Registered Nurses’ experiences of patient participation in hospital care: supporting and hindering factors patient participation in care

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Background: Promoting patient participation in care is an international priority identified by the World Health Organization and various national bodies around the world and an important aspect of person-centred care. 

Aim: The aim of this study was to describe Registered Nurses’ experiences with patient participation in nursing care including their barriers and facilitators for participation.

Method: The study setting was a University Hospital in Sweden. Interviews were conducted with twenty Registered Nurses working at medical wards in 2013. Thematic data analysis was used to analyse the transcribed interview data.

Results: Twenty nurses from four wards in two hospitals were included. Five themes emerged from the analysis including listening to the patient, engaging the patient, relinquishing some responsibility, sharing power and partnering with patients. The core theme ‘partnering with patients’ was enacted when nurses listened to and engaged patients and when they relinquished responsibility and shared power with patients. In addition, hindering and facilitating factors to participation were identified, such as patients wanted to take on a passive role, lack of teamwork which participants understood would enhance interprofessional understanding and improve patient safety. Patient participation was hindered by medical jargon during the ward round, there was a risk of staff talking over patients’ heads but sometimes inevitable having conversations at the patient’s bedside. However, nurses preferred important decisions to be made away from bedside.

Conclusions: It all came down to partnering with the patient and participants described how they made an effort to respect the patients’ view and accept patient as a part of the care team. Identified hindering factors for participation were lack of teamwork, patients’ taking on passive roles and communication during ward rounds having conversations at the patient’s bedside. Nurses wished for a change but lacked strategies on how. Nurses preferred important decisions to be made away from bedside.

Keywords: nurses, patient participation, care, partnering with patients, obstacles, enablers.

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Introduction

Promoting patient participation in care (PPC) is an international priority identified by the World Health Organization and various national bodies around the world (1, 2), and an important aspect of person-centred care (3, 4). The defining features of patient participation in the context of nursing care include the need to have an established relationship between the patient and nurse, the surrendering of some power or control by the nurse to the patient, the sharing of information and knowledge between patients and nurses and finally active mutual engagement in either intellectual or physical activities (5). Thus, PPC may involve participation in decision-making (6, 7) as well as other aspects of care, including patients monitoring their progress and the
effects of care and by providing suggestions for improving care (8). Ultimately patient participation contributes to the patients’ own safety (9, 10).

The body of literature on patient participation, both theoretical and empirical, has burgeoned in the past decade or so, resulting in a number of reviews and other analytic papers. In two reviews, patient participation was examined in its own right (11, 12). From their review of 33 studies, Angel et al. identified five key elements of patient participation: the patient’s situation, time, knowledge from the patient’s and nurse’s perspective, the nurse’s attitude and the relation. Tobiano et al. concluded that both patients and nurses on medical wards desire patient participation but patient willingness and nurses’ approach may challenge active participation. Patient participation has been examined in relation to patient safety activities, sometimes using the terms involvement and engagement, yet still including participation in their analyses (9, 13–15). Its relationship to other concepts such as empowerment (16), engagement (17), involvement (18) and patient-centred care (19, 20) has also been examined. In a review of 286 studies and concept map, participation was identified as a behaviour associated with patient enablement, empowerment and engagement (16). In another review of 60 papers, patient participation was identified as a core component of patient-centred care (19), whereas in another systematic review and concept analysis of 417 articles, the term ‘involvement’ was captured in two of 15 dimensions of patient-centred care (20). Overall, this body of work clearly suggests there are multiple conceptualisations of patient participation, with no clear consensus of its distinction from related concepts. In fact, a recent analysis suggests terms such as partnerships and involvement integral to the concept of ‘person-centred participation in health care’. Although the terms participation and involvement are often used interchangeably, the term ‘partnership’ is a related but different to these former concepts. Theoretically, patient participation may be enhanced when patients feel as if they are partners with nurses in their care and vice versa, but previous research and analyses on participation focuses on the need for positive relationships, rather than partnerships. Thus, while participation and partnerships are related, the causal link between the two has not been established (21).

This body of theoretical work has drawn on a large and diverse body of empirical research. However, there have been a number of studies conducted specifically to understand patients’ views of participation. Patients and families opinions on participation in specific clinical activities have also been studied, such as bedside handover (22, 23), ward round (24) and decision-making (25–27). There have also been recent studies focusing on patient participation in nursing care in general (28). Some of this work has focused on patients (29) or nurses perspective (30), whereas others have compared the two (28). To date, this body of work suggests that there is a continuum of participation, with some patients preferring active participation while others prefer passive. This work also suggests that there are both benefits and challenges of patient participation. For example, when patient participation is promoted, there is better sharing of important clinical information (11).

