

ORIGINAL REPORT

ACTIVITY AND PARTICIPATION IN HOME REHABILITATION: OLDER PEOPLE'S AND FAMILY MEMBERS' PERSPECTIVES

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Objective: To explore the experiences of older people and their supporting family members in relation to home rehabilitation, with a focus on activity and participation.

Methods: Qualitative interviews were carried out with 6 older people and 6 family members at 1 and 6 months after the older person's discharge to their home. Qualitative content analysis of the data was carried out. The International Classification of Functioning, Disability and Health provides a guiding framework for rehabilitation.

Results: Informants' experiences of home rehabilitation contributed to the formation of 6 categories: (i) living with a frail body; (ii) striving for well-being in daily life; (iii) being close at hand; (iv) feeling dependent in daily life; (v) struggling to carry on; and (vi) striving to be at home.

Conclusion: Older people's goals were to return to daily routines and to perform meaningful activities without feeling dependent on other people. Family members' participation was crucial. Psychosocial support and autonomy were essential for facilitating activity and participation. Healthcare professionals should consider each individual's unique experiences along with the significance of being at home.

Key words: rehabilitation; older people; family member; interviews; qualitative research.

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INTRODUCTION

Growing older is a process involving both gains and losses (1) as well as an increasing risk for illness (2, 3). A guiding concept in care is to encourage older people to remain in their homes for as long as possible (4). There is also a current trend for the family to take increasing responsibility in caring for older people in European countries (5, 6). The increase in the older population within society brings with it a number of challenges for health and social care, meaning in turn that more attention must be paid to rehabilitation at home for older people. The need to provide appropriate rehabilitation services according to the individual's wishes, an increasing awareness of the need to

use healthcare resources efficiently, and the desire to reduce the length of stay in acute hospital beds are factors that contribute to the use of alternative settings for rehabilitation, including the individual's own home (7). Activity and participation are central components of an individual's rehabilitation towards independence (8), which is rarely described in the context of older people receiving home rehabilitation. In rehabilitation, it is furthermore essential to identify aspects of activity and participation that have an impact on an individual's functioning (9).

Studies have indicated that therapy-based rehabilitation services for patients living at home after a stroke have a beneficial effect on the individual's ability to perform activities of daily living (10), and that multidisciplinary rehabilitation may assist older people in recovering after a hip fracture (11). However, more research is needed to further elucidate this area. Other studies have shown that family members' participation in home rehabilitation is considerable, e.g. assisting in personal care and exercises, ultimately having an impact on the outcome of the rehabilitation (12). Clinical outcomes for these informal caregivers involved in older people's rehabilitation has been reported as bringing a potential risk of poor mental health (13) experienced as a strain (14) and to have limited impact on relatives' health-related quality of life (15). Factors important to older people's life satisfaction both during and after rehabilitation include the ability to be active, be independent, and have strategies to adapt to new circumstances after the illness (16) and acquire a sense of confidence in everyday life (17).

It is a challenge for society to provide services to meet older people's needs in changing healthcare settings (18). Aspects of activity and participation that can impact older peoples' rehabilitation and family members' involvement are highly relevant. The International Classification of Functioning, Disability and Health (ICF) provides a guiding framework for rehabilitation and can facilitate communication among professionals (8, 19). Based on an integrative biopsychosocial model of disability, the ICF consists of two parts, covering: (i) functioning and disability, and (ii) contextual factors. Functioning and disability comprise 3 components: body functions and structures, activities, and participation, whereas contextual factors comprise environmental and personal factors. According to the ICF, activity is the execution of a task or an action by an individual, and participation is involvement in a life situation (8).

In the ICF, activity and participation are viewed in relation to health-related conditions (8). In this study the ICF concepts are used in practice since they represent a common language for functioning, disability and health. For healthcare professionals working in home rehabilitation, identifying aspects of activity and participation has important implications for meeting older people's rehabilitation needs. In addition, activity and participation are considered important aspects of rehabilitation. The services available may vary according to different countries' public healthcare systems and geographical areas. However, knowledge of the significance of home rehabilitation from the perspective of older people and family members specifically focusing on activity and participation is limited and needs to be further explored in different healthcare contexts. More knowledge about these matters will increase the possibility of designing rehabilitation services that enhance the quality of home rehabilitation for older people and also take into consideration the views of family members. Therefore, this study aims to explore older people's and their supporting family members' experiences of home rehabilitation with a focus on activity and participation.

