



To what degree and how do healthcare professionals in nursing homes and homecare practice user involvement? A mixed methods study

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Abstract

Background: Involving patients and users may contribute to sound quality and safety in healthcare services. We examined the degree to which and how user involvement is practiced in daily work and in quality improvement in nursing homes and homecare.

Methods: Mixed methods design. Focus groups and individual interviews with managers ($n=45$), and employees ($n=40$) from 15 Norwegian care settings were conducted. Data were analyzed via systematic text condensation. Survey data from four homecare services ($N=139$) and four nursing homes ($N=165$) were analyzed using descriptive statistics and t -tests.

Results: Participants focused on supporting independence in users and involved them in activities that increased coping. Knowing users was an important prerequisite. Challenges related to poor communication leading to several cross-pressures between users, relatives and healthcare professionals. There were no differences between nursing homes and homecare on the degree of user involvement in daily work and in quality improvement; both scored significantly lower on the latter.

Conclusion: User involvement is an important part of the daily work of healthcare professionals in care settings. Participants seemed to lack knowledge on how to use patients' experience to inform quality improvement. A key remedial strategy is training healthcare professionals in involving users in quality improvement.

Keywords

User involvement, quality improvement, quality and safety, nursing homes, home care services

What is already known on this topic?

- User involvement contributes to sound healthcare quality
- There is limited research on how best to involve users in nursing homes and homecare in order to improve quality and safety

What does this study add?

- Illustrates how user involvement can be achieved in daily practice, and common challenges related to user involvement
- Indicates the need for more knowledge among healthcare professionals on how to involve users in quality improvement

Introduction

There is a growing focus in the healthcare sector on involving patients and users, ensuring that they play a more active part in their own healthcare (Snyder & Engström, 2016). Involving patients may contribute to sound quality and safety in healthcare services (Coulter, 2011; Institute of Medicine, 2001). In Norwegian policies, quality is defined as services that are clinically effective, safe, patient-centered, timely, efficient, and coordinated (Ministry of Health and Care Services, 2018), which is in line with the definition used by the Institute of Medicine (2001). A systematic review by Doyle et al. (2013) argued that patient involvement is an important part of quality in healthcare, and is strongly linked with patient safety and clinical effectiveness. In this paper we consider quality and quality improvement to include those three dimensions.

Although the concept of patient-centered care has received scientific attention for over fifty years (Groene, 2011), the first serious initiatives began around two decades ago when it increasingly became embedded in policies, laws and guidelines in many developed countries (Department of Health, 2003; Kohn et al., 2000; Ministry of Health and Care Services, 2001; Secretary of State for Health, 2000). Literature reviews conclude that patient involvement is associated with positive outcomes such as patient satisfaction, better health outcomes, and lower healthcare costs (Doyle et al., 2013; Ocloo & Matthews, 2016; Snyder & Engström, 2016). The use of patient experiences in quality improvement efforts, however, seems to be insufficient or lacking (Snyder & Engström, 2016; Wiig et al., 2013), although doing so can have positive benefits such as better patient outcomes and positive changes to service delivery (Ocloo & Matthews, 2016). It is potentially challenging to recruit patients to quality improvement projects, and health professionals have raised concerns that it is the most willing and able patients who participate, who are not necessarily representative of the patient population (Ocloo & Matthews, 2016). A Norwegian multi-level study by Wiig et al. (2013) concluded that there is a lack of patient involvement in quality improvement in hospitals, and that relevant tools to measure and use patient experiences in quality improvement work are missing. On the other hand, research has shown that it is possible to involve patients at most stages in healthcare (Ocloo & Matthews, 2016), including in safety initiatives (Vaismoradi et al., 2015), in quality improvement efforts (Armstrong et al., 2013; Vennik et al., 2016), and in clinical practice (Angel & Frederiksen, 2015; Snyder & Engström, 2016). For involvement of patients in quality improvement projects to be successful, the patients must be involved early on in a non-hierarchical structure, where effective communication channels are established between patients and other team members (Armstrong et al., 2013). Furthermore, there must be a clear rationale for involving the patients, with

clearly defined roles and responsibilities tailored to the specific context (Armstrong et al., 2013).

In their narrative review of antecedents, forms, and consequences of patient involvement, Snyder and Engström (2016) suggest a model for patient involvement consisting of enablers (patient and staff factors and organizational systems), patient involvement activities (decision making, delivery, development and research), and consequences (patient satisfaction, health outcomes). They argue that specific factors at individual level (e.g., patient education, empowerment, training and education of staff) and organizational level (service systems) are important preconditions for patient involvement, and that these factors should be included in an integrative approach to the concept and practice of patient involvement.

