Author's response to reviews

Title: Patient neglect in healthcare institutions: A systematic review and conceptual model

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Author's response to reviews: see over
Dear Ms Pafitis,

Thank you for reviewing and requesting a revision of our manuscript ‘Patient neglect in healthcare institutions: A systematic review and conceptual model’ for BMC Health Services Research.

We have attempted to fully address the comments made by the reviewers, and I have attached a list of responses to each point. The reviewers’ comments were extremely helpful, and have aided us in developing the conceptual, theoretical, and presentational aspects of the paper. If you have any further questions regarding the manuscript, please do not hesitate to get in touch.

Sincerely yours,

Tom Reader
Please find below our responses to the comments made by the reviewers in their assessment of the paper ‘Patient neglect in healthcare institutions: A systematic review and conceptual model’. References to page and paragraph numbers indicate where changes have been made to the manuscript (in red font) in response to reviewer’s comments.

**Reviewer 1**

1. **Structure:** "My key comment about the paper is that the review could be made more accessible to the readers if the structure of the paper followed more closely the structure of a systematic review. I do understand of course that the authors had to introduce some conceptual clarification alongside extracting evidence from the papers they retrieved. However, I do think that with some rather slight rearrangement the paper will become more familiar to the eye and hence more digestible to clinical and patient safety readers – as follows":

We agree with this comment; reviewer 1 indicates that the conceptual development is an original outcome of the review, and that this should be more explicit in order that the literature review follows a more familiar structure. We have changed the presentation of the review so that it is clear that we systematically consider (1) the conceptual definition of neglect, (2) the forms of behaviour associated with neglect, (3) the reported frequency of neglect, and (4) the causes of neglect. Previously (1) was embedded in the overview of the study findings, and we have now addressed the meaning of neglect more directly (see response to comment 2). We hope this presentational change makes the manuscript easier to read through, and we have changed the manuscript at several points. These include sections in red font on page 6 and page 9 (both bottom paragraphs), and also some restructuring of the abstract (page 2, indicated in red font).

2. **Methods:** "I think the last part of Figure 1 (data extraction) should be removed from the figure (so the figure reads more like a 'traditional' flowchart of a systematic review ending with no of papers included). This part should be a separate para in the Methods”

We have removed the fourth box from the flowchart (data extraction) and have described it in the methods section (bottom paragraph, page 7).

3. **Results and Discussion:** Results should be separated from Discussion. In Results, I think the authors should have a section where they report their conceptual work (possibly after the first para of page 8). The concepts of caring/outcome neglect and also the distal/proximal causes should be introduced here – so it becomes clear to the reader that these are the authors’ own work. Then the evidence table can follow, with comments on the various findings as the authors have provided already (parts 1, 2 and 3 of Results are really the findings).

As suggested, we have separated the results and discussion section.

Reviewer 1 highlights the fact that the process of our conceptual refinement of patient neglect is not as clearly described as it might be, and we have tried to address this directly. We feel that the conceptual refinement of patient neglect should probably be placed at the end of what is now section 1 of the results (the meaning of patient neglect). Please see highlighted sections on pages 9-13 (to the section entitled "re-conceptualising patient neglect") which have been restructured in the following way.

Our initial conceptual refinement came from a realisation that i) neglect is unlike error or abuse, but often overlaps with these concepts, and ii) that studies of neglect are often
investigating two distinct things (caring neglect, and procedure neglect: we have renamed this from outcome neglect). Procedure neglect focuses on failings in the quality of care according to institutional metrics (but does not explain why it has occurred, for example it may occur due to error or carelessness), and caring neglect to failings by staff to care (e.g. show compassion) about patients: however caring neglect is a subjective and difficult to objectively verify. The current definitions of patient neglect do not take into account this subtlety – they simply refer to healthcare staff failing to meet the needs of a patient, and are not explanatory. To explain our rationale for developing the concepts of procedure and caring neglect, we now review the definitions of neglect in the studies identified from the literature review, and describe the conceptual problems with these definitions in relation to medical error and patient abuse. This leads to a section entitled "Re-conceptualising patient neglect", which presents the conceptual work that emerges from the initial review of 'the meaning of patient neglect'.

4. **Discussion.** The discussion should then be a separate part of the paper, where the findings are commented on and where the conceptual model of figure 2 is introduced – all in all this is not very different from what is report at present. What I am suggesting is some rearrangement.

We have changed the conclusions section to now be a discussion section. It is slightly expanded, and presents the model. This re-arrangement, as indicated by reviewer 1, helps the literature review to apply a more familiar format.

