2021

Safety participation at the direct care level: Results of a patient questionnaire

Lenora Duhn
Queen's University

Nathaniel Gumapac
Queen's University

Jennifer Medves
Queen's University

Follow this and additional works at: <https://pxjournal.org/journal>

Part of the [Health Policy Commons](#), and the [Health Services Research Commons](#)

Recommended Citation

Duhn L, Gumapac N, Medves J. Safety participation at the direct care level: Results of a patient questionnaire. *Patient Experience Journal*. 2021; 8(1):59-68. doi: 10.35680/2372-0247.1506.

This Research is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

Safety participation at the direct care level: Results of a patient questionnaire

Cover Page Footnote

Acknowledgements: The support of Dr. Christina Godfrey, PhD, Associate Professor, School of Nursing, Queen's University; and Dr. Kimberley Sears, PhD, Associate Professor, School of Nursing, Queen's University, in conducting this study is acknowledged. The healthcare staff and physicians at the study site are thanked for enabling this research, as well as the participants and their family members for their significant contribution in advancing our knowledge in this area. This article is associated with the Policy & Measurement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PolicyMeasure

Safety participation at the direct care level: Results of a patient questionnaire

Lenora Duhn, *Queen's University*, duhnl@queensu.ca

Nathaniel Gumapac, *Queen's University*, nnpp@queensu.ca

Jennifer Medves, *Queen's University*, jennifer.medves@queensu.ca

Abstract

Understanding how patients can be engaged in safety-related activities at the direct care level is of current relevance given global efforts to reduce harm in hospitals. As part of a multiphase study, including a descriptive, exploratory qualitative study (Duhn & Medves, 2018), patients were asked to respond to a brief questionnaire to quantify how they viewed their patient-reported safety participation behaviours while in hospital. This paper is a summary of those responses. The 8-item questionnaire was, in part, used to help address a secondary research question of the larger qualitative study, specifically: What behaviours do patients report in promoting their safety while receiving care in hospital? Patients completed the questionnaire at the end of the face-to-face in-hospital interviews. Twenty-eight adult inpatients completed the questionnaire. Fifteen participants indicated that they 'always' or 'usually' checked their hospital medications; this was the second lowest rated activity. Most participants (n=20) believed they could rely on their knowledge and alertness to protect them from health-care error. Seventeen participants were in the high participation category. Given the prevalence of medication errors, patient involvement warrants further examination, including system supports to increase feasibility. Overall, a standardized, valid and reliable patient engagement in safety measure for the direct care level is required.

Keywords

Patient safety behaviours, direct care level, questionnaire, patient-reported participation activities, patient engagement

Introduction

In Canada, rates of hospital harm continue to be problematic, with national rates estimated to range from 7.5% as revealed in the first Canadian study [based on fiscal year 2000]¹, to more recent reports of 5.6% [based on year 2014-2015]² and provincial (Ontario) rates of 5.9% [based on April 2015-March 2016].³ The provincial study³ further illuminated the scope of hospital harm, estimating that the impact totaled 407,696 acute hospital days and 1,088,330,376 Canadian dollars. This type of monitoring provides important, if troubling, information in helping us understand the quality of health-care, without which we would not be able to track and trend improvement progress.

Similarly, measurement of adherence to patient safety strategies is necessary to determine if and how approaches are being applied and whether they prove effective. Patient engagement in patient safety at the direct care level as a way to prevent hospital harm is one such approach that has garnered much interest in recent years. A limitation, however, has been the lack of standardized understanding and measurement of *patient engagement in all aspects of safety and harm prevention* during hospitalization. As

part of a larger multi-phase study about discerning patient perspectives and behaviours to engage in safety at the bedside,^{4,5} we included the only previously developed general quantitative measure⁶ that we could find in the peer-reviewed literature as a way to obtain additional insights in this additional complementary study phase. The results of that patient-reported safety participation behaviours questionnaire are provided in this paper.

