Author’s response to reviews

Title: Patient and Provider experience and perspectives of a risk-based approach to multidisciplinary chronic kidney disease care: a mixed methods study

Authors:

Michelle Smekal (msmekal@ucalgary.ca)
Helen Tam-Tham (tamh@ucalgary.ca)
Juli Finlay (jlfinlay@ucalgary.ca)
Maoliosa Donald (donaldm@ucalgary.ca)
Chandra Thomas (Chandra.Thomas@albertahealthservices.ca)
Robert Weaver (rgweaver@ucalgary.ca)
Robert Quinn (rob.quinn@albertahealthservices.ca)
Kin Tam (kin.tam@ahs.ca)
Braden Manns (Braden.Manns@albertahealthservices.ca)
Marcello Tonelli (cello@ucalgary.ca)
Aminu Bello (aminu1@ualberta.ca)
Navdeep Tangri (ntangri@sogh.mb.ca)
Brenda Hemmelgarn (Brenda.Hemmelgarn@albertahealthservices.ca)

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Author’s response to reviews:

January 10, 2019

To: Dr. Tariq Shafi
Associate Editor, BMC Nephrology
Re: Re-submission of manuscript (BNEP-D-18-00744)

Dear Dr. Shafi,

Thank you for the opportunity to respond to the constructive comments made by the reviewers on our manuscript submitted to BMC Nephrology. Please find enclosed the revised manuscript entitled, “Patient and Provider experience and perspectives of a risk-based approach to multidisciplinary chronic kidney disease care: a mixed methods study”. Details of the point-by-point responses made to the reviewers’ comments appear below. Changes made to the manuscript are in quotations below. The corresponding tracked changes are included in the re-submitted manuscript. We believe the changes have improved the manuscript and hope that you agree that it is now suitable for publication.

Sincerely,

Michelle Smekal and Brenda Hemmelgarn
(for the co-authors)
Reviewer reports:

Jennifer E. Flythe, MD, MPH (Reviewer 1):

Major Comments

1. The authors report using a directed content analysis. In the Hsiu source cited, in a directed approach, "analysis starts with a theory or relevant research findings as guidance for initial codes." The authors note that they did not apply a theory to guide analysis. What relevant research findings did they use?

Thank you for highlighting the need for further explanation regarding our directed content analysis approach. We utilized our pre-implementation findings (Smekal et al 2018) to focus post-implementation data collection and analysis, and have summarized the pre- and post-implementation coding relationships/category summaries in the supplementary material (Appendix 5). As our goal was to provide a follow-up to the perceived and anticipated benefits and challenges previously expressed by participants in our pre-implementation qualitative study, the current study provides a descriptive account of post-implementation experiences and perceptions specifically. We apologize for the lack of clarity in our original submission, and have expanded on this in the methods section (page 8) to clarify our approach:

"Based on findings from the pre-implementation qualitative study [13], we applied a directed content analysis [17] approach to focus the interview guides, identify relationships between the pre- and post-implementation code definitions and to qualitatively describe [18] participant perspectives; we did not apply a theory to guide analysis. We also asked open-ended questions to identify new content categories and extend our conceptual framework relating to the benefits and challenges of a risk-based approach to multidisciplinary CKD care [17]."
2. The identified themes are more topical than descriptive. Would suggest revisiting the titles of the themes and making them more descriptive. For example, "transition process for low-risk patients" is a topic, not a theme. Often, but not always, themes begin with gerunds to impart more feeling/description. In their current form, the themes are labels with different perspectives provided underneath. They are not coherent themes that cross-cut the interviewees.

We agree with the reviewer that the descriptions are more topical, with less detail and feeling than typically included within themes. The descriptions that we have used however are reflective of the qualitative content summarizing our results. Upon further reflection we realize that these in fact are not themes, as they are not a meaningful essence that runs through the data as the reviewer has noted, but are in fact more consistent with categories. In qualitative research categories are defined as a collection of similar data, enabling researchers to identify and describe the characteristics within that category. This in fact was our objective. Therefore, we have changed the terminology throughout from “theme” to “category”. We thank the reviewer for bringing this to our attention, and note that the confusion between categories and themes has also been documented in the literature (Morse 2008). We have made the relevant changes throughout the documents.

