Reviewer's report

Title: Health Information Management and Care Quality for Children Assisted with Tracheotomy: A Qualitative Study

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Reviewer: Bryan Stone

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I appreciate the opportunity to review this qualitative research paper authored by Jay G. Berry and colleagues.

The study questions are focused and well-described; exploring perceptions/experiences of parents and providers regarding health information management in the study population including specific reference to care plan development and coordination of care. They chose to study the population of children with medical complexity including a need for tracheotomy for airway/ventilatory management. They included 8 patient’s mothers who were essentially hand-picked based on a higher likelihood of representing “information-rich cases that offer strong examples of how health information flow is related to quality of care”, along with some of their providers, in only 2 health care systems; making this a fairly focused study population which filled the needs of this study but makes generalization more difficult.

The methodology is qualitative and is a good example of a systematic approach to analyzing and summarizing qualitative results from individual and focus group interviewing. Based on their well-founded methodology, the resulting data is valid for interpretation.

The manuscript is well-written and organized. There is adequate description of the data including examples of interview responses that serve to illustrate issues identified.

The discussion and conclusion sections are likewise well written, but tend toward over-generalization not always reflecting the narrowness of the study population and setting, and straying from language more typical of qualitative research such as clearly identifying results as participant perceptions rather than direct observations or quantifiable findings. It might also be advisable to emphasize the value of this study in directing future research questions (rather than answering them) and what some of those questions might be. I felt that the conclusion introduced additional important information management interventions that were not addressed in the discussion section.

Limitations are clearly stated in general. The 2 main limitations for me are the limitations in sample selection with an inherent bias toward “information-rich” cases at an extreme end of the spectrum of children’s health care in a very specific health care setting and their providers of record; along with the
limitations inherent in qualitative research.

The study is well referenced and acknowledges prior work upon which it builds.

Major Compulsory Revisions:

None.

Minor Essential Revisions:

The abstract accurately summarizes the study. I would suggest amending the title to “Health Information Management and PERCEPTIONS OF Care Quality for Children Assisted with Tracheotomy: A Qualitative Study

Abstract: Results: start first sentence with “These children…” [don't feel it should be generalized to all children with tracheotomy]

Are the patient participants in a “medical home” primary care setting?

Methods: Study Participants: 3rd Paragraph: Tracheotomy providers eligible for participation were identified through chart review (rather than by asking parents); why? Of the 15 providers accepting enrollment offers, how did overlap of care appear? (Were all the patients represented by each of the categories of provider including physicians-PCP, ENT, pulmonology, PICU; nursing-primary care, home, school, hospital; RT, and equipment vendors)? . Were some patient-provider experiences overrepresented?

Discussion: Paragraph 1: 1st sentence: would continue to use the word “perceptions” and “in this study population and setting” while discussing findings related to “care quality” and when addressing "generalizability" statements.

Sentence 1: “…health information management and PERCEPTIONS OF IT'S IMPACT ON care quality…”

Sentence 2: “The study SUGGESTS (rather than “uncovers”) a health care system…”

Sentence 3: Rather than laying the issue of maintaining comprehensive health records on the shoulders of providers, consider “THE SYSTEM (rather than “Providers”) is not maintaining…”. 

Sentences 4, 5, and 6 seem to imply that it is not reasonable to assign the task of keeping this comprehensive record to parents, and that it is reasonable to assign it to providers who “benefit…but question its accuracy…” when parents are doing it. I would appreciate a bit more information to support this opinion, or, if applicable, add comments clarifying the provider's opinion about who should be assigned this "task" to round-out this discussion.

Sentence 7: I would appreciate more detail about solutions that were explored. The Conclusions paragraph seems to refer to additional solutions that are not otherwise discussed in the Discussion section.

Discussion: Paragraph 2: Last sentence: consider “…may be at risk for this type of fragmented information exchange (rather than “care”) during outpatient and
community health care encounters...”. Also, why did you not include inpatient encounters?

Discussion: Paragraph 3: 1st sentence: Do the tracheostomy providers have difficulties due to “poor information management”, or is it a problem with assigning responsibility for specific aspects of the patient’s care to the various physician providers (or both)?

Discussion: Final paragraph: To continue the theme of drawing conclusions from qualitative research, consider changing “…findings of this study may lead to important implications for the healthcare that children with tracheotomy receive.”; to something along the lines of “…findings of this study may help guide future investigations into the impact of improved health information systems in management of complex care such as that seen in children with tracheotomy.”.

Conclusion: You introduce the ideas of “…a sharable EHR…” and “…a case manager or “information coach”, or other healthcare personnel…”. I would like to see more discussion of these in your Discussion section; particularly if you feel your interviews might have shed light on these possible solutions. They seem a little out of place appearing only here in the Conclusions.