Background

Patient engagement has been conceptualized as "...patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system – direct care, organizational design and governance, and policy making – to improve health and health care"⁷ (p. 224), with degrees of participation.⁷ Carman and colleagues⁷ caution against equating the terms "patient engagement" with "patient- and family centered care" – the first, active partnership and the latter, a broader term of a vision for care that respects patient preferences in decision-making. Further differentiating patient engagement and participation, one can see its application to patient safety, as related though

distinct from patient participation in, as example, chronic disease management.⁸

Patient engagement in patient safety has been proposed as a means to help with harm prevention, gaining more interest and endorsement in recent years.⁹⁻¹³ One of the most prominent strategies has been about handwashing, including having patients ask their health-care providers if they washed their hands prior to providing care.¹⁴⁻¹⁶ Investigating specific safety tasks or activities is important, but health-care delivery is complex and there are many factors and interactions across the continuum of one's hospital stay that can result in harm. With this in mind, and as part of the first author's doctoral thesis, we wanted to understand what patients thought about their role in partnering for safety at the bedside, what safety meant to them, and to learn about any actions they might have taken throughout their hospital stay. A multi-phase study was undertaken, including a scoping review⁵ and a qualitative study⁴ that included a supplementary questionnaire (reported herein). In part, a goal of this research was to contribute findings for furthering the work in establishing a recognized, comprehensive valid and reliable measure to quantify *all* relevant patient engagement in safety activities at the direct care level. Measurement in this area is of timely importance given the efforts to encourage patient participation in safety in all its many facets.

Methods

Objective

The objective of the larger qualitative inpatient study was to learn about patients' understanding, comfort and ease, as well as their activities (self-directed or otherwise) in assisting their safety at the direct care level while in hospital.⁴ As part of this objective, the additional component of that study, that is reported herein, included using a quantitative approach (questionnaire) to further examine patient safety behaviour.

Research questions

The main research question of the larger qualitative inpatient/outpatient study was: *How do patients and families describe health-care safety and what are their attitudes and beliefs about their role in promoting it while receiving care in hospital?*⁴ An additional secondary research question aligned with the quantitative approach included: *What behaviours do patients report in promoting their safety while receiving care in hospital?*⁴

Research design and setting

A descriptive, exploratory design was used for the qualitative study⁴, and a quantitative questionnaire was used at the conclusion of these in-person interviews as a supplementary phase. The location for the study was Ontario, Canada. The study site was a general community

hospital that included 24 medical/surgical beds and a level 2 intensive care unit.

Participants

In the larger qualitative study, adult inpatients and outpatients receiving care at the study site, and family members if desired by the participant, were eligible to participate.⁴ The inclusion criteria was: 18 years of age or older; able to speak and read English; able to provide consent; medically stable as determined by a health-care provider; and inpatient participants must have spent a minimum of one night in hospital and be preparing for discharge. Twenty-eight inpatient participants (n=12 women, n=16 men) ranging in age from 40 to 93 years of age (average age 71.6 years old) completed the participation questionnaire – a sample size determined based on meeting the primary objectives for the qualitative study phase. Ten individuals were being cared for in the acute care unit; nine were in the special care unit; five were in complex care; and four were in convalescent care.

Questionnaire

As a supplementary (quantitative) way to add additional insight to understanding patient participation in safety behaviours at the direct care level, an eight-item closed-ended questionnaire developed by Weingart and colleagues was used with inpatients.⁶ The questions (developed as part of a larger questionnaire) are about patients' participation in clinical activities believed to promote safe care.⁶ The authors acknowledged that they could not find a validated instrument "measuring patient participation in inpatient care" (p. 270), and this necessitated their development of the questionnaire based on literature review and focus groups.⁶ The Likert-type questionnaire has not been tested psychometrically (J. Weissman, personal communication, November 21, 2012), though the authors report having ten former patients review the first seven questions as part of a cognitive testing process. Permission to use the instrument was provided by the primary author (J.S. Weissman). It is noted that we made some wording changes to facilitate clarity (i.e., Questions 1, 2, 4, 6, and 7, we changed the wording from "During that (or the) hospital stay..." to "During your hospital stay..."; Question 5 we changed the word 'doctors' to 'health-care team').

Procedure

The associated university health sciences research ethics board, as well as the study site granted ethics approval for the multi-phase study, which included this quantitative patient questionnaire (HSREB 6007637, NURS-299-12). As described in detailed within the qualitative study,⁴ the nurses helped identify eligible participants in the inpatient units, and staff provided recruitment brochures to potential participants, who were then introduced to the first author if they requested and the face-to-face interview was then conducted. The quantitative questionnaire was

provided after the open-ended questions and dialogue occurred. It was conducted in an interview style where the participant either read the statements to themselves or the interviewer (L.D.) read them aloud, and then participants provided the answer they wished documented as their response on the interviewer's copy. Participants were encouraged to add additional thoughts during and after answering the questionnaire as they wished.