METHODS

This study used a descriptive qualitative approach with recurrent interviews. Interviews help us to gain insight into people's own experiences (20). Data was collected approximately 1 month after the older persons' discharge from hospital and again at 6 months. One of the strengths of using interviews is that the interviewed person is given the opportunity to narrate in his/her own words. One essential assumption adhered to in an interview approach is that the interviewer and the informants are interrelated and interacting with each other. In order to obtain good qualitative data it is important that the researcher has the skills to build trust in the interview situation. Nonetheless, informants may still mention what they think the researcher wants to hear. Also, it is essential that the researcher reflect upon his/her prior understanding of the issue under study and how it may influence the research process. Further ethical consideration is crucial when interviewing because researchers become involved in the informants' personal lives (20). In this study the first author, who performed the interviews, has a profession as a district nurse with clinical and research experience in the field of geriatric rehabilitation and home care, and the co-authors are experienced healthcare professionals and researchers with theoretical familiarity in the area.

Study setting

This study was carried out within a municipality in northern Sweden, including a small city and the surrounding countryside. At the time of the study, healthcare services in the municipality, including rehabilitation for older people at home, were provided by multidisciplinary teams. Each team included professionals such as a physiotherapist, occupational therapist, district nurse, nurse assistant, home helper, home-help officer responsible for needs assessment, and a home-help officer in charge of home help. Medical services were provided by doctors in primary care and at the hospital.

Informants

The informants ($n=12$) comprised a consecutive sample of 6 older people, 4 men and 2 women aged between 66 and 92 years (mean 82), along with 6 family members, 4 spouses and 2 daughters aged between 52 and 84 years (mean 70). Four of the older people were married and living with their spouses, while two were widowed and living alone. Each of those two older people living alone had the family member (i.e. daughter) living in the neighbourhood.

All informants lived in their own homes, in houses or apartments. The inclusion criteria for older people were: being aged 65 years or older, having been treated at a clinic for illness or injury, having an estimated time for rehabilitation at home of more than 4 weeks, and being able to speak Swedish. Older people who showed signs of impaired cognition or were in need of palliative care were excluded. The first author informed the staff in the discharge-planning team at the hospital about the study. During discharge planning, the staff recruited and informed the older people and the family members and handed them a letter about the study. The older people were asked to name and give permission to contact one family member assumed to be involved in rehabilitation at home. The first author then contacted informants by telephone to give more information on the nature of the study and to arrange an interview time. Of the 25 older people eligible, 10 named no family member and 9 declined to participate because they felt too frail to manage the interview. The informants gave their written informed consent, and were guaranteed confidentiality. The study was approved by the ethics committee of the Medical Faculty of Umeå University [doi: 05-040M], Umeå, Sweden.

Data collection

Data was collected via recurrent interviews (20) performed by the first author in the informants' homes. A total of 15 interviews was conducted. Interviews were performed jointly ($n=9$), i.e. the older person and the family member together, or individually ($n=6$) according to the informants' wishes. Joint and individual interviews supplement each other (21). The intention of the interviewer was to create an atmosphere that encouraged the informants to speak freely and to narrate in their own words. The interviewer sought to achieve this aim by using a conversational style, silent listening, and probing questions during the interviews.

The interviews began with an open question focusing on the informants' experiences of home rehabilitation. The content of the interviews covered the informants' experiences of activity and participation that were considered of importance in home rehabilitation (cf. 8). The interview opened with the request, "Please tell me your experiences with home rehabilitation." Probing questions were asked, such as, "Please tell me more," "What happened next?" and "How did you feel?" The interviews lasted between 25 and 50 min and concluded with the question, "Is there anything you would like to add?" All interviews were audio-taped and transcribed verbatim, except in one case where notes were taken because the informant declined to be audio-taped. Data was collected between September 2005 and January 2007.

Data analysis

Qualitative content analysis was performed on the interview text (20). First, all interviews were read several times in order to acquire the sense of the message. Secondly, the text was divided into meaning units, consisting of a sentence, several sentences, a paragraph, or several paragraphs with similar meanings. Thirdly, the meaning units were condensed, which refers to the process of shortening while still preserving the core, and then labelled with codes. Fourthly, the codes were compared in order to find similarities and differences and then sorted as being activity-related or participation-related. Finally, the codes were abstracted and grouped together into 6 categories.

