

Manuscript Title: Health professionals' perspectives of next of kin in the context of reablement

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## **Abstract**

**Aim:** To describe health professionals' perspectives of next of kin in the context of reablement.

**Method:** A total of 49 health professionals from different organizational levels participated. Their ages, genders, experiences, and professions varied. A total of 10 focus group discussions were held in two municipalities. The data analysis was conducted using a constructivist grounded theory approach.

**Result:** The core category was identified as *negotiating between themselves*. Two categories captured the different dimensions of the core category: *facing a dilemma with next of kin in reablement* and *ambiguous motives for collaborating with next of kin*.

## **Conclusion:**

In collaboration with next of kin, it is important for health professionals to be aware of and manage the possible differences in expectations and opinions concerning reablement. Health professionals need to acknowledge that next of kin can be a source of support for older adults. They also need to take into consideration that next of kin may need support, information, and education associated with their roles as next of kin to older adults.

**Keywords:** primary healthcare services, rehabilitation, home-based service, family, caregiver

## Introduction

Rehabilitation at home is currently part of both national and international health policy for an ageing population [1,2]. It offers opportunities to facilitate activities and participation in one's home environment [3] and may reduce stress for next of kin and other family members [4]. Next of kin are often the main support for older adults receiving rehabilitation at home [5], and their contribution is important to the sustainability of the welfare state [6]. As a result, many Western countries are now attempting to improve collaboration between health professionals and next of kin by encouraging the latter to assist older adults so that they can stay at home as long as possible [7]. Thus, next of kin are considered an important resource in health care. Bøckmann and Kjellekvold [8] and the WHO [2] recommend that collaboration with next of kin should be included in all health services. Few studies have explored the health professionals' perspectives of next of kin in reablement and their experiences and thoughts about collaboration. This article is based on a study of health professionals working with reablement in two Norwegian municipalities. The aim of the study was to describe health professionals' perspectives of next of kin in the context of reablement.

In line with the challenge mentioned above, reablement (also known as restorative care in Australia and the USA [1]) is an approach that aims to assist older adults, irrespective of diagnosis, to continue with their desired activities – as well as the activities of daily living – and to increase their independence [9–11]. Older adults who receive reablement have a functional decline or a risk of functional decline, often following an accident or period of illness [12]. However, there are no standard definitions or descriptions of the reablement intervention [13,14]. Legg et al. [13,p.242] define reablement as “*a short and intensive intervention*”. In addition, Glendinning and Newbrunner [10,p.33] describe the aim as “*to help people do things for themselves, rather than having things done for them*”. Reablement is often a part of public home care services, and it provides assistance in such a way that

older adults develop both confidence and practical skills to conduct everyday activities themselves. Moreover, reablement aims at enabling participation in society [15–17].

There is little knowledge about how health professionals view collaboration with next of kin [18] and about the role of next of kin during reablement. According to Tønnessen and Kassah [19], there is insufficient clarity regarding the limits for the involvement of next of kin in different situations and how the distribution of responsibility should be assigned between next of kin and health professionals in health care in general. This may be even more challenging in the context of reablement, since it aims to enable participation rather than simply providing traditional help and care. Hjelle et al. [20] explored next of kin perspectives in reablement and found that next of kin were not invited to work with health professionals to improve and facilitate the reablement process of the older adults. Furthermore, next of kin in their study wanted a system, routine, culture, and attitude change that would enable them to share information and knowledge with health professionals. According to Moe and Brinchmann [21], a dialogue between the older adults, next of kin and health professionals is important in the reablement process.

In a study among older adults receiving home care, the findings indicate that health professionals were not aware of how next of kin participated in the daily lives of their older relatives [22]. However, Vik and Eide [23] found that health professionals regarded the family both as facilitators for the older adult's participation, since family expected to engage with and participate together with the older adult, and as a barrier for participation, when they asked for more help than the older adults needed. This aligns with the study by Tamm [5] of the views held by occupational therapists regarding next of kin and their roles in rehabilitation at home. Next of kin were found to be regarded as either a source of help and a communication link or, in some cases, a hindrance in the rehabilitation process if they were helping too much, made unreasonable demands, or did not support or have faith in the

rehabilitation plan. To summarize, there is a need to further explore how collaboration between health professionals and next of kin in reablement is seen from the health professionals' perspectives. To promote government policy provisions for this kind of collaboration, it is necessary to generate knowledge about how the professionals perceive next of kin in the context of reablement. The research question is the following: How do health professionals perceive their collaboration with next of kin in the context of reablement?

### **Material and methods**

A constructivist grounded theory (CGT) approach inspired by Charmaz [24] was chosen. Charmaz's [24] approach is systematic, even if the guidelines can be flexible in the data collection and analysis. In order to capture health professionals' perceptions of next of kin, focus group discussions were chosen. Such discussions offer participants opportunities and may inspire them to discuss and compare their experiences [25]; they are suitable for exploring the interpretation, interactions, and norms of social groups [26]; and they can help participants express both positive and negative opinions more easily [27].

