Author’s response to reviews

Title: Patterns of Illness Disclosure among Indian Slum-Dwellers: A Qualitative Study

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Version: 1 Date: 01 Aug 2017

Author’s response to reviews:

August 3rd, 2017

Philippa Harris, Editor
BMC International Health and Human Rights

Dear Prof. Harris,

It is with excitement that we resubmit to you a revised version of manuscript IHHR-D-17-00007, Patterns of Illness Disclosure among Indian Slum-dwellers: A Qualitative Study for the BMC International Health and Human Rights. Thank you for giving us the opportunity to revise and resubmit this manuscript. In keeping with our last communication, I am resubmitting this revision before the agreed upon deadline, August 3rd, 2017. We appreciate the time and details provided by each reviewer and by you and have incorporated the suggested changes into the manuscript to the best of our ability. The manuscript has certainly benefited from these insightful revision suggestions. We look forward to working with you and the reviewers to move this manuscript closer to publication in the Journal of BMC International Health and Human Rights.
We have responded specifically to each suggestion below, beginning with your own. To make the changes easier to identify where necessary, we have numbered them.

Editorial Comments:

Comment. Many thanks for indicating that formal ethics approval was not required in India. Could you please provide us with a letter from the relevant ethics committee confirming this or a link to the relevant research regulations for our records?

Reply: A National Ethics Meeting to discuss “The Draft Code of Ethics for Research in Social Sciences and Social Science Research”, was held on the 29th and the 30th of May 2000, in Mumbai, India as an attempt to address ethical issues collectively in Indian community. The process of evolution of the draft guidelines involved the formation of a committee that is National Committee for Ethics in Social Science Research in Health (NCESSRH) comprising eminent academics across India, namely Ghanshyam Shah, Lakshmi Lingam, V R Muraleedharan, Padma Prakash, Thelma Narayan, Ashok Dayalchand, Manisha Gupte, Sarojini Thakur, Geetanjali Misra, and Radhika Chandiramani. Because of the general lack of information regarding ethical requirements for social science research, we personally consulted Prof. Ghanshyam Shah, who explained to us that the objective of the committee is to draft and update ethical guidelines over time, but it is not a formally established ethical committee with the aim to assess study protocols. Further, during our conversation with him he indicated that no attempts were thereafter made to institutionalise any ethical committee for social science research. Therefore, because no proper ethical board is present, formal approval is not required for social science research involving human participation in India. He also mentioned that code of ethics truly lies with the researcher himself/herself who carry out the study with human participants.

In the absence of a formal committee that could assess the study ethical conformity, we scrupulously followed the guidelines framed by National Committee for Ethics in Social Science Research in Health (NCESSRH) in order to conform to the standardise code of ethics in research in Indian context (http://www.cehat.org/go/uploads/EthicalGuidelines/ethicalguidelines.pdf).

Also the claims made by Prof. Shah are substantiated in the text accessible here: http://www.anusandhantrust.org/centres/Ethics_in_health_research_-_A_social_science_perspective.pdf
Links to the documents are also provided in the text (Page no 9/ Line no.221) as end note (please refer page 51/Line no.1152)

Comment. Please ensure that your manuscript contains a Declarations section before the references, with ALL of the following subsections:

* List of abbreviations

* Ethics approval and consent to participate

* Consent for publication – as you are not publishing identifying patient data, you can write "Not applicable" in this section

* Availability of data and materials – see details below

* Competing interests

* Funding

* Authors' contributions

* Acknowledgements.

Reply: We have incorporated the entire requisite by adding a Declaration section before the references in the revised manuscript. Please peruse in the manuscript (Line no.900 to 941).
Reviewer reports:

We thank the reviewers very much for providing constructive comments on the manuscript. We feel that the suggestions have led to a revision work that substantially improved the article. We provided detailed point-by-point response below, expressing how each comment has been addressed.

Reviewer 1

Roger AyimbillahAtinga:

Comment1. Given that this study was designed qualitatively, the use of a structured questionnaire to collect data, highlight the lack of direction to any particular paradigm. The methodology lack structure and that has affected sequencing of ideas. May be sub-titles will help authors present ideas chronologically. Authors should describe how in-depth interviews and semi-structured interviews were framed. This should be presented as part of the methodology to enable the reader know well ahead of the findings

Reply 1. We thank the reviewer for this comment and for all the comments below which touch upon the methodology and the paradigm used. We realized that our methodological section may have carried unclear passages, which we have now tried to rectify.

First and foremost, we did not use a structured or closed questionnaire for our data collection. Interviews were in-depth, semi-structured conversations with the respondents, in line with a qualitative, emic, inductive tradition of enquiry (Garcia, 1992; Godina & Mccoy, 2000; Saville-Troike, 1989; Patton, Hong, Patel & Kral, 2017; Patton, Hong, Patel & Kral, 2017). To avoid any confusion, we removed the word “questionnaire” and replaced it with “interview schedule”.

We added details on how the interviews have been framed and which topics have been covered. We added the following passage at page 7 /line no.177-187

The questions were open-ended in nature, in line with the emic perspective of this study that aims to gather in-depth understanding of the socio-cultural context, respondents’ perceptions and self-constructed meanings (Garcia, 1992; Godina & Mccoy, 2000; Saville-Troike, 1989;
Patton, Hong, Patel & Kral, 2017). Rapport was already established between the researcher and the participants through frequent visits in the field, participating in their day to day activities and after the first session of interviews where we explored and discussed about their perception on health. To understand the reporting behaviour of the participants, the interview schedule encompassed questions on perception about the concept of illness, threshold for recognition of illness, aetiology of illness, types of confidantes, types or nature of illnesses (minor, chronic, communicable, reproductive and sexual related ailments) that are either shared and not shared, underpinning causes of disclosure attitude and timing of disclosure.


Comment 2. Analysis should begin with how the data was processed and refined. Next present the approach to thematic analysis.

