



The Experiences and Needs of the Elderly Receiving Home Nursing Services in Relation to the Support Given by Family and the Experiences and Needs of Family Members of the Elderly in Relation to Supporting the Elderly

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Abstract

The aim of the research was to describe the experiences and needs of elderly people receiving home nursing services in relation to the support given by family, and the experiences and needs of family members of elderly people receiving home nursing services in relation to supporting their loved ones. The sample consisted of elderly people receiving home nursing services and their family. A semi-structured interview was used for data collection. Qualitative content analysis was used for data analysis. The experiences of the elderly were related to independent coping skills, communication with family, health, and support provided for them.

The needs of the elderly were related to various support options and the organization of support. The experiences of family in relation to supporting the elderly were related to experiences of providing support, the service provided by nurses, personal responsibility, interpersonal communication and supporting family member's own health. The needs of family members in relation to supporting the elderly were related to the need for time off and their own time, needs in relation to patient transport and its organization, needs in relation to patient care and household chores, needs in relation to supporting family member's own physical and mental health, and the need for state benefits.



Introduction

In Europe the number of patients receiving out-patient treatment (including patients receiving home nursing care) has increased over the past ten years. This is because the care of the elderly by their family has decreased. One of the influencing factors is the decline in cohabitation between generations [1]. The proportion of the elderly in the population is increasing in all countries, and thus the demand for home nursing services is also rising [2]. In Estonia, 299,016 home nursing visits were registered in 2010 and 420,635 in 2015, which shows nearly 30% growth [3]. The aim of the home nursing service is to improve the quality of life and maintain independence by assessing the patient's needs and carrying out activities that enable the elderly to live at home [2].

The elderly have various needs due to illness, such as the need for help with personal hygiene, emotional or social needs [4]. Most of the time, the caregivers of the elderly are their children and spouses, nearly 10% of informal caregivers are overburdened and unable to continue with care [5]. Several care service providers take care of elderly patients, however, due to collaboration issues between different providers, patients themselves are often the only ones with a complete overview of their care. Since many elderly people have memory problems, the information they provide cannot always be considered reliable. Therefore, family members should have good knowledge of elderly's life and care service providers [6]. Family members who provide care for elderly often feel emotionally powerless in their role as a caregiver, despite this, only three quarters of caregivers use outside help [7].

The experiences and needs of the elderly and their family have primarily been studied in terminal conditions [8-10] or from the point of view of patients with dementia in home nursing [11,12]. There are few studies that address the experiences and needs of support of elderly patients receiving home nursing services and their family. Previous studies have outlined that family members who are taking care of the elderly have mental health problems, a higher risk of poverty, and poorer physical health compared to family members who do not have to take care of an elderly family member living at home. When the family member of the elderly person becomes ill, they are also unable to take responsibility for the home care of an elderly family member. In addition, it has been found that family members experience social isolation, a desire to communicate with their acquaintances [13]. Since caring for elderly family member is exhausting, it can also cause insomnia for family members, as they have to respond to the elderly's problems even at night [14].

Elderly patient's family needs information and training, professional support, effective communication, and legal and financial support. In addition, family members have the need to be treated as a person with their own personal needs, the need for high-quality communication between all parties (reliable and flexible service, information and training), the need for a shared approach to care (the need for personal space for shared responsibility), the need for empowerment (the need for supportive space, and for emotional connection) [13].

In previous studies, it has been found that about 30% of the elderly studied spent most of their time at home with family members. Elderly people living with family members experience more cognitive and physical health problems and have impaired functional performance. Relatives living with the elderly

have a greater burden of care and support [5]. 22% of informal caregivers suffer from stress caused by the condition of the patient they are caring for and their personal resources. A great burden of continuous monitoring related to care, injury prevention and home safety is observed [15].

Although home nursing is expected to increase in the future, the family members of an elderly person still play an important role in caring for their loved one. Therefore, consistent cooperation between the home nurse and elderly's family is crucial [16]. The relationship between the family living with the elderly and the home nurses is important, especially in situations where the patient is not aware of the seriousness of their condition. Positive collaboration between the caregiver and the nurse leads to practical benefits, for example in terms of assessing the patient's needs and improving access to the necessary care [15].

If there is an elderly person in the family who suffers from a chronic disease, the life of the family members will also change. Family bears the burden of practical tasks: getting groceries and going to the pharmacy, arranging and cleaning living areas, activities which the sick person can no longer contribute to. All this requires time, energy, motivation and constant care and patience. The duties of a family member in relation to caregiving place him in a new role in the family and change their identity. They feel themselves to be in a central position in the family, because they are depended on and they are the decision-maker [17,18].

