Author’s response to reviews

Title: A qualitative analysis of information sharing for children with medical complexity within and across health care organizations

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Author’s response to reviews: see over
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Dear Ms. Flory Mae Calumpita,

We thank you kindly for your editorial comments and review of manuscript: 1269718009994695, “A qualitative analysis of information sharing for children with medical complexity within and across healthcare organizations. We have attached a completed RATS checklist. We have revised the manuscript based on the helpful comments provided by the reviewers. We believe that these revisions (highlighted below) strengthen the manuscript. We look forward to your response.

Sincerely,

Laura Quigley

Editors Comments

1. RATS guidelines

In accordance with BioMed Central editorial policies (http://www.biomedcentral.com/about/editorialpolicies#StandardsofReporting), could you please ensure your manuscript reporting adheres to RATS guidelines. Can you please include a completed RATS checklist as an additional file when submitting your revised manuscript.

We have completed a RATS checklist, attached to this submission. Based on the RATS guidelines, we have made a number of changes to increase the clarity of our methods in the manuscript.

New line (page 5, methods): “A qualitative study design with data analysis informed by a grounded theory approach was utilized.”

New line (page 5, methods): Additionally, the RATS guidelines for reporting qualitative studies were adhered to.

New line (underlined, page 8, methods): “The first data source was secondary data from previously conducted semi-structured interviews with parents (n=5) and focus groups with HCPs (n=15) of CMC, from a study focused on experiences with written care plans (Care Plan Study). All participants were recruited by a Research Assistant not involved in their clinical care.”

New line (underlined, page 8, methods): “The second data source was data from an evaluation study of a strategic initiative focused on integrated care for CMC in the TC-LHIN between SickKids, HBKR, and TC-CCAC (the Integrated Complex Care Model, or ICCM). This included interviews with parents of children with medical complexity (n=12) and HCPs, including those in manager roles (n=21) of CMC enrolled in the model. Participants were also recruited by a research assistant not involved in clinical care.”
Please see reviewer #2, comments #3 and #4 for additional changes to the manuscript that assist in compliance with RATS guidelines.

2. Tables as additional files

We notice that you have included tables as additional files. If you want the tables to be visible within the final published manuscript please include them in the manuscript in a tables section following the references.

Based on reviewer feedback regarding the results section of this paper, we have decided to include quotes in text rather than in table format. In compliance with your guidelines, we have attached the figure as a pdf titled “Figure One. Barriers to Information Sharing”. We have also included a new file, as suggested by the reviewers in their comments (see below), as “Figure Two. Facilitators of Information Sharing”.

Reviewer #1

1. Minor essential revision. I think the introduction would be clearer if the second paragraph was about written care plans – drawing on the Adams paper – stating that the written care plan is a mechanism to achieve integrated and coordinated care. The third paragraph then emphasizes that developing and implementing a written care plan requires effective information sharing between all parties. Revising the introduction in that manner would set up the reader to understand the methods more clearly, since the study participants were really discussing care plans and information sharing just came up frequently enough to merit a secondary analysis.

Thank you for this valuable feedback. We agree that by reorganizing the introduction to first introduce the use of written care plans and then move on to discuss how issues associated with information sharing were important to further explore to allow optimal use of written care plans. We have rewritten the introduction to incorporate these changes. We moved the information from the third paragraph regarding the use of written care plans to the second paragraph. The third paragraph then focuses on information sharing.

2. Discretionary revision. Abstract, Background: I think the third sentence could read “The written care plan is an excellent test case for how well information sharing is currently occurring.”

Edited line (page 1, Abstract and Background): We have changed the sentence to read: “Written care plans for CMC are an excellent test case for how well information sharing is currently occurring.”

3. Discretionary revision. Results: Generally I find it easier to read qualitative results findings by having quotes embedded in the text. I did find the quotes in the Table, but I think some snippets in the text would enhance readability.