Reply 2. Thank you for this comment. We added a passage indicated how the data has been processed and refined, namely between the transcription phase and the analysis phase. Please see the sentences addressing this comment at page 8/Line no.203-216:

Interviews that were tape-recorded with the participant’s consent and interviews that were taken as field notes were first translated into English and then were transcribed verbatim. All data was double-checked for unclear passages and for potential translation errors. Passages that raised
doubts were cross-checked by the first and second author and further discussed with the translator, if applicable.

Once the bulk of text deriving from the interviews had been cleaned and processed, data were analysed using the ‘thematic analysis’ method. The analysis was carried out manually in accordance with the guidelines of Braun & Clarke, 2006. Initially the data were read several times to ensure a thorough understanding. Patterns within the data were manually identified, coded and subsequently labelled according to their meanings. Codes sharing a common meaning were grouped under non-overlapping themes or categories. These themes were re-examined for further refinement by comparing them with the original messages in the participant’s accounts of their experience pertaining to their perception of illness, their propensity to accept illness and their attitude towards reporting.

Results

Comment 3. The theme "coping with insecurities of the slum" and its content does not match up. The theme need to be modified accordingly.

Reply 3. Thank you for this comment. We indeed realised some inconsistencies between titles of the themes and the empirical evidence associated with them. As suggested we have rephrased the title of this sub-theme as Coping with livelihood and financial insecurities of everyday life to better reflect its content. In addition to that, we have thoroughly and majorly revised the presentation of themes, the quotes and the sequence to ensure: consistency, minimize overlap and sharpen the distinction across themes and added value of each. Please see the revised version of the articles, pages (line no.) 10 (264), 14 (362-363), 20 (509)..

Comment 4. The theme "Therapeutic value of disclosure" and its content also have partial or no similarities.

Reply 4. As response to this, we would like to highlight that many women in our study through socialization have internalized the fact that complex female biology leads to frequent female-related health problems that require attention before they worsen. Such perception has made them sensitive towards illness and they become easily anxious. Therefore, therapeutic value does not refer to physical healing; rather, it is used to indicate psychological relief/utility they receive
by sharing their experiences of illness and possible solutions with people having similar experiences. Such act provides them encouragement and a way out to deal with their illnesses.

To address this point, we have now made this section more compact and to-the-point. We hope that these modifications, which can be appreciated at page 23/line no.572-583, clarifies the concept that we aim at conveying. The modified passage reads as:

Women are found to be very sensitive towards illness or any bodily discomforts and show more willingness to express symptoms of distress to others for psychological relief compared to men. Sometimes expressing distress more often had to do with the complex reproductive systems and represented a deliberate self-encouragement a coping mechanism. Most women consider female related health problems as unavoidable because of the complexity of the reproductive system. Such belief has emerged from their socialization process where since childhood they are being informed and made to believe that their biological composition is responsible for making them morbid and even face death.

Therefore, women developed the coping strategy of reassuring themselves by continuously expressing their distress to others. One woman said that by informing others they actually comfort themselves that everything will be alright, not everyone has to face death in a similar way (indicating to reproductive related mortality).

Comment 5. Portions of the content describing the themes overlap. Please take steps to address that. Ideas should not be repeated. It makes the work unnecessarily bulky.

Reply 5. Thank you for this point. We have carefully screened the whole manuscript and indeed found a few passages that overlapped across themes or that could be shared across themes. We have reassigned some passages and removed others, to make the manuscript more compact.

Also, as mentioned before we have majorly revised the grouping of the themes and the presentation sequence. In particular we specify that in page 9 and 10/Line no.242-262:
In general, the findings highlight that the decision to disclose illnesses as well as the choice of confidantes are influenced by the complex interplay of gender, nature of illness, marital status, and socio-economic conditions. During the coding procedure and while presenting the results, an attempt has been made to systematize the findings and disentangle the main themes from the inherently much more complex nexus of causes. For grouping the themes, four main aspects of illness disclosure have been used, which mirror our main research questions: 1. Choice of confidantes 2. Reasons for delaying disclosure, 3. Reasons for not delaying disclosure; 4. Reasons for not disclosing. Within these overarching topics, twelve themes emerged, namely: healthcare professionals as the last recipients of illness disclosure, social norms and fear of future social sanctions driving the choice of confidantes, bearable physical burden, negative prior experience of illness, coping with livelihood and financial struggle of everyday life, unbearable discomfort, therapeutic value of disclosure, fear of unfamiliar illnesses, previous negative outcomes of non-reporting or delay, withdrawal as a coping strategy, perceived threat to social image and degenerated slum environment atmosphere are presented themes motivating the choice of confidantes, early illness disclosure, delayed illness disclosure or non-disclosure. Because however the themes per se are disconnected from the specific category, but are grouped in one for the sake of systematization, we number the twelve themes subsequently and not in connection with the larger topic.

Comment 6. This sub-theme "women developed the coping strategy of reassuring themselves by continuously expressing their distress to others" fits better in the theme discussion who do the dweller disclose illness.

Reply 6. We thank the reviewer for this comment. We carefully considered and decided to keep the paragraph where it originally stood, because of the following reasons. While the theme “healthcare professional as the last rest of illness disclosure” focuses on whom the slum-dwellers report to, at different stages of their illness, the “therapeutic value of disclosure” instead considers that, regardless of the interlocutor, women derive psychological relief by the sheer act of disclosing. In the indicated paragraph, the interlocutors are not specified, or can be generally assumed to be other women. Instead, the important point is that the act itself of disclosing has developed over time as coping mechanism towards the illness or the fear of illness. Hence, we believe it is an important passage of “therapeutic value of disclosure”.

We hope that we have convinced the reviewer by providing convincing arguments to our position. Should however this not be the case, we are open to modifying in accordance to the reviewer’s suggestion.
Comments 7. Portions of the content are redundant; not linked appropriately to the themes. "Fear of future social sanctions" should come after "social norms driving illness disclosure" to improve upon the flow.

Reply 7. We agree with the reviewer. We have incorporated this recommendation by combining together the “fear of future social sanctions” with “social norms”, and placing both as drivers in the choice of a confidante. This has been one of the many modifications that we have made to the text in addition to carefully screening the results, improving our selection of quotes, and reducing the number of concepts touched upon in every theme. We believe this exercise has improved readability, sharpened the distinction between themes, reduced the overlap and improved the flow by proposing a more compact result section.

