Author’s response to reviews

Title: Identifying and Addressing Gaps in the Implementation of a Community Care Team for Care of Patients with Multiple Chronic Conditions

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Author’s response to reviews:

Thank you for the opportunity to revise our manuscript, and for the very helpful comments from the reviewers. We have significantly changed the bulk of the manuscript with significant attention to the methods, which were noted by all reviewers as needing attention. Our detailed response to all reviewer comments is included below.

Nancy Byl (Reviewer 1): General Comments

Comment 1: I was impressed with the number of concerns raised on the first review and the authors were given an opportunity to respond. It is still a concern about whether this is a research report or a descriptive report on administering a CCT program. In the end, it is not clear that something novel was created.

Response: Thank you for your critique. With your comments and that of the other reviewers, we have significantly expanded upon the writing and clarified what we believe was unclear. We hope you find the new version of the manuscript more clearly describes the research process and the novelty of the implementation support that was created as a result.

Comment 2: There are a lot of editorial changes still needed in this amended version. Initial pilot study information and results need to be in the past tense. There are many long, long sentences. Many of these should be two sentences. There are plural verbs that should not be plural.

Response: Thank you for pointing these inconsistencies out. We have edited the introduction to separate longer sentences into two, have reviewed past-tense verbs. There is one paragraph regarding CCT process that remains in present tense verbiage, but we have clearly indicated why at the beginning of the paragraph.
“Briefly, we have summarized the way the program worked during its research evaluation phase and continues to work as it continues to operate in clinical practice. Patients appropriate for the CCT program are adults with chronic health conditions who are overwhelmed. Typically, their struggles are both burden of illness and treatment, and they have been identified as unable to carry out their self-management in full. A care coordinator, social worker, public health nurse, or other primary care clinician can identify eligible patients. After enrollment, a member of the CCT meets patients in their home for a comprehensive assessment of their health and living environment. Then, the CCT holds an initial group meeting with the patient and their support persons at their primary healthcare clinic. During this meeting, the CCT focuses on patient strengths to leverage them to improve self-care and on identifying patient and family priority concerns. Based on the strengths and concerns assessed, the CCT creates with the patient and their support person(s) a shared action plan to address their priority concerns. The action plan includes concrete tasks, delegates each task to a member of the CCT, the patient, or their caregiver, sets up a timeline for completion and follow-up, and indicates the expected results. Additional deliverables of the CCT meeting include a Crisis Prevention Plan and a Circle of Support. The Crisis Prevention Plan indicates patient-identified changes signaling a difficult day and the way they will obtain assistance before the situation spirals out of control. The Circle of Support includes community and informal resources available to assist the patient with self-management activities. A copy of each group meeting proceedings and the Action Plan is made available to all team members, patients, and caregivers at the end of each group session. The work of implementing the Action Plan takes place over the subsequent 12-week period. The CCT meets again with the patient and their caregiver(s) following the 12 weeks to re-evaluate progress toward goals, address new problem areas, and finish any outstanding tasks.”

Comment 3: The purpose of this study was to create an implementation tool kit (AIDED) to bridge the gap between the needs of the patients with multiple chronic conditions and available community programs. The aim of the study was to develop an implementation toolkit to sustain referrals to the CCT in the future. The gap should be restated in this purpose statement

Response: We have reformulated our aims statement according to other reviewers comments, and the sentence that leads into the aims statement at the end of the introduction. It now reads in this way which we hope alleviates your concern:

“Therefore, there was a need to assess the additional implementation support that was required to support continued referral to the program and to develop the materials and processes needed to aid in that implementation.

Methods

Aim

Therefore, the aims of this study were to identify (1) the cognitive and structural needs of clinicians, social workers, and nurse care coordinators to effectively refer appropriate patients to the CCT and (2) the value these stakeholders derived from referring to and receiving feedback
from the CCT. We then sought to translate these needs and value-propositions into an implementation toolkit to sustain referral to the CCT in the future, particularly as the program was concluding its research phases and transitioning to serving as a clinical service.”

Comment 4: In the pilot study, patients reported improvement on the Patient Assessment of Chronic Illness Care (PACIC) but there were no significant differences in pain, or anxiety/depression compared to the control group. In the full study initiated, they did not include any outcome measures regarding whether it was successful. The goal was to develop a toolkit but use an existing model of CTT: Assess, Innovate, Develop, Engage and Devolve (AIDED) Model for Dissemination, Diffusion and Scale UP. The methodology was relatively brief. Did it include the same type of action plan as described in the pilot study?

