RESEARCH ARTICLE



Patient participation in municipal elderly care from the perspective of nurses and occupational therapists

Kajsa Lidström Holmqvist^{1,2} | Inger James²

Correspondence

Kajsa Lidström Holmqvist, University Health Care Research Center, P.O. Box 1613, SE-701 16, Örebro, Sweden. Email: kajsa.lidstrom-holmqvist@ regionorebrolan.se

Funding information Örebro University

Abstract

Aim: The aim of this study was to describe how nurses and occupational therapists in municipal care of older people define and implement patient participation in their daily work.

Design: This study had a cross-sectional design. Data were collected using an online questionnaire.

Methods: The questionnaire had both closed and open-ended questions. One-hundred and fourteen nurses and occupational therapists responded. Data were analysed with descriptive statistics and thematic analysis.

Results: Two main themes were identified as follows: "The professionals' perspective at the centre – Patient participation to enhance compliance" and "The patients' perspective at the centre – Patient participation as an ongoing process." The themes covered a continuum. On one extreme, patient participation was equated with making the patient comply with what the professionals wanted to do. On the other extreme, all power was transferred to the patient. The first theme was restricted to the decision-making process. The second theme covered the entire care or, rehabilitation, process.

KEYWORDS

health services for older people, nurses, occupational therapists, patient participation

1 | INTRODUCTION

The global goal for healthcare services is to be based on people's needs and desires. Patients all over the world should be able to participate in decisions about their health and health care (World Health Organization, 2015). This requires a partnership where personnel share power with the patient (Aveling & Jovchelovitch, 2014; Renedo, Marston, Spyridonidis, & Barlow, 2015). In Sweden, Acts and reforms have strengthened patient power, which has not been successful.

Sweden lags far behind other high-income countries when it comes to patient's involvement in decisions about their care

(Myndigheten för vårdanalys [The Swedish Agency for Health & Care Services Analysis], 2016), and in many work places, it has not been prioritized (Myndigheten för vårdanalys [The Swedish Agency for Health & Care Services Analysis], 2015). Furthermore, focus has been on patient choice (Dent & Pahor, 2015; Fredriksson, Eriksson, & Tritter, 2018) rather than active participation in decisions (Dent & Pahor, 2015). Health care is described as having an institutional character, where the patient is seen as an object (Statens offentliga utredningar, 2013) where the tasks in the care are prioritized before the person's needs (Smebye, Kirkevold, & Engedal, 2012) Thus, on 1 January 2015, the new Patient Act (Patientlag, 2014) was introduced with the intention of creating a shift in power to the patient.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2019 The Authors. *Nursing Open* Published by John Wiley & Sons Ltd.

¹Faculty of Medicine and Health, University Health Care Research Center, Örebro University, Örebro, Sweden

²Faculty of Medicine and Health, School of Health Sciences, Örebro University, Örebro, Sweden

Thus, patient participation is of growing significance in practice (Statens offentliga utredningar, 2013; Patientlag, 2014) and has been described as the patient's involvement in the decision-making process that concerns health (Ringdal, Chaboyer, Ulin, Bucknall, & Oxelmark, 2017), a set of values such as meaningful engagement, choice, control and inclusion. Participation can also be seen as receiving information about illness, diagnosis and planned treatments (Ekdahl, Andersson, & Friedrichsen, 2010). In a concept analysis by Sahlsten et al. (Sahlsten, Larsson, Sjöström, & Plos, 2008), it is defined as a relationship between the patient and the nurse/healthcare personnel, where the power is handed over to the patient. Information and knowledge are shared where they together have an active engagement in the care. One prerequisite for power shift could be equality and a dialogue initiated by staff where time is allocated to a conversation about how an older person wants to participate in his/her care (Algilani, James & Kihlgren, 2016). To create a relationship with the intention of enhancing the patient's opportunities to participate and reach his/her goals has been emphasized (Holmqvist, Holmefur, & Ivarsson, 2013; Taylor, 2008), where a responsive relationship that creates an emotional closeness between patient and professional becomes important (Hedman et al., 2015; Moser, Houtepen, Spreeuwenberg, & Widdershoven, 2010).

