Author’s response to reviews

Title: Explicit and implicit information needs of people with depression: A qualitative investigation of problems reported on an online depression support forum

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Author’s response to reviews:

Reviewer 1 Report

A. Major compulsory revisions

1. Title and methods: Are we absolutely sure that only ‘people with depression’ participated in the online depression support forum? Or could also relatives of people with depression access and participate in this forum? If the latter is the case, the title should be revised to ‘explicit and implicit information needs of users of an online depression support forum’. Currently, the methods sections contains too less information on the BlueBoard forum to judge who is using this forum.

   Although people without personal experience of depression (e.g. carers, friends) could participate in the forum, the current analysis did not include their comments. The authors have added information to the Methods (Analysis) Section to clarify this query.

2. Abstract and manuscript: What do the authors mean by ‘consumers’? The whole population or a population with depression? The authors should clearly define what they mean with ‘consumers’ and use the word accordingly throughout the manuscript. E.g.: background section of abstract: ‘Consumer knowledge about depression is particularly important because depression is highly prevalent and causes substantial disability and burden.’ This sentence makes sense if this is about the general population … if you are a patient, it does not matter if your disease is highly prevalent or not.

   The authors have defined the meaning of consumers within the introduction and amended the specified sentence within the abstract.

3. Background: third paragraph: add a reference for this definition of explicit and implicit information-seeking.

   The terms explicit and implicit information-seeking were derived by the authors following review of literature and have not previously been defined in this way.
The introduction section containing these terms has been re-written to clarify this.

4. Methods: data collection: add more background information about the BlueBoard as this is essential to put the data source into context. Is this a forum hosted by academia or hospital or? Who is moderating? What happens in case of reports of serious problems? Free access? Access only for patients or also for relatives? How can people get to know about this forum? What is the aim of the forum? How is it organized?

Additional material addressing these queries has been added in the methods section.

5. Methods: sampling: please add a figure on sampling of data. The way the numbers are presented and the relationship between the different numbers is unclear. If one is trying to make sums, they do not match. Please, start with the total number of posts, then differentiate for each of the three forums used and provide exact numbers for each forum in each year. Explain how the final number of 335 (or is it 334?) has been reached. A forum ‘members only’ has been used, this means that not all users of the forum can access that part – why is that? What is the definition of a post? Is this one message posted on the forum or is it a treat of messages peer-to-peer on the same topic? Please clarify on how the number of ‘an adequate sample of 3000 posts’ has been defined. Clarify also the sampling procedure more in detail as well as the selection criteria used. Have posts been selected randomly or??? More information is needed on the procedure used for the selection of the posts.

In order to clarify the data sampling, the section within the methods section has been rewritten more clearly and with additional information.

Although brevity in the manuscript was needed, the following provides greater detail for the Reviewer’s information: The Members Only forum was created at the suggestion of regular participants who requested a closed forum where communication (possibly of a more personal nature) could take place only between people who had some familiarity with each other.

6. Methods: analysis: last sentence: has analysis been validated by coding by a second researcher? If not, please acknowledge for this in the limitations and explain why this was not done.

One researcher conducted the data analysis, although the data was discussed with a 2nd researcher (as now specified in the manuscript). The current study chose this method in accordance with conclusions by qualitative experts that inter-rater assessment of qualitative data does not guarantee reliability or validity, and that a methodologically rigorous approach (used by a single interpreter) will result in an accurate reflection of the phenomenon. This explanation has been inserted in the Methods section. Nonetheless, in acknowledgement that some readers may have continuing reservations, this aspect of the methodology has also been included in the limitations section.

7. Results: sample: a summarizing sentence would be helpful: ‘N posts contained
N questions by N patients/users’. ‘Personal experience’: what is meant by this: suffering from depression yourself or being a relative of such a person? Please be specific (see also comment A.1).

As suggested, a summary sentence has been added to the results section. The meaning of ‘personal experience’ has now been clarified (refer to the analysis section).

8. Results: sample: does this mean that no demographic data at all is available? The authors state ‘there was evidence that participants …‘: is this evidence based on the content of the transcripts of the posts? If yes, how was this assessed (being from a rural area or not)? Please provide more information on this. Acknowledge for this in the limitations of the discussion section.