Response: This indeed was confusing in the original version of the manuscript. We believe we have now more clearly indicated that the research reported in this manuscript was specifically done at the completion of pilot research (cited in the manuscript) at the conclusion of research funding to ensure that implementation gaps were identified and carefully supported to sustain the program as a clinical service. We have added language into the introduction and aims that clarify this including the aims copied above and the final paragraph of the introduction:

“Based on the positive pilot findings and solid stakeholder endorsement of the CCT’s assistance to patients, there was strong interest in moving the CCT from a research-funded pilot program to a sustainable resource available to the local community and primary care practices. However, there were challenges that were identified to making this desire a reality. First, past research indicated challenges in enacting healthcare-community connected partnership,11 and CCT champions acknowledged a lack of awareness about the CCT amongst primary care physicians, care coordinators, and social workers in both healthcare systems. Therefore, there was a need to assess the additional implementation support that was required to support continued referral to the program and to develop the materials and processes needed to aid in that implementation.”

Comment 5: The researchers used an existing model of a CCT to create a tool kit of seven components. The seven components were not clear. Looked like 5 were: (Assess, Innovate, Develop, Engage, Devolve). This was the same as the model for the CCT. What were the other two components?

Response: We are sorry this was confusing. Assess, Innovate, Develop, Engage, and Devolve (AIDED) was the conceptual framework used to inform data collection, analysis, and toolkit development. The 7 components were those listed in box 1. We have included subheadings in the methods that more clearly indicate AIDED as a conceptual framework, and also mention Box 1 both in the results and the discussion to clear any confusion about the 7 components we are discussing.

Comment 6: There seemed to be little concern about problems of physical independence of patients with multiple chronic disabilities in this model. The patient example was focused on
finances primarily. Were there any examples where physical needs were met or independence was achieved?

Response: Thank you for noting this. All patients included in the CCT had complex healthcare issues including physical capacity deterioration, and most were referred from care coordinators who were already working with patients, their healthcare team, and their families. Most patients referred had other capacity problems, such as social or financial. These were less straightforward for the healthcare team and care coordinators to address; these were also issues that the CCT could address that the clinicians interviewed pointed out as the most valuable, given other healthcare and community services did focus on physical capacity problems. We have included most of this information now in the first paragraph of the results section:

“During the Assess phase, our chart review revealed that there was no standardized method to document CCT referrals and CCT program outcomes in the electronic health record. We also learned that patients were referred for a variety of capacity problems: financial, physical, emotional, and social. All patients had physical capacity problems, but had additional capacity deficits that prompted their referral to the CCT. While the financial and physical capacity issues were certainly complex, the majority of them were fully addressed during the CCT program. Whereas the social and emotional capacity issues were addressed during the CCT, their nature made them more difficult to fully resolve during the program. Because of the varying status of issues addressed for individual patients, the need for clear communication and re-integration into traditional primary care was strongly needed.”

Comment 7: I am not sure what was new in this “study”. I suppose it was new to create a brochure for the Community Care Team at the Mayo Clinic with instructions about eligibility and contact information to work with a social worker. This should be clarified.

Response: We hope that the additional clarification of the aims and the seven toolkit components clarifies these issues. Specifically, the study identified the implementation gaps required to be addressed in order to sustain the CCT beyond research as a clinical resource. Those implementation gaps were addressed with the 7 toolkit components listed in Box 1: an executive summary about the program, postcard that can be used by clinicians to refer, including an exact script to help patient-clinician communication, 5 minute prepared presentation for clinical champions, referral process diagram that clarified confusion amongst referrers to the program about the processes, patient success stories that highlight stakeholder-provided value, and a documentation template to ensure a standardized feedback loop back to primary care after CCT program completion.

Comment 8: The conclusion was that a toolkit for a Community Care Team was created and implemented in a well-resourced healthcare system to improve referrals to the program and give feedback to primary care providers. The health care system should have been described in the methodology.
Response: There are two healthcare systems that the CCT was implemented in, and these were mentioned in the introduction. We have added clarification about the types of healthcare systems. This information can be found in the third paragraph of the introduction.