### ***Study context***

In Norway, each municipality has the responsibility to organize the public health services in such a way that they meet the needs of the people who live there [16]. This study was carried out in two Norwegian municipalities: one a town of 190,000 inhabitants and the other a rural municipality of 7500 inhabitants. Both municipalities had initiated the reablement intervention within the previous four years. In the town, reablement was organized as an integral part of the home care services. The inclusion criteria for reablement was older adults who already received some home care services. The home care services in the town were also responsible for screening eligible participants in reablement. A physiotherapist and an

occupational therapist were responsible for the assessment and evaluating. In the rural municipality, the reablement was organized by a separate team, and they were more flexible in the inclusion criteria. Health professionals in home care services, the local hospitals and rehabilitation centres and older adults themselves and their next of kin could refer to reablement. Assessment for inclusion was done in collaboration with a registered nurse from home care services, along with a physiotherapist and an occupational therapist from the reablement team.

Regardless of the organization, services in both municipalities were based on a multidisciplinary team approach where therapists, registered nurses, and other employees of the home care service collaborated. The professionals collaborated and assisted the older adult (65+ years) with an individual physical training programme and practising everyday activities important to helping the older adult towards their goals. The reablement intervention often lasted for 4–6 weeks, and during this time, the older adult received reablement from either a therapist or health professional from the home care services, often called a home trainer, up to five times a week.

### ***Participants***

Initially, a purposeful sampling strategy was used [24]. Health professionals currently working within the field of reablement were invited to participate in focus group discussions. First, professionals working in home care were recruited: Participants in these first focus groups consisted of registered nurses, health workers, student nurses, social educators, and occupational therapists (OTs; Groups A–E). Following these focus group discussions, we saw a need to continue with theoretical sampling as suggested by Charmaz [24]. Then, two groups with professionals working in multidisciplinary teams (OTs, OTs' assistants, registered nurse, social educator and physiotherapists) were included (Groups G–H) in these discussions.

Based on the preliminary analysis, it became apparent that there was a need to include information from the project group and managers (Groups I–J), because we were interested in their reflections and intentions about the collaboration with next of kin in reablement. Finally, one more group of health professionals (Group F) was recruited. The number of participants was 49: there were 26 recruited in the town and 23 in the rural municipality (table 1). To obtain variety in meanings and experience, the participants varied according to gender, age, range of work experience, and educational background.

### ***Data collection***

Data were collected between February 2015 and December 2016 from 10 focus groups, which all met once. According to Krueger and Casey [25], the recommended number of participants in focus groups is between 5 and 8. Although that was our plan, some of the groups changed due to illness and ended up consisting of 3 to 9 participants. As recommended by Krueger and Casey [25], we used a moderating team when we conducted the focus group discussions. This included an assistant who helped with practical matters, took notes, posed follow-up questions, and produced a summary of the discussion at the end of the session. A masters-level student led 5 of the focus group discussions (Groups A–E) together with the second author (KV); 4 (Groups G–J) were led by KV and one assistant; one (Group F) was led by the first author (FAJ) and KV. A semi-structured focus group guide starting with open questions about reablement gave the participants the opportunity to discuss the topics openly, while at the same time providing a chance for them to offer spontaneous comments. Furthermore, questions concentrated on specific experiences of collaboration with next of kin and next of kin's involvement were posed. Examples of open-ended questions are the following: How did the start of reablement go? How would you describe reablement? Examples of specific questions are the following: What is your approach to next of kin in

reablement? How do you collaborate with next of kin? How do you relate to next of kin in reablement compared with other services you provide? The moderator encouraged the participants to discuss their different experiences and views about next of kin. The focus groups' discussions were recorded and transcribed verbatim. The study was approved by the Norwegian Social Science Data Services (project no. 40458). All participants received oral and written information about the study and gave their written consent before the focus group discussions started. We used an iterative process in the data generation and analysis as described by Charmaz [24]. This gave us the opportunity to use information from early focus group discussions to generate discussions in later focus groups that were more focused. After the 10th focus group (Group F), we decided to end the data collection because we noticed no new information came up in the discussion.

### ***Analysis***

The analysis of the focus group discussions with health professionals is inspired by Charmaz's [24] description of constructivist grounded theory, where a constant comparative method is central and by which researchers "*aim for abstract understanding of studied life and view their analyses as located in time, place and the situation of inquiry*" [24,p.342]. Both authors began the analysis by reading through all the transcribed interviews and listening to the tape recordings of the focus group discussions.

