Author's response to reviews

Title: Barriers and facilitators to primary care for people with mental health and/or substance use issues: A qualitative study

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Version: 3  
Date: 4 September 2015

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September 4, 2015

Re: Manuscript 1368061671729028 - Barriers and facilitators to primary care for people with mental health and/or substance use issues: A qualitative study

Dear Dr. Burton,

Thank you very much for the opportunity to revise this manuscript for possible publication in BMC Family Practice. We appreciate the thoughtful reviewer comments, and are committed to improving our manuscript to the high calibre appropriate for publication in your journal.

We have carefully considered all of the suggestions provided by both reviewers, and offer the following responses:

Reviewer 1

The methods were somewhat limited in that all the patients and providers were self-selected for participation and both groups were given financial incentives to participate.

We now note as a limitation that patients were self-selected (see lines 621-4). As described in lines 139-41, service provider participants were not self-selected, but were purposively selected for expertise on the topic. Providing honoraria to acknowledge participants’ time and contributions is standard practice in our setting. Further, our Research Ethics Board evaluates the proposed amount of honoraria to ensure that it is appropriate and will not act as an undue incentive to participate. As such, we do not consider the participant honoraria to be a
limitation of our study.

1. Methods page 4 line 59 – define “family health team” and the providers this consists of.

We now include a definition of family health team appropriate to the local context of the study. Because this phrase already appeared within a bracket, we have included this definition as an endnote.

2. Methods page 4 line 65 – state the organization and city associated with “Center for Addiction and Mental Health.” Is this affiliated with an academic organization?

As described in lines 124-5, the Centre for Addiction and Mental Health is a tertiary care hospital fully affiliated with the University of Toronto, Canada.

3. Results – the results could be more clearly indicating by listing the themes derived from the coded transcripts in a table.

In this version of the manuscript, we have not added a table of themes, only because this would directly duplicate the material summarized in Figure 1. However, we are happy to add a table or to replace the Figure with a table at the Editor’s discretion.

4. There is no reference indicated for reference #19. Also references #20 and 21 are missing.

Our apologies for this oversight. The entire reference list has been reviewed and corrected as necessary.

5. Discussion – collaborative care models between mental health and primary care have been extensively reported and there are systematic reviews and metaanalyses published, the authors should site some of these recent reviews.

Some of the key citations on this topic have now been added (see lines 644-58).

Reviewer 2

Definitions are unclear and the language used for each construct varies throughout the paper. For example, is a mental health “issue” the same as a mental health disorder? How is this defined?

We have clarified our definition for the term mental health issue, as well as provided a rationale for the use of this term over others, in lines 100-21. Specifically, this section reads: In this study, we used the language “mental health and/or substance use issues” in reference to conditions associated with mental health, the use of substances, or the combination of the two that have impacted an individual’s quality of life. We used this language in contrast to language such as “psychiatric disorder” or “addiction” at the request of our community partners, in order to a) respect individuals as the authorities to define for themselves whether their mental health/substance use is problematic or requires intervention, b) acknowledge the harm that has sometimes been done to individuals and communities through the application of diagnostic labels, and c) be inclusive of factors situated outside of the individual (e.g., discrimination, poverty) that often coexist with and have significant impacts on individuals’
mental wellbeing and/or use of substances. In this paper, we use other language only where necessary to be consistent with the authors of the original studies cited.

Next, in some cases the authors seem to over-interpret quotations and draw conclusions that may or may not be associated with the intent or spirit of the quotation. We have addressed each of the situations of concern to the reviewer, either by softening our interpretation or by providing additional quotations to support our interpretation. Our response for each individual concern is detailed below.

Further, I think the organization of the results could be improved and perhaps should be presented with subheadings within each type of factor (Client, Provider, Health System) that matches those in theoretical model (Figure 1). We appreciate this suggestion for reorganization and have revised the Results section as suggested.

In addition, it would be useful to know how the authors determined which concepts would become themes and about how many client or provider quotations supported each theme.

We now provide more information about the analytical process in lines 192-7. We have not provided information about the number of quotations associated with each theme, as that approach would be inconsistent with the qualitative methodology of the study (for discussion of this issue, please refer to Pyett, P.M. (2003). Validation of qualitative research in the “real world”. Qualitative Health Research, 13(8), 1170-1179.

Finally, although I am a strong advocate of qualitative research and its utility in informing policy and intervention, I think the authors have perhaps understated the limitations and overstated the implications of the study. We have addressed the specific limitations and implications of concern to the reviewer, as noted in detail below.

Major Compulsory Revisions
1. Lines 48-50: “However, minimal research …” Surely there has been some research on barriers and facilitators to access primary care for people with mental health (and possibly substance use) disorders that can be cited here. Even a quick internet search yields a number of publications. And, if there is a dearth of literature, the few studies that have examined this should be cited and the larger literature on barriers and facilitators to primary care (in general) also should be cited. (I see there is one cited in the discussion section, but I believe there is more than one study on this important topic.) We have now expanded our literature review to include the most relevant recent studies; please refer to lines 48-83.