3. The combined analysis of patient and provider perspectives is a little challenging to interpret. The authors note that, within some themes, they make comparisons between patients and providers, suggesting (and as seen in the quotation data provided) that there are differences between provider and patient perspectives. Thus, how can they be combined under a singular theme? The differing perspective relate to the "topic" but a "topic" is not the same thing as a theme. Did patients and providers contribute equally to each theme? That is not likely, and in the case of job satisfaction, the theme (or topic) is not applicable to patients. Is this the case for any of the other topics/themes?
Similar to our pre-implementation qualitative study, we collected and aggregated data concurrently with a goal of describing the overarching experiences and perceptions following implementation of the risk-based approach to care. Similar to our pre-implementation findings, we have been careful to highlight areas of agreement/disagreement between and within participant groups in the results. We reported perspectives using terms such as “most patients” or “a few nurses” to indicate relative proportions. Further, we have included an expanded table of quotes in the supplementary material (Appendix 4) that indicates the role of each participant (patient, family member, nurse etc) to further support our findings. We are confident that the included categories were sufficiently described by both patient and provider participant groups, with the exception of Job Satisfaction and Anticipated Concerns, which we have now amended to indicate that these only apply to Providers. We also acknowledge that there were a greater number of provider participants and have included this important limitation in the discussion, page 18:

We acknowledge that the qualitative component of this study included a larger number of healthcare providers than patients; however, data saturation was achieved in both groups despite differences in sample size.

4. "Access to resources outside of the CKD clinic" - The text in this section suggests that all felt like they had enough resources but quotations reveal that one provider was not referring eligible patients back to routine care out of concern for inadequate monitoring. This is not acknowledged in the text.

Thank you, we have edited the text on page 12 to reflect this:

"A few providers expressed concern about access to preventive education and adequate monitoring outside of the multidisciplinary clinic; one provider in particular indicated they were reluctant to discharge low-risk patients because they were not ‘confident’ that the ‘right amount of supervision and care’ would be provided. However, several providers reported there were many resources in the community, such as primary care networks and nutrition classes/resources. Some providers suggested that the perception of inadequate monitoring in the community might be due to a lack of ‘respect’ toward primary care in general."
5. "Anticipated concerns": This topic appears to apply only to providers as it is noted that patients did not express concerns about progression. Again, question as a theme if not applicable to both patients and providers. Also, I do not understand the choice of the term "anticipated."

Thank you, as noted in response #3 above we have clarified our results to indicate that two themes, Anticipated Concerns and Job Satisfaction, apply only to providers. We have also brief definitions for each category in the results section.

Since our pre-implementation findings revealed patient and provider concerns about discharge of low-risk patients from the multidisciplinary clinic, this was an important content area to extend and clarify post-implementation. We chose the term “anticipated” because these are perceived concerns about future potential problems that patients may experience and not descriptions of problems that have occurred since the risk-based approach was implemented. Long-term follow-up is a component of the next phase of our research program, including evaluation of patient outcomes following discharge from the multidisciplinary clinic.

6. "Reduce patient stress"- Some of the quotations reflect providers' perceptions of patient attitudes. Did patients, themselves, express reduced stress or did this predominantly come from provider perceptions of patient stress? The latter is weaker.

The reviewer raises an important point – upon reflection we believe “Patient Reassurance and Reduced Stress” is a more appropriate descriptor for this category. A number of patients interviewed expressed feelings of reassurance after finding out that their risk of kidney failure was low and some were relieved that they no longer needed to attend as many appointments (Supplemental Material, Appendix 4). Providers also indicated that they felt that many patients felt reassured and relieved and were happy they did not need to attend as many appointments. We have changed this category in the relevant places throughout the materials.

7. All but 1 of the patient interview participants had been in CKD clinic > 5 years. It seems plausible that patients in CKD clinic for less time may not have been as confident when transitioned back to routine care or might have had different experiences. Lack of inclusion of more patients earlier in their CKD clinic experience prior to discharge to routine care is a weakness- findings may not be transferable to patients with lesser CKD clinic experience.
We agree and have added this to the limitation section on page 18:

"Most of the patients who participated in the interviews had been exposed to multidisciplinary care for >5 years prior to discharge and may be inherently more proactive, which may have impacted our findings relating to self-efficacy and may limit transferability of these findings to patients with lesser multidisciplinary clinic experience."

8. Could the authors provide descriptive statistics on the length of the interviews?

We have added the interview duration to the methods section, page 7:

"Patient and provider interviews were approximately 20 minutes."