Data management and analysis

Data was kept confidential throughout the study and stored in a locked cabinet in a locked office. Descriptive statistics were used to summarize the eight-item safety participation questionnaire.

Results

There was a range of reasons as to why participants were admitted to the hospital, and all individuals had previously had an encounter with the health-care system, with 11 inpatients describing a health-care error(s) (personally or via a family member).⁴ Table 1 [See Appendix] is a summary of the participants' responses. It is acknowledged that given the questionnaire was completed in-person with individuals, some individuals (unexpectedly) chose to provide additional information, describing their selected response by adding more context and or qualification as to why it was not a 'completely' accurate representation. As relevant these additional qualitative responses were included in the content analysis of the larger qualitative study⁴, and select comments are included to provide further illustration. The Cronbach's alpha was 0.759 (questions 1-7).

Overall, most participants felt they knew about their medical problem or condition for which they were admitted, with 17 (61%) indicating they either knew 'a lot' or 'some'. Some questioned the timing of this understanding such as whether this included what they knew about the condition previous to and in preparation [as relevant and possible] for hospitalization, and or whether it was general knowledge about the health problem or specifics of their health.

Of the participants, 22 (78.6%) felt that they 'always' or 'usually' were well enough to talk with health-care providers. For some who did not respond with 'always', comment was made that the severity and limitation of one's health initially prohibited this interaction until there was a degree of recovery.

Twenty-one participants (75%) thought that it was 'very easy' or 'somewhat easy' to find a health-care provider when they wanted information about care or treatment. Where there was perceived difficulty, comment was made that *They* [health-care providers] *haven't got time*, and some noted it as not applicable stating, *I don't think I ever tried to*

do that. There were other participants who deliberated on the nuances between answer options, with one individual stating, *Man, it's almost in between very easy and somewhat easy*.

Twenty participants (71.4%) felt that health-care providers had described positive and negative attributes of treatment options. Additionally, most participants identified that they were comfortable with their participation in the decisions the health-care team made about treatment, with 22 individuals (78.6%) agreeing that it was the 'right amount'. For some this meant not participating, but they were content with that role, so it was still the 'right amount' for them, such as one gentleman who stated, *Well I could of as much as I wanted, but I had so much confidence in them I didn't really feel I had to because it was all explained to me*. For others it revealed a lack of involvement and or confusion grasping the essence of the question - *I don't know if I did anything, like that's kind of an odd question. I don't think I made any decision; I would say less than wanted - I think, if I'm understanding the question right*.

Thirteen participants (46.4%) perceived that visitors (family or friend) 'always or usually made sure' their health-care wishes were being followed by the hospital staff, and 10 participants (35.7%) commented visitors "sometimes" or "never made sure". For some there was indication that this was not needed or that it was the role of visitors, as stated by one participant who said, *I had company here but they didn't have to do anything...everything was being taken care of*.

Fifteen participants (53.6%) indicated that when they received medications in hospital, they 'checked always or usually'. A number of participants further elaborated on their exact actions (or lack thereof) and their reasoning. Some said, *I wouldn't know except, I know sometimes I get one, sometimes I get three...I check the amount*, while others described, *I always look in there [medication cup] and say well what is this, because they're different colours*. Still others were searching for some 'signs' of familiarity as possible - *I always looked at them...and the number...and if they were the right colour but they didn't have a name on them, but they looked like our Ibuprofen from home and Tylenol*, or were more casual in their approach - *sometimes I just said what is this for again?* Others, including those who might not have received medication prior to hospitalization, and who did not check, commented they did not because they did not know their medications. Some checked because they knew mistakes could be made, and some, knowing mistakes could be made, refrained from checking, describing that *I trust them implicitly*.

The final question was how much a participant could rely on their knowledge and alertness to protect them from health-care error, and 20 participants (71.4%) believed 'a lot or some'. Additional comments to give more context

to responses included, *it depends on what you're in for and how you're feeling*.

