.9%) older people aged 65 years and over in Lithuania. According to the average growth forecast by the Statistical Office of the European Union, the proportion of older people in Lithuania is expected to rise to 672,000 by 2050, an increase of more than 17%. Demographic changes are closely linked to the increase in healthcare and long-term care services [15, 16]. In Lithuania, the long-term care network is underdeveloped, mainly based on institutional care and informal care, with fragmented home-based services in the social and health sectors that are inaccessible to a large portion of the population. In 2014, 47% of older people in need of long-term care had not received services [17]. Although the implementation of outpatient home nursing services in Lithuania started as early as 2008 on the basis of an order issued by the Minister of Health of the Republic of Lithuania, home care services have been actively implemented only since 2021. According to the 2021 Nursing and Social Services for the Older People Assessment Report, outpatient home care services were 10 times less resource-intensive than inpatient nursing services in Lithuania [18]. Although the tendency for home care services to be provided by informal caregivers still exists, current directions have been moving more towards services being provided by the healthcare professional team. However, assessment of the attitudes of not only service providers but also the attitudes of people towards these services is important.

For several reasons, it is important to assess and monitor home care services from the perspectives of both providers and recipients. Firstly, the services are new, having been launched in Lithuania in 2021, and are still evolving in terms of content and organization. Secondly, it is crucial to understand and ensure that the needs of the people receiving the services are identified and met so that services can be adapted accordingly. Thirdly, providers

themselves need to contribute to the transformation of the national healthcare system.

The aim of this study was to investigate the older people's experience and related factors while receiving home-based long-term care services.

To achieve this goal, the following research questions were posed:

What is the experience of receiving home-based long-term care as an older people?

What factors contribute to the acceptability and high quality of these services?

Methods

Study design

Our research team aims to comprehensively identify the experiences and personal insights of the health-care- and social-care-related needs of Lithuania based older adults who receiving home care services. Furthermore, we also seek to identify means of optimizing the use of available home health care resources in a manner that improves such persons' wellbeing.

The scope of the present paper concerns comprehensive in-depth research into the personal experiences of older people who are receiving home care service, as well as the impact these new services on certain aspects of their own lives.

Our team of researchers chose a qualitative research approach in which older people's experiences were investigated as a phenomenon through face-to-face individual interviews to obtain a more in-depth understanding of the experiences and personal insights of the participants. Individual interviews are commonly used in healthcare research as a suitable way to elicit rich data about a participant's experience. Individual interviews also provide an opportunity to obtain evidence that healthcare professionals can employ to develop improved healthcare practices. The study was performed in the second-largest city Kaunas in Lithuania; Kaunas is located in the center of the country and has socioeconomic indicators that are similar to the national averages.

The recommendations for qualitative research [19] and the COREQ checklist in the results reporting [20].

Participants

The study invited older individuals receiving long-term care at home to participate. To recruit these participants, we focused on a large family medicine clinic in Kaunas City, which serves approximately two-thirds of the city's population. We identified suitable people from these clinics who met the inclusion criteria. Inclusion criteria were:

- 1) A person must receive long-term care services at home.

- 2) A person has a low, medium, or high nursing need according to the Nursing Needs Assessment Questionnaire [21]. The procedure for identifying the need for outpatient home care services was determined on a scale: up to 15 points – no need for outpatient home care services; 15 to 29 points – low need for outpatient home care services; 30 to 44 points – medium need for outpatient home care services; 45 points or more – high need for outpatient home care services. The maximum possible score was 93 points.
- 3) A person must be in the older age group (65 years and over).
- 4) Exclusion criteria were people undergoing active medical treatment, such as chemotherapy, surgical interventions, or other; people at an institutional caring home; and people receiving palliative care.

As the first step, we contacted community nurses and nurse practitioners to inform them about our study. We then asked them to identify eligible people with low to medium nursing care needs.

Seventeen individuals with low to medium nursing care needs participated in the study. It was noted that individuals with high nursing care needs were unable to participate.

Data collection

The primary researcher conducted the interviews. Based on the analysis of the limited research available in the field of home care and long-term care at home—since many countries are still in the process of implementing these services—the research questions were formulated [22–24].

Individual interviews require careful consideration of the interview environment. The interviewer created a non-threatening atmosphere by emphasizing that all ideas were valued and respected while maintaining privacy, and thus, the interviews were carried out in the participants' own homes. Interviews were conducted using a semi-structured interview guide with the following questions:

1. What are older people's experience of receiving nursing care at home?
2. What challenges do older people face in accessing nursing care services at home?
3. What emotions do older people experience while receiving nursing care at home?

