Author’s response to reviews

Title: Women’s experiences of receiving care for pelvic organ prolapse: A qualitative study.

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Author’s response to reviews:

Subject: Submission of a revised manuscript.

Manuscript title: Women’s experiences of receiving care for pelvic organ prolapse: A qualitative study.

Reference ID: BMWH-D-18-00619. R1
Dear Editor

Thank you for the opportunity to revise the manuscript in light of peer-review comments and generous extensions of time to complete the revisions. We have now addressed the comments raised by peer-reviewers and the editor and feel that these have improved the quality of the manuscript significantly.

Below we provide a table presenting three columns: the issues raised by peer-reviewers, our response to those issues and the changes made in the manuscript. In the revised manuscript, the changes in text are shown in blue font colour. We have attached a MS Word file containing this table of responses and changes.

We hope that our response to the comments and changes we have made to the manuscript are satisfactory and our paper is worthy of publication in BMC Women’s health.

Thank you for considering the revised submission. Please do not hesitate to contact us should you require further details.

Yours Sincerely

Purva Abhyankar

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No.

Reviewer/Editor Comment

Authors’ response

Changes to manuscript

Editor’s comments

1.

Abstract - Conclusion - Should be resumed to the conclusions of the study. Could be more precise.

We believe the conclusions indeed reflect the study’s findings. Further guidance on how these could be revised would be helpful.
2.

Introduction - You could reduce this section by removing lines 102-118. Lines 134-139 could be moved into methods.

The lines 102-118 have been removed and those from 129-139 (see suggestion from reviewer 1) have been moved to methods in a condensed format.

3.

Methods - You could check out the COREQ checklist for qualitative studies.

We have gone through the COREQ checklist carefully and have included the methodological details which were omitted previously. Other aspects have been addressed through other comments (e.g. data saturation, methodological framework etc).

e.g. Details of data collection: They were facilitated by two female members of the research team, KS (lead facilitator, an allied health professional and PhD; research fellow on the project, experienced in qualitative and focus group interviewing), and SW (support facilitator, a qualified physiotherapist and PhD, research fellow on project) using a semi-structured approach. Facilitators, not known to participants prior to data collection, made introductions during initial contact and focus groups. At the beginning of discussions, facilitators explained that the purpose of the focus groups/interviews was to explore women’s experiences of prolapse care and their ideals for a person-centred service, which would be fed back to local service planning meetings.

4.

You have to explain why from 39 positive answers only 22 entered in the analysis.

This was purely due to practical and logistical difficulties the research team experienced in arranging the focus groups with all potential participants within the study’s timescale. Firstly, the geographical spread of the selected sites was vast, with some regions being quite remote and rural. Arranging times, dates and venues convenient to all interested women in local areas proved a significant challenge. Secondly, as also explained in the paper, this data collection was part of the phase 1 of the PROPEL project, which meant that it needed to be completed within a reasonable time period allocated for phase 1. To meet the wider study aims, a pragmatic approach was necessary. The same reasons prevented a focus group being held in one location.

Responses expressing interest in the study were received from 39 women. However, practical difficulties of setting up dates, times and venues of convenience to interested participants, partly due to the remote and rural location of the sites, meant that data could only be collected from 22 women.
5.
You have obtained data with different techniques (focus groups and telephone interviews) and you have to explain why you did this.

This was done for pragmatic rather than theoretical reasons. Telephone interviews were conducted due to the unavailability of participants for a focus group in the local area within the study time period. This was due to the remote and rural geographical location and participant ability to travel. The paper included a sentence to explain this:

The initial plan was to hold four focus groups across the three sites (one site hosting two focus groups due to the large geographical size of the service area), with a minimum of four participants per focus group. However, participant availability prevented a focus group being held in one location due to remote and rural geographical location and participant ability to travel. Instead four individual telephone interviews were conducted with consenting participants in that area, using the same topic guide as for the three focus groups.

6.
You have to cite your theoretical reference. Why did you not use individual interviews? You did not explain this

Reasons for using focus groups, rather than individual interviews as our main data collection tool, are now provided on page 5, along with supporting theoretical references. These are as follows:

‘Focus groups, rather than individual interviews, were used as they a) offer a more naturalistic setting than being interviewed by a lone and unfamiliar interviewer {King et al, 2018}, b) stimulate greater elaboration and re-evaluation of opinions, allowing opportunities to qualify, amplify, amend or contradict stated views through interaction with others {King et al, 2018}, and c) have been shown to be more useful in exploring sensitive topics as participants feel less exposed and more reassured by similar concerns/opinions by others {Namey et al, 2017}.’

