Author's response to reviews

Title: Wake up, wake up! It's me! It's my life! Patient narratives on person-centeredness in the integrated care context: A qualitative study

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Author's response to reviews: see over
Response to reviewers

Reviewer: Michel Botbol

Major compulsory revision

1) Clinical experience shows that the need to be understood is also important for many patients. I wander why this has not been considered as one of the core theme for person-centredness. It would be useful for the reader that the author explains more how he select the six core themes he proposes and eventually why some themes could be missing.

This is a very important comment made by the Reviewer. The need to be understood is one of the main underlying processes behind the concept of Space (feeling ‘seen’, heard, understood) which is the main ‘story’ of this manuscript. While we didn’t mention the need to be understood as a standalone component, it is woven throughout the other components of the paper, and particularly by the first 3 components: “Holism” (to be acknowledged as a whole person); “Naming” (to be acknowledged as a unique, equal, respected person); “Heed” (to be heeded and have un rushed visit to be able to tell their story).

To meet the reviewer’s recommendation we added a description of how the need to be understood is interlaced in the “Heed” theme. The reason patients want to be listened to and to have enough time to tell their story, is because they predominantly want to be understood. Please see the addition in the ‘Heed’ paragraph (pg. 13).

We also added a paragraph on the process of selecting the six themes (please see the last paragraph of the ‘Data analysis and Thematisation’ section on pg. 9. The 6 core elements emerged from the thematic analysis aspiring to develop a model describing ‘what constitutes person-centredness in the integrated care context’. We wished to create a model which will include different dimensions of person-centredness. The 6 elements emerged from the theoretical underpinning of concepts previously described person-centred care, yet not specifically in the integrated care context (e.g. shared-decision making, continuity of care etc.).

We also mentioned the contribution of bodies such as the International College of Person-centred Medicine, the Kings’ Fund in the UK, the Picker Institute, the International Foundation for Integrated Care, and the International Alliance of Patients’ Organizations, the Patient-Centered Outcomes Research Institute, to the definition of person-centredness in the integrated care context.

2) The concept of space as opposed to translucence is not fully adapted to describe the very interesting concept introduced by the author. It seems to me that; "consistence" or "consistency" would be more appropriate.

Following the second reviewer’s recommendation, we revised the concept of the ‘space’ and ‘translucence’. The reviewer suggested to eliminate the theme of Translucence and to describe the findings as presence and absence of space rather than space vs. translucence. The experience of ‘translucence’ (i.e. felling unseen, unheard) is now described as an outcome of lack of space but now as standalone theme.
Consistence refers to a harmonious uniformity or agreement among things or parts; the way in which a substance holds together. We were not sure how it could best describe the 6 themes describing person-centred care. Perhaps the reviewer could better explain the meaning of consistence in the sense of overarching theme for the 6 elements.

**Minor essential revision**

3) In their chapter on compassion (line 362) the authors seem to use indifferently sympathy and empathy. I suggest to differentiate the two concepts.

Thank you for drawing our attention to the difference between the terms, we revised accordingly focusing on empathy which is more closely related the concept of compassion discussed in the paragraph.
Reviewer: Kara Walker

Reviewer’s report:

Overall: Overall this manuscript about person-centered care is timely and relevant. As healthcare systems around the world work to involve patients and become more patient-centered, it is critical to understand what patient perspectives are in the very definition. Although I continue to quibble with separating person vs. patient centered terminology, this paper does an excellent job of refining the terms for the reader.

Strengths: The manuscript uses existing literature on the subject matter to guide the reader. Clearly the semi-structured interviews gave a wealth of data for analysis, among patients who use care frequently.

Weaknesses: The patient population may have some very unique views, as they are older and diabetic. The introduction should provide some context to why is this important and how many typical visits or types of providers that the typical patient in the study may be seen on a routine basis. Additionally, the overarching theme of Space and Translucence should be combined as they reflect opposites of one another to clarify and underscore the findings. Finally, some of the quotes do not add to the discussion and should be removed or revised.