Despite the growing realization about the importance of involving patients and users in healthcare, and increasing research activity on the topic, the literature is inconsistent in defining user involvement and how it can best be achieved (Ree et al., 2019). This is especially the case for nursing homes and homecare settings, as most healthcare research is conducted in hospitals. Due to medical advances and health reforms, people are living longer with chronic diseases, resulting in an increasingly aging population, and growing pressures on nursing homes and homecare services. Knowing how to best involve users in order to improve quality and safety in these healthcare settings is therefore essential to ensure a sustainable care sector in the future. Thus, there is a call for more knowledge on how healthcare professionals practice user involvement in their daily quality and patient safety work, as well as in quality improvement efforts.

The aim of this study was to explore to what extent and how healthcare professionals (managers and employees) in nursing homes and homecare services practice user involvement. The aim was executed through the following research questions: (1) To what degree do healthcare professionals practice user involvement in their daily work and in quality improvement? (2) How do healthcare professionals involve patients in their daily work and in quality improvement? (3) What are the challenges related to practicing user involvement?

Methods

This study is a convergent parallel mixed-methods design (Creswell, 2014). We combined data from qualitative interviews and surveys. Qualitative data was used to explore *how* user involvement is practiced in nursing homes and homecare services, while the quantitative data show *to what degree* user involvement is practiced. Both perspectives are important to gain more thorough insights in the study topic, and the data complement each other, resulting in a deeper and broader understanding of user involvement in nursing homes and homecare services.

Recruitment and sample

The study is part of the SAFE-LEAD primary care project (Johannessen et al., 2019; Wiig et al., 2018). Managers and employees from nine Norwegian municipalities across 15 units (eight nursing homes and seven homecare services) participated in the qualitative part of this study. In addition, a survey on managers and employees ($N=304$) was conducted in eight of the units in October 2018. Among the participants, 94.1% were female (nursing homes: 92.1%, homecare services: 96.4%). Although homecare had slightly higher levels of unskilled workers, the samples had relatively similar distributions on age, occupational status and years of employment (Table 1), and Chi-square tests for independence revealed no significant differences between the samples.

Table 1 Descriptive survey sample information in nursing homes, NH (n=165) and homecare, HC (n=139).

Age	n (%)		Occupational status	n (%)		Years of employment	n (%)	
	NH	HC		NH	HC		NH	HC
20-29	20 (12.1)	14 (10.1)	Managerial position	11 (6.7)	9 (6.5)	Less than 1 year	20 (12.1)	6 (4.3)
30-39	39 (23.6)	33 (23.7)	Min. 3 years higher education	67 (40.6)	59 (42.4)	1-5 years	41 (24.8)	38 (27.3)
40-49	26 (15.8)	40 (28.8)	High school education	79 (47.9)	56 (40.3)	6-10 tears	27 (16.4)	35 (25.2)
50-59	50 (30.3)	38 (27.3)	Assistant (unskilled)	3 (1.8)	12 (8.6)	11-15 years	24 (14.5)	19 (13.7)
60 +	30 (18.2)	14 (10.1)	Administrative personnel	2 (1.2)	1 (0.7)	16-20 years	20 (12.1)	29 (20.9)
			Other	3 (1.8)	2 (1.4)	21 years +	33 (20)	12 (8.6)

The units were selected to represent variety in location (urban and rural), as well differences in size of municipalities and units. Co-researchers from the development centers for nursing homes and homecare services from three different counties assisted in the recruitment, by either contacting managers in the participating units directly or providing researchers with contact information. One of the homecare units was recruited by a master's degree student in the SAFE-LEAD project (M3, homecare). Participants were involved in different phases of the SAFE-LEAD project in the period 2017–2019. In total, 40 employees and 45 managers participated in the qualitative part of this study.

Data collection

The qualitative and quantitative data collection took place in parallel (Creswell, 2014). We conducted a total of nine focus group interviews and 12 individual interviews with managers ($n=54$), and 11 focus group interviews with employees ($n = 51$) (Table 2).

Table 2 Qualitative data collection and setting

Municipal	M size (ca N of inhabitants)	Units*	No. of units	Focus groups (FG) and individual interviews (ii) with managers	Focus groups with employees
M1	< 5000	NH+ HC	1+1	1 FG (n=5)	0
M2	5-10 000	NH	1	1 FG (n=3)	1 (n=4)
		HC	1	2 FG (n=3+4)	2 (n=4+4)
M3	135-140 000	NH	2	1 Ind 2 FG (n=8+8)	2 (n=6+4)
		HC	1	1 FG (n=4)	2 (n=4+3)
M4	70-75 000	NH	2	3 Ind	2 (n=6+5)
		HC	1	1 Ind	0
M5	15-20 000	HC	1	2 FG (n =4+4)	2 (n=6+5)
M6	10 – 15 000	HC	1	2 Ind	0
M7	20 – 25 000	NH	1	2 Ind	0
		HC	1	1 Ind	0
M8	15 – 20 000	NH	1	1 Ind	0
M9	< 5000	Municipal level		1 Ind	0
Total		NH: 8 HC: 7	15	9 FG, 12 Ind (n=54)	11 (n = 51)

*HC = home care, NH = nursing home. Some of the managers participated in focus group interviews on two different occasions, so the number of participants in the focus groups is larger than the number of participants in the study. Managers in home care and nursing homes in M1 participated in focus groups together.

