

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	IDENTIFYING PRIORITY POLICY ISSUES AND HEALTH SYSTEM RESEARCH QUESTIONS ASSOCIATED WITH RECOVERY OUTCOMES FOR BURNS SURVIVORS IN INDIA: A QUALITATIVE INQUIRY
AUTHORS	Jagnoor, Jagnoor; Bekker, Sheree; Chamania, Shobha; Potokar, Tom; Ivers, Rebecca

VERSION 1 – REVIEW

REVIEWER	Molly Marino RTI International, United States of America
REVIEW RETURNED	31-Oct-2017

GENERAL COMMENTS	<p>Abstract: Clear and well defined.</p> <p>Introduction: Concise and sets up the need for the research well.</p> <p>Methods:</p> <p>- "This study was informed by systems thinking" is a rather broad statement. I would like to hear more about how were the features of systems thinking influencing the work. For example, sampling criteria, interview guide/questions asked, coding, interpretation etc. Perhaps a diagram here to show how the conceptual framework influences study design would be helpful.</p> <p>"A qualitative participatory research approach was used" I am not clear on how your study design was participatory research? It seems like a traditional qualitative inquiry based upon the current description.</p> <p>- A copy of the interview guide or sample of questions should be presented.</p> <p>- In Table 1, it would be nice to get a sense of how long these individuals have been working with burn injuries and burn survivors, and how much of their time is currently spent with this type of patient population.</p> <p>- The results and discussion largely rest upon the clarity of Figure 1. It is not entirely clear what the color coding system means, and where all of the elements of the figure are derived from. A stronger link between the findings and each specific portion of the figure needs to be established. Perhaps an early figure explaining your conceptual framework and the elements of "systems thinking" you are employing would facilitate that. Further, the Gaps seem to be tacked on to the bottom of the figure. If the entire diagram is the system, then gaps are part of the system that are needs/features not currently being met by care for burn survivors. If these gaps were incorporated into their respective parts of the system diagram and then somehow delineated as Gaps/Needs not being met, the figure</p>
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	and results would be clearer and stronger.
REVIEWER	Rachel Kornhaber National Burns Unit, Sheba Medical Center, Israel
REVIEW RETURNED	26-Dec-2017
GENERAL COMMENTS	<p>Thank you for allowing me to review the manuscript titled: "I was an untouchable" – Stigma, shame and social systems: recovery for burns survivors in India. Research into burns care and rehabilitation is as the authors' state the 'forgotten global public health crisis'. This manuscript reads well and highlights an important area in burns care.</p> <p>*The title does not reflect the study as the word "untouchable" is only evident in one quote participant 8 (in which some words were not clear therefore, the quote in itself needs to be clarified). The word shame apart from the title and page 21 is not mentioned in the results or the participant quotes.</p> <p>*Whilst it is difficult to include all participants in such a large qualitative study, there is an emphasis on certain participants throughout e.g. participants 12, 24, 23.</p> <p>* On page 3 FGDs is used with no explanation of the acronym and it is not until the 2nd paragraph on page 8, that one is provided.</p> <p>* The tables are not provided with an explanation of the abbreviations e.g. Table 2 no explanation for FGD or IDI is provided. Furthermore, IDI is not mentioned anywhere in the manuscript.</p> <p>*The diagram (Figure 1) on page 28 is not label with a Figure and some of the words are occluded e.g. financial, morbidity and withdrawal. Furthermore, it is a very busy diagram that would benefit from some graphic expertise.</p> <p>*Table 2 the words 'purposelymale' need to be separated with a space.</p> <p>*Table 3 containing the participant quotes, many of these quotes resonate with burns care and rehabilitation globally. What is new knowledge and unique about burns care in India? This needs to be more overt in the results and resonate in the discussion.</p> <p>*The discussion is rather brief and could be expand to discuss the wider literature in relation to the importance of burns care in Indian and the unique Indian experience.</p> <p>*Greater synthesis of the findings is required as the participant quotes stand alone in Table 3.</p> <p>*The referencing for BMJ Open requires all journal titles to be abbreviated and not in full as the authors have displayed in the reference list.</p> <p>* Qualitative research requires a COREQ checklist that should be submitted which is to ensure transparency for qualitative reporting (See link below for COREQ statement) https://www.equator-network.org/reporting-guidelines/coreq/</p>

VERSION 1 – AUTHOR RESPONSE

Dear Dr Emma Gray,

We thank the editor and reviewers for their insightful and helpful feedback in improving this manuscript. We have responded to each point below in turn, and have indicated any changes in the manuscript in red text.

Please do not hesitate to contact me for further information.