Provision of demographic data was not prerequisite to participation in the online bulletin. However - as the reviewer suggests – the post transcripts provided evidence of some participants’ gender, age and place of residence. This has now been clarified within the manuscript (Results section) and included within the limitations section.

9. Results: themes: it would be useful to have more differentiated information if there were differences available between explicit and implicit information-seeking. If not, please state as such.

The authors agree with the reviewer’s point, however, it was not possible to further differentiate the two forms of information-seeking. Acknowledgement of this point has now been added at the beginning of the Discussion.

10. Results: themes: please add numbers of patients systematically for all paragraphs as it is done in most of them, but not in all of them. Please, be consistent in the way of reporting the results.

Due to the nature of qualitative research it is considered desirable to minimise the focus on quantitative elements in the current manuscript. Counts were listed only in order to demonstrate that a theme or sub-theme was recurrent or to enable numerical comparisons (i.e. the table). In order to avoid apparent inconsistencies in reporting, some numbers have been amended in the results section and an explanation provided.

11. Results: themes: page 16: quote. Please add some context specific information on Australia about costs and reimbursements of treatment for depression in the discussion section to enable the reader to put these results in context. Is the Australian situation much different from other countries.

Participant reports indicated that some participants lived overseas (as reported under Sample characteristics). As implied by the reviewer, treatment costs are likely to vary depending on where participants live, and generalisability is limited. Consequently, the authors did not consider it appropriate to discuss the cost of treatment/out of pocket expenses in Australia specifically, or to make a very brief (and inadequate) attempt to cover the issue at a worldwide level.
12. Discussion: themes: in every paragraph, the authors conclude that more information is needed as well as strategies and ideas. The authors should add more specific data on what kind of information is needed, search for literature to add information of effective strategies. The results presented in this manuscript are – if you are working with this group of patients – not very surprising. It would add value to the manuscript if the authors could refer the reader to more specific suggestions and strategies (and adding references on these) for implementation in daily practice. What should health care professionals do to provide the necessary information to their patients?

The authors have added some material to the discussion on specific strategies. However, describing the specific strategies is beyond the stated goal and scope of the current manuscript, and it is not possible to do this consistently and coherently due to the extent and range of the problems and the detail required. Furthermore, there are also existing inadequacies in the current body of knowledge on how to resolve the problems of depression that necessarily limit the capacity to specify evidence-based strategies.

13. Discussion: add references when referring to diagnostic criteria (page 23 – which ones DSM?), sleep difficulties (first sentence) and negative impact of insomnia on motivation.

References have been added in relation to the points on diagnostic criteria and sleep difficulties. However, there was no assertion that insomnia impacted on motivation; rather, the wording - which stated “As with lowered motivation, insomnia can negatively impact on level of functioning …” - meant that sleep difficulties can affect level of functioning, just as motivation can affect functioning. Nonetheless, this section has been reworded to clarify the issue.

14. Discussion: last paragraph of page 24. I doubt if provision of information will be sufficient here? Addressing stigma (public and personal stigma) should be done as well … and it is know that providing information is not efficient in the long term to change stigma. Please, rework this paragraph accordingly. More complex strategies might be needed.

The authors agree with the reviewer that more complex strategies are needed to address stigma. Further discussion has been added to address this point.

15. Discussion: mode of information delivery: be more specific on the kind and the format of information needed? Which other health care professionals can contribute? Psychologist, pharmacist, nurse …? Treatment of depression requires a multidisciplinary approach – it is recommended to address roles to other health care professionals beside the GP.

The reviewer makes a good point and material has been added to the discussion of the manuscript that addresses this.

16. Discussion: limitations: add some more limitations from a methodological point of view: no demographic data, data analysis performed by one person,
inclusion of patients or relatives, … Regarding the last sentence: I agree but other strategies might be needed to address the information need for people not using the internet.

Additional limitations have been acknowledged and text added to address the additional point.

17. Conclusion: last sentence: not only the general community but also health care professionals might benefit from more information.

This point has been added in the discussion.

