Author's response to reviews

Title: Exploring the Usefulness of Comprehensive Care Plans for Children with Medical Complexity (CMC): A Qualitative Study

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Author's response to reviews: see over
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Dear Editor(s),

We would like to thank you for the thoughtful peer review of this manuscript. We have made important revisions to the manuscript based on the reviewers’ feedback. We believe that these revisions have strengthened the manuscript. We look forward to your response.

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Reviewer #1’s Comments:

1. Background: The research question is not clearly articulated in the Background. The research question mentioned here is different from what is presented in the abstract.

This is an excellent point. The background section of the abstract has been modified and contains the same research question as the background section of the paper.

New edit underlined (page 3): The purpose of this qualitative study was to understand the usefulness and desired content of comprehensive care plans by exploring the perceptions of parents and health care providers (HCPs) of children with medical complexity (CMC).

2. The rationale for studying this topic is not well presented. Berry et al have done a similar study: “Health information management and perceptions of the quality of care for children with tracheotomy: A qualitative study. Berry JG et al. BMC Health Services Research. 2011: 11(117).” So, it appears to me that this study is not unique. The authors should cite Berry et al’s article and describe how their study is different from Berry’s study. The population may be slightly different, but that does not warrant another study.

We thank the reviewers for drawing our attention to this recent publication. The paper by Berry et al. aimed to look at how health information management systems and information sharing affected the perception of care for children with tracheotomy. It also aimed to look at how the exchange of health information could be improved between providers. While Berry et al.’s study mentioned the concept and perceived utility of care plans; the subjects in this study did not have formal care plans. This study utilized similar qualitative methodologies and found many gaps in the health care system that demonstrated the need for a care plan that was created by providers (not to place the burden on
parents) and that newer technologies for information sharing could be utilized for maintenance and upkeep of patient information for children with tracheotomy. This study did not evaluate the contents of a care plan but rather demonstrated the need for one.

There are important differences in aims and methodology between our study and that published by Berry et al. Specifically, our study utilized the qualitative method of grounded theory to look at the usefulness and desired content of a care plan that was created by a nurse practitioner in collaboration with the family. There has been no study to date to look at the content needed in a care plan and this study is the first to do so even though care plans are widely used in practice.

The background and the discussion have been updated to incorporate the findings from Berry et al.’s work, with a particular focus on the unique contribution of our study. We have revised both the background section and the discussion section (please see response #29 to reviewer #1) to include this work as well as additional publications noted by reviewer #2 (please see response #1 to reviewer #2).

New edit, Background, underlined (page 4): Work done by Berry and colleagues looking at the experiences of parents and health care providers caring for children with tracheotomy demonstrated the need for provider led care plans and the utilization of web-based technologies in order to enhance care coordination and the secure management of health information across sites of care [14]. Furthermore, the value of care plans in diverse environments and for multiple uses has been established [15-18].

New edit, Background, underlined (page 4/5): Resources and toolkits for the creation of care plans have been developed in recent years [20-22], however, research supporting the content and use of care plans is limited. Care plans have been bundled into some evaluations of the medical home [16, 18, 23], however, there have been no known studies specifically focused only on care plans. Given that the creation and maintenance of care plans is resource intensive, their value and utility merit focused study.

New references added to background/rationale of the paper:


3. Methods - Design: The authors need to provide a rationale for choosing qualitative methodology and design. What value does this approach provide?

Thank you for this comment as it has allowed us to reflect critically on our choice of methodology. Qualitative methodology is used to study understudied areas where there may be multiple value laden perceptions. It provides rich descriptive data that describes personal experiences and complex phenomena that are difficult to assess with quantitative methodologies. In order to fully explore the breadth and experiences of both parents and health care providers, a qualitative methodology is critical.