Some of the managers and employees participated in focus group interviews on two different occasions, so the number of participants in the interviews is larger than the total number of participants in the study. All interviews were semi-structured and lasted for about 90 minutes (focus groups) and 45 minutes (individual interviews). The interview guides for three of the focus group interviews (M3, homecare) focused solely on user involvement, with questions such as “What do you do to involve users and relatives in your unit?”, and “Are user- and next-of-kin experiences used in quality improvement work, and if so, how?”. The interview guides for the other interviews consisted of several questions concerning how managers and employees work with quality and safety, and challenges in their daily work, including questions about user involvement. The data regarding user involvement was utilized in this study. Examples of questions were “How do you collect and utilize user- and next-of-kin experiences?”, and “What do you do to ensure user involvement at your unit?”. All interviews were audio-recorded and transcribed by the researchers or a professional transcription service.

Survey data was collected electronically by email in 2018 using SurveyXact. We surveyed eight of the units, four Norwegian homecare services ($N=139$) and four nursing homes ($N=165$). Surveys explored to what degree healthcare professionals practice user involvement in their daily work and in quality improvement at system level. Response rates were 65.0% (nursing homes) and 67.5% (homecare).

The questionnaire survey

The questionnaire consisted of several questions and scales related to quality and safety in nursing homes and homecare. In addition, we mapped demographic information, including age, gender, occupational status, and years of employment. The following scales were used in this paper:

User involvement in daily work was measured by the Norwegian validated version of the Person-centered Care Assessment Tool, P-CAT (Edvardsson et al., 2010; Rokstad et al., 2012). The scale consists of 13 items measured on five-point Likert scales from 1 (disagree completely) to 5 (agree completely). Examples of items were “Users are offered the opportunity to be involved in individualized everyday activities” and “We are free to alter work routines based on users’ preferences”. The wording on some of the items were slightly adjusted in the homecare survey to fit the context (e.g., ‘users’ instead of ‘residents’). Furthermore, one of the items was excluded in our surveys as it did not fit with the homecare setting (“Residents are able to access outside space as they wish”). In this study, all items in the scale were computed as a mean score and used as a measure of user involvement in daily work. The Cronbach’s alpha value was .836 for the total sample (nursing homes, $\alpha=.845$; homecare, $\alpha = .828$).

User involvement in quality improvement was measured by a short six-item scale adapted from Consumer Participation Questionnaire, CPQ (Kent & Read, 1998; Storm, et al., 2011). The scale was originally developed and validated for Norwegian mental health services (Storm et al., 2011), and the wording of some items was therefore slightly modified to fit the nursing homes and homecare settings. All items ranged on five-point Likert scales from 1 (never) to 5 (frequently). Examples of items were “Are results from user surveys systematically used in improvement work among health personnel in your unit?”, “Are user representatives involved in teaching and training sessions with health personnel in your unit?”. In this study, all items in the scale were computed as a mean score, and used as a measure of user involvement in quality improvement. The Cronbach’s alpha value was .878 for the total sample (nursing homes, $\alpha=.896$; homecare, $\alpha = .849$).

Analysis

Qualitative analysis

The first author (ER) extracted the data from the transcriptions that in some way concerned user involvement. The extracted data material was then analyzed using systematic text condensation, which is a descriptive cross-case analysis strategy (Malterud, 2012). ER and IA cooperated on the analysis, which consisted of four steps:

1. Read through the data material to get an overall impression and make preliminary themes related to the research questions. Examples of preliminary themes were: knowing the patient, self-help, unclear roles and expectations, lack of capacity and communication gaps.
2. Establish code groups based on the preliminary themes in a collaborative negotiation between the authors. Careful reading of the data material to select units of meaning related to the code groups. An example of a code group was: "User involvement is about supporting users in activities that increase their expectancies of coping, and knowing them is an important prerequisite".
3. Condense the units of meaning in each code group into text sections, and sort them into subgroups. Examples of subgroups in the code group above were: "User involvement is about supporting users in activities that increase self-management and coping", and "Knowing the users well is an important prerequisite for user involvement".
4. Reconceptualize and synthesize the condensates to provide meaningful descriptions of the results section.

Statistical analyses

IBM SPSS Statistics version 25 was used for the statistical analyses. Each question had to be answered before moving on to the next, and the dataset has therefore no missing values.

