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RESEARCH ARTICLE



Frail community-dwelling older persons' everyday lives and their experiences of rehabilitation – a qualitative study

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ABSTRACT

Background: The number of older persons with frailty is increasing, and rehabilitation to improve the consequences of frailty are important for both the individual and society. However, the perspective of older persons themselves in research and planning of interventions is scarce. **Aim:** The aim of this study was to describe frail older persons' everyday lives and their experiences and views of rehabilitation.

Material and methods: Twenty older persons were interviewed, and analyses were performed using a qualitative content analysis method.

Results: The two main categories were 'Frailty impacts everyday lifé and 'Experiences and perceptions of rehabilitation'. The participants described that they had to adapt their everyday lives in line with their health conditions. They all used strategies and were dependent on support in their activities of daily living. Their social network had decreased. All participants strived to stay active and independent, and wanted rehabilitation and support from professionals, experiencing decreased access to rehabilitation.

Conclusions and significance: Frail older persons are a vulnerable group who often need support in everyday life. There is room for improvement when it comes to helping frail older persons to stay active and facilitate participation in both individual and group interventions.

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KEYWORDS

Frailty; occupational therapy; physiotherapy; primary care

Introduction

In Sweden, about 10% of citizens are aged 75 or older and this proportion is expected to increase in the coming decade [1]. Most older persons feel relatively well, manage themselves at home and only rarely use primary or hospital care [2,3]. However, the risk of multimorbidity and disabling conditions that could result in frailty increases with age. A systematic review based on 21 cohorts shows that about 11% of community-dwelling older persons are frail, and about 41% are pre-frail, although the prevalence differed [4].

Frailty can occur as the result of several medical conditions and can be defined as a clinical state with an increase in vulnerability for developing dependency and/

or mortality when exposed to stressors [5,6]. Morley et al. [6] describe physical frailty as a medical syndrome with multiple causes that is characterised by diminished strength and endurance and reduced physiologic function, which increases vulnerability and frailty.

Frailty is associated with significant costs for healthcare and community services compared with the total population of community-dwelling older persons. Hospitalisation is one risk that increases with frailty [7,8]. It also leads to reduced autonomy, well-being, quality of life, risk of loss of activities of daily living (ADL) [9] and participation restrictions [10]. Hence, it is an important issue for healthcare to identify older persons with frailty to meet their needs from a holistic viewpoint and to offer interventions

and rehabilitation tailored for frail older persons that also consider the degree of frailty [8,11–13]. More efficient routine clinical practices must be developed to meet the complex needs of patient-centred care [6,14,15]. For example, Nord et al. [16] have shown promising results in a recent study when it comes to reducing the need for hospital care days by introducing comprehensive geriatric assessment (CGA) in primary care. CGA has also shown positive effects on the activities of daily living for frail older persons [17].

While the vast majority of research on frailty focuses on developing and distributing assessment scales of the physical and medical conditions [8], there are also a number of studies with interventions aiming to improve the consequences of frailty [18,19]. In a systematic review of randomised controlled trials, De Labra et al. [19] showed that frail older persons benefit from rehabilitation with exercise interventions, with positive effects on falls and fear of falling, mobility and muscle strength. Takatori and Matsumoto [20] also concluded that exercise combined with social participation could play a role in reversing frailty progression. Other studies have found that occupational therapy can contribute to improvements in ADL, mobility, quality of life and social participation [18,21-23], though additional research is needed [22]. Multi-professional interventions such as home visits and meetings with information and discussions were found to have long-term effects of postponing dependency in ADL among older persons at risk of developing frailty [24].

Previous studies have shown a need for more knowledge about frailty, emphasising the importance of including the perspective of frail older persons when improving and planning for rehabilitation and healthcare for this group, through assessments and interventions together with the interprofessional team and relatives [25,26]. For example, Rose et al. [27] described how frail older persons perceived that they could participate in shared decision-making in rehabilitation if they were provided with enough information, and sufficient motivation, self-confidence and family support. Recent studies have also suggested that the perspective of the older person with needs to be included in [14,15,25,28,29]. Berge et al. interviewed frail older persons who had participated in a randomised controlled trial (RCT) about their involvement in research [28]. They conclude that there seems to be a variation in how frail older persons want to and can be involved in research, but that their voices need to be heard to avoid health services being based on the wishes and perspectives of other stakeholders.

Studies including frail older persons' experiences of rehabilitation are few, especially concerning their past experiences of rehabilitation, but there are studies including older persons involved in the rehabilitation program. In a qualitative study, community-dwelling older persons described their experiences of home rehabilitation as a process that was ongoing, with the goal of continuing to perform meaningful activities [30]. In a rehabilitation context for older persons, an agency-centred approach is suggested where efficient interventions could be dependent on the older person's life and previous experiences, never viewing the person as "only a patient" [31].