2. Lines 161-163: “In addition to finding and maintaining a family physician who was willing to follow an unstably housed patient …” The previous quotation is used to support he statement that many clients experience unstable housing and do not have a fixed address. This line implies that the quotation supports the idea
that clients have difficulty finding a physician who was willing to follow them.
While I’m sure there is great difficulty following patients who are unstably housed
(and, I suppose some providers might not even be willing to try), neither this
quotation nor any of the others provided, supports this concept.
The wording has been revised to be more specific, as follows: Both clients and
service providers perceived that it was challenging to find and maintain a family
physician in the context of unstable housing. Further, an additional quote has
been added to support this finding: “I think it’s hard anyway to get a family doctor,
so it’s even harder to get a primary care provider if you don’t have a phone, if you
don’t have a number where they can reach you. If you’re very transient. If you’re
not living in one place.” (Whitney, nurse practitioner) (see lines 250-5).

3. Lines 163-164: “These practical barriers also determined the extent to which
clients considered primary care to be a priority relative to more acute issues ...”
This statement is problematic for two reasons. First, it seems to over-interpret the
quotation. Although “practical issues” may have been commonly cited by clients
and providers as a barrier to care, the study does not examine the extent to
which clients considered primary care to be a priority. Next, the statement
attempts to interpret client sentiment from a provider quotation. Just because
providers perceive that basic needs that must be met does not mean that clients
do not consider their health care to be a priority.

We have revised the wording to avoid making the presumption that clients did not
consider their primary health care to be a priority (specifically: These practical
barriers determined the extent to which clients were able to make their primary
care a priority relative to more acute issues such as housing and food security).
However, the finding that clients often could not make their health care a priority
was supported by many quotations from both clients and service providers; for
brevity we had included only one service provider quotation. We have now added
an additional quotation from a client participant, describing an example of a time
he was unable to follow through with recommended testing due to financial
barriers: “I tried even to get blood tests or something... they go, ‘What? You don’t
have a health card so you’re gonna have to pay cash for it.’ So then never mind,
‘See you later’ and then I leave.” (James, age 53, has a regular provider) (see
lines 267-77).

4. Line 450: This states that the sample is diverse and includes individuals with
substance use issues, but the results section indicates that the study only
included patients with mental health issues. Either the results section needs to
state that individuals with substance use disorders were included in the study (if
they were) or the focus on people with substance use disorders needs to be
dropped.
The proportion of participants reporting a substance use issue is now reported in
the text in lines 221-3, as well as in Table 1.

5. Lines 451-460. It is a given that findings from a qualitative study with a
convenience sample is not going to be transferrable or generalizable. Thus, a
discussion of lack of generalizability because of the sample being from an urban
area of Canada is not necessary. More appropriate would be to remind the
reader that the results are not generalizable because of the sampling method, selection bias, the exploratory nature of the questions, etc..

We have added a sentence to remind the reader that a qualitative study is not intended to generalize to a broad population (As a qualitative study, our findings are not intended to be generalizable to the broad population of individuals living with mental health/substance use issues, lines 605-7). However, we disagree with the reviewer that it is not relevant to consider the transferability of our findings to other research contexts. Many consider attention to this to be an important consideration in the assessment of qualitative research studies (see for example Roller & Lavrakas (2015) Applied Qualitative Research Design: A Total Quality Framework Approach. New York: Guildford Press). As such we have retained the section regarding transferability but ensured that this is differentiated from the concept of generalizability through the use of more precise wording.

6. Line 464: I am concerned about concluding that primary care providers lacked knowledge about mental health and/or substance abuse when only 2 physicians participated in the study and no quotations to this effect by any providers were included or discussed.

This statement has been reworded to be clear that this refers to the perceptions of participants in this study (see line 326). Also, we have added an additional service provider quotation in support of this point (“If somebody has a mental health issue, if somebody just has schizophrenia, people are frightened. People don’t know enough about it. They don’t have enough education – they feel like it would be too complicated to manage.” (Whitney, nurse practitioner), lines 333-5).

7. Line 471: “… results of this study point to the value of interdisciplinary models of primary health care.” Although I personally believe that these models have value, I don’t know that this study alone actually points to their value. At most, the study suggests that lack of this type of care might be a barrier to access to and quality of care and that further research may be warranted.

This section has been reworded to more clearly reflect the findings of our study (lines 640-44).

8. Line 494: “This study has elucidated some of the mechanisms for disparities in morbidity and mortality …” I think it would be more accurate to say that the study has identified barriers and facilitators to access to primary care for people with mental health and substance use disorders. Eventually, reducing these barriers could facilitate access to care which could, in turn, increase healthcare and ultimately improve morbidity and mortality. I think the sentence as it is presented is an overstatement.

The wording has been revised as suggested (line 679).