We used descriptive frequency analyses to examine the degree of user involvement in daily work and in quality improvement. To provide a visual image of the rating on these variables, we calculated the average number of positive scores per variable by adding the percentage of positive scores (four or five) on each item, divided by the number of items in the scale or dimension. Negatively worded items were reversed before the calculation. Independent *t*-tests were used to investigate differences between nursing homes and homecare (independent group variable) on the two dependent variables user involvement in daily work and user involvement in quality improvement. The *p*-value was set to .05. To test the assumptions of normality we used Q-Q plots, Shapiro-Wilks test of normality and *Z*-values (dividing the skewness and kurtosis values by their standard deviations). As a 'rule of thumb' the distribution was considered to be normal for *Z*-values below 3.29 for medium-sized samples ($50 < n < 300$) (Kim, 2013). Although the Shapiro-Wilks' test suggested potential violation of normality, Q-Q plots and *Z*-values indicated normal distribution of our variables in the two samples. Moreover, results from the non-parametric Mann-Whitney *U* test were comparable to results of *t*-tests. We therefore decided to report results of the parametric tests.

Mixed-methods analysis

Our qualitative and quantitative analyses were completed separately and then integrated in a side-by-side comparison in line with Creswell (2014). The qualitative component is the main component in our study and we use the quantitative component to help us consider the extent of this topic in a larger sample. We merged data to address the overall aim of the

study exploring to what extent and how managers and employees in nursing homes and homecare services practice user involvement.

Ethics

The Regional Committees for Research Ethics in Norway regarded the study to not be regulated by the Health Care Research Act, and thus not be within their mandate. The Norwegian Centre for Research Data approved the study (NSD, ID: 54855). The project followed the principles of the Helsinki Declaration. All participants gave written informed consent. In the survey, the informed consent statement was provided at the very beginning of the electronic questionnaire, stating that participants consented to participate by responding to the questionnaire.

Results

The results reveal to what degree and how managers and employees in nursing homes and homecare practice user involvement in their daily work and in quality improvement, and challenges they experience. The qualitative results are presented first, followed by the quantitative categories.

Qualitative results

User involvement is about supporting users in activities that increase their expectancies of coping, and knowing them is an important prerequisite

The participants emphasized promoting self-help as an important part of their user involvement practices. Their goal was for the users to manage as much as possible themselves, and being independent. For example, they did not butter the bread for them or dress them unless they were unable to do it themselves. The participants focused on training the users to become as independent as possible, as that increased the users' expectancies of coping and their self-esteem. Despite having strict time-schedules, they tried to be patient and set aside time to guide them instead of doing it for them, even if the latter would often be quicker. The participants tried to find helpful support tools tailored to the users' specific needs, in order for them to manage more of the daily chores themselves, such as putting a chair and a handrail in the shower. By observing how the users managed the different activities, they could provide them with tips in how to make it easier, or safer.

The participants tried to involve patients in meaningful activities and social gatherings, such as shared lunches where the patients prepared and served other patients and employees at the nursing home once a week. Homecare users also had the opportunity to take part in daycare centers or activity centers to meet other people and participate in activities where they were offered activities such as courses in fly tying, knitting, painting, languages and cooking. All of the participants said that it had become increasingly focused on person-centered care in the municipalities in recent years, which had resulted in changes to usual practice. The primary contact role, meaning that one employee had the main responsibility for a number of users, had become part of usual practice in most of the units, at least in their protocols. In practice however, many struggled to make things work as they were supposed to, resulting in less continuity, and challenges regarding user involvement. Overall, there was an increasing focus on having regularly dialogue with the users, and most settings had implemented a routine where the primary contacts had the responsibility for asking patients what was important for them. Once a year all the units had a special day dedicated to user involvement focusing on the importance of taking users' wishes into consideration in their daily work.

Participants tried their best to fulfil the users' wishes, such as choosing what to eat and drink, whether they wanted to eat in their own room or dine with others, and participate in activities. They focused on letting the users be in control of their own life as much as possible.

We always encourage them to try themselves first, and then I am here if you need a helping hand and don't manage it. But we try to be skilled at standing with our hands behind our backs and then rather guide and talk them through for example a care situation (Employee, home-care, M3).

Successful user involvement was more likely to happen when the participants knew the users well. In homecare, having fixed work lists where staff visited the same patients over time was perceived as positive to get to know the users, and the participants expressed that users seemed to appreciate being met with health personnel they knew. This also applied to nursing homes with permanent staff working in specific departments with the responsibility for the same patients over time. It was a way of building trust, confidence and openness between users and employees. Management tried to facilitate for fixed shift-schedules, and some of the municipalities had implemented a computer system that could distribute employees in homecare according to where the users lived. However, employees said that the system did not always work as intended and it was often challenging to maintain continuity. Sudden changes often occurred, both related to patients' needs and employees being off work, resulting in rearrangements of the schedule.

Many of the participants from both nursing homes and homecare said that they involved the users by listening to them and getting to know them, trying to come up with solutions together with the patients based on their needs or wishes. Having good conversations and cooperation was key, they said. Knowing the users also helped employees to notice quickly if there were any changes in the users' health condition. Fixed lists, as well as having primary contact roles, were considered significant for continuity, patient follow-up, and knowing the users both in terms of their health condition, but also regarding their needs and wishes. User involvement was particularly perceived as a challenge regarding patients with dementia, since the patients often had a hard time expressing their needs and they had difficulties knowing the employees. Fixed lists were therefore considered especially important with these patients. One employee in a nursing home said the following regarding fixed lists:

I also feel that it [fixed lists] helped me do a good job, that I follow up and that they appreciate that they know us well. It becomes a security. And it also makes our everyday life less stressful, because you calm it down a bit. At least when you work several days in a row, you can sort of plan pretty well. You have some influence on that list then (Employee, nursing home, M3).