Even though previous studies have emphasised the importance of considering the perspective of the frail older person at high risk of hospitalisation in rehabilitation and research, studies are still scarce. Including their perspectives on living with frailty and their experiences of rehabilitation could contribute to the further development and improvement of targeted care and rehabilitation. Therefore, this study aims to describe frail older persons' everyday lives and their experiences and views of rehabilitation.

Methods

Design

In this qualitative study, we used individual interviews with open-ended questions as we wanted to explore and describe the participant's own experiences and perspectives [32]. The interviews were analysed using content analyses according to Graneheim and Lundman [33].

Participants and settings

Participants were recruited from the longitudinal pragmatic intervention study "Proactive healthcare for frail elderly persons" [34]. The project is a randomised multicentre study (with a quantitative and qualitative approach) with the aim of evaluating the effect of targeted primary care for frail older persons. An intervention group was selected according to a scientifically developed prediction model [35]. A validated algorithm that included ICD-10 diagnoses, care visits, age and gender was used to identify frail old persons at a high risk of hospitalisation from medical records [35]. Nine primary healthcare centres (PHCs) in Östergötland in the southeast health region of Sweden were included in the intervention, together with ten PHCs in the same region as controls. The older persons in the intervention group were invited to take part in the intervention, which involved the offer of a health visit with a comprehensive geriatric assessment (CGA) screening by a nurse and a physician. Based on this screening, an individual care plan was prepared and, if necessary, a member of rehabilitation staff (occupational therapist/physiotherapist) from the existing healthcare institution (primary care, home healthcare or community care) was contacted for further assessments and possible interventions. This meant that the interventions were individual-based and varied for different people. The control group received the usual care. For more details, please see the study protocol [34]. Participants in this qualitative study were part of the intervention group and had been invited to a health visit in connection with the start of the main study, but it was not known to the researchers at the time of the interview whether they had received any further rehabilitation interventions in the project. We used a purposive sample [36] as we wanted to have a broad (in turns of living situation/ area/region/gender) and representative overview from the intervention group in the main project and of frail older people still living in their own homes in a region in central Sweden [32]. Inclusion criteria were age over 75, being part of the intervention group, living in ordinary housing, having self-reported dependency in at least one ADL activity on the ADL staircase [37] and/or self-reported pain and/or balance problems in the baseline questionnaire included in the project. The participants were invited by letter, including written information about the study. They were then thoroughly orally informed about the study by phone, and again before the interview started.

A total of 29 people were contacted, nine of which declined to participate. The 20 participants who consented to participate represented eight out of the nine PHCs that took part in the intervention. Their age ranged between 78 and 92 years old, with a mean age of 85.5 years. More than half were women (n = 12; 60%). Seven people lived alone and thirteen lived with a spouse or partner. One participant had just moved from ordinary housing into a nursing home when the interview took place. They were all living in ordinary housing when they were included in the main study [34]. Thirteen participants lived in apartments and six in houses. The majority lived in or near a city, while five people lived in more rural locations.

Data collection

The interviews were conducted between November 2018 and February 2019 by the second author. All interviews, except for one, took place in the person's home. One person chose to come to the geriatric clinic for the interview. The interviewer had the experience of rehabilitation of older persons, working as an occupational therapist. The interviews were recorded and lasted between 15 and 67 min, with a mean duration of 43 min. An interview guide with open-ended questions was used to capture the participants experiences and needs for rehabilitation. The following key questions were asked. When needed explorative questions and follow-up questions were used such as "Can you tell me more about that?"

- Can you describe an ordinary day and what you do?
- Can you describe your capability in everyday life?
- What does rehabilitation mean to you?
- Have you been offered any form of training/treatment/advice to increase function in everyday life?
- Can you see any obstacles to taking part in training or rehabilitation?
- Do you know where to turn if you need help with rehabilitation? Please describe how and where.

Data analyses

The interviews were transcribed verbatim and analysed using qualitative content analyses [33]. At first, the authors (MJ, MN, AÖ) read all the interviews several times to get a good understanding and overview of the material. In the second step, the authors separated the text into meaning units (1-3 sentences) that described the participants' everyday life and their experiences, needs and perceptions of rehabilitation. In a third step the meaning units were condensed (keeping close to the text), and in the fourth step, they were labelled with codes. The codes were meant to reflect and describe the condensed unit briefly. At first, all authors coded some interviews separately and then compared codes and discussed them together. After discussion, the codes were sorted into groups by authors MJ and AO in which similarities and differences were compared. The groups were then sorted into subcategories and categories. During all steps, reflective discussions were held between the authors resulting in moving forward and backward between the different steps until a consensus was reached within the group. Quotations are used to illustrate the text. Examples of the analyse process can be seen in Table 1.

