ABSTRACT

Purpose of article: Patient participation is characterized by dyadic patient-nurse interactions that enable patients to passively or actively participate in communicative and physical care activities. Less research has been conducted on nonparticipation. Examining this phenomenon may highlight issues to address and identify strategies that may ultimately promote patient participation and move the rhetoric of patient participation to a reality. The aim of this secondary analysis was to explore hospital patients’ and nurses’ perceptions of nonparticipation in nursing care specifically focused on communication and self-care.

Design: Secondary supplementary analysis of qualitative data. We collated original transcripts from one dataset that included 20 patient and 20 nurse interviews conducted at two hospitals in Australia, in November 2013-March 2014.

Methods: Interviews were arranged into units of analysis dependent on group (patient/nurse) and setting (public/private hospital) and were reanalyzed using manifest, inductive content analysis.
Findings: Two categories were found: 1) nurses impede two-way clinical communication; and 2) patients and nurses disregarding patients’ self-care efforts. These categories describe that nonparticipation occurred when nurses inhibited communication, and when patients were not involved in self-care while hospitalized or during discharge planning.

Conclusions: Perceptions of nonparticipation differ across settings, having implications for how patient participation recommendations are enacted in different contexts.

Clinical relevance: There is no one-fit-all approach; nurses need to identify common instances of nonparticipation within their setting and develop and implement strategies to promote patient participation, that are suited to their context.

Keywords: Consumer Participation; Patient Centered Care; Nurse-Patient Relations; Nursing Care; Patient safety.

MAIN TEXT

INTRODUCTION

Patient participation in care is associated with a reduction in patients’ length of stay, hospital readmissions, mortality, and improvement in patients’ quality of life and satisfaction (Park et al., 2018; Sharma et al., 2018). Internationally, hospital policies, standards, and frameworks commonly advocate for patients to have a role in their own care, to improve the quality and safety of healthcare (Frankel, Haraden, Federico, & Lenoci-Edwards, 2017). Participating in care is a patient’s right and represents a contemporary and consumerist perspective on healthcare (Carman, Lawrence, & Siegel, 2019). Patient participation in care is both a principle of and a strategy to achieve patient-centered care, a central tenet in hospitals internationally (Scholl, Zill, Härter, & Dirmaier, 2014).

An agreed definition of patient participation in care is lacking, and many words are used interchangeably for participation like involvement, empowerment and engagement (Menichetti, Libreri, Lozza, & Graffigna, 2016). Antecedents to patient participation include
information exchange with patients, an encouraging attitude displayed by the healthcare professional, a caring and reciprocal relationships between the patient and healthcare professional, and an environment that supports patient participation (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; Nilsson, From, & Lindwall, 2019). Defining attributes of patient participation, or how it is characterized in clinical practice, are patients taking part in communicative activities including shared decision making, and physical point-of-care activities such as self-care (Castro et al., 2016). There needs to be ongoing dialogue between patients and nurses to negotiate how patients participate in communicative and physical point-of-care activities (Snyder & Engström, 2016).

In hospitals, patient participation in care is often not achieved (Herrin et al., 2016). By virtue, it is plausible that nonparticipation is common in hospitals. A deeper understanding of nonparticipation, focusing on context-specific instances of nonparticipation, may illuminate issues that clinicians, improvement leaders or researchers could address to move the rhetoric of patient participation to reality. In turn, these insights may identify strategies that may ultimately promote patient participation.

METHODS

Design

This study was a secondary, supplementary analysis of qualitative data (Heaton, 2008; Long-Sutehall, Sque, & Addington-Hall, 2010). The purpose of supplementary analysis is to undertake analysis of an emergent issue that was not fully addressed in the parent study (Heaton, 2008; Ruggiano & Perry, 2017). Secondary analysis methodology can be a cost-effective approach for researchers, and maximizes the use of data collected while reducing burden on participants (Ruggiano & Perry, 2017). Ruggiano and Perry’s (2017) three recommendations for reporting secondary analysis of qualitative data were adhered to: 1)
clearly and transparently report the type of secondary analysis conducted, researchers involvement in parent study, and how the parent study and secondary analysis differ; 2) provide explicit details about how ethics approval was gained and how participants were protected; and 3) report strategies to enhance rigor and report limitations.