Comment 8. I don't see how this theme "Harshness of slum environment" relate to the subject matter under investigation.

Reply 8. We thank the reviewer for raising this point. For clarification we have first started with reframing the title of the theme as Degenerated slum atmosphere impeding disclosure through which we have reflected that slum environment plays a pivotal role in shaping the attitude of the slum dwellers towards disclosing of illness. We in this theme attempted to illustrate how the structural phenomena of the slum community (disintegrated life, poverty, inequality, crime, fragile physical infrastructure) have an overpowering effect on their health seeking attitude. Their struggle being in a slum community leave no space for health concerns, hence, reporting illness that mark the threshold of health care hardly gets recognised.

Discussion

Comment 9. Discussion should be modified to suit revisions to the results.

Reply 9. Discussion have been modified according to the revisions done in the result and can be viewed in (Pages 31-35/ Line no.767-774,781,784,785,809-815,825-828,830,831,833,842-853,854,859-862,865,868-873)
Conclusion

Comment 10. The conclusion should be present ideas about implication of the study's findings to policy and practice.

Reply 10. We have incorporated this suggestion. We have modified the conclusion and tried to address the implication of the finding towards policy and practice as follows (pages 35 & 36/ line no. 875-877,886,890-895):

The study can indicate a pathway to the policy makers and exemplify that disclosure comprises an important component of health seeking behaviour and prior to treatment seeking. Therefore for a successful mechanism of health care resources and improvement of health care utilization by the slum dwellers, disclosure pattern need to be addressed within a local socio-cultural context where slum dwellers reside. This can be attained by encouraging the slum dwellers to share their feelings about illness more openly by decreasing their sense of marginalization, the inhibition from disclosing to certain people and increasing professionals awareness of unsupportive social interactions.

Reviewer 2
Srinivasan Kannan

Comment 1. In Abstract lines 32 and 33 authors stated "Slum dwellers do not always disclose their illness to professionals." It looks like they are blaming the dwellers. Instead of blaming them authors may ask why were they not ready to disclose. It sounds like it their duty to do so. A power over the participants is felt from the beginning of the paper.

Reply 1. We thank the reviewer for raising this important point. Because our objective in this paper lies in understanding the very foundation of why slum-dwellers are not ready to disclose, we are very willing to remove or rephrase any sentence that suggests the opposite or that conveys a perspective of power over the participants, which is not felt at all on our side. We have therefore rephrased this sentence as follows (page 2/line no.32,33,34,53) and highlighted:
Adequate health service delivery in urban slums does not necessarily result in improved health outcomes, as slum dwellers follow certain traits when it comes to disclosing their illnesses to professionals. Behavioural action in this connection often leads to poor health-seeking behaviour and under-utilization of existing formal health facilities. The ways that slum people use to communicate their feelings about illness, the type of confidantes they choose and the supportive and unsupportive social and cultural interactions they are exposed to have not yet been studied in the Indian context, which constitutes an important knowledge gap for Indian policymakers and practitioners alike. The purpose of this study therefore is to examine for comprehensive illnesses in Indian slums the patterns of illness disclosure and the underpinning factors that shape their disclosing attitude.

Comment 2. One more thing which is not clear is whether the authors uses Etic or Emic perspective. For the benefit of authors, "an emic perspective attempts to capture participants' indigenous meanings of real-world events emic more relevant in the interpretation of a culture and in the understanding of cultural experiences within a particular group (GARCIA, 1992; GODINA & McCOY, 2000; SAVILLE-TROIKE, 1989)." On the other hand, "etic perspective encompasses an external view on a culture, language, meaning associations and real-world events." The use of an etic perspective or approach to research is beneficial as it enables comparisons to be made across multiple cultures and populations which differ contextually.

Reply 2. We thank the reviewer for this piece of information and recommendation. Given the nature of the study, in which we are exploring health perceptions and related health-seeking behaviour from a socio-culture context, we have used an emic approach. In this limelight we attempted to give voices to the slum-dwellers since researchers’ perceptive commonly adopted in etic approaches may create some established prejudices about the slum dwellers and the environmental and social structure where they dwell. Further, we have adopted a bottom-up approach that is culture-centered approach, a theoretical perspective of health communication. Also, we are examining the self-conceptualization of health-seeking behaviour, where the described behaviours are seen from the perspective of cultural insiders, in constructs and meaning drawn from their self-understandings of the cultural system as a working whole. Etic accounts based on survey data are often dismissed because researchers remained at a distance from respondents, potentially insensitive to how respondents were affected by their questions (Geertz, 1983). In line with this perspective, no generalization of the findings to other contexts is sought for nor pursued.

We have now made this point clear in the manuscript in several passages, for example the following page 7/line no 177-179:
The questions were open-ended in nature, in line with the emic perspective of this study that aims to gather in-depth understanding of the socio-cultural context, respondents’ perceptions and self-constructed meanings (Garcia, 1992; Godina & McCoy, 2000; Saville-Troike, 1989; Patton, Hong, Patel & Kral, 2017).

We thank the useful references, which have been now incorporated (see lines 179).


Comment 3. Another thing to be noted is, in general, for qualitative studies researchers use inductive approach. But, in this paper the authors were fully using the deductive logic. That is common in quantitative studies. It suggests that this is a part of a larger study with a quantitative component in it. This is not disclosed in the beginning of the paper.

Reply 3. We thank the reviewer for this observation, which is linked to other similar remarks throughout the reviewers’ comments. We would like to clarify that we have used a fully
inductive approach: we begin by the search for pattern from observation and the development of events or phenomena from our data and then attempted to understand the relationships among them. As mentioned earlier we used an emic perspective (reference included at page7/line no.179), which emphasized the social-constructivistic, culture-centered nature of meaning, and we did not use any priorly defined theoretical framework to interpret our findings. At this point we fail to see how this approach could be considered deductive, but we have tried to be fully clear about this in the text. Should our approach still be unclear we will be very willing to follow the reviewer’s suggestions on how to improve it.