Clarifying expectations to avoid cross-pressure is an important first step for user involvement

Participants often experienced that the users' wishes and expectations did not match what the services could actually offer them. To clarify the role of the services, the participants proposed a joint information letter from the municipalities to users of homecare and nursing homes, indicating that the services are continuously changing. The letter should contain information about what the services can offer and clarification of roles, to help users and next-of-kin being more prepared of what to expect. Some employees stated that they often got the impression that users perceived them as caretakers, messengers, taxi services or interlocutors. The participants were repeatedly asked to help the users with things that were not part of their job, such as taking out the garbage and doing the dishwashing.

Sometimes the participants experienced conflict between what the users wanted and what employees thought was best for them from a health professional perspective to maintain health or postpone further functional impairment. They struggled to maintain professionally sound services without forcing the users to do things they did not want to. If they were unable to fulfill the users' wishes, they should at least be allowed to convey what is important for them and to be taken seriously, they said. In homecare for example, they called to notify users if they were running late, and experienced that this was appreciated. The problem, the participants said, was not being late or changing plans and routines, but not including and informing users when doing so. They stated that user involvement was not about the user deciding all services, but to have a dialogue within the limits of help and assistance they were able to provide. Some said that user involvement first became a problem when users' wishes conflicted with employees' room for maneuver or their safety. A homecare manager gave an example of a dispute that arose when users did not want bed lifts or hospital beds because it did not look good in their living room:

User involvement is not actually a problem until it is contradictory, it is what we struggle the most with, that we have staff to pay attention to, and then it does not matter what Mrs. Hansen wants if the backs of the staff get hurt. If they do not want us to use a bed lift, then what? We have many conflicts regarding such things (Manager, homecare, M3).

The participants' experiences of being in a cross pressure also applied in relation to next-of-kin. Next-of-kin were primarily considered as an important resource, and participants found it helpful involving them in the care as it eased the burden for employees and resulted in better care for the users. It was however challenging when next-of-kin came in as a third party disagreeing with both the users and healthcare professionals, resulting in a triangle that was difficult to untangle. For example, some next-of-kin set goals on behalf of the users, even when the users were fully capable of making their own decisions. In such cases the employees often had the next-of-kin wait in a separate room in order for them to make specific goals together with the user based on his/her wishes. Often the employees realized that next-of-kin's unreasonable demands and dissatisfaction were due to the fact that they were insufficiently informed about the users' health status or the role of the healthcare service. Next-of-kin were often not aware of the health service's vision of facilitating independence by letting the users do as much as possible themselves without help. The participants stressed the importance of informing next-of-kin what person-centered care was all about, and how the focus in healthcare had changed in recent years. A decade ago, in nursing homes, it was for example common that all patients were dressed and ready to eat breakfast together in the dining room at 9AM, and some next-of-kin still expected this. The participants then had to explain that they now tried to organize according to each participant's needs and wishes, meaning that some might choose to sleep longer or eat breakfast in their own room. Both managers and employees wished better channels of communication, such as apps and information screens. Having a good relationship and regular dialogue with next-of-kin made it easier to involve users in their own care.

Communication with our user group and next-of-kin is incredibly important. We need to ensure quality of care at the first meeting between us, the patient and the relatives, and to be clear on what the services entail. Then we can clarify some of the expectations while being accommodating and welcoming of them (Employee, homecare, M3).

The majority of the units had established collaboration with the municipalities' 'decision offices', which are services regulated by the municipalities, dedicated to take over the responsibility of assessing patients' needs for services and making care plans. These offices made prioritizations and decisions based on a specific set of criteria for receiving homecare and nursing home services. On one hand, participants stated that this was positive as it eased the work pressure, especially for the managers who previously did these assessments. Before introduction of the decision offices, managers would often stay late at work every Friday, covering shifts and planning homecomings for discharge-ready patients, which was tremendously time consuming. On the other hand, employees stated that they had less influence on patients' care plans now, even though they had a dialogue with the decision office. Participants stated that they sometimes found the decisions made by the decision office too strict and wanted to do more for the patients than the criteria allowed. Furthermore, there were situations where the approved care plans did not match with what the users actually needed or had asked for. In such cases, user involvement was lacking, they said, because someone had made a decision without properly involving the user. Participants expressed that they tried to be flexible and did not always adhere to the plan, as they perceived it as important to listen to the patient and try to involve them in their care as far as possible. It was however a challenge that users and next-of-kin often assumed that the employees and managers were responsible for the services offered to the patients, as illustrated by this quote from an employee:

It must always go through them [the decision office]. And there are many relatives who think that they can just call here and get sort of higher [priority] ... and get help for other things and ... but it doesn't work that way because we get the orders from the decision office. When we increase the help through the decision office, we get more hours, which means that we get paid more for the tasks we do. So that part has a lot to do with economy (Employee, homecare, M3).

