Author's response to reviews

Title: Exploring the views and experiences of callers to the PANDA Post and Antenatal Depression Association Australian National Perinatal Depression Helpline: a cross-sectional survey

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Author's response to reviews: see over
Dear Editor,

Re: Review of manuscript MS: 1442771365164291, titled ‘Exploring the views and experiences of callers to the PANDA Post and Antenatal Depression Association Australian National Perinatal Depression Helpline: a cross-sectional survey’

Thank you to both the reviewers for their time and constructive feedback. Please find below a point by point response to the reviewers’ comments.

Reviewer: Gill Thomson

Major Compulsory Revisions

1. Abstract:
Thematic headings should be included in the results section.

The global theme is now included in the results in the abstract.

The conclusion also reads as a re-iteration of some key findings rather than a conclusion to the study? This section should be revised to include practice implications/recommendations.

The conclusion has been revised, and now reads:
‘Callers reported positive experiences of accessing support from the PANDA National Perinatal Depression Helpline. The Helpline was described as an accessible and acceptable telephone support for individuals experiencing perinatal mental illness. The findings of the study will be useful in informing future service provision, review, and implementation.’

2. Background:

a. Paragraph starting on line 77 (p. 3) feels to be out of context, and does not tell us much in terms of what is effective? This section requires further information and should be appropriately integrated in this section (e.g. to substantiate barriers and facilitators information?).

This section of the background has been revised to improve clarity and flow.

b. Cindy-Lee Dennis’ (2003) definition of peer support from her concept analysis would be more appropriate to include (page 4, line 101 onwards).

Cindy-Lee Dennis’s definition has now been included (page 5, line 94-98).

c. Further details regarding the PANDA service should be provided, e.g. what is the recruitment criteria for volunteers (particularly as it appears that ‘having a mental illness’ does not appear to be
a shared characteristic for all?), length/content of training for volunteers, are the counsellors trained professionals, how does the service operate, i.e. do volunteers take the initial call and then decisions are made about who will call them back, i.e. volunteer, counsellor etc.? How many volunteers/counsellors are employed/work in the service?

Further detail regarding the above points has been added to the background section (page 7-8, line 136-168), and a new figure (Figure 1) has been developed to improve clarity.

d. An overview of the ‘whole study’ should be included (i.e. page 7, line 172-174)

A brief overview of the whole evaluation has now been added (page 8, line 173-179).

3. Method:
   a. Further details on the recruitment into the evaluation should be included, i.e. were all callers asked whether they would like to participate in evaluation by the volunteers (e.g. at the end of the call), or did you just approach ‘anyone’ who called in this timeframe?

   New detail has been added to this section which hopefully improves the clarity of the processes we utilised (page 9, line 190-197).

b. Was a detailed information sheet provided to the participants? Please include/make reference to such.

   The following sentence has been added to the data collection section (page 10, line 212-216):
   
   ‘A detailed letter was sent with the invitation explaining the purpose of the study. The letter explained that all responses would remain anonymous, that they would be sent directly to the research team, and a decision not to participate or any responses provided would not impact on any current or future contact with the Helpline.’

c. Were the reminders issued to everyone, or just targeted to non-responders (in which case it is difficult to claim that researchers ‘were not aware of the client’s identity’ (p. 8, line 201). Further clarification is required.

   The following section has been revised to address the above request (page 10, line 216-220):
   
   ‘Callers were sent two reminders using the same method (either email or postal) that they had initially been contacted with, one two weeks after the initial contact and the second two weeks after the first reminder. As all responses were anonymous it was not possible to send reminders to only those who had not completed the survey, and therefore a note was included thanking those who had already responded for their time.’

d. Additional details on the survey questions should be included.

   Additional details regarding the survey questions have been included (page 9-10, line 199-207):

   ‘The survey was adapted from a previous survey of PANDA callers conducted as part of a Master’s study in 2012 [32]. The adapted survey was piloted with experienced maternity clinicians and perinatal researchers who reviewed the survey for content, flow, face and
content validity. The survey consisted of 23 questions, and included a range of closed and open-ended questions, as well as a number of statements with Likert-type scale response options, i.e.: ‘strongly agree’, ‘agree’, ‘neither’, ‘disagree’ or ‘strongly disagree’. Demographic questions were also included. The questions explored how callers had heard of PANDA, number of contacts, overall experiences with the Helpline, call content, views regarding organisational features, referrals to other support services, and suggestions for changes to the Helpline.’