Specific comments.

Comment 4.In line, 80 lay arena and lay understanding’ is a connotation that the authors are health professionals and the participants are non professionals. This is the reason the authors expecting the population to follow their expertise related health practices such as Allopathic medicine. They may also have home remedies and alternative medical practices among the members. Need to clarify that.

Reply 4. Our intention was purely to show that prior to consulting any health professionals advise regarding the time of seeking and the type of professional to be approached (informal, formal, ayurvedic) is sought for at the familial (parents and relatives)or at communal level (neighbours and friends). Hence we used the term lay understanding and arena to indicate to the reader that self-care is usually the first and predominant health activity employed by people. To substantiate our argument we have also provided a related reference (Sánchez, 2007). It is not our intention to make any statement here regarding what kind of therapy is being used by them as this is a very different issue that we have addressed in another article about health-seeking behaviour.

Please also note that the authors are not health professionals, hence there is no prior expectations of the authors regarding specific treatments.

Comment 5. In addition, people who are included in the study are from lower socio-economic status. In general they have higher threshold for the illness. This makes one to feel healthy until they reach the threshold. On the other hand, the middle income group or rich have lesser thresholds and start feeling sick even with a low level of discomfort they report they are ill. This necessitates the authors to discuss on the thresholds.

Reply 5. We completely agree with the reviewer. Our discussion on the nature of thresholds for reporting of both men and women are reflected in pages 11, 13, 14/line no. 287-298, 324-332, 337-337,.....

Also please note that, in line with a qualitative, inductive, emic perspective used in this study, it is not our intention to generalize these findings of this study to other contexts, such as middle-income groups.

Comment 6. In Line 85, the authors stated, "expressing illness". Is this sharing illness experience? If so, this may be corrected.

Reply 6. Thank you, the suggestion has been incorporated.

Comment 7. Lines 86 to 88 clearly showing authors used closed end questions. As discussed earlier, this suggests they are following deductive logic. Whether qualitative method is an appropriate option for such a deductive study? Usually, as much as possible we use open ended questions and probe further on the subject from response we get. This gives a feel this is quantitative study in the name of qualitative form submitted to the journal. This needs to be justified. Or if this is based on a larger study which comprises of both quantitative and qualitative components with the same questions a reference to the report or the other part of the study need to be given.

Reply 7. We thank the reviewer for this comment and for all the comments below which touch upon the methodology and the paradigm used. We realized that our methodological section may have carried unclear passages, which we have now tried to rectify.

First and foremost, we did not use a structured or closed questionnaire for our data collection. Interviews were in-depth, semi-structured conversations with the respondents, in line with a qualitative, emic, inductive tradition of enquiry (Garcia, 1992; Godina & McCoy, 2000; Saville-Troike, 1989; Patton, Hong, Patel & Kral, 2017). To avoid any confusion, we removed the word “questionnaire” and replaced it with “interview schedule”.
In addition to that, we have now included details on how the interviews have been framed and which topics have been covered. We added the following passage at pageXX7/line no.175-187:

A semi-structure interview schedule was constructed based on the basic framework of Arthur Kleinman’s Explanatory Model of Illnesses (EMs) (Kleinmn, 1998; Kleinman & Benson, 2006). The questions were open-ended in nature, in line with the emic perspective of this study that aims to gather in-depth understanding of the socio-cultural context, respondents’ perceptions and self-constructed meanings (Garcia, 1992; Godina & McCoy, 2000; Saville-Troike, 1989; Patton, Hong, Patel & Kral, 2017). Rapport was already established between the researcher and the participants through frequent visits in the field, participating in their day to day activities and after the first session of interviews where we explored and discussed about their perception on health. To understand the reporting behaviour of the participants, the interview schedule encompassed questions on perception about the concept of illness, threshold for recognition of illness, aetiology of illness, types of confidantes, types or nature of illnesses (minor, chronic, communicable, reproductive and sexual related ailments) that are either shared and not shared, underpinning causes of disclosure attitude and timing of disclosure.


Also, we would like to clarify that there is no quantitative component, neither to this study nor in the larger study we are referring to. The whole project that has investigated health-seeking behaviour in Indian slums has used purely qualitative methods of enquiry and a purely inductive, emic perspective throughout.

Comment 8. Further, if we give a thought, we need to include things such as taking rest, exempt from duties, diet modification and so on need to be included in addition to the disclosure. These are the common things one need to include in such community studies.

Reply 8. We thank the reviewer for indicating this recommendation. The aspects cited are certainly important phases of clinical pathway during treatment or self-management of illness. However, this study specifically focused on exploring the reporting behaviour of the slum dwellers once they accept an illness, hence in a pre-treatment stage. Our intention is to show that reporting behaviour, which occurs once the slum-dweller has recognized an illness, is an important component of health-seeking behaviour of slum-dwellers in India, which is the main focus of the larger study we refer to. Reporting behaviour, as based on disclosure choices and on the type of confidantes slum-dwellers disclose to, drives future action on treatment seeking behaviour. Taking rest, exempt from duties, diet modification are certainly important aspects of the subsequent treatments or self-management choices, but may fall beyond the scope of this study, which is to explore illness disclosure behaviour.

Comment 9. In lines 88 to 90, authors loosely used a phrase this will help in health policy making process more effective. This need to be deleted.

Reply 9. We have now rephrased the entire passage as follows (page 3/lines XX89-95):

Hence, exploring how the slum people disclose illnesses and translate them into lively activities (deciding either to seek help or avoid) could help policymakers in designing tailor-made measures to improve slum-dwellers’ health status. Insights in illness-reporting patterns and in the
type of confidantes that slum dwellers choose are crucial to raise health awareness related to clinical and alternative healthcare treatments, which are available, but often remain underutilized, to the detriment of slum-dwellers health and well-being.

We hope that this new formulation is satisfactory and removes the previous ambiguity.