New edit underlined (page 5): A qualitative approach to inquiry was employed as this iterative, interpretive approach was well-suited to exploring and describing complex and nuanced interactions between parents and HCPs and the subjective experiences of both groups in using a care plan. Specifically, this qualitative study was informed by a grounded theory approach. As an approach to qualitative methodology, grounded theory seeks to generate a theoretical explanation for a specific set of processes or activities that is influenced by a diverse set of perspectives [28, 29].

4. Methodology: what is the rationale for choosing interviews for parent level data and focus groups for HCP level data?

Semi-structured interviews were conducted with parental participants as this method allows participants to openly express thoughts and feelings while ensuring that common topical areas are covered. In-depth qualitative interviews were preferred over focus groups for parent participants as it promoted a secure environment in which to express feelings and discuss confidential information. Furthermore, conveniently scheduled interviews place less burden on parental participants who already have very busy and complex lives as they were not required to leave their home or community but could schedule the interview at a convenient place (i.e. home) and time.

New edit underlined (page 8): Individual interviews afforded parents confidentiality to openly express thoughts and feelings while ensuring flexibility in terms of time and location.

Health care providers were recruited for participation in one of three focus groups. This method of data collection typically facilitates intra-group communication in an effort to generate a rich source of data from all group members (Kitzinger J. Qualitative Research: Introducing Focus Groups. BMJ 1995; 311:299-302) and is ideal for people who will be likely to communicate with each other in a group setting. Parents, unlike HCPs, tend to come from more diverse linguistic, educational and cultural backgrounds which can make intra-group communication challenging.

New edit underlined (page 8): HCP participants were invited by the study research assistant to participate in one of three focus groups. This method of data collection was chosen as it generates rich data from all group members within a single meeting and is ideal for participants who will be likely to communicate in a group setting [32] and allows for the rich exchange of ideas among participants.
5. What is the rationale for combining qualitative data from 2 different approaches (focus group and interviews)? The focus group questions look very different from the parent interviews (page 7)

Using qualitative inquiry approaches, one can integrate multiple methods of data collection within a study. Different methods can enhance the credibility of a study (triangulation of data). Parents and health care providers use comprehensive care plans in different ways and therefore the questions we asked the two groups were slightly different. Both the interview guide and the focus group guide were developed from clinical experience and the literature. Both consisted of open-ended questions and probing questions intrinsic to the examination of care plans as we felt would be relevant to the user (i.e. parent or HCP). Both led to themes that were common across both HCPs and families, while allowing us to explore some differences in responses between the two groups.

6. Participants: The details about participants and recruitment are not clear. The authors need to mention if all children had a care plan, who developed those, how did it look like, Where they the same from one child to another. Some of this information is presented later, but it is difficult to understand the study population without this information.

Thank you for this comment. We have edited the participant section to clarify details surrounding participant selection, care plan development and use as well as the structure and components of the care plan that study participants had.

New edit underlined (page 6/7): All eligible parent participants had children who were patients in a complex care program at a tertiary academic health sciences center. The program is a co-management model that has been previously described [30, 31]. Inclusion criteria to the complex care program includes children with a chronic condition that are technology dependent and/or users of high intensity care, medically fragile, and require coordinated care due to provision of services by multiple providers in multiple settings. At the time of this study there were approximately 200 patients in this program. All children in this program receive a template-based comprehensive care plan. They do not receive any other forms of care plans. The content and order of presentation included; child’s name, hospital number, insurance information, guardian/parent name and contact information, child’s primary and secondary diagnoses, a brief overview including pertinent emergency medical management, diet, technological supports, a succinct system based review of medical issues with relevant supporting data, a social history section, and contact information for all hospital and community based care providers.

Already in text but re-worded and re-situated (page 7): The care plan is created by a Pediatric Nurse Practitioner in collaboration with the family. The care plan takes approximately 4-6 hours to create and is integrated into the child’s electronic medical record. The family is also encouraged to carry their own copy and to use it for all health-related interactions [27].