Based on the scoring of items 1-7 as described by Weingart and colleagues,⁶ 11 participants (39.3%) were categorized in the low participation category (0-4), and 17 participants (60.7%) were in the high participation category (5-7) [see Table 2, Appendix; *patient identified not applicable*, which was added, did not receive a score]. Although this element of the study was not intended or powered for statistical comparisons, a Fisher's exact test of independence was completed between individuals categorized with low or high participation and their question eight responses (the amount they could rely on their knowledge and alertness to protect them [A lot/some, n=20 or A little/not at all, n=8]), and the results were significant ($p=0.030$, two-sided), suggestive that more perceived participation was associated with a higher level of belief in their knowledge and alertness to keep themselves safe.

Discussion

This questionnaire was used as a complement to participant narratives within a multi-phased study about opinions, perspectives and behaviours related to patient engagement in safety at the direct care level. Given the paucity of patient safety participation measurements available at the time of study completion, the questionnaire developed by Weingart and colleagues⁶ was chosen for its relevance and ease of completion. Although the sample was substantively larger in the Weingart et al.⁶ study (n=2025) in which the aim was to learn about the scope of patient participation and its association with quality of care and patient safety among a sample of recently discharged patients from hospitals in Massachusetts, United States, similar patterns exist between the studies.

In both this study and Weingart et al.'s⁶ study most patients reported participation activities, and there was a greater proportion of individuals categorized in the 'high' participation category (61%, 81% respectively). Further, there was similarly high rates in this study and Weingart et al.'s⁶ study among the participants in their belief of their knowledge and alertness to protect themselves from health-care errors during hospitalization (71%; 84% respectively). Additionally, in both studies, participation was significantly associated with perception of one's belief in their knowledge and ability to safeguard themselves while in hospital, with higher participation aligned with greater confidence (Weingart et al.'s⁶ study, $p<0.001$).

The most prominent among the participation activities was similar, for the most part, between this study and that of Weingart et al.⁶ as well. The highest rating of participation related to involvement with the health-care team in the decisions about one's health-care. In this study, the

second activity with the highest rating was how often participants felt well enough to talk with their doctors and nurses, with 78.6% stating 'always/usually'. In the Weingart et al.⁶ study, that activity was rated second as well (86% stating 'always/usually'), along with the question of how easy or difficult it was to find a health-care provider to address information needs about care or treatment (86.7% stating 'very easy/somewhat easy'). In this study, the lowest rated activity was about having a family member or friend ensure health-care wishes were followed (46.4% reported 'always/usually'). This was followed by how often participants reported checking their medications (53.6% stated 'always/usually'). In the Weingart et al.⁶ study, the lowest rating related to checking their medications (39.4% stated 'always/usually').

Overall, while the comparisons must be viewed with caution, given the aim, design, and resulting sample sizes were different between this study and that of the Weingart et al.⁶ study, the similarity of patterns are noteworthy given the participants were from different countries. In particular, given the prevalence of in-hospital medication errors and as such the importance of checking of medications, as well as how patients had described medications as more "personal and relevant to one's control" in the larger qualitative study⁴ (p. 6), it is an important finding that the action of consistently checking one's medication in hospital was quantified as one of the least engaged activities. The reasons for this possible lack of engagement can include system limitations⁴, such as how the same medications may be of a different brand within health-care settings affecting, for example colour - a reported cue that patients in this study used for verification. Other reasons are that individuals did not know their medications and or perhaps did not feel the need to check on a *regular* basis and, especially given their health status, relinquished that control to trusted providers. Focused efforts on this element of engagement are warranted.

Advantages/Limitations of the Questionnaire

One of the main advantages in using this questionnaire was that it often did serve to advance the conversations with participants. As the primary author (L.D.) conducting the interviews, I became much more aware of the need for clarity with language and phrasing of questions, and as well acquired a greater appreciation of the limitation in requiring individuals to select a sole response for such complex and nuanced issues. There was benefit in completing the questionnaire with the participants, as it allowed for much greater insight into how individuals were interpreting and responding (or wanting to respond) to questions. For instance, individuals would report they did not check their medications because they did not know the medications they were to be administered. This gave insight into the reasons for their actions, which is meaningful if one is to initiate improvements.