The patient's relatives experience insufficient support from other family members, insufficient financial support, insufficient cooperation, and lack of time to take care of themselves. The elderly themselves, on the other hand, perceived these problems significantly less. More than the elderly, the patient's family wanted to receive information about elderly's state of health, express positive feelings and control their aggressiveness [19].

The patient's family often lack information about support systems [14] and also often have insufficient knowledge about caring for a loved one at home, and therefore nurses' task is to empower the patient's family so they could to cope with the taking care of their elderly family member [20].

A systematic review published in 2019 looked at various research papers on the needs and preferences of caregivers of elderly living at home. Caregivers of the elderly were mostly partners, family members, but also friends and neighbours. The comprehensive international database was compiled from research papers published between 1988 and 2016 and addressed four common themes: (1) informational needs; (2) support needs; (3) organizational needs and (4) recognition of societal needs. The biggest need was to get a short break from the role of caregiver. Either for a few hours, a day, or a week. They wanted to find a reliable and safe place for their loved one, either in an adult day centre or a nursing home, which was often difficult because of distrust. According to research, a short-term vacation has a positive effect on the caregiver, reducing burn-out, stress, and depression. In addition, it was found that to get better support in coping with the role of a caregiver, there could be more information about various financial benefits, support groups and workshops. Caregivers want various e-services, monitors and robot aides that would reduce their workload. The role of a carer is demanding and according to the study it should be recognized and understood more. Recognition gives strength to cope with dissatisfaction and isolation [21].

The purpose of the research is to describe the experiences and needs of elderly people receiving home nursing services in relation to the support of family, and the experiences and needs of the family of elderly people receiving home nursing services in relation to caring for their loved ones.

Material and methods

Study design, setting, and sample

A qualitative, empirical, and descriptive research has been chosen as it is suitable to describe this topic. The experience and needs of the elderly receiving home nursing services and people closest to them have not been adequately studied and this study helps to better understand the related issues. In Estonia there has been no previous research on this topic.

The qualitative test method describes the phenomenon to be investigated from the perspective of the people involved [22]. The method is suitable for use when there is little information on the subject matter, as well as for sensitive issues [23].

The sample consists of the elderly and their family members who live together, who receive home nursing services from Koduõde OÜ (member of the Medicum Group). Before collecting the data, the survey and the criteria for the selection of subjects was introduced to the nursing managers and home nurses. The nursing managers of the company assessed the compliance of the examined criteria, and the convenient sample was selected of the people that met the criteria. Nursing managers made preliminary oral agreements with the selected people to participate in the survey and obtained consent to transfer participants' contact details to the research authorities.

The criteria for selecting the elderly receiving home nursing included a patient receiving home nursing services and living together with a close person; he/she lives in Tallinn; speaks and understands Estonian; is over 65 years old; agrees to participate in the survey. The planned sample was made up of a minimum of 5 elderly people, until the data saturation, with the maximum of 9-12 people who receive home nursing services. The consent to the interview was obtained from 9 people. Interviewees were recruited until data saturation. After 9 interviews, no new topics emerged, and a saturated database was formed.

The selection criteria for close people living together with the elderly receiving home nursing care included: A close person to the patient receiving home nursing care who is living together with him/her; the patient is over 65 years old; they live in Tallinn; close people speak and understand Estonian; they agree to participate in the survey. The planned sample was made up of a minimum of 5 family members of elderly patients, but the interviewees were recruited until the data saturation. There was no saturation at the end of these interviews, and they ended when they reached the minimum number. The reason was the lack of interviewees who had given their consent. The maximum sample size was planned for 10-12 family members of elderly patients receiving home nursing services, but in reality, the sample was limited to 5 family members of patients receiving home nursing who agreed to participate in the survey.

Only the elderly who speak Estonian and their close people were included as research subjects, as a qualitative work and a small sample does not allow for more general conclusions. Besides, the Russian language skills of the researchers would not have allowed the quality of interviewing at the same level as with Estonian speakers.

Data collection

A semi-structured interview was conducted to collect data on elderly patients receiving home nursing and their close people. Semi-structured interviews allowed the questions raised during the dialogue to be repeated between intended open questions, and more detailed answers in case of incomplete answers or the deviation from the subject. During the interview, the researcher could change the order of questions and ask for additional questions if necessary. Interviews with elderly people took place between July and August 2019 and with their close people between August and September 2019. The first call was made to the interviewees to introduce the purpose of the research and the need for an interview. Then the time and place of an interview was also agreed. Before the interview was conducted, the subjects were re-informed about the purpose of the survey and their rights, and an interview took place after the informed consent was signed and recorded. The coding was used to ensure anonymity, the codes being known only to the researchers. This guaranteed a free and trustful relationship between the interviewer and the interviewee.