“Modeled after Vermont’s Blueprint for Health, the Community Care Team (CCT) was developed and implemented in a county in an upper Midwestern state. The county is served by two healthcare delivery systems, both that have substantial primary care practices. One healthcare system is a large academic medical center and the other is a community hospital medical center.”

Comment 9: As part of the conclusion, the authors recommended that future research should test to see if the CCT program improves patient health. This recommendation should be in the discussion. The authors should indicate why they did not measure patient outcomes.

Response: We have now included in the first paragraph of the discussion information regarding why further patient outcomes are not available.

“First, the included work was conducted at the completion of pilot funding for the program to support its transition to a clinical resource. Because of this, additional patient outcomes are not available beyond what was reported in the earlier pilot publication.”

We had already included the recommendation about future research in the last paragraph of the discussion:

“Importantly, this support for patient capacity may impact patients’ health outcomes. For example, interventions to reduce 30-day readmissions that provided rich support for patients’ capacity were more effective than interventions that provided little or no support for patients’ capacity. Future research should seek to prospectively test the full-scale implementation of the CCT and of other similar programs to understand their impact on other patient-important outcomes, such as health status, readmissions, and overall quality of life.”

Albert Farre (Reviewer 2):

Comment 1: Thank you for inviting me to review this paper, which reports on the development of a toolkit to support future referrals to a programme of chronic care delivery, the Community Care Team (CCT), for which there is pilot data to suggest positive outcomes from both patient and health services perspectives. My main concern with this manuscript is that it does not seem to document a research process as such: for example, the aim/question as stated (page 6, lines 57-60) is solely concerned with the development of a toolkit, rather than concerned with the examination of a research problem; this is reinforced by the conclusions, where the authors state that they successfully created a toolkit as their main finding; but most importantly, there are no research design/methods reported in this paper.
Response: Thank you for noting this important issue in the original version. We have significantly revised our aims, methods, and results to clearly indicate the research that was done, which ultimately led to the development of the toolkit. Indeed, the research process was very glossed over in the original version, but is hopefully more evident in this revision. Furthermore, we also revised the beginning of our discussion to clearly reflect these modifications:

“We used the AIDED Model to examine the implementation gaps, user-needs, and stakeholder-perceived value of the CCT. Ultimately, this led us to the development of an implementation toolkit with seven unique components (Box 1) to create support for sustainable referrals to the CCT from primary care clinicians.”

Comment 2: The AIDED model is not a methodological framework, as argued by the authors in their response letter to the previous reviewers. The AIDED model could have been used as a conceptual/theoretical framework, to inform either or both data collection and data analysis, but it cannot be characterised as a methodological framework. Alongside this, there is no rationale provided for choice of data collection methods and, very importantly, there is no mention of sampling strategy, participants' recruitment and study setting, or data analysis methods employed. Considering that some of this methodological points had already been raised by previous reviewers, and that the authors had attempted to address them in this revised version of the manuscript, I therefore conclude that the methodological basis of this study was in fact of poor quality (rather than just poorly reported). As a result of the methodological issues, the nature and meaningfulness of the findings presented is this paper cannot be well understood.

Response: This was a very valid concern. We have significantly revised the methods section to reflect that AIDED is used as a conceptual framework, noted by subheading. We have also significantly expanded on our description of methods during each of the AIDED phases:

“AIDED Process

Assess

The purpose of the Assess phase was to understand what the CCT had accomplished for patients referred to and graduated from the program, as well as to understand the information needs of potential referrers (clinicians, care coordinators, and social workers) to the CCT program. To do a comprehensive assessment we conducted 13 chart reviews of previous CCT patients, conducted an observation of a referral, and an observation of a CCT home visit post-referral. To conduct our chart review, the lead author (KB) was provided a list of patients referred to the program between November 2014 and April 2016 (n=27). Patient clinic identifiers were then scanned through a research ethics database to identify if there were eligible for research chart review; those that were not chart review eligible were excluded (n=1). Patients who completed both program visits (n= 16) were then purposefully selected based upon referring individual (typically a care coordinator) and time of referral (early in the program and late). In total, 14 charts were reviewed. CCT visit notes were reviewed and the following information was extracted from the charts using an excel spreadsheet: chronic conditions, precipitating factors to
CCT referral, patient capacity needs using a previous classification structure, 22 issues of patient treatment burden, 23 key takeaways from the first CCT visit and the follow-up CCT visit. KB also took reflexive notes in the Excel spreadsheet regarding her takeaway learnings from each chart and from constant comparison of the charts.