7. Also, there is lack of information about how many children received care plans of whom how many were eligible for the study.

All 200 children in the complex care program had a care plan and the majority had had it for over 3 months. Participants were recruited from this program and subsequently they all had a care plan.
The subset of 15 parents chosen to participate was chosen based on a theoretical sampling model, whereby participants are purposively chosen based on emerging themes and theory.

Please refer to new edit noted in response #6 to review #1

New edit, underlined (page 7): Initial purposive sampling for the sample sought sample diversity related to child age, diagnoses, home location, family constellation, and cultural and socioeconomic background. This purposive sampling was augmented by theoretical sampling in the tradition of grounded theory methodology.

8. The HCP participant information lacks details. How many HCP provided care for children who had used care plans? Of these, how many were eligible? What were the exclusion and inclusion criteria?

Clarification regarding the HCP participants has been added the participants section to. All HCP in the study had provided care for a child with a care plan. We did not systematically collect data on the number of providers that each of the children were cared for; recent work by our group has shown that, on average, CMC in Ontario see 13 different outpatient clinicians and this study has been referenced in the background section of the manuscript. Purposive and subsequently theoretical sampling was used to target participants among these clinicians who would provide rich diverse data.

New edit underlined (page 7): Pediatricians and pediatric nurse practitioners within the tertiary academic health sciences center or from related community practices who cared for a child with a comprehensive care plan were invited to participate. Participants were excluded if they had not cared for a CMC with a care plan. Written, informed consent was obtained from all parent and HCP participants prior to their participation in the study. Initial purposive sampling for the sample sought sample diversity related to HCP sub-specialty, inpatient vs. outpatient practice experience and variety of patients cared for. This purposive sampling was augmented by theoretical sampling in the tradition of grounded theory methodology.

9. Information about HCP is presented in a table, but is not referenced in the text. So it is difficult to understand who the HCP participants are from this paragraph.

Thank you for pointing out this omission. This table is currently referenced in last sentence of the last paragraph in the data collection section.

New edit underlined (page 9): Information regarding the clinical expertise and experience of focus group participants was also collected (Table 1).

10. How many HCP participated in the 1st, 2nd and 3rd focus group respectively?

New edit underlined (page 9): Two focus groups were comprised of four participants and one comprised six participants.

11. Timeline: The study was performed over a one year period. It does not say what exactly the time period was?
New edit underlined (page 10): Over a one year period from February 2009 to February 2010, individual interviews (n=15) were held with parents and three focus groups (n=15) were held with HCPs of CMC, at which point thematic saturation was felt to be obtained.

12. Were the HCP focus groups and parent interviews conducted concurrently?

New edit underlined (page 8): Interviews and focus groups were held concurrently in order to facilitate the constant comparison method of analysis (theoretical sampling and theme saturation).

13. Care Plans: how do the authors define “not using a care plan for 3 months” for exclusion criteria?

This is now clarified in the participants section.

New edit underlined (page 7): Parents recruited for this study had to have had the care plan for a minimum of 3 months in order to ensure that parents had the opportunity to use the care plan several times and across multiple health care sites.

14. What is the rationale for excluding them based on this time frame? These cases may be informative as they may have had problems with care plans.

We excluded these parental participants as we were concerned that they may not have had an opportunity to use the care plan which would therefore affect their ability to participate effectively in the interview. We specifically tried to seek out negative cases (i.e. cases where the family did not like the care plan), as these cases were extremely informative. We did ask many questions that we hoped would address issues with care plan use to find out if it was not being used or if specific content was not useful or there was additional content needed. We recognize this may be a limitation and have added to the limitations discussion.

New edit underlined (page 18): We chose a minimum 3 month usage time for care plan study eligibility, but in doing so, despite actively seeking out negative cases, we may have missed some informative cases in which care plans were not found to be helpful.