Aims

The aim of this secondary analysis of qualitative data was to explore patients’ and nurses’ perceptions of nonparticipation in nursing care. Specific research questions were:

- What are hospital patients’ and nurses’ views of nonparticipation in communication?
- What are hospital patients’ and nurses’ views of nonparticipation in self-care?

Data sources

The dataset came from a parent study, which was an ethnography including 40 interviews and observations, exploring patient participation in nursing care (Blinded for peer review). We did not use observational data in this secondary reanalysis as it did not address the research question posed. The same authors conducted the parent study and this secondary reanalysis study.

The parent study data collection methods were semi-structured interviews with patients and nurses, and inductive content analysis was used. Interviewees were probed for their perception of patient participation with questions including: ‘Can you tell me what patient participation in care means to you?’, ‘Can you think of any further role you would like patients to take in their care?’ ‘What things help/hinder you to undertake patient participation in care?’. The wording differed slightly for patients and nurses. Interviews took place November 2013-March 2014. All interviews were conducted on medical wards at one public and one private hospital located in two different Australian states. Australia has a two-
tier health system. The public system is ‘universal’, free for all healthcare, funded through Medicare, whereas the private system is user pay, with the vast majority of private patients having private health insurance to cover most hospital costs (Department of Health Australian Government, 2012).

The first step was to obtain the dataset. Interview data were collected from a locked filing cabinet at the site they were kept; access was easy as the researchers were involved in the parent study. Datasets were available as professionally transcribed transcripts. Step two was screening. The 40 interview transcripts were read, and re-read, and it was determined that data were sufficient and appropriate for the aim of the current study, as experiences of hindrances to participation were present (Long-Sutehall et al., 2010). We explored the transcripts looking for descriptions of nonparticipation based on Eldh and team’s (2004, 2006a, 2006b, 2008, 2010) work on this phenomenon. Although not all patients and nurses held the same opinion on nonparticipation, all 40 transcripts had evidence of nonparticipation and were included in this secondary analysis.

**Ethical considerations**

Human Research Ethics Committee (HREC) approval was granted by the participating hospitals and university for the parent study. The HREC was notified of the secondary analysis occurring and provided approval. Like the parent study, participant confidentiality was assured by reporting findings in a grouped manner and using pseudonyms.

**Secondary data analysis**

Qualitative, inductive content analysis was used (Elo & Kyngäs, 2008), which was consistent with the analysis methods used in the parent study methods, however a different aim was addressed. First, for data management, all transcripts were put into the data management program, NVivo 10 (QSR International Pty Ltd, 2014). Second, all transcripts
were read through again (separate to screening) to increase familiarization. After reading the transcripts again, it was evident that most had evidence of nonparticipation, however, these were presented as ad hoc instances, and were not the entire focus of transcripts, thus, the depth of analysis undertaken was manifest analysis. Manifest analysis occurs when the researcher provides concrete descriptions about what the participants said, staying very close to their words and the obvious visible text (Bengtsson, 2016). Third, the units of analysis were determined, which is when the researcher decides how the sample is analyzed. Upon reading the transcripts, diverging opinions between patients and nurses, and public and private hospital participants became evident. Thus, the dataset was condensed into four smaller units of analysis: 1) 10 private hospital patient (PtPriv) interviews; 2) 10 private hospital nurse (NrsPriv) interviews; 3) 10 public hospital patient (PtPub) interviews; and 4) 10 public hospital nurse (NrsPub) interviews.