This questionnaire did have limitations. For instance, the phrasing of some items resulted in some participants seeking clarification. As example, when the first question was asked, individuals said prior to coming to hospital they did not know anything about the medical condition for which they were admitted and were prepared to have that as their answer. The participants described a progression of not knowing anything to gaining more knowledge as their hospitalization progressed. The wording of the question made it difficult to capture that variability.

Question two presented challenges to some individuals. One individual, as an example, indicated she felt well but due to her stroke was initially not able to speak clearly to the team. The wording of the question did not provide options to recognize change over time. Similarly, others noted that initially they did not feel well enough to talk, but they progressively got better and became more engaged. The wording of the question made it difficult to illustrate this dynamic. Additionally, most participants indicated they felt well enough to talk with health-care providers but, as designed, the survey did not include a query as to the frequency of this kind of engagement which would provide rich information.

A few participants said question three and four did not apply to them. Question three is about the ease or difficulty *in finding* health-care providers to get information about one's care and treatment. The individuals who commented offered that they had never tried to find a provider, so could not reasonably judge the ease or difficulty. Also, the question indicates 'doctor or nurse' and it may be that it is easier to find one over the other, yet it cannot be distinguished in the answer options. Question four was designed to understand if patients had both positive and negative implications of treatment options explained to them by providers. In some instances, participants stated that they did not have any treatment options and therefore did not feel equipped to answer the question, or that they had to ask the providers for the information.

Question five, about a patient's participation in the decisions the health-care team made about their care, did not allow participants to articulate the degree of that participation. One participant might have said they participated 'about the right amount' (as over 78% did), but this did not distinguish whether they were actively involved or not involved at all – only that it was the right amount for them. It does allow one to glean that, for the most part, individuals seem happy with their level of participation, but does not illuminate the degree and nature of their self-identified participation. Some participants also had trouble understanding the intent of the question, and the way it is formatted and structured made it difficult to easily comprehend.

Some of the participants queried the wording and meaning, as well as the lack of inclusion about one's changing health condition in question six about visitors (family members or friends) helping to ensure patients' health-care wishes were followed by staff. A few individuals wanted to distinguish between visitors who would have no involvement in their care but came to see about their well-being and keep them company, versus family members who had greater engagement in the individual's care, which was not distinguished in the question. The participants also questioned the wording of 'wishes', as there was a perceived difference between making sure the staff responded if the participant needed immediate attention versus thinking about health-care wishes as a broader, more complex concept (e.g., including such things as end-of-life planning). One participant, after telling me about an urgent care issue at another site, expressed it as *he [her son] made sure that I was being looked after but as far as my wishes, he's never discussed them with me*. Additionally, some participants wanted to acknowledge that family members might have had an initial role in supporting the participant when they were in the acute phase of their illness, but as they stabilized and progressively felt better, they perceived there was no need for their intervention. Included with that was the perception of the quality of the care that the participants felt they were receiving, eliminating the need for a family member to do anything, as everything as they understood it was being managed. The interpretation of the question was queried as to whether the family member needed to be actively pursuing issues with staff or doing something (e.g., making a decision about a matter) in order to score them as 'making sure' or being involved, as opposed to a supportive role to patients in assisting them to act.

The question about checking medications (question 7) was limited in information. In answering that question, some participants wanted to justify their answer by adding, as example, that they looked at the number and colour of the medications or whether they were visually similar to their medications from home. Additionally, a participant indicated 'did not check' medications and yet had described earlier in the qualitative phase⁴ asking the provider for information about their medications. It may be that individuals interpreted 'checking' in different ways. Overall, the question as it is written does not account for *how* individuals check and the participants varied in the approaches they used. Given the discrepancy in how one could define 'checking', clarity of this would be useful.

The participants queried the answer options for the final question about one's knowledge and alertness. Some participants wondered about the difference between 'some' and 'a little' and were hesitant that the choices did not provide a completely accurate representation. A family member asked whether this question related to *medications* or overall, so there may be some benefit in being more

explicit in the wording, such as: ‘regarding your care overall when in the hospital...’

Overall, to maximize the usefulness of the questionnaire for future studies, changes to it as outlined would be beneficial. The revised questionnaire should then be pilot tested and full validity and reliability reported if other researchers are going to find it of significant value.