It would appear self-evident that there must be a willingness on the part of the nurse to allow patients to participate in care. An early qualitative study of four nurses working on rehabilitation wards in an English hospital identified that nurses thought patient participation involved both formal and informal information exchanges and included involving patients in both care planning and caregiving (31). A decade later, in early 2000s, an Australian study used focus groups of 20 nurses and observation to explore nurses perceptions and behaviours towards partnering with patients (7). Nurses in this study thought patient participation was important and wanted to support it. Yet, nurses’ attitudes may not be congruent with their actions and behaviours. Observations showed that nurses did not involve patients in decision-making, nor did they respond to patients’ attempts for communication (7). Another Australian study reported elderly patients in acute health care viewed nurses as experts and understood that as ‘patients’ they should do as they were told (32). Furthermore, as they saw nurses to be very busy, patients became more passive (32). Challenging factors for patient participation have been shown to include patients’ willingness, nurses’ approach and confusion around expectations and roles (11). Finally, an international survey of 536 nurses and 468 physicians at four hospitals in four countries found over 90% of nurses said it was important to ask about and respond to patients’ expectations, yet only 20% reported routinely asking patients what their expectations of hospital were (33). Given this emerging, disperse body of knowledge, and limited understanding of the barriers and facilitators to patient participation in the Swedish context, the current study aims to understand Registered Nurses’ experiences of patient participation in care. This can provide a foundation to support the nurse–patient relationship and improve participation in co-creation with patients both in a national and international context.

**Aim**

The aim of the present study was to describe Registered Nurses’ experiences of patient participation. Specific research questions were

1. What are nurses’ experiences of patient participation in nursing care and what influences these experiences?
2 What activities do nurses associate with patient participation in nursing care and what influences participation in these activities
3 What do nurses’ perceive to be the barriers and facilitators of patient participation in nursing care?

Methods

This interpretive study used thematic analysis to understand nurses’ experiences of PPC. A thematic analysis is a method for identifying, analysing and finding patterns (themes) within the collected data (34). Thematic analysis organises and describes the data in rich detail and interprets various aspects of the research topic (35).

Setting and sample

The study was set in two public hospitals, both part of a University Hospital setting, Sweden. The two hospitals are geographically diverse, but in the same city, admitting similar kind of medical patients, although the catchment areas varied in terms of socio-economic groups. Together, the University hospital employs about 5300 nurses and approximately 80 Registered Nurses were employed on the specific wards. Information (oral and in writing) about the study and invitation to participate was presented to nurses in staff meetings at the wards, by two of the researchers (LO, MR). In discussion with team leaders at each hospital to whom the nurses had shown interest to participate in the study, a purposive sample of Registered Nurses, working at four medical wards (two at each hospital), were invited to participate in the study. Nurses of different age, gender and work experience were approached to ensure variation and enrichment of data (36). Twenty-six nurses agreed to participate initially; however, six of those declined participation due to lack of time or no interest of the subject. Finally, twenty nurses participated in the study, five from each ward. The interviews were conducted independently by all authors and continued until no new subcategories emerged and there was comparative quotations. To strengthen credibility, the analysis was conducted within the research team. Examples of questions are as follows: Please tell me what patient participation in patient care means to you? What are some examples of how patients currently participate in their hospital care? What are some examples of patient participation that you get patients to undertake? How do you go about encouraging these forms of patient participation? What things would help you to make the patient participate in care? What is hindering patient participation at your workplace? Interviews took place at a time and place of mutual convenience at the hospital and lasted about 30 minutes. The interviews were digitally recorded and transcribed verbatim. Demographic data about the participants were collected before starting the interview.

Data analysis

The data transcriptions comprised 123 pages. Thematic data analysis (34) with an inductive approach was used to analyse the interview data. Data were sorted into two groups; nurses’ description of their experiences of patient participation, and their perceptions of barriers and facilitators of patient participation. The data from each group were analysed. We analysed the data transcript by transcript in an iterative manner, returning to previous transcripts to assess similarities and differences in codes and themes as they were emerging. Thus, we used the constant comparative method to identify and evaluation differences and similarities in transcripts. The themes formed the basis for the presentation of the results with a selection of illustrative quotations. To strengthen credibility, the analysis was conducted independently by all authors and continued until no new subcategories emerged and there was agreement on final themes. To promote trustworthiness of the data, we used a purposive sample reflecting a variety of nurse characteristics and experiences.