Ethics

All participants gave their informed written consent prior to participation. All data were coded to ensure

Meaning unit	Code	Subcategory	Category
To train on something so that it goes better in everyday life.	Training	Thoughts on rehabilitation	Experiences and perceptions of rehabilitation
It's not easy to get old anyway, much that deteriorates then when it comes to hearing and sight and ability to think. It's a fate you have to find yourself in.	Getting old Functional limitations	Adaptation and strategies in everyday life	Frailty impacts everyday life
I would not be able to do without her. If I were to be alone, I would not be able to cope.	Wife helps	A need for help and support in activities of daily living	Frailty impacts everyday life

Table 2. Categories and subcategories.

Subcategories
Adaptation and strategies in everyday life A need for help and support in activities
of daily living
A decreasing social network
The importance of staying active
Experiences of rehabilitation
Thoughts on rehabilitation
Accessibility as an obstacle to rehabilitation

confidentiality and the quotations are anonymized. The regional ethics committee in Linköping approved the main study (Dnr: 2016/347-31) as well as this qualitative study (Dnr: 2018/115-32). The study was conducted in accordance with the Declaration of Helsinki [38].

Results

Two main categories and seven subcategories emerged (Table 2). The results are presented under each category below.

Frailty impacts everyday life

All participants described how living with frailty affected everyday life.

Adaptation and strategies in everyday life

All participants described that they had been forced to adapt to their functional limitations to manage everyday life and the activities they used to do. Adaptations included strategies, such as taking frequent breaks, simplifying or giving up activities, such as driving or cooking, or using various technical aids. One participant who wished to remain independent described having to accept that not every household chore was carried out:

'I think it's a little bit nice to manage on my own, as much as possible. Although it is clear, there is a lot that is being neglected, but, but that's how it is, yes. Life goes on.' (14)

The participants described their limited functions and energy due to pain, poor sleep, poor balance, and side effects of medication. 'And it varies. Some days I feel nothing, and some days I have to hold onto furniture and [my wife] and ... not to fall over.' (8)

The participants told how they still strived to do everything they could do by themselves and continue with the habits and routines that they had done before. Limitations due to a fear of falling or ending up in a situation they could not cope with were described. Many had personal alarms for home care services as a source of security. The participants said that they usually had to bring company outside the home for shopping or going to the doctor. One person described that he had certain routines for daring to go out, such as always bringing a mobile phone. The participants also described how activities took longer to perform, for example, due to moving more slowly with a walker.

A need for help and support in activities of daily living

All participants reported being dependent on support in everyday life in some way. Several had support from relatives such as spouses and children, not being able to cope by themselves:

'But I would hardly manage alone. I do not know; I have not thought about... I do not want to think about that idea. But one must face the reality, and it is probably that I can't cope alone.' (8)

Many of them also expressed a situation of sadness when they needed assistance in their shared household, and not being able to contribute to the household chores:

'Yes, I cannot move so much, you know, I cannot lift so much then, you know. And I understand that [my wife] gets tired of me sometimes, because she has to do everything.' (12)

Many performed the simpler everyday chores themselves, such as getting up and getting dressed and making something to eat. Someone stated that cooking was an activity they really wanted to do, but that it took too much effort.



It was common for the participants to also receive support from the home care service. It was perceived differently; some participants were very satisfied:

'Otherwise, you can imagine that you get up and get dressed and so on. But I get help with that. I think it feels, it feels good. They do not hunt for one or the other but take it at my pace.' (2)

Others wanted far more continuity and more knowledgeable and professional staff. A few participants took care of relatives themselves, dealing with those activities and social groups outside the home that was important in order to have some recreation of their own. Many everyday tasks felt cumbersome and difficult. One participant mentioned that it was no fun getting help from acquaintances; instead, they wanted to socialise in other ways and preferred to turn to volunteer organisations for help.

A decreasing social network

The participants described how their social networks gradually had shrunk. Most of their social contacts were with their close family, either in person when relatives came to visit or by telephone, which was considered important.

'The phone is very important, that is. That's my contact with the outside world, you could say. So, the phone, if I were to ... if I got rid of it now, I would miss it.' (2)

Other important sources of social contact included neighbours, former colleagues and contacts created through social activities. Some indicated that these social contacts occurred regularly, especially when it came to social activities in groups. However, it was also mentioned that everyday variations of their functional limitations affected their opportunities to establish new contacts or keep appointments.

Some participants mentioned that the home care service staff were important social contacts. They could even be experienced as friends. One person mentioned the lack of proximity and that the home care service staff could sometimes give a hug, which was greatly appreciated. One disadvantage of home care services was that there were so many different people. Here, the contact person was important for continuity. There were, however, several wishes for increased social contact and interaction for more stimulation and variation in everyday life. One participant felt that the range of leisure activities for the elderly was very limited and mentioned that bingo, for example, is not appreciated by everyone. A desire was also expressed for more special cafés and restaurants in the immediate area as

meeting points where, for example, visually impaired people could get help and support.