Yours sincerely,
Jagnoor

(on behalf of all co-authors)

****Authors' response to editor**

Editor Comments to Author:

- Please include the study design in the title. Ideally, the title would be split into two parts rather than three, so you may need to consider removing the title at the start. The title should consist of the research question, the study design and the location - this is the preferred format of the journal.

****We have revised the title and it now reads: "Identifying priority policy issues and health system research questions associated with recovery outcomes for burns survivors in India: a qualitative inquiry"**

- Please complete and include a COREQ checklist, ensuring that all points are included and state the page numbers where each item can be found. The checklist can be downloaded from here:

<http://www.equator-network.org/reporting-guidelines/coreq/>

****We have completed and included the COREQ checklist in this resubmission**

- Please include the name of the ethics committee that approved your work. You do not need to anonymise this in the text, as BMJ Open operates open peer review.

****We have included the name of the ethics committee, on page 5.**

****Authors' response to reviewers**

Reviewer(s)' Comments to Author:

Reviewer: 1

Reviewer Name: Molly Marino

Institution and Country: RTI International, United States of America

Please state any competing interests or state 'None declared': None declared.

Please leave your comments for the authors below

Abstract: Clear and well defined.

Introduction: Concise and sets up the need for the research well.

Methods:

-"This study was informed by systems thinking" is a rather broad statement. I would like to hear more about how were the features of systems thinking influencing the work. For example, sampling criteria, interview guide/questions asked, coding, interpretation etc. Perhaps a diagram here to show how the conceptual framework influences study design would be helpful.

****We have expanded on the methods section to better explain how systems thinking influenced this research, a participatory research approach to co-design future interventions. The methods section now reads: "The research underpinned by systems thinking used participatory research for identifying priority areas for research, health system and policy aims to co-design interventions for the same.**

This study reports on the second phase of data collection in the participatory action research model. It informs on the networks, views health in the broader dynamic social and economic context,

recognizing patterns and interrelationships with the aim of structuring those interrelationships in more effective, efficient ways. (12, 13).

Qualitative inquiry (14), consisting of interviews and focus group discussions (FGDs), was used to identify the needs of patients and carers within the burns healthcare context, as well as the experiences of healthcare providers and key informants, to develop acceptable approaches to address these needs in this setting. "The rich diagram, illustrates underlying mental models used during analysis. Rich diagrams (the precursor to Causal Loop Diagrams) are typically prototypes used to illustrate feedback and interactions among health system actors within a complex adaptive system (12, 13). For this study, development of the rich diagram assisted in the initial identification and interpretation of the setting and feedback loops that emerged in the context of burns care in India."

- "A qualitative participatory research approach was used" I am not clear on how your study design was participatory research? It seems like a traditional qualitative inquiry based upon the current description.

**On review, we agree with this sentiment, and concede our original wording was ambiguous. We have updated the manuscript and included a new reference (14) to focus on the traditional qualitative inquiry that this research was, but have also explained the participatory approach in detail as above, this study reports on second round of data collection and further research is planned to co-design interventions for burns care, in future.

- A copy of the interview guide or sample of questions should be presented.

**We have included this as: "Appendix 1 – Interview and focus group discussion topic guides"

- In Table 1, it would be nice to get a sense of how long these individuals have been working with burn injuries and burn survivors, and how much of their time is currently spent with this type of patient population.

**Thank you, our oversight, agree that this information would be useful in further contextualising and have revised the table with an additional column in Table 1 "Years worked in burns care."

- The results and discussion largely rest upon the clarity of Figure 1. It is not entirely clear what the color coding system means, and where all of the elements of the figure are derived from. A stronger link between the findings and each specific portion of the figure needs to be established. Perhaps an early figure explaining your conceptual framework and the elements of "systems thinking" you are employing would facilitate that. Further, the Gaps seem to be tacked on to the bottom on the figure. If the entire diagram is the system, then gaps are part of the system that are needs/features not currently being met by care for burn survivors. If these gaps were incorporated into their respective parts of the system diagram and then somehow delineated as Gaps/Needs not being met, the figure and results would be clearer and stronger.

**As per above, we have updated the methods section to better show our research approach.

We have restructured the results and discussion sections, and in doing so moved much of the contextualising text (formerly the results sections on Themes 1-4) into the discussion for clarity.

We have also included an introduction to this section, which reads: "The aim of this study was to identify priority policy issues and health system research questions associated with recovery outcomes for burns survivors in India. To contextualise our findings, we first present a discussion of the findings and how this was used to inform the development of the rich diagram (Figure 1). Next, we will integrate this research into the wider context of burns, policy, and health systems in India. Finally, this section will present considerations and research questions that emerged from this research."