15. How long have the parent participants of CMC been using the care plans?

Length of parental usage of the care plan was used as inclusion criteria (minimum of 3 months – see response to question #13/14 including new edits) but we did not collect data on the length of time that each care plan was actually used.

16. Did families use multiple types of care plans (page 9)? Or were different types of care plans (e.g. emergency information forms) shown to families during the interviews? The authors need to describe how care plans were used.

The complex care plan in this study is created by the complex care team and it given to families in paper and electronic format. Families are only given one version of the care plan (a comprehensive one). The team asks families to carry a copy with them at all times and use it at all health interactions and wherever else they see fit (e.g. daycare). During the interview, it was explained to parents that
the questions asked pertained to the care plan provided to them by the complex care team. They were not specifically asked if they used any other type of care plan but they were asked if they carried any other documents in addition to the care plan.

New edit underlined (page 6): Participants eligible for recruitment included parents of CMC who had a comprehensive care plan and HCPs who had provided care for a child with a comprehensive care plan.

New edit underlined (page 6/7): All children in this program receive a template-based comprehensive care plan. They do not receive any other forms of care plans. The content and order of presentation included; child’s name, hospital number, insurance information, guardian/parent name and contact information, child’s primary and secondary diagnoses, a brief overview including pertinent emergency medical management, diet, technological supports, a succinct system based review of medical issues with relevant supporting data, a social history section, and contact information for all hospital and community based care providers.

New edit underlined (page 7): The family is also encouraged to carry their own copy and to use it for all health-related interactions [27].

17. How often are they updated?

The timelines for updates varies from patient to patient depending on when they are at the hospital or clinic. This variation and lack of standardization is noted in the “Areas for Development” section of the paper.

New edit underlined (page 7): It is updated at clinic visits and during inpatient admissions.

In paper underlined (page 16): Parents and HCPs shared thoughts about how best to achieve this aim, including: (1) storing the care plan on a centralized electronic database accessible by all involved HCPs; (2) initiating regular, scheduled reviews of the care plan by the parents in collaboration with one designated HCP; and (3) providing education about the implementation and use of the care plan itself to HCPs and institutions.

18. They mention that the care plan is in the EMR. Do HCP review these care plans routinely when taking care of CMC?

The care plan is accessible through EMR. Anecdotally, we know that many HCPs review care plans routinely, however, a comprehensive audit of care plan utilization by all providers within the circle of care was beyond the scope of this study.

19. Do parents bring a copy of care plans to share with HCP (see work by Chris Stille were parents act as intermediaries).

The complex care team strongly encourages families to carry this with them at all times however it is the choice of each individual family whether or not they choose to do so. Please also see response to reviewer #1 response #28.

New edit underlined (page 7): The family is also encouraged to carry their own copy and to use it for all health-related interactions [27].
20. Can they provide a copy of the care plan that is currently used?

Excellent point. A description of the contents of the care plan studied is now included.

New edit underlined (page 6/7): The content and order of presentation included; child’s name, hospital number, insurance information, guardian/parent name and contact information, child’s primary and secondary diagnoses, a brief overview including pertinent emergency medical management, diet, technological supports, a succinct system based review of medical issues with relevant supporting data, a social history section, and contact information for all hospital and community based care providers.

21. More description about the complex care program is needed to interpret this study. The sentence “Parent participants were recruited from a Pediatric Complex Care Program similar to …” should be deleted because there is wide variation between programs for CMC in different institutions.

We agree and have deleted this sentence. We have also added much more detail in the participants section of the paper describing the complex care program from which the parental participants were recruited.

New edit underlined (page 6): All eligible parent participants had children who were patients in a complex care program at a tertiary academic health sciences center. The program is a co-management model that has been previously described [30, 31]. Inclusion criteria to the complex care program includes children with a chronic condition that are technology dependent and/or users of high intensity care, medically fragile, and require coordinated care due to provision of services by multiple providers in multiple settings. At the time of this study there were approximately 200 patients in this program.