4. Results:
   a. While the thematic network model works very well, with clear interpretive themes generated, it is usual to describe the ‘global theme’ first and making it explicit how the organising themes network/inter-link together. I would suggest that the presentation of this information is re-organised.

   The presentation of this information has been reorganised and the global theme is now presented first (page 14, from line 313).

   b. While overall the blend of interpretations and quotes is well done, there are occasions where multiple quotes that reflect the same points are included, e.g. p. 16 (line 383-387), p. 18 (line 411-419), p. 18. Checks to prevent against unnecessary repetition of quote material should be undertaken.

   This section has been revised and two quotes removed to reduce repetition:

   Page 16, line 383-384 (original manuscript) quote removed

   Page 18, line 411-412 (original manuscript) quote removed

   c. p. 17, line 391-394. This sentence seems to suggest that it was after all the analysis had been undertaken (although this then lends the question as to which approach was used?), it was decided to just apply Attride-Stirling’s thematic network analysis model – rather than using this approach from the offset? This requires revision.

   This section has been reworded to improve clarity and now reads (page 14, line 314-317):

   ‘During early data analysis it became clear that there were commonalities between answers to both questions, which led to the decision to present the analyses as a thematic network; recognising the overall picture the two analyses were able to create whilst keeping the two sides of the network, each originating from responses to different questions separate.’

5. Tables: ‘Missing data’ should be made more explicit across the tables (i.e. tables 1 & 2) as it unclear as to why totals do not add up to 124?

   The number of callers who answered each question is provided in each line of the tables. In order to make this clearer, the following statement has been added to the methods section (page 11, line 239-241):

   ‘Some respondents did not answer every question within the survey, and so for some questions the denominator changes. This has been made explicit within tables with each question presented with its own denominator.’
Why is the number after the variable not the same as the n value (Table 4)?

The following footnote has been added to the bottom of Table 4 to improve clarity (page 32):

‘These questions could be answered as ‘yes’ or ‘no’. The n provided above is the number of respondents who answered the question, and the n and % in the columns indicates the number and percentage who answered ‘yes’.

Minor Essential Revisions
1. As Attride-Stirling’s model is referred to as ‘thematic network analysis’ – this terminology should be used throughout in order to differentiate it from a general ‘thematic analysis’ method.

This has been amended throughout, except one instance directly under the heading ‘Exploring what callers had gained from their contact with PANDA’ (page 14) in order to avoid repetition of the word ‘network’.

2. Information on classification of risk (p. 7) would be better presented in table format – this will make it easier to follow and will prevent against repetition in the text.

   Thank you for this suggestion - please see new Figure 1.

3. It is unclear as to why the recommendation regarding increased availability of the helpline service is the only one that is emphasised in this paper (i.e. conclusion), when actually all are valid/important to consider?

   While there were a variety of recommendations for service change, by far the strongest recommendation made by survey respondents was for increased hours of availability.

   The conclusion has been re-worded to slightly change the emphasis on this recommendation (page 23, line 524-528):

   ‘Respondents emphasised the accessibility, acceptability and value of the telephone service, and made recommendations for changes to the service including increases in hours of operation to enable greater responsiveness at times of need, reduced waiting times, and access to continuity with the same volunteer and/or telephone counsellor.’

4. Can numerical information on callers’ classification of risk be included in the results section (albeit that this won’t apply for those living outside of Victoria)?

   Unfortunately this information is not available as we do not know the identity of the respondents and therefore do not know what level of ‘needs’ they were assessed as having.

5. p.13, line 317 reads as if it also relates to the significance/benefits of anonymity in using a helpline service?

