Reviewer's report

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

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Reviewer: Paul Young

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The authors conducted a qualitative study to examine if the quality of care of children with a tracheotomy might be affected by how well information about their care was shared among their multiple healthcare providers and by these multiple providers with the child’s parents. Because they expected to find that sharing was poor and that this, in turn, would have a negative effect on care quality, they also examined whether an electronic, personally controlled health record (PCHR) had the potential to improve the situation.

The study addresses an important problem, namely the care of children with chronic complex problems that require care from a variety of medical specialists, primary care physicians, home care, community and school nurses, and home care and equipment companies. The care of children with tracheotomies who also have other problems, such as a neuromuscular disability, is a particularly important area to study because the children are at high risk for mortality and morbidity, which often has a clear relationship to less than optimal care.

The authors chose to conduct interviews or focus groups with a small number of parents and providers in order “to acquire richly-detailed, verified experiences and perceptions” from the study subjects. The advantage of this approach is that virtually every perception or experience of a parent or provider can be uncovered. In contrast, a survey or questionnaire may miss those items that the researcher did not think to include. The disadvantage is that the strength or prevalence of a perception or experience cannot be ascertained. Many researchers follow a qualitative study with a more quantitative one such as a survey that includes all of the themes evoked by a qualitative study and asks a larger sample to rate their importance on a Likert scale. Because this study is limited to a relatively small number of participants, it would be premature to conclude that the themes described by the authors are applicable to the universe of parents and providers of children with tracheotomies. Although the authors acknowledge this in the limitations section of the paper, the wording and tone of the results and discussion seem to imply (at least to this reviewer) that the findings have a strength or truth that may not be justified. For example, the second and third sentences of the discussion reads, “The study uncovers a health system ecology characterized by poorly defined provider roles and responsibilities, inadequate communication, delays, and omissions of care information. Providers are not maintaining comprehensive health records for these children.” Although this may very well be true for the providers and parents studied here, it is a stretch to suggest that the reader should assume that they
apply to the healthcare system as a whole. On the other hand, most of the findings have a degree of face validity that will resonate with clinicians who are involved in the care of children with tracheotomies or other similarly complex conditions.

In an attempt to overcome the problems associated with the various failings identified in the care of the children, the authors posed as a solution the use of a personally-controlled health record (PCHR). Unfortunately, but importantly, the subjects of their study identified several barriers that would likely prevent their effective use. The most important of these appears to be that the providers, at least, are concerned that the information in such a record might not be accurate or reliable, especially if the responsibility for maintaining it was with the parents or was not clear. Qualitative studies often lead to the generation of hypotheses, and this study is no exception. Because the authors identified several important barriers to their use, it seems clear that there needs to be a study that tests whether an electronic record based in the child’s medical home would actually improve care or not.

I have a few specific comments.

Abstract: the conclusion that “a medical home … may be unfeasible…. is either poorly written or unrelated to the study. The feasibility of a medical home is not the subject of the paper. Moreover, “improved information sharing” is not an end in itself; rather it is a tool that might improve care. I would advise rewriting it to summarize the findings listed in the results section.

Introduction

In general this is well written and provides a sufficient rationale for the importance of the two research questions. However, the second half of the first question suggests something that the authors do not provide data about, namely the quality of care received. They do answer the question, “how well is health information regarding the care of children with a tracheotomy shared?” A small point—several times in the paper the authors use a semicolon inappropriately. The last sentence of the introduction is a sentence with a single subject and compound predicate. No punctuation is needed before the and. If the sentence seems too long, use a period and make the second exploration a new sentence.

Methods

It was not clear whether the providers’ data all came from focus groups or whether some was provided through individual interviews. This is provided for the parents and should be for the providers. The method used to determine “theme saturation” is not provided.

Results

These are well presented. The vignettes support the four themes. It was somewhat surprising to me that neither the parents nor the providers seemed concerned about the security personal health information in an electronic record and the potential problems associated with the balance between access and protection.
Discussion

Other than the sweeping nature of the first paragraphs that I already alluded to, this section is well written. The results do not provide even anecdotal comments that there were problems with the quality of care as implied by the third paragraph, e.g., “alarming” situations. The final sentence of the paragraph is, of course, one of the possible hypotheses arising from the study.

Conclusion

I would rather see the inclusion of some of the testable hypotheses that this qualitative study suggests. A sharable EHR managed by a case manager or other individual may indeed improve outcomes for children with chronic complex conditions; it just needs to be shown that it does.

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

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