7.
To my opinion, you have performed a content analysis instead of a thematic analysis. This is a good paper (https://onlinelibrary.wiley.com/doi/full/10.1111/nhs.12048) that helps to differentiate between one and other.

We maintain that our analytical method was thematic, rather than content. The paper in the link (Vaismoradi et al (2013)) argues that thematic and content analysis overlap considerably and the main difference between the two is the quantification of qualitative data. Our analytical approach does not involve any attempts at quantification, and involve a degree of interpretation that is usually found in thematic analysis.
However we acknowledge that our description of the analysis approach and process was not explicit and clear and our themes reflected the scope of the theme’s content rather than the meaning/pattern in the data. We have made two changes to address this:

1. We have made explicit our aims of analysis, underlying assumptions, approach to analysis and phases used in the analytical process. We have drawn on Braun and Clark (2006) to guide this reporting, which is a key citation used in Vaismoradi et al (2013) paper to describe thematic analysis.

2. We have refined the names of our key themes to reflect the patterns of meaning contained within the theme.

Data analysis: Lines 192-229

Results: Renamed themes:

Evaluating what is Normal
Hobson’s choice of treatment decisions
Trial and error of treatment and technique

8.

Results - You should create a paragraph regarding the main results.

A paragraph summarising the main results of the study is included in the first part of the discussion, which also serves as a useful prelude to the discussion of those results. We feel it would be repetitive to create another paragraph in results section to summarise the main results. However, if the editors feels strongly about this, we can move the results summary paragraph to the top or end of the results section.

9.

The lack of demographic data is serious and this gives a great limitation to understand what were the characteristics from your group of women. You simply don't know who are these women, what they do, for how long have they studied, etc.

We are aware of this and have acknowledged it as a limitation within the discussion.
Another limitation is that no socio-demographic data were collected from the women who took part in the study, which means that we have no objective information on women’s age, socio-economic status, education and occupation.

10

Discussion - Needs to point out a theoretical framework

We have made the theoretical framework explicit in study design and data analysis. We have also included this framework within our discussion when summarising our findings.

Design: The study used a cross-sectional design with a qualitative approach, drawing on the theoretical lens of symbolic interactionism (a sociological and social-psychological perspective) to understand health behaviour based on the meanings that individuals ascribe to objects and/or actions in their everyday lives (Blumer, 1969; Carter and Fuller, 2015).

Data analysis: Data were subjected to thematic analysis driven by our theoretical interest in the area of interactional/communicational aspects of person-centred care (17). The analytical aim thus was to provide a rich and detailed qualitative account of the ways in which women’s interactions with health professionals and services shape their experiences of care.

Discussion: Lines 443-459.

11

Lines 670-673: You should write examples of similarity between your data and other studies.

Lines 674-675: what are the new insights this study provide?

We have expanded on this and added the following text to illustrate examples of similarity between our data and other studies as well as highlight new evidence (rather than insights – we have removed that term) provided by our study.

Our findings on experiences of seeking care confirm those reported in previous literature (5, 22-27), but also provide new evidence on the experiences of involvement in decisions around diagnosis and treatment. While some of the barriers for seeking help such as lack of knowledge about symptoms, beliefs about ageing, tendency to minimise the importance of symptoms, feelings of shame and embarrassment, and difficulty talking to others are well documented in previous studies (5, 22-24, 26), our study sheds light on important but often under-acknowledged (25) barriers present within the clinical encounter that add to the diagnostic delays, viz. the dismissive response from primary care professionals, their lack of knowledge of symptoms, prevention and treatment and lack of proactive intervention. Our findings are consistent with previous research suggesting that prolapse treatment decisions are preference-sensitive, i.e. they depend on women’s unique values, preferences and needs (4, 10, 28, 29). However, our study is
also the first to highlight the lack of choice, opportunity and support for women’s involvement in making treatment decisions and the need for more person-centred care.

12

Did you think about performing a metassynthesis of qualitative studies regarding this topic? Would strengthen the manuscript.