Ethical considerations

The study was approved by the Ethical Review Board of the University of Gothenburg. (Application No 693-13) and conformed to the Declaration of Helsinki (38).
Participants were given both written and verbal information about the study, and were informed that participation was voluntary and they could refrain from participation at any time without consequences. All participating nurses gave informed consent.

Findings

Five themes emerged from the analysis including listening to the patient, engaging the patient, relinquishing some responsibility, sharing power and partnering with patients (Fig. 1). This final partnering with patient theme appeared to be contingent on the enactment of the other four themes. In addition to these themes, nurses perceived both hindering and facilitating factors to patient participation.

The theme listening to the patient reflected the nurses’ willingness and experiences of patient participation in nursing care, to get to know the patient and their goals, plans and preferences. Participants described how they spent time with the patient in order to connect with them, using questioning to draw the patient into conversation and learn about the patients’ views. They viewed the patient as a resource and by understanding the patient; they were better able to do their job. Some also described how the patient could correct inaccuracies. By checking with the patient, nurses thought they could better tailor their care to the patient. Participants noted that taking the time to get to know the patient was an investment that paid off in terms of easing nurses’ work.

When I stand in front of a patient, I take a deep breath and stay there until he or she seems to have said all there is to be said. Sometimes this tests my patience but it’s well worth it, pays it off /206

The best reminder is the one from the patients, you notice when you’re a bit too quick, and don’t discuss enough with them, everything takes more time and the climate becomes a bit bad and not as good as it could be... if this happens I often sit down for a chat and things turn out fine. It’s exactly this that patient participation is -when you communicate with each other. /201

Engaging the patient, the second theme, indicated the activities nurses used trying to involve patients in their care and plans for future care. By providing options and allowing patients to choose, nurses promoted active patient involvement. They suggested it was important to portray a permissive attitude, allowing patients to ask questions, seek advice and state their opinions. Participants used a number of tools to engage patients, such as the shared use of communication boards, diaries, care plans and transfer summaries. For the most part, they facilitated communication and information sharing. But a few participants said that by simply informing patients of plans, they were engaging patients. They used open questions, to let patients tell their story.

To let the patient be a part of the planning, in three days we think you may be well enough to start planning discharge, and to be part of the planning on a daily basis. /204

What investigations are being discussed, and why and how do we reason about this, that they are part of it. 104

By asking patients of previous risk incidents, patient safety could be improved. Nurses described they could see that this old lady might be at risk of falling, so by asking the patient of previous incidents of falling, further strategies could be implemented to prevent falls. Another important issue for patient safety was instructing patients to use the bell to call the nurse whenever needed. A well-informed patient contributed to patient safety.

The third theme relinquishing some responsibility captured nurses’ desire to have patients actively undertake some of the tasks and activities nurses generally performed. It involved helping patients understand what needed to be done and encouraging patients to help themselves when possible.

Today we do work a lot to get patients’ involved in decision making, to do their own care planning, since there are quite a few who says no to investigations, which also is a kind of participation. /208
While for the most part participants spoke positively about sharing responsibility with patients, a few seemed to see it as opportunities for nurses to lessen their work, expecting patients to take on some of ‘their duties’.

Yes, some of them [patients] are almost shocked when I tell them to make up their own beds. One of my patients dropped his jaw the other day when I told him I wouldn’t make up his bed, ‘as you could very well do it yourself’… and if you have the strength to do it you can do it yourself…” /205

Sharing power, the fourth theme, reflected nurses’ willingness to surrender some of their power to the patient. They described how they willingly shared information with patients, updating them on plans and options. Participants asserted that if patients understood their own conditions and were part of discussions, they would more likely adhere to treatment plans. Some participants described how they respected the patient’s choices and decisions, even if they did not agree with them. But, participants also believed that because of their professional knowledge, there were some areas in which patients were experts in living with their own medical conditions.