The analysis consisted of initial and focused coding, memo writing, and comparative comparison, as described by Charmaz [24]. The first author performed the initial coding, where fragments of data, words, lines, segments, and events were studied according to their content. To remain close to the data, the initial codes were recorded in everyday language and using words as close as possible to those used by the informants themselves; e.g., "It is up to the older adults whether they want the family involved"; "No contact with the family"; "Doesn't see much of the family"; "Different family relationships"; "Sharing responsibility"; "The



families are actively involved”; and “Unbiased information”. In the next stage, the codes that belonged together were clustered into focused coding; i.e., the initial four codes were grouped into “Not always a need to involve the family”, while the remaining three were converted to “Understanding that the family is involved and assisting”. All the focused codes were studied in relation to each other and constantly compared, and a pattern was searched for. The relationship between the three preliminary categories “What the health professionals perceive as important for the older adults”, “How the health professionals describe the purpose of collaboration with the families”, and “The dilemmas arising from different expectations” were gradually transformed into conceptual categories at a higher level of abstraction. Both authors participated in the analytical process, and codes and categories were discussed. Memo writing was done, as thoughts, reflections, and questions concerning the data were noted and included in the analysis. The analytical process led to the core category *negotiating with themselves*. This is, in turn, related to two broad conceptual categories describing *facing a dilemma with next of kin in reablement* and *ambiguous motives for collaboration with next of kin*. All the categories, regardless of their level of abstraction, are related to the main category, as described in table 2.

Insert table 1. Insert table 2.

## **Results**

### ***Negotiating between themselves***

The core category *negotiating between themselves* illuminates the discussion between health professionals and the discrepancy in motives for when, how, and if collaboration with next of kin could take place. The health professionals frequently referred to the next of kin as the children of the older adults, and “daughter” was frequently used in the focus groups. Negotiating between themselves reflects how health professionals need to negotiate and

manage the different expectations and opinions; e.g., their professional recommendations, understanding the situations of next of kin, and when it is appropriate to collaborate with next of kin. There were no common guidelines for how preferred collaboration with next of kin should be. Nevertheless, there was experience that collaboration with next of kin could be beneficial for the older adult. However, as one of the occupational therapists stated: *“I don’t think we have been good enough at involving next of kin”* (Group F). Further, the different dimensions of *negotiating between themselves* will be presented through the categories *facing a dilemma with next of kin in reablement* and *ambiguous motives for collaborating with next of kin*.

#### *Facing a dilemma with next of kin in reablement*

This category describes how health professionals experienced the dilemma of collaborating with next of kin in reablement. On the one hand, this had to do with how the health professionals had an understanding of the next of kin’s situation. For example, they sympathized with next of kin and understood that they were afraid and worried about their older relatives and their reasons for requesting health services from the municipality. On the other hand, the health professionals experienced how they assessed the need for assistance differently from the next of kin. This was seen particularly when the health professionals perceived the older adult’s everyday performance as better than their next of kin did. One registered nurse from the rural home care group said that in such cases: *“It was difficult to disagree with next of kin”* (Group E). Several of the participants from the focus group discussions pointed out that the consequences of these situations could be exhausting and unpleasant for them. They had to spend extra time persuading and negotiating with next of kin concerning whether reablement was the right type of assistance for their older adult.

*Understanding the situation of next of kin.* The health professionals understood that next of kin needed to be certain that their older adult was properly looked after and received the assistance to which he or she was entitled from the municipality's health service. They sympathized especially with next of kin whom they felt had legitimate reasons for not being available to assist their older adult on a regular basis; e.g., those who lived in other towns far away. One physical therapist explained: *"I understand that they are anxious when you are far away from your mother [who is] 80 to 90 years of age"* (Group F). Furthermore, health professionals received different requests from next of kin; for instance, that the professionals should pop in to see their mother or father in order to assure the next of kin that everything was alright. A registered nurse pointed out: *"It is a safety for relatives that we go by either daily or once in a while"* (Group B).

Another interesting finding concerned the requests that health professionals received from next of kin. Often, such requests were related to traditional home care tasks. Examples were requests for help with personal care, medicines, or practical assistance at home. One manager said: *"Supply obviously creates demand. It depends what people know. Nobody requests reablement, because they have no idea it exists. Therefore, they often request services like practical assistance and such like. Then they learn that resources are limited, and this can lead to the creation of a need greater than it is, just to make sure some help is available"* (Group J). This quote reflects the health professionals' awareness that next of kin made their requests based on services with which they were already familiar. At the same time, they understood that next of kin were trying to make clear why the older adult needed practical assistance. Various aspects of the requests from next of kin were discussed. One aspect was that the health professionals at times felt pressure to provide reablement only to reassure next of kin. This relates to the dilemmas experienced by health professionals when they provided interventions not in line with their professional judgements but based on the

needs of next of kin. However, in such cases, health professionals chose to emphasize the next of kin's situation. For example, it could be difficult to reject a request from next of kin about assisting their older adult if the older adult had recently fallen at home. One registered nurse said: *"Next of kin contact us if their parents have fallen. Then it becomes difficult for us to tell them their parents should not be assisted by us"* (Group E). One last finding relating to "understanding the situation of next of kin" was how they perceived that the next of kin was helping the older adult a lot in his or her everyday life and was getting exhausted. As a manager said: *"When you look a little closer, then it is actually next of kin that helps"* (Group D). Several of the participants agreed that next of kin did a lot for the relatives. *"Relatives are tired. For sure!"* said a health worker (Group C). The quotes illustrate the health professionals' dilemma regarding supporting next of kin and their professional judgement in reablement, which aims to support the older adult to become independent. However, the findings indicate that, even though health professionals understood that next of kin were tired, they did not provide specific support directed towards the next of kin's needs regarding how they could better manage their situation.