Evolving Patient Participation in Safety Measurements: Years 2010 - Current

To determine if the questionnaire by Weingart et al.⁶ was used in other studies, a cited reference search of Web of Science was conducted (June 2020). Although there were no studies identified, in a secondary search using the databases MEDLINE and CINAHL for recent surveys and questionnaires involving overall measurement of patient participation in safety activities at the direct care level (excluding those about one dimension only such as medication safety), four additional questionnaires/surveys were obtained, two of which appear related¹⁷⁻²⁰ and one¹⁸ which drew from a related earlier survey²¹ [see Table 3 in Appendix].

Currently, there is no ‘gold standard’ instrument or questionnaire to quantify patient participation in all relevant *safety* activities generally at the direct care level in hospital. The measures presented in Table 3 vary, as example, in the content (device safety or not), the referenced setting (in-hospital, doctor’s office, pharmacy) and length (seven to 36 items), yet they all included some common dimensions such as personal health knowledge, communication with professionals, and medication safety. Understanding and conceptualizing all dimensions of safety, as well as balancing brevity, clarity, as well as whose perspective (e.g., patient and or provider) and frequency of assessment, are essential considerations for measurement development in this area.

Schwappach’s⁹ application of the Theory of Planned Behaviour to patient engagement in patient safety is also an important reminder of how we capture and distinguish individuals’ intent to participate or act versus actual behaviour. The questionnaire by Lee et al.¹⁸ may account for these by measuring attitudes toward a behaviour, their willingness to perform it, and their experience with performing the behaviour. Measuring these factors can reveal areas of improvement by highlighting, as example, disparities between self-efficacy and performance. Overall and undoubtedly, a reliable and validated standard instrument to measure in-hospital participation will be an important future goal to aid consistency in reporting and for comparisons at the clinical and research levels, as well as in determining effectiveness or areas for improvement in patient engagement in safety.

Study Strengths and Limitations

This patient participation in safety questionnaire was part of a larger study^{4,5} with acknowledged strengths and limitations. This additional component of the study is a clear advantage given the additional insights it provided into not only the questionnaire items and structure, but as well the content. Participants, more often than not, wanted to talk about their answers, and it allowed for a way of identifying discrepancies, as well as unpacking, clarifying, and or validating information. The use of this particular questionnaire in this study is not without limitation. The questionnaire did not have psychometric testing reported, and it was only used in this study as a complement to the in-depth qualitative interviews conducted with a relatively small sample size for quantitative testing (n=28 inpatients). It must be acknowledged as well that social desirability biases and perceived self-efficacy may have led to over-reporting of safety behaviour.

Conclusion

The patient-reported participation safety activities questionnaire used in this study was a succinct way to capture patient behaviours at the direct care level. It highlighted one of the lowest ranked in-hospital activities – medication checking – and contributed to existing findings that more involved participation is associated with confidence in one’s safeguarding ability. All research findings, regardless of scope, are important to reflect on and disseminate. The study is another advancement as we continue to learn and develop our ways of knowing about and understanding patient engagement in patient safety.

Data Availability Statement

Research data are not shared due to privacy/ethical reasons.

References

1. Baker GR, Norton PG, Flintoft V, et al. The Canadian Adverse Events Study: the incidence of adverse events among hospital patients in Canada. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*. 2004;170(11):1678-1686.
2. Chan B, Cochrane D. *Measuring patient harm in Canadian hospitals: What can be done to improve patient safety?* Ottawa, Canada: Canadian Institute for Health Information, Canadian Patient Safety Institute;2016.
3. Tessier L, Guilcher SJT, Bai YQ, Ng R, Wodchis WP. The impact of hospital harm on length of stay, costs of care and length of person-centred episodes of care: a retrospective cohort study. *CMAJ*. 2019;191(32):E879-E885.