The degree to which someone wishes to participate in their own care may vary from person to person, but advanced age does not affect a patient's legal right or willingness to participate in care (Statens offentliga utredningar, 2013; Patientlag, 2014). However, the person may have low self-esteem (Larsson, Sahlsten, Segesten, & Plos, 2011) and will assume a passive role which may mean being marginalized (Aasen, Kvangarsnes, & Heggen, 2012; Halskov, Lauridsen, & Hoffman, 2017). To express needs and be able to participate in and influence, healthcare decisions can require courage (Vicente, Castren, Sjöstrand, & Sundström, 2013) and self-confidence (Foss, 2011), and even if older persons do not participate in decision-making, they may still want to have the opportunity of participating in their care (Foss & Hofoss, 2011). However, nothing takes place in a vacuum; the environment dynamically influences participation (Hammel et al., 2008). Traditionally, older persons who are chronically ill are seen as dependent, vulnerable and passive where the staff/personnel make the assessment (Halskov et al., 2017). This culture of practice needs to change (Poulos et al., 2017). Thus, it is the responsibility of healthcare professionals to create conditions for participation (Svensk sjuksköterskeförening, 2014; Swedish Association of Occupational Therapists, 2016). This responsibility may be complicated by the entry of artificial intelligence (AI) into health care. The use of AI in health care is growing, that is through clinical decision support systems, monitoring systems and smart homes. It is seen as one of the solutions to the future challenges in health care with a growing older population. However, Al cannot easily replace the communication and professional relationship between patient and professional (Reddy, 2018), meaning challenges when it comes to patient participation.

In Swedish municipal care of older people, nurses and occupational therapists are responsible for care and rehabilitation and are in that sense key professionals. Together with assistant nurses, they constitute the key team that work in the older person's home, ordinary housing or in nursing homes, on regular basis. Other professionals, such as physicians or physiotherapists, are normally not employed in the municipality, but serve as consultants. Nursing is the nurse's specific competence where the care is to be provided in partnership with the patient (Svensk sjuksköterskeförening, 2014). Common nursing interventions in municipality care are such as medication, wound care and to promote self-care in relation to different health issues. The specific competence for occupational therapists is to enable persons to perform their daily activities in a meaningful way where the rehabilitation takes place in collaboration with the person (2016). Common occupational therapy interventions in municipality care are the prescription of and training in the use of assistive devices, housing adaptations and promoting engagement in activities.

Nurses and occupational therapists should work to support and promote participation where they have a moral responsibility for their actions, which should be carried out in accordance with scientific methods and proven experiences and applicable laws and regulations (Svensk sjuksköterskeförening, 2014; Swedish Association of Occupational Therapists, 2016).

Previous studies have identified several barriers to participation such as staff regarding an older person as lacking in knowledge (Wikström & Emilsson, 2014), staff not listening (Dyrstad, Testad, Aase, & Storm, 2015; Garcia, Harrison, & Goodwin, 2016) lacking empathy, having a paternalistic attitude (Larsson et al., 2011) and deciding on treatment (Aasen et al., 2012).

The above literature review shows that laws are not complied with neither current nor previous laws and that older persons wish to be involved but may suffer from low self-esteem. It also shows that the professional is responsible for creating participation but that the professionals' response to older persons does not always promote participation.

Only through understanding the perspective of those who can enable participation, that is nurses and occupational therapists, can knowledge be acquired about what needs to be changed. The aim of this study was therefore to describe how nurses and occupational therapists in municipal care of older people define and implement patient participation in their daily work.

2 | METHODS

This study had a cross-sectional design where the respondents answered an online questionnaire. Data were analysed with descriptive statistics for closed questions and thematic analysis (Braun & Clarke, 2006) for open-ended questions.

2.1 | Recruitment of respondents

Nurses and occupational therapists were recruited in a larger Swedish urban municipality. Inclusion criteria were that they worked

TABLE 1 Distribution on working place

Working place	Frequency	Relative frequency
Nursing home	38	33%
Home care	62	54%
Day care rehabilitation/ dementia/social	3	3%
Management for the disabled	4	4%
Others/unspecified	7	6%

with older persons in municipality health care, either in ordinary housing or at a nursing home. The managers for the respective professions were contacted to receive their consent to conduct the study. After consent was granted, an inquiry was submitted via an email list to all occupational therapists (N = 120) in the current municipality. No corresponding list for nurses was available. Instead, managers forwarded the inquiry to all unit-coordinating nurses who, in turn, forwarded it to the nurses at the units. At the time, there were 188 nurses employed.

The inquiry included an information letter with a link to an online questionnaire. The letter provided information in accordance with the Helsinki Declaration (World Medical Association, 2001). It described the aim of the study, what participation involved, how data would be handled, analysed and presented, voluntariness and, finally, that responding to the questionnaire would be regarded as informed consent. According to the Swedish Ethical Review Act about research on humans (Lag om etikprövning av forskning som avser människor, 2003), research into healthy adults involving no sensitive personal data does not fall under the Act. Consequently, no Research Ethics Committee approval was obtained.

2.2 | Data collection

A study-specific questionnaire was developed. It initially comprised demographic questions to describe the participants such as occupation, work experience and place of work. There was also a question about the respondents' knowledge of the Participation Act (Patientlag, 2014). This was followed by three broad open questions where the respondents were asked to describe in own words. First, the participants were asked to describe how they defined patient participation, and this was followed by questions on how they implemented patient participation in their daily work and what they did to make their work with patient participation visible to others than themselves. Each participant was given access to the questionnaire through a link in the inquiry email. Two reminders were sent after one and two weeks, respectively.