***Assessing the need for reablement differently.*** This subcategory covers how the health professionals experienced that next of kin, the older adults, and the professionals themselves could have different assessments about older adults' needs. For example, an occupational therapist said: *"A daughter may have different ideas from those of her mother or father. In such cases, it is the user who must decide who is their main next of kin. We have to take that into account"* (Group F). When there was disagreement between older adults and/or their next of kin, the health professionals mostly supported the former, because older adults receiving reablement were considered as autonomous, independent, and responsible for themselves and their everyday lives.

Furthermore, some of the assistance provided by next of kin was regarded as unnecessary from the professionals' reablement perspective. For example, the health professionals had observed that the older adults often managed perfectly well to carry out more everyday activities than expressed by their next of kin. One of the participants from the rural therapist team said: *"Next of kin are pretty good at underestimating their relatives"* (Group G). Health professionals perceived that the next of kin were limiting the older adults' opportunities to be active and participate in activities, such as going to the shops or using the stove or shower on their own. Some next of kin clearly stated activities that they felt the older adults should not do on their own because they (the next of kin) feared consequences such as falls or injuries. A third aspect was that health professionals could see that next of kin gave older adults too much practical and physical assistance. This kind of help was described as an "assistance trap" among the professionals. One occupational therapist said: *"There are probably many who provide informal help as a matter of course in everyday life, as families often do, without realizing that what they are actually doing is setting up an assistance trap. Maybe they post a letter because they are, in any case, going to walk past a letterbox, or they take the rubbish out. It is really okay to involve them to a greater extent, but often people simply do not stop and think. They mean well, but they fail to consider the consequences this may have in the longer term"* (Group F). This quote reflects the experience among health professionals that the contributions made by next of kin were not always in line with the aim of reablement, namely, the older adults' participation in everyday life and increased independence.

Consequently, the health professionals perceived that next of kin at times considered reablement to be a threat to the ordinary home care service older adults had received from the local authority. One occupational therapist talked about the daughter of an elderly woman who had participated in reablement: *"Yes, she was rather negative about the whole setup. She*

*was worried we would remove some of the services provided for her mother, and of course, some of this fear was then transmitted to the user”* (Group F). During the discussions, health professionals pointed out that removing certain services was not the aim but was considered a bonus.

#### *Ambiguous motives for collaborating with next of kin*

This category demonstrates how health professionals sometimes perceive there is “not always a need to include next of kin” and, at other times, perceive that “including next of kin is useful”. This ambiguity can be illustrated by the therapist who stated: *“Older people are, in a way, competent people who have consent. They can reflect on their own situation and take responsibility. So for the most part, it is, in a way, not relevant to contact next of kin.*

However, the same therapist reflected: *“It could, of course, be appropriate to include next of kin, daughter and son and everything like that ... We have had relatives by chance when they have been present”* (Group H). This statement captures the health professionals’ ambiguity when collaborating with next of kin.

***Not always a need to include next of kin.*** As previously noted, neither municipality had any systematic approach for when and how next of kin should be contacted or involved in reablement. However, health professionals perceived that there was not always a need to involve next of kin in reablement. In these situations, this was a conscious choice made by the health professional. For example, as the quote above illustrates, many of the older adults were independent and managed on their own in their everyday lives; consequently, the health professionals felt that it was the older adults’ responsibility to contact their next of kin.

Another experience related by the health professionals was that they saw that older adults had different kinds of relationships with their next of kin, and this affected how the professionals involved the next of kin. One auxiliary nurse said: *“We get pretty close to some families, and*

*we obviously observe both well-functioning and dysfunctional families”* (Group F). The findings indicate an uncertainty among health professionals, especially when they met dysfunctional families. Some health professionals felt it was not their job to interfere between an older adult and their relationship to their next of kin.

***Including next of kin is useful.*** This last subcategory comprised three reasons why including next of kin was useful for the health professionals in reablement. First, next of kin were providing important information and knowledge that, sometimes, the older adults themselves could not communicate clearly. One of the physiotherapists put it this way: *“Next of kin often come up with contributions that the end user (the older adult) may not be able to, or dare to, express”* (Group G). Additionally, the health professionals found that next of kin were sometimes able to provide a more nuanced picture of the actual everyday life of the older person. Second, health professionals experienced that next of kin could be useful collaboration partners in motivating the older adults to take part in their reablement, as well as to continue to motivate their next of kin after the end of the reablement period. As one occupational therapist said: *“Next of kin are really important when it comes to motivating them [older adults] to keep it up, to continue with the training. It is difficult for us to follow this up, as we are so rarely there, since those who have undergone reablement often have very little extra assistance. So it’s important that the next of kin who are there daily, or at least often, speak to them and can follow this up. For example, just by asking: ‘Have you walked up and down the stairs today?’ That sort of thing, just to help them keep it all up, because that is really necessary”* (Group F). However, this quote illustrates the health professionals’ experiences of how next of kin could provide strong support, since the health professionals had limited time capacity for follow-up when the reablement process had ended. In addition, the health professionals mentioned everyday activities that they themselves could not take part in; for example, going shopping or for a walk. Therefore, the

health professionals wished to involve the next of kin in these everyday activities with the older adults. This finding may indicate that health professionals to some extent have insufficient resources to follow up activities outside older adults' homes.