Fourth, coding occurred. To facilitate this step, ‘meaning units’ were determined, with the smallest meaning unit being half a sentence, the largest meaning unit was two sentences (See Table 1). The researcher read meaning units with an open mind, identifying areas of transcripts that answered the research questions. Each meaning unit was given an inductively generated code. Fifth, the researcher reviewed each transcript after coding meaning units and identified un-coded areas. These unmarked areas were scrutinized and left un-coded if they did not relate to the research aim. Sixth subcategories were developed, which were codes grouped together that shared common characteristics. Seventh, sub-categories were grouped together to form higher order categories that described the ‘what’ (i.e. perceptions). The researcher drew flow diagrams to assist with step five and six. For reporting of the secondary analysis, select meaning units were presented in-text as quotations, and Table 1 was developed to show how meaning units became categories, to enhance transparency.

[Table 1 here].
Rigor

The reanalysis was rigorous because the aims, methodology, methods of the original dataset fit with the aims of the secondary analysis, enabling researchers to easily undertake reanalysis (Ruggiano & Perry, 2017). Several other strategies were used to make this reanalysis rigorous. The same researchers involved in primary data collection and analysis, undertook secondary analysis. This heightened credibility as they understood the context, had been immersed in data previously, and co-created interviews, facilitating immersion in the data and their ability to interpret the data to answer new research questions (Heaton, 2008; Long-Sutehall et al., 2010; Ruggiano & Perry, 2017). The parent study interviews were conducted across diverse settings and participant were recruited using maximum variation techniques, facilitating a more credible understanding of nonparticipation to be developed. Credibility was established as the researchers conducting secondary analysis had an understanding of the phenomenon of interest, and are PhD trained with skills in qualitative content analysis. Finally, the researcher leading the analysis kept recorded her emerging perceptions during analysis and reflected on its content throughout the analytic process. This helped her become aware of how her thoughts might be influencing the analysis and to ensure her findings were consistent with the new research question.

To enhance dependability, we have provided clear descriptions of our analytic process, including examples of the process, to allow replication. Although one author undertook analysis, the emerging findings were reviewed by members of the team for interpretational confirmability. Finally, to enhance confirmability, each aspect of the analysis process is available as an audit trail (i.e. NVivo files, flowcharts, iterations of results).

RESULTS

The characteristics of the units of analysis are available in supplementary table 1. For patients, PtPriv were older, required more assistance, and had visitors more frequently than
PtPub, PtPriv and PtPub reported similar levels of physical and psychological wellness. For nurses, NursPub had a higher median age, reported more years in the nursing profession, but worked fewer hours per fortnight than NrsPriv.

Two categories were found: 1) nurses impede two-way clinical communication; and 2) patients and nurses disregarding patients’ self-care efforts. A description of the categories is below.

**Nurses impede two-way clinical communication.** Nonparticipation in clinical communication was similar for PtPriv and PtPub. Nonparticipation occurred when nurses were dismissive, had ineffective communication or made limited efforts to build rapport:

“…it becomes a mothering instinct. I hear of people who just park them under the shower and turn the shower on and I think, god that is so wrong…..I chitchat a lot to them. I usually tell them what I’m doing as I’m going” (NrsPub1). Patients shared experiences of nonparticipation when patients tried to contribute to the care plan but were hindered by nurses’ approach: “…it doesn’t make any difference if you think you’re right, and you say to them, they won’t take any notice sometimes.” (PtPriv1).

Nonparticipation was evident for NrsPub, as sharing information with patients was valued but not accepted, due to perceived rules and legalities. NrsPub stated doctors or other healthcare professionals had to share patient information with patients and families about care and treatment updates: “They are always asking what’s actually happening, and procedures which are going to happen…we nurses can’t give them too much information.” (NrsPub2).