2.3 | Data analysis

Demographic questions were analysed with descriptive statistics using IBM SPSS Statistics 22. Open questions were analysed using thematic analysis (Braun & Clarke, 2006). In phase one, all data were compiled and were read repeatedly by both authors. Each meaning

unit was discussed, and notes with ideas about coding were written. Memos were also made about interesting content. In phase two, coding of data was performed by the first author using NVivo 11.0 software (Edhlund & McDougall, 2017). Efforts were made to be as inclusive as possible, to not exclude any content that might be interesting later in the analysis. Notes were written about aspects that could become themes later on. In phase three, the codes were sorted into potential themes and an initial thematic map with themes and sub-themes was developed (Braun & Clarke, 2006). In phase four, the themes and sub-themes were refined by both authors. An effort was made to cohere data in a meaningful way and also make clear distinctions between the themes. The themes were compared with the entire data set, and a final thematic map was made that illustrated the final two main themes. In phase five, each theme was described, and the sub-themes were used to give structure to the two main themes. Finally, the themes were named. In the sixth phase, the findings were reported in writing, including the use of quotations to enhance trustworthiness.

3 | FINDINGS

3.1 | Respondents' characteristics

In all, 114 nurses (N=62) and occupational therapists (N=52) responded to the questionnaire. The response rate for nurses was 33% and for occupational therapists 43%. The response rate to different questions did not differ. The mean year of work experience was 17 (SD 11). The distribution of main place of work is presented in Table 1.

Seventy-nine per cent (N = 90) of the respondents worked with patient participation on a daily basis, 17% (N = 19) did it sometimes, and 3% (N = 3) answered that they did not work with patient participation. Two per cent did not answer the question. 56% (N = 64) had not read about, or received, information about the Patient Participation Act (Patientlag, 2014).

3.2 | Findings related to patient participation

No prominent differences emerged between nurses and occupational therapists regarding patient participation. However, there was a difference in how well they expressed what they meant was important knowledge, or information, regarding the patient to facilitate patient participation. The occupational therapists focused largely on knowledge about habits, roles and important activities for the patient. The nurses said that it was important to listen to the patients' experiences, but did not specify what kind of knowledge was important to facilitate patient participation.

The two main themes are illustrated in the thematic map in Figure 1. The themes cover a continuum. On one extreme, patient participation is equated with making the patient comply with what the professionals want to do. On the other extreme, all power is handed over to the patient. The themes are separated by their focus, where the first theme puts the professional at the centre and is

Compliance Power shift

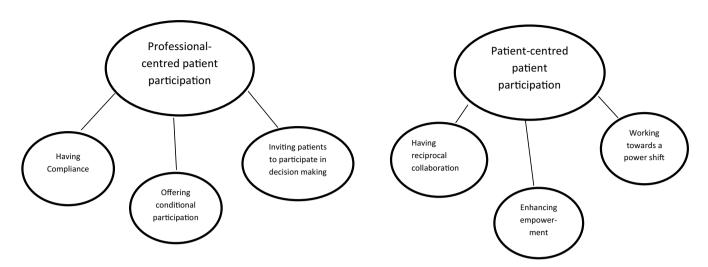


FIGURE 1 The continuum of patient participation. Themes and sub-themes

restricted to the decision-making process. The second theme puts the patient at the centre and covers the entire care, or rehabilitation, process. Each theme is described below with quotations from nurses and occupational therapists (OT).

3.2.1 | The professionals' perspective at the centrePatient participation to enhance compliance

This theme was characterized by its professional-centred focus where the professionals' perspective was more important. Another characteristic was the view of patient participation as restricted to participation in a specific part of the care process, the care decision-making process.

The respondents described how they decided the agenda and to what extent the patient could participate. Compliance was described as central, and interaction with the patient aimed to help the patient see why their suggestions had to be followed. Thus, this theme had a clear focus on the professional and what he/she thought. To achieve compliance, the respondents stated that they used an instructive approach in the interaction with the patient. According to respondents, decisions were documented in the patient's medical record to show that they had involved the patient in care decisions. Some respondents' answers seem contradictory. They stated that patient participation was not something they thought about in their daily work, but at the same time, they gave examples of patient participation related to decision-making. The respondents found that information provided by professionals was central in this theme, and three different sub-themes related to information were identified in the respondents' descriptions where the first sub-theme represented one extreme of the continuum. The sub-themes were as follows: Having compliance, offering conditional participation and inviting patients to participate in the decision-making process.

Having compliance

The first sub-theme was characterized by providing information with the aim of receiving legitimacy for the care the professional wanted to offer and making the patient understand why he/she had to accept and comply with such care:

The patient receives information about the care in order to understand what is going to be done (nurse).

