Author's response to reviews

Title: Parents' perceptions on offspring risk and prevention of anxiety and depression: A Qualitative Study

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Author's response to reviews: see over
Dear Mr. Carlo Rye Chua, and Dr. Suzanne Dziurawiec,

We would like to thank both reviewers for the detailed and constructive comments and gladly accept your invitation to revise and resubmit our manuscript 1790172651220962 entitled *Parents' perceptions on offspring risk and prevention of anxiety and depression: A Qualitative Study*. We did our utmost to comply with the comments that were raised by the reviewers and hope that this revision satisfactorily addresses the main concerns.

In the following, we will detail how we addressed each of the concerns that were raised.

Report Reviewer 1: Helen M Correia

Generally, the study makes an important contribution to the field, not only in relation to parental perspectives on participation in preventive programs, but also more generally to the potential improvements in completion and quality of RCT’s. The authors efforts and attempts to identify how participation and engagement in the research process and interventions can be enhanced is a task rarely undertaken (or at least rarely published), and this should be recognised. In addition, the commitment to the process of including parents as co-researchers/interviewers as part of the qualitative approach should be acknowledged.

Some revisions are suggested/needed. These are broadly stated below and clarified in an attachment.

We would like to thank the reviewer very much for the extensive feedback. We believe that the remarks vastly contributed to the improvement of the paper. We will address each point of the comments in detail below.

Minor Essential Revisions

1. The language in which interviews were conducted and analysed (as well as translated etc) should be stated.

   If not in English, it should be specified at what point they were translated and how such translation might affect the subsequent analysis and interpretation of data.

   Indeed, the interviews were not conducted in English, which did not get attention in the paper yet. With regard to this topic, Van Nes, Abma, Jonsson, and Deeg (2010) do two recommendations that we followed throughout the process of writing the paper (1) staying in the original language as long as possible (analyses and discussions were in Dutch and we only translated the selected citations); (2) the researcher to operate as a translation moderator and to use a professional translator (in our study, translation and back-translation was performed by a professional translator and two of the researchers ‘in side-by-side procedure’).


   In line with the reviewers comment, on page 12, we added “Interviews and analyses were conducted in Dutch. For the purpose of this paper, the topic list and citations were translated and back translated by a native English speaking professional Dutch-English translator (member of the Society of English Native Speaking Editors), and two of the Dutch authors (MN and HF).”

2. Description of previous literature (Stallard et al 2004) may be incorrect
“These two studies, however, lack information that may be relevant in the context of prevention activities. First, they only included mothers and patients and did not encompass fathers’ or partners’ perspectives…”

This statement needs to be revised or clarified as it does not apply to the Stallard study (which did, for example, include fathers?)

We agree with the reviewer that this statement is unclear. We revised the statement:

“These two studies, however, lack information that may be relevant in the context of prevention activities. First, they only included patients and did not encompass partners’ perspectives…”

3. The process around selection of participants and saturation needs to be more clearly articulated.

Quality procedures: “Saturation was discussed in the research team and reached in this study after 24 interviews”

In “selection of participants (para 2)” it indicates that 33 participants were invited and 9 declined (n=24). This needs to be clarified as at present it is worded as though saturation was conveniently reached based on the number of participants who consented. The process needs to be more clearly articulated eg specifying whether participants were selected via purposive sampling and recruitment ceased after saturation (after 24 interviews), resulting in 33 requests to participate with nine declining.

In line with the reviewer’s comment, we clarified the selection of participants by changing the paragraph explaining the inclusion an attrition of participants. The paragraph now reads:

“In qualitative research, the process of data collection and analysis ends when ‘saturation’ is reached [19]. This is the point where no information is added and data replication occurs. Participants were selected via purposeful sampling and recruitment was ceased after saturation (after 24 interviews), resulting in 33 requests to participate with nine declining. Of these nine, two parents did not volunteer any reason; one had already participated in a large national cohort study and the larger RCT [13]; two only stated ‘not interested’. Others provided different reasons like being too busy in general, too busy rebuilding the house, or too busy managing their own anxiety. Others did not want to talk about, or be reminded of their (past) disorder. Eight of these nine parents had also declined participation in the clinical trial.”

The information about saturation in the paragraph about quality procedures is omitted.

4-6. Aspects of the process of data analysis need to be more clearly articulated, including an examination (or rationale) of why a grounded approach fits this particular study.