We agree with the reviewer regarding this comment and have decided to embed the most descriptive quotes in the text rather than in table format.
New lines (page 11-12, Results): “Probably different systems [across the various organizations and/or] the fact that they are on different platforms [impacts on information sharing]. Whose system is it? I think because of the timing and because of our different perspective there will be times that information on one system will vary and there’ll be duplication but even contradictory statements.” (Privacy Officer 2)

New lines (page 12, Results): “…Staff Physicians have access to many of these documents on the electronic patient chart. The residents or the fellows do not have access. That alone makes this document probably useless to some extent”. (Care Plan Study, HCP)

New lines (page 13, Results): “An electronic Care Plan can be e-mailed to people who are participating in care. The problem with e-mail has obviously to do with confidentiality and security relating to different e-mail systems and servers.” (Care Plan Study, HCP)

New lines (page 13, Results): “And I have no idea how the other parts of the team are communicating. I’m not copied on anything over email. It’s a big black hole from the family perspective…..so that would be my first suggestion, is to copy me on [it].” (ICCM Study, Family)

New lines (page 14-15, Results): “I find when patients get admitted, we often find out when the discharge summary gets faxed to the office … And it’s a problem, because parents perceive that you’re involved, and you know what’s going on, and sometimes they don’t contact you and then their kid arrives in the office with a discharge summary, it’s not good. And it happens very often. Even from ICU admissions.” (Care Plan Study, HCP)

New lines (page 15, Results): “Who’s going to consistently look at [the care plan] and consult with all the teams to make sure it’s followed. I think that’s kind of what I struggle with.” (ICCM Study, Family)

New lines (page 15, Results): “You highlight one of the problems that sits in many institutions, is who is actually responsible and accountable for the overall care of the patient […] identifying the responsible or accountable owner of the care plan is paramount….” (Care Plan Study, HCP)

New lines (page 14, Results): “…we didn’t start even with a shared nomenclature or a shared vocabulary or a shared language about even how to cases review. Depending on which key worker started the conversation, you know, it was a very different approach.” (ICCM Study, Steering Committee Member)

New lines (page 16, Results): “…we have to interpret the Act, and the Act says you have to keep information private and not share it in an unsecure way.” (Privacy Officer 1)

New line (page 16, Results): “…That then goes back to the e-mail, whether or not it’s appropriate. It all depends on whom I’m contacting. Some [subspecialists] are very stickler about [communicating via email] because I have an outside account. I have an [organizational account] but I can’t access it from home and I’m only down here one day a week. So I just use my own e-mail and some of them will be fine, and some staff have said “I can’t talk to you”. (Care Plan Study, HCP)
New lines (page 17, Results): “All of us are in the business of looking after these kids, but our interface with each other is, even though it’s extensive, it’s not formally looked at and developed as strategic directions for any of our organizations extensively.” (ICCM Study, Steering Committee Member)

New lines (page 17, Results): “One of the things that has not occurred in the electronic patient chart here, although there are many sections that include different elements of the chart, there is not one for a Care Plan.” (Care Plan Study, HCP)

New lines (page 18, Results): “If we start doing our documentation in email it doesn’t get to the patient record. You don’t have the record that you did communicate. Although we do have a method to get emails to the record, most organizations don’t……… And again that’s what I worry about if it’s easy to email and people communicate that way all the time, from a medico legal point of view you really want that to be part of the record.” (Privacy Officer 3)

New lines (page 18, Results): “…think having some model around staff being more fluid between the three organizations so that you are not just [one organization’s] employee but you somehow have a relationship with the other [organizations]…fluidity may be important”. (Privacy Officer 3)

New lines (page 19, Results): “I think if more of the partners along the health care continuum and within the circle of care had access to a single integrated record and even if it only gave us access to parts or they’re access was tracked and individually could say I’m okay with my GP having it or my pharmacist or whatever.” (Privacy Officer 2)

New lines (page 19, Results): “So I think e-mail is huge…l’ve seen e-mail that has worked really well not only within but also across service providers and different agencies, so I think that’s huge.” (ICCM Study, HCP)

New lines (page 19, Results): “Our ultimate next step is to develop [the electronic system] so that we have that opportunity for real-time integration and data entry.” (ICCM Study, Steering Committee Member)

New lines (page 20, Results): “Just speaking from a Nurse practitioner standpoint, I think of my role as the glue that holds different pieces together…As long as there’s a consistent person [updating the care plan], then I think that it will minimize the risk of things being missed.” (Care Plan Study, HCP)

4. Minor essential revision. Results, page 11, Lack of Comprehensive Communication Plan: it was not clear in the text what this was referring to. The Table’s quote is a little clearer at what the authors are referring to: effective information sharing requires a clear expectation about how and when information is transferred from one place to another. Some revision in the text for clarity is appreciated.