Older people had interviews in their homes, as many of them had no transport or it appeared to be the most convenient and secure option for them. In an interview with an elderly, the researcher focused on their quality of life, coping with everyday tasks and need for aid. The interview with the elderly included the following topics: Introductory questions (age, gender, the areas in which they have support from family members); experiences of the support given by close people (duration, relations with close people, pleasant and unpleasant experiences related thereto); needs of elderly people related to the support given by close people (areas where it is needed most, opportunities to provide assistance); questions from the elderly (the person in need) to the interviewer. A total of 9 interviews were conducted. The shortest interview lasted 2 minutes and 52 seconds, the longest 23 minutes, and 48 seconds. The reason for a short interview was when the elderly were feeling unwell or not talkative. Interviews with subjects were not repeated if the author received the answers and the interview was sufficiently informative to be used in the survey. The average length of the interview was 13 minutes.

Interviews with the family members were conducted partly in homes, where they lived together with the elderly. The reason for this was that the elderly could not be left alone at the time. One interview took place at the café at the request of a close person and one interview at the workplace as time was limited. The interviews lasted up to one hour. In some cases, there was a tendency to deviate from the subject between the interview questions as close people had few opportunities to communicate and express their experience and needs. There was a free conversation between the questions and after the interview to ensure a smooth and efficient outcome for the data collection during the interview. At the time of the interview, the researcher focused on the close person-to-elderly relations; the extent of the elderly's needs; the state of health of the close person; his/her daily coping and need for additional support. The interview with the family member of the elderly included the following subjects: Introductory questions (age, gender, what does it mean to support a person close to them, areas in which family members have received information or training about elderly care); the close person's experience of supporting the elderly (how long the elderly has needed support, their relationship, the activities to support the elderly, empathy,

pleasant and unpleasant experiences related to care; needs of the close person regarding support (what is important in supporting the elderly, related needs, what opportunities to inform about needs, needs for additional assistance and support, their own health problems which have emerged while supporting the elderly), questions from close person to interviewers.

Ethical contacts

The study was authorized by Medicum and the Tallinn Research Ethics Committee (Decision no 2743). Prior to the start of the interview, the interviewees were informed on the purpose and use of the data, the right to withdraw from the survey at any time and the right to use the data collected. Informed consent was signed with one copy for the researcher and the other for the subject. The signed informed consent forms were retained only in a location accessible to researchers until the end of the survey.

The full texts of interviews are available only to the people involved with carrying out the survey. Only quotes that do not allow identification of participants were used in the research. All interviews were coded, and the codes are only known to the people involved in the survey. The full texts of the interviews are not published, and these are not publicly available on the Internet. After the end of the survey, data files, including recordings, were deleted.

Data analysis

Inductive content analysis shall be used where there is insufficient knowledge of the phenomenon or where such knowledge is not sufficient to carry out the survey. A deductive content analysis is used if the structure of the analysis is operable

from previous knowledge and the purpose of the study is to test theory [23]. The research has been conducted using inductive content analysis, as there is little information available about the phenomenon under research.

Data collection and data analysis were carried out in parallel. Immediately after each interview, recording of the interviews was transcribed word by word. All transcribed texts were identified only by codes known to the researchers. During the analysis of the interviews, the substantive codes were revealed. During the preparatory phase of the data analysis, all the texts of the interviews were read and analysed using as a unit a thought, sentence, or words. In the case of inductive content analysis, the organization of qualitative data was followed by open coding, category creation and abstraction. Subcategories were grouped into categories of upper categories and into the main categories. An example of the category formation is given in **Table 1**.

Results

Experiences and needs of elderly people receiving home nursing services regarding the support of family

Experiences of elderly people receiving home nursing services regarding the support of family

The main category of elderly people’s experiences of support from loved ones consists of four upper categories: 1) experiences related to independent living, 2) experiences related to communication with loved ones, 3) experiences related to health, and 4) experiences related to support provided. The distribution of the categories formed as a result of the data analysis is presented in **Table 2**.

Figure 1: An example of the formation of categories.