They really do trust us that much. /106

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Factors hindering and facilitating patient participation

Hindering factors. Participants identified a number of hindering factors to be overcome in order to facilitate patient participation (Fig. 1). Some of these obstacles related to the patient characteristics’, such as his/her physical condition, cultural background and language as well as their understanding of their condition. When patients lacked this understanding, participants thought patients were less able to participate in their own care. Participants suggested some patients were not interested in actively becoming involved in their own care, preferring to take on the ‘traditional’ passive patient role.

I’m fascinated by patients who just kind of ‘accept’ everything we say, and so many of them just take the mug with pills and swallow without asking. They really do trust us that much. /110

Other hindering factors related to the nature of the work, the ward routines, with engrained nursing routines and a traditional culture of not involving the patient acting as a deterrent to patient participation. The way the ward round was performed was perceived as hindering patient participation, and there were time constraints. There were not enough time for shared conversations between patients, physicians and nurses. To start the round early in the morning, discussions between physicians and nurses took place in a room away from the patients’ bedside. Then, when they did approach the bedside, they had a brisk conversation from which the patients were ‘locked out’ and after this there was a ‘walk around’.

For true partnerships to occur, participants said they had to understand patients’ expectations and their goals. This understanding of who the patient is influences patients’ participation and in conjunction with encouraging patients to speak up and share in decision-making with the physicians and nurses reflects the previous four themes.

To use the patients’ own picture about the kind of care they wish, how they want it to be like. To consider their kind of situation. /104

To let them know that this is a team, we work together here, and they are as important as I am for the outcome of this. It’s important that they feel they can speak up, that we listen they can participate and be involved in care. 105

It appeared these previous themes facilitated the development of patient–nurse partnerships. In order to partner with patients, participants described how they had to respect the patients’ view and accept the patient as a part of the care team.

It’s almost unethical to not let the patient participate in their own care, it is a Human Right to be involved in decision making concerning your own life and your own body. 201

You have a kind of partnership that if you do this for me and we do that for you, thus we agree on mutual expectations. That they do participate on this. 207
We should have considerably more time for each patient [in the wardroom] so we could spend more time with them. These short meetings are not sufficient, you still miss a lot and I think the patient would be able to participate more if we had more time for them. To talk with the patient. /102

We just walk out of there and then discuss with the physician, we come together and decide without the patient; a decision is made without the patient. . . /103

Some participants could not envisage active patient participation because it was not part of their current practice. Other participants said there were some things patients should not know about their condition and/or plans, suggesting that some conversations with other health professionals were not meant to be shared with patients. Some perceived time constraints, medical jargon and resistant condescending attitudes to change as hindering active patient involvement. Some participants described a lack of knowledge on how to increase patient participation, how to invite, motivate and promote patient participation in a suitable way.

The nurses expressed a lack of teamwork and interprofessional collaboration. They believed each profession did not know what the other one was doing. The nurses, physicians and patients never had discussions together; it was the physician who had the dialogue with patients about serious matters.

Yes, it is the doctor who does it [speaks with the patient]. We do not know what they have said. We do not know how much we dare say./208

Participants asked for a greater interprofessional consensus when it came to patient care.

Just a simple thing like the physician refer for an x-ray, and the patient is scheduled for the examination, but we have not had the time to inform the patient about it, and he/she doesn’t know until the janitor comes to transport the patient bed, and they don’t understand anything /205

Finally, some participants believed that actively involving patients in discussions about their conditions and plans would compromise patients’ privacy, in situations where sensitive information was discussed when several patients shared the same room. The participants seemed to lack strategies for this. Thus, participants described having conversations at the patient’s bedside, but making decisions away from the patient.

This about integrity and being in a four-bed room, it’s not very nice for the patient to speak about their personal problems when another patient is listening behind the curtains, in that way everything is not revealed. /205

Facilitating factors. Participants described a number of facilitating factors to promote active patient participation (Fig. 1). These aids included written communication tools such as care diaries and the use of I-pads to allow nurses and patients together to document patient information on the electronic medical record. The use of I-pads would also allow patients to gain access to their medical records. The use of a communication board at the nurse’s office was also helpful.

We have this care diary, which is very good as it makes the patient participate. You document why the patient is here, what is planned, if there should be a physiotherapist involved and what to face when returning back home. /203

Nurses noted brochures could assist patients in understanding their conditions and treatments; however, they said nurses’ need to actively review information contained in the brochures in order for patients to learn. Nurses found care plans as helpful tools, for care quality assurance but also as a reminder of what to information patients about. Families were viewed as a potential resource to promote patient participation because of their intimate knowledge of the patient, but some participants revealed paternalist attitudes of families might actually hinder participation. Nurses used a specific medication cart, and when caring for patients, they could easily deliver medication bedside and include patients in this.