New edit (page 14, Results): “Lack of Clear Expectations for Ongoing Information Exchange”
5. Discretionary revision. Discussion, page 15, first full paragraph: the second sentence “Studies reiterate the need for care...” is a very long sentence and needs to be shortened and/or divided into two sentences.

Edited line (page 21, Discussion): We have split this sentence into two sentences and it now reads: “Studies reiterate the need for care that emphasizes coordination between sectors of the health care system, however, the health care system was largely designed to address acute episodes of illness rather than provide an ideal platform for addressing care for chronic conditions.[8, 27] This is exacerbated by fee-for-service funding structures that also promote a focus on episodic service delivery and communication,[9] as opposed to system redesign that promotes chronic disease management by bundled payments, spread of registries and electronic information systems, and targeting the highest risk patients for outreach and follow-up.[28] “

Reviewer # 2

1. There have been many studies of electronic and personal health records, both important ways to share information, and the barriers and facilitators for their use, which actually overlap with present findings and barriers, including privacy, security, interoperability, institutional cultures etc (e.g. Beard et al JAMIA 2012; McGinn et al BMC Med 2011; Tang JAMA 2006; Bates, Health Affairs 2005; Silvester Med J Austral 2009 etc.)... Also, the present findings are not placed in a context alongside other literature (even if this is from adult practice), though the authors do refer to barriers to information sharing identified in the children with special needs literature. I think there should be reference to what is known in the field more broadly, and then perhaps focus in this area, and whether it might be expected to differ from the larger field, and explain in this way what this study was intended to add. Clarify the study rationale based on gaps in the literature.

We agree that information related to the barriers and facilitators of electronic and personal health records is important to expand upon in the Background. The following lines have been added to the Background:

New line (page 3, Background): Patients and caregivers indicated the importance of having access to this central record and sharing ownership of their health information with physicians.[13]

New line (page 3, Background): The use of electronic health information systems is a common proposed medium to improve communication between providers and patients/caregivers. [17, 18]

New lines (page 3-4, Background): Advantages of an interoperable electronic system may include future financial benefits from avoiding redundancies and improving efficiency of administrative time [17, 19] and from lower chronic disease management costs, lower medication costs, and lower wellness program costs.[18] Additionally, these systems can improve patient safety and quality of care [17] by reducing medical errors, improving continuity of care [18, 19] and improving patient access to information to help them manage chronic disease.[17, 18] The optimal medium would provide an ongoing connection between patient and physician, changing encounters from episodic to continuous.[18]
New lines (page 4, Background): While various jurisdictions have proposed models to create interoperability across electronic health information systems,[20] studies have identified a number of difficulties introducing a common, secure platform including financial constraints (i.e. expensive, risky investment with uncertain returns)[22, 23], limited interoperability between systems and other applications [17-19, 22, 23], privacy and security concerns [17, 18, 22, 23], concerns regarding maintenance of the system [22], issues integrating the system across different organizations [18], the lack of a common language across disciplines.[21] and the lack of a timely and easily accessible repository of medical information.[16]

New line (page 4, Background): Concerns at the individual provider level have also been identified and include lack of time, heavy workload, motivation to use system, perceived ease of use, and familiarity with electronic systems.[23]

New line (page 4, Background): There are not many examples of successful electronic care plan implementation. [24]

We have also edited the last paragraph of the Background to better illustrate the existing knowledge gap and how this study fits in with the existing literature.