Experiences and perceptions of rehabilitation

Living with frailty affected the participants' current opportunities to exercise and participate in various forms of rehabilitation. All had experienced previous periods of rehabilitation due to various reasons.

The importance of staying active

Almost all participants said that they had the motivation and willingness to train and stay physically active, doing things, and that they could see the importance of rehabilitation. However, their functional limitations had a major impact on how the day went.

'I try to [stay active]. Now I have not been out. I am trying though. I was out for a while and walked with a walker in the parking lot here. So, to get your legs up and running.' (3)

They performed some quiet activities to "keep up". Reading newspapers, watching TV/films, and listening to the radio were described as important activities, and doing crosswords, sudokus, puzzles and needlework were also mentioned.

They expressed a desire for rehabilitation such as training to help them feel better and to gain increased mobility, alleviate pain or cope with more things that they were unable to do now. Based on previous experiences, many participants felt that they would be supported by a group and thus better motivated to go and train.

'And it is just that when you do the exercises at home, it won't be the same. You cheat. And everyone says the same thing, that is. There, we usually talk at the pool there, and everyone says it, it is much better, group exercises rather than individual exercises. Because it will not be the same.' (11)

Others, however, experienced the benefits of exercising at home and not having to go to another location. Many participants said that old age means one cannot expect to be as physically active as before. One participant described how intrinsic driving force and initiative had become worse over time and that on some days it was difficult to get things done, which also affected whether or not training was carried out at home. The motivation to exercise at home was also negatively affected by the fear of falling and getting hurt.

'Yes, so I am very scared to fall. Because ... it sounds a little harmless to fall, but it is not. (laughter) It is really scary.' (9)

Experiences of rehabilitation

All participants had had many previous contacts with health care and rehabilitation services during their lives. They expressed that they had received very good support and care from rehabilitation professionals, with clear goals and training in relevant tasks in both outpatient and inpatient care. They were also pleased with other interventions, such as getting technical aids and housing adaptations:

'I got this special chair [disability work chair on wheels]. Now I got it, after the last foot operation. And then I was so proud so I thought, I can do without this, I do not need help. But then my occupational therapist insisted that I have a chair, at least. And that has been my salvation. Because I have taken care of the household and so on.' (14)

Many described how they had received individual home training programmes but had found it difficult to manage this on their own for a longer time. They missed the continuity of having someone to give them instructions, support them and follow up on results. Previous rehabilitation periods were carried out in connection with, for example, hip or arm surgery, but follow-up of both rehabilitation and selftraining at home was experienced as being insufficient or even omitted.

'It was meant to be that [rehabilitation after surgery], but I haven't heard anything from them [the physiotherapists] at all. There have been a lot of things going on, but it all came to nothing.' (12)

However, some of the participants mentioned having long periods of rehabilitation, e.g. with the same physiotherapist, and described their experiences as positive, instilling trust and confidence.

It was also mentioned that some expectations of the previous rehabilitation periods were not met, such as getting certain housing adaptations, receiving sufficient instructions regarding training or satisfaction with the effects of training. A couple of participants felt that they had been pushed too hard in hospital care. They described that pain and reduced energy had not been considered by the rehabilitation staff. Negative experiences from short-term care (community care) also emerged where some participants experienced harsh treatment from ward staff and a poor rehabilitation environment with many seriously ill patients on the same ward. However, when elaborating on their experiences of rehabilitation, participants

described that it was difficult to know who every professional was that they had met on various occasions, and thus what could be considered rehabilitation.

Thoughts on rehabilitation

The participants described rehabilitation as some form of help to regain abilities to manage everyday life, focussing on exercising and training to improve for example physical functions, getting started, feeling better or improving health. They also mentioned the significance of rehabilitation for everyday life. One participant said:

'Well, I guess it means that you should exercise something so that will improve everyday life.' (4)

Even if some participants described their ownership of the rehabilitation process, many of the participants emphasised that rehabilitation also had to include professional support, such as physical therapy, receiving technical aids, water gymnastics or a medical procedure. Two of the participants did not express any perception of the concept, and one associated it with getting a massage from a spouse. One participant indicated that rehabilitation is about being able to work despite having a disability.

Accessibility as an obstacle to rehabilitation

All participants described that they experienced their ability to move around in the community as impaired, and they were dependent on being close to both care and rehabilitation facilities. This was ascribed to functional limitations, illness, and their day-to-day conditions. Most of the participants had stopped driving and had limited opportunities to use transport services, or relatives who would be able to help. Weather conditions (e.g. snow), difficulties getting in and out of cars and difficulties with parking facilities were also described as obstacles. The transport service trips were described by the participants as a time-consuming and laborious part. The journey, combined with training, took too much energy.