B. Minor essential revisions

1. Abstract: results: how many questions/needs were identified within this sample of 134 participants?

This material has been added to both sections.


The findings of the specified study have now been included. Because the specified study investigated a particular and restricted area of information need (medication) rather than being a broader exploratory study (as were the other studies in the introduction), the findings of Zwaenepoel et al. have been incorporated in the Discussion section.

3. Background: second paragraph: Online message boards. The authors should elaborate more on the differences between and diversity in available forums/boards. Some of them have a more commercial background whilst others are professionally supported from a medical point of view. This diversity should be acknowledged and explained in more detail.

The reviewer is correct that differences exist between online forums/boards. In the current paper, however, the focus of the research is on the types of information needed rather than the sources for obtaining such information. Consequently, in the background section the authors wish only to point out the broad options for seeking information and do not see it is appropriate here to delve into the finer details of the possible sources.


The meaning of asynchronous has been clarified in the methods section.

5. Results: sample: it would be helpful to have a frequency table to have an idea on the numbers of questions asked by the patients (are most of them asking 1
question; or the majority has 3 of them?). This information might be an additional indication for the information need.

Considering the fact that all of the questions were asked by separate participants except for one instance (i.e. one participant asked two questions), the suggested information has been added in the text (as opposed to a table) (refer to p 7). This pattern indicates that directly asking others for information is a tendency observed in approximately one-third of participants and therefore does not only reflect the information-seeking behaviour of a select few. This point has now been included in the manuscript.

6. Results: themes: page 10: ‘board rules precluded explicit reporting of suicidal thoughts and self-harm actions’. Please, explain more on how this preclusion is working (can be added to methods section).

The board rules have been further explained in the Methods section.

7. Results: themes: page 14: add a footnote explaining abbreviations ‘SAM4 and ‘SJW’. What are the active compounds of these products?

Please see response to 8 below.


In accordance with typical APA formatting guidelines, a Glossary has been added to the manuscript to explain these abbreviations.

9. Results: themes: disclosure and stigma: Were there any patients reporting being afraid of disclosing their depression but did do it and received understanding of their surroundings? It would be stigmatizing to report only negative experiences.

Although it is possible that people may overcome their fears and receive positive responses from others, there were no observed reports of such in the current data.

10. Results: themes: comorbid: last sentence. Be specific about ‘other health issues’ … which ones?

The text has been amended.

11. Discussion: first paragraph: ‘consistent with findings from other studies’: add the type of patients and the setting of these other studies.

The two other studies were also investigations of online mutual help groups, and similarly, either no - or very restricted - demographic information was available. However, the setting has now been described in the manuscript.

12. Discussion: page 25: information and medicines: information is also a very important element in achieving compliance in a population with depression. Please, add this to the discussion.
Mention of the important role of information in medication adherence has been added to the discussion.

13. Discussion: mode of information delivery: page 27: second paragraph: ‘consumers involved in development’ … I agree but also in the evaluation of information. For medicine information, a tool – the Consumer Information Rating Form (I. Krass – Patient Education and Counseling) – is already available. Please refer to this kind of tools.

Consumer involvement in evaluation of information has now been added.

C. Discretionary revisions
1. Avoid the use of words like ‘we’ (background of abstract) and ‘it is not surprising’ (several times in discussion section).

These suggestions have been addressed by making changes to the manuscript.

2. Background: second paragraph: additional reference for ‘help seeking behavior’ can be added: see for references in PubMed on the ESEMeD study.

Papers on the suggested study have been examined and included in the manuscript.

3. Avoid the use of the words ‘evident’ and ‘apparent’ in the manuscript as they are rather strong words. Suggestion: replace by ‘observed’, ‘present’, …

These words have been substituted for the majority of instances.

4. Table 1: add to caption: ‘The number of mentions …’

This suggestion has been incorporated.

Reviewer 2 report

MINOR REVISIONS
1. The paper describes a qualitative analysis of posts to three related internet for depression. The data used is a little old (2004-2006) and I think the authors should at least comment on this (is it likely to affect their findings? – e.g. has the way people interact with the web changed? Have the people who use the web changed?)