5. **Introduction.** One final minor point: the past sentence of page 6 (“The overall aim...interventions”) should be removed from there – it is a Discussion statement, really, in my view.

This has been changed to “The overall aim of the review is to contribute to the public dialogue and academic understanding of neglect”, which reflects the material presented in the introduction.

6. **Overall.** All in all, excellent work – my key point is to separate what is conceptually novel (and hence to actually highlight the authors’ intellectual effort) from what is factually based on the reviewed papers.

Many thanks for these constructive points. They chime with the comments of reviewer 2. To achieve the distinction between the review material and our own conceptual work, we have added a new section (1) which explains why our literature leads us to judge that a new definition of patient neglect is needed; we then put propose one in a sub-section. The discussion then advances this conceptual work.

**Reviewer 2**

1. **Missing bracket at the end of Results section in the abstract**

   This has been replaced, thank you for noticing it.

2. **22845 would read better as 22,845 on page 4**

   A comma has been added to the figure.
3. **Review material and conceptual model.** The conceptual model in Figure 2 mentions staff attitudes under caring neglect (e.g. the first paper in Table 1 cites data on rudeness in nurses; Jewkes et al., 1998). A wholly unscientific search in Science Direct (3.9.12) for [ALL ("nurses’ attitudes")]] gives 1,729 papers. A ‘glance’ at the first page shows some which might plausibly inform the conceptual model in Figure 2. For example (Kade et al. (2004) describe gaps and delays caused by nursing attitudes towards abortion procedures. To stress, it is not clear how many of these ‘other’ papers might be gathered by the original search on neglect and/or be excluded via screening for relevance, primary data etc. However, Kade et al. (Op Cit.) do not mention neglect but do cite the patient experience, staff rudeness and delays to procedure; thus their paper looks plausible for inclusion not in Table 1 (strict systematic protocol) but in Figure 2 (wider conceptual model). This confirms that the concepts within the model are broader than those within the search/ methodology. The authors have searched for neglect literature then carefully examined that for antecedents (left), typologies (middle) and consequences (right) of neglect (Figure 2). This adds analytic strength to the review and the inferences made are clear. However, including ‘staff attitudes’ in the typology raises the possibility of a staff attitudes literature review that might, if similarly analysed, show ‘neglect’ as a consequence (e.g. failings in care, harm etc. as in Figure 2). A similar case can be made with antecedents cited in the model (e.g. looking at the literature on high workload/staff shortage for failings in care which may arise). Hurst (2005) again does not mention neglect but draws connections between nursing workload (proximal causal factors in Figure 2) and care quality. This is not an insurmountable problem. The dialectic between inductive and deductive reasoning in analysis is well known and is recognised by the authors in the section on conceptualizing patient neglect where they say that ‘In reviewing the data captured within the research studies, it became apparent that further reflection was required on the meaning of patient neglect’. However, I think the relationship between the model and the systematic treatment of neglect (just 14 papers analysed) needs to be made clearer.

Discretionary revision: Perhaps it could be stressed here that the basic model is generated from analysis of the literature from the systematic search but that some of its descriptive aspects are informed by the authors’ more general awareness of the types of antecedents, behaviours and outcomes that occur when healthcare systems do not function optimally (see for example papers they cite in discussion).

Reviewer 2 highlights a very important point regarding the role of other literatures in informing our thinking on the concept of patient neglect, and separating this from the factual information derived from our review. This point was also highlighted by reviewer 1. We have taken some steps to remedy this.

First, we have introduced a new section (1) which reviews how publications in the literature search define patient neglect. This is clearly juxtaposed against other literatures (e.g. error and abuse), of which we have knowledge. Please see our response to reviewer 1, comment 3 for a description of this section. In essence, it attempts to show how these other literatures have informed our understanding of patient neglect.

Second, our description of caring neglect has been simplified. In the previous version, we referred to attitudes in our definition of caring neglect – yet as indicated by reviewer 2, the data from our review inferred this but did not actually demonstrate it. Thus, in our definition of caring neglect, we now simply refer to caring neglect as “staff behaviours which lead patients, family and the public to believe that staff are unconcerned with patients’ emotional and physical wellbeing” (please see page 14, both paragraphs). This definition is maintained in table 1, and the conceptual model. Poor attitudes are often
attributed to incidences of caring neglect (which are behaviours that are subjective and often below the threshold of institutional monitoring). We hope our amended definition better reflects the literature review.