'But for me, it's too far to go so I only drive one day a week then. Because otherwise it will be too much. Not for the sake of gymnastics, but it is the ride back and forth that is difficult.' (11)

Even small details could be an almost impossible obstacle to overcome:

'I took part in water gymnastics for as long as I did, so I... But then it became impossible, you know,



because then, I couldn't, I couldn't... The changing room, you know, it was about not being able to hang up my clothes... Because there are little things like that that get so big.' (15)

The participants stated that they would call their primary healthcare centre when they would need care and to get in touch with rehabilitation professionals. However, contacting healthcare was described as increasingly difficult:

'But then I also really thought that I might call a physiotherapist to hear if I can have some exercises myself, at home. I've been thinking about that every day for a week now, but it has not happened so I haven't heard if I could get there.' (4)

Uncertainty about what rehabilitation there was, what could be achieved with rehabilitation, and who they had been in contact with before was described by several participants.

Financial obstacles were also described. One participant however was not aware of the right to get assistive technology and had bought some assistive technology himself, including the walking aids he needed. Another obstacle was described when it came to getting to and from rehabilitation facilities using a transport service which was perceived as expensive. There was also a noticeable reduction in the community's access to rehabilitation facilities due to economic cutbacks.

Discussion

This study focuses on frail older persons, their everyday lives, and their experiences of rehabilitation. The results show that all participants value being - and want to be - physically active and independent in everyday life, but they did not always manage this due to illnesses and functional limitations. Their health conditions made dealing with everyday life complicated, and they were prevented from participating in rehabilitation and social activities outside the home due to factors such as changes in the structure of their day, difficulties sleeping and pain. They had to adapt to and accept these facts and did so in different ways - sometimes in line with what earlier research has reported [39,40]. For example, in the study conducted by Dunér [39], older people valued being independent and maintaining their autonomy, and in order to do so, they had to adapt to their level of strength and get help from different sources. In our study, all participants were dependent on help in some way and from different sources and were aware that they could not cope on their own. To help community-dwelling frail older persons remain active and to enhance independence, a holistic approach is suggested for interventions and rehabilitation, with respect to both their complex medical needs and the perspective of the individual [41,42]. Occupational therapy can be helpful both with ADL training, technical aids or education to home care staff.

All participants in our study described previous experiences of rehabilitation that were both positive and negative. Many of the participants had positive experiences from group-based training, however, transportation has now become a barrier. Obstacles to taking part in rehabilitation and exercise programmes, such as transportation and mobility problems and functional limitations, have also been highlighted in other studies [43-45]. In a study where people with mild frailty were interviewed about what they want from a home-based health promotion programme, most of the participants identified advice on physical exercise to improve mobility and a focus on independence as being important. Social networks were also mentioned as an important topic [40].

The participants in our study also described their experiences of the positive effects of group rehabilitation when it came to physical exercise, and how this was helpful for their motivation to exercise. Earlier research has also pointed this out [46]. Participants in our study also highlighted their own role in their rehabilitation process, and how they experienced a lack of motivation. A lack of motivation to exercise on their own, a fear of falling and a fear of doing the wrong movement were examples of obstacles to following exercise programmes alone at home. A need for professional support was expressed, such as having the same physiotherapist for a longer period and follow-up sessions. Earlier research has also identified this need. Facilitators for physical exercise as part of rehabilitation include participating in group exercises and follow-ups carried out by professionals [47], and supportive coaching and "oneself" are essential for recovery [48]. As described in the review conducted by Franco [43], environmental barriers were also mentioned, such as stairs, heavy doors and distance hindering participation and accessibility.

The importance of person-centred, tailored interventions and continuity for frail older people is clear from both the results of this study and earlier research [11]. Striving to continue living at home and a desire for continuity in contact with rehabilitation staff and home service staff were also seen in Björkman Randström et al.'s study [30]. It was also shown in our study that some had difficulties knowing whom to contact and what kind of training was available if, for example, they had problems with balance. It is therefore important that their contact nurse or physician at the PHC has good knowledge about local rehabilitation arrangements, as well as knowledge about what physiotherapists and occupational therapists can do for frail elderly persons. In terms of primary care teams, rehabilitation staff such as physiotherapists and occupational therapists are organised in special rehabilitation centres and these are not located at the PHC. Most of them do not serve a specific area or a specific PHC. In rural areas, physiotherapists and occupational therapists are sometimes located at the PHC. In Sweden, a new government reform aims to give citizens "good quality, local healthcare" [49]. Whether nor not this reform will benefit frail older people when it comes to rehabilitation is a question for future studies.