Additionally, we conducted 11 interviews with current and potential referral sources to the CCT including three physicians, two CCT staff, four nurse care coordinators, and two social workers. These interviews were used for design purposes, rather than formal qualitative analyses, and therefore, the interviewer (KB) took detailed interview notes and reflections on design implications immediately following the interviews and discussed summary findings every two weeks with co-investigators DH and CV. A sample interview guide is included as an appendix. Finally, we conducted two observations, one in the context of a social work visit where a CCT referral might be made and another in the context of a CCT enrollment home visit. These observations were done for design purposes as well, to provide additional contextual information beyond the chart reviews and interviews. KB conducted the observations and took detailed notes while in the field and reflections upon completing the observations.

Innovate

We used the information gathered during the Assess phase to inform the Innovate phase. Specifically, we first summarized our learnings about the referral process, patient successes and struggles, and feedback clinicians were receiving. We then met as a team (KB, DH, CV) to discuss these findings, identify key gaps in the overall clinical process of the CCT, from referral to patient graduation and clinician feedback, and propose potential solutions to these problems. These solutions became the foundation of the implementation toolkit.

During the Innovate phase, we worked with stakeholders (referrers to and delivers of the CCT program) to iteratively design the implementation toolkit to support sustainable referrals to and feedback communication from the CCT. Specifically, CV and DH shared toolkit components with CCT stakeholders including referring clinicians, social workers, and care coordinators to elicit feedback. We used feedback to iteratively modify toolkit components.

Develop

During the Develop phase, we worked to develop stakeholder engagement to prepare potential champions for the CCT referral process for the toolkit’s dissemination. These stakeholders included those consulted during the Assess and Innovate phases and also included clinicians in primary care at-large at the two referring institutions. We continue to work with identified implementation champions to Engage them and additional referrers to Devolve the toolkit throughout the champions’ social networks.”

Gianfranco Damiani (Reviewer 3):
This is an interesting and original paper showing how to enact and improve the activities of Community Care Teams. This article is well written and organized. Anyhow some major revisions are needed.

Comment 1: In the Abstract session the numbers of chart reviews, interviews and observations have to be considered results and so coherently reported in the results subsession.

Response: We have made this correction in the abstract and have also revised the abstract to reflect the other changes made to the paper.

Comment 2: In the Background session the Authors reports: .." When illness and treatment burden overwhelm patients' and their caregivers' abilities and resources or capacity to self-care, patient outcomes suffer…” This statements could be fruitfully enriched with some considerations coming from the article of Buja et al. BMJ Open. 2018 Jul 28;8(7):e020626. doi: 10.1136/bmjopen-2017-020626. Developing a new clinical governance framework for chronic diseases in primary care: an umbrella review.

Response: We have now cited this paper with a sentence about its contributions in the first paragraph of the background.

“The prevalence of multiple chronic conditions, currently affecting three in four adults 65 and older, is growing.1,2 These patients suffer from both a high burden of illness and a high burden of treatment.3 When illness and treatment burden overwhelm patients’ and their caregivers’ abilities and resources or capacity to self-care, patient outcomes suffer.4 Recent work has highlighted the need for care processes to emphasize patient-centeredness in treating multiple chronic conditions, and patient-family engagement as a method for making patient-centered care a reality.5 The Chronic Care Model (CCM) supports the idea of leveraging community programs to support patients and their caregivers in self-managing their chronic conditions.6 However, this component has lagged behind the adoption of other model elements, such as improving clinical information systems.7,8 Additionally, implementations of the CCM have not supported patients’ capacity in some fundamental ways. Elements of capacity support noted missing in CCM interventions include providing practical resources, such as assistance with financial or transportation problems and assisting patients with leveraging their social networks to handle the burden of illness and treatment.9”

Comment 3: In the Methods session the Authors have to specify more analytically what they mean as chart reviews, interviews and observations, referring to the conceptual frameworks of each of these techniques and then how they apply these tools in the Assess process.