This category varied across settings; NrsPriv did not share instances of nonparticipation, stating they shared information in-person or over the phone with patients and families, and in particular, family were viewed to encourage patient participation and assist the patient when home: “*Family education is also important to make sure the patient is taking the things... There’s a lot we (nurses) can do.*” (NrsPriv2).
Nonparticipation in bedside handover was evident for all units of analysis. NrsPub and NrsPriv stated that sharing information at bedside handover was high-risk due to patient confidentiality concerns, resulting in: “...a lot of the nurses here don’t want to stand by the bed, and they like to stand by the folder outside the door” (NrsPriv1). Further, some nurses were not comfortable with patient participation in bedside handover, viewing it as: “...a little awkward.” (NrsPriv4). For patients, PtPriv and PtPub did not feel engaged in handover, lacked role clarity and confidence to participate: “...yes, most times at the doorway, you’ll hear them just walking slowly in talking to each other saying now that’s just a new one...” (PtPriv2).

Patients and nurses disregarding patients’ self-care efforts
In this category there was divergence across settings. In the public setting, PtPub and NrsPub wanted patients to participate in self-care, but nurses were forced to overlook this due to organizational pressures. Whereas in the private setting, there were perceptions that patients chose not to participate in self-care. Nonparticipation was evident in the PtPub and NrsPub datasets, where discharge pressures meant nurses were unable to sufficiently engage patients prior to discharge and ensure their self-care capacity. NrsPub reported keeping an eye on patient capability for self-care during hospitalization but faced pressures to discharge patients quickly, with one nurse sharing an experience of being unable to see her patient before discharge: “...they just push them out and we do that as well because we are oppressed from the organization point of view. You need to discharge those patients, because we have new ones...I personally think it was inappropriate, not to get to see them [the patient], if they’re alright, or if they’re not, even just to a normal say goodbye... they are still human beings and they are not numbers” (NrsPub3). This resulted in NrsPub prioritizing organizing patient transport and getting patients discharged quickly without patient participation. PtPub felt a lack of control during discharge, passively waiting for instructions: “...just let them do what
they’ve got to do and tell me when they’re ready to throw me out, that’s about it. They’re throwing me out tomorrow I hope.” (PtPub1). In this category, private hospital data was divergent; PtPriv reported being engaged and informed during the discharge process, while NrsPriv viewed both patients and families as partners in the discharge process, they understood patient capability to return home, and sent them home supported (i.e. with educated family or to a care facility): “...we’re not just taking care of the patients; we’re taking care of the whole thing ... because who’s taking care of them at home? We do often have a lot of people who live with their wife or husband.” (NrsPriv3).

Nonparticipation was evident in private hospitals, because some private hospital participants reported lower patient participation in self-care, regardless of patient capability. NrsPriv stated that patients expected to receive good quality care and believed that the healthcare professional knew best, rather than ‘partnering’ in self-care: “Some patients are really reluctant sometimes they think that when they come into the hospital everything gets done for them...” (NrsPriv5). Some PtPriv wanted to receive good quality care and enjoyed being looked after, rather than partnering to undertake self-care: “I love the people coming to help me. As soon as I hear them, I think, oh, it’s the nurse” (PtPriv3). Public setting patients and nurses views varied in this category, stating they were working towards a shared goal, to get patients to participate at their maximum level of independence in self-care while in hospital: “I just help the nurses as much as I can, with whatever they’ve got to do...with pressure care and stuff like that...” (PtPub3).

DISCUSSION

In this secondary analysis, nonparticipation in communication was consistently seen across groups and settings. Nurses’ behaviors often determined patients’ nonparticipation in communication and more challenges were uncovered at the public setting compared to the private setting. Nonparticipation in self-care varied across sites; in the private setting
nonparticipation during hospitalization was evident, while in the public setting nonparticipation in ensuring patients’ self-care abilities once home was uncovered.