4. Duhn L, Medves J. A 5-facet framework to describe patient engagement in patient safety. *Health Expect.* 2018;21(6):1122-1133.
5. Duhn L, Godfrey C, Medves J. Scoping review of patients' attitudes about their role and behaviours to ensure safe care at the direct care level. *Health Expect.* 2020;23:979-991. <https://doi.org/10.1111/hex.13117>
6. Weingart SN, Zhu J, Chiappetta L, et al. Hospitalized patients' participation and its impact on quality of care and patient safety. *International journal for quality in health care : journal of the International Society for Quality in Health Care.* 2011;23(3):269-277.
7. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health affairs (Project Hope).* 2013;32(2):223-231.
8. Longtin Y, Sax H, Leape LL, Sheridan SE, Donaldson L, Pittet D. Patient participation: current knowledge and applicability to patient safety. *Mayo Clinic proceedings.* 2010;85(1):53-62.
9. Schwappach DLB. Review: engaging patients as vigilant partners in safety: a systematic review. *Medical care research and review : MCRR.* 2010;67(2):119-148.
10. Davis RE, Jacklin R, Sevdalis N, Vincent CA. Patient involvement in patient safety: what factors influence patient participation and engagement? *Health expectations : an international journal of public participation in health care and health policy.* 2007;10(3):259-267.
11. Vaismoradi M, Jordan S, Kangasniemi M. Patient participation in patient safety and nursing input - a systematic review. *Journal of Clinical Nursing.* 2015;24(5-6):627-639.
12. Berger Z, Flickinger TE, Pfoh E, Martinez KA, Dy SM. Promoting engagement by patients and families to reduce adverse events in acute care settings: a systematic review. *BMJ quality & safety.* 2014;23(7):548-555.
13. Doherty C, Stavropoulou C. Patients' willingness and ability to participate actively in the reduction of clinical errors: a systematic literature review. *Social Science & Medicine.* 2012;75(2):257-263.
14. Alzyood M, Jackson D, Brooke J, Aveyard H. An integrative review exploring the perceptions of patients and healthcare professionals towards patient involvement in promoting hand hygiene compliance in the hospital setting. *Journal of Clinical Nursing (John Wiley & Sons, Inc).* 2018;27(7-8):1329-1345.
15. Butenko S, Lockwood C, McArthur A. Patient experiences of partnering with healthcare professionals for hand hygiene compliance: a systematic review. *JBI Database of Systematic Reviews & Implementation Reports.* 2017;15(6):1645-1670.
16. Davis R, Parand A, Pinto A, Buetow S. Systematic review of the effectiveness of strategies to encourage patients to remind healthcare professionals about their hand hygiene. *The Journal of hospital infection.* 2015;89(3):141-162.
17. Hwang JI, Kim SW, Chin HJ. Patient Participation in Patient Safety and Its Relationships with Nurse's Patient-Centered Care Competency, Teamwork, and Safety Climate. *Asian Nursing Research.* 2019;13(2):130-136.
18. Lee NJ, Ahn S, Lee M. Mixed-method investigation of health consumers' perception and experience of participation in patient safety activities. *Bmj Open.* 2020;10(3):13.
19. Sahlström M, Partanen P, Azimirad M, Selander T, Turunen H. Patient participation in patient safety-An exploration of promoting factors. *J Nurs Manag.* 2019;27(1):84-92.
20. Sahlstrom M, Partanen P, Turunen H. Safety as experienced by patients themselves: a Finnish survey of the most recent period of care. *Research in Nursing & Health.* 2014;37(3):194-203.
21. Marella WM, Finley E, Thomas AD, Clarke JR. Health care consumers' inclination to engage in selected patient safety practices: a survey of adults in Pennsylvania. *Journal of Patient safety.* 2007;3(4):184-189.

Appendix Table 1. Patient-reported Safety Participation Behaviours Questionnaire (n=28 inpatients)

<i>Question with Answer Option & Response n(%)</i>					
1. During your hospital stay, how much did you know about the medical problem for which you were admitted?					
	A lot*	Some*	A little	Not at all	
	12(42.9)	5(17.9)	5(17.9)	6(21.4)	
2. During your hospital stay, how often did you feel well enough to be able to talk with your doctors and nurses?					
	Always*	Usually*	Sometimes	Never	
	17(60.7)	5(17.9)	6(21.4)	0(0)	
3. When you wanted information about your care and treatment, how easy or difficult was it to find a doctor or nurse to tell you what you wanted to know?					
	Very easy*	Somewhat easy*	Somewhat difficult	Very difficult	Patient identified not applicable
	15(53.6)	6(21.4)	3(10.7)	2(7.1)	2(7.1)
4. During your hospital stay, when decisions had to be made, how often did your doctors and nurses describe the good and bad things about your treatment options?					
	Always*	Usually*	Sometimes	Never	Patient identified not applicable
	16(57.1)	4(14.3)	3(10.7)	3(10.7)	2(7.1)
5. Did you participate in the decisions your healthcare team made about your care...?					
	Less than wanted	About the right amount*	More than wanted*	Patient identified not applicable	
	3(10.7)	22(78.6)	1(3.6)	2(7.1)	
6. During your hospital stay, did you have a family member or a friend visit you? If yes, did that person help you make sure your health care wishes were being followed by the hospital staff?					
	Visitor always made sure*	Visitor usually made sure*	Visitor sometimes made sure	Visitor never made sure	No visitors
	10(35.7)	3(10.7)	6(21.4)	4(14.3)	2(7.1)
					Patient identified not applicable
					3(10.7)
7. During your hospital stay, when you were given medicines, did you ever check to make sure that they were the correct ones? If yes, how often did you check the medicines given to you by the hospital staff?					
	Checked always*	Checked usually*	Checked sometimes	Did not check	
	11(39.3)	4(14.3)	3(10.7)	10(35.7)	
8. In general, when in the hospital, how much can you rely on your own knowledge and alertness to protect yourself from medical errors?					
	A lot	Some	A little	Not at all	
	7(25.0)	13(46.4)	7(25.0)	1(3.6)	

