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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Answers to Reviewer 2

Margarida Custódio, PhD (Reviewer 2): I begin by congratulating the authors for the good work done in this second version. In general, it is more explicit, clear and concise. Despite your effort I think you can go further in reducing your paper by being even more focused, summarizing and integrating information.

Answer: We have further significantly reduced the length of the paper to make it more focused, as the reviewer suggests.

One or two aspects need clarification
Please consider the comments below
Method
Line 173-180 - you explain that Follow-up questions were adapted to each participant with a focus on parents’ experience of their child's stay at the NICU, emotional issues, the sources of psychological support that had been available to them and their views on its extent and quality. You include some examples of the questions in the interview. Where these questions used for all participants or just for some (as there were adapted)?

Answer: Follow-up questions were not necessarily the same for all participants but were adapted to the individual participant’s narrative. However, certain areas of inquiry were present in all the interviews; the sample follow-up questions included in the article, or very similar ones, were asked of all the participants.

Did you ask parents about their needs for psychological support or deduced those needs from the verbatim about their experiences and emotions? Or from their responses about "sources of psychological support".

Answer: The parents were asked about their needs for support and whether they considered these had been met, but their descriptions of their reactions, experiences and emotions were also elicited in the interviews and analysed as reflecting parents’ needs (to take a simple example,
complaints about receiving insufficient information from staff would indicate a need for information to be given in a more thorough way). See also the response to the next question, below.

Data analysis

Line 194 ,195 - you wrote "Thematization focused on data concerning parents' descriptions of their needs of psychological support from the NICU and its staff". I wonder how you captured parent's description of their needs. Did they describe them?

Answer: In some cases, parents directly described their needs; in other cases they described them indirectly through descriptions of their experiences at the NICU, problems they encountered, views expressed of the behaviour of staff, etc. The method of analysis used allows for analysis of both.

Results

In this version your results are much better structured. Congratulations!!!

However,

- In the first Theme: - Emotional Support
  Some confusion remains about," parental needs"; "parental preferences"; " what parents value in their relation with the staff"; "parental negative evaluation". Please consider clarifying considering your aim (1) parental needs and (2) how staff as meet these needs

Answer: We have clarified the text to correspond better to the aims of the paper, as suggested.

The subtheme: Unclear roles of the various professions is to extensive, descriptive and even repetitive. Please consider reducing it by integrating some of the results.

Answer: We have significantly condensed the section, as suggested. We have also further condensed the subsequent parts of the Results section.

Discussion and Conclusions

In this version there is an important effort to reduce discussion. Despite this effort the discussion remains too long. Please consider summarizing and not being so extensive in the topic Nurses' need of support and adequate working conditions, as it not the aim of your study.

Answer: We have further reduced and focused the discussion as requested by the reviewer. In particular, we have cut the paragraph concerning nurses’ own need of support, as we agree with the reviewer that it is not directly related to the aim of our paper. However, we do feel it is important to mention the impact of staff working conditions on the extent to which parents’ psychosocial needs can be met. When staff are inadequate in number and pressed for time and/or lack adequate training and experience, medical care for the infants is prioritized and support for families tends to be addressed inadequately.
Answers to Reviewer 3

Anabela Araujo Pedrosa, Ph.D (Reviewer 3): Thank you for the opportunity of reviewing the article intituled "Psychological support for parents of extremely preterm infants in neonatal intensive care: a qualitative study". This is a very pertinent study, since the birth of a preterm baby is a major stressful event, facing the parents with very difficult challenges in terms of present and future adjustment. Increasing knowledge about difficulties felt and how to address it should be a priority in research in health settings, so I congratulate the authors for their choice and work.

The paper is clearly written and is interesting to read; the main objectives are also clearly stated and the abstract summarizes well what will follow in the text. References are balanced and up to date.

From the title and through the paper the authors aim to further clarify the "psychological support" needed by parents of extremely preterm infants cared for several weeks or months in a NICU, and following parents' answers they explore how these needs of support are met by different health professionals. It would be preferable to focus on or naming it "psychosocial needs" or preferably "psychosocial support" (for example, on the abstract and line 114) for parents of extremely preterm babies, since throughout the text there is reference not only to the psychological support - which should and must be given by psychologists, but also to other forms of instrumental and emotional support, which should mobilize all professionals working with parents in the NICU. This may seem a too rigorous view, but language is powerful and important - and we stand by the position of giving the due credit to specific interventions - such as psychological support - which of course does not undermine the importance of all forms of support given by a multidisciplinary team working with parents. We would advise the authors to change the terminology.