New Line (page 4-5, Background): Anecdotally it is known that there may be barriers to the sharing of written care plans for Children with Medical Complexity. [25] The existing literature related to electronic system use and information sharing consists of mostly adult populations. Furthermore, the existing literature focusses on the sharing of a static document (i.e. an electronic health record). The sharing of a care plan requires families and health care providers across organizations to build and manage a dynamic document. Given the critical importance of communication through information sharing in high quality care of complex patients at high risk of poor care coordination, written care plans for CMC are an excellent test case for studying how well information sharing of a dynamic document is currently occurring.

New references:

2. Methods, Data collection: It would be helpful to have more information on the interviews: scope, form, content, structure; and whether interview content was comparable across sources or not.

New lines (Page 8, Methods): “Parents of CMC participated in an in-depth, semi-structured interview at a time and location of their convenience lasting between 60 and 90 minutes. Individual interviews allowed for confidentiality to openly express thoughts. The interview guide questions explored parents’ experiences in creating and using the care plan, the meaning of having a care plan, and perceived key components and gaps in the care plan. HCPs participated in focus groups that were held at the Hospital for Sick Children and lasted 90 minutes. The focus group guide included questions exploring HCP understanding of care plans, their past use of care plans, perceived key components of the care plan and perceived impact of care plans.”

New lines (Page 8-9, Methods): “Interviews and focus groups were semi-structured and facilitated using a standardized guide. Individual interviews ranged from 20 to 70 minutes in length. Questions for key informants explored real-world application of the ICCM, as well as successes and lessons learned to support refinement, future replication and expansion. Questions for parents explored family experiences with the model, perceived continued gaps in care, and overall satisfaction. Similarly, although the sharing of medical information was not the main focus of this study, many participants commented on the phenomenon.”

New line (Page 9, Methods): “Individual interviews with privacy officers lasted approximately 30 to 60 minutes and covered questions related to the barriers to and facilitators of the exchange of medical information for children with medical complexity that operate at the organizational level (e.g. procedures, policies, and priorities).”

3. Data Analysis: It would be helpful to have more information on how coding was done. It seems only three (out of 50 something interview) were coded by more than one person. Is that adequate for triangulation? Who coded all the others?

Thank you for drawing this to our attention. A preliminary meeting occurred after the first three interviews were coded to confirm the coding structure, however, all of the interviews were coded by the two reviewers (ALD and LQ). The manuscript has been edited to reflect this. Additionally, given that the full research team then reviewed the coding and developed key themes, we feel that adequate triangulation was achieved.

New lines (Page 9-10, Methods): “Two independent coders (ALD and LQ) conducted secondary analysis of interviews with parents of CMC and health care professionals involved in care of CMC, primary data analysis of interviews with privacy officers of associated organizations and peer coding structures were compared to ensure trustworthiness.” … “Emerging themes related to barriers and facilitators to information sharing were identified by the two coders and the full research team (LQ, ALD, SA, CM, EC).”

4. Results: There was something unedifying about the way the findings are presented. A lot of details and elements are presented in a somewhat scattered way, but without much effort to synthesize and integrate. And where this is done, it is not clear sometimes how the authors
batched things as they did. A couple of specific examples: Lack of Common Language (under Theme 2: Focus on Episodic Care) is not well situated under Focus on Episodic Care, but is related to some other notion of care that is fragmented across sites. Similarly under Organizational Priorities: refers to care across settings, each of which may have different policies, but this is not, to my view, a problem of Organizational priorities.

Please see the response to Comment # 3 from Reviewer # 1 regarding some of the restructuring of the results. Specifically, quotes were added in-text rather than in table to allow for clarity of the results. We agree that lack of a common language is not well situated under focus on episodic care. It has been moved to the section on Lack of a Common Platform. We also agree that ‘organizational priorities’ does not fit under the previous theme heading and have edited the theme heading to better include this sub-theme.