To ensure credibility, as one aspect of trustworthiness (22), the process of analysis involved back-and-forth movements between the whole text, meaning units, codes, and categories. The interpretation of the text was carried out by the first author and confirmed by the co-authors. The authors discussed the analysis process and minor disagreements in a critical dialogue until consensus was achieved.

RESULTS

The analysis formed the following categories related to activity: Living with a frail body; Striving for well-being in daily

life, and; Being close at hand; and the following categories related to participation: Feeling dependent in daily life; Struggling to carry on; and Striving to be at home. The categories are described below and illustrated by quotes from the transcripts. A number within brackets after a quotation represents each informant. An overview of the results is presented in Table I.

Living with a frail body

The diagnoses necessitating rehabilitation included contusion of hip, hip replacement, cerebral vascular disease, and leg muscle injury. In addition, the older people self-reported one to several diseases that caused various functional limitations. Some of the older people described themselves as very frail at the time of homecoming. Activities were limited by pain, and without drugs daily life would have been unbearable. Pain also caused sleeplessness and fatigue; as a result the older people sometimes lost courage and found it difficult to summon the energy to perform activities in daily life.

“It’s thanks to the painkillers, otherwise I wouldn’t be anything and so at night then, I’m awake a lot, it’s pain” (Older person 1).

Striving for well-being in daily life

Despite facing bodily obstacles to recovery, the older people set goals for both the immediate future and the longer term. The goals were a balance between what they wished for and what they saw as being realistic to manage. After returning home, it was difficult to perform their previous physical activities, and an overall goal was to regain the physical strength to lead as normal a life as possible. The older people found it essential to have help for a wide range of activities such as personal care and to move outside the home. Fear of falling was experienced as a hindrance to activity. Having another person close at hand inspired feelings of security.

“Basically, she [the wife] has just had to deal with me all the time, in the beginning I was nothing short of a baby” (Older person 3).

In the beginning, the older people had expectations of quick recovery, and were willing to undergo intensive training; however, they later realized that recovery takes time. The capacity for recovery seems to be tied to personality; this was described as having a strong will to reach the expected outcome:

“It’s simply based on a ‘damn it, I will get up!’ in the spring, both wheelchair and canes will be gone” (Older person 2).

Intertwined in the process of managing activities in daily life, the older peoples’ focus was on bodily improvement to regain

physical functions. Assistive devices facilitated activities and contributed to feelings of independence, but their use was not always a matter of course. The situation was described as being one of a struggle to be reconciled to the use of a walker or wheelchair that enabled them to move around.

“I’ve kind of become tied to this walking frame. It sort of doesn’t belong to me, but I need it for training and for walking here in the flat” (Older person 4).

Reciprocal interactions between the older person and the therapist, along with clear self-training instructions from the therapist, contributed to the older people’s self-confidence and strengthened their ability to be persistent in training over time. At the same time, others were dissatisfied when they experienced insufficient information on how to exercise or use their assistive devices and when they felt that too much responsibility was being placed on them to train by themselves. They reflected on whether training at home really was effective, feeling that more continuous supervision from therapists was needed.

Being close at hand

The activities performed by family members in connection with older people’s rehabilitation were described in terms of helping, observing, and being supportive and encouraging. The family members had to be flexible and adapt to changed circumstances over time. It was gratifying for them when they observed improved health conditions in their loved one. The family members perceived their engagement as a natural part of the relationship, but also as extra work and as being quite demanding. It was a challenge to discover and act on an appropriate level to promote independence and autonomy for the older people.

“I can’t lift him, but I can lift his arm and rub some cream on him, make sure he takes his medicines. But I have told him that now he should remember by himself to take it” (Family member 7).

Feeling dependent in daily life

The impaired functional capability, which confined the older people to the home and restricted their participation in society, was disclosed as a physiological strain. Their aversion to being dependent was expressed, though they also recognized their need for help. Also adding to physiological strain was fear of being taken ill again and doubt about recovery. Some older people in these situations experienced limited or absent psychological support, while others’ descriptions were that conversations with professionals in the team made their physiological strain easier to live with.

“Sometimes you just want to cry, you feel so helpless, can’t go out by yourself or anything. I often think the way people act towards you is more important than any of the medicines” (Older person 5).

