Author’s response to reviews

Title: Psychosocial Support for Parents of Extremely Preterm Infants in Neonatal Intensive Care: A Qualitative Interview Study

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Author’s response to reviews:

Dear Editor,

We thank the reviewers for their comments. We have now revised the manuscript according to their suggestions.

We think that these changes have improved our manuscript and hope that it will be acceptable for publication in BMC Psychology in its present form.

Sincerely,

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Responses to reviewers’ comments (our responses preceded by an asterisk (*) for the sake of clarity)

Reviewer reports:
Ana Fonseca (Reviewer 1): Thank you for the opportunity to review the paper entitled Psychological support for parents of extremely preterm infants in Neonatal Intensive Care: A qualitative interview study. This is a very important topic with important implications for clinical practice. Exploring the perspectives of parents may pave the way to a better understanding of their needs, and to the subsequent design of intervention approaches that can be tailored to the
The paper is clearly written and well-organized. There are however some topics that should be improved before considering it for publication.

1 - The goals/target of the study should be better defined. The authors talk about "needs of psychological support" and "how the organization/staff meets or fail its needs". Although in the introduction the authors make a good case about the impact of parenting a preterm infant hospitalized at the NICU and give some context about the family-centred care approach, it would be important to clarify what is meant by "needs of psychological support" - as these needs are not exclusively met by psychologists but by the staff; wouldn't be preferable to consider "psychosocial needs" or something similar? I would also like to see greater detail when describing prior studies about parent's needs (this would facilitate the interpretation of current data).

* "Psychological support” refers not to support given specifically by psychologists but to support that addresses needs in the psychological domain (e.g. cognitive or emotional support) as opposed to, for example, physical, medical, practical or economic needs.

2- The authors state that research has focused on identifying parental needs rather than explored how and why these needs are met; this is one of the major goals of the study. However, when looking to the results, it is hard to have a global picture on how these parental needs are globally met or not. If is possible that the fact that parents identify one topic as a need is per se indicative that the need is not met? Please introduce some additional reflections on the discussion about this topic.

*Parental needs are variable, complex and dependent on many factors. As shown by our results, parents also have different demands and expectations of the NICU and its staff, and express different degrees of satisfaction with the support they received. Likewise, participants reported that individual staff members varied in their ability to meet parents’ needs of psychological support. It would therefore not seem legitimate based on a qualitative study like this one to, as it were, present a blanket assessment of how well the NICU globally meets parents’ needs. What we can see from our results is that certain needs recur in parents’ accounts and that both strengths and weaknesses in the NICU’s ability to meet these needs emerge.

*That parents identified some topic as a need does not imply that the need was not met, as parents also describe support they were actually given, i.e. ways in which their needs were met.

3 - Methodological issues:
- The experience of having twins and of one of them has died, may encompass additional challenges and needs. How was this taken into account in the study?

*Each of the parents participating will have had unique challenges related to his or her child’s hospitalization (e.g. particularly dangerous illness in the child, single parenthood, the parents’ own illness…). We have not attempted to trace the effect of these individual circumstances on the parents’ needs, which would have required more of a case-study approach, and have instead focused on the description of needs actually presented by the parents.
How the authors addressed the possibility of mutual influences/contamination within the couple, as the interviews were conducted together? How this may have influenced the results?

*We did not aim to investigate the needs and experiences of each member of a couple in isolation from the other. As the couples had been through the experience together it seemed most appropriate to interview them together (in those cases where both parents were interested in participating).

- Please be more specific about the type of questions - for example, the authors state that they asked about "emotional and existential issues that had arisen..." - how existential issues are related with needs of support? I think that given some examples of questions will enhance the presentation.

*As the reviewer suggests, we have included some examples of follow-up questions that were used.

- Data analyses: Please give more information about how many researchers were responsible for coding, how the coding process was verified (inter-rater agreement?), etc.

*Both authors were involved in this process and reached agreement on coding and thematization. This information has been added to the text.

We have closely adhered to the protocol for trustworthy qualitative content analysis outlined in Graneheim & Lundman (2004) (ref 19 in the text).

- What software was used for data analysis?

*NVivo 11; this has been added to the text.

- How did the authors define the number of interviews? The saturation of thematic content was a criteria?

*We chose a number of interviews similar to or greater than the samples used in qualitative studies with comparable methods and aims (compare e.g. Gallagher et al, 2018 (ref. 16), Turner et al, 2014 (ref 21)). We consider that thematic saturation was achieved with this sample size.