A description of changes in web interaction over the last 6 years would be a useful addition to the manuscript. Unfortunately, a search of existing literature did not reveal sufficient evidence to enable considered comments, therefore the age of the data is now noted as a limitation within the manuscript.

2. The background section is good but I am aware of a couple of papers which are not cited which the authors may want to have a look at and include:
• In a qualitative interview study of 33 inpatients with bipolar affective disorder, Pollack identified six conceptual areas of information need, concerning: (1) self management of the disorder; (2) understanding the disorder; (3) managing daily life; (4) living in society; (5) relating to others; and (6) relating to self. [Pollack LE. Informational needs of patients hospitalized for bipolar disorder. Psychiatric Services 1995; 46: 1191-4.]

• In a small retrospective analysis of case-notes, Llewellyn-Jones et al. investigated the questions psychiatric outpatients asked at the end of consultations. Of course, this will be influenced by the quality of the preceding interaction. The authors found that most questions asked by this population (who tend to have chronic conditions) related to medication issues - about stopping, reducing or side effects. [Llewellyn-Jones S, Jones G, Donnelly P. Questions patients ask psychiatrists. Psychiatric Bulletin 2001; 25: 21-24.]

• I’m also aware of a (as then) unpublished North American doctoral dissertation which describes the design of a website for people with depression. This may now have been published. As part of this study the author asked visitors to the website to complete an online questionnaire concerning the information they were seeking. This was therefore a self-selected sample of Internet users, who were already seeking information from a website, asked to identify the topics of most interest to them. The results show that among all respondents, the topics of greatest interest were: ‘causes of depression’; ‘recent research on depression’; and ‘helping yourself if/when you are depressed’. The topics of greatest interest to the subgroup of people who were seeking information about themselves were ‘helping yourself if/when you are depressed’; ‘feelings of hopelessness/helplessness’; and ‘causes of depression’. [Price P. Needs assessment of those who seek information about clinical depression via the Internet. Dissertation Abstracts International: Section B: The Sciences and Engineering 2002; 62: 4800.]

Given the findings of these three (admittedly small) studies, the authors may want to mention them in their discussion of the present study’s findings.

The authors appreciate the reviewer’s suggestions. One of the works (the Dissertation) could not be obtained at an affordable cost but the other papers have been examined and are now included within the manuscript.

3. Within the methods section I would like a little more detail on the inductive approach. Did the authors (for example) use well recognised techniques such as constant comparison, or seeking out deviant cases? Both can be useful in testing out emergent categories/themes.

Considering the goals of the current study and nature of the data, analysis involved using an approach analogous to grounded theory. This has now been included in the Methods section.

Some consideration was given in the current analysis to the existence of deviant
cases but neither it nor constant comparison was employed specifically to the extent that would warrant being described in the methodology.

4. Did only one researcher read the data and identify themes? Did other researchers read some or all of the data? Was there any discussion to agree themes, refine ideas, resolve disagreements etc?

Further explanation has now been added to the manuscript to address this query. Please refer to the response to Reviewer 1, point 6.

5. Results section states that all contributors had personal experience of depression. I would like clarity on two points – does ‘personal experience’ mean they had depression? (or does it mean either they or e.g. a family member had depression?). Also, did all contributors have ‘personal experience’ as the authors excluded other contributions from the sample, or because this is what their consecutive sample contained? Incidentally, for clarity I would suggest adding the word ‘consecutive’ to the ‘Sampling’ paragraph page 6 (“A consecutive sample”).

In response to this query material has been added in the Methodology (Analysis) section. Please refer to the response to Reviewer 1. The definition applied means that the sampling was not consecutive.

6. Results section says “there was evidence..” about sex and age variability. What was this evidence? (Just needs more explanation).

Please refer to response to Point 8 Reviewer 1. Greater explanation has now been provided in the manuscript (p7).

7. A total of 134 participants is stated – is it possible that there were individuals with multiple logins? Where steps taken to reduce chance of this? It is a general issue with internet research (and internet identity more generally) – it is not a criticism of this paper but the authors may wish to comment.

An explanation addressing this query has been inserted in the Methods section.