Please also see our response to Reviewer 2 below about the rich diagram and its purposive 'messiness'.

Reviewer: 2

Reviewer Name: Rachel Kornhaber

Institution and Country: National Burns Unit, Sheba Medical Center, Israel

Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below

Thank you for allowing me to review the manuscript titled: "I was an untouchable" – Stigma, shame and social systems: recovery for burns survivors in India. Research into burns care and rehabilitation is as the authors' state the 'forgotten global public health crisis'. This manuscript reads well and highlights an important area in burns care.

-The title does not reflect the study as the word "untouchable" is only evident in one quote participant 8 (in which some words were not clear therefore, the quote in itself needs to be clarified). The word shame apart from the title and page 21 is not mentioned in the results or the participant quotes.

**We have revised the title and it now reads: "Identifying priority policy issues and health system research questions associated with recovery outcomes for burns survivors in India: a qualitative inquiry"

-Whilst it is difficult to include all participants in such a large qualitative study, there is an emphasis on certain participants throughout e.g. participants 12, 24, 23.

**Thank you for this keen observation. We do not feel this is disproportional to a problematic degree, in light of the larger aims of this research (meaning saturation rather than coding saturation, as per reference 17).

-On page 3 FGDs is used with no explanation of the acronym and it is not until the 2nd paragraph on page 8, that one is provided.

**We have revised this section to read the full 'focus group discussions' rather than the acronym.

-The tables are not provided with an explanation of the abbreviations e.g. Table 2 no explanation for FGD or IDI is provided. Furthermore, IDI is not mentioned anywhere in the manuscript.

** We have revised this table to read the full 'focus group discussions' rather than the acronym. We have removed reference to IDI as this is not necessary to the manuscript.

-The diagram (Figure 1) on page 28 is not label with a Figure and some of the words are occluded e.g. financial, morbidity and withdrawal. Furthermore, it is a very busy diagram that would benefit from some graphic expertise.

**We have ensured that labels are labelled correctly, and are in the correct format.

Next, we agree that graphic expertise would improve this diagram, however this is planned for future research. Our purpose here was to develop a 'prototype' to a future Causal Loop Diagram and is explained in this new paragraph under methods: "The rich diagram, illustrates underlying mental models used during analysis. Rich diagrams (the precursor to Causal Loop Diagrams) are typically prototypes used to illustrate feedback and interactions among health system actors within a complex adaptive system (12, 13). For this study, development of the rich diagram assisted in the initial identification and interpretation of the setting and feedback loops that emerged in the context of burns care in India."

-Table 2 the words 'purposivelymale' need to be separated with a space.

**We have corrected this typo

-Table 3 containing the participant quotes, many of these quotes resonate with burns care and rehabilitation globally. What is new knowledge and unique about burns care in India? This needs to be more overt in the results and resonate in the discussion.

**We have restructured the results and discussion to more overtly make this link, particularly between the quotes and Figure 1.

-The discussion is rather brief and could be expand to discuss the wider literature in relation to the importance of burns care in Indian and the unique Indian experience.

**We have restructured and expanded the discussion section to address this comment, and in particular to the unique Indian experience have added this paragraph: "However, in practice, severe bottlenecks in accessing government health care services compel households to seek private care, often resulting in high out-of-pocket payments. Significant inequalities with respect to health care access and health outcomes exist between states, rural and urban areas, socioeconomic groups, castes, and genders. Past decades have seen several initiatives targeted at improving primary healthcare systems, however the focus has been on infectious conditions and maternal and child health."

-Greater synthesis of the findings is required as the participant quotes stand alone in Table 3.

**We have restructured the results and discussion sections, and in doing so moved much of the contextualising text (formerly the results sections on Themes 1-4) into the discussion. We hope that this improves clarity, along with the new introduction and new text added to this section as per above.

-The referencing for BMJ Open requires all journal titles to be abbreviated and not in full as the authors have displayed in the reference list.

**We have corrected the referencing style for BMJ Open

-Qualitative research requires a COREQ checklist that should be submitted which is to ensure transparency for qualitative reporting (See link below for COREQ statement)<https://www.equator-network.org/reporting-guidelines/coreq/>

**We have completed and included the COREQ checklist in this resubmission

VERSION 2 – REVIEW

REVIEWER	Dr Rachel Kornhaber National Burns Unit, Sheba Medical Center, Israel; Univeristy of Tasmania
REVIEW RETURNED	19-Jan-2018
GENERAL COMMENTS	<p>Thank you for allowing me again to review this manuscript now entitled: IDENTIFYING PRIORITY POLICY ISSUES AND HEALTH SYSTEM RESEARCH QUESTIONS ASSOCIATED WITH RECOVERY OUTCOMES FOR BURNS SURVIVORS IN INDIA: A QUALITATIVE INQUIRY.</p> <p>Abstract: under strengths and limitations 1st point: This research will enable... is too definitive and would suggest 'may facilitate'.</p> <p>Methods 2nd paragraph and 2nd sentence states 'The rich diagram'</p>

