Author's response to reviews

Title: Technology-dependency among patients discharged from a children's hospital: a retrospective cohort study

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Author's response to reviews: see over
The Editors
BMC Pediatrics

Dear Editors:

On behalf of my coauthors, I am pleased to resubmit our manuscript, “Technology-dependency among patients discharged from a children’s hospital: a retrospective cohort study,” to BMC Pediatrics for consideration of publication.

We very much appreciated the comments of the 2 reviewers as well as the advice offered by the editors. As you will see in the revised manuscript and the detailed response to the reviewers’ comments (appearing on the pages that follow), we incorporated nearly all the suggestions. In brief overview, we 1) improved the flow and logic of the manuscript by reorganizing the material so that observations and arguments that motivated the study now appear in the background section and not in the discussion section; 2) focus much more consistently on the phenomenon of technology dependency, regarding the overlapping category of children with special health care needs as an important contextual variable and not as a second focus; 3) provide data that compares subjects with and without technology dependence; 4) simplified the presentation of statistics in the abstract and converted a table into a figure so as to ease interpretation; 5) corrected a coding error in the data whereby 4 cases that were judged to be technology-dependent one of the investigators had not had the underlying technology (medication, device, or both) recorded; 6) formatted the article and files in proper BMC medical journal format; 7) proof read the revised and reformatted manuscript thoroughly.

We believe that the resulting manuscript is much more cogent, and for this we are grateful. Please don’t hesitate to contact me with any questions or concerns.

Sincerely,

Chris Feudtner, MD PhD MPH
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The Pediatric Advanced Care Team (PACT)
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REVIEWER ONE:

General
This manuscript provides an interesting glimpse of the extent to which children discharged from a tertiary medical center are technology dependent. The manuscript is well written and addressed an existing gap in the literature. With additional changes, I think the manuscript will be a useful addition to the literature.

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Major Compulsory Revisions

1. The authors classify children as having special health care needs as well as dependence on technologies; however, the title and the majority of the discussion focus exclusively on technology dependence. The makes the CSHCN classification seem like an afterthought. The authors should either remove the focus on CSHCN, i.e., making it another independent variable, or discuss the implications of the findings with regard to CSHCN.

   We have refocused the entire manuscript on TD, and have treated CSHCN as an important contextual variable.

2. The authors do not addressing the timing aspect of the CSHCN definition delineated by MCHB. How did the authors estimate the duration of illness? Similarly, how did the authors classify children who were discharged on a drug for a limited time period, such as a 10-day course of antibiotics? Overall, I feel like I need more information on how the CSHCN definition was operationalized.

   In the Methods section of the manuscript, we mention the duration of illness aspect of the MCHB definition and now provide more information about how the 4 raters made their judgment regarding whether a case represented a CSHCN, and more explicitly address the judgmental quality of this determination and how this motivated our examination of agreement and criteria that 3 or 4 of the 4 investigators needed to agree that the case represented a CSHCN.

3. I assume that the technology dependence definition included medications. If so, the authors need to make that explicit in the methods. How did the authors decide which medications warranted classification as technology dependent?

   Yes, medications were included, as we now make clear in the Methods section and elsewhere in the manuscript. To warrant the TD classification, the medications had to pass the same test as devices; namely, the withdraw or failure of the medication would likely result in a deterioration of health that would require a hospitalization.

4. The authors should detail the characteristics of cases were there was disagreement over the child's classification as CSHCN or TD.

   We now do this in the Methods section for the TD cases.

5. I am puzzled by the descriptive of the percent of children who are TD. The authors state that 41% are TD and 16% are device dependent, 32% drug dependent and 11% device and drug dependent. The latter three numbers neither sum to 100% (for the subsample of children who
are TD) or 41%. A more useful breakdown would be, among those TD, the % who are device dependent only, the % who are drug dependnet only, and the % who are drug and device dependent.

We very much apologize for this confusion. On review of the dataset, we identified a clear error in the dataset regarding the ratings recorded for one of the investigators regarding 4 subjects; the investigator had flagged the cases as technology-dependent but the reason (the underlying technology) was not flagged. This error had caused the proportion of device dependent children to be under-estimated at 16%; the true proportion is 20%, and this is now reported in the manuscript. In response to this issue, we reassessed the entire dataset and this issue stood out as the only encoding inconsistency. The second reason that this portion of the analysis may have been confusing is that overlapping nature of these sets (TD, TD-medications, TD-devices, TD-both, CSHCN). The math within the TD classification is that 20% (devices) + 32% (medications) - 11% (both) = 41% (TD). To make this more sensible to the reader, we have converted the former table into Figure 4, which graphically depicts these overlapping sets.