22. On page 6, when talking about care plans, the authors need to refer to the sample Care Plan in Appendix.

Thank you. We have described the contents of the care plan now in the manuscript.

Please see response # 21 to reviewer #1

23. Sampling: Details of sampling are not provided. Is this a convenience sample? A purposive sample?

In keeping with the main principles of grounded theory this study uses theoretical sampling (Strauss A, Corbin J. Basics of Qualitative Research. Newbury Park, CA: Sage; 1990). This point has been more clearly outlined in the manuscript.

New edit underlined (page 6): Theoretical sampling, whereby participants are purposively chosen based on emerging themes and theory, was used to guide participant selection.

24. In page 7, there is a mention about ensuring “targeted” sampling, but the definition of what the ‘target’ sample was and the process to ensure ‘target sampling’ is not provided.
Thank you. The term targeted has been replaced by “purposive” and “theoretical” sampling to more accurately reflect the sampling that occurred.

New edit underlined (page 9): Consistent with grounded theory, data analysis began immediately upon completion of each interview and focus group. This prompt ‘data collection-to-data analysis’ approach, based on tenets of grounded theory methodology, allowed for ‘theoretical’ sampling in formulating and re-formulating working hypotheses, and the efficient development and testing of hypotheses (through subsequent interviews and analysis) and theme saturation [29].

25. Was the interviewer and the focus group facilitator the same person?

The focus groups were all facilitated by one research assistant (RA). The interviews were divided between this RA (50% of the interviews) while 50% were conducted by a second RA.

New edit underlined (page 8): A research assistant with master level training and extensive experience in focus group facilitation (RM), who was not involved in direct patient care or in construction of the care plan, conducted the focus groups with HCPs. The parent interviews were conducted by two RAs (RM and VJ) with master level training and experience in qualitative interviewing.

26. Data analysis: page 8: what was the procedure used to check results with parents? Were similar procedure used for HCP?

New edit underlined (page 10): Following data analysis, member checking of results with parent participants was completed in accordance with standard qualitative research methodology to ensure the credibility of findings. Member checking occurred through review of the findings by four parent participants, all of whom felt that the findings described their experience. Although member checking was not completed with health care providers, peer debriefing of the findings allowed health care providers to share their insight on the findings.

27. Results: When describing the quotes, it would be useful to have an identifying number for a parent or HCP because it is unclear if the same parent/ HCP contributed to all the quotes and if there is representation across interviews/ focus groups.

Thank you for this excellent point. We have added participant numbers and descriptors to all quotes in the text and tables to demonstrate broad representation.

28. Discussion: Need to reference prior work (Berry JG, Stille C and others’) in this area. Limiting to CMC is not necessarily a limitation and may be strength since parent interviews are ‘data rich’ because of the complexity of these children.

We agree that CMC are an appropriate population to study care plans. We have included the articles mentioned (Berry and Stille) above as well as others to strengthen the discussion section of the paper.
New edit, areas for development, underlined (page 16): Work in this area suggests the utilization of new technologies (e.g. internet for shared care plans) however barriers related to privacy and personal health information continue to slow progress [14].

New edit, discussion, underlined (page 16): Emerging research demonstrates the benefits of care plan use for children with complex health care needs [14, 16, 18]

New edit, discussion, underlined (page 17): Interestingly, in their study examining the perspectives of parents and physicians on the role of parents as information intermediaries, Stille and colleagues found that parents were more comfortable than physicians in holding this role. However, the degree to which parents felt comfortable in this role varied [27]. These findings reveal an important implication of the findings from this study in that care plans should be considered a complementary practice. From a safety lens the content of the care plan has the potential for varied use and interpretation which could equally result in a positive or negative outcome. The care plan should not replace discussions between parents and HCPs related to the child’s most up-to-date treatment plan and it should not be assumed that all parents are similarly comfortable acting as information intermediaries. Furthermore, clear guidelines around who updates the care plan and how often are crucial.