From the descriptions, the patient appeared to be more of an attendant rather than being involved. The professional wanted to receive the patient's approval for the care:

I always tell the patient what I want myself and the patient to do and also ask if the patient wants to do this (OT).

Offering conditional participation

The second sub-theme could be described as conditional participation where the respondents chose which options would be presented to the patient. In these options, the patient could choose which one he/she liked best:

I usually talk to the patient about various treatments or alternatives that exist to provide the patient's care and let the patient be involved as well as possible (nurse).

Inviting the patient to participate in the decision-making process

The third sub-theme described a more collaborative approach to decision-making where the respondents stated that they invited the patient to discuss what goals were central to the care or rehabilitation and then offered suggestions that were discussed in

dialogue. The patient and the professional made a mutual decision that was documented in the patient's care plan and medical record:

Together with the patient, we work on a rehabilitation plan based on the patient's goals and treatment expectations (OT).

3.2.2 | The patients' perspective at the centre – Patient participation as an ongoing process

This theme was characterized by its focus on the entire care process, not restricted to decision-making but covering all interaction with the patient during care. An antecedent for the theme was the focus on reciprocal collaboration that was based on the patient's perspective, with the goal that patients should own their own care process. The respondents empowered the patient and saw themselves as a role model for other professionals in terms of patient participation and tried to visualize this through their actions in relation to both patients and colleagues. Patient participation was not restricted to any specific part of the care process but an ongoing process covering all encounters. The sub-themes, Having reciprocal collaboration, enhancing empowerment and working towards a power shift, describe how the respondents worked in deliberately to reach what they thought was the goal of patient participation – a power shift.

Having reciprocal collaboration

This first sub-theme was characterized by the respondents' efforts to adopt the patient's perspective and create a collaborative relationship. They described that they listened actively and used conversation as a means of informing themselves about the patient's views regarding their needs and goals. Participation was considered an always present process from first to last contact, meaning that there was an ongoing process to enhance patient participation. By treating the patient as an equal, the respondents stated that they tried to show the patient that he/she was at the centre. The patient made the decisions with the support of the professional:

I ask the patient to describe how he/she lived and carried out different activities earlier in life in order to give me an idea of what the patient wants today. What are the patient's current habits? What does he or she want to do today?(OT)

Enhancing empowerment

Empowerment and autonomy regarding care were seen as important and form the second sub-theme. The respondents stated that they continuously worked actively to help the patient feel competent. The respondents emphasized the importance of participation and that their role was to be there for the patient. One way

of showing this was to explain why the patient's participation was important:

I talk with the patient and point out that his/her opinion is important and that my work is based on the patient's needs, experiences, habits and roles (OT).

Through their actions in daily work, the respondents tried to visualize their participatory focus and some of them considered themselves to be role models for assistant nurses by showing them how to work in a patient-centred way:

When I cooperate with colleagues, I am clear that I see patient participation as a natural part of the care relationship (nurse).

Working towards a power shift

In the third sub-theme, some respondents described that they went beyond empowerment and described an ongoing process towards a power shift where they handed over power to the patient. They regarded themselves as performers that realized the patient's will. In this approach, they also regarded themselves as advocates for the patients and acted as representatives of the patients towards other groups of professionals or persons:

...[the patient is] like a conductor and those of us working around the patient are the instruments that will make the desired musical sound (nurse)

4 | DISCUSSION

The aim of this study was to describe how nurses and occupational therapists in municipal care of older people describe and implement patient participation in their daily work. The findings showed two themes: one illustrating a professional-centred perspective with a primary focus on nurses and occupational therapists and another illustrating a patient-centred perspective focusing on the patient. These two themes are on a continuum between viewing patient participation as making the patient compliant and a power shift where the patient controls the care. Previous studies on patient participation in municipal care of older people have primarily focused on barriers (Aasen et al., 2012; Larsson et al., 2011); (Dyrstad et al., 2015; Garcia et al., 2016; Wikström & Emilsson, 2014) and less on how professionals work. This study adds knowledge that could be valuable in developing patient participation in municipal care of older people.

Our findings showed a divided picture of how the respondents viewed and worked with patient participation. The theme "The professionals' perspective at the centre," were primarily about information to the patient during the decision-making process. An informed patient is central in the Patient Act (Patientlag, 2014), and previous research on patient participation has focused on receiving information (Ekdahl et al., 2010) and involvement in decision-making (Foss, 2011; Ringdal et al., 2017). A patient can participate on different

levels, either as an attendant or through involvement, where the latter presumes engagement, self-esteem and social connection (Imms et al., 2017). Our findings showed that the respondents regarded the patient as an attendant in care and that they had to make them comply and/or notify them about what the professional had decided to do. The third category had more elements of involvement although these were still in a delineated part of the care. This is not sufficient to fulfil the requirements of the Patient Act (Patientlag, 2014). Patient participation at the level of involvement in the entire care process is necessary. The second theme "The patients' perspective at the centre" covers the entire care process and describes how the professionals actively worked to involve the patient and create an equal relationship where they tried to enhance empowerment and work towards a power shift. The findings in this theme fulfil most of the intentions of the Patient Act where the patient is involved in the entire care process (Patientlag, 2014). However, too many professionals do not work as the Patient Act intend. The reasons may vary, and some of them - healthcare culture and emotional engagement - are discussed below.