The system and organization constitute room for maneuver concerning user involvement

Available financial resources in the municipalities and units limited the degree that participants were able to take into account the wishes of users and next-of-kin. For example, there was a limited number of available rooms in the nursing homes, and patients were therefore often declined when applying to stay. Transitions were also often regarded as challenging. A manager at a homecare service told of a patient coming home from a nursing home where they had put her in a wheelchair for a few weeks. They were shocked, because she was fine when she left home. Such setbacks for users often happened during transitions, which was frustrating for participants in homecare who had spent a lot of time training and helping patients to manage their daily lives as independently as possible.

The participants also highlighted challenges related to part-time positions, especially in regard to some weekend positions that were needed to cover the schedule, and in getting hold of people with professional competence. They talked about the lack of time in daily work and exemplified this with the challenge of being up to date on the latest patient care reports and plans, in addition to their main task of providing good patient-centered care for all the patients. One of the units implemented iPads that employees could use to read up on care plans and reports, but the other systems did not interact with the iPad, and therefore limited the information they got. Even if they tried to prepare themselves by making worklists for the upcoming week, things suddenly happened because the system was unpredictable, and things were often changing.

We say that people should read up on reports, we should write good care plans, action plans, that they should be up to date how Mrs. Olsen prefers things done. Obviously ... there is often not enough time. You have many [users] to visit (Manager, homecare, M3).

Most of the participants said there had been an increased focus on user involvement at the national level in the recent years, resulting in new systems and routines regarding how they worked with user involvement. They had for example implemented whiteboards with overview of patients' health status and assigned primary contacts, making it easier to keep updated. Some units had user representatives in project groups when implementing interventions or changes to their units. One of the homecare units included user representatives in a project about health technology, and said that they played a significant role in the development of new solutions. However, other participants said they often struggled with getting the users or next-of-kin to participate in change processes or projects, and that they usually received little input from them when they were present.

On questions related to whether and how users were involved in quality improvement, there were no explicit or consistent answers from participants. A few managers reported that they had user councils at their units, and many employees were either not aware of whether they had such councils, or they did not know what their purpose was. Some nursing home managers said they had user councils where next-of-kin were represented, but not the users themselves. There were some examples of changes in practice at a local level based on input from user councils, such as letting users eat their meals in their private rooms, instead of fixed meal gatherings in the shared dining room, which had been common routine. Participants from units that regularly used such councils perceived it as helpful, making them aware of things they often took for granted when working at the same place for a long time, such as remembering to wear name tags. Participants stated that they always worked to involve users and next-of-kin in the daily practice, but to a lesser extent in a systematic way. Most units had feedback forms available for users and next-of-kin to fill out if they had complaints or feedback about the services, but could not account for whether and how these forms were used to inform practice.

The municipalities conducted user surveys regularly as this was a national requirement. Few participants said that they actually used the data to inform their work practice, e.g., what they did well and what they could do better, and what interventions and prioritizations they should conduct to improve quality. One of the units conducted their own user survey related to a newly implemented dementia project and planned to conduct another related to implementation of new health technology. The majority of the units however only conducted the surveys that were required and did not use the data to inform or change practice. Some did not even know what the data was used for or how they could get access to it, as illustrated by this quote from a nursing home manager:

As a manager in a nursing home, I remember we had a user survey a long time ago, I think it was on national basis, but we didn't get any feedback on it, so I know nothing about the effect, I think it was at a higher level (Manager, nursing home, M2).

Quantitative results

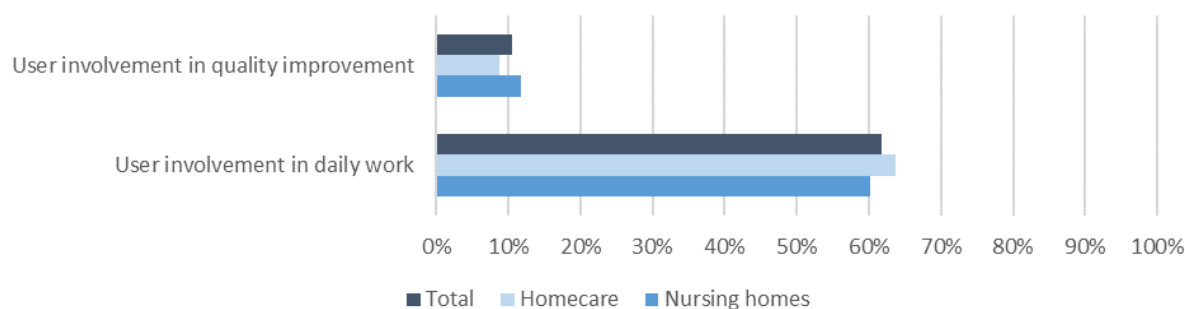
There was a significant positive correlation between user involvement in daily work and in quality improvement (Table 3).