The third and last reason to include next of kin concerns informing them about what kind of intervention reablement implies. In this way, expectations can be clarified and written information may be provided. One of the occupational therapists described it this way: *"Next of kin can have both positive and negative influences, and that's exactly why it's so important to provide good information about what it is, how it works, and what they are taking part in"* (Group F). The health professionals found some next of kin had a negative attitude towards reablement. The informants quoted several comments made to them by next of kin, such as: *"My mother is over 90, and the time has come for her to receive help with everything; she is old and should not have to do anything herself now"* (Group A, health worker). Another occupational therapist quoted another daughter who said: *"No, my mum should not be doing exercise, she is far too old, over 90, and needs to take it easy now"* (Group G). Another recurring argument was: *"They have been paying tax for over 50 years, and now the time has come for them to sit back and receive help"* (Group J, manager). These statements are not unique. Several of the focus group discussions centred on stories of next of kin disagreeing with the reablement approach. Interestingly, some participants argued that the view that older adults are entitled to sit back and receive assistance was also found both within the health profession and in society generally. For that reason, it was considered useful to include next of kin right from the outset. Furthermore, many health professionals expressed it was most appropriate that the registered nurses or auxiliary nurses working in home care should contact the next of kin, since there was often a need for traditional home care when the reablement period was finished.



## **Discussion**

The research question for the study was the following: How do health professionals perceive their collaboration with next of kin in the context of reablement? The study identified the complexity of health professionals negotiating between themselves. Although next of kin were considered important partners in future health services [2,8,21], our study reveals the following paradox: Even if health professionals regard next of kin as important partners and useful to collaborate with in reablement, they are concurrently not always sure there is a need to collaborate with or include them. One possible interpretation could be that the health professionals emphasize reablement as a person-centred intervention. This view of reablement involves showing respect to older adults by ensuring that they have the knowledge and information they need to make their own decisions in everyday life. The significance of older adults feeling that they were being treated as unique persons was confirmed. According to a study carried out by Randström et al. [3], an individualized approach was important for older adults who participated in rehabilitation at home. Another possible explanation for why health professionals did not always see a need to collaborate with next of kin in reablement could be that the health professionals did not see the older adults as dependent on their next of kin. In such cases, the involvement of next of kin could be regarded as taking autonomy away from the older adults. In this respect, reablement may be influenced by Western culture, where there is a strong focus on the individual and independence is regarded as valuable. Reablement is often described as a person-centred intervention, where the aim is to improve or increase the older adult's independence [12,28]. This focus on the individual can be found across other health interventions and in different health disciplines or professions [29,30].

Given the aim of increased independence for older adults, the importance of the interaction between older adults and their next of kin is not given much emphasis in

reablement. Kirby [31] questions the perception of independence as something just positive, since placing just a positive value on independence favours mostly middle-aged adults and removes a sense of worth from fragile older adults, as they are dependent on society to a much greater degree. Kirby further points out that independence and mutual dependency need to be understood as necessary in order to function in everyday life. We are born dependent on our family carers, and we depend on our social environment to develop and feel safe [31]. In Bonder's [32] study of the family activities of fragile older adults, the findings show how the activities were characterized as an "exchange", where the older adults sometimes did things for the family, and at other times, the family did things for the older adults; sometimes they were simply happy to carry out activities together. Brashler [33] argues it is useful for health professionals to view the family as a legitimate unit of care and start to communicate a commitment to the entire family. Witsø et al. [22] point out the importance of health professionals being aware of the support older adults receive from their next of kin. Our study shows that, even if the health professionals were aware of the support and assistance given to the older adults by their next of kin in everyday life, they lacked routines for combining their work of promoting increased independence for the older adults with the inclusion of next of kin as partners in reablement. Our suggestion to health professionals is to acknowledge that older adults can be considered mutually dependent on their social surroundings regardless of their level of functioning. A family-centred perspective may enable health professionals to develop a better understanding of next of kin in reablement.

Our findings also indicate health professionals were somewhat reluctant to include next of kin given the variety of relationships they observed between the older adults and their next of kin. This can be understood with Bonder's [32] description of families as complex and, in many cases, all embracing. Moreover, health professionals in our study may have

been uncertain how to collaborate with next of kin who stated their family members needed to receive traditional home care instead of reablement.