We found that nonparticipation occurred when nurses did not communicate with patients, which is similar to previous work with Swedish patients on nonparticipation (Eldh et al., 2004, 2006a; Eldh et al., 2006b, 2008, 2010; Eldh, Luhr, & Ehnfors, 2015). Increasingly, there are various opportunities in hospitals to promote patient participation in communication like bedside handover (Tobiano, Bucknall, Sladdin, Whitty, & Chaboyer, 2018), ward rounds (Redley et al., 2019) and hourly rounding (Sims et al., 2018). However, consistent with our findings, nurses may not deliberately promote patient participation in these activities, which can be due to their lack of confidence in engaging patients (Tobiano et al., 2018). Researchers have shown that nurses lack knowledge of patient participation theory and skills in communication strategies to support patient participation, which may be why nurses in our study impeded communication with patients (Barello et al., 2017). In a recent systematic review, researchers demonstrated that communication skills training for nurses resulted in nurses displaying more facilitative behaviors towards patients and open-ended questions, and increased patient participation in conversations (Kerr, Ostaszkiewicz, Dunning, & Martin, 2020). However, there is a lack of communication skills training available for the acute care setting, presenting a future research opportunity (Kerr et al., 2020).

In our study, nonparticipation occurred when nurses disregarded opportunities to engage patients in self-care. Other researchers have shown that dressing and hygiene are common activities to promote patients’ self-care in hospital, yet nurses often do not encourage patient participation, instead focusing on task completion (van Belle et al., 2020). Our findings are similar to a recent systematic review, where nurses often failed to encourage and motivate patients’ self-care capabilities beyond hospitalization, while the patient was still in hospital (Tobiano, Jerofke-Owen, & Marshall, 2020). However, there is a lack of high-
quality evidence supporting interventions to promote patients’ self-care in hospital; meaning interventions to date are unfit to guide nurses’ practice (D. A. Richards, Hilli, Pentecost, Goodwin, & Frost, 2018).

We found that some private hospital patients chose to not participate in self-care. Currently, patient participation frameworks/continuums view patients giving or receiving information as the lowest level of on the participation continuum (Carman et al., 2013; Drenkard, Swartwout, Deyo, & O’Neil, 2015; Eldh et al., 2015). Thus, this suggests that nonparticipation is not conceptualized as part of patient participation frameworks/continuums. However, allowing patients to choose if they prefer nonparticipation is consistent with a patient-centered approach to care. Given patients in our study wanted non-participation, clinical tools to assess patients’ preference for participation should be trialed, to genuinely offer patients the choice for nonparticipation, and to allow nurses to act upon or negotiate nonparticipation with patients (Eldh et al., 2015; Jerofke-Owen & Garnier-Villarreal, 2020).

Our findings reveal differences in nonparticipation across settings. In public hospitals, nonparticipation occurred because nurses limited communication due to perceived rules and efficiency needs. Our findings support those from previous research conducted in public hospitals, where nurses were concerned about sharing medical information with patients (Anderson, Malone, Shanahan, & Manning, 2015) and expressed their struggle, as managerial and government targets demanded speedy discharges, without active patient involvement (Connolly et al., 2009). On the other hand, in the private setting expectations of receiving a service rather than patients participating in care resulted in nonparticipation. Researchers have demonstrated that private hospital patients have high expectations of care and healthcare professional responsiveness (Suki, Lian, & Suki, 2011), and in Australia, the community
expect private hospitals to deliver higher quality care than public hospitals (Hardie & Critchley, 2008).

Our findings suggest different implications for public and private settings. The results we found may stem from the different core-values that private and public hospital management hold. In public hospitals, high levels of bureaucracy and frequent public policy changes impact operations, resulting in lower management autonomy (Edwards & Saltman, 2017), and a stronger focus on cost-cutting and efficiency measures (Brunetto et al., 2012). Focusing on these priorities means patient-centered care reforms have had slower uptake in public settings, when compared to private settings (Kelly, 2005), which is why public hospital nurses in our study may have limited communication and self-care opportunities for patients. Private hospital nurses are substantially more satisfied with their management (Brunetto et al., 2012), and in turn, feel greater job empowerment and perceive that they work in a more productive nursing environment than public hospital nurses (Brunetto, Farr-Wharton, & Shacklock, 2010). Thus, public hospitals may require more efforts to enhance patient participation. Researchers have demonstrated that an organization-wide approach to enhancing patient-centered care is most fruitful, where managers clear patient-centered organization missions are developed and innovative patient-centered interventions are implemented (Gabutti, Mascia, & Cicchetti, 2017).