The older people felt gratitude for their family members’ engagement and participation in the rehabilitation. They described feelings of being a burden and of a sense of guilt when they had to rely on family members to help them with personal care and when the responsibility for the household lay to a great extent on family members. They experienced a

Table I. Overview of the categories describing older people’s and family members’ experiences of home rehabilitation

Older people	Family members	Older people and family members
Living with a frail body	Being close at hand	Striving to be at home
Striving for well-being in daily life	Struggling to carry on	
Feeling dependent in daily life		

gnawing anxiety over how their family members would manage to get through the amount of work they had to do, and felt that this put the family member at risk for ill health:

“I have kind children. They did start by coming here every day. But I told them that they should not feel obligated to do so” (Older person 1).

Struggling to carry on

Family members' participation in the rehabilitation was shown as a struggle with a variety of feelings and practical things to carry on. Their mood and capacity to be supportive were influenced by hope for the older person's recovery as well as worry for them and concern about their own health. Lack of information on how to use technical aids made them appear as being incapable of helping, and also created risky situations. Being supportive and taking increasing responsibility for work at home was ultimately described as succumbing under the load. They had to lower their own demands regarding practical tasks at home, and allow themselves to accept help to let them manage to be supportive all the way. Opportunities for recreational activities were described as scarce, because of both lack of time and a hesitation to leave the older person in someone else's care.

“As long as you have the energy and as long as it's possible, I mean, he's not getting worse” (Family member 8).

Striving to be at home

A striving to be at home was expressed both by the older people and the family members; continued rehabilitation at home was seen as the best place for recovery. Being at home was defined as having autonomy in everyday events. The home contributed to well-being. There were different descriptions about participation in the planning of rehabilitation. Some meant that they had had the opportunity to be listened to, while others were not sure with whom they should talk to in the team. One prerequisite for the informants' participation in the rehabilitation was a mutual relationship between them and the team. The older people and the family members described factors such as being treated with respect, being listened to, and being supported by skilled staff as contributing to satisfaction with home rehabilitation.

At the same time, the older people and the family members disclosed strain and anxiety when the physical and psychological boundaries of the home were erased and it became a working place for the team, with people frequently coming in and out. There were feelings of limited autonomy and disregarded integrity, which were expressed both by the older people and family members. Having continuity in service, especially from the home help, was described as an area for improvement.

“There are so many people coming here, and there are always new ones. You feel like you have lost your home, even though I get out of the way when they come” (Family member 12).

DISCUSSION

The findings of this qualitative study demonstrate 6 categories essential for older people and family members' perspectives on

activity and participation while receiving home rehabilitation. All the categories suggest necessary ingredients to take into account to achieve successful home rehabilitation. The findings revealed that the older people experienced rehabilitation as an on-going process, taking bodily capability into consideration and a striving for well-being. Family support was perceived to be necessary for the older peoples' rehabilitation. The findings indicated that informants had to deal with feelings of dependency and non-participation during rehabilitation.

Although the older people expressed an awareness of being frail, frailty could become something positive, in the sense that it is a condition that helps them rethink intermediate goals to reach previous physical conditions or knowing that this is the possible level to reach and no more, and adapt everyday life to this circumstance. This inner strength can be seen as resilience and is described by Wagnild & Young (23) as a capacity to manage difficulties in life that can be related to health. Therefore, we ought not to undervalue either the physical or the psychological capabilities of older people during rehabilitation.

Our findings show that obvious hindrances to activities were older people's problems with pain, sleep deprivation, and fatigue. These are common and inadequately addressed among older people (24–26). Our study indicates that older people's goal-setting aimed at identifying bodily capacity and achieving meaningful activities in everyday life. In this on-going process, help and support from family members and professionals were accepted as a matter of course. Young (27) argues that an essential part in the rehabilitation process for older people is to help them realize their potential and to find role fulfilment.

The present study also revealed that family members had a significant role for the older people's rehabilitation. Others have also found this to be the case (28). Although findings in our study illuminate caregiver strain, findings also show that family members identified positive aspects such as hope for the future and contributing to the older person's ability to be at home. As similarly reported out in other studies (29, 30), psychological support was limited and psychological strain was evident among informants in our study. Despite extensive literature on the need for support for family caregivers (e.g. 31, 32) this is not a reality in this case in our study and indicates an area for improvement. Even if the family members in our study represented two perspectives, i.e. spouses living with the older person and daughters not living with the older person, the findings in this small sample showed that family members reported similar experiences.