Recommended revisions:

I have detailed recommended both minor and major revisions point by point below:

Major compulsory revisions:

1. In the first paragraph on page 4, background, the citations suggested that patient centeredness is linked to higher quality of life, lower anxiety and depression. Given that this patient population has diabetes, it would be excellent to include a citation that suggests an improvement in diabetic outcomes when there is greater shared decision making, continuity of care, or patient empowerment. There is a literature that exists in this space and should be discussed and included.

References added.

2. On page 5, the introduction of the term “knowledge dominance” is also linked to “paternalism” and again this need to move away from the physician assuming they have all the decision making ability. I would again encourage the authors to include this term and a link to a few more references.

References added.

3. On page 5, at the bottom of the page, the authors state that integrated care models are in “only 2 of 9 European countries”. I would be interested in who is making that judgment. Is this patients who state their care is not integrated or is this based on some external criteria and label of care models.

This classification was provided by PROCARE - the EU Fifth Framework Project ‘Providing integrated health and social care for older persons (Leichsenring, 2004; www.euro.centre.org/procare). One of the project’s aims was to identify different approaches to integration as well as structural, organisational, economic and social-
cultural factors and actors that constitute integrated and sustainable care systems. The classification builds on the subjective experience of the researchers participating in PRO-CARE and evidence given in the national reports of this project. If the reviewer feels the classification is inappropriate, we would remove it.

4. On line 118, page 6, the sentence is confusing. I would remove the part of the sentence relevant more to “continuity” of care rather than “shared decision-making” and just leave the latter part of the sentence about “felt less involved”.

Corrected.

5. On page 7, top of the page, this sentence about governments’ ethos implies that it is government’s role to deliver person centered-care. For an international audience and to make the statement more generalizable to other countries, I would recommend taking the second part of this sentence out.

Corrected.

6. On page 8, in the description of the sample, it leaves the reader wanting a bit more detailed information on the patients included in the findings section. I would recommend a short tabular summary of the patients included (ie average age, average comorbidities, % of those who know their GP, HbAIC or any other health outcomes that may be available and relevant).

The participants were people with diabetes and/or people over 75 years old who were registered with the pilot. Twelve of them (55%) were male and 10 were female and all of them were above 50 years old. Further data was not collected, as they felt more relevant for a quantitative analysis. As mentioned in the method section, this study was a part of a large-small mixed-methods evaluation of the Northwest London Integrated Care Pilot. A detailed quantitative patients demographics of the population studies in the evaluation were detailed in the quantitative streams of the evaluation:


7. As a major recommendation to the presentation of the themes, the authors should eliminate the theme of Translucence. All of the other themes are in the positive and connected by “Space”. The findings captured by translucence could be described but not labeled in the paragraph on page 17. The mix of themes with a positive and negative is confusing to the reader. The other subthemes do not have a positive and negative. The figure should be revised to only include “Space”. The table should then be revised to just be the presence and absence of space.
We agree with this comment and revised accordingly. The experience of ‘translucence’ is now described as an outcome of lack of space, but not labelled as a theme.

8. Suggestions to revised the quotes:

a. Page 11, line 236, please remove this quote as it is inflammatory. Recommend shortening it at “… Because they’re giving me no respect…” If this quote is shortened, please clarify the use of parenthesis for “person”. It may need to be replaced by brackets.

The quote was shorten and the parenthesis for “person” were replaced by brackets.

b. Page 12, line 256, both of the quotes are about mental health needs. I would recommend replacing this quote that pertains to another healthcare need to describe this theme.

We appreciate the reviewer’s comment, but suggest to retain these quotes. The substance of the ‘Holism’ theme is that providers should see the patient holistically, having psychological as well as clinical needs. The quote exemplifies how attention to psychological needs was appreciated by the patient as mindful attention of the providers to their needs.

c. Page 15, line 137, please exchange or remove this quote. It does not clarify the theme for the reader.

The quote was removed.

9. On page 20, please cite literature on the importance of “continuity of care”

References added.

Minor essential revisions:

1. On page 7, top of the page, line 132, suggest revision to “receive more person-centered care”. – Corrected.

2. On line 138, remove the extra comma. – Corrected.

3. Revise line 445, to capitalize “Current” – Corrected.