An example from the database	Substantive code	Subcategory	Upper category
<i>"It's not necessary, I can cope with my own pension"</i> (Int 4)	Wants to cope independently	Positive experiences with independent coping	Experiences related to independent coping with daily life
<i>"...so first of all I try not to bother anyone."</i> (Int 7)	Does not want to depend on anyone		
<i>"...yes, all alone. Isolated."</i> (Int 7)	Isolation	Negative experiences regarding independent coping with daily life	
<i>"I don't have anyone at all. I am all alone..."</i> (Int 1)	Loneliness		

Table 2: Experiences of the elderly regarding the support of family.

Substantive code	Subcategory	Upper category
Wish to cope on their own	Positive experiences related to independent coping with daily life	Experiences related to independent coping with daily life
Wish to be independent		
Isolation	Negative experiences related to independent coping with daily life	
Lack of cohabitation with family		
Loneliness		
Memories of family	Positive experiences when communicating with people close to them	Experiences with communicating with people close to them
Likable acquaintances		
Disagreements	Negative experiences when communicating with people close to them	
Prejudices		
Temperamental family member		
Exhaustion	Health issues	Experiences related to health
Balance disorder		
Blood circulation problems		

Help provided by family	Help provided for health issues	
Help provided by a home nurse		
Family member as a carer	Experiences with care provider	Experiences related to support provided
Professional helpers		
Communication using means of communication	Experiences related to means of support	
Support duration		

The first upper category describes the positive and negative experiences of the elderly regarding independent living. The elderly try to cope by themselves as long as possible and within the limits of their possibilities. The majority are convinced that positive thinking and motivation in coping with life helps them. Elderly people living alone often feel rejected by society and people close to them. More than half of the elderly interviewed for this research live alone.

"It's not necessary, I can cope with my own pension." (Interview 4)

"... I live here all alone. How to say...the daughter of one of my divorced wives lives next door. In short, we are not close, we are good...yes, all alone. Isolated." (Interview 7)

The second upper category describes positive and negative experiences related to communicating with a person close to them. Positive emotions experienced when communicating with loved ones and acquaintances give the elderly vitality and confidence. At the same time, due to age and helplessness, disagreements and dissenting opinions may occur in the communication between the elderly and people close to them:

"Though, yes, I have some nice acquaintances to talk with." (Interview 7)

"...that feeling of support when you are sad, you put your head on their shoulder and you feel that you are full of energy and strength." (Interview 3)

"Well, every now and then, all people have disagreements, I mean I'm...I'm an old person, they are a young person. They have their own interests and activities, and they may not always coincide with my thoughts, so with this thought I ask myself why do they do this? But at the same time, I understand that they are young people, their life is still ahead of them." (Interview 3)

The third upper category describes the experiences of the elderly in relation to health, where various health problems could be observed in the interviewees due to their age. The elderly were also offered help with various health problems:

"Oh.. this fatigue started gradually settling 10 years ago." (Interview 7)

"Parkinson's disease." (Interview 6)

"Well, it has happened that I have also fallen down in the store and lost consciousness. I didn't walk alone for several years, now I have a rollator that I use. But I used to go with this other one...and then I also fell. This is because I have a blood circulation problem of this degree, so I might simply black out." (Interview 5)

"...the home nurse comes /.../ Yes, she helps me with my back every day and my skin in general /.../ She takes care of my back, because I can't do it by myself." (Interview 1)

"They get groceries and help me wash my back." (Interview 5)

"If I need help, even to do my hair or while taking a shower when I feel that I'm afraid to go by myself..." (Interview 2)

The fourth upper category describes the elderly's experiences with the provision of support. Most of the support providers for elderly people interviewed are the elderly's children or grandchildren, a home nurse, and also social workers. The elderly described different means of support. Due to the seriousness of health problems, effective communication with loved ones is extremely important for the elderly. Surprisingly, it turned out that the time of need for support is very different among the interviewees, and as it lengthens, the need for help also increases. These are especially noticeable in elderly people living alone:

"I have, but sometimes I have to ask for help. Well, I don't have any bellhops. I am very embarrassed to ask someone for. /.../ As I say, I try to bother my family as little as I can." (Interview 7)

"In everything that I need, they bring groceries, the social worker comes twice a week if I need groceries or something or... The nurse visits me three times a week in the mornings." (Interview 2)

"They call...but I have to say that my granddaughter and I have done this thing that we communicate via Skype...not talking on Skype, but because I might fall down, she goes to work and opens Skype and I write to her that now I'm going outside and now I'm back at home." (Interview 5)

"Well, I'm already...I guess I've been...isn't it five years already, is it? Yes, five years, I think... I don't remember when I... if you want to know exactly, I have to get a... but I have the feeling that it has been five years, if not more." (Interview 1)

"... I stopped walking on my own two feet some 3-4 years ago." (Interview 7)

The needs of the elderly receiving home nursing services in relation to the support of family members

This main category consists of two upper categories: 1) needs related to various support options and 2) needs related to the organization of support. The distribution of the categories that emerged as a result of the data analysis is presented in **Table 3**.