A facilitating factor was to enact a person-centred model of care by involving patients in care, to let the patients tell their story. The nurses made an effort to include patients in how they were reasoning in the nursing process. They empowered patients by respecting their knowledge and saw them as a person.

I try to think of it this way as having the human being, the person, in the centre. Not just being a disease. /209

Discussion

The five themes that emerged from the results were ‘listening to the patient’, ‘engaging the patient’, ‘relinquishing some responsibility’, ‘sharing power’ and the final core theme ‘partnering with patients’. This last theme appeared to be enacted when nurses listened to and engaged with patients and when they relinquished some responsibility and shared power with patients. Thus, our data suggest partnerships result from participation, as the nurses interviewed saw partnering with patients as a positive outcome from participation or as a core aspect of participation. These findings resonate with findings from an earlier concept analysis of nurse–patient partnerships (39). These authors identified both structural attributes and processes associated with partnerships. Structurally, they assert partnerships go through a number of phases with aims, roles and responsibilities negotiated in each phase. Our themes of listening to and engaging patients reflect the structural component of roles nurses undertake. Gallant et al. (39) identified power sharing and negotiation as the two core
processes in nurse–client partnerships. Our themes of relinquishing some responsibility and sharing power overtly reflect the power sharing process; however, our findings reflect the discussions between nurses and patients in terms of what patients will take more responsibility for; a less overt form of negotiation. In an Australian study, patients report the power imbalance between themselves and nurses as a major deterrent for active participation (11). A more recent synthesis of three previous concept analyses that used the concept analysis methods advocated by Rogers identified that sharing responsibility, information and decision-making are the core attributes of partnerships (40). They go on to suggest partnerships require trust and respect, with open honest communication, and the sharing of power between nurses and patients. Some of the nurses in our study described partnership as a human/patient right, but in order for this to occur; the patient had to be seen as a person, as an expert on his or her disease and life, rather than being reduced to a disease (41).

Lack of time was a hindering factor for the participants in the present study. Similarly, the ‘issue’ of time was a finding in a review (6) on patient participation in patient safety as well as in a meta synthesis of four studies exploring person-centredness (42). Different interpretations of the meaning of time were present among staff and patients, and the authors suggest that time to achieve person-centred care is an issue for further development (42).

On the other hand, nurses in the present study found strategies to change their work processes by showing the patient special interest and by spending just a small amount of extra time gave them a lot back, it was really worthwhile.

Further, nurses described how they empowered patients by surrendering some of their own power to the patients, as they willingly shared information with patients, updating them on plans detailing options. The participants wanted to invite patients to share knowledge and information. The nurses spoke of releasing tension, to let go of their nursing care, and instead help the patients help themselves, although some patients did not expect this. These findings have been confirmed by others showing that nurses build close collaboration with patients by daring to release control and be nondirective in order to support patient to be open and share his/her expectations (43).

There was no ongoing discussion among colleagues on how to actually include the patients, though this was something the nurses wished for. The participants found they actively had to make participation happen, to actually help or promote patients to participate in their own care. Sahlsten et al. (43) stresses that nurses need strategies for guiding patients towards meaningful experiences and learning in order to balance the nurse–patient relationship in quality assurance to improve patient participation. The patient participation has been explained as interaction in a dynamic nurse–patient process (44).

Current practice and nursing routines hindered the nurses in our study to optimise communication and patient participation. One example was the ward round where communication was not ultimate. The use of a medical jargon decreased patient understanding and hindered patient participation; there was a risk of staff talking about and over patients’ heads. Although the nurses described it as acceptable having conversations at the patient’s bedside, they appreciated that important decisions should be made away from the patient. The ward round was seen as an important place and time-point for information exchange in hospital care. According to Weber et al., (45) patients receive about 20 pieces of medical and treatment information during a round on an internal medicine ward. Ward rounds take a substantial amount of time and results in round related work occupying nurses’ time. The authors claimed the ward round to be a ‘central marketplace of communication’ in hospital. In the present study, the nurses found it important that the patients were encouraged to participate and that the communication was comprehensive for patients.