Comment 10. In Line 91, the concept of future demand estimation. Demand is a quantitative entity. Based on the present paper using qualitative methods, authors cannot estimate the demand. The authors seem to be discussing the quantitative study component to this qualitative paper. This further confirms the study has both quantitative and qualitative components. The scope of the present paper is only the qualitative aspects of the study. The authors need to restrict their discussion limited to qualitative components. This leads the paper to deductive approach. Authors need to disclose this.

Reply 10. We would like to reiterate that this study (investigating disclosing behaviour) as well as the larger study (investigating health-seeking behaviour) is purely qualitative, with no quantitative component. The improper usage of words might have reflected different connotation of the sentence. However we tried to clarify by rephrasing the sentence and the entire passage (reported in the previous reply)

Comment 11. line 129 - There was a mention on a larger study. At the end of the sentence a superscript 'a' is given. But the explanation is missing.

Reply 11. Explanation was there in the endnote (starts from line no.1133). It reads as follows:

The present paper is a part of a broader qualitative study that examines the health-seeking behaviour in terms of health beliefs, health practices, reporting behaviour and treatment-seeking behaviour of urban slum dwellers in four different slums, selected from two Indian cities.
Comment 12. line 127 experience illness suggest they shared their status. Then how can one say they keep to themselves (line 132-not reporting).

Reply 12. As mentioned in the methods section the participants for this study have been selected from a cohort of a larger study. In the larger study we asked all the participants as whether they experienced any illness. We observed that they readily answered to the question as yes/no. 218 participants out of 245 participants reported that they experienced illness within a period of one year, however they were not initially ready to discuss the type of illnesses they experienced when asked. When questioned further we realised that not everyone responded to illness in a similar manner but most of the participants follow some particular behaviour regarding disclosure of different illnesses with underpinning complex socio-cultural factors. Three categories in connection to the reporting behaviour emerged: those who delayed in disclosing their illness, those who disclosed their illness without delaying and those who did not disclose at all. We therefore focused our study on this sample of respondents, which includes 48 men and 33 women from the first category of delayed reporter, 11 men and 68 women from the second category of non-delayed reporter and 46 men and 12 women who did not revealed or reported their illness to anyone. Individuals in the latter category did not disclose their illness to anyone at the moment at which the problem occurred, but did report the illness episode to the researcher.

Comment 13. In line 132 there was a mention that the participants are not reporting illness. While, in line 127, says participants who experience illness were included the study. That means they have shared the status while selecting. There is a contradiction in line 132.

Reply 13. We have already addressed this answer in question no.12. Individuals in the category of non-reporters experienced illness in the one year prior to the study, chose not to disclose their illness to anyone at the moment at which the problem occurred, but did report the illness episode to the researcher.

Comment14. Line 134 says the authors used one year as a recall period. This looks very long. One can have maximum of six months as we can remember event for last six month at the most. Justification for the same had to be given. And also need to discuss how this did not affect the findings of the study.
During the pilot study we realised that six months recall period was too limited to collect extensive data on reporting behaviour. We attained data saturation after two to three interviews since many participants reported of not experiencing any major or minor incident related to illness within six months. Hence, one-year recall period was used for both minor and chronic illnesses. A study by Kjellsson, Clarke, & Gerdtham, (2014) also indicates that using a recall period of one year is preferable to scaling up a recall period of one, three, or six months. According to Sudman et al., 1984, respondents are aware about their opportunity of risk when questioned about the more recent period and prefer disclosing a more distant but salient event. Such an approach might influence their responses and has been suggested as a way to reduce reporting error.


Comment15. In line 135, age of participants is mentioned as 16 years. This suggests they are eligible for consent. The consent form details are not provided in this section.

Reply 15. We have explained how the consent has been required and gathered in the ethical considerations section (page 8&9 /lines 218-232).

Comment16. In line 149 the usage of questionnaires is confusing. In general, questionnaires are self administered tool. But for a qualitative interview one will not use questionnaire. There is something wrong in the tool. Please explain this.
Reply 16. Thank you very much for pointing this out to us. Indeed the term questionnaire closely recalls closed-end surveys typically used for quantitative studies as well as self-administered tools.

The term in this context is not appropriate. We did not use a structured or closed questionnaire for our data collection. Interviews were in-depth, semi-structured conversations with the respondents, in line with a qualitative, emic, inductive tradition of enquiry (Garcia, 1992; Godina & Mccoy, 2000; Saville-Troike, 1989, Patton,Hong, Patel & Kral,2017). To avoid any confusion, we removed the word “questionnaire” and replaced it with “interview schedule”.

In addition to that, we have now included details on how the interviews have been framed and which topics have been covered. We added the following passage at page7/lines 175-187:

A semi-structure interview schedule was constructed based on the basic framework of Arthur Kleinman’s Explanatory Model of Illnesses (EMs) (Kleinmn,1998;Kleinman & Benson,2006). The questions were open-ended in nature, in line with the emic perspective of this study that aims to gather in-depth understanding of the socio-cultural context, respondents’ perceptions and self-constructed meanings (Garcia, 1992; Godina & Mccoy, 2000; Saville-Troike, 1989, Patton,Hong, Patel & Kral,2017). Rapport was already established between the researcher and the participants through frequent visits in the field, participating in their day to day activities and after the first session of interviews where we explored and discussed about their perception on health. To understand the reporting behaviour of the participants, the interview schedule encompassed questions on perception about the concept of illness, threshold for recognition of illness, aetiology of illness, types of confidantes, types or nature of illnesses (minor, chronic, communicable, reproductive and sexual related ailments) that are either shared and not shared, underpinning causes of disclosure attitude and timing of disclosure.


Comment 17. Ethics and consent process are missing in methods section. This was not found till the line 160.

Reply 17. We have now added an “ethical considerations” paragraph in the methodology section (page 8&9 /lines 218-232).

Comment 18. Authors need to state whether they have used any software for analysis. If not they need to state analysis was done manually. There was no mention till the line 172 on this.

Reply 18. Thank you, we have incorporated the recommendation and pointed out that the coding has been done manually already at page8/liness209,211XXX and as follows:

The analysis was carried out manually in accordance with the guidelines of Braun & Clarke, 2006.