6. Please clarify if the data on use of a medical device was collected at the time of discharge or during the hospitalization only.

We now state in the Methods section that the determination of TD was based on the use of devices or medications at the time of discharge.

7. In the first paragraph of the discussion the authors state that their findings suggest that more attention should be given to this group of children? What in their findings suggest that? Clearly the prevalence of special health care needs and TD is higher in this sample than in the general pediatric population, but that is expected given that they are hospitalized children. Why should we be concerned about this group? I think the authors need to frame the discussion better. For example, the point made in the second paragraph about the concentration of these children in pediatric referral centers has financial implications for these centers _if_ reimbursement is inadequate.

We agree that we had asserted this point in the previous version of the manuscript, and no longer do so, instead focusing on what issues ensuring research should address.

8. How do the findings "outline an interconnected pattern of reasons why the phenomenon of technology dependency warrants study"?

We agree that this was an unclear way to frame the previous manuscript’s discussion. We have now relocated this part of our argument and the associated figure into the Background section, because these considerations motivated our study and provide rationale for some of our definitional and analysis decisions.

9. How could a TD child not be a CSHCN (Table 3 footnote)?

We again apologize, as this was an error now corrected.
10. I think the authors should add some bivariate comparisons of TD children vs. non-TD children with regard to payer status, age, diagnosis, etc.

   We have done so in the last paragraph of the results section.

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Minor Essential Revisions

Overall
1. Avoid use of parenthetical remarks: either incorporate them into the sentence or remove them.

   We accommodated this stylistic consideration wherever we thought that the sentence structure was too complex or the meaning unclear.

Abstract
1. Sentence 1: change "be increasing" to "increase"

   Done.

2. Space missing after 0.56

   Done.

3. Remove the sentence, "One patient died." Add the following clause to the next sentence, "Of 100 discharges ..."

   We removed mention of the 1 death. We mention the 100 size sample at the beginning of the Results section.

4. The percentages listed for device and medication dependency do not make sense.

   Corrected, as detailed above.

Introduction
1. I assume that the Medicaid waiver to which the authors refer was for long term care services at home. This point should be clarified.
2. Place reference 7 after the period.
3. Remove "who are" from the final sentence.

   All done.

Methods
1. The authors need to clarify the operationalization of their definitions. Specific examples might be helpful.

   We now provide more details in the Methods section.

2. How were the instruments pilot tested?
We now describe the pilot testing in the Methods section.

3. Paragraph three: change "based on the date contained therein determined" to determined.

Done.

Results
1. The results section is very choppy. Several paragraphs could be combined to improve flow.

Done.

Tables
Revise percentages on Table 3

Done, and then converted into Figure 4.

REVIEWER TWO:

General
This is an interesting paper that has the potential to contribute to the area. However there are some methodological and presentational issues that need attending to before publication.

Major Compulsory Revisions
ABSTRACT
The abstract will need revising in light of the comments below.

Currently what was achieved in the study appears to be inaccurately presented i.e ‘we measured the proportion of children discharged from a children’s hospital who are ……’

We now use the term “assessed” instead of “measured”.

I am not sure why medians rather than means are presented in the results section of the abstract.

We use medians as our assessment of central tendency because of the truncation of age by our age cut-off and because of the skewing of the length of stay and medication data.

INTRODUCTION
I am not sure that it is accurate to state that there are only a ‘handful’ of studies in this area. A more accurate statement in relation to this particular study may be that very little is known about prevalence and incidence. Quite a few studies have now looked at psycho-social impact and support needs.
We agree, and no longer use this phrase or couch our argument for the study along these lines.

A clear study aim/research question would be helpful at the end of the introduction. I do not feel that this study has really examined the issue of caring ‘burden’ – many assumptions appear to be being made in relation to this aspect that the data does not support.

We have clarified our statement of the research aims, and no longer emphasize the burden of care.