   We agree with the reviewer’s comments that for this woman anonymity was an important feature of the service. This quote has been used to demonstrate the development of the basic theme ‘phone service accessible and acceptable’. Many callers commented on how acceptable and accessible the service was, although what made it this way was different for different callers. For this woman, anonymity was an important feature. For other callers it
may have been that they did not need to make an appointment to access support or that they did not need to leave the house and therefore feel a pressure to look ‘presentable’ and ‘together’. We have included the below description of the theme to better reflect this (page 15, line 341-343):

‘Callers emphasised the increased accessibility and acceptability of the telephone service, describing it as easy, relaxed and not rushed, anonymous, and available and responsive at the time of need, as it was not appointment based’

6. p. 13, line 319, some interpretation of the quote material should be incorporated into this sentence.

This sentence has now been revised to (page 16, line 350-351):

‘Callers made some explicit comments regarding how PANDA was different to other specific services they had accessed, describing less positive experiences with these services:’

7. p. 14, line 328-329 – why are words being underlined within the quote?

This woman returned her survey in the post and had underlined these words herself. We have kept the underlined words so as not to lose this emphasis, and have highlighted this within the text as follows (page 16, line 361-362):

‘(woman’s own emphasis - Participant 129 – 34 year old woman, called regarding self)’

8. p. 14, line 335-338 – the sub-themes should be re-ordered so they match how they are presented in the text and it should read as ‘parenting advice/support’ not ‘practical advice/support’ in this section.

The subthemes have been reordered to reflect the way they are discussed in the text (page 16-17, line 367-370).

Thank you for identifying this typo – it has been corrected.

9. Discussion: Further limitations relate to those who actually use the helpline service, i.e. older, generally well educated, and most within high SES bracket, etc.

The following section has been added to the strengths and limitations section to address the above comments (page 22-23, line 506-513):

‘The callers who access the PANDA Helpline are mostly female, older, and generally have a high level of education and income. While this is not representative of the general birthing population within Australia, or of those who experience perinatal mental illness, it was the aim of this study to explore the experiences of those accessing the Helpline and our sample reflected these characteristics.’

Discretionary Revisions:
1. While overall this is a well written paper, there are a few occasions of unnecessary repetition, e.g. p. 3, line 81 onwards, long sentences, p. 21 (line 479-482) and unusual terms, e.g. ‘response fraction’. A final/thorough proof read should be undertaken to address such issues.

We have made a number of edits to the paper (as detailed above). We have also deleted the term ‘response fraction’.
Reviewer: Dawn Kingston

Please consider the following revisions:

Abstract:

-one sentence on the survey would be beneficial e.g., if survey was developed for this study that would be a useful detail e.g., Developed for this study, the survey comprised xx questions using Likert-type scales to collect information about demographics, satisfaction and usability of the service. Thematic analysis was undertaken for responses to open-ended questions.

We have edited the methods section in the abstract:

‘Methods: A cross-sectional survey design was used. All new callers from 1st May to 30th September 2013 were invited to participate. The survey included 23 questions using Likert-type scales, demographic and open-ended questions. Thematic network analysis was undertaken for responses to open-ended questions.’

Line 69 – should perhaps be just ‘a recent overview …’ (versus of meta-analysis). This review was more of an overview but not a ‘systematic’ review of recent meta-analyses. Would reduce confusion that that paper was a systematic review of existing meta-analyses

This sentence has been removed as part of our revision process.

Overall – the background section could be tighter. For example, lines 69-76 (although important information) do not seem directly related to the research question, and form a bit of a tangent. Not sure this section is needed (detracts from the flow of argument you are making) Similarly, lines 77-80 seem out of place and lines 81 through 97 make unique points, but unlinked to the research questions. So – overall, please make the background tighter in terms of creating a flow of information that supports and leads to the overall purpose of the paper

The background section has been revised to address the above comments (page 4-5, line 63-90).

The discussion of interventions reads more like a separate literature review – unlinked to the purpose of the paper. I suggest tying in the peer support evidence more to the PANDA Post and Antenatal Dep Association discussion.

Based on comments from both reviewers, the background section has been revised. We think the overall flow has improved and is hopefully satisfactory to both reviewers.