Indicate whether analysis involved the use of any specific qualitative analysis software (if used).

We did not use qualitative analysis software.

“Each interview was analyzed separately by two individual researchers. Differences regarding emerging labels were discussed.”

Whilst differences were discussed, clarify how differences were resolved (eg third party?)
Initially, a third party was appointed (KS) to resolve differences when needed. However, discussing differences always lead to a solution without the need of a third party. We changed the sentence on page 13 to clarify this issue:

“Differences regarding emerging labels were discussed and resolved.”

“An inductive content analysis was performed in line with the grounded theory approach”

Putting aside debates about grounded theory and associated methodologies, there should be a distinction made between a grounded theory approach and grounded theory methodology. To what extent is GT appropriate for this study? Some rationale as to why this particular approach or methodology is appropriate (as distinct from other qualitative approaches) is needed.

In line with the reviewers comment, we clarified why we chose for Grounded Theory methodology by adding the following (p. 13):

“An inductive content analysis was performed in line with the grounded theory methodology [24]. Grounded theory is a systematic methodology for investigating personal experiences. This method involves the discovery of theory through the analysis of data, making it especially suitable for investigating perceptions and experiences without predefined hypotheses, in order to discover new insights or theories.”

Discretionary revisions

7. Clarification for why some of the questions were included would be useful

“What are parents’ (fathers and mothers, patients and partners) experiences with regard to their own depressive and anxiety disorders and their children’s vulnerability and resilience”

This is clearly a useful question, but given it sounds as though the dominant intent is to determine why parents don't participate in an RCT, it might be useful to add why this information is useful.

In line with the reviewer’s comment, we explained the importance of the first research question on page 7:

“It has been theorized that before investigating parents’ reasons for (not) participating in a study on offspring risk for anxiety and depression, parents’ perceptions of offspring risk and resilience, and whether parents’ link their own psychopathology and parenting style to offspring risk should be first investigated.”

8. The results could be restructured, combining some of the domains which contain overlapping themes

- Some of the quotes seem to overlap across sections such that they may be worth combining rather than separating them according to question. For example in examining the experience and impact of anxiety and depression (both personally and in parenting) quotes across specified categories show some overlap Eg #23 “I think their upbringing wasn’t really different, I mean, that’s what we aimed for at least, to be as neutral as possible. But well, of course they noticed something, probably, for sure they will have noticed more than they are aware of.”
#3 “The children have emotional antennae. If I had a bad day, they sensed that immediately.”
We found it important to make a distinction between the impact of parent psychopathology, and its impact on parenting, because these different impacts may have different implications for the focus of preventive activities. Therefore, we separated the two. In labeling the quotes, we found that the categories were distinguishable in a meaningful way. It appeared that parents who initially discussed their parenting style as neutral as the interview progressed realized that parent psychopathology on its own was noticed by offspring. Especially #23 shows this difference between impact of parenting and impact of psychopathology.

In line with the reviewers' comment, we changed paragraph 2 accordingly, and added:

“However, parents also realized that the impact of parenting and the impact of parent psychopathology on family QoL can be two different things:”

- It might be worth combining section 4 and 5 (Participation in a preventive randomized controlled trial and experiences and advice with regard to participating in randomized controlled.

We wanted to make a distinction between parents' ideas about participation before starting and their experiences when started. Note that the second group is just a subsample of parents who participated. We wanted to differentiate between perceptions and experiences. Therefore, we did not combine section 4 and 5. However, we agree with the reviewer that table 5 (reasons for participating), is more closely related to section 5 (about parental experiences), than table 6 (reasons for not participating). Therefore, we switched table 5 and 6, mentioning barriers to participation first, before focusing on participating parents.

9-10. Some of the theme labels could be re-considered to better reflect the content of the themes (in text and in tables)

Theme headings: Perhaps reconsider the wording of the themes, which seem to be more category descriptors rather than themes per se (the themes seem more clearly articulated in the discussion headings). For example, the theme “Focus on children in parental Treatment” might be misleading as it suggests that there was a focus on children, when in fact the opposite seems to be the case?

We agree with the reviewer and changed the theme “Focus on children in parental treatment” to “Lack of focus on children in parental treatment”.

Table 2: Theme headings, Eg Reasons for participating

Again these are more of a category descriptor, in this case defined by the research question. It might be worth re-considering the choice of labels used for themes, or perhaps provide some example of sub themes identified

In line with the reviewers' comment, we clarified the main themes of section 4 and 5 in table 2 by adding subthemes.