9. What was the survey response rate among patients? Among providers? Essential to report this.

We have included the survey response rate for providers on page 15:

"Of the 75 healthcare providers, 40 (53%) completed the workplace satisfaction survey in the pre-implementation phase and 33 (44%) in the post-implementation phase."

We are unable to provide a response rate for patients, as we did not capture the exact number of surveys that were distributed to patients or picked up and completed in the clinic waiting area. The multidisciplinary clinics see approximately 260 non-dialysis patients face-to-face/month and we collected surveys for 3 months pre- and post-implementation. Therefore, our estimated response rate is approximately 23% (176/780) in the pre-implementation phase and approximately 30% (237/780) in the post-implementation phase. Given that this is an estimate only rather than a precise response rate we have not included it in the manuscript, but rather have listed it as a study limitation on page 18:

"The pre- and post-implementation surveys were anonymous, so it was not possible to determine if participants completed both surveys to pair survey responses, or to determine the response rates."
10. The lack of linkage at the respondent level is a major limitation of the survey. This is acknowledged in the discussion but it also needs to be clear in the methods. It makes the results very difficult to interpret as we do not know if the pre and post responses come from the same patients. This is a major limitation.

We appreciate the reviewer’s comments; we were unfortunately not able to link respondent surveys pre- and post-implementation (patient surveys were available in the clinic waiting area and we elected to keep provider surveys anonymous to hopefully encourage participation and more reflective responses). If we had been able to identify patients then we could have taken the pairing into account in the analysis. However, by assuming the two samples were independent, representing different groups of patients, our analysis was likely conservative. That is, had we been able to pair the small number of patients who may have responded to both surveys, the standard errors for the estimates of the pre-post changes would likely have been smaller, which would have increased the statistical significance of the results.

Per the reviewer’s suggestion, in addition to acknowledging this limitation in the discussion section, we have included a sentence in the methods section (page 9) noting the anonymous nature of the survey, which did not allow us to link pre and post responses:

"The patient and provider surveys were collected anonymously and therefore it was not possible to link pre- and post-implementation survey responses."

This also highlights the importance of employing a mixed methods approach to address our research questions.

11. In the discussion the authors note that patients did not perceive a substantial impact to their care. This is not entirely true as some patients continued to call their prior case managers after being discharged back to routine care- suggesting incomplete confidence in their new level of care.

While some nurses noted that patients were still calling them post-discharge, many of these patients were calling to retrieve their lab results (in Alberta, patients do not yet have access to their laboratory results (though this will be changing soon) and must call or visit a healthcare practitioner to obtain their results). We are not able to speculate whether patients were calling due to incomplete confidence in their new level of care. Although we have included the nurses’ perceptions in our results, this is an important consideration and we will explore this in greater detail in the next phase of this work.
In the conclusion, the authors note that patients and providers reported that this approach "improved sustainability". Were interviewees directly asked about sustainability? How was sustainability defined? Did patients really refer to sustainability? Does this conclusion accurately reflect the collected data?

We thank the reviewer for pointing this out. Sustainability is a concept/category that was coded within the “Targeted care” category. We have added additional detail regarding this category to be more descriptive (from the Supplementary Material, Appendix 5) in the results section on page 11 to clarify:

"Targeted care: This category includes reference to personalized medicine, targeting care based on individual needs, ensuring patients are seen in the most appropriate setting, and sustainability of the risk-based model of care."

We also moved an additional patient quote, discussing conservation of resources and allowing the clinic to focus on patients with greater need, from the supplementary material (Supplementary Material, Appendix 4) to the illustrative quotes (Table 3) to strengthen the patient-participant contribution to this content category:

"Patient: We have been discussing the issue for six months or once a year for awhile and I assumed when they gave me the letter saying that I was now below the 5% threshold for likely dialysis in the next two years and would not be using the clinic facilities completely but simply meeting with [nephrologist] that would probably would go to the one year [appointment] and when we talked about it this February we decided that would be frequent enough and he is available if something happens. If nothing happens then he can spend the time looking after those who still have more need than I do. It was included in the letter that said that due to this grading, I would no longer make use of the kidney clinic service, but only the nephrologist.

Interviewer: and what did you think of that letter?

Patient: I thought it was very appropriate. We need to conserve our resources and use them where they are needed and I think at this point in time, that was something I didn’t need, so I know there’s always more people, there’s more demand than we can meet."
Minor Comments

13. Abstract should name location of this study.
Thank you, we have added the study location to the abstract.

14. What kind of education was provided to patients about KFRE?
Targeted education was not provided to patients. Some providers may have discussed the KFRE with their patients, but there was no explicit education requirement.