* Scored as a positive participation activity (value of 1 each); total participation score ranged from 0-7 (excluded question 8).

Appendix Table 2: Association of Patient-reported Safety Participation Behaviours with Perception of Knowledge and Alertness to Protect Oneself from Medical Errors In-Hospital (n=28 inpatients)

		Participation [†]		p-value (2-sided)
		High (%)	Low (%)	
Knowledge and Alertness	<i>A Lot/Some</i>	15 (53.6)	5 (17.8)	0.030*
	<i>A Little/Not at All</i>	2 (7.1)	6 (21.4)	

[†]Participation: Low (0-4 activities); High (5-7 activities).

*Fisher's Exact Test; significant at $p < .05$.

Appendix Table 3. General Patient Safety Behaviours at the Direct Care Level: Select Measurement Instruments (2010-current)

Author & Year	Questionnaire Name/Description	Design	Topics (<i>as summarized by current article authors</i>)	Psychometrics
Hwang et al. (2019) ¹⁷	Patient Participation Activities Questionnaire	20 Items 4-point Likert scale Participation dichotomized as “High” or “Low”.	Personal Health Knowledge Communication with Professionals & Self Advocacy Safe Routine practices Medication Safety	Cronbach’s $\alpha = 0.91$. Expert Review for Content Validity. (n=479 nurses)
Lee et al. (2020) ¹⁸	Patient Participation Practices Questionnaire*	13 Items 4-point Likert scale Categorized into “Importance”, “Willingness” & “Experience” of the participation activity.	Personal Health Knowledge Communication with Professionals & Self Advocacy Family Involvement Medication Safety	Cronbach’s $\alpha = 0.814, 0.900, 0.844$ for the three sections. (n=493 health consumers)
Sahlström et al. (2019) ¹⁹	Patient Experience with Patient Safety (PEPS) Questionnaire	36 Items 5-point Likert scale	Personal Health Knowledge Communication with Professionals & Self Advocacy Device, Treatment, Medication Safety	Cronbach’s $\alpha = 0.929$ **Expert Review (n=4) for Content Validity **Patient Review (n=5) for Face Validity (n=462 patients)
Sahlström et al. (2014) ²⁰	Patient Experiences on Patient Safety (PEPS) Questionnaire	27 Items 5-point Likert scale	Personal Health Knowledge Communication with Professionals & Self Advocacy Device, Treatment, Medication Safety	Cronbach’s $\alpha = 0.88$ **Expert Review (n=4) for Content Validity **Patient Review (n=5) for Face Validity (n= 175 patients)
Weingart et al. (2011) ⁶	Patient-reported Participation Activities Questionnaire	7 Items*** 4 to 6-point Likert scales Participation dichotomized as “High” or “Low”.	Personal Health Knowledge Communication with Professionals & Self Advocacy Family Involvement Medication Safety	Cognitive Testing with 10 former patients (questions 1-7). (n=2025 patients)

* Based on a survey by Marella et al. (2007)²¹

** This testing appears the same/consistent between the two study papers by Sahlström et al. (2014, 2019).

*** Additional (relevant) question included: “In general, when in the hospital, how can you rely on your own knowledge and alertness to protect yourself from medical errors?”