Table 3 Means, SD and Pearson correlations between study variables

Total (n=304)	Mean	SD	1	2	3	4
1. User involvement in quality improvement	2.16	.81	1			
2. User involvement in daily work	3.65	.54	.216**	1		
3. Occupational status			.132*	.008	1	
4. Years of employment			-.080	.005	.158**	1
Nursing homes (n=165)	Mean	SD	1	2	3	4
1. User involvement in quality improvement	2.16	.58	1			
2. User involvement in daily work	3.66	.86	.167*	1		
3. Occupational status			.190*	-.020	1	
4. Years of employment			-.045	.138	.216**	1
Homecare (n=139)	Mean	SD	1	2	3	4
1. User involvement in quality improvement	2.15	.74	1			
2. User involvement in daily work	3.64	.50	.293**	1		
3. Occupational status			.057	.044	1	
4. Years of employment			-.139	-.218*	.081	1

* $p < .05$. ** $p < .001$.

In nursing homes, occupational status had a significant positive association with user involvement in quality improvement, while years of employment were negatively associated with user involvement in daily work in homecare (Table 3). However, all correlations were weak ($r = .10$ to $.29$). Independent samples t -tests showed that there were no significant differences between nursing homes and homecare services on user involvement in daily work (mean difference = $.013$, 95% CI: $-.110 - .137$; $t(302) = .212$, $p = .08$). Furthermore, the t -tests showed that there were no significant differences between nursing homes and homecare on quality improvement (mean difference = $.015$, 95% CI: $-.166$ to $.196$), $t(302) = .163$, $p = .87$). Both nursing homes and homecare services scored considerably lower on user involvement in quality improvement than in daily work (see Figure 1 and Table 3). Only 8.7% of participants in homecare and 11.8% in nursing homes responded positively (four or five) on questions about user involvement in quality improvement.



Figur 1 Average percentage positive responses on the variables 'user involvement in quality improvement' and 'user involvement in daily work'.

Discussion

This study provided several examples of how healthcare professionals (managers and employees) in nursing homes and homecare services involved users in their daily care where their main focus was on supporting independence in users and involving them in activities that increased their expectancies and realities of coping. Knowing the users was an important prerequisite for user involvement. Challenges were related to poor communication leading to cross-pressures between users' wishes, requests from relatives and the healthcare professionals' agenda. Both the qualitative and quantitative findings indicated that the utilization of user experiences in quality improvement was either inadequate or completely absent. There were no differences between nursing homes and homecare on the degree they practiced user involvement in their daily quality work and in quality improvement, but both scored significantly lower on the latter.

According to Skagerstrøm et al. (2017), user involvement can be hindered by factors related to the patient, the employees, and the healthcare system. The authors argue that employees have responsibility in creating opportunities for patients to be involved. Our study showed how employees create such opportunities for patients, by listening to them, asking them about their preferences, getting to know them, and facilitating self-management. Several previous studies also emphasized the importance of the patient–staff relationship, spending time with users to know them well, and sharing of information and knowledge as important preconditions for patient involvement (Angel & Frederiksen, 2015; Oxelmark et al., 2018; Vennik et al., 2016). Our study adds to previous research however, by showing how lack of information sharing might impede involvement not only by not knowing how to best involve the users, but also by leading to unclear roles and unrealistic expectations, or a mismatch in expectations between employees, users, and next-of-kin. A mixed-methods study in cancer care showed that the triangle between employees, patients and next-of-kin is experienced as challenging not just by employees, but also by next-of-kin (Bergerød et al., 2020). The study illustrated next-of-kin experiences of being on a parallel track with those of patients, while having different needs for information, which was often not sufficiently met by employees in the healthcare services (Bergerød et al., 2020). Our study supports the stated need for development of better communication channels and ways of involving next-of-kin to avoid miscommunication and cross-pressure and improve healthcare quality (Bergerød et al., 2020). There is a need for more research on barriers and facilitators to partnerships between users, next-of-kin and employees (Olding et al., 2016).

In contrast with our findings, an observational study by Tobiano et al. (2016) found that patients were rarely involved in self-management activities and preventative healthcare. Similar to our study however, user involvement was promoted by good communication and information sharing between employees and users. The authors concluded that it seems difficult to enact user involvement (Tobiano et al., 2016). For example, only a few users took part in planning of their own care. Healthcare professionals in our study gave some examples of giving users opportunities to plan their own care, but this was more related to well-being aspects such as deciding when and where to eat, than to direct healthcare such as choosing treatment or medicine management. There were however several examples of how participants supported users in self-help practices to promote users' independence, coping, and self-management. It can be debated whether such support is more about facilitating user empowerment than about user involvement. Patient involvement and empowerment are often used interchangeably (Anderson & Funnell, 2010), but Castro et al. (2016) argue that patient involvement is an important precursor for patient empowerment. Castro et al. (2016) propose a model of antecedents, attributes and consequences of patient empower-