Table 3

Substantive codes	Subcategory	Upper category
Mental connection	Need for emotional support	Needs related to different support options available
Physical contact		
Communication needs		
Grocery shopping	Need to cope with everyday life	
Cleaning the apartment		
Doing laundry		
Beauty services		
Personal hygiene procedures	Need for various support providers	
Family		
The role of home nursing		
Support services	Need for various means of support	Needs related to organizing support
Close communication		
Calling		

In the case of needs in relation to various support options, it became apparent that the elderly have a very high need for emotional support. Having people close to them and their support is crucial. It is necessary for the elderly to have a social circle, communication with children and grandchildren is very important. Positive emotions in communication with loved ones undoubtedly improve the quality of life of the elderly. Visits from family and friends are always welcome:

“Great support, I have very good sisters and a brother /.../ I have support and my granddaughter also helps me.” (Interview 2)

“... my children have supported me a lot, with such closeness. And through it you experience love, because there is an empty place left by your husband, and you feel that you are not alone.” (Interview 8)

The second subcategory describes the needs of the elderly in coping with daily life. Most of the elderly have tried to cope with their daily life, but still need the help and support of family and other people close to them:

“Mainly getting groceries, cooking and sometimes also preparing food...”. (Interview 3)

“...they help me bathe, yes.. it's also nice when they come to visit. They make up my bed too.. I can handle the laundry myself, but I can't hang up big items to dry by myself. I can't hang up a duvet cover, because of asthma, I get short of breath”. (Interview 5)

“I have...someone who has been my hairdresser for a very long time. Fifteen years. They come and do my hair at home, because I can't go out anywhere anymore. Such nice people. Nice acquaintances. We are not even remotely related.” (Interview 1)

Regarding the needs related to the organization of support, the interviews with the elderly revealed that they need help on

many levels to cope with everyday life. They especially need reliable help from their family. Due to the health condition of the elderly, there is often a need for home nursing services. A trusting communication between the home nurse and the person in need is crucial. For one of the interviewees, a valuable support service was using the Internet on their own. The elderly have needs for various forms of support. The majority of the elderly use communication tools frequently. Personal agreements are important:

“That kind of support, yes.. /.../ Helping their loved ones.” (Interview 6)

“The nurse visits me three times a week in the mornings, I had a thrombosis in my leg, now she is treating it...” (Interview 2)

“I mean I order groceries through E-Selver.” (Interview 7)

“... well, they ask if I need anything, alright. They, we already have an agreement that every weekend one of them goes and gets...gets the groceries.” (Interview 4)

““We communicate closely.” (Interview 9)

Experiences and needs of the family of elderly people receiving home care services in relation to supporting their elderly

Experiences of the family of elderly people receiving home care services in relation to supporting their elderly

The main category Experiences of the family of elderly people receiving home nursing services consists of five upper categories: Experiences affecting support; experiences of the service provided by nurses; experience with personal responsibility; experiences related to interpersonal communication; experiences related to family member's own health. The distribution of the categories that emerged as a result of the data analysis is presented in Table 4.

Table 4

Substantive codes	Subcategory	Upper category	
They do not like anything related to support	Experiences which interfere with providing support	Experiences which influence providing support	
Many daily activities and lack of their own time			
Caregiving burden is too heavy			
Learned helplessness of the elderly			
The elderly person is not bedridden			
The person has not needed any help	Experiences which motivate providing support		
Daily activities are not a problem			
Positive attitude			
Home nurse's advice	Experiences related to satisfaction		Experiences with the services offered by nurses
Satisfaction with home nursing service			
Satisfaction with nurses' work			
Has not received any training	Experiences related to receiving information		
Does not need much information			
Responsibility	Experiences related to the sense of duty	Experiences related to personal responsibility	
Being alert			
Responsibility to take care of their family member			
Self-taught	Experiences related to independently acquired knowledge		
Life experience			
Interpersonal disagreements	Negative experiences related to communication	Experiences related to interpersonal communication	
Disagreements with family member			
Memory problems			
Elderly working against caregiver's orders	Positive experiences related to communication		
Relaxed communication			
Good interpersonal relationship			
Elderly is interested in family member's health and well-being			
Love for the elderly	Experiences related to health issues of the family member	Experiences related to the health of family member who is giving support	
Elderly is not interested in health of the family member			
Elderly does not pay attention to their health			
Exhaustion			
Depression	Family member's experiences related to maintaining their own health		
Lifting heavy items			
Deterioration of health			
Family member seeks help to improve their health			
Family member is concerned about their own health in relation to elderly's coping abilities			