We agree with your comment, “CMC is not necessarily a limitation and may be strength since parent interviews are 'data rich' because of the complexity of these children” and have added this additional edit.

New edit, underlined (page 5): These children are defined by high health care use, have even greater potential needs for care coordination [5], frequently involving multiple HCPs [26], in various places over long periods of time [27] have and thus are likely a data rich patient cohort who would substantially benefit from care plans.

Reviewer #2’s comments:

1. Authors state in the abstract that care plan “value and utility have not been studied”. In fact, there are studies of care plans that the authors would find helpful to integrate into this article’s background and conclusion section:

Thank you for this excellent comment. While care plans have been previously studied as part of bundled interventions focused on comprehensive care coordination, our study is the first to our knowledge to specifically focus on evaluating the utility of care plans. We have reviewed each study for its specific care-plan related content and these reviews are outlined below with the studies. We have also referenced these studies in the both the background and discussion sections of the paper as outlined below and believe that this strengthens the manuscript:


This study examined the impact of care coordination performed for children with special health care needs (CSHCN) who received their care in a medical home from the perspective of caregivers and
health care providers. Children were randomized to either an intervention group (care coordination and creation of a written health plan) or non intervention group (regular care). This study did not evaluate the care plan content or how it was useful but rather sought to see if having a care plan (in addition to other care coordination components) was helpful. This study found that for the caregivers having a care plan in addition to many other components of care coordination (e.g. home visits, creation of care goals) was considered helpful. The health care providers in his study did not comment on the care plan.

This study provides evidence for the use of care plans from a caregiver perspective (although what kind of care plan was not described) as a component of care coordination. Therefore further study into care plan content and usefulness is still needed.

We have referenced this study in both the background and discussion sections of the paper.

New edit, Background, underlined (page 4): Furthermore, the value of care plans in diverse environments and for multiple uses has been established [15-18].

New edit, Background, underlined (page 5): Care plans have been bundled into some evaluations of the medical home [16, 18, 23], however, there have been no known studies specifically focused only on care plans.

New edit, discussion, underlined (page 16): Emerging research demonstrates the benefits of care plan use for children with complex health care needs [14, 16, 18].


This paper is currently referenced in the background section of the paper and evaluates the impact of a complex care program in a tertiary care center. The impact was measured by evaluating resource utilization, charges and payments. Formal investigation of the care plan was not undertaken in this study however anecdotal date reported that health care providers liked care plans as they were time saving.


This study evaluated the feasibility and the impact of a medical home model in a rural area of the United States. It found that comprehensive care (which included a written care plan) benefited children with chronic health conditions who lived in rural areas.

We have referenced this study in both the background and discussion sections of the paper.

New edit, Background, underlined (page 4): Furthermore, the value of care plans in diverse environments and for multiple uses has been established [15-18].

New edit, Background, underlined (page 4): Resources and toolkits for the creation of care plans have been developed in recent years [20-22], however, research supporting the content and use of
care plans is limited. Care plans have been bundled into some evaluations of the medical home [16, 18, 23]

New edit, discussion, underlined (page 16): Emerging research demonstrates the benefits of care plan use for children with complex health care needs [14, 16, 18].


This retrospective study of adult patients compared clinical biomedical measure pre and post and intervention. The primary intervention was the implementation of a plan-of-care tool (POC). The POC was a one page template checklist for 6 common adult diagnoses (e.g. Coronary artery disease, high blood pressure, diabetes) that was filled out by the physician and was given to the patient. It looked at personal health goals, lifestyle changes to reach this goal and plans for this. The POC was not a care plan. The study demonstrated significant improvement in clinical outcomes for those who used the form.

We have referenced this study in the background section of the paper.

New edit, Background, underlined (page 4): Resources and toolkits for the creation of care plans have been developed in recent years [20-22], however, research supporting the content and use of care plans is limited.