ment that fits with how participants in our study facilitated self-help to increase expectancies of coping and confidence in users. Examples are dialogue and patient involvement (antecedents), enabling processes and self-determination (attributes), and coping and self-management (consequences) (Castro et al., 2016). In line with our findings, a previous Norwegian study also found that employees in the homecare services perceived user involvement to be about involving users in activities and making the users independent and self-reliant (Johannessen & Steihaug, 2019). However, the authors raise questions about whether the services' strong focus on self-help activities and self-reliance makes it difficult to enact user involvement, as the users might feel forced to participate in these activities, not being allowed to choose whether they would like to become self-reliant (Johannessen & Steihaug, 2019).

The cross-pressure between the different stakeholders was also affected by factors in the healthcare system. The system forms the framework in which involvement is possible (Angel & Frederiksen, 2015). In line with our results, several studies show that structural characteristics such as poor staffing, turnover, heavy workload and busy schedules set limits to the possibilities the healthcare personnel have to provide for the optimal level of care and time spent with the patients (Bishop & Macdonald, 2014; Friedman et al., 2016). Our study furnished several examples of how employees negotiate with the system, trying their best to accommodate patients' wishes, even when organizational and system factors act as obstacles. For example, they adjusted their work lists and did not always follow the care plan set by the decision offices in order to meet patients' needs and preferences.

Both nursing homes and homecare services in our study scored low on questions related to user involvement in quality improvement work. It can be questioned whether this is due to the high number of employees in the survey responses, compared to the low number of managers. However, the quantitative data were in line with the qualitative analysis, showing only a few examples of patient involvement in quality improvement. Although managers generally were more familiar with these procedures than employees, several managers also struggled with questions related to whether and how user involvement was practiced in quality improvement. Many healthcare organizations have routines for collecting information about patient experiences through for example surveys, but the information gained is rarely used for quality improvement (Snyder & Engström, 2016; Wiig et al., 2013). This was also evident in our study. Several national and municipal guidelines existed to ensure the practice of user involvement in quality improvement in the nursing homes and homecare services. Municipalities' user councils and national user- and patient surveys were examples of such system level initiatives. However, the degree of actual implementation of such initiatives varied across the units, and only a few of the units actually used the information gathered through surveys and user councils to improve healthcare quality. Sheard et al. (2017) suggest a conceptual framework for understanding why it is challenging to make improvements based on feedback from patients, including aspects related to staff (belief that it is worthwhile listening to patients), structural aspects (available resources and team autonomy), and organizational readiness to change. Patient involvement in quality improvement can only occur when there is an individual and organizational capacity to change (Sheard et al., 2017).

Strengths and limitations

The main strength of this study is the diverse sample including both managers and employees in several units in municipalities that varied in size and location, thereby securing a range of different perspectives and nuances to the research questions. The study is further

strengthened by the mixed-methods design combining qualitative in-depth data with quantitative data which provide thorough insight in how and to what degree user involvement is practiced in nursing homes and homecare services. The data from the different data sources complement and support each other, giving increased credibility to the study findings. The scale used in this study to measure user involvement in quality improvement was developed and validated on a Norwegian sample in the mental health services context, and has not been previously validated in the contexts of nursing homes and homecare services. However, the Cronbach's alpha values of the scale indicated acceptable level of reliability. Presenting results from factor analysis was beyond the scope of this study, but future research should further explore the psychometric properties of the scale in these settings.

Qualitative data was collected by use of different interview guides. However, all included questions related to user involvement, and both managers and employees were represented in the responses to the different guides. Patients were not included in the study. Patients might have different perceptions regarding whether and how user involvement is practiced and should therefore be included in future studies. Observational data could also be collected in future studies to explore whether managers and employees practice as they preach.

Conclusion and implications

This study documented several examples of how managers and employees in nursing homes and homecare involve users in their daily care. Their main focus was on supporting independence in users and involving them in activities that increase their expectancies of coping. Knowing the users well seemed to be an important prerequisite for user involvement. Challenges were related to miscommunication and insufficient information exchange leading to cross-pressures between the health personnel's professional agenda and the expectations and wishes of users and next-of-kin. There seemed to be a lack of user involvement in quality improvement efforts. Managers and employees should receive training and education in strategies to involve users in quality improvement activities, and competence in exploiting information gained from users to inform and change practice. Effective communication channels between employees, users and next-of-kin and provision of prompt information about the role and agenda of the healthcare service should be part of standard procedures in all nursing homes and homecare services.

Medforfatter Siri Wiig er en av gjesteredaktørene for dette temanummeret. Derfor har den redaksjonelle behandlingen og beslutningen om publisering av artikkelen blitt håndtert av de andre gjesteredaktørene i samarbeid med ansvarlig redaktør, og Siri Wiig har ikke hatt innsikt i vurderingsprosessen.

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