Thank you for this valuable suggestion. A meta-synthesis would indeed be of value to this area of research. However, we feel that conducting a meta-synthesis (which would require a systematic approach to literature searching as well as a secondary analysis of qualitative data from previous studies) would be beyond the scope of this paper. We will consider this suggestion for a future study.

13

Conclusions - Should reflect your data and not suggestions for future studies. Be more straightforward to the results

We believe that the conclusions indeed reflect the study’s findings and there is no reference to future studies within conclusions. We would appreciate further advice/guidance on how these can be made more straightforward to the results.

14

References - Should be revised, there are minor errors.

Reference list has been updated and errors corrected.

Reviewer 1

15

Initially I thank you for the opportunity to review this article.

Qualitative research has been gaining ground among scientific articles, however its method and analysis of results need the same or greater rigor of quantitative studies.

Thank you for all the valuable and helpful suggestions. We have attempted to address these as follows.
Title:

I suggest change to:

"Women's experiences of receiving care for pelvic organ prolapse. A qualitative study."

There is a lot of information in the title. The "experience of women" already reflects the current concept of "person-centered care". In my opinion the study design gets better at the end of title.

Thank you for the helpful suggestion. Title changed as suggested.

Women’s experiences of receiving care for pelvic organ prolapse: A qualitative study.

Abstract:

Please include "an intentional sample of 22 w…." in methods.

We have used the term ‘purposeful’, rather than ‘intentional’ as this is the most commonly used term in qualitative sampling of this type. As explained below in response to comment 23 in methods, the study sites were sampled purposefully. To reflect this, we have changed the sentence in the abstract to:

Twenty-two women receiving prolapse care through urogynaecology services across three purposefully selected NHS UK sites took part in three focus groups and four telephone interviews.

I suggest that in the results or discussion the importance of the multi-professional team in approaching treatment options should be addressed.

Thanks you for this important suggestion. We have added this to the first sentence in address this:

As prolapse treatment options expand to include more conservative choices, greater awareness and education is needed among women and professionals about these as a first line treatment and preventive measure, alongside a multi-professional team approach to treatment decision making.’
K-words: I suggest change "patient experience" for "woman experience"

Exclude "health care delivery", change "patient choice" for "woman choice".

We have made these changes in keywords.

prolapse, person-centred care, shared decision making, women’s experience, health services, women’s choice.

20

Introduction:

too long

I suggest to exclude

line 95-97 "In the reality of clinical practice, decisions are also likely to be influenced by practitioner skills, preferences and knowledge as well as availability and access to treatments."

line 121-124 "A detailed understanding of women's experiences of interactions with different health professionals and health services throughout their prolapse care is essential to improve the person centered ness of services."

The above lines have been removed.

21

Line 129-139 " Within PROPEL, the local sites were provided …to prove insightful for designing women's health services internationally." this can be briefly described in study methodology.

These lines have been moved to methodology and condensed as follows:

Within PROPEL, the local sites were provided with resources to identify and train staff to deliver PFMT for women with prolapse, with the staffing and format of service delivery being determined locally through a series of service planning meetings in phase 1 of the project. To provide a service-user input to these planning meetings, focus groups with women receiving care for prolapse in local areas were conducted exploring current experiences of services and care, preferences for service delivery models and their visions for a responsive and woman-centred service. This paper reports the findings from these focus groups as they are likely to prove insightful for designing women’s health services internationally.
Methods

Sample: Please include that is an intentional sample

The sampling strategy for this study was influenced by the PROPEL study design, which adopted a realist evaluation approach involving multiple case study design. Thus, our three NHS sites were selected purposefully to reflect variation in geographic location (rural/urban), different service delivery models, and previous involvement in POPPY trial. However, within each site, the sampling cannot be claimed to be purposive as all women receiving care for prolapse at the time of the study were eligible and invited to participate and data were collected from those who responded with an interest in participation.

We have added further explanation about our sampling in the paragraph on page 6, to explain this:

Sampling decisions were influenced by the PROPEL study design which involved a realist evaluation approach using multiple case study design. Sampling was purposeful at the level of NHS sites to maximise variation in service delivery contexts and women’s experiences of service and care within these differing contexts. Three NHS sites were selected purposively to reflect a mix of: urban/rural locations; previous involvement/non-involvement in research into the effectiveness of PFMT for prolapse, namely the UK Pelvic Organ Prolapse PhysiotherapY (POPPY) trial (7); and current differences in service delivery models (see Table 1). Within the three sites, the sampling frame centred on women’s experiences of receiving prolapse care and needs and priorities for person-centred service. The criteria for potential participants were females >18 years, seeking and receiving care for prolapse through the local gynaecology/women’s health service between November 2016 and March 2017.