In the section describing PANDA – Please describe where the PANDA helpline is advertised e.g., how do women access it/learn about it, how widely advertised it is

The following information has been added to address the above comments (page 7, line 136-139):

‘Callers hear of the PANDA Helpline through different pathways, including midwives and other maternity care providers, general practitioners, maternal and child health nurses, the PANDA website, and word of mouth from friends and family.’
-what was the rationale for survey completion 4-8 weeks post-contact, versus right after contact?

The following section has been adapted to make the rationale for this more explicit (page 9, line 190-197):

‘All new callers to PANDA, from 1st May to 30th September 2013 were invited to participate in the survey four to eight weeks after their initial contact. Callers’ contact details, such as an email or postal address, were obtained by PANDA staff and/or volunteers during their first call as part of ‘usual care’ on the Helpline. Callers were contacted four to eight weeks after the initial contact as it was anticipated that most would no longer be in contact with PANDA and that the timeframe was recent enough for accurate recall. Sample size calculations were not performed as the survey was part of a larger service evaluation and was designed and timed to maximise the number of possible participants while also meeting the time constraints of the overall evaluation.’

-what was the expertise of colleagues who reviewed the survey?

The methods section has been revised and now reads (page 9, 199-201):

‘The survey was adapted from a previous survey of PANDA callers conducted as part of a Master’s study in 2012 [32]. The adapted survey was piloted with experienced maternity clinicians and perinatal researchers who reviewed the survey for content, flow, face and content validity.’

-how were survey reminders delivered?

To make this process clearer this section now reads (page 10, line 209-220):

‘Surveys were sent to all new callers within the study period by email if PANDA had email details or by hard copy with a reply paid envelope if only a postal address was available. The surveys were sent by PANDA and received by the research team; therefore, the research team had no knowledge of the caller’s identity, and the PANDA staff had no access to callers’ responses. A detailed letter was sent with the invitation explaining the purpose of the study. The letter explained that all responses would remain anonymous, that they would be sent directly to the research team, and a decision not to participate or any responses provided would not impact any current or future contact with the Helpline. Callers were sent two reminders using the same method (either email or postal) that they had initially been contacted with, one two weeks after the initial contact and the second two weeks after the first reminder. As all responses were anonymous it was not possible to send reminders to only those who had not completed the survey, and therefore in that case a note was included thanking those who had already responded for their time. Return of the survey was taken as consent to participate.’
-what measures were taken to reduce data entry error of hard copy surveys?

The following has been added to the analysis section of the paper (page 10, line 224-225):

‘Data were entered at the time of the evaluation by a member of the research team, and checked by LB. No errors were identified. Data cleaning included range and logic checks.’

-what % of data were missing?

Different questions had different rates of missing data, however the denominator is made clear for all questions reported (denominators can be found within the tables).

-details of survey structure needed e.g., broadly, what topics did the survey cover, total # questions in the survey

This section now reads (page 9-10, line 201-207):

‘The survey consisted of 23 questions, and included a range of closed and open-ended questions, as well as a number of statements with Likert-type scale response options, i.e.: ‘strongly agree’, ‘agree’, ‘neither’, ‘disagree’ or ‘strongly disagree’. Demographic questions were also included. The questions explored how callers had heard of the PANDA service, the number of contacts they had with the service, their overall experiences with the Helpline, call content, their views regarding the importance of organisational features, referrals to other support services and the outcomes of these, and if callers had any suggestions for changes to the Helpline.’

-hoW does the response rate of 30% compare to previous PANDA survey? Please describe under strengths and limitations.

To address the above comments this section (page 23, line 514-518) now reads;

‘The response to the survey was similar to the survey of callers to the PANDA Helpline in 2012, which was 32% [32]. However, this is somewhat lower than earlier surveys of new mothers in Victoria [44] and is reflective of a widespread reduction in responses in population-based studies noted in the literature [45]. The response from this population could be expected to be lower than in other studies considering those contacting PANDA are likely to be experiencing distress.’

-how do the demographics of this group compare to the general demographics of women delivering in Victoria?