Some misconceptions about what rehabilitation and occupational therapy mean, as it comes to older persons was spoken, some participants referring it to work and not being in need of that in their current living situation. The same misconception about occupational therapy for older people has also been noted in an Australian study [50]. As professionals, we need to improve the information we provide to older people about their rights, where to get support with rehabilitation and what different professions can offer. Information about what occupational therapy and physiotherapy can provide for this group can also be improved on a societal level. Many of the participants in our study were unsure whom to contact when they needed rehabilitation (physical training, technical aids, etc.), and the information on websites, for example, does not reach most frail older adults. This must also be considered when planning for future care and the fact that many want to stay at home if possible. Rehabilitation for frail older people should not only be delivered by professional rehabilitation staff, but the whole team should work with a rehabilitative approach including the home-service staff.

Decreased social contact due to the loss of friends (as a result of old age) and problems with mobility and transportation for social participation were also mentioned by many participants. Suggestions for solving these issues included more meeting points near where they lived and more variation in leisure activities at activity centres for older people. Social participation and knowledge of local services have also been highlighted in other studies as important aspects of health promotion programmes [40,51].

This study took place just before the Covid -19pandemic, and social contact for older people has certainly not improved since then [52]. Having a phone was mentioned as an important part of their social life, but none mentioned using any other information and communication technology (ICT) as a tool for social contact or healthcare contact. This is both a challenge for the rehabilitation of frail older persons and an issue for future studies [53]. ICT use among frail older persons has also been noted by other researchers as being less frequent than among nonfrail older persons [54,55]. Coaching for physical training and everyday life activities, conducting follow-ups and participating in groups that use ICT requires further investigation in connection with frail older adults. The fact that many older adults currently have neither the necessary knowledge and nor ICT devices must be considered when planning studies [53]. The fact that social isolation due to the Covid-19 pandemic has probably made many older people more physically inactive is also a challenge for healthcare [56]. This was not a concern at the time of data collection but is certainly an issue for further studies.

Methodological considerations

As we wanted to explore frail older persons own experiences and perceptions, using a qualitative design with individual interviews was chosen [36]. Even though this study is limited to the experiences of 20 participants in the intervention group, we managed to include both genders and different living statuses and ages to ensure variation in their experiences. It was obvious that they all had some experience of rehabilitation in different ways and settings, and both inpatient and outpatient perspectives emerged. This strengthens the transferability of the study [32]. However, we did not know at the time of inviting the participants whether they had received any special rehabilitation within this project. One interview was very short, lasting only 15 min. However, this respondent was very direct and answered the questions without hesitation. None of the respondents mentioned or referred to the main project when it came to special rehabilitation interventions. Many of them referred to experiences that were before the main project started and interventions that presumably were not connected to the health visit. Therefore we don't know whether including participants from the control group would have made any difference in the result.



To enhance trustworthiness, the interviewer had previous knowledge of working with rehabilitation and older people. This was an advantage when creating a good atmosphere, and for being able to understand and ask follow-up questions when required. The analyses have been carried out by all the authors, further enhancing transferability. The fact that we discussed codes and categories throughout the analyses strengthens the results and their credibility [33]. The findings of this study are limited to a Swedish context in terms of the healthcare and rehabilitation structure. However, they can probably be transferred to other settings in the Western world where the organisation of healthcare and socio-economic standards is similar.

Conclusions

Frail older persons are a vulnerable and heterogeneous group, and often have a great need for support in everyday life. Our study is based on the perspectives of the older persons themselves. From their perspectives, access to rehabilitation and support can be improved. Individual assessments and person-centred care are necessary. However, there seems to be room for improvement when it comes to helping frail older persons to stay physically active and facilitating participation in both individual and group interventions. It is suggested that future studies focus on how frail older persons can be informed, motivated and supported in rehabilitation and everyday life, and in enhancing independence at home. A future challenge is to study how information and communication technology could be used in healthcare interventions and rehabilitation for community-dwelling frail older persons.

Clinical messages

- Frail older persons' perspectives need to be considered when planning for rehabilitation and healthcare interventions.
- Physical and informational access to rehabilitation needs to be improved and adapted for frail older persons.
- Adapted group interventions for physical exercise and social contact are needed.
- Knowledge of rehabilitation is important for all healthcare professionals.