The first upper category "Experiences affecting support" consisted of two subcategories: experiences that interfere with support and experiences that motivate support. The family members included in the sample all reported significant lack of time, and as a result, the main problem was fatigue and the risk of burning out. Family members feel the obligation and responsibility to take care of the elderly, even though they do not like it. At the same time, with many responsibilities, it was felt that family members also found positive aspects and used positive thinking. Family members feel love for the elderly, and this motivates them to provide care:

"...Well, if he didn't have me, he wouldn't exist. After all, he absolutely cannot cope without a family member." (Interview 3).

"...I don't understand where the line is, is it easier to say that I can't, I'm not able to and I don't want to, or that's the way it really is." (Interview 4).

"...I think that, in a sense, it is a natural part of life. If things are natural and there is love, then there are no problems. If you love that person, it's natural to help them." (Interview 5).

The second upper category "Experiences related to the service provided by nurses" is formed by two subcategories - experiences related to satisfaction and experiences related to information. Three out of five respondents were satisfied with the quality and volume of home nursing. Two out of five respondents even wanted to reduce nurse visits. Two family members in this study did not receive and one did not need additional help or information:

“...Our home nurse and a family nurse are top notch.” (Interview 3).

“...We have two home nurses, one comes in to apply band aids once a week. I told them to come once a week, that there was no point in coming every three days, that I could change the band aids myself if necessary. They take a shower anyway and then need new band-aids. Once a month, another nurse comes to draw blood.” (Interview 1).

“...The family nurse came by and didn't tell us how to do it, then the next time we talked about this topic. They still have this bed sore now, but it's not that bad.” (Interview 1).

“...Haven't looked for help, haven't researched, haven't received it. So far, I haven't considered it necessary.” (Interview 2).

The upper category "Experiences related to personal responsibility" consists of two subcategories - experiences related to a sense of duty and experiences related to independently acquired knowledge. In interviews family members describe a constant feeling of being on guard and had taught themselves to cope as needed:

“...Then they practically sit in the corridor and wait until I come. Or whether I will come at all.” (Interview 2).

“...I sleep next to them and I'm always on guard.” (Interview 3).

“...Life has taught me.” (Interview 3).

The upper category "Experiences related to interpersonal communication" consists of two subcategories - negative experiences related to communication and positive experiences related to communication. The negative aspects of communication make caregiving difficult and lead to exhaustion of the family member. The positive factors of communication contribute to smooth and motivated assistance:

“...When I come to say something, I say it once, twice. ...then I raise my voice. Then they say why are you always yelling at me, and it's like that all the time.” (Interview 2).

“...Possible disagreements specifically stem from their former profession in raising children.” (Interview 4).

“...Sometimes there are misunderstandings. The thing with

food is that they argue all the time that I give them too much food. I said that then you have to go to a nursing home, they won't feed you there at all.” (Interview 3).

“...Until they have managed to do something again. An old person is like a small child. Takes all things out and starts to investigate, leaves everything all over the place. I say put it back, but well.. At least a small child learns, but an old person doesn't learn anymore!...That's it, sometimes they really do not cooperate.” (Interview 1).

“...Very lovable. I love him very much and my father loves me very much”. “...There are no daily disagreements.” (Interview 5).

“...They worry about me.. They keep telling me to lie down and rest, lie down and rest... We have no worries, we have coped together for 51 years.” (Interview 3).

The upper category "Experiences related to a family member's own health" consists of two subcategories - experiences related to one's own health problems and experiences related to maintaining one's own health. Family member's own health problems pose a great risk for the family member to burn out and lose the strength and will needed to care for the elderly. Family members neglect their own health because the elderly person's condition is worse. Family members also paid attention to their own health, and all relatives were also worried about the elderly's ability to cope because of their own health:

“...Not interested. Well, yes, when I have a headache or I'm lying down in bed and they can't see me.” (Interview 4).

“...I don't get a break, nobody gives it to me.” (Interview 3).

“...If I have to undergo surgery again, then a series of problems will arise yet again.” (Interview 5).

The needs of a family member in relation to supporting the elderly

This main category consists of five upper categories: need for rest and own time; needs related to patient transport and its organization; needs related to patient care and household chores; the family member's own physical and mental health needs; the need for state support. The distribution of the categories formed as a result of the data analysis is presented in **Table 5**.

Table 5: The needs of a family member in relation to supporting the elderly.