Third, the conceptual model now adopts the refined definitions described above, with concepts not reviewed in the literature search being removed from the model. To some extent, development of the model to incorporate factors such as attitudes is the next step of this research. On page 29 (bottom paragraph) we highlight that our model still however draws on assumptions from organisational psychology, and speculates on the patient outcomes of caring and procedure neglect.

Fourth, we highlight the overlap between the literature on attitudes, patient expectations of care, and patient neglect on both page 8 (paragraph 1) and page 30 (bottom paragraph). These show that patient neglect often involves concepts explored in other disciplines (e.g. staff attitudes, compassion, patient beliefs about good care), and that these are relevant for understanding patient neglect. However, they did not meet the review criteria as they did not focus explicitly on patient neglect (yet, they did influence our thinking, and are relevant). Future research will aim to start integrating these different fields of research.

4. Conceptual model (Figure 2)
Figure 2 contains a number of categories of interest.

Error/failure and abuse
The distinction made is between ‘unintended errors or failures in the caring of patients that occur due to factors such as workload, system design, or training/competence’ versus ‘Deliberate attempts to harm patients through withholding care (e.g. due to a breakdown in staff-patient relationships)’.

Abuse (knowingly acting against the best interests of the patient) is straightforward enough is that it fits with the somewhat wider concept of a rule-violation (a deliberate choice of an individual to deviate from rules; Goodman et al., 2011).

It is difficult to do justice to the large literature on human error in a model like this, but I am not sure the denoted ‘unintended errors’ is helpful. WHO (2009 p16) are clear that ‘Errors are, by definition, unintentional’. However, it can be argued that whilst outcomes may be unintended errors are better classified in behavioural terms rather than by their effects. Some errors (principally modal ones) involve intended behaviours that for one reason or another (e.g. acting on misinformation) have unintended consequences. Here, the course followed is wrongly believed to be correct at the time (contrast with attention lapses or physical errors of perception).

Discretionary revision: The authors are familiar with taxonomies of error; perhaps the error/failure box might include some short description which

We agree with the point above, and have decided that it may be simpler to remove error and abuse from the model. The text differentiates between error, abuse, and neglect, and it may be over-complicating things (we were probably over-ambitious) to introduce error into the model. Furthermore, as indicated in reviewer 2 comment 3, it may be more effective to have the model reflect the literature review (in which error etc is considered, but not reviewed). Error is certainly very important for understanding patient neglect, however further detangling may be required before it can be fully modelled (we make this point in page 32, final paragraph).

5. Discretionary revision: Also, I would not tend to ‘couple’ the errors in the top ‘box’ with their causes/ antecedents. The model does this already via distal and proximal
antecedent boxes and I think it is conceptually more elegant without defining errors in terms of their antecedents.

Please see the response to comment 4, which describes the removal of error from the conceptual model.

6. **Terminology.** Finally I wonder if ‘outcome neglect’ is the clearest possible term for falling short of ‘objective and observable standards’ (Figure 2). The final three boxes of the model, whilst termed ‘impact’, read like patient outcomes, which is a well-known concept around harmful impacts on patients including ‘psychological trauma’ (Ausserhaufer et al., In Press). Discretionary revision: I wonder if outcomes could be exclusive to the right hand side of the model and the types of neglect distinction redrawn around the perceptive/subjective versus ‘objective’ distinction which the authors make; Material neglect? - just an idea.

We agree with this, and have amended some of the concept names. ‘Outcome neglect’ is now termed ‘Procedure neglect’, which we feel is more appropriate as it refers to objective failings in care (which are typically proceduralised). The model structures has been changed somewhat to better reflect the amended definition of caring neglect. Patient outcomes are seen as occurring from procedure neglect, and we indicate that we have not reviewed these in our current study (page 29, bottom paragraph).

7. **Conclusion:** I think the paper is methodologically clear (Figure 1) and it is easy to read. The conclusions in Figure 2 are supported in part by the data in Table 1. However, the conceptual model of neglect introduces terms that are themselves meaningful but are not included in the search syntax.

Discretionary revision: This opens up the possibility that there is a wider literature (examples given here are staff attitudes and workload) that could feed into an antecedent- neglect- impact model. My recommendation is that this is made explicit. Then, as well as the future directions mentioned in the paper, work could explore the different areas of the neglect model to examine further whether it is substantially robust.

Many thanks for this very useful observation – we have changed elements of the paper in order to reflect it. We feel it is a stronger piece of work, and conceptually more refined.