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References

- [1] SCB. Population Statistics. https://www.scb.se/hittastatistik/sverige-i-siffror/manniskorna-i-sverige/sveriges-befolkningspyramid/2021.
- Collerton J, Davies K, Jagger C, et al. Health and disease in 85 year olds: baseline findings from the Newcastle 85+ cohort study. BMJ. 2009;339:b4904.
- Nägga K, Dong H-J, Marcusson J, et al. Healthrelated factors associated with hospitalization for old people: comparisons of elderly aged 85 in a population cohort study. Arch Gerontol Geriatr. 2012;54: 391-397.
- Collard RM, Boter H, Schoevers RA, et al. Prevalence of frailty in community-dwelling older persons: a systematic review. J Am Geriatr Soc. 2012;60:1487-1492.
- Fried LP, Tangen CM, Walston J, et al. Frailty in older adults: evidence for a phenotype. J Gerontol A Biol Sci Med Sci. 2001;56:M146-M157.
- Morley JE, Vellas B, Abellan van Kan G, et al. Frailty consensus: a call to action. J Am Med Dir Assoc. 2013;14:392-397.
- Chi J, Chen F, Zhang J, et al. Impacts of frailty on health care costs among community-dwelling older adults: a meta-analysis of cohort studies. Arch Gerontol Geriatr. 2021;94:104344.
- Clegg A, Young J, Iliffe S, et al. Frailty in elderly people. Lancet. 2013;381:752-762.
- Vermeiren S, Vella-Azzopardi R, Beckwée D, et al. Frailty and the prediction of negative health outcomes: a meta-analysis. J Am Med Dir Assoc. 2016; 17:1163.e1-1163.e17.
- [10] Rand D, Sternberg SA, Gasner Winograd R, et al. The contribution of frailty to participation of older adults. Int J Environ Res Public Health. 2022;19:1-9.
- [11] Kurpas D, Gwyther H, Szwamel K, et al. Patientcentred access to health care: a framework analysis of the care interface for frail older adults. BMC Geriatr. 2018;18:1-17.
- [12] Gwyther H, Shaw R, Jaime Dauden EA, et al. Understanding frailty: a qualitative study of

- European healthcare policy-makers' approaches to frailty screening and management. BMJ Open. 2018; 8:e018653.
- Cowley A, Goldberg SE, Gordon AL, et al. Rehabilitation potential in older people living with frailty: a systematic mapping review. BMC Geriatr. 2021;21:533.
- [14] Hoogendijk EO, Afilalo J, Ensrud KE, et al. Frailty: implications for clinical practice and public health. Lancet. 2019;394:1365-1375.
- [15] Dent E, Martin FC, Bergman H, et al. Management of frailty: opportunities, challenges, and future directions. Lancet. 2019;394:1376-1386.
- [16] Nord M, Lyth J, Alwin J, et al. Costs and effects of comprehensive geriatric assessment in primary care for older adults with high risk for hospitalisation. BMC Geriatr. 2021;21:263.
- [17] Wilhelmson K, Andersson Hammar I, Westgård T, et al. Positive effects on activities of daily living one year after receiving comprehensive geriatric assessment - results from the randomised controlled study CGA-Swed. BMC Geriatr. 2022;22:180.
- [18] De Coninck L, Bekkering GE, Bouckaert L, et al. Home- and community-based occupational therapy improves functioning in frail older people: a systematic review. J Am Geriatr Soc. 2017;65:1863-1869.
- de Labra C, Guimaraes-Pinheiro C, Maseda A, et al. Effects of physical exercise interventions in frail older adults: a systematic review of randomized controlled trials. BMC Geriatr. 2015;15:154.
- Takatori K, Matsumoto D. Social factors associated [20] with reversing frailty progression in communitydwelling late-stage elderly people: an observational study. PLOS ONE. 2021;16:e0247296.
- De Vriendt P, Peersman W, Florus A, et al. [21] Improving health related quality of life and independence in community dwelling frail older adults through a client-centred and activity-oriented program. A pragmatic randomized controlled trial. J Nutr Health Aging. 2016;20:35-40.
- Fritz H, Seidarabi S, Barbour R, et al. Occupational [22] therapy intervention to improve outcomes among frail older adults: a scoping review. Am J Occup Ther. 2019;73:7303205130p1-7303205130p12.
- Fisher AG, Atler K, Potts A. Effectiveness of occupational therapy with frail community living older adults. Scand J Occup Ther. 2007;14:240-249.
- Gustafsson S, Eklund K, Wilhelmson K, et al. Long-[24] term outcome for ADL following the health-promoting RCT-elderly persons in the risk zone. Gerontologist. 2013;53:654-663.
- Cowley A, Goldberg SE, Gordon AL, et al. Exploring [25] rehabilitation potential in older people living with frailty: a qualitative focus group study. BMC Geriatr. 2021;21:165.
- Westgård TW, Dahlin-Ivanoff S. Ottenvall hammar [26] I. Feeling respected as a person: a qualitative analysis of frail older people's experiences on an acute geriatric ward practicing a comprehensive geriatric assessment. Geriatr Gerontol Int. 2019;4:1-12.
- [27] Rose A, Soundy A, Rosewilliam S. Shared decisionmaking within goal-setting in rehabilitation: a