Historically, the culture in health care has been directed towards a self-focused exercise of the professions where the patients are subordinate and are expected to follow the professionals' instructions. These expectations or conceptions are, in many ways, rooted in healthcare organizations and maintained by both professionals and patients. Changing such an approach is not easy. In Sweden, the impact of the Patient Act has been investigated in hospital care (Myndigheten för vårdanalys [The Swedish Agency for Health & Care Services Analysis], 2015). The results are discouraging. Little has happened, and managers pay minimal attention and attach little importance to patient participation. The Act is described as having no impact and that the patient's position has not been strengthened, it has remained unchanged or has even weakened (Myndigheten för vård- och omsorgsanalys [The Swedish Agency for Health and Care Services Analysis], 2017). As the priority of patient participation in municipal care of older people has not been investigated, it is not possible to draw any conclusions. However, our findings indicate a need for change of culture that permeates all care of older people. This is threatened by the fact that today's organizations are in a state of continuous quality development with primary focus on productivity and efficiency. Too much focus on efficiency may negatively affect the professionals' emotional engagement towards patients. Artificial intelligence (AI) has already made its entry in care of older people and is supposed to be one key to the challenges in future health care in general and in care of older people specifically. However, to rely on, that is, clinical decision support systems is a potential threat to patient participation. Automatic suggestions for one treatment make the professional less open to other possible treatments. There is also a risk that professionals will be even more focused on themselves and the AI instead of the patient. Communication and reasoning between patients and professionals and establishing a professional and therapeutic relationship is hard to replace with Al. Therefore, a cohabitation between AI and professionals has been suggested (Reddy, 2018). However, the risks of being technical and professionally

focused are still there and need to be accounted for in the development of such models.

Our findings can be seen as illustrating where professionals' emotional engagement lies and can be discussed in relation to Morse's model of emotional engagement (McCabe & Timmins, 2013; Morse, Bottorff, Anderson, O'Brien, & Solberg, 1992). The model differs from being patient-focused versus professional-focused, in both cases on two levels. Being patient-focused on a primary level means being genuinely committed emotionally and being focused on the patient's response. This is in line with the theme; the patients' perspective is at the centre of the reciprocal collaborative relationship between patient and staff, where staff enhance empowerment and work towards a power shift. This theme can also be seen as an illustration of the concept of patient participation, as defined by Sahlsten et al. (Sahlsten et al., 2008). However, this focus requires emotional energy and strength, which is exhausting. To protect themselves, professionals learn to be patient-focused on a secondary level. They can share personal experiences, empathy, humour and use encouragement and informative reassurance. However, this kind of behaviour is taught and involves a pseudo engagement and a distance that results in the patient possibly not being convinced that all his/her concerns have been taken into account (Morse et al., 1992), due to a lack of engagement on the part of the professional.

To be professionally focused on a primary level means that professionals protect themselves from becoming emotionally involved with the patients. They dehumanize the patient, create distance and become "busy professionals." This could be in line with the theme; the professionals' perspective is at the centre. The professionals said that the patient had to accept and comply. However, they offered conditional participation by inviting the patient to participate in decision-making, but they kept the power themselves. This can be interpreted as the professionals being partly engaged but not reaching the secondary level.

On a secondary level, it means a mechanical response where the patient is objectified and faced with an artificial sense of compassion and false encouragement (McCabe & Timmins, 2013; Morse et al., 1992). This could result in the patient not telling the professional how he/she feels physically or mentally (McCabe & Timmins, 2013). Our findings not only illustrate that professionals take a stand and choose how they want to work, but are also much more complex. Being professionally focused requires less emotional engagement. Thus, it can be a way of avoiding stress-related illness. A work situation that is too demanding can transform a previously patientfocused professional into a self-focused professional, as a survival strategy. Previous research has shown that to work with older patients in a person-centred way, moral stress decreases (Sjögren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2015) and job satisfaction increases (Ericson-Lidman & Strandberg, 2013). However, working in a person-centred manner presupposes a power shift from the professional to the patient, which is in line with our results where patient participation should be seen as an ongoing process, in a reciprocal collaboration, covering all encounters. It is important to emphasize to managers and organizations that prioritizing patient participation with the patient in focus is essential in sustainable care of older people.