Another obstacle was lack of teamwork. Nurses, nurses’ aides and physicians were working in parallel tracks on the ward. The reason for this was due to an overall idea about teamwork being too much time-consuming. Nurses wished for all healthcare professionals to work together in a team. Similarly to our results, others found that nurses wished for more interprofessional collaboration and that lack of cooperation was a barrier to improving patient safety (46). Teamwork is known to improve patient safety and enhance interprofessional understanding (47).

Patient participation and patient engagement are two terms that are sometimes used synonymously. An overview of 10 review articles about patient engagement identified that methods to engage patients included information provision, patient activation and patient-provider collaboration (48). These authors described patient engagement methods as ‘tools or strategies, applied as part of the clinical workflow, that supports patients through a process of being involved as partners in their own health care and decision making activities’ (p. 282). Our findings are possible indicators of interpersonal strategies that may promote patient engagement. Further, some of the obstacles and enablers to patient participation we identified could be used to develop other tools and processes to promote patient engagement. For example, redesigning the ward round including developing a structured process to provide patients with overt opportunities to be involved, as has been done elsewhere may facilitate patient participation (49). Recent Swedish research that has focused on patient participation in the ward round identified the brevity of the ward round, the use of medical jargon and a lack of invitation for the patient to participate were all barriers to patient participation (24). Thus, there is a developing body of evidence on how the ward round may be improved to become more patient-centred.
Patient engagement has been defined as actively involving and supporting patients in health care and treatment decisions and activities (48). Patient participation has been associated with patient enablement, empowerment and engagement (16). The participants found it unethical to not let the patient participate in their own care, there was a need to recognise and respect the patients as experts of their own disease and to realise this nurses had to understand patients’ expectations and goals. Additionally, it was necessary to encourage patients to speak up to facilitate the development of patient–nurse partnerships, while some patients were not interested and preferred to take on the ‘traditional’ passive patient role. Our work contributes to the body of knowledge concerning nurses’ need of actively promote and encourage patients to really participate in care, as some patients were not interested to participate they just trusted the nurses to do the job. Congruently, Flynn (50) discuss patient-centred care as a shift from do to and for patients to doing with patients and patient describes partnerships as ‘respect me, hear me and work with me’.

**Limitations**

There are a number of limitations to this research. First, while the study was conducted in two hospital settings, it reflects one region in Sweden only and may not be generalisable to other settings. However, the interviews yielded rich data and included nurses from wards that had enacted a person-centred model of care, providing breadth to the data. Second, the interview data reflect nurses’ self-reports, which may not mirror their actual behaviours. Third, the way some of the interview questions were angled may have encouraged nurses to respond in a socially accepted manner, that is assuming patient participation was something good, which could have influenced the nurses’ responses. Finally, we interviewed nurses and the findings reflect their perspective, and not those held by other healthcare professionals or patients. It is also possible that despite using a purposive sample (36) and interviewing 20 nurses, we missed some important experiences, that may have emerged had other nurses been interviewed.

**Conclusion**

In order to partner with patients, participants described how they made an effort to respect the patients’ view and accept the patient as a part of the care team. There were also hindering factors such as patients wanted to take on a passive role. Another contributing factor was lack of teamwork. The nurses, nurses’ aides and physicians were working in parallel paths on the ward, while the nurses expressed a wish for all staff members to work together in a team which they understood would enhance interprofessional understanding and improve patient safety. The communication during the ward round was not always optimal, patient participation may be hindered by medical jargon and there was a risk of staff talking over patients’ heads. It was sometimes inevitable having conversations at the patient’s bedside. However nurses preferred important decisions to be made away from bedside, and in spite of not knowing patients’ view this was not seen as a big issue. However, the nurses wished for a change but lacked strategies on how. Future studies should focus on how the ward round is performed how to facilitate teamwork in order to better enable patient participation.

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**Author contribution**

Wendy Chaboyer suggested the study design which as discussed and finalised together with all authors. Lena Oxelmark and Mona Ringdal did all the data collection and analysed the data together with Kerstin Ulin and Wendy Chaboyer. Lena Oxelmark drafted the manuscript with critical intellectual input from Wendy Chaboyer, Mona Ringdal and Kerstin Ulin. Tracey Bucknall contributed with critical revisions for important intellectual content.

**Ethical approval**

The study was approved by the Ethical Review Board of the University of Gothenburg, application No 693-13.

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