The interviews took place between June and August 2022. Interviews were digitally recorded and transcribed verbatim by a professional transcription service. The interviewer also recorded field notes during the participant

Table 1 People's sociodemographic characteristics

Characteristics	N (%)
Age in years	
65–69	1 (6)
70–79	6 (35)
80–89	6 (35)
90–97	4 (24)
	Mean = 82.6
Gender	
Female	14 (82)
Male	3 (18)
Need for nursing services	
Low	3 (18)
Medium	14 (82)
Duration of nursing services	
9–12 months	3 (18)
13–18 months	14 (82)
Living condition	
With spouse	5 (29)
With child	5 (29)
Alone	7 (42)

interviews to document nonverbal behaviors and notable aspects of the home environment.

Data analysis

After the individual interview had been completed the audio recordings were transcribed verbatim. Two independent researchers systematically reviewed the entire dataset and coded the data by selecting the closest coding terms for the words used by the participants.

Later, each researcher's coded transcripts were compared with the others, and this showed that the majority of the codes were similar. Any coding differences that were found were resolved through securing common consent among the researchers.

Meaningful words and key phrases were independently assigned codes by two members of the research team and then compared for agreement. Codes were then sorted and organized into themes. Atlas.ti version 9 was employed to store and facilitate data organization, coding, and retrieval [25].

The data analysis was based on the inductive approach and the thematic analysis strategy with the aim of effectively identifying and summarizing the problems experienced by the participants [26].

Braun and Clarke's thematic analysis method is an iterative process consisting of six steps: (1) becoming familiar with the data, (2) generating codes, (3) generating themes, (4) reviewing themes, (5) defining and naming themes, and (6) locating exemplars [26, 27].

Table 2 Themes and subthemes

Themes	Subthemes
Challenges faced by older people receiving long-term care at home	<ul style="list-style-type: none"> • State of health • Social support network • Emotional support
The impact of home care services on people's social well-being	<ul style="list-style-type: none"> • Religiosity/Spirituality • Autonomy • Communication • New technologies
Older people's contradictory emotions regarding care delivery	<ul style="list-style-type: none"> • Change • Expectations • Solutions • Getting involved

Research ethics

Participants were informed of the purpose and the course of the study, risks and benefits, as well as their rights to terminate their participation at any time without denial of customary services. Participants then signed an informed consent. Ethical permission was granted by the Bioethics Centre of Lithuanian University of Health Sciences (authorization number *BEC-ISP(M)-104*).

Results

There were 17 participants in the study. The majority were female ($n=14$). The youngest person was 65 years old and the oldest was 97 years old. The distribution of people by age, gender, need for nursing care, length of time receiving home care services, and cohabitation is shown in Table 1.

Within this study three main themes with associated subthemes emerged: 1) **Challenges faced by older people** receiving long-term care at home; (2) The impact of home care services on people's **social well-being**, and (3) Older people's contradictory **emotions** regarding care delivery (Table 2).

Theme: challenges faced by older people receiving long-term care at home

The first theme that emerged from the data pertains to participants' perspectives on the challenges faced while receiving long-term care at home. Three interrelated themes emerged from the data, illustrating that nursing care at home is a multi-dimensional, challenging, and holistic process that must address the physical (state of health), social (social support network), and psychological (emotional support) needs of the older people.

Chronic health conditions require ongoing management, which can be a complex and time-consuming process that requires coordination between the individual, family caregivers, and healthcare providers.

All people in the study faced a major challenge when it came to their health – physical disability, which was usually accompanied by pain:

"The biggest challenge for me is the back pain. Morally, it also has an impact, because lying down for so long is no joke. It's been a year since I've been bedridden." P10.

Participants were most affected by the idea that they could not walk at all, and they were always at home. For some, this caused anger, and a feeling of inferiority; and for others, they saw themselves as a lying vegetable:

"For me, the thing that makes life most difficult is the difficulty of moving around. It's hard for me that I can't go anywhere anymore, that I must sit on the sofa at home all the time." P14.

In addition to the physical suffering, many people felt guilty that their relatives had to take care of them; that they were a burden:

"I'm getting used to it, but it's hard that I have to be a burden to others." P6.

Respondents also emphasized feelings of loneliness and the weakening or complete loss of social ties:

"Lonely like a wolf, from window to window and that's it. This loneliness is worse than illness..." P17.

Theme: the impact of home care services on people's social well-being

The second theme related to contextual factors associated with people's social well-being. Within this theme there were four subthemes identified: Religiosity/Spirituality, Autonomy, Communication, and New technologies.

