Reviewer's report

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

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Reviewer: Savithri Nageswaran

Reviewer's report:

This paper uses qualitative methodology to understand the usefulness and the desired content of care plans for children with medical complexity (CMC). This is an important issue for the care of CMC and the topic has clinical and research significance. However, the paper has many methodological flaws.

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. 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.

Methods

This study, as presented, has many methodological weaknesses.

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

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

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

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

Timeline: The study was performed over a one year period. It does not say what exactly the time period was? Were the HCP focus groups and parent interviews conducted concurrently?

Care Plans: how do the authors define “not using a care plan for 3 months” for exclusion criteria? 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. How long have the parent participants of CMC been using the care plans? 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. How often are they updated? They mention that the care plan is in the EMR. Do HCP review these care plans routinely when taking care of CMC? Do parents bring a copy of care plans to share with HCP (see work by Chris Stille were parents act as intermediaries). Can they provide a copy of the care plan that is currently used?

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.

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

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

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

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

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.

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 a strength since parent interviews are 'data rich" because of the complexity of these children.

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Not suitable for publication unless extensively edited
**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I declare that I have no competing interests