Patterns within the data were manually identified, coded and subsequently labelled according to their meanings.

Results

Comment 19. In Line 179, authors discussed multiple reasons made the participants to disclose illnesses. The reasons discussed may not be true for all diseases. It will be different for different diseases. For instance, sexual health or reproductive health may have different way of disclosing than of the normal illness like simple fever. In some case, other illnesses which are considered to be stigma may have different approach. Authors need to clearly state whether they have asked questions for any specific illness or just a general question for all illnesses.

Reply 19. We completely agree with the reviewer. In order to tackle this comment, we have taken several actions. First, we clarify in our methods section that our interview schedule encompassed questions about various types of illnesses and did not restrain our enquiry to one specific category (page7/linesXXX182-187).

Second, we point out at page9/liness243&244 that disclosing patterns stem from a complex interplay of various factors, an important one being the type of illness (lines 238-241):

However, they also revealed multiple reasons pertaining to sexual and reproductive health or illnesses that come with social stigma makes it difficult for them to disclose their illnesses so openly to the family, society and often to the professionals.

In general, the findings highlight that the decision to disclose illnesses as well as the choice of confidantes are influenced by a number of intertwined factors. Through the first interviews with the respondents we realised that not everyone responded to illness in a similar manner but most of the participants follow some particular behaviour regarding disclosure, which relies on a complex interplay of gender, type of illness, marital status, socio-economic conditions and socio-cultural factors.
Third, we have now included illustrations from different types of diseases and we cite the peculiarity surrounding reproductive health in various themes. For example, relating to social norms and fear for future social sanctions, the stigma associated with female issues emerges very strongly (pages 14-18/lines 365-450)

Fourth, we have included this point in our discussion (page32/lines 809-815)

Further, stigma and social exclusion specifically attached to some illnesses – such as related to sexual and reproductive health – appear to heavily influence disclosure behaviour, in terms of disclosure delay and choice of confidantes. Hence illness disclosure behaviour, particularly of women participants cannot be viewed in isolation, and should be understood within a complex nexus of determinants related to gender, type of illness, type of confidantes, socio-economic and socio-cultural conditions.

Comment 20. Line 197. Many terms used in the paper did not have any reference. Authors need to provide reference for the terms used. For instance, 'social penalty' needs reference. Likewise, authors need to provide reference for the terms used in the paper.

Reply 20. Thank you for this comment, which highlighted for us that the language we used was not always clear. We have now changed the term social penalty as negative and informal social sanction. We have also carefully screened the article to identify unclear passages and made changes accordingly.

Comment 21. Line 204 suggests the importance of rest when a person is sick. This was discussed earlier by the reviewer.

Reply 21. Indeed, as mentioned earlier taking rest is an important part of the care pathway, self-management and treatment. However, as already pointed out, the focus of this work is on an earlier step related to disclosure decision/reporting behaviour, which is considered as an important component of health-seeking behaviour, which will ultimately lead to care decisions.
Comment 22. Line 222 The quote from line 222 suggests that the participants follow different disclosing strategies. This may not be called as non-disclosure. If the participant discloses either in a formal way or in an informal way such as a person who counsel them may be considered as disclosure. This may be the bias of authors towards the modern medicine. This could also be an outcome of using only the etic perspective for research.

Reply 22. We definitely agree with the reviewer. In this section in fact we have attempted to show that women do discloses their illness, in what manner they do so and to whom. This section is not about non-disclosure, but considers the variation in the choice of confidantes, which we describe as gender related, but also dependent on the type of illness. Women in fact select different confidantes based on the nature and social implication associated with the illness.

This study attempts to explore the reporting patterns, including the types of confidantes, variation in attitudes and beliefs towards reporting of those who confide illness without delay, those who delayed in confiding and those who did not disclose at all. In doing so, we would like to reiterate that a purely emic, qualitative, inductive approach has been used. No generalization is sought for, and not etic perspective has been used.

Comment 23. Line 243 is clearly showing the attitude of doctors. This needs further discussion as this would contribute to non-disclosure among the members of the community.

Reply 23. Indeed the quote underlines the distance that some slum-dwellers perceive (especially women) from formal healthcare professionals. We agree with the reviewer that this can influence the disclosure pattern, however we think that, rather than inducing non-disclosure, such distance leads to disclose to either family members or informal healers, rather than to doctors and can be read as (page 12/lines 321-323). This is also emerging from the theme “healthcare professional as last recipient of illness disclosure”.

Such distance that women perceive from formal healthcare professionals influences their disclosure pattern, inducing disclosure to either family members or informal healers, rather than to doctors.

Comment 24. In line 395, ‘Coping with insecurities of the slum’, suggests that there are safety issues. But the concept discussed here is on their job security. Authors may use different term for security. Authors may refer Maslow theory of motivation.
Reply 24. Thank you for this comment. We indeed realised some inconsistencies between titles of the themes and the empirical evidence associated with them. As suggested we have rephrased the title of this sub-theme as Coping with livelihood and financial insecurities of everyday life to better reflect its content. In addition to that, we have thoroughly and majorly revised the presentation of themes, the quotes and the sequence to ensure: consistency, minimize overlap and sharpen the distinction across themes and added value of each. Please see the revised version of the article, pages (line no.) 10 (264), 14 (362-363), 20 (509).

Also, thank you for suggesting the link between the findings and Maslow theory of motivation. We have incorporated this point in the discussion (page34/lines 842-853) as:

Nevertheless, slum environment plays a pivotal role in shaping the attitude of the slum dwellers towards disclosing of illness. Structural phenomena unique to the slum community (disintegrated life, poverty, inequality, crime, fragile physical infrastructure) have an overpowering effect on their health seeking attitude. Their struggle being in a slum community leave no space for health concerns, hence the need for reporting illness hardly gets recognised. This construction, evoking the myriad of complex needs, desires, and forces driving their health seeking behaviour, conforms very well with Maslow’s theory of motivation based on the “hierarchy of needs” (Maslow, 1943). This theory explains that higher level needs, such as health, family, relationship, security of environment, employment are dependent upon the fulfilment of lower level innate or basic needs such as food, shelter, and sleep. Slum-dwellers in this study confirm that health is perceived as a higher order need, which can be attended to only once the more basic needs are met.