Data Collection: KS and SW (one lead facilitator who was experienced in qualitative methodology and conducting focus groups, and one support facilitator who had knowledge in the subject area) - please include the academic background and profession of KS and SW.

The academic and professional background details have been added as follows (as per COREQ guidelines):

KS (lead facilitator, an allied health professional and PhD; research fellow on the project, experienced in qualitative and focus group interviewing), and SW (support facilitator, a qualified physiotherapist and PhD, research fellow on project)
Was informed consent obtained for each woman participant? If yes, include in method.

This is already stated in the Data collection section on page 7. We have clarified this as:

Each participant provided individual written consent prior to or on the day of the focus group/interview.

25

It is necessary to talk about the theoretical reference used before the software nVIVO.

We have cited the theoretical and methodological reference – Braun and Clark (2006) to support our analytical approach and process.

Data were subjected to thematic analysis (Braun and Clark 2006) with the aim of providing a rich and detailed qualitative account of women’s experiences and needs of care. Our analytical approach was theoretical as our research question was focussed on the interactional aspect of women’s care experiences. Using this approach we systematically identified, analysed and reported key patterns within the data relating to these aspects.

26

Results

Please change "Findings" for "Results"

This change has been made.

27

This topic is too long and tiring, needs to be reduced, there must be one or two "texts / speech" for each category or sub category. And at most two, when there is ambivalence.

The results need to be rewritten in a more concise way. This part of the article does not grab the attention of the reader, needs to be more objective, the "texts / speech" can also be shorter. And very direct answers like "exactly" do not need to be included.

Thank you for this valuable suggestion. We have now shortened the results, written them in a more concise way and have removed redundant quotes. The results section has now been reduced to 8 pages from 16 pages.
Figure 2: Final coding framework for focus group/interviews - I suggest a more creative figure to show the creation of the final coding framework.

A more creative figure has been added to depict the final descriptive coding framework. Consequently, figure 3 (depicting the analytical coding frame) has also been replaced with a new one, in order to be consistent with figure 2.

Fig 2 and 3.

Discussion

It's the best part of the paper..

But it is not "a relatively small cohort of women" but an intentional sample in a qualitative analysis.

We have modified this sentences as:

The study’s limitations include a relatively small number of women recruited from three geographic areas of the UK only, which may have a potential impact on the transferability of findings.

To say that "meaning the generalisability of the findings is unclear" is to disbelieve the methodology used. This phrase needs to be rewritten.

We have modified this sentence as follows to suggest a potential, rather than a certain impact on transferability (rather than generalisability, which is often not the aim of qualitative studies):

The sentence following this indicating similarity of our findings with those of other studies across Europe, America and Asia, provides assurance of the transferability of our findings.

Additionally, similarity of our findings with those of studies on women’s experiences of prolapse and of seeking care for prolapse from across the world, in Europe (5, 23), America (22, 24, 25,
27) and Asia (26) provides further assurance that the experiences may be transferrable beyond the context of the specific healthcare system involved in this study.

Both in the discussion and in the conclusions it is necessary to be very clear that the health care team must be multi-professional since this is not the reality in many places.

We have added the following sentences to the discussion and conclusion:

Discussion:

Prolapse care should be delivered in multi-professional teams to increase availability of a wider range of treatment options and an unbiased and informed approach to treatment decision making.

Conclusion

There is a need for a multi-professional approach to prolapse care to widen women’s access to these choices.

Reviewer 2

The article has theoretical relevance, and its objective adds knowledge and quality to the practice of care. It is well written and clear in its methodological outline. However, some methodological aspects compromise the reliability of the study findings. The following considerations come to improve the authors' perspective on the work design.

Thank you for the positive comments. We have tried to address the issues raised in the revised manuscript.

The study does not make use of a specific theoretical-methodological reference that subsidizes the authors' discussion regarding the content analysis findings in the literature. Although this is not an obligation, it confers robustness to the study and can enrich the discussion about the data. Considering that the main objective of the study was to know the experience of these women, the Phenomenology could be the theoretical methodological reference that would better meet the proposed objective. Such consideration follows as a suggestion.
Our approach to data analysis was thematic and we followed guidance by Braun and Clark on using thematic analysis (2006). We did not adopt a phenomenological approach; hence we do not feel comfortable with referring to the study as phenomenological.