Our findings illustrate that conditions for informant's participation in rehabilitation were shown as obtaining and having knowledge and being informed according to their needs. Findings also have made evident the importance of autonomy, which involved feelings of being treated as a unique person, being confirmed, and being desirous of individualized rehabilitation. According to Mangset et al. (33), “to be treated with dignity and respect” was identified as a core factor contributing to older patients' satisfaction with rehabilitation services. Articulation of these aspects in relation to our study raises the meaning of seeing beyond immediate needs and having authenticity in the encounter.

Furthermore, the present findings clarified that being in the home environment facilitated activities and participation. Similarly, Åberg (16) found that a common ideal for older people's rehabilitation was continuity in activity in a familiar life space. Other work within the literature highlights the importance for professionals' awareness of what constitutes a therapeutic landscape in terms of healing and recovery from illness, as well as maintaining health and well-being for individuals in the home environment (i.e. therapeutic landscapes include the links between place and health (34, 35).

Our findings show that, in addition to being at home, there was a striving for feeling at home, as the home became a workplace for the professionals. The meaning of home was eroded when the informants' senses of privacy, integrity and security were limited. The findings provide evidence for essential ethical consideration by professionals and managers when the home becomes a setting for rehabilitation and care. As Liaschenko (36) stated, professionals are faced with the challenge of maintaining ethical and moral attitudes i.e. autonomy and protecting and enhancing participation in order to avoid depriving individuals of power in their own homes.

Several issues need to be addressed when interpreting the results of this study. The sample size and number of interviews were based on the ambition to obtain sufficient data for the analysis (37). The interviews were rich in content and therefore could be considered adequate in number to achieve variation in the analysis. Recurrent interviews helped the informants to reflect on their situations, needs, and unmet needs, and therefore facilitated them in expressing thoughts about their experiences. At the start of the interview, during introduction, the interviewer (first author) advised informants about her professional background and that she was not involved in healthcare in the municipality. This potentially allowed informants to express their experiences more freely. Interview questions were kept as open as possible to allow freedom of interpretation to permit informants to tell their stories. During the interviews, the informants shared experiences, thoughts, feelings and, concerns with the first author, which shows that they felt comfortable in the interview situation.

Furthermore, it is important from an ethical point of view, as it takes into consideration the older people's and family members' desires to be interviewed jointly or individually.

In addition, it is necessary to consider the impact of performing joint and individual interviews. Joint interviewing (38) is positive in the sense that it provides participants with the opportunity to negotiate and jointly construct responses regarding shared experiences. Limitations of joint interviews could be that one partner dominates the dialogue. In this study, the dyads spoke freely about their experiences and complemented each other in their stories. One strength was that the first author was familiar with the issue being studied but this also gave rise to a minor risk that the author's extraction of data may have been advised by preconceived ideas. The researchers reflected critically and discussed their prior understanding throughout the research process in order to achieve a result that was based in the data. In this qualitative study, the ICF components pro-

vided a scientific basis for developing increased understanding of individuals' experiences of rehabilitation performed in the home environment. The fact that the study was based on participants and a setting in one region specific to the Swedish context may be seen as limiting transferability, since particular socio-political contexts shape practice. Although the results cannot be generalized, we believe that they reveal knowledge applicable to similar contexts.

For clinical practice in community care, it is central to consider the complexities of home rehabilitation as parts of activity and participation and also as integral components in health and social care, along with the significance of "home", which can help healthcare professionals give more focused support. This will ensure that influencing aspects are addressed so that older people and family members receive quality rehabilitation services. Ethical issues encountered with individuals in their homes ought to be discussed among professionals in their daily work in order to highlight aspects of autonomy in rehabilitation. To advance our knowledge, further studies should focus on the development of assessment instruments for identification and measurement of participation and psychosocial aspects in home rehabilitation. In addition, studies should focus on interventions using the ICF for planning and documentation of rehabilitation and care among multiprofessional teams working in the municipality.

In conclusion, the study identified aspects of activity and participation in a broad sense among family members and older people receiving home rehabilitation. The findings emphasized that person-centred rehabilitation is required to support older people and family members during the process. Overall, applying for home rehabilitation was revealed by the informants to be perceived as a sum of its intertwined parts, and was illuminated as relying to a great extent on the older people's actions as well as on family members' involvement and healthcare professionals' attitudes. It highlights the informants' strengths, but also their feelings of dependency in everyday activities in their striving to live as normally as possible. Psychosocial support and alleviation of pain were identified as areas with room for improvement. Taken together, these findings highlight that assessment and rehabilitation planning must take into account several aspects of older people's lives, as well as the views of family members.

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