Comment 25. The point discussed is about how one is concerned about job security and problems related to work. It did not refer to safety and security of family members. It sounds like the security of family members. There are also mentions on girls feel unsafe and insecure in temporary shelters. Please clarify.

Reply 25. Indeed. Within the major revision that led to revise themes’ presentation, titles and sequence, we have developed two different themes: one related to “coping with livelihood and financial insecurities of everyday life” (page20/line 509) and the second related to Degenerated
slum atmosphere impeding disclosure (page29/line 728). Through this theme we have reflected and rephrased as follows (lines728-739):

The slum dwellers occupy marginal positions in the socio-cultural system of the community, inhabit in an unfit environment. In this relation, some male and female participants expressed that they had to struggle to cope with many slum related practical issues such as dealing with environmental decay, poor infrastructural facilities, displacement, poverty, and crime, which severely undermined their sense of safety and security. Many of them described their struggle on some of these issues. They believe that, prior to focussing on any health-related activities such as identifying, disclosing and treating illnesses, faulty basic infrastructure should be addressed, such as improper toilet facilities, improper shelter, open drains, sewages and basic needs should be satisfied, like proper sleep, clothes, food. The feeling of unsafety arising when these basic needs are not met and secured can overpower their attitude of sharing illness.

Comment 26.In Line 470, usage of the term, 'female disorder' looks like a literal translation of the term from a regional language. It does not communicate the point.

Reply 26. Thank you for pointing this out, we have incorporated the comment by rephrasing the term into “female related health problems” (page23/line576).

Comment 27.Theme such as number 5 on 'Reasons for not disclosing illness' is purely based on deductive logic.

Reply 27. We gave this remark careful thought and realised that indeed the presentation of our emerging themes was confusing and misleading. Defining an emerging theme as “reasons for not disclosing illness” seems to impose a researcher’s category or predefined mental scheme on the respondents’ perceptions, as it infuses a respondent’s perception already with a purpose or meaning. This was not our intention, nor we used any predefined theoretical framework to guide our analysis or interpret our findings. Rather, once in the field, through the first interviews with the respondents we realised that not everyone responded to illness in a similar manner but most of the participants follow some particular behaviour regarding disclosure, which relies on a complex interplay of gender, type of illness, marital status, socio-economic conditions and socio-cultural factors. Three categories in connection to the reporting behaviour emerged: those who delayed in disclosing their illness, those who disclosed their illness without delaying and those who did not disclose at all. We used these categories for grouping the themes, an added one additional group related to the choice of disclosure recipient (confidantes).
The themes per se are disconnected from the specific category, but are grouped in one for the sake of systematization and based on the researcher’s understanding of the influence that the specific theme exerts on disclosure behaviour. We have expressed the same as follows (page9,10/lines 242-261):

In general, the findings highlight that the decision to disclose illnesses as well as the choice of confidantes are influenced by the complex interplay of gender, nature of illness, marital status, and socio-economic conditions. During the coding procedure and while presenting the results, an attempt has been made to systematize the findings and disentangle the main themes from the inherently much more complex nexus of causes. For grouping the themes, four main aspects of illness disclosure have been used, which mirror our main research questions: 1. Choice of confidantes 2. Reasons for delaying disclosure, 3. Reasons for not delaying disclosure; 4. Reasons for not disclosing. Within these overarching topics, twelve themes emerged, namely: healthcare professionals as the last recipients of illness disclosure; social norms and fear of future social sanctions driving the choice of confidantes; bearable physical burden; negative prior experience of illness; coping with livelihood and financial struggle of everyday life; unbearable discomfort; therapeutic value of disclosure; fear of unfamiliar illnesses; previous negative outcomes of non-reporting or delay; withdrawal as a coping strategy; perceived threat to social image; and degenerated slum environment atmosphere, are presented themes motivating the choice of confidantes, early illness disclosure, delayed illness disclosure or non-disclosure. Because however the themes per se are disconnected from the specific category, but are grouped in one for the sake of systematization, we number the twelve themes subsequently and not in connection with the larger topic. Table 3 summarizes these themes portraying the different reasons of disclosure pattern among men and women.

Discussion

Comment 28. What is new about the findings in the paper? Many of the findings are already known. In India this is a common problem faced by many. As we know all urban people have roots in villages. This is similar to the patterns found in rural areas. The slum dwellers continue their rural lifestyle in urban slums.

Reply 28. In light of the emic perspective used in this study, the novelty of this work resides in unravelling the patterns of illness disclosure in the specific setting under exam, namely Indian urban slums. Low-income, resource-constrained settings are characterised by a high level of idiosyncrasy and specificity, which impedes any generalization of findings to other contexts or the transfer of evidence collected in other contexts to the one under investigations. Hence,
findings and patterns found in other settings, even in Indian context, cannot be used as a vantage point to understand illness disclosure behaviour in Indian urban slums. By contrast, comparisons are possible and sought for. Based on the reviewer’s observation, the fact itself that respondents replicate their disclosure behaviour of their rural counterpart is very interesting, as it reveals that the cultural imprinting deriving from their rural roots overpowers the influence of urban life. We have incorporated this point in the discussion (page30/lines 767-773).

Comment 29. Authors interpreted some of the excuses as participants' coping strategies. That does not justify the finding.

Reply 29. Thank you for this point. We feel that it is beyond our capability as researchers as well as beyond the focus of this paper to assess whether the reasons provided by respondents are “excuses” or not. What we can do is only to report the respondents’ point of view, according to which some men use non-disclosure as a way to distract themselves from health issues and as a way to not be constantly reminded about their health problems. In this sense, we define this choice as a coping strategy.

Comment 30. Throughout the paper the authors have number of assumptions about illness. They need to define them first. And this would have been explained to the participants well before data collection. For example, ‘pain, discomfort, inability to perform duties and so on’, need to be explained before. This has to be validated with illness prior to data collection.