Another reason why the health professionals experienced the negotiation between the expectations of older adults and their next of kin as fairly demanding could be understood in the light of the findings from Bøckmann and Kjellevold [8]. According to them, health professionals have to balance many values and considerations when making decisions about health assistance, particularly when the patient, the next of kin, and the health professionals themselves have differing assessments of the need and the desire for assistance. Health professionals need to have a proper understanding of the fundamental values and considerations that take priority to be better qualified to manage demanding next of kin. It might be a strength for health professionals to include a family-centred approach in reablement. A family-centred approach will allow health professionals to acknowledge and respect next of kin's needs without sacrificing older adults' interests or authority [33]. Previous studies of older adults with dementia and living at home have shown programmes and interventions with a family-centred approach, where the intervention is provided in the older adults' homes and next of kin are trained and receive individualized support, have proved to be effective for both older adults and their next of kin [34].

Similarly to Tamm's study [5], health professionals in our study expressed it was unclear how they could include next of kin as a collaborative partner when they opposed to or negative towards the intervention. Further, the health professionals in our study pointed out that next of kin often requested more assistance for the older adults than the older adults themselves wanted or than the health professionals had determined was necessary. Several other studies discuss next of kin being overprotective and, thereby, contributing to limiting older adults' opportunities for participation in everyday life [5,22,35]. In our study, the health professionals saw the next of kin as someone who underestimated the older adult's capacity.

Therefore, health professionals emphasized the need to clarify the different perceptions of what older adults could and needed to do to continue to participate in desired activities. According to Witsø et al. [22], it is necessary for the health professionals to establish a dialogue between the older adults and their next of kin to clear up discrepancies between them. However, not enough time was set aside for health professionals to collaborate with next of kin to the extent that they could see was required [22]. Time issues were also found to be a challenge for the health professionals in our study. They did not have enough time and scope to carry out and follow up the interventions they felt were necessary to improve older adults' independence and opportunities to participate in desired everyday activities (both during and after the reablement intervention). For that reason, next of kin could be regarded as a resource, since they could help motivate and support older adults. However, our findings indicate health professionals used next of kin as an extension of the health service in reablement. This can be understood as having too few resources to follow up older adults as they experience they are needed. Nevertheless, health professionals need to be careful to use next of kin as an extension arm, since the next of kin must not be forced into a caring role or to take on comprehensive tasks because the public health service is insufficient [36]. This might be a challenge for health professionals to relate to. Hjelle et al. [37] argue that health professionals require time to give older adults sufficient supervision and support so they can carry out everyday activities themselves.

### **Methodological issues and limitations**

Focus group discussions were chosen because this approach inspires the participants to discuss and compare their experiences [25]. However, focus group discussions can influence the participants and may have resulted in suppressed or altered opinions for the sake of the group. Another issue is the potential discrepancy in how health professionals and next of kin

may see the older adult's situation. This is an important issue that requires further discussion. In the current study we have just illuminated the health professionals' construction and perspectives. Additional studies ought to illuminate the perspectives of next of kin and focus on how they wish to collaborate with health professionals working in reablement without compromising the autonomy of older adults. A third limitation is that the study is limited to two municipalities in a Norwegian context and thus cannot be regarded as representative of how all health professionals experience collaboration with next of kin. However, this is not the purpose of this qualitative study. Based on the literature and our findings, we may assume that it is possible that health professionals working in both reablement and home care will recognize some of the experiences regarding collaboration with next of kin, since the discussions between the health professionals in our focus groups were not limited to next of kin in the reablement process but also included next of kin generally. The findings may also be valuable to other health professionals working with home-based services for older adults. Finally, according to Charmaz [24], the aim of grounded theory is to develop a theory, although few who use the method actually do. As this is the first article of several where we explore relationships between next of kin in the context of reablement, the findings from this study are considered as building blocks for a future development of a potential theory of next of kin in the context of reablement.

## **Conclusion**

As seen in this study, health professionals negotiate between themselves and need to manage the different expectations and opinions that occur in reablement. The findings indicate how health professionals regard next of kin as a resource; however, they are also faced with a dilemma when it comes to judging the necessity of including next of kin in reablement. Health professionals do not appear to have sufficient scope regarding routines or adequate

time to include next of kin as equal partners. To improve the reablement intervention for older adults and their next of kin, we suggest health professionals need to acknowledge that next of kin can be a support for the older adult but also need support, information, and education linked to their role concerning the older adult.

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### **Disclosure statement**

