Reviewer's report

Title: The struggle against perceived negligence. A qualitative study of patients' experiences of adverse events in Norwegian hospitals

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Reviewer: Alissa L. Russ

Reviewer's report:

Summary: The authors report results from interview with 15 patients who experienced adverse events. Interviews were conducted 1-10 years (average 4) after the actual event occurred. The authors make effective use of interview quotes and present an important and compelling perspective: the patients'. There are several grammatical issues in the abstract and throughout the manuscript; translating to English is understandably challenging, but these need to be addressed for readers. I agree that there is a need for more research on patients' perspectives, but much more detail is needed on the methods and I have concerns about the long timeline between the adverse events and follow-up interviews. The discussion also needs substantial improvement. Specific comments are below.

Major Comments:

1. TITLE: "Negligence" seems too definitive, especially given limitations of the methods, and that only patient perspectives (not provider or broader healthcare system) were collected. "Perceived negligence" (if patients used the term "negligence") or "The struggle to be heard" may be some alternatives.

2. ABSTRACT: There are several grammatical issues in the abstract. Just as one example, the last sentence of the "background" was difficult to interpret. Also, "Foucault's power relationship theories" appeared abruptly and needs more introduction/explanation; this is likely more appropriate for the manuscript text, rather than the abstract.

3. INTRODUCTION:

a. The Introduction does not adequately recognize prior, related research on patient perspectives. The discussion mentions several articles on patient perspectives that I expected to be summarized in the Introduction. For example:


b. "Up until now, patient safety activities and research into adverse events have largely had a system-based and biomedical focus [13]. This is a top-down approach and the patient voices are often absent in patient safety research and patient safety programmes [14]." I agree that more attention is needed on patient perspectives, but it is not accurate to imply that system-based approaches exclude the patient. In fact, patients are the center of one of the widely recognized, system-based models (SEIPS; see Holden et al, SEIPS 2.0: a human factors framework for studying and improving the work of healthcare professionals and patients” Ergonomics, 2013)

4. METHODS

a. Line 113. The "Thematic Interview Guide" should be provided in an Appendix so readers can assess the interview questions and validity of results. Were at least some of the same questions asked across patients for consistency?

b. More details are needed on the qualitative analysis: What was the expertise/background of the analysts? Was any qualitative software used? How were discrepancies between analysts resolved? More references are needed to support the choice of qualitative methods.

c. Line 102: patient incidents were collected across "several local hospitals". How many different hospitals?

d. Line 104: "The interviews were conducted 1 to 10 years after the adverse event, with an average of 4 years." This is a very long time between the incident and follow-up interview; memory and recall accuracy are known to degrade over time. Provide more rationale for this choice. Why was no maximum time limit set as an inclusion criterion? This should be noted as a study limitation.
5. RESULTS.

a. Line 137: "The discharge epicrises were also analysed, in light of whether they described the events and in what way they were presented. After this, we divided each interview into three parts: the event itself, the significance for life after the event and circumstances relating to apology/compensation. This article is about the event itself." I expected to see results from all three parts described in the same manuscript, especially since they are somewhat linked together. Presenting all three would strengthen the contributions of this manuscript.


c. Table 2 seems unnecessary. The organization of Table 3 was difficult to interpret.

6. DISCUSSION

a. The discussion seems overly long and warrants a more structured/focused approach.

b. The acknowledgement of the struggles of healthcare personnel and their experience as a "second victim" is important and was good to see in the discussion (line 330).

c. Starting line 161: I was surprised that all "before treatment" cases in this study involved cancer, while all "during/after treatment" involved other (non-cancer related) patient cases. Why might this be? This should be included in the discussion.

d. Several points in the discussion seem overreaching, beyond the data presented from the 15 patients. For example, line 218: "The descriptions reveal possible barriers to openness and might indicate that patient experiences are probably not used for further learning and improvement, at neither individual nor system level." Also, line 339: "This is a sign of professional and organisational cultures that do little to actively admit errors or create learning and demonstrates a poor ability to introduce measures that safeguard safety and the patients' best interests." There are hospital systems that use safety data to make changes and inform system improvements. The study was conducted in a limited number
of hospitals, and only interviewed patients, yet the above statements seem to imply hospitals in general.

Minor Comments:

"User perspectives" is generally associated with usability studies, which are different methods than this research. Suggest replacing with "patient perspectives" throughout.

Unless direct quotes from the interviewees, avoid use of jargon, such as "cards close to their chest" (line 56) and "triple shake" (discussion, line 314).

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

No

Does the work include the necessary controls?
If not, please specify which controls are required in your comments to the authors.

Yes

Are the conclusions drawn adequately supported by the data shown?
If not, please explain in your comments to the authors.

No

Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?
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Not relevant to this manuscript

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Please indicate the quality of language in the manuscript:

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