Response: We have significantly revised the methods section to provide a great deal more information about the chart review, interview, and observation purpose and process. The revised methods section is pasted above, as this was a similar concern to reviewer 2.
Comment 4: In the results sessions the Authors state: "…During our interviews, we learned that the lack of identifiable and robust documentation created a barrier to implementation of the program; people who referred to the CCT found it difficult to find and to understand what happened during the CCT process, the status of the patient's situation at the completion of the program, and what further actions were required on the part of the primary care team. Additionally, clinicians indicated that a strong feedback loop to describe the patients' successes was also the best promoter of future referrals, based on their past experience with other programs. In the discussion they have to specify the potential impact of these limitations and explaining how they could be properly addressed.

Response: We have clarified through our revision of the methods and results that each toolkit component was designed to meet the implementation gaps that were uncovered through the AIDED process. We have also now revised the first paragraph of the discussion section to clarify this as well.

“We used the AIDED Model to examine the implementation gaps, user-needs, and stakeholder-perceived value of the CCT. Ultimately, this led us to the development of an implementation toolkit with seven unique components (Box 1) to create support for sustainable referrals to the CCT from primary care clinicians. Each toolkit component met an implementation gap identified through our AIDED process. For example, the documentation template for CCT visits was designed to address the lack of uniformity in reporting uncovered through the chart review and echoed by referring clinicians who expressed confusion about outcomes from the program in their interviews. This process also served to strengthen the feedback loop from the CCT to the primary care team after patients complete the 12-week program.”

Hilde Eide, PhD (Reviewer 4): Review: BHSR-D-19-00663R1

Comment 1: The overall topic of the paper is important; many pilot studies and RCTs are performed; but few leads to sustainable implementation and regular use as soon as projects are finished. The pilot study was published in 2013/2014/2017 (refs 12, 13,15). It is unclear if implementation challenges are established as result in ref 17, a paper under review. It is also unclear when the current study is performed as the time the research is performed is not stated in the paper.

Response: We have significantly revised the paper to clearly reflect that the implementation challenges that were acted upon to develop the toolkit were a result of the research conducted through the AIDED process. We have also updated the beginning of the AIDED process section to clearly identify the research in this manuscript was done from June 2016 – January 2017.

Comment 2: The paper could be strengthened by description of the study design of the study and a specification of how the data are analyzed and combined.
Response: We have revisited our methods section and expanded it considerably. This was a similar concern amongst all reviewers, and the revised methods is copied and pasted in the reviewer responses above.

Comment 3: The authors could use subheadings to support the structure.

Response: This was a very helpful suggestion. We have added subheadings in the Methods and Results section. To the methods we added second level headings for Aims, Ethics Review, Conceptual Framework, and AIDED Process, and third level headings for Assess, Innovate, and Develop. To the Results we added subheadings for Assess, Innovate, and Develop.

Comment 4: Title: The rationale for the aim of creating sustainable CCT is not well established in the paper - thus the title should be changed to cover the content of the study - and possibly the methodology.

Response: We recognize that the original title could be confusing, and therefore have renamed the paper accordingly “Identifying and Addressing Gaps in the Implementation of a Community Care Team for Care of Patients with Multiple Chronic Conditions”

Comment 5: Abstract: Theory about implementation is missing - what are promising models and how does these inform the current study? Probably move ref 18 and 19 to the background.

Response: We think that this is likely because of the lack of clarity provided around the AIDED Model, which is not a theory but an implementation science conceptual framework, which was used to guide the design. We also now clearly indicate the other conceptual works that underpinned our methods to understanding the implementation, which included user-centered design principles and past work on patient capacity and treatment burden. These are now clearly indicated in their own paragraph under the Conceptual Model heading in the Methods:

“Each step of the AIDED model is conducted in phases but the process is not entirely linear. We used this conceptual model to inform our data collection and analysis process. Additionally, our methods were informed by a user-centered design approach, which focuses on deeply understanding the needs of the user, in this case, healthcare professionals intended to refer patients to the CCT, and iteratively designing products or solutions to their needs.”

Comment 6: Aim should be moved to the methods section.

Response: We have made this adjustment.

Methods:
Comment 7: Description of design is missing.

Response: We believe this has been clarified through the revised methods section, copied above.