METHODS
I have found it confusing about whether this study is focusing on admission or discharge. The title suggests that discharge is the focus but many references are made to admission and admission records being assessed. It might have been appropriate to collect some of the demographic data from the admission record (e.g. insurance) but data on devices, medications, TD assessment etc should have been collected at discharge. It may be that this was what happened but it is not clear in the paper.

The focus is on discharge. We now make this clear throughout the manuscript, and replaced the term “admission” with “hospitalization” in all instances where we meant the latter.

I would recommend the authors seek the advice of a statistician in presenting the data. Further information is required on how the sample size was calculated. Confidence intervals appear to be used inappropriately (e.g. in relation to demographic data) – ranges might be more appropriate to present. Actual numbers are not reported – a number and a percentage should be presented when reporting results e.g. 12 (6%) or 6% (n=12). I accept that this may have been done because the sample size is 100.

The sample size was calculated with regard to the precision of the resulting estimates of proportions. The key issue is that one can, from a random sample, estimate the proportion of the source population that has a certain characteristic, with the 95% CI providing a gauge of how precise this estimated proportion is. We now make this clear in the manuscript text, and removed the 95% CIs from the abstract.

I would have thought that any child who had died during admission would have been excluded (and another child sampled) as the paper is about characteristics at the point of discharge.

Patients who die are discharged from a hospital. A study of discharges should include patients who are discharged as dead.

It might have been helpful if the OTA definition of technology-dependence was used. Many studies use this. At the very least it would have been helpful to have a complete listing of the devices/technologies included in the study as a figure. On page 9 wheelchairs appear to have been included in this definition – I am aware of no studies in the area of TD children that have included wheelchairs as a technology/device. Have they been included in this study? If so they do not meet the study definition (p8). If they have been included this may account for the high
numbers of TD children found. Were children dependent on naso-gastric tubes, oxygen and ventilation excluded or were there none in the sample?

We had considered using the OTA definition when we designed the study, but for reasons now indicated in the Background section, where we compare and contrast our definition of TD with the OTA report, we opted for our definition. The 2 cases who used wheelchairs were dependent upon other devices as the reason for their TD determination. Table 2 includes all the devices observed in this sample.

Consideration of the dimensions of TD is useful (figure 1). The sentence underneath the definition of TD on p8 does not make sense to me – what does ‘threshold consequence’ mean, hospitalization does not appear on the figure.

We have offered a different description of how our definition focused on a failure consequence in the Background section of the manuscript.

The presentation of how many children were TD is confusing. On page 9 26% used a medical device (including a wheelchair). On p10 41% were TD (including medications). This should be more clearly presented so we know how many were TD (preferably excluding wheelchairs) at discharge. The route of medication administration could also be clarified. Oral administration would not generally be considered a TD whereas IV would be.

As described above, we have corrected and clarified our presentation of this data. We do not agree with the exclusion of oral medications as never meeting the TD criteria, for the reasons explained in the manuscript’s background section.

The data could probably be explored more e.g. what type of home care provision did children with different needs/dependencies receive. Just some simple cross-tabulations of different variables.

We provide this in the last paragraph of the Results section.

Is it possible to extrapolate from a sample of this size (100) to the population (11,000) and estimate what proportion would have been TD?

Yes, as mentioned above and in the manuscript.

Tables will need modifying in light of above.

Done.

DISCUSSION
The limitations are identified well. I thought that the discussion went beyond the results from study at times. At present the authors do not discuss their findings in light of other epidemiological studies – if comparisons are not possible because of methodological or population differences this could be stated.

Prior epidemiologic studies did not study a hospitalized cohort of patients; comparisons would not be as informative as we might wish.
I feel that Figure 2 is superfluous – the points are made in the discussion and it is unusual for a figure to appear for the first time in the discussion.

We relocated this figure into the Background section, redrew it, and believe it is now warranted.

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Minor Essential Revisions
There are some typos in the paper. Some are identified below but not all.

INTRODUCTION
Line 1 - ‘Proportion’ rather than ‘fraction’ might be a better term to use. Also children’s hospitals (plural).

We changed to ‘proportion’ and made the correction to a possessive.

The accepted term is technology-dependent rather than technologically dependent which is used here and at other points in the paper.

We made this terminology consistent throughout the manuscript.

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Discretionary Revisions (which the author can choose to ignore)