Author’s response to reviews

Title: The importance of power, context and agency in improving patient experience through a patient and family centred care approach

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Version: 1 Date: 19 Jul 2019

Author’s response to reviews:

18th July 2019

Dear Reviewers

We the authors would like to thank you for your extensive and detailed comments on our paper. We found your comments very helpful and think they have helped us to considerably strengthen our paper.

Reviewer #2: The manuscript "The importance of power, context and agency in improving patient experience through a patient and family centred care approach" focuses on a relevant issue. However, the Introduction section could use further work, there is little novelty in the results and the discussion does not engage sufficiently with the existing literature. The Methods section also needs revisions.

Authors’ response: All sections of the article have now been revised in line with the reviewer’s comments as detailed below and tracked in the paper.
The manuscript "The importance of power, context and agency in improving patient experience through a patient and family centred care approach" focuses on the topic of patient experience improvement how power, agency and context act to enable or constraint it. While this is a relevant topic, the paper could be strengthened by taking on revisions along the lines suggested below.

Introduction

Given the centrality of power and agency in this manuscript, it would be useful to have a more thorough theoretical review of these concepts and to provide some examples of how they may shape patient experience, not least by enabling or constraining patient and public involvement. Moving the sub-section "Realist Social Theory" up from the Methodology to the Introduction could help achieving this.

Authors’ response: We have moved the sub-section on realist social theory to the introduction and have enlarged it by providing a more thorough theoretical review of power and agency. Specifically, because our paper takes a realist approach, we have described how Margaret Archer’s work on structure and agency relates to our work. New theoretical references have been added on agency (Archer 2000, 2007), power (Allen 2008, Allen et al 2014), and structure (Nairn 2009), alongside how agency and power have been analysed in patient experience research (Griscti et al. 2017; Jorgensen et al. 2018). Pages 6-7.

Although the authors are right to state that several PPI models fail to address issues of diversity, inclusivity and power, our modified participation chain model has attempted to critically address these issues and to identify the factors enabling involvement in health care by minority groups who have been traditionally excluded from the participatory arena (ref. below).

Authors’ response: Many thanks for this reference which we have now included within our literature review, to highlight where PPI models have included factors of diversity and inclusion. We have also provided further clarification on page 5, about what we mean concerning tokenism and lack of inclusivity in current NHS practice.

As the research question is very much centred on staff teams, it would also be important to expand further on the issue of staff experiences, how these are influenced by power relations, structure and individual agency and how, in turn, those may influence patient experiences namely by facilitating or constraining the implementation of patient and family centred-care.

Authors’ response: We have added a reference to Maben et al.’s (2012) work that evidences how patient experiences have their antecedents in staff well-being and positive, empowering working environments, where staff themselves are empowered to enable high quality patient care. We have highlighted that: “The extent to which staff and patients can challenge and change institutions to facilitate patient-centred care can be a contingent process, dependent on institutional cultures, resources, networks, relationships and staff’s ability to instigate change (Farr 2018)”. Page 7.
In light of the importance of issues related to service organisation it would be helpful to provide information about two care pathways under study, the type of patients who are most likely to endure stroke and hip fracture, and the composition of the services where they are cared for.

Authors response: We have included these details for background information in Appendix 1 as the theoretical section and more quotes have increased the length of the paper. Pages 33-34.

Methodology

It is not clear when observations took place, by how many researchers, for how long, and how data was registered and included into the overall data analysis.

It would also be important to detail how many participants took part in each of the focus groups, what were their professional backgrounds, how many moderators were involved, how long did they last and how was data registered. Concerning the interviews, it would be important to detail whether the interviewer was the same as the one undertaking observation and the focus groups, and their average duration. Perhaps having a table with participants' socio-demographic characteristics could help to get a better grasp of the sample, both regarding the staff and the patients and relatives included in the study.

What determined the discontinuation of data collection? And how was the quality of the findings ensured?

Authors’ response: We have included an additional table as Appendix 2 linked to the Methodology section to address the details above. We have also provided an additional statement in the methodology on page 11 to explain what determined the discontinuation of data and on page 12 under the Coding and Analytic Framework to address the point on quality. We did not formally collect full socio-demographic data. We have also not provided specific details on participants professional backgrounds in the focus groups for the reasons mentioned below on anonymity and confidentiality. We have however provided a general table of staff roles [see Appendix 3] to further illustrate the types of staff that participated in the study.