Substantive codes	Subcategory	Upper category	
The elderly cannot be left alone	Need for their own time	Need to take time off, rest and have their own time	
Limited freedom			
Exhaustion	Need to take time off		
Not being able to take time off			
Difficulties with patient transport	Needs related to patient transport	Needs related to patient transport and its organization	
Helping with the patient's mobility			
Need for mobility equipment			
Absence of ramp			
Transport for elderly disabled person is not provided	Needs related to transport organization		
Wheelchair-accessible van is too expensive			
Meal preparation	Help with chores		Needs related to taking care of the patient and household chores

Cleaning and doing laundry	Need for support person/caregiver	Needs related to the physical and mental health of the family member who is providing care
A person, who could come in for help if needed		
Help with self-care activities		
Concerns related to undergoing a surgery	Needs related to the physical health of family member who is providing care	
Cardiovascular issues		
Musculoskeletal issues		
Feeling that they are important	Needs related to the mental health of family member who is providing care	
Need for appreciation		
Depression		
Concern for the well-being of the elderly in the future	Family member is disappointed in public services	Need for state support
The state and various agencies do not respond or care		
The systems do not add up	Flaws in national system	
Does not receive rehabilitation, although it has been paid for and prescribed		
Wish to reduce home nursing services		
Wish to consult family nurse by themselves	Decreased need for nursing care service	
One home nurse instead of two		

The first upper category described the family member's need for rest and their own time and included two subcategories: the need for their own time; the need for rest. Family members are exhausted from being constantly on guard and from the lack of freedom for their own time; fatigue and the need for rest were the common features of all the subjects:

"...The need for freedom...I say I would really like to point it out, that 2-3 hours every day." (Interview 5).

"...For example, I can't go away for more than one evening, my vacations as such are currently out of the question, because I can't take them with me." (Interview 4).

"...I am an elderly person myself, I would also like to rest more." (Interview 2).

The upper category "Needs related to patient transport and its organization" consists of two subcategories - needs related to patient transport and needs related to transport organization. Relatives had different needs regarding the transportation of their loved ones and the organization of transportation:

"...I would like to get some fresh air, to go for a walk outside. I would like to go outside. We don't have that ramp and we can't go outside." (Interview 3).

"...Didn't find the necessary aids in the disability equipment store either." (Interview 1).

"...Because he has this prostate cancer, he has to go for tests all the time. We have to pay a total of 50 euros per visit to give a blood sample at Ravi St. 18. This wheelchair-accessible transport is his legs and it's so expensive!" (Interview 3).

"...We could have a new car, then we could take my mother for a ride. Well now, the old one is fine too." (Interview 1).

The upper category "Needs related to patient care and household chores" consists of two subcategories - the need for help in household chores and the need for a support person/caregiver. Daily household activities were the most tiring for family members and they needed help with it, and most family members had a need for a support person or carer.

"...Since I also have to go to work and they don't cook for them-

selfs, I have to prepare their lunch in advance." (Interview 4).

"...How do I carry shopping bags when I'm not allowed to? Time goes by so quickly, there is nothing else but cooking and shopping and the day is over. I'm tired. I would also like to watch some TV, but oh well." (Interview 3).

"...Why can't I get this support person..."; "Perhaps you will find me someone. To help out."; "...To get groceries a couple of times a week, and then I would like the apartment to be cleaned once a week. And change the sheets twice a month."; "...Maybe come in for a couple of hours to help. If they would cook, it would also be great."; "...The hardest thing for me is cleaning. "Someone to come in and help." (Interview 2).

"...If, for example, I wanted to go on a trip for five days, I would know that I have a person who would come and bring them cooked meals and check on them to make sure everything is alright." (Interview 4).

The upper category "Physical and mental health needs of a family member" consists of two subcategories - needs related to the physical health of a family member and needs related to the mental health of a family member. Family members also have health problems themselves and need more attention and support in this regard. The majority considered the well-being of the elderly to be more important than meeting their own health-related needs. Feeling needed seemed to be one of the main motivators in caring for an elderly person, but if the elderly person or someone else does not recognize the loved one for his or her efforts, the whole caregiving process seems more exhausting:

"...My leg and back are hurting. The vertebra is out and still hurts. Then I get frustrated. That's why I scream. They want to talk to me and then I tell them to be quiet. I was afraid to go in for surgery, I was worried that if it failed, I wouldn't be able to move anymore. (Interview 1)."

"...Sometimes I get pains in the chest. Chest pains are from fatigue, stress." (Interview 2).