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## References

- [1] Cochrane A, McGilloway S, Furlong M, et al. Home-care 're-ablement' services for maintaining and improving older adults' functional independence (Protocol). The Cochrane Library 2013;11:1–14.
- [2] World Health Organization (WHO). World report on ageing and health. 2015; Luxembourg, 1–260.
- [3] Randström KB, Asplund K, Svedlund M, et al. Activity and participation in home rehabilitation: Older people's and family members' perspectives. *JRM* 2013;45(2):211–216.
- [4] Wade D. Describing rehabilitation interventions. *Clin Rehab* 2005;19(8):811–818.
- [5] Tamm M. Relatives as a help or a hindrance – a grounded theory study seen from the perspective of the occupational therapist. *Scan J Occup Ther* 1999;6(1):36–45.
- [6] Hansen T, Slagsvold B, Ingebretsen R. The strains and gains of caregiving: an examination of the effects of providing personal care to a parent on a range of indicators of psychological well-being. *SOCI* 2013;114(2):323–343.
- [7] Huber M, Rodrigues R, Hoffmann F, et al. Facts and figures on long-term care. Europe and North America. European Centre For Social Welfare Policy and Research, 2009.
- [8] Bøckmann K, Kjellevoid, A. Pårørende i helse- og omsorgstjenesten: en klinisk og juridisk innføring [Next of kin in health and care services: a clinical and legal introduction]. 2. utg. ed. 2015, Bergen: Fagbokforl. Norwegian.
- [9] Tuntland H, Ness NE. Hverdagsrehabilitering [Reablement]. 1 ed. 2014: Gyldendal Akademisk forlag AS. Norwegian.
- [10] Glendinning C, Newbrunner E. The effectiveness of home care reablement – developing the evidence base. *IJIC* 2008;16(4):32–39.
- [11] Aspinall F, Glasby J, Rostgaard T, et al. Reablement: supporting older people towards independence. *Age Ageing* 2016;0:1–5.
- [12] Glendinning C, Baxter K, Rabiee P, et al. Home care re-ablement services: investigating the longer-term impacts (prospective longitudinal study). York/Canterbury: Social Policy Research Unit (SPRU)/Personal Social Service Research Unit (PSSRU), 2010.
- [13] Legg L, Gladman J, Drummond A, et al. A systematic review of the evidence on home care reablement services. *Clin Rehab* 2015; 30(8):741–749.

- [14] Sims-Gould J, Tong CE, Wallis-Mayer L, et al. Reablement, reactivation, rehabilitation and restorative interventions with older adults in receipt of home care: a systematic review. *JAMDA* 2017;18(8):653–663.
- [15] Førland O, Skumsnes R. Hverdagsrehabilitering—En oppsummering av kunnskap [Reablement – a summary of knowledge]. 2016, Senter for omsorgsforskning, vest. Norwegian.
- [16] St. Meld. 21. Ansvar og meistring. Mot ein heilskapleg rehabiliteringspolitikk [Responsibility and coping: towards a holistic rehabilitation policy]. 1999, Det kongelige sosial- og helsedepartement: Oslo. Norwegian.
- [17] United Nations. The standard rules on the equalization of opportunities for persons with disabilities, DoP Information, Editor. 1994, United Nations.
- [18] Vik K, Lilja M, Nygård L. The influence of the environment on participation subsequent to rehabilitation as experienced by elderly people in Norway. *Scan J Occup Ther* 2007;14(2):86–95.
- [19] Tønnessen S, Kassah BLL. Pårørende i kommunale helse- og omsorgstjenester, forpliktelser og ansvar i et utydelig landskap [Next of kin in municipal health and care services, obligations and responsibilities in an ambiguous landscape]. 2017, Oslo: Gyldendal Akademisk. Norwegian.
- [20] Hjelle KM, H. Alvsvåg H, Førland O. The relatives' voice: How do relatives experience participation in reablement? A qualitative study. *JMDH* 2017;10:1–11.
- [21] Moe C, Brinchmann BS. Optimising capacity – a service user and caregiver perspective on reablement. *Grounded Theory Review* 2016;15(2):25–40.
- [22] Witsø AE, Eide AH, Vik K. Professional carers' perspectives on participation for older adults living in place. *Disabil Rehabil* 2011;33(7):557–568.
- [23] Vik K, Eide AH. The exhausting dilemmas faced by home-care service providers when enhancing participation among older adults receiving home care. *SJCS* 2012;26(3):528–536.
- [24] Charmaz K. *Constructing grounded theory*. 2014: Sage.
- [25] Krueger RA, Casey MA. *Focus groups: a practical guide for applied research*. 4th ed 2009, Los Angeles, CA: Sage.
- [26] Halkier B. *Fokusgrupper* [Focus group]. 2. udg. ed. 2008, Frederiksberg: Samfundslitteratur. Norwegian.



- [27] Dahlin Ivanoff S, Hultberg J. Understanding the multiple realities of everyday life: basic assumptions in focus-group methodology. *Scan J Occup Ther* 2006;13(2):125–132.
- [28] Winkel A, Langberg H, Wæhrens EE. Reablement in a community setting. *Disabil Rehabil* 2014(preprint):1–6.
- [29] Dickie V, Cutchin MP, Humphry R. Occupation as transactional experience: a critique of individualism in occupational science. *J Occup Sci* 2006;13(1):83–93.
- [30] Laliberte Rudman D. Enacting the critical potential of occupational science: problematizing the ‘individualizing of occupation’. *J Occup Sci* 2013;20(4):298–313.
- [31] Kirby AV. Beyond independence: introducing Deweyan philosophy to the dialogue on occupation and independence. *J Occup Sci* 2015;22(1):17–25.
- [32] Bonder BR. Family occupations in later life. *J Occup Sci* 2006;13(2–3):107–116.
- [33] Brashler R. Ethics, family caregivers, and stroke. *Top Stroke Rehabil* 2006;13(4):11–17.
- [34] Graff MJ, Vernooij-Dassen MJ, Thijssen M, et al. Community-based occupational therapy for patients with dementia and their care givers: randomised controlled trial. *BMJ* 2006;333(7580):1196.
- [35] Rostgaard T, Graff L. Med hænderne i lommen – Borger og medarbejders samspil og samarbejde i rehabilitering [With hands in pockets: citizens and health professionals collaborating and cooperating in rehabilitation]. KORA. 2016. Danish.
- [36] Meld. St. 29 (2012–2013). Morgendagens omsorg [Future Care]. Helse- og omsorgsdepartement: Oslo. Norwegian.
- [37] Hjelle KM, Skutle O, Førland O, et al. The reablement team’s voice: A qualitative study of how an integrated multidisciplinary team experiences participation in reablement. *JMDH* 2016;9:575–585.