Edited heading (page 15, Results): “Theme 3: Policies, Standards, and Organizational Priorities”

5. Other issues with data organization and presentation: Figure 1: some sub themes/elements are mentioned/ described further in text, others not (e.g. Causal Conditions under Common Platforms) (e.g. does Marginalized Families really fit under Theme Common Platform?) Does Different Language across Organizations fit under Focus on Episodic Care (above)?

Based on your feedback, we have edited the figure to represent the changes addressed in comment # 4. Specifically, a) ‘causal conditions’ was removed, b) ‘consequences’ was removed, c) marginalized families was edited for clarity to “marginalization of families”, which we feel is appropriate as this sub-theme is related to the lack of accessibility of the common platform for families themselves, d) we have moved common language to common platform and e) we have changed “policies and standards” to “policies, standards, and priorities”.

6. Finally, why is there a Fig 1 for Barriers but no counterpart for the section on Facilitators?

We agree that a Figure 2 illustrating the facilitators of information sharing can be useful. Please see the newly attached figure.

7. Discussion: Much of the discussion is quite wide-ranging and goes beyond study findings. Some comments do not even appear to belong in Discussion, e.g. bottom of pg 14: “Frontline HCPs were less conservative...”. This seems more like a study finding, but I was not aware of such comparisons while reading the Results section. It would be helpful to concentrate the discussion on new insights from this study: e.g. that parents are not very worried about privacy or confidentiality; that there are differences in priorities among stakeholders, and related findings.

We have limited our discussion to mostly reflect the study findings, comparing and contrasting it with existing literature. We have moved the sentence “Frontline HCPs were less conservative...” to the results section. We also added a sentence to more clearly describe that our findings are related to differing priorities across privacy officers, health care providers, and front line staff. We found that privacy officers were more concerned about having the highest security measures, while the families were less concerned about security measures and more concerned about ease of communication. Please find a description of our edits below.
Deleted line (page 20, Discussion): Frontline HCPs were less conservative in their interpretation of PHIPA.

New line (page 16, Results): Interestingly, frontline HCPs were less conservative in their interpretation of PHIPA than SCs and privacy officers, especially in regards to the use of email.

Added Line (page 22, Discussion): Our study findings illustrate that there is a difference in priorities between those at the organizational level (i.e. privacy officers), those on the front lines (i.e. health care providers and families).

New Line (page 22, Discussion): Our study findings illustrate that there is a difference in priorities between those at the organizational level (i.e. privacy officers), those on the front lines (i.e. health care providers and families).

Edited line (page 22, Discussion, addition is underlined): Privacy officers continue to express concern about the security of email (even through an encrypted server like ONEMail) and discourage its use in many situations.

Deleted line (page 22, Discussion): ...however adoption of a secure email method currently available in Ontario (ONEMail developed by eHealth Ontario) across all organizations may allow increased email communication. It remains unclear how many providers elect to use the currently available encrypted email. System.

New line (page 22, Discussion): Health care providers are inconsistent in their use of email, likely because they are trying to adhere to the privacy laws passed along from their privacy officers meanwhile maintaining adequate communication with their patients.

8. Limitations: Perhaps note that health care for CMC is not actually all in the realm of physicians and hospitals sources; there are many other players such as community based therapists. It would be interesting to know their views on information sharing too.

We agree that there are many other key players in health care for children with medical complexity, many of which were not interviewed for this study. We agree that it is important to note that our study did not incorporate the perspectives of other key players. We have added the following sentence to the limitations section:

New line (page 23, Discussion): Additionally, there are many key players located outside of the hospital or physician office setting (i.e. community based physiotherapists or occupational therapists) who were not interviewed for this study and would likely add an important perspective.

9. Carefulness: More care needed in checking for typos and accuracy and completeness of references. Typos: pg 6 line 4: privacy 'statues'; References: Refs #8 – please check if this is the correct reference, Ref #14 is incomplete, Ref #27: should there be an URL link?

The accuracy and completion of references has been checked. Reference # 8 is correct, reference # 14 has been completed, and reference # 27 now includes a URL link. All other references were double-checked for accuracy and completeness.
Edited line (page 7, Information Sharing Context): We have corrected the typo of “statues” and replaced it with “statutes”.