The power shift is central in the Swedish Patient Act (Patientlag. 2014) and in the literature on patient participation (Sahlsten et al., 2008). The intention of the Act, to shift power to the patient, is perhaps even more important in care of older people. Professionals work in the patients' homes and, in this sense, are guests. From a human geographical perspective, it can be explained by place and space (Clifford, Holloway, Rice, & Valentine, 2008). For the patient, the home is a place, a final destination where they spend most of their time. For the professional, the patient's home is a space, one of many spaces, that they travel through as a temporary guest during a working day. It is important that the professional values the patient's home as a place where the patient is in charge. In person-centred care, the older person should possess the power and not have to adapt to the professional. However, we found that the patient does not always have the power. The professionals could decide the agenda and to what degree the patient participate. This may be due to the traditional perspective that older persons who are chronically ill are seen as dependent, vulnerable and passive where it is the professionals that make the assessment (Halskov et al., 2017). There is a risk of dehumanization when professionals think that older persons are too ill to participate (Wikström & Emilsson, 2014) or suffer from cognitive impairment and are not able to make decisions and therefore not involved in their care (Poulos et al., 2017). However, even older persons with dementia might be able to participate since their capacity for decision-making varies from day to day (). Our findings may indicate that in municipal care of older people there is a need to develop the professionals' awareness and provide opportunities and strategies to work towards the power shift. However, patient participation is not only important for older patients, but also for all patients regardless of age. It is reasonable to believe that our findings can also be relevant for patients of all ages.

4.1 | Methodological considerations

The choice of respondents was based on that nurses and occupational therapists are responsible for the planning and implementation of care and rehabilitation in the current municipality and should be a part of the daily work. This could be considered a limitation, and another approach could have been to include assistant nurses as they are closest to the patient (James, Fredriksson, Wahlström, Kihlgren, & Blomberg, 2014). However, they are not responsible for the care and depend on nurses and occupational therapists in respect of how to carry out the care. Nevertheless, it is first when a consensus prevails regarding values, attitudes and terminology that it can be possible to fully implement person-centred care (Wolf, Ekman, & Dellenborg, 2012). Therefore, in future studies it is important to examine assistant nurses' perspective, as well as other consultative professions.

Different ways of including nurses and occupational therapists were used in this study. Forty-three per cent of the occupational therapists responded, which is slightly higher than the mean response rate for web surveys in general (Shih & Fan, 2008). For the nurses, the calculation of the response rate was difficult. If we assume that all nurses received the inquiry, the response rate would be 33%. However, we could not verify whether all unit-coordinating nurses forwarded the inquiry and it is reasonable to believe that some nurses were not reached. This is a limitation of this study. Our findings did not reveal any differences between the professions in regard to patient participation. However, this study was quite small, and in future studies, it would be interesting to separate nurses and occupational therapists.

There was an advantage that the respondents answered the questionnaire anonymous, which we believe contributed to that the self-focused perspective has also been made visible. There could be a risk of a "bias" in interviews, because only those who are interested in the issue might participate. A disadvantage is that the results have less depth. On the other hand, the survey gives a more transferable result

In conclusion, this study contributed with findings showing that nurses and occupational therapists work with patient participation in both a professionally centred and a person-centred way. They are on a continuum from compliance to power shift. To work in a personcentred way and thereby fulfil the requirements (Patientlag, 2014) regarding patient participation, focus needs to shift from focus on the professional to focus on the patient. This might seem easy but is a challenge in today's healthcare environment where much effort is put into doing the right things in terms of documentation requirements, efficiency and economy. Regulations alone cannot change a culture. Structural changes are needed to ensure that support systems, such as AI, are designed in a way to permit person-centred care. It must be done actively by professionals who do not focus on themselves or firstly on productivity and efficiency. It requires an emotional engagement where the power is handed over to the patient in person-centred care.

ACKNOWLEDGEMENTS

This study was supported by School of Health Sciences and University Health Care Research Center, Faculty of Medicine and Health, Örebro University, Sweden.

CONFLICT OF INTEREST

The authors report no conflict of interest.

AUTHOR CONTRIBUTION

All authors have contributed significantly and are in agreement with the content of the manuscript.

ETHICAL APPROVAL

According to the Swedish Ethical Review Act about research on humans, research into healthy adults involving no sensitive personal

data does not fall under the Act. Consequently, no Research Ethics Committee approval was obtained. The ethical principles of the Helsinki declaration were followed.