Table 1. Characteristics of 49 individuals who participated in 10 focus group discussions

| Focus group   | Gender | Age (years) | Profession                     | Work experience (years) |
|---|--------|-------------|--------------------------------|-------------------------|
| A (Town)<br>Home care   | F      | 25          | Registered nurse               | 6                       |
|   | F      | 30          | Health worker                  | 7                       |
|   | F      | 25          | Registered nurse               | 3                       |
|   | F      | 37          | Occupational therapist         | 21                      |
| B (Town)<br>Home care   | F      | 23          | Registered nurse               | 1,5                     |
|   | F      | 22          | Registered nurse               | 5                       |
|   | F      | 30          | Occupational therapist         | 2,5                     |
| C (Rural)<br>Home care  | F      | *           | Health worker                  | 19                      |
|   | F      | *           | Auxiliary nurse                | 4                       |
|   | F      | 30          | Health worker                  | 14                      |
|   | F      | *           | Auxiliary nurse                | 15                      |
|   | F      | *           | Registered nurse               | 7                       |
|   | F      | *           | Apprentice health worker       | 3                       |
|   | F      | *           | Registered nurse               | 17                      |
|   | F      | *           | Registered nurse               | 10                      |
|   | F      | *           | Registered nurse               | 25                      |
| D (Rural)<br>Home care  | F      | 51          | Auxiliary nurse                | 22                      |
|   | M      | 43          | Registered nurse               | 18                      |
|   | F      | 25          | Student nurse                  | Student                 |
|   | F      | 41          | Registered nurse               | 18                      |
|   | F      | 35          | Auxiliary nurse                | 9                       |
|   | F      | 48          | Auxiliary nurse                | 10                      |
| E (Rural)<br>Physiotherapy and Occupational Therapy Department  | F      | 28          | Registered nurse               | *                       |
|   | F      | 30          | Social educator                | *                       |
|   | F      | 53          | Health worker                  | 14                      |
| F (Town)<br>Health and Welfare Office<br>Home care<br>Physiotherapy and Occupational Therapy Department | F      | 42          | Occupational therapist         | 20                      |
|   | F      | 28          | Occupational therapist         | 4                       |
|   | M      | 51          | Auxiliary nurse                | 10                      |
|   | F      | 48          | Occupational therapist         | 18                      |
|   | F      | 30          | Physical therapist             | 6                       |
| G (Rural)<br>Health and Welfare Office<br>Reablement team<br>Manager, home care                         | F      | 34          | Social educator                | 7                       |
|   | F      | 36          | Occupational therapist         | 5                       |
|   | F      | 48          | Occupational therapy assistant | 20                      |
|   | F      | 35          | Occupational therapist         | 1                       |
|   | F      | 51          | Registered nurse               | 23                      |
| H (Town)<br>Physiotherapy and Occupational Therapy Department   | M      | 49          | Physical therapist             | 11                      |
|   | M      | 48          | Physical therapist             | 4                       |
|   | M      | 37          | Occupational therapist         | 3                       |
|   | F      | 38          | Occupational therapist         | 18                      |
| I (Town)<br>Project Management Team   | F      | *           | Physical therapist             | 22                      |
|   | F      | *           | Registered nurse               | 33                      |
|   | F      | *           | Occupational therapist         | 21                      |
|   | F      | *           | Physical therapist             | 40                      |
|   | F      | *           | Registered nurse               | 33                      |
| J (Town)<br>Health Managers   | F      | *           | Registered nurse               | 31                      |
|   | F      | *           | Occupational therapist         | 34                      |
|   | F      | *           | Physical therapist             | 38                      |
|   | F      | *           | Occupational therapist         | 36                      |
|   | M      | *           | Registered nurse               | 15                      |

\* = missing data

Table 2. Core categories, categories, and subcategories

| Core category                         | Category   | Subcategory  |
|---------------------------------------|--|--|
| <b>Negotiating between themselves</b> | Facing a dilemma with next of kin in reablement      | <i>Understanding the situation of next of kin</i>    |
|                                       |  | <i>Assessing the need for assistance differently</i> |
|                                       | Ambiguous motives for collaborating with next of kin | <i>Not always a need to involve next of kin</i>      |
|                                       |  | <i>Including next of kin is useful</i>               |