Extremely premature birth is a rare occurrence (about 0.4% of births) and the participating families represent a large percentage of the potential participants from the hospital in question who met the inclusion criteria at the time the study was conducted.

The interviews were retrospective. The time since hospitalization ranged between one week and 4 months. Do the authors found different patterns of descriptions as a function of this feature, or the pattern of needs was similar in the different interviews?

*No such patterns were discernible. In any case, given the qualitative nature of the data, it would not be possible to draw valid conclusions about such patterns even if we suspected their existence.
4 - Results. The results are presented in a very detailed way, being difficult to the reader to follow. Maybe the introduction of a figure with the main themes and subthemes may be useful. The frequency of which each theme/subtheme was mentioned could also be important to describe - we will gather a clear picture of the universality/specificity of different needs.

*When appropriate, we have indicated whether one, some, or many participants mentioned a particular point. We have purposely refrained from indicating frequencies in more detail than this, in order to avoid giving the impression of quantifying results drawn from qualitative data, which would involve drawing conclusions that it would not be valid to draw from this type of material (there has been no attempt to recruit a statistically representative sample of participants). As suggested by the reviewer, we have included a table with the themes and subthemes.

5 - In the discussion, the authors present the results found with detail. I will suggest summarizing the results and to focus more on providing possible explanations for them. Although I understand the organization in different topics, I don't think we should split between emotional support and organizational issues. All these topics (including the ones related with providing emotional support) have implications for the organization of services and this should be clearer. Moreover, the discussion puts a strong emphasis on nurses, while the initial background refers to different professionals - I think this should be taken into account.

*We have considerably shortened the discussion as suggested to avoid excessive reiteration of the results. We agree that all the topics discussed can be related to organizational factors, and have somewhat restructured the discussion so as to avoid giving the impression that organizational issues have relevance to some topics but not others.

The focus on nursing staff reflects the fact that, as we note, the great majority of parents’ contact with NICU staff involves nurses and that the task of providing psychological support for parents largely falls on them.

Margarida Custódio, PhD (Reviewer 2): The study aimed to explore the needs of psychological support of parent’s while in NICU after the birth of their extremely premature infants, and to assess their perceptions on how NICU staff meets or fails to address these needs. Authors used a qualitative methodological approach.

Although not innovative, studies on support for parents when the onset of parenting occurs in a dramatic situation should be encouraged. This study presents contributions for the practice of health professionals. However, there are weaknesses that should address by the authors.

Without doubt the paper would need shortening. It may also be helpful for authors to work with a native speaker of English to review some use of language.

*We have shortened the paper (background, results and especially the discussion) considerably and tightened the structure.

*The paper was written by a native English speaker (AB).

Some comments and suggestions:
Background
While the introduction is generally adequate, it could be improved by being more concise and focused on the review of literature on the emotional needs and preferences of parents of premature and extreme premature child while they are in NICU.

*We have shortened and streamlined the background in order to make it more focused.

Aim
Research questions
148 - It is not clear what you mean by "forms of psychological support". Could you clarify? The structure of the sentence of first research question should be review.

*“Psychological support” refers to support that addresses needs in the psychological domain (e.g. cognitive or emotional support) as opposed to, for example, physical, medical, practical or economic needs. We have modified the sentence referred to by the reviewer for greater clarity.

Methods
-Participants
159 - remove "from"
164 -167 - I suppose you are referring to the newborns in the sample, but it isn't explicit in the text; consider gathering all the information about the newborns by moving the lines 174 to 177 to begin in line 167

170 - Consider change "did not know Swedish" to "were not fluent in Swedish language"
171-173 - As these lines do not contain information about the participants consider moving to "Procedures"

* We have restructured the section the reviewer refers to and made changes as suggested above.

It would be interesting to know more information about the 27 participants: mean age; socio-economic level; academic level

* We have included some demographic information: age (range and median); origin (number of foreign-born participants). We have not categorized participants according to socioeconomic or academic level. We have data on the professions of the participants but do not include this information for reasons of confidentiality (extremely premature birth being as rare an occurrence as it is) and because we do not see it as particularly relevant.

194-195 - About the interview, it not explicit what you mean by "appropriate questions" in follow-up. Was there a frame with dimensions coming from your research questions (aims)?