ORCID

Kajsa Lidström Holmqvist https://orcid.org/0000-0002-5799-3045

REFERENCES

- Aasen, E. M., Kvangarsnes, M., & Heggen, K. (2012). Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. Scandinavian Journal of Caring Sciences, 26(1), 61–69.
- Algilani, S., James, I., & Kihlgren, A. (2016). Experiencing participation in health care: "through the eyes of older adults". Open Journal of Nursing, 6, 62–77.
- Aveling, E.-L., & Jovchelovitch, S. (2014). Partnerships as knowledge encounters: A psychosocial theory of partnerships for health and community development. *Journal of Health Psychology*, 19(1), 34–45.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Clifford, N., Holloway, S., Rice, S. P., Valentine, G. (2008). Key concepts in geography. London, UK: Sage.
- Dent, M., & Pahor, M. (2015). Patient involvement in Europe-a comparative framework. *J Health Organ Manag*, 29(5), 546-555.
- Dyrstad, D. N., Testad, I., Aase, K., Storm, M. (2015). A review of the literature on patient participation in transitions of the elderly. *Cognition*, *Technology* & *Work*, 17(1), 15–34.
- Edhlund, B., & McDougall, A. Nvivo 11 essentials. Lulu. com; 2017.
- Ekdahl, A. W., Andersson, L., & Friedrichsen, M. (2010). "They do what they think is the best for me". Frail elderly patients' preferences for participation in their care during hospitalization. *Patient Education* and Counseling, 80(2), 233–240.
- Ericson-Lidman, E., & Strandberg, G. (2013). Dealing with troubled conscience in municipal care of older people. *Nursing Ethics*, 20(3), 300–311.
- Foss, C. (2011). Elders and patient participation revisited–a discourse analytic approach to older persons' reflections on patient participation. *Journal of Clinical Nursing*, 20(13–14), 2014–2022.
- Foss, C., & Hofoss, D. (2011). Elderly persons' experiences of participation in hospital discharge process. *Patient Education and Counseling*, 85(1), 68–73.
- Fredriksson, M., Eriksson, M., & Tritter, J. (2018). Who wants to be involved in health care decisions? Comparing preferences for individual and collective involvement in England and Sweden. *BMC Public Health*, 18(1), 18.
- Garcia, T. J., Harrison, T. C., & Goodwin, J. S. (2016). Nursing home stakeholder views of resident involvement in medical care decisions. *Qualitative Health Research*, 26(5), 712–728.
- Halskov, G., Lauridsen, S., & Hoffman, P. K. (2017). Patient involvement in home health care: Elderly patients' perspectives on roles and responsibilities in the collaboration with home care nurses. *International Journal of Integrated Care*, 16(6), 1–8.
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19), 1445–1460.
- Hedman, M., Pöder, U., Mamhidir, A. G., Nilsson, A., Kristofferzon, M. L., & Häggström, E. (2015). Life memories and the ability to act: The meaning of autonomy and participation for older people when living

- with chronic illness. Scandinavian Journal of Caring Sciences, 29(4), 824–833.
- Holmqvist, K., Holmefur, M., & Ivarsson, A. B. (2013). Therapeutic use of self as defined by Swedish occupational therapists working with clients with cognitive impairments following acquired brain injury: A Delphi study. Australian Occupational Therapy Journal, 60(1), 48–55.
- Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2017). Participation, both a means and an end: A conceptual analysis of processes and outcomes in childhood disability. Developmental Medicine and Child Neurology, 59(1), 16–25.
- James, I., Fredriksson, C., Wahlström, C., Kihlgren, A., & Blomberg, K. (2014). Making each other's daily life: Nurse assistants' experiences and knowledge on developing a meaningful daily life in nursing homes. The Open Nursing Journal, 8, 34.
- Lag om etikprövning av forskning som avser människor. Lag om etikprövning av forskning som avser människor [Law on ethical approval for research on humans], SFS 2003:460 (2003).
- Larsson, I. E., Sahlsten, M. J., Segesten, K., Plos, K. A. (2011). Patients' perceptions of barriers for participation in nursing care. Scandinavian Journal of Caring Sciences, 25(3), 575–582.
- McCabe, C., & Timmins, F. (2013). Communication skills for nursing practice. New York: Palgrave Macmillan.
- Morse, J. M., Bottorff, J., Anderson, G., O'Brien, B., Solberg, S. (1992). Beyond empathy: Expanding expressions of caring. *Journal of Advanced Nursing*, 17(7), 809–821.
- Moser, A., Houtepen, R., Spreeuwenberg, C., Widdershoven, G. (2010). Realizing autonomy in responsive relationships. *Medicine, Health Care and Philosophy*, 13(3), 215–223.
- Myndigheten för vård- och omsorgsanalys [The Swedish Agency for Health and Care Services Analysis]. (2017). Lag utan genomslag. Utvärdering av patientlagen 2014-2017 [Law without impact: Evaluation of th Patient Act]. Rapport 2017:2: Myndigheten för vård- och omsorgsanalys [The Swedish Agency for Health and Care Services Analysis]; [cited 2017 December 5]. Available from: https://www.vardanalys.se/wp-content/uploads/2017/03/2017-2-Lagutan-genomslag-webb.pdf
- Myndigheten för vårdanalys [The Swedish Agency for Health and Care Services Analysis]. Patientlagen i praktiken en baslinjemätning. Patient Act in practice: A baseline measurement. 2015:1 Stockholm: Myndigheten för vårdanalys [The Swedish Agency for Health and Care Services Analysis]; 2015 [cited 2015 November 21]. Available from: https://www.vardanalys.se/wp-content/uploads/2017/12/2015-1-Patientlagen-i-praktiken.pdf
- Myndigheten för vårdanalys [The Swedish Agency for Health and Care Services Analysis]. Vården ur befolkningens perspektiv 2016 en jämförelse mellan Sverige och tio andra länder. [Health care from the perspective of the population 2016 -A comparision between Sweden and ten other countries] Stockholm: Myndigheten för Vårdanalys [The Swedish Agency for Health and Care Services Analysis]; 2016.
- Patientlag. Patientlag [Patient Act]. SFS 2014:821. (2014).
- Poulos, C. J., Bayer, A., Beaupre, L., Clare, L., Poulos, R. G., & Wang, R. H., ... McGilton, K. S. (2017). A comprehensive approach to reablement in dementia. Alzheimer's Dementia, 3(3), 450–458.
- Programme OotHRP. Guidance and procedure: Research involving perosns with cognitive impairments. University of California, Los Angeles.
- Reddy, S. (2018). Use of Artificial Intelligence in Healthcare Delivery. [cited 2019–03-21]. In T. F. Heston eHealth -Making Health Care Smarter [Internet] (pp. 82–97). London, UK: IntechOpen. Available from: https://www.intechopen.com/books/ehealth-making-healt h-care-smarter/use-of-artificial-intelligence-in-healthcare-delivery
- Renedo, A., Marston, C. A., Spyridonidis, D., BarlowJ. (2015). Patient and Public Involvement in Healthcare Quality Improvement: How organizations can help patients and professionals to collaborate. *Public Management Review*, 17(1), 17–34.