In Lithuania, the number of religious believers is over 80%, with the majority being Catholics. Therefore, participants were asked if religiosity was a significant factor for people receiving home care and how they expressed it. The participants reported an increased need for religiosity and a search for strength in faith as a positive result to home care services:

"I am a very religious person; I am protected by God. I used to go to the church all the time, but now I only pray at home. There are a lot of things you can't solve by yourself. And when you ask for it, it seems to suddenly happen, it all works out." P8.

They were also pleased that home care allowed them to remain independent and stay in their own homes for as long as possible, rather than having to go to the hospital:

"Just stay at home, my opinion of hospices is very bad. I don't want to; I really don't want to go anywhere." P2.

Nursing care at home provided people with increased social support, as nurses were able to develop close relationships with people and their families. This led to feelings of connection and belonging. Social well-being refers to the extent to which a person feels connected to others, has a sense of belonging and feels supported by their community [25].

The application of new technologies (home video cameras, panic buttons, global positioning system (GPS) devices) in home care had both positive and negative impacts on the social well-being of the people.

On the positive side, participants said that the technology helped them call for help more quickly in the event of an emergency:

"It's obviously a good thing. Because what am I afraid of, if I ever get sick, my husband wouldn't even be able to call an ambulance." P13.

However, people also identified certain inconveniences caused by these technologies:

"If I had to, I wouldn't really want to, because I have a toilet seat right next to my bed. It would make me uncomfortable with the cameras, maybe I don't need them." P4.

Theme: older people's contradictory emotions regarding home care delivery

The third theme related to people's contradictory emotions regarding receiving long-term care at home. Within this theme four subthemes were identified: changes in their own lives, expectations of service providers, empowerment to make their own decisions, and involvement of others in home care.

The appearance of home care services made a significant difference to people's lives and quality of life. All participants shared positive experiences. They were happy that various manipulations and tests could be carried out at home and that they no longer needed to go to the clinic:

"... I am happy, I just didn't expect such a thing, I didn't even know it was possible." P2.

Participants had even higher expectations of home care services, such as more visits, specific care, mobility equipment, and transportation services:

“And if there was a service to take you to doctors’ appointments when you need it, that would be great.” P5.

In order to have an equal relationship between a person and health professional, it was important to treat people as autonomous and to build a reciprocal relationship and empower them to make their own health decisions. Participants felt they had a voice in their care and were able to make decisions:

“I feel very free about this, I have no problem with it, I always discuss the condition with the doctors and nurses together.” P2.

When looking into the experiences of older people in home care, the role taken by relatives, professionals, or neighbors was important. Participants identified that it was teamwork and that each person was responsible for different areas:

“My family helps me because they make me meals, provide me with medicines and take care of all kinds of ailments. But I really appreciate your service, I don’t know what it would be like without physiotherapy and when you come to take tests. I think it’s like a teamwork here.” P6.

Discussion

The present study examining older people who received long-term care in the home revealed a variety of experiences and challenges, differing attitudes of the impact of home care on social well-being, and contradicting emotions. Nursing care for older people in their homes is an important aspect of health care, as it helps maintain their autonomy/independence, dignity, and quality of life [26]. Research has shown that people want to stay at home to recover after various injuries or other serious illnesses [27, 28]. Therefore, home health care can be beneficial because it keeps people exactly where they want to be – at home and with their families. A study by researchers in the United States found that people who received care at home were less likely to be hospitalized or taken to the emergency room [29]. The research findings from a scientist in Iran indicated that the quality of life for older individuals receiving long-term care at home and living with their families was significantly higher than that of residents in nursing homes [30].

Challenges receiving home care

Findings from this study indicate that older people receiving nursing care in their homes faced challenges, especially in daily living assistance. When they experienced a

reduced quality of life because they needed help in activities of daily living such as bathing, dressing, grooming, and toileting; their situation made them feel uncomfortable and more aware of their decreasing autonomy. The challenges that emerged most prominently were physical, social, and psychological factors. This was also relevant in studies conducted by other authors. People experienced anxiety due to physical challenges when they were unable to perform tasks that were once routine and easy [31, 32].

Social wellbeing of the older people receiving home care

As many older people become frail and in need of care, it is likely that health professionals will become increasingly important to them at times when existential problems arise [33–35]. However, research showed that healthcare professionals struggled to meet people’s existential needs [35, 36]. Caregiving could have significant implications on the social well-being of individuals. In this study, end-of-life issues, fear of suffering and death, and the need for religiosity were dominant in terms of people’s existential needs.