This study did not evaluate care plans but rather demonstrates the benefit of care coordination and case management services by telephone to children with special health care needs in relation to hospital resource utilization. Care plans were not a major component of this study; we elected to not cite this study.


This paper presents 2 case studies that demonstrate successful components and actions related to transition of adolescents to adult care. Components of this transition such as a written health history summary and an individualized transition plan are discussed as necessary components of this model. Although not specifically focused on care plans or younger children, this paper provides support for the notion of a care plan and, accordingly, we have referenced this study in the background section of the paper.

New edit, Background, underlined (page 4): Furthermore, the value of care plans in diverse environments and for multiple uses has been established [15-18].

7. There could be greater elaboration about the barriers to care plan sharing across settings, as well as some mention of the danger of providers accessing care plans that are outdated. An incorrect care plan may be worse than no care plan at all. The key issue of who is responsible for
maintaining the accuracy of a shared care plan is critical and must be addressed in the conclusion of this paper.

Thank you for the suggestion. Safety concerns related to out of date care plans are an important consideration, as is how to access and share the care plan. There was also disagreement between HCPs and parents about who should hold ownership and updating responsibility. We have made revisions to the manuscript as noted below.

New edit, discussion, underlined (page 17): From a safety lens the content of the care plan has the potential for varied use and interpretation which could equally result in a positive or negative outcome. The care plan should not replace discussions between parents and HCPs related to the child’s most up-to-date treatment plan and it should not be assumed that all parents are similarly comfortable acting as information intermediaries. Furthermore, clear guidelines around who updates the care plan and how often are crucial.

New edit underlined (page 15/16): Participants suggested standardizing the administration of the care plan and called for enhanced support for and awareness of the care plan across health care institutions. Parents and HCPs shared thoughts about how best to achieve this aim, including: (1) storing the care plan on a centralized electronic database accessible by all involved HCPs; (2) initiating regular, scheduled reviews of the care plan by the parents in collaboration with one designated HCP; and (3) providing education about the implementation and use of the care plan itself to HCPs and institutions. Work in this area suggests the utilization of new technologies (e.g. internet for shared care plans) however barriers related to privacy and personal health information continue to slow progress [14].

8. Are limitations of the work clearly stated? Limitations are discussed in terms of the sample. This section could be enhanced by also stating that this study occurred in Canada where there is universal access to care; other countries’ health systems might have fewer or greater barriers, depending on the structure of health records, the system of support of families, and the accountability and responsibilities of care providers.

Thank you this is a good point. The limitations section of the paper has been edited.

New edit underlined (page 18): This study occurred in Ontario, Canada where there is universal access to health care. This may limit the generalizability of findings to other jurisdictions which might have fewer or greater barriers, depending on the structure of health records, the system of support of families, and the accountability and responsibilities of care providers.

9. The authors would benefit from referring to the studies cited in #1 that describe care plan processes and outcomes to varying degrees.

Please see response # 1-6 to reviewer # 2

10. Add further citations and reduce the claim that this is the first such study.

Please see response # 1-6 to reviewer # 2
11. Consider more discussion of safety concerns if out-of-date care plans are accessed; consider discussing the difficulty of accountability for care planning and updating care plans.

Thank you for the suggestion. Safety concerns related to out of date care plans is an important consideration, therefore we have added the line below. This was not the focus of our interviews and focus groups but was a component and was addressed as a perceived outcome. While full comment is beyond the scope of this paper this would be an excellent idea for a follow-up study or secondary analysis of the data.

New edit, discussion, underlined (page 17): From a safety lens the content of the care plan has the potential for varied use and interpretation which could equally result in a positive or negative outcome. The care plan should not replace discussions between parents and HCPs related to the child’s most up-to-date treatment plan and it should not be assumed that all parents are similarly comfortable acting as information intermediaries. Furthermore, clear guidelines around who updates the care plan and how often are crucial.