1179

- Ringdal, M., Chaboyer, W., Ulin, K., Bucknall, T., & Oxelmark, L. (2017). Patient preferences for participation in patient care and safety activities in hospitals. *BMC Nursing*, 16(1), 69.
- Sahlsten, M. J., Larsson, I. E., & Sjöström, B., Plos, K. A. editors. An analysis of the concept of patient participation. *Nursing Forum*. 2008; 43:2–11: Wiley Online Library.
- Shih, T.-H., & Fan, X. (2008). Comparing response Rates from Web and Mail Surveys: A meta-analysis. *Field Methods*, 20(3), 249–271.
- Sjögren, K., Lindkvist, M., Sandman, P. O., Zingmark, K., & Edvardsson, D. (2015). To what extent is the work environment of staff related to person-centred care? A cross-sectional study of residential aged care. *Journal of Clinical Nursing*, 24(9–10), 1310–1319.
- Smebye, K. L., Kirkevold, M., & Engedal, K. J. (2012). How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Serv Res.*, 12(1), 241.
- Statens offentliga utredningar. SOU 2013:2. Delbetänkande av Patientmaktsutredningen [Partial report of the Patient Authorization]. In: Socialdepartementet, editor. Stockholm: Regeringskansliet; 2013.
- Svensk sjuksköterskeförening. (2014). Kompetensbeskrivning för legitimerad sjuksköterska [Competence description for registred nurse]. Stockholm: Svensk sjuksköterskeförening.
- Swedish Association of Occupational Therapists. (2016). Competence descriptions for ocupational therapists. Nacka, Stockholm: Sveriges Arbetsterapeuter.
- Taylor, R. (2008). The intentional relationship. Occupational Therapy and Use of Self. Philadelphia, PA: F.A. Davies Company.

- Vicente, V., Castren, M., Sjöstrand, F., Sundström, B. W. (2013). Elderly patients' participation in emergency medical services when offered an alternative care pathway. *Int J Qual Stud Health Well-Being*, 8(1), 20014.
- Wikström, E., & Emilsson, U. M. (2014). Autonomy and control in everyday life in care of older people in nursing homes. *Journal of Housing* for the Elderly, 28(1), 41–62.
- Wolf, A., Ekman, I., Dellenborg, L. (2012). Everyday practice at the medical ward: A 16-month ethnographic field study. *BMC Health Serv Res*, 12. 184.
- World Health Organization. WHO global strategy on people-centred and integrated health services: Interim report. 2015.
- World Medical Association. World Medical Association Declaration of Helsinki. Ethical principles for medical research involving human subjects. *Bulletin of the World Health Organization*, 2001;79(4):373.

How to cite this article: Holmqvist KL, James I. Patient participation in municipal elderly care from the perspective of nurses and occupational therapists. *Nursing Open*.

2019;6:1171-1179. https://doi.org/10.1002/nop2.302