The following section has been added to the strengths and limitations section (page 22, line 496-505):

‘The representativeness of the survey sample was assessed by comparing routinely collected demographic data on all new callers over the previous ten-month period (January-October 2013). Survey respondents were generally representative of all new callers to the Helpline January - October 2013; mostly female (91%), married (78%), between the ages of 30-40 (70%), and from the state of Victoria (53%) [31]. Due to the way perinatal statistics are
reported in Australia, the only demographic characteristic that could be used to compare our sample directly with the whole population of birthing women in Australia is mean age with callers to PANDA older than the overall population (mean age 32.4 versus 30.1) [40]. Marital status data were only available for the state of Victoria. Women in our sample more likely to be married (78.1% versus 69.1%) than the overall childbearing population in Victoria in 2011 [41].

-just as a matter of interest, please report response rates also by mode of delivery e.g., email vs hard copy

This was documented in the results section as follows (page 11, line 250-251):

‘Thus, there was potential for 405 surveys to be completed and of these 124 responses were received, 24 hard copy and 100 via the online survey; a response of 30%.’

-please explain line 484 – what is meant by ‘reflective of a widespread reduction in responses in population-based surveys’

There has been discussion in the literature regarding the widespread reduction in responses received in population-based surveys in recent time. This sentence has been amended to now read (page 23, line 514-518):

‘The response to the survey was similar to the survey of callers to the PANDA Helpline in 2012, which was 32% [32]. However, this is somewhat lower than earlier surveys of new mothers in Victoria [44] and is reflective of a widespread reduction in responses in population-based studies noted in the literature [45].’

-please add to the discussion a few points on differences between % of callers seeking help on postnatal vs antenatal mental health (e.g., 45% vs 14%)

The following has been added to the discussion (page 20-21, line 454-464):

‘Overall, callers reported very positive experiences of their contact with the PANDA National Perinatal Depression Helpline. The majority of callers reported feeling better emotionally after speaking with someone from PANDA. Respondents had initiated contact with PANDA for support, information, and reassurance, with over one third of callers seeking crisis help and support. The reasons callers had initiated contact with the Helpline align well with the focus of the organisation as a telephone Helpline offering information, support and referral services. The large difference between the number of respondents seeking information for postnatal depression and anxiety (44%) compared to antenatal depression and anxiety (14%) might in part be explained by the greater clinical and research focus on perinatal mental illness in the postpartum period compared with pregnancy [37], or PANDA’s origins as an organisation focusing on supporting women experiencing postnatal depression.’

-how do the findings match with PANDA's service vision e.g., it seems that most callers contacted for support, reassurance, and information. Was this the original design for PANDA?

The following sentence has been added to the discussion (page 20, line 457-459):
‘The reasons callers had initiated contact with the Helpline align well with the focus of the organisation as a telephone Helpline offering information, support and referral services.’

Are there areas of PANDA’s service delivery model that are recommended based on the reasons for contact identified?

We asked a number of questions about PANDA’s service delivery, including hours of operation, and access to continuity of staff and/or volunteer (Table 5). We have reported that data and based our recommendations about the service delivery model based on these results. We have not made any amendments to the paper regarding this, but would be happy to if the reviewer would like.

- Re number calls made to PANDA, I think it would be beneficial in Table 3 to identify the n/% of callers who called a single time. — therefore perhaps dividing the data into 1 call, 2 calls, 3-4, >=5

This table has been amended to demonstrate this information (page 31).

- please add footnote to table 1 re remaining 20 women e.g., sample size 124, 104 accounted for in this table

The following statement is included in the analysis section of the methods to address this (page 10-11, line 227-230):

‘Some survey questions were not asked if a respondent indicated that they had contacted the Helpline for someone other than themselves, such as a partner or family member. As a result some data presented are for respondents who called for themselves only; this is made explicit within tables as ‘called regarding self’ or ‘called regarding partner/other’.’

Table 1 lists specific (n=) values for each question, indicating the number who answered the question, and lists only those who called regarding themselves or a partner.

-were any data collected re follow-up e.g., if PANDA representative recommended a referral or resource, did the caller follow up? If so – please include in findings.

We have added the following sentence (page 12, line 263-265):

‘Eighty-six (76%) callers reported that PANDA suggested they contact other support services, and of those 74 (88%) reported that they were able to access these services.’

- Under authors’ information...missing surnames?

Surnames have been added.