Discretionary Revisions:

Introduction: 4th paragraph, second sentence, consider changing “preclude” to “impede” as preclude implies an impossibility not just a difficulty accomplishing something.

Methods: Study Participants: Last sentence in this subsection: “…offer strong examples of how health information flow related to quality of care.”; insert the words “is” and “perceived” (“…offer strong examples of how health information flow IS related to PERCEIVED quality of care.”)

Results: 2nd paragraph: Consider making this point 2 of your results section as the concept of being “in charge” is a critical concept. (As a related question of interest, was a provider identified as being “in charge” of the child's healthcare?)

Results: Section 3: This section appears to advocate for a simple electronic replacement for the current large loose-leaf paper collections, which would provide a degree of convenience in collecting and recording information (if the information is initially electronically formatted and shareable), and for ready accessibility (if web-based). It did not seem to advocate for a shared EMR system. It was not clear how it would “reduce their current burden of home record keeping” since they would have to enter a bunch of information initially, then continue to collect, enter or scan, and otherwise record information just as they now do with paper systems.

Results: Section 4: This section really provides the critical elements of the shared record aspect of health care (although I’m not sure it was represented well by the interview comments). It seems to largely undo much of the discussion that follows.
Results: General: From the comments, there seems to be a sense of hopelessness on the part of providers regarding the feasibility of developing a shared record; and a sense that if it is going to happen, it is a reasonable responsibility to give to parents/patients (including in the parent’s own comments where they frequently seem to have accepted this responsibility despite not being happy about it). Apparently, from Results, Section 3, paragraph 2, 3rd sentence: “Providers felt that using parents as the centralized “home” for the (sharable electronic) record could improve communication, care coordination and care plan development”. The parents, however, expressed a feeling that it was unfair to burden them with a record keeping responsibility. It seemed the parent’s opinion received emphasis in the results and discussion. For a variety of reasons, it seems to me that parents are, in fact, in the best position to do this; with the providers job perhaps to clarify what is “critical” information for parents to collect and maintain, educate them about this, and provide tools (data collection sheets, etc.), rather than doing it for the parents (at least until we are much further along in a shared EHR system). Collecting a bunch of paper for the sake of the “paper trail” as it was referred to, is clearly much more work and much less useful than a systematic collection and recording of pertinent information in an accepted format for ready sharing in different care settings. Creating paper templates and educating parents would seem to go a long way toward resolving the issues with the current paper based parental record keeping solution or an electronic alternative.

Discussion: Paragraph 4: Last sentence: Consider eliminating the word “additional”.

Discussion: Paragraph 5: Although a PCHR solution is brought up in the results section, my take on the participants from earlier comments is that they actually don’t see this as a very viable solution.

Discussion: Paragraph 6: This nicely reviews the reasons why the study did not support a PCHR solution. Consider changing the last sentence to something like “…PCHR would become an electronic, accessible version of what is already being done on paper by parents.” rather than “…PCHR would become an unused “shadow file” with limited use.”; unless that is what the parent’s current approach (loose-leaf binder full of papers) is.

Discussion: General: One of the things lacking from both the current parent paper collection and a PCHR as discussed is a uniformly formatted and specific summary sheet that might overcome many of the obstacles in using these forms of patient/parent managed comprehensive health records.

Table 1: the last question on both the parent’s schedule and the provider’s schedule might have been better framed as “How could we HELP (child’s name)’s providers...” (rather than “make”). Do you think the wording of these questions might have impacted responses? (How closely did you follow the exact wording in the table when interviewing?)
Minor issues not for publication:

One interviewer is identified as JGB (Methods: Data Collection Procedures:) and one reviewer as JB (Methods: Qualitative Analysis:); are they the same person? If yes, please use either JGB or JB for both instances.

Results: 1st paragraph (1.): last sentence: “…fragmented within in multiple medical…” should be “…fragmented within multiple medical …”.

Results: Section 3: Paragraph 2: Sentence 2: consider changing “…could eliminate the task of retrieving, sharing and communicating….“ To “…could eliminate the difficulties with retrieving, sharing and communicating….“ I suggest this because the task is not changed, the ease of completing the task is improved by the electronic record.

Discussion: Paragraph 5: Last sentence: change “…alleviate the both the parent and provider…” to “…alleviate both the parent and provider…”. I am not sure “impute” is the correct word for this sentence.

Again, thank you for a well thought-out, methodologically sound, well-written study that will raise questions that will lead to further research in information management and its impact on the quality of care in complex chronic disease in children. Those of us interested in this population very much appreciate your efforts.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

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.