*We have given some examples of follow-up questions in the text. An interview guide was used but questions were adapted and modified during the interview process in response to the specifics of each participant’s account.
Data analyses

209-211- In the text you wrote that themes emerge from "capturing the meaning and implications of the categories in relation to the research questions". Could you be more explicit? Were there predefined dimensions? You have two research questions. Did you identify parental needs, and afterword's explore their perceptions on how health professionals, and NICU as an organization, meet these needs?

* The analytic process was highly inductive, as mentioned in the text, and themes were derived from the data through the process of coding and categorization instead of being predefined. Likewise, the research question was modified and refined as analysis proceeded. Material in the data relating to these two research questions (on the one hand, needs expressed by the parents; on the other hand, ways in which they considered their needs had been met or failed to be met) were intertwined to a high degree in the parents’ accounts and part of the process of analysis involved conceptually differentiating between these dimensions.

Results

This part of your text should be review. You have interesting results but the way you structured your themes and subthemes is confusing. It is too long, with some subthemes including information that do not relate to the Theme. There must be internal coherence within each of the themes. Furthermore, quotes are too long and some of them are not clear.

*We have reviewed the results section and the thematic structure so as to avoid confusing the reader and ensure the internal coherence of each theme. The subheadings in bold under the subthemes were never intended to signify separate categories within a theme or subtheme, but were only included for ease of reading. We have removed these subheadings to avoid confusing readers on this point.

See also the replies to the specific comments below.

*We have made many of the quotations shorter, reviewed them for clarity and eliminated one or two that seemed superfluous.

Some examples and suggestions:
233 - Theme 1 - "Emotional Support" - Consider describing the themes before presenting the subthemes
235 - Subtheme: "Empathic treatment by staff" - Consider changing to "Empathic attitudes from de staff".

* We have retained the name of the subtheme since the analysis does not concern the attitudes of staff (which the parents were unable to perceive directly), but rather parents’ perceptions of how they were treated by staff.
In this subtheme you include, in a confusing way, parental needs and desires; parental views of sources of support; parental perceptions on health professionals' attitudes; and recommendations for health professionals.

I recommend restructuring and clearly distinguish between parental needs (e.g. need for emotional comfort, hope and honesty by the staff; need to be heard; need to be respected on their preferences) and parental perceptions on how the staff meets these needs. Recommendations for health professionals should be remove and include in Discussion or in Conclusions.

344 - Subtheme "Other parents as a unique source of understanding" - Consider changing to "Other parents as a unique source of support"
This is a subtheme on sources of emotional support and should be describe like that.

*We have changed the name of the subtheme as the reviewer suggests.

379 - Subtheme "Unclear roles of the various professionals"
This is a subtheme on sources of support. It should be completely restructured. Mixing e.g. "the role of the contact person" and "overburden staff less capable of offering emotional support" in the same subtheme is very confusing. Indeed, some of the information should be remove to Discussion or even to Conclusions.

*The subheadings under the theme, such as “overburdened staff less capable of offering emotional support”, were not intended to represent separate categories within a theme or subtheme, but were only included for ease of reading. We have removed these subheadings as they apparently risk confusing readers.

521 - "Feeling able to trust the health care provider"
This theme should be described, and its coherence with the research questions (i.e. the needs for psychological support and how professionals meet these) must be explained.

635 - "Support in balancing time spend with the infant and other responsibilities"
This is an important theme and it is coherent with your research aims. Nevertheless, you should consider restructuring and clearly distinguish between parental needs of this subject and parental perception on how health professionals meet their needs. Your thoughts or considerations on parental perceptions and their implications on health professional attitudes, should be included in Discussion or in Implications for practice.

711 - Subtheme Privacy and solitude - Consider changing to "Emotional privacy" or just "Privacy"
Again, in this subtheme you include information on parental needs and desires mixed with e.g "being affected by exposure to other families' problems" which is not a category on its own but one of the reasons for parental need for privacy. I recommend restructuring.

*We have renamed the theme simply “Privacy” as suggested by the reviewer.
*The subheadings under the theme, such as “being affected by exposure to other families’ problems”, were not intended to represent separate categories within a theme or subtheme, but were only included for ease of reading. We have removed them where they risked causing confusion on this point.

Discussion and Conclusions

The discussion is far too long as currently written. There is too much reiteration of the results. Consider being less descriptive as the results are already very explicit. I suggest you to focused on answering your research questions in a concise way after reflecting on the main results, then link to the broader literature, and discuss the implications for practice, and future research.

*We have considerably shortened the discussion, for less reiteration of the results and a greater focus on the main implications of our results.