11-14. Some clarifications may be beneficial (eg improving interpretation of quotes, summarising of key themes identified in tables).

11: #9 “[Father] was saying like, ‘You don’t have any problems because of me’. But it was so obviously present, the elephant in the room.”
It might be worth clarifying the context for this quote as it is not immediately obvious that it is (presumably) a partner or how this relates to a “more negative atmosphere”

We agree with the reviewer’s comments. In line, we added more information in order to improve the interpretation of this citation, by adding the following sentence (page 17):

“A partner of a father with a depressive disorder remembered that in the acute phase of the disorder, her husband’s depression influenced the atmosphere at home.”

12: Communication about parental mental illness: To what extent are some of the quotes provided regarding some of this secrecy also about stigma and shame?

This paragraph is descriptive for parents’ problems with communicating with their children about their disorder. Reasons why parents find this difficult have both to do with stigma, shame, and an inability to describe their mental illness in age-appropriate terms.

In line with the reviewer’s comment, we therefore added the following information to paragraph 2:

“For some parents, having to talk to their children about their disorder was a reason not to participate (also see paragraph 4). Parents were ashamed and afraid of what their children might think when they would discuss the parent’s mental health problems.

#8 “I think I am secretly really afraid of that, of what she [daughter] might say.”

13: Parental perspectives on the need for professional help for their children: “While parents emphasized the advantage of also helping the children” - This does not seem to be suggested by the previous section, which was about the presumed lack of focus on children. Clarify?

We agree with the reviewer that this sentence is unclear. We meant that parents in general recognize the importance of prevention. Therefore, we changed the sentence (p. 24) to:

“While parents in general recognize the importance of prevention for offspring, a lot of parents found it difficult to articulate what kind of help they would want.”

14: Participation in a preventive randomized controlled trial: “Reasons for (not) participating in a prevention-focused study with your children are extensive.” - A general yet brief summary of key themes associated with decisions to participate or not participate should be specified rather than just stated in the table.

In line with the reviewer’s comment, we added the following summary of the key themes in paragraph 4 ‘Participation in screening and a preventive randomized controlled trial’.

“Parental overburden was an important reason for parents not to participate in preventive research with their children. Parents indicated not having the time nor the energy to participate. Factors related to parental overburden were parental symptoms, the need to end the ‘mental health care period’ in their life, the required time investment and paperwork associated with participating in an RCT, and the fact that participation was experienced as confronting.

Other reasons for parents not to participate were related to child burden. Parents wanted to protect the children from possible negative effects of participation, or found their children too young to
know about their parents’ illness, and to participate in research. Parents with children aged 8-12 discussed that they might participate in preventive research when the children are older. Parents reckoned that older children might be more aware of their own and others’ emotions, might be better able to talk about them, and might furthermore be better able to make their own decisions with regard to participation to research and intervention. However, in families with children aged 12 and older, an important reason for not participating was that these adolescents were not interested and refused to participate. Furthermore, stigma, shame and embarrassment about anxiety and depression or being in treatment were reasons for parents for not participating. Finally, some parents mentioned no worries about the children as a reason for not participating in screening and prevention.

---Table 5 about here---

Parents who acknowledged the need for prevention were motivated to participate in the study. Recognition of their own symptoms or disorder in their offspring, the need for support for themselves and their children, and prevention of child problems were reasons for parents to participate. Also, helping others by participating, and knowledge about scientific research were mentioned by parents as reasons for participating. Finally, some parents discussed participation with their children, and children themselves were interested and motivated to participate.

---Table 6 about here---“
Reviewer 2: Cathy Creswell

Reviewer's report:

Many thanks for inviting me to review this paper. It was well written, thoughtfully executed and I found the results very interesting and useful. I am not an expert in qualitative methods however this appears to have been conducted to a high standard- notable strengths include the inclusion of patient interviewers and validation, and the inclusion of multiple raters. The discussion provides useful reflection on implications for preventative efforts aimed at children at risk by virtue of parental psychopathology.

We are very grateful for the reviewer’s time and comprehensive feedback. We will address each point of the specific comments in detail below.

I have no recommendations for major revisions.

Minor revisions:

1. I was surprised that no further ethical permissions were required to conduct the qualitative interviews with participants, especially given that some of the participants had not consented to the prior RCT. It will be important to know that this decision was ratified by the ethical approval body.