9. Line 498: “The results support the greater availability of collaborative models…” I think this also is an overstatement. More accurate would be something like “the results support further testing of collaborative models of care for this population …”

This sentence has been edited as suggested (line 684-5).

Minor Essential Revisions
10. Line 26: “Mental health and/or substance use issues.” These should be defined. Any disorder? Severe mental illness? Substance abuse or dependence? Addiction?

We now define this, and explain the rationale for the use of this language, in lines 100-21 (and as described above).

11. Line 36: This sentence begins with a statement about treatment rates for mental illnesses but not substance use disorders but then notes the unmet need for substance use problems as well. Are substance use problems being considered a mental illness? If not, the beginning of the sentence should also mention substance use disorders/problems/issues (whatever term the authors decide on).

This wording has been revised for consistency (However, treatment rates for these conditions are low around the world, see line 37).

12. Line 40: An example is provided for the under-screening of people with mental health issues. Is there also evidence of under-screening and under-treatment of those with substance use disorders?

We now cite additional literature pertaining to substance use issues in this section; please see line 42.

13. Lines 45-46: “…quality of primary care …” I believe these studies refer to access as well as quality of primary care.

This text has now been revised accordingly (Yet, individuals with mental health and/or substance use issues report poorer access to and lower quality of the primary care received relative to those without, line 47).

14. Lines 47-48: This is a strong statement. Is there a citation to support it?

This statement was deleted in the process of revising the Introduction to enhance the literature review.

15. Lines 69-70: How was “serious mental health and/or substance use issue” defined for eligibility purposes?

Additional information about this eligibility criterion is now provided in lines 128-33. Specifically, we used self-identification to determine eligibility, and if potential participants asked for clarification regarding this criterion, they were provided with the following definition: “We are looking for people whose mental health and/or substance use issues have impacted their quality of life, although they may have experienced periods of recovery or well-being. Participants may have been diagnosed with a psychiatric condition and/or an addiction, although this is not a requirement.”

16. Lines 82-83: “…field-tested with members of the research team who identified with the participant groups.” It is not clear to me what this means.

This has been clarified in lines 147-8, (i.e., research team members who were themselves service users or providers).

17. Line 98: An explanation of the “modified grounded theory approach” would be helpful.
Additional detail about both grounded theory analysis and our modification of it are now provided in lines 164-81.

18. Line 104: “In keeping with the community-based participatory action approach ...” This approach also should be explained.

More information about the community-based participatory action approach is now provided where first mentioned in lines 91-4.

19. Line 118: Was an inter-rater reliability statistic calculated when the independently coded transcripts were compared? If not, why not?

No, inter-rater reliability statistics were not calculated in this study. Again, this would not be consistent with the grounded theory approach applied in our research. The purpose of multiple coders in this study was not to ensure that both coders found identical patterns in the data, as would be the idea behind an inter-rater reliability statistic. Rather, our methodological approach presumes that each analyst will bring a different lens to the data as a result of their differing experience and expertise related to the research topic. Divergence in initial coding is therefore valued in this approach, as it reflects a richer and more complex analysis of the data.

20. The Analysis section should include some mention of the criteria for a concept being included in the paper as a theme.

More detail regarding the theme identification process is now included in lines 192-7.

21. Lines 138-139: “... and self-identified as having a depressive, anxiety or psychotic disorder.” You state earlier that the clients had either a mental health or substance use disorder. Were there none with a substance use disorder? If so, this is important to point out earlier when describing your sample (e.g., in the abstract, in the methods section).

As noted above, information about substance use issues in this sample has now been added in lines 221-3 and in Table 1.

22. Lines 208, 216, 222, 232: The authors refer to “participants” where elsewhere they are more careful to distinguish between client and provider participants. Was it both types? Just clients? This distinction should be made throughout the paper.

This distinction has now been made explicit throughout.

Discretionary revisions

23. Line 10: “Practical” is vague. I think the authors are referring here logistical barriers? Something more descriptive than “practical” would be preferable.

We have changed this category to “Socioeconomic” barriers which we feel more accurately reflects the findings in this section.

24. The authors may wish to consider adding subheadings to the Results/Discussion section that correspond to the main themes in the theoretical model. For example, under client-level factors, include “practical (or logistical) barriers” and “mental health experiences and side effects.” Also, as you do in the
“Provider-Level Factors” section, I would start each section with a brief overview of the primary themes you found.

The Results section has been reorganized as recommended.

25. Line 388: Models of care. The way I read this section, it seems to me like the barrier is the lack of collaborative, interdisciplinary care, not the more general “models of care.” The authors may wish to change the way they describe this barrier.

This subheading has been revised as recommended (line 541).

We hope that these revisions have addressed the Reviewers’ concerns to your satisfaction, and improved the quality of our paper. We welcome feedback about any additional revisions that are required prior to publication.

Thanks once again for your consideration of this manuscript.

Yours sincerely,

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