Answer: We have adopted the reviewer’s suggestion (see lines 29, 47, 49, 97, 111, 133, 173, 191 and subsequent occurrences of the term throughout the paper).

In the Background section, line 69, please considerer defining corrected age as gestational age minus the number of weeks born prematurely; the given definition is somewhat confusing.

Answer: We have changed the term corrected age to postmenstrual age (gestational age plus chronological age) in order to avoid confusion. (Background, line 64.)

The authors state the importance of family-centred care - which evidence shows should be the "golden standard" for caring in a NICU - and mention the impact of the experience of having a baby committed to such a unit in the process of bonding between parents and their child; given the vast data concerning attachment processes and their pervasive impact in future development, the authors may consider reviewing the impact on attachment instead (or at least mentioning it, also).

Answer: We have added a mention of existing research on the consequences of extreme prematurity and parental posttraumatic stress on attachment (Background, line 93ff.)
In the Method section, authors mention the exclusion criteria, but it would be helpful to explain these further; why were parents of twins when one of the babies has died included in the study? Couldn't their needs be shaped by this major event? And why not include parents whose child had been referred to habilitative services - was there other reason than a possible ethical criterion? Parents in such hard situations probably have specific needs which may cause harm and even trauma when nor met. Is this a future line of research the authors may want to pursue? We would like to see these options explained further in the Methodological considerations subsection.

Answer: It is certainly likely that the loss of one twin shaped the needs of the parents who had gone through this experience. However, the other participants will have experienced other unique difficulties related to their child’s hospitalization (including e. g. particularly severe illness in the infant, single parenthood, insufficient social network, events prior to delivery, the mother’s own illness…). All of the parents’ and infants’ individual circumstances surely contributed to their needs. We see it as a strength of the sample of participants that they represented a wide variety of specific circumstances and backgrounds, within the already limited group of parents of extremely premature infants.

Answer, continued: Families of infants discharged to habilitative services, who make up an extremely small group with severe handicaps, were excluded mainly for ethical reasons (at the suggestion of the Regional Ethics Committee). It was considered unsuitable to approach parents who would probably still be in crisis for participation in the study.

When both the parents were interviewed, where the answers from mothers and fathers analysed separately? Were there differences between mothers' and fathers' psychosocial needs?

Answer: Mothers’ and fathers’ answers were not analysed separately and it was not part of our aim to ascertain differences between mothers’ and fathers’ psychosocial needs in the NICU (something for which, in any case, the type of sample and method used in the present study would not be suitable). Also, as each couple had been through the experience together, we considered it most appropriate to interview them together (in those cases where both parents were interested in participating). That being so, it would not make sense to separate one parent’s responses from the other’s into different data sets.

Was the infants' age at the time of the interviews chronological or corrected age (line 171)?

Answer: Chronological age.

Line 176 - Please consider using "psychosocial support"; the same in line 195 - "psychosocial needs", line 204, 738 and others.

Answer: We have changed the term throughout, where applicable, as suggested by the reviewer.

Line 191 - Wouldn't "were sorted into categories and subcategories" be more precise?
Answer: In general, codes were sorted into subcategories and then subcategories into categories (in other words, smaller units formed before larger ones).

The Results section is very informative and clearly illustrates the categories and subcategories that researchers had chosen based on the content of the interviews; the vignettes/quotes were helpful and well chosen.

In the Discussion section, the authors achieve to make a good summary and discussion of the themes found; although it would probably make the paper too large, we would've liked to read more about how to address the needs reported by parents, or how to better fulfil it.

The paper would also gain in having "limitations of the study" and "future lines of research" subsections included in the discussion; there is mention of Methodological considerations, which are scarce.

Answer: We have added a paragraph concerning directions for future research. (Discussion, line 702ff.)

Line 42 - Please review the sentence that starts with "How best..." - it's of course correct, but its meaning would be clearer if formulated in a way such as "It is worth exploring how best ...".

Answer: We have reordered the sentence as suggested by the reviewer (Line 661f.).

Overall, this is an interesting and important paper, since it allows a better knowledge about the psychosocial needs of parents with an infant needing NICU care, and how to address it in order to lessen stress and to promote adjustment.