	<p>which rich diagram and is the diagram part of their results?</p> <p>Data collection: 1st paragraph 'all data collection was For this study' there is an inappropriate capital 'F' as it is not a proper noun.</p> <p>Results; The table need formatting including the columns where words are cut off and parts of the transcript are hidden from the reader. In addition, where acronyms such as PD and OPD are used in the participant quotes, these need to be defined in parenthesis [] to give context to the reader.</p> <p>Discussion; 1st paragraph Next, we will integrate.. is this referring to this paper or another study planned? as the tense may need to be altered to clarify. Under theme 4 sub heading, Point 2 has etc at the end, avoid using etc in as it does not value add to the discussion. Point 3 states A feeling - is the word perception more appropriate term to use here?</p> <p>There has been recent publications in the peer reviewed literature that has investigated models of care in burns care and rehabilitation, and prior to publication, integrating some very current peer reviewed literature would be of benefit to the study as the discussion has limited referecning to the greater peer reviewed literature.</p> <p>Conclusion: The phrase 'invisible faces of burns', is this a direct quote from Bhate-Doesthali et al., 2015.and is a page number required?</p>
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VERSION 2 – AUTHOR RESPONSE

Dear Dr Emma Gray,

We thank the editor and reviewers for their insightful and helpful feedback in improving this manuscript. We have responded to each point below in turn, and have indicated any changes in the manuscript in red text.

Please do not hesitate to contact me for further information.

Yours sincerely,
Jagnoor

(on behalf of all co-authors)

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Reviewer(s)' Comments to Author:

Reviewer: 2

Reviewer Name: Rachel Kornhaber

Institution and Country: National Burns Unit, Sheba Medical Center, Israel

Please state any competing interests or state 'None declared': None declared

Abstract: under strengths and limitations 1st point:

This research will enable... is too definitive and would suggest 'may facilitate'.

Response: We agree and have revised the text to say "This research informs the development of acceptable models of burns care from consumer, provider and health manager perspective."

Methods 2nd paragraph and 2nd sentence states 'The rich diagram' which rich diagram and is the diagram part of their results?

Response: Indeed we report "rich diagram" as in methods explaining on how we approached and analysed data. Figure 1, is not a rich diagram but an interim presentation between rich diagram and causal loop diagrams. Figure 1, presents the factors influencing burns recovery outcomes and we have now revised the text to clarify this "For this study, we present the initial identification and interpretation of the setting and inter-relationship of factors that emerged in the context of burns care, influencing recovery outcomes in India."

Data collection: 1st paragraph 'all data collection was For this study' there is an inappropriate capital 'F' as it is not a proper noun.

Response: Sorry we went through the manuscript a few times but could not find the above typo. If we have missed it, we request journal staff members to rectify this at proof reading stage.

Results;

The table need formatting including the columns where words are cut off and parts of the transcript are hidden from the reader. In addition, where acronyms such as PD and OPD are used in the participant quotes, these need to be defined in parenthesis [] to give context to the reader.

Response: we have re-formatted the table and included parenthesis as suggested. And rechecked for formatting all through the table.

Discussion; 1st paragraph Next, we will integrate.. is this referring to this paper or another study planned? as the tense may need to be altered to clarify.

Under theme 4 sub heading, Point 2 has etc at the end, avoid using etc in as it does not value add to the discussion. Point 3 states A feeling - is the word perception more appropriate term to use here?

Response: For first paragraph the sentence has been revised to say "We integrate this research into the wider context of burns, policy, and health systems in India...."

Point 2: We have deleted "etc"

Point 3: We would like to retain the word "feeling" as it refers to social exclusion and feelings as expressed by participant, not their perception or even thoughts.

There has been recent publications in the peer reviewed literature that has investigated models of care in burns care and rehabilitation, and prior to publication, integrating some very current peer reviewed literature would be of benefit to the study as the discussion has limited referecing to the greater peer reviewed literature.

Response: Thank you and it is good to be able to refer to some common challenges across diverse context. We have now included reference

Conclusion: The phrase

'invisible faces of burns', is this a direct quote from Bhate-Doesthali et al., 2015.and is a page number required?

Response: “ The invisible face...”,is the title of the research article so we have not revised for page number. (Bhate-Deosthali P, Roy N. The invisible face of burns in India. Curr Med Res Prac. 2015;5(2):53-4.)