Reply 30. We see the point raised by the reviewer here, and we gave it some careful thought. Of course, participants are likely to have varying understanding of illness, as well as pain, discomfort, inability to perform duties, and of any illness-related concepts, which are inherently socially constructed. As such, for the same condition, different levels of pain and discomfort can arise across individuals, as well as for the same individual at different points in time. On the one side, explaining and defining such concepts to the respondents before the study would have failed to create a sort of “average understanding” of these constructs, because these remain inherently confined to a subjective sphere. On the other hand, such effort of explanation to average out how respondents experience these constructs would have felt as an imposition of the researcher’s point of view and would have violated our emic perspective of gathering in-depth, subjective, socially constructed perceptions. Hence, we feel that we are consistent to the nature of the study by leaving the definition and meaning of these constructs to the interpretation of the respondents, fully aware that individual experiences cannot be compared.
We have included this very explanation in our methodology and incorporated the same essence in our limitation with some rephrases (page34/lines 868-873) as follows:

Lastly, because the participants were left free to interpret concepts of illness, pain, discomfort, inability to perform duties, and of any illness-related aspect, and to use their self-constructed meanings, these may likely to change in the future, and across people. In line with a social-constructivist, emic perspective, findings cannot be generalized to other social groups, nor to the same social group over time.

Comment 31. In line 745 acknowledgement of illness is questionable. What do authors mean by that? The authors' perspective may be different from that of the participants. In epidemiology, host, agent and environment interaction leads to different states of health in an individual. In that case how the host discloses the state of health by many of the manifestations need to be recorded. This needs one to go on documenting many of the acts of participants through observations. This could not be done by verbal disclosures.

Reply 31. After studying the disclosure pattern of the respondents we have come to the conclusion that illness stems first of all from subjective experiences and perspectives. Participants do not always recognize disease or ailments as illness but may consider some conditions as normal discomforts that will get healed in its own course. By acknowledgement we mean here that the participant himself/herself consider an ailment as a disease. Once the illness is recognised, the subsequent action is the disclosure decision, in which the individual may or may not disclose their illness (with an intention to treat) to others due to the influence of the complex socio-cultural environment, gender, nature of illness, etc.

Comment 32. In Line 785, it is not only isolation and rejection it is also linked to social sanctions.

Reply 32. Thank you, we have incorporated this comment and rephrased as follows (page33/line828)

However, the cultural impacts become weak in case of fatal illnesses and at times overlap with those social impact that discourages the participants from opening up to everyone so as to avoid the burden of isolation, social sanction and rejection of both self and family.
Comment 33. In line 787, a social phenomenon is simplified to a binary option. This is a oversimplified option. They cannot be classified just as black or white, but need to address the grey areas as well.

Reply 33. We have rephrased as follows (page33/lines 829 - 831):

In our findings we observed that the choice of disclosure is a complex decision and is based upon potential risks and benefits of disclosing, which are in turn multifaceted and relying on factors such as gender, type of illness, marital status, timing, confidantes, etc.

Comment 34. In Line 795, where is the finding on managerial support on the paper. It is not mentioned anywhere.

Reply 34. We agree with the reviewer, the word is misleading and not matched by empirical evidence. We have deleted it.

Comment 35. In Line 798, in qualitative inquiry we do not discuss sample size. The authors are confusing this with the larger quantitative study.

Reply 35. We have rephrased this sentence with “the large number of respondents”. We allows ourselves to clarify once again that there is no larger quantitative study. The larger study is also purely qualitative.

Comment 36. In Line 803, it is not clear who interviewed the participants. Whether men interviewed men participants, women interviewed women participant. It is not clear from the methods. If it was not followed the above this would affect responses. Hence, that need to be mentioned in the article. This may be a limitation.

Reply 36. Both men and women have been interviewed by the main researcher, a woman. While this favoured openness of female respondents, who are traditionally more reserved, it could have introduced a bias in gather male perspectives. We have now recalled this point in the limitations as follows (page34/lines 859-865).
both men and women have been interviewed by the main researcher, a woman. While this favoured openness of female respondents, who are traditionally more reserved, it could have introduced a bias in gathering the male perspectives.

Comment 37. It is also not clear where was the interviews conducted. Whether at their homes or workplace? This would affect the responses.

Reply 37. We included this information at page 6/lines 159,168. Women were interviewed in their house while men were interviewed during their leisure period or sometimes in their workplace near their homes.

Comment 38. In Line 809, objective of qualitative study may not be for generalizing to larger population. This could not be a limitation.

Reply 38. Very true. We have removed the sentence.

Comment 39. In Line 818, the term masculine ego looks like participants self-perceive. Actually masculinity is socially constructed phenomenon. Most of the times, a person respond to his alter more than ego.

Reply 39. We have addressed this comment by rephrasing the title of the theme, which now reads as “Threat to perceived social image”. Indeed masculine ego may be too specific and valued, and may not be felt as such by all male respondents who contributed to the emergence of this theme. Hence, we feel the new title as more appropriate. Thank you for pointing this out.

Comment 40. In Lines 821 to 26, the reasons for disclosure and non-disclosure excluded the cost aspect or affordability of healthcare. There was a mention in the results section on that.

Reply 40. Indeed, that is correct. We have now revised the conclusion to better incorporate all the results/emerging themes. Please see the revised conclusions at page 35/lines 875-877, 886,890-895.
Comment 41. There are Quacks called Bengali doctors in different slums in Northern India. Similar quacks will be there in Kolkatta and Bengalore as well. There was no mention on the quacks. This needs to be included. Is this because authors did not take a note on them? Even in cities like Chennai has quacks in slums. The Bengali doctor concept is common among the immigrant workers from Northern India in Chennai and other cities.

Reply 41. Thank you for raising this interesting point. In this paper we have identified informal health care providers only as one of the confidantes for women participants but we have distinguished among different categories. By informal health care providers we mean clinically unregistered practitioners, including quack or village local healers migrated to the city. We have described extensively with specifications these different types of health care providers in another paper discussing treatment-seeking behaviour given their relevancy in that sort of discussion.