Limitations

While this study has several strengths, we acknowledge there are some limitations. First, evidence of nonparticipation in interviews was somewhat sparse as this was not the focus of the parent study interviews, meaning we could only undertake manifest analysis. For instance, few examples of nonparticipation in self-care were provided, meaning self-care activities like medication management were not explored in-depth. While this study is a first step in providing a better understanding of this phenomenon, more in-depth research is
required. Second, the results of the reanalysis may not be transferrable, as the patient role in
Australian healthcare systems may differ to other countries. However, we have used diverse
units of analysis including both nurse and patient participants across public and private
hospital settings, and have provided descriptions of patient roles, allowing researchers to
judge the applicability of findings to their settings. Third, some may argue that data collected
for a primary purpose and aim, may not be useful for secondary analysis (Heaton, 2008),
however the interview questions asked in the parent study were deemed applicable to address
the aims of this secondary analysis. Finally, our dataset are over five years old. There is
suggestion that patient roles in participating in hospital care are becoming clearer (Rowland,
Brosseau, & Houle, 2018). At the time data were collected a call was made for a patient
revolution, where patients play a leading role in their care (T. Richards, Coulter, & Wicks,
2015). Since that time there is increasing evidence for the influence of patient participation
interventions on patient outcomes, with a systematic review of 16 studies showing
encouraging results for the impact of patient-centered interventions on fall rates and
appropriate medication use (Rossiter, Levett-Jones, & Pich, 2020), yet these interventions are
yet to be integrated into practice (Sharma et al., 2018). Given the time it takes to implement
evidence into practice, and the systematic approach to implementation required, it is likely
that our datasets still provide valuable insights for practice today.

CONCLUSION

Patient participation in care is an international recommendation; however, this study
suggests that nonparticipation is a reason why there may be a gap between health care
recommendations and practice. The results of our reanalysis show nonparticipation in
communication was evident when nurses were dismissive in their communication and when
bedside handover did not involve patients. Further, nonparticipation in self-care was evident
in discharge planning and activities of daily living while hospitalized. For clinicians and
researchers, there are opportunities to enhance nurses’ communication skills and develop strategies to promote patients’ self-care in hospital to reduce instances of nonparticipation. Overall, nonparticipation varies based on context (public/private). If differences in perceptions of nonparticipation in care were found in two hospitals within one country, it begs the question; how do we effectively apply across-the-board recommendations for patient participation across settings? The answer may be in adopting an individualized approach to addressing nonparticipation issues within settings. Future research should investigate context-specific strategies that encourage nurses to achieve higher levels of participation.

**CLINICAL RESOURCES**


Planetree International resources: https://resources.planetree.org/

Engaging patients in communication at transitions of care:


**REFERENCES**


**Table 1.** Data analysis process example
<table>
<thead>
<tr>
<th>Example meaning units</th>
<th>Codes</th>
<th>Subcategory</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>But you can only let them know so much because a lot of the information’s got to</td>
<td>Following the rules</td>
<td>Feeling restricted</td>
<td>Nurses impede two-way clinical communication</td>
</tr>
<tr>
<td>come from either physio, the doctor, OT, you know, it’s got to come from them.</td>
<td>Getting blamed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When they’ve got a bit of attitude, like if their a bit grumpy or something like that</td>
<td>Inability to inform patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>or, something’s not going their way or a bandage is not going on properly or something</td>
<td>It’s not my job</td>
<td></td>
<td></td>
</tr>
<tr>
<td>like that, you feel a bit weird in that respect.</td>
<td>Monitoring information</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Withholding information</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The manner of the nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wanting nurses to interact</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>