Findings

Although the authors refer to the occupation of most of the participants they cite, it would be helpful to have citations matched directly to specific participants (for example defined by occupation and a number, or classified according to their relationship to a care pathway and a number). This would enable readers to assess the range of views on a specific topic and to understand how particular groups of participants may identify more or less with a certain issue. For example, although 19 patients were interviewed and five focus groups were held with 14 patients and 8 relatives, there’s is only one citation by one patient in the Findings section and none from relatives. So there seems to be a wealth of empirical material that has not been shared and which could make Findings more interesting and robust.
Authors response: We have not been able to match citations systematically to staff and patients/relatives on individual pathways because we need to be careful not to compromise participant anonymity, because the Trusts where the research was carried out are identifiable by co-author affiliations, therefore it may be relatively easy to identify specific job-holders and family participants. However, we have provided more detail on the numbers of patient and relative participants with good and poor experiences on the different pathways [under the findings section pages 12-13], added more explanation on participant numbers in the methodology section [pages 10-11] and used a greater number of quotes from both pathways when illustrating an issue. We believe that using different quotes throughout the findings section will also evidence our findings more robustly. We have added further quotes from 10 patients and 5 relatives [pages 13-17]. In order to identify the range of views more clearly on the different pathways, we have now also stated which pathway they are from and provided numbers so it is clearer where different individuals are being quoted. We have also added 11 additional quotes from staff participants [pages 16-19 and page 22].

The Findings report on the role played by context in facilitating or constraining a good patient experience. However, the issue of agency is under-developed and the issue of power could be more substantively illustrated by citations directly addressing power struggles and disempowerment.

Authors’ response: We have developed the section on individual team behaviours and attitudes to further develop issues of power, agency, and empowerment and disempowerment. In particular, we highlight the issue of how staff hierarchies seemed to affect communication with patients, adding quotes from both patients and staff that explore their experiences of communications, in relation to staff values and hierarchies. Pages 16-17.

There is no mention to findings emerging in connection to the participatory action research approach.

Authors response: We have included a section at the end of the findings and in strengths and limitations to reflect on the participatory action research approach, how it links to our findings and how it could be improved in further studies Page 25 and pages 31-32. We have also provided more details on the Research Advisory Groups in the methodology [page 10]

It is not clear how information from observations may have been included in the Findings.

Authors response: We have now included an explanation of this in the methodology section [see page 10].
Discussion

The Discussion could benefit from more critical engagement with the existing literature about power and agency in connection to patient experience improvement. At times, it feels as if the Discussion is still adding to the Findings. For example, it is stated that "staff also saw themselves as patient advocates" though this is not clearly reported in the Findings section.

Authors’ response: We have moved this sentence to the findings and added in a quote to evidence this. The quote reads: ‘I shout at bed managers because that’s my job, I have to be a voice for my stroke patients. They don’t like me but I’m not here to please … if somebody is in the bed where a stroke patient should come, the bed manager will get a roasting from myself.’ Page 18

It is also stated "patient empowerment has not translated into patients' everyday experiences". This statement would need to be supported by some citations from patients showing how they may have felt constrained (and by what) in exerting agency and having a say in their care.

Authors’ response: We have now added quotes to the findings section, to back up this discussion statement. New quotes in the findings section on individual team behaviours and attitudes include:

“In my opinion, you’re told what’s going to happen to you and you ain’t got no say in the matter” (Hip fracture ward patient (8)

‘Just being acknowledged that I existed would have been really very nice’ (Stroke ward, patient relative (9)

‘he was suffering from dementia and he couldn’t communicate with anybody…….he was so terribly lonely, he was crying’, [his wife thought ‘they [nurses] could have tried to communicate with him better than what they did’ [she continued]:‘They were just going in with his medicine…….saying, Hi X and that was it, out again’ (Stroke ward relative (11).

The husband of a stroke patient noted with respect to communicating with his wife while she was ‘out of it all’ with her stroke: There was no backup at all [for his wife], she seemed to be a nonentity’ (Stroke ward patient relative 14).

Also after discharge in outpatient clinics, patients commented about the lack of opportunity to ask questions: ‘There wasn’t the time, they were more interested in in and out’ (Stroke patient 12).
It is not clear what the purposes of the partnership between researchers, lay members and staff were and what achievements they enabled. It would be helpful to describe in greater detail how that partnership can be fostered and how less powerful groups may benefit from inclusive participation.

Authors response: This has now been addressed in an additional section on PPI at the end of the findings and in the strengths and limitations section to reflect on the participatory action research approach. We have then referred to this in the Discussion section as well as strengthened our comments in the discussion to talk about greater partnership working. Pages 29-31

In order for the advantages inherent to the use of a multi-methods approach to be more evident, it would be necessary to clarify what sort of information was gathered through each of the methods used and how it was triangulated.

Authors’ response: We have included an additional table in the Methodology section to provide these details of what sort of information was collected through each of the methods. Data from different sources was integrated, rather than triangulated (Moran-Ellis et al. 2006) at the analysis stage, using the two clinical pathways as a framework to understand both staff and patients’ experiences. We have now explained this in the analysis section.

Sentences starting in lines 441 and 457 are too similar.

Authors response: These have now been edited.

Yours sincerely

Authors of the paper