As per the guidance by Braun and Clark (2006) we have made explicit our aims of analysis, underlying assumptions, approach to analysis and phased used in the analytical process.

See lines 192-229.

The text does not specify the criteria for inclusion or exclusion in the study.

The inclusion criteria were specified in the methods section. Within each site, any women who were receiving care for prolapse through local services at the time of the study were eligible to take part. We did not exclude any women. We have revised and clarified the relevant text on page 6.

Within the three sites, the sampling frame centred on women’s experiences of receiving prolapse care and needs and priorities for person-centred service. The criteria for potential participants were females >18 years, seeking and receiving care for prolapse through the local gynaecology/women’s health service between November 2016 and March 2017.

The sociodemographic data collection of the participants was not performed. Although this has been placed as a limitation, this is an important limitation from the point of view of knowledge of the sample profile.

This has been acknowledged in the study’s limitations as:

Another limitation is that no socio-demographic data were collected from the women who took part in the study, which means that we have no objective information on women’s age, socio-economic status, education and occupation.

The losses were not justified. 39 accepted to participate in the study, but only 22 were included.

Please see response to Editor’s comment #4.
A mixed collection of data occurred by associating focus groups and telephone interviews, it is believed in the attempt not to decrease the number of participants because of the difficulty in gathering all in face-to-face focus groups. This was a major complicator of the study, as there is no homogeneity in the way the data were collected.

We agree that this may be a complicator of the study. However, this was a pragmatic approach adopted due to practical difficulties of arranging a focus group in one area, which included remote and rural regions. We have acknowledged this as a limitation with added reasons for why we believe this may not have compromised the trustworthiness of the findings.

Finally, the combined use of focus groups and individual interviews for pragmatic reasons may have lowered the homogeneity in the data collection process, with a potential threat to the trustworthiness of findings {Morse, 2003}. However, absence of any observed differences in the type of data collected by each method and convergence of key themes across the two methods may suggest enhanced trustworthiness of findings {Lambet and Loiselle, 2008}.

38

The use of the saturation criteria in data collection was not mentioned. Could not the number of participants be expanded? Do the authors consider the results enough to meet the objective proposed by the study?

Data saturation was indeed monitored through analysis of data in parallel with data collection. This issue was inadvertently omitted in the paper. However, we have now added the following sentences to clarify this:

Sample size was guided by preliminary data analysis taking place simultaneously with data collection to identify data saturation. No new themes emerged from the data after about three focus groups and two interviews. Data collection was ended when data saturation was confirmed following further two interviews.

39

In the results, an identified category was omitted by the authors because it was not related to the women's care experience. Such a data would need to be clarified, especially since the purpose is the experience of women and this should not be restricted to the researchers' inquiries.

Braun and Clark (2006) suggest that thematic analysis can be used to provide a rich description of the entire dataset or a detailed account of particular aspect. We have adopted the latter approach. Both are equally valid approaches as long as the particular approach taken is made explicit.

Our analytical focus was on providing a detailed and more nuanced account of the interactional/communicational aspects of women’s experience of care. As such we focussed on
the data that related to women’s experiences of interactions with healthcare professionals. We have now made this explicit in the data analysis section while discussing our approach and assumption during analysis process. As this focus is made explicit upfront, we have removed any reference to codes/themes that did not relate to interactional aspects of care.

Data were subjected to thematic analysis driven by our theoretical interest in the area of interactional/communicational aspects of person-centred care (17). The analytical aim thus was to provide a rich and detailed qualitative account of the ways in which women’s interactions with health professionals and services shape their experiences of care. Using this approach we systematically identified, analysed and reported key patterns within the data relating to the interactional aspects (21).

In the presentation of the article, there are many authors who were not described in terms of their respective participation in the study.

As the study formed part of the wider study (PROPEL), the author list reflects the contributions of the study team throughout this study including conception, design, data collection, analysis, interpretation and write up. The author contributions are listed at the end of the manuscript:

MM, SH, KG, DM, ED, AE, HM, EC, PA and JW were involved in the conception and design of this study. KS and SW led the data collection, PA, IU and JW led the data analysis in discussion with KS and SW. DT and MMF provided stakeholder input to the overall study. All authors read and approved the final manuscript.