Social well-being is also directly linked to loneliness. A quantitative study by Norwegian researchers found that loneliness was more common among those in poorer physical health, those who felt helpless, those who needed help with daily activities, and those who were dissatisfied with life. Women and people who had no relatives were also more likely to feel lonely [36]. Our study showed that the strength of social ties and the loneliness of people depended strongly on their marital status, favorite activities, and their own attitudes. For the social well-being of the individual, it was important that the person’s existential needs were met; care was provided while preserving the person’s dignity and autonomy [37], no matter where a person received services, in the hospital or in their home. Home nursing services were not only about nursing procedure but also about social interaction, which was very important for people, especially those who were lonely. People who participated in the interview said they appreciated the opportunity to call for visiting nurses and talk, complain, and discuss different issues. People felt safer and more comfortable when they were able to complain to someone directly.

The quality of life for people can also be improved by incorporating new technologies into the home care process. Virtual tools like remote personal monitoring devices and telehealth, which are being used to supplement the in-home visits people receive from home health staff, yielded a positive experience for older people [38]. Although participants in our study had some misgivings about the use of new technologies in care, they agreed that it would help them to deal with unplanned situations such as calling the ambulance in case of an emergency case or just calling the nurse. Religion and spirituality

were important aspects for older adults when it came to psychological and social well-being. It is believed in god that a higher level of religiosity might be associated with lower instances of depression and greater life satisfaction [39].

Older people's participation in the process

People's expectations of health care continue to rise, which needs to be properly managed to improve outcomes and reduce liability. Understanding people's expectations may increase their level of satisfaction with care and it makes it easier for health professionals to provide person-centered care [40]. Receiving medical care at home eliminated many of the transportation barriers associated with healthcare access. And while most people appreciated convenient care access, it was particularly beneficial for sick or injured people who needed care. People who used apps that enabled them to access health care and rehabilitation found that the technology was very convenient because they did not have to go to a medical institution [41, 42]. Participants in this study were very positive about nursing and other medical services they received at home. People mentioned that home care service was excellent; the staff came and drew blood as needed and performed other required procedures. Therefore, findings revealed that providing services at home was convenient and saved time for family members.

The goal of home health care is to help people improve, regain their independence, and become as self-sufficient as possible. To best serve and support people, home health clinicians are advised to see a person as a partner in care with great influence on how and when the care is delivered. Home care services should be tailored according to patient-centered factors such as basic needs, values, and beliefs [14, 43]. Patient-centered care allows health care professionals to treat each individual as unique, establishing warm relationships, which enables the provision of high-quality services [36].

Strengths and limitations

In Lithuania, the home-based long-term care system is divided between health and social services, each with its own eligibility conditions, needs assessment criteria, and procedures. This division leads to unmet needs for some individuals and a duplication of services for others. To better address the needs of older people, it is essential to investigate their needs, expectations and obstacles for receiving service.

The main strength of this study was its ability to capture data on the implementation of new home-based long-term care services in Lithuania and help identify relevant issues. However, the study also has several limitations. Firstly, since home-based long-term care services

in Lithuania are new, there were no established benchmarks to compare aspects such as service content, participant engagement, and needs. Secondly, participants were unfamiliar with assessing and articulating their needs within this context, potentially resulting in less accurate responses. Lastly, there may have been some influence from the researchers during the interviews.

Conclusions

Our research provides key insights into the demand, challenges, and desires of older people for home-based long-term care in Lithuania. Firstly, it highlights that older individuals receiving such care often face challenges like deteriorating health conditions and loss of independence, alongside weakening or lack of social relationships. As a result, they need emotional support, which can be difficult to provide due to social isolation.

The study also explores the impact of home care services on individuals' social well-being, noting how these services can support older adults through religiosity/spirituality, autonomy, communication, and new technologies. Additionally, it addresses the conflicting emotions older people may have about the delivery of care.

The findings from this study provide a foundation for developing evidence-based guidelines for home-based long-term care.

Abbreviations

WHO World Health Organization

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Author contributions

AN and AB made the design of the work, created methodology. AN carried out data collection, analysis and interpretation, prepared original draft. AB reviewed and edited the first draft. JN substantively revised and edited the work. All authors have made substantial contributions to the conception of the work and approved the final manuscript.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Participants were informed of the purpose and the course of the study, risks and benefits, as well as their rights to terminate their participation at any time without denial of customary services. Participants then signed an informed consent. Ethical permission was granted by the Bioethics Centre of Lithuanian University of Health Sciences (authorization number (BEC-ISP(M)-104).

Consent for publication

Not applicable.

Competing interests

The author AB declares that has competing interests – is the Editorial Team Member. Other authors declare that they have no competing interests.

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