8. On page 27 the authors cite Powell & Clarke (Health Expectations 2006) in relation to the need to hear other people’s experience. I would also suggest looking at what this paper says about people undertaking their own research (which I think the present study shows); and what it says about the different aspects of other people’s experience. I only mention these because I think the data in the present study is consistent and I think the authors could say more about the (implicit) need that their participants have for seeking out lay (peer) opinions online.

Thank you for this suggestion (and also for that made below). The authors have
made additional comments in the discussion with reference to the specified papers.


Additional material has been added as suggested.

MAJOR REVISIONS
These relate to the findings and discussion

1. The theme 'coping with depression' was the least satisfactory for me. It felt confused between a description of symptoms that patients were reporting (and seeking help for) – e.g. lack of motivation, sleep problems, etc. – and an attempt to examine why people were seeking help. I think this section could be rewritten to be more focussed on the underlying information need than on a more descriptive account of the problems people described. What seemed important to me was the need to understand how other's cope, and to ask for help from peers. That is what came through the extracts as I read them. E.g. page 12 “I would like to hear about…”. Or on page 11 someone asking “why is it I feel so alone and scared..?”. For me this qualitative piece of research should aim to get at some of the underlying motivation – why are people going online to ask these questions from anonymous peers? What do the questions they ask tell us about their motivations (beyond simply describing the problems they have)?

The reviewer makes an interesting point and additional material has now been included in the discussion (Mode of Information Delivery section) that focuses on the underlying motivations for seeking information in this online context. Because the goal of the current manuscript was to determine the areas in which people need information and a consistent approach is required, the authors believe that the Themes section should remain focused on the types of problems people report experiencing.

2. Page 13 quote under medication “could someone offer me an opinion please?” – why is this person seeking a lay opinion? What need is this addressing – is it a lack of information on depression medication, or actually are they seeking something they cannot find from traditional/formal sources – i.e. specifically a lay opinion from a fellow service user. Likewise on page 14 the person asks about side effects. But why have they chosen to do so on a discussion forum rather than just use Google or similar? Could the need here be for peer information as distinct from professional? Do they want a lay view on side effects – i.e. what others have experienced? Page 15 on professional services, again what I find intriguing is the seeking of a lay opinion, in this case after the author has already asked their family and psychiatrist.
It is interesting and of importance that some people seek a lay opinion rather than or in addition to the use of other resources, and the authors have now commented further on this in the discussion.

3. Understand depression theme – seems to be mainly about cause and diagnosis – just wonder if ‘theme’ could be narrowed to these areas? Was there sufficient on other aspects?

As the reviewer points out, the ‘Understanding depression’ theme is primarily about cause and diagnosis; and this fact has now been stated in the Results section. Nonetheless, this theme also contains other subthemes that the authors consider important (i.e. recognition of depression initially, recognition or acknowledgement of the need for treatment, and the concept of recovery). Manuscript word restrictions mean these facets cannot be further developed, however, they are still considered of interest and value, and the authors believe that removing this material from the results section and narrowing the theme would result in a loss of useful information.

4. I didn’t think ‘comorbid health problems’ really fitted as a theme. Might be better as a mention in the discussion? There just didn’t really seem to be much analysis in this theme which was more a descriptive list.

Although comorbid health problems may relate less directly to depression, it was considered appropriate to view them as a theme because of their relationships with depression and the expected futility of trying to address depression in the absence of dealing with these other conditions. However, it is true that minimal analysis was presented for this theme. Consequently the results section relating to this theme has been modified and material added to illustrate its relevance.

5. In the discussion section page 23, second paragraph. The authors discuss addressing motivation and enjoyment issues, and they acknowledge that this is about addressing the illness. I think there needs to be clarity between information to inform (empower, support choice, feel less alone etc.), and psychoeducation/bibliotherapy type information aimed at treatment (authors mention increasing motivation and boosting pleasure). Perhaps this distinction needs to be made in the introduction?

The authors are unsure exactly what the reviewer is requesting but have added comments in the discussion about providing supportive information that assists the person experiencing problems and information that directly relates to treating depressive symptoms.