Manisha Jhamb (Reviewer 2):

1. Please provide some additional background for the MDC clinics –
   a. how many patients are seen annually? After the KFRE implementation - how many patients were affected/discharged.

These are important statistics. We don’t have this data currently, but data collection is underway for the quantitative phase of analysis (phase 3).

   b. Once patients are discharged, do all of them go to a new nephrologist or have the option of staying with the nephrologist associated with multi-disciplinary clinic?
Thank you for pointing this out, patients discharged from multidisciplinary care to general nephrology remain with their nephrologist. We have clarified this in the study setting section on page 6:

"Patients at higher risk of kidney failure (2-year KFRE ≥10% or eGFR ≤15 ml/min/1.73m2) were recommended to receive multidisciplinary care, including a nurse case manager, dietitian, pharmacist, and social worker, while lower-risk patients (2-year KFRE <10%) were recommended to receive care from general nephrology (remaining under the care of their primary nephrologist with referral-based access to allied health professionals, but without a nurse case manager)."

2. For qualitative interviews,
   a. Please elaborate on the rationale why only the low risk patients were interviewed?

We have reorganized and expanded on the methods (page 6) to further clarify our rationale:

"Our pre-implementation findings [13] revealed both patient and provider concerns relating to care experience and quality for lower risk patients who would be risk-stratified out of the multidisciplinary clinic, or considered ineligible, following KFRE implementation. Consequently, our study focuses on the perspectives and experiences of low-risk multidisciplinary clinic patients who were discharged from multidisciplinary care following KFRE implementation and explores satisfaction of these low-risk patients as well as satisfaction of higher-risk patients who remain in, or were referred to, the multidisciplinary clinic during the study timeframe."

b. At the time of interview, what was their average duration since discharge from the clinic (i.e. did they have enough time to experience CKD care outside of the clinic)?
We conducted the interviews one-year following implementation, therefore, participants had been discharged from multidisciplinary care within the previous 12 months. Long-term follow-up is a component of the next phase of our research program, including evaluation of patient outcomes following discharge from the multidisciplinary clinic. We have addressed this limitation in the discussion section on page 18:

"Moreover, interviewed patients had been discharged from multidisciplinary care within the previous 12 months, following implementation of the risk-based approach, and therefore their described experiences and perceptions are reflective of this limited period."

3. What was the consent rate –
   a. how many pts/providers were eligible for interview?

We have expanded the results (page 10) to include consent rate specifics:

"Of the 23 eligible patients approached by clinic nurses to obtain consent for contact by the research team, 13 consented to be contacted and 10 refused. Of the 13 patients contacted by the research team, nine provided consent and participated in a telephone interview; one family member self-referred and participated in a telephone interview (Table 1)."

and

"Of the 75 healthcare providers eligible for an interview, 17 responded to the email invitation and participated in an interview (Table 2)."

b. Were there any pre-specified strata for patient/provider selection to ensure adequate representation of subgroups - such as age of patients, or years in profession/in ckd clinic for providers - heterogeneity in responses from such subgroups may be important to interpret and generalize the results
No, we did not selectively sample with pre-specified strata. We achieved heterogeneity with respect to gender for both patients and providers, and professional role. The average age of CKD patients at the multidisciplinary clinics tends to be older, in general.

4. Inclusion of family member - I would recommend to remove this participant from analysis as 1 family member's opinions are not going to be representative

We recognize the concern raised by the reviewer, however our strong preference is to include the responses from the family member. As this study is qualitative-descriptive, the family member’s voice is considered equally important. Given the importance of family members in the care of patients with CKD their views and input are important considerations.

5. How long were the phone interviews?

Please see Reviewer #1, question 8, above.

6. For the surveys - what was the response rate? How many patients were low vs high risk in post implementation phase? These factors may cause significant selection bias

For survey response rate, please see response to reviewer #1, question 9.

We were not able to collect the KFR of survey respondents to determine high- vs. low-risk (this was not feasible as only a very small number of multidisciplinary clinic patients might know their KFR value and be able to accurately report this on the survey). We included a question regarding eGFR level, to hopefully collect a self-reported indicator of kidney function (not risk), but many patients did not answer this question, presumably they did not know their eGFR.
References