- mixed-methods study. Clin Rehabil. 2019;33: 564-574.
- Berge I, Barenfeld E, Dahlin-Ivanoff S, et al. [28] Challenging oneself on the threshold to the world of research - frail older people's experiences of involvement in research. BMC Geriatr. 2020;20:410.
- Haak M, Ivanoff S, Barenfeld E, et al. Research as [29] an essentiality beyond one's own competence: an interview study on frail older people's view of research. Res Involv Engagem. 2021;7:91.
- [30] Randström KB, Asplund K, Svedlund M, et al. Activity and participation in home rehabilitation: older people's and family members' perspectives. J Rehabil Med. 2013;45:211-216.
- [31] Pikkarainen A, Vahasantanen K, Paloniemi S, et al. Rehabilitation agency of older adults in group-based intervention. Scand J Occup Ther. 2019;26:411-422.
- [32] Polit DF, Beck CT. Nursing research principles and methods. 9th Edition ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2012.
- [33] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today. 2004;24:105-112.
- [34] Marcusson J, Nord M, Johansson MM, et al. Proactive healthcare for frail elderly persons: study protocol for a prospective controlled primary care intervention in Sweden. BMJ Open. 2019;9:e027847.
- [35] Marcusson J, Nord M, Dong H-J, et al. Clinically useful prediction of hospital admissions in an older population. BMC Geriatr. 2020;20:95.
- Patton QM. Qualitative research & evalutation methods. 3rd ed. California: Sage Publications; 2002.
- [37] Sonn U, Grimby G, Svanborg A. Activities of daily living studied longitudinally between 70 and 76 years of age. Disabil Rehabil. 1996;18:91-100.
- [38] World medical association declaration of Helsinki: ethical principles for medical research involving human subjects. Pub L No. 2013;20:2191-2194.
- Dunér A, Nordström M. Intentions and strategies among elderly people: coping in everyday life. J Aging Stud. 2005;19:437-451.
- [40] Frost R, Kharicha K, Jovicic A, et al. Identifying acceptable components for home-based health promotion services for older people with mild frailty: a qualitative study. Health Soc Care Community. 2018;26:393-403.
- [41]Shaw RL, Gwyther H, Holland C, et al. Understanding frailty: meanings and beliefs about screening and prevention across key stakeholder groups in Europe. Ageing Soc. 2018;38:1223-1252.
- Randström KB, Wengler Y, Asplund K, et al. [42] Working with 'hands-off' support: a qualitative study of multidisciplinary teams' experiences of home rehabilitation for older people. Int J Older People Nurs. 2014;9:25-33.
- [43] Franco MR, Tong A, Howard K, et al. Older people's perspectives on participation in physical activity: a systematic review and thematic synthesis of qualitative literature. Br J Sports Med. 2015;49: 1268-1276.



- Åhlund K, Ekerstad N, Bäck M, et al. Preserved [44]physical fitness is associated with lower 1-year mortality in frail elderly patients with a severe comorbidity burden. Clin Interv Aging. 2019;14:577-586.
- Buttery AK, Martin FC. Knowledge, attitudes and intentions about participation in physical activity of older post-acute hospital inpatients. Physiotherapy. 2009;95:192-198.
- [46] Maula A, LaFond N, Orton E, et al. Use it or lose it: a qualitative study of the maintenance of physical activity in older adults. BMC Geriatr. 2019;19:349.
- Boutevillain L, Dupeyron A, Rouch C, et al. [47] Facilitators and barriers to physical activity in people with chronic low back pain: a qualitative study. PLOS One. 2017;12:e0179826.
- Pol M, Peek S, van Nes F, et al. Everyday life after a [48] hip fracture: what community-living older adults perceive as most beneficial for their recovery. Age Ageing. 2019;48:440-447.
- [49] SKR. Omställning till nära vård https://skr.se/halsasjukvard/kunskapsstodvardochbehandling/primarvard naravard.6250.html2021.
- [50] Rahja M, Laver K. What does the Australian public know about occupational therapy for older people? A population survey. Aust Occup Ther J. 2019;66: 511-518.

- Dahlin-Ivanoff S, Gosman-Hedström G, Edberg A-[51] K, et al. Elderly persons in the risk zone. Design of a multidimensional, health-promoting, randomised three-armed controlled trial for "prefrail" people of 80+ years living at home. BMC Geriatr. 2010;10: 27.
- [52] Seifert A, Cotten SR, Xie B. A double burden of exclusion? Digital and social exclusion of older adults in times of COVID-19. J Gerontol B Psychol Sci Soc Sci. 2021;76:e99-e103.
- Pilotto A, Boi R, Petermans J. Technology in geriat-[53] rics. Age Ageing. 2018;47:771-774.
- [54] Keränen NS, Kangas M, Immonen M, et al. Use of information and communication technologies among older people with and without frailty: a population-based survey. J Med Internet Res. 2017; 19:e29.
- [55] Lee DR, Lo JC, Ramalingam N, et al. Understanding the uptake of digital technologies for health-related purposes in frail older adults. J Am Geriatr Soc. 2021;69:269-272.
- [56] Said CM, Batchelor F, Duque G. Physical activity and exercise for older people during and after the coronavirus disease 2019 pandemic: a path to recovery. J Am Med Dir Assoc. 2020;21:977-979.