The upper category "Need for state support" consists of three subcategories - family member's disappointment in state

services, flaws in the state system, and reduced need for nursing services. Family members are struggling with problems that involve large expenses and are impossible for them to fulfil. In most cases, the needs concern basic and primary needs, such as hygiene needs, going outdoors, going to the doctor. Family members are frustrated with state systems and that help is unavailable. Relatives expressed their disapproval of the inadequacy of the national system. Family members were disturbed when several nurses instead of one nurse were doing the nursing work. They prefer one person they are used to. The family members also wanted to go outside to consult the family nurse, and some were offered more home nursing services than they would prefer:

"...We are dismissed from all agencies, no one cares." (Interview 3).

"...My husband tells me to send him off to a nursing home or psychiatric hospital...I wonder what will happen if I die first, what will the children do." (Interview 2).

"...The systems are not working properly. We haven't received rehabilitation anyway, because they don't have legs. A plan was made, which cost more than 300 euros, but rehabilitation is not offered, because they do not want someone who doesn't have legs. The state cannot guarantee it for us. We have been prescribed a wheelchair-accessible van and physical therapy, but we don't get anything. They don't provide lunch there either, and then we have to go and pick them up.... The system could be more reasonable, the wheelchair-accessible van should be more accessible." (Interview 3).

"...The home nurse visits once a month. Some time ago the nurse used to visit every day. We don't want a stranger, all by ourselves. They also don't want a stranger to take care of them... We don't like having two nurses, one is enough." (Interview 3).

Discussion

The research addressed the experiences and needs of both the elderly receiving home nursing services and their family members. Half of the elderly lived alone and were dependent on their family members, and felt isolated, as it was not possible to leave the house independently due to mobility problems. Since patients are forced to stay at home, communication with loved ones and their visits are helpful. The elderly have a crucial need for emotional support. Supporters of the elderly are children or grandchildren, a home nurse, and also social workers.

Experiencing positive emotions with family members and acquaintances gives the elderly vitality and confidence. At the same time, due to age and helplessness, disagreements and dissenting opinions may occur in the communication between the elderly and their family members. At this point, we can discuss differences between generations, where different generations have their own beliefs and life values. If an elderly person is used to doing things their own way, it is difficult to get used to new things.

Most of the elderly have tried to cope with their daily lives, but still need the help and support of their loved ones. The elderly need help on many levels to cope with everyday life. They especially need reliable help from their family. Due to the health condition of the elderly, there is often a need for home nursing services. A trusting communication and relationship between the home nurse and the person in need is very important. The majority of the elderly frequently use various means of communication. Personal arrangements are important.

Family members of elderly patients face several challenges in caring for their loved one. Both family members and the elderly are generally satisfied with the home nursing service. However, one nurse is preferred, this would also help to achieve a trusting relationship between the patient, the patient's family members and the home nurse. However, the interviews revealed that home care services alone are not enough to cope. Relatives feel exhausted, they have to be on guard all the time and complain about the lack of free time.

In addition, many family members have health problems themselves, which make them worry both about themselves and whether they will be able to adequately support their elderly due to their own health problems. Often, family members neglect their own health problems, thinking that the elderly's health and livelihood are more important. This in turn leads to mental health problems and exhaustion. In the past, research has shown that nearly 10% of informal caregivers are overburdened and unable to continue caring [5]. Previous studies have pointed out the mental health problems of family members, a higher risk of poverty, and worse physical health compared to those family members who do not have to care for an elderly family member living at home. [13] Family members living with the elderly have a greater burden of care [5].

It has been found that relatives of elderly patients need information and training, professional support, effective communication, and legal and financial support [13]. Previously, it has also been found that family of patients often lack information about support systems [14]. The present study revealed that family members were aware of various support systems, but were not satisfied with the support provided by the state. Rather, families try to cope by themselves. Support services have been created by the state, but often they are not available, or you have to pay for them, which worsens their financial situation. Relatives had various needs regarding the transportation and its organization for an elderly family member. Relatives are burdened by daily household activities, and they feel the need for a support person. Family members want their own time and rest, but unfortunately there is no support system in the form of a support person, who would relieve them from caregiving duties for a period of time. The need for time and rest from the role of a caregiver has also emerged in an earlier study [21].

Conclusions

The research results show that both the elderly who receive home nursing services and their family members need more support in terms of coping at home, so that the needs of both would be met. Support systems for the elderly and their family and their availability should be revised at state level. Although families were mostly satisfied with the home nursing service and had a good relationship with the home nurse, they still preferred one person to perform visits. The frequency of the home nurse's visit should be discussed with the elderly and their family members.

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