As stated in the ethics statement on page 9, ethical approval was sought for the randomized controlled trial (Medical Ethics Committee of the University Medical Center Groningen, NTR2888). This committee approved of asking participants whether they wanted to participate in the RCT, and whether they were ok with being contacted in the future. Participants who consented to participation in the RCT and consented with being contacted in the future were asked to participate in the qualitative study. In order to include participants who refused to participate in the RCT, we also contacted people who refused to participate in the RCT but who did consent with future contact. Only these participants were additionally contacted and asked to participate in the qualitative study. In line with the reviewers comment, we therefore specified (p.9): “For the sub-study, we only contacted parents who had previously received information about the larger study, and who provided written consent to be contacted by phone or email. Furthermore, since the sub-study involved a one time one hour interview only, no additional ethics approval was sought.”

2. It is stated that schizophrenia or other psychotic disorder was an exclusion criteria for the trial- but one participant refers to their experience of psychosis. Can this be clarified?

The mother (#10) who referred to her psychosis was a partner of one of the patients asked to participate. We did ask about the partner’s psychopathology, and relied on information parents provided themselves. This mother stated she had been suffering from depression, and later on, in the interview mentioned a psychotic episode. We agree with the reviewer that since we are studying the effect of parental anxiety and depression, this citation is confusing.

Therefore, we deleted this citation and added another one:

“A mother described how her anxiety disorder influenced her parenting style and caused her to worry more about her daughter:

#17 “…in the beginning I took her with me everywhere. She wasn’t allowed to go anywhere alone, but now she’s older and she wants to be away from me more frequently… noooo, no way.”
3. It would be helpful to add some brief information on the nature of the intervention offered in the RCT, particularly as a central issue in parent's reluctance to participate was the inclusion of their children (so making the level of child/parent involvement clear from the start would be useful).

We agree that it would be helpful to add some information on the nature of the intervention. In the paragraph ‘selection of participants’, we added some brief information (see p. 10):

“The trial included a 10 session preventive behavioral training for children, with 2 individual parent sessions, aimed at preventing offspring anxiety and depression. The training focused on reducing risk and increasing resilience in offspring, including modules on (1) family functioning and social network, (2) being proud of strengths, (3) positive emotions and events, (4) problem solving, and (5) approach behavior and activation. The therapist addressed each of the modules in the first sessions and then elaborated on the most appropriate module(s) for each child.

Discretionary revisions

1. The fact that parents typically did express concerns about their offspring's mental health presumably reflects the fact that the families were selected on the basis of children having elevated symptoms. It might be helpful to acknowledge this, so it does not suggest that this concern is a general function of high levels of parental anxiety or depression.

Participants in the larger study (screening and RCT; Nauta et al., 2012, BMC Psychiatry) were first contacted based on parent psychopathology. They were asked for participation in screening and prevention as part of one informed consent procedure (as recommended by the ethics committee). As a first step, screening took place: offspring were screened for additional risk factors (such as elevated symptoms). Thus, all patients who were parents were asked to participate in the study regardless of child symptomatology. Offspring with additional risk factors then participated in the randomization for the preventive intervention. Therefore, patients who were asked to participate in the larger study of screening and preventive intervention did not automatically have offspring with elevated symptoms. Thanks to the reviewer’s comment, we realized that it is unclear that the larger prevention study consisted of both a screening for risk factors as well as a controlled trial. Thus, when we mentioned the RCT, we meant the whole study, including the screening. We made changes throughout our paper in order to clarify this:

In the background section, when discussing the RCT, we changed ‘RCT’ to ‘prevention study for offspring, consisting of a screening and a randomized controlled trial’ (p. 4). In the ethics statement, we changed ‘RCT’ to ‘prevention study, consisting of screening of offspring for additional risk factors and a randomized controlled trial’ (p. 9). On p. 10, selection of participants, we also changed randomized controlled prevention trial’ to ‘multicenter prevention study, aimed at preventing depressive and anxiety disorders in offspring of depressed and anxious parents, including a screening for high risk and a randomized controlled trial [13].’

In the rest of the document, we changed RCT to ‘prevention study’.

We hope that the present revision satisfactorily addresses the main concerns raised the reviewers and look forward to hearing from you,
With kind regards,
also on behalf of the coauthors.

Helma Festen