Comment 8: The AIDED model is chosen; why? - this needs to be seen as a natural step following the background.

Response: Our reasons are now clearly stated in our methods section following the aims:

“Because our aims were primarily focused on the evaluation of current implementation processes to sustain the CCT in practice, we approached our methods with an implementation science lens. Specifically we selected an existing implementation science framework, the Assess, Innovate, Develop, Engage, and Devolve (AIDED) Model for Dissemination, Diffusion, and Scale Up (Figure 1), which is focused on the sustainability and scale-up of existing interventions.”

Comment 9: Different methods are used for data collection and need more description. How the data were analyzed (charts, observation and interviews) need more description.

Response: These issues have fully been clarified in the revised methods section, which has been copied and pasted above in response to similar concerns from other reviewers.

Comment 10: Who were the stakeholder group in the innovate phase and the identified implementation champions - need more description.

Response: We have now expanded on the information about stakeholders in the Innovate section of our methods:

“We used the information gathered during the Assess phase to inform the Innovate phase. Specifically, we first summarized our learnings about the referral process, patient successes and struggles, and feedback clinicians were receiving. We then met as a team (KB, DH, CV) to discuss these findings, identify key gaps in the overall clinical process of the CCT, from referral to patient graduation and clinician feedback, and propose potential solutions to these problems. These solutions became the foundation of the implementation toolkit.

During the Innovate phase, we worked with stakeholders (referrers to and delivers of the CCT program) to iteratively design the implementation toolkit to support sustainable referrals to and feedback communication from the CCT. Specifically, CV and DH shared toolkit components with CCT stakeholders including referring clinicians, social workers, and care coordinators to elicit feedback. We used feedback to iteratively modify toolkit components.”

Results:
Comment 11: A bit more data about the background data if possible: charts being reviewed (as age, gender, ethnicity, referral reason, type of health problems); informants, stakeholder group, champions (number, age, gender, e.g.); what type of network; should be displayed. Could be a table.

Response: We previously included in the Assess methods the types of stakeholders interviewed. We do not have any information beyond specialty listed about stakeholders previously provided. We did have additional information on patient characteristics included in the chart review and have now summarized that information in Table 1. An appropriate call out for Table 1 is included in the first paragraph of the results section:

“During the Assess phase, our chart review revealed that there was no standardized method to document CCT referrals and CCT program outcomes in the electronic health record. Patient characteristics of chart reviewed patients can be found in Table 1. We also learned that patients were referred for a variety of capacity problems: financial, physical, emotional, and social. All patients had physical capacity problems, but had additional capacity deficits that prompted their referral to the CCT. While the financial and physical capacity issues were certainly complex, the majority of them were fully addressed during the CCT program. Whereas the social and emotional capacity issues were addressed during the CCT, their nature made them more difficult to fully resolve during the program. Because of the varying status of issues addressed for individual patients, the need for clear communication and re-integration into traditional primary care was strongly needed.”

Discussion:

Comment 12: The use of the word "successful" was commented on in the earlier review. I would prefer that the word should be removed and changed to that "the AIDED model was useful in the process of creating an implementation tool kit".

Response: We removed the word successfully from the first paragraph of the discussion to leave the process more neutral:

“We used the AIDED Model to examine the implementation gaps, user-needs, and stakeholder-perceived value of the CCT. Ultimately, this led us to the development of an implementation toolkit with seven unique components (Box 1) to create support for sustainable referrals to the CCT from primary care clinicians. Each toolkit component met an implementation gap identified through our AIDED process. For example, the documentation template for CCT visits was designed to address the lack of uniformity in reporting uncovered through the chart review and echoed by referring clinicians who expressed confusion about outcomes from the program in their interviews. This process also served to strengthen the feedback loop from the CCT to the primary care team after patients complete the 12-week program.”

Comment 13: It is unclear what sustainable referral is. Was there some kind of evaluation of the use of the toolkit during the last phase? If yes - this should also be included in the method
section, and in the result section. If not, there is no evidence for sustainability and this word should be removed.

Response: While the aim was to identify implementation gaps and create supportive structures to address those gaps as the program moved from research to a clinical services, we were not able to assess the result of our implementation efforts due to the conclusion of research funding. We have removed sustainability from the title, and made our intentions clearer in the background and aims of the paper about the transition from research project to clinical service.