

PEER REVIEW HISTORY

BMJ Paediatrics Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Training and support for caring for a child's gastrostomy: A survey with family carers
AUTHORS	Page, Bethan Butler, Siobhan Smith, Colette Lee, Alex CH Vincent, Charles A

VERSION 1 – REVIEW

REVIEWER	Reviewer name: Lorna Fraser Institution and Country: University of York, United Kingdom of Great Britain and Northern Ireland Competing interests: None
REVIEW RETURNED	03-Mar-2021

GENERAL COMMENTS	<p>The authors have presented survey findings on a very important topic - training of care of children with a gastrostomy device. There are a few issues that would improve this paper prior to publication.</p> <ol style="list-style-type: none">1. Please report the paper accord got the CHERRIES statement on online surveys.2. Introduction - please introduce the concept of the difference in training between parents and HCPs3. Methods - I was confused regarding the first qualitative survey - is this published elsewhere? If so reference here, if not and it it part of this study than full recruitment, analyses etc needs to be added here4. PPI statement is very generic - please add what the impact of the PPI was5. what was the upper age of child to be included in this study?6. I am surprised that further information on the other needs of the children was not collected or reported. A child with an isolated gastrostomy is quite different to a child who is also ventilated etc7. 25% of the sample were excluded as the survey was incomplete - more information would be helpful here, surly part completed questionnaires would be useful for some of the questions?8/ 43% of the children had a gastrostomy more than 5 years ago - comment on issues of recall bias needs to be addressed.9. Is there any evidence that trainman has improved or change at all over time?10. I think it is unusual to see such clear recommendations from a survey data only - I would urga some caution or reflection on these data.
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REVIEWER	Reviewer name: Mary Salama Institution and Country: Birmingham Women's and Children's NHS Foundation Trust, United Kingdom of Great Britain and Northern Ireland Competing interests: None
REVIEW RETURNED	26-Mar-2021

GENERAL COMMENTS	<p>Congratulations on a clear and important paper on this topic. The lack of demographic data is unfortunate as I would be particularly interested in location of families. It would be interesting to see if the medical team perception of training offered is different to the work as done as viewed by parents. It would also be really interesting to look at language barriers and cultural framing of feeding tubes as I suspect this varies considerably.</p> <p>Mary</p>
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VERSION 1 – AUTHOR RESPONSE

Comment	Response
<i>Editor in Chief</i>	
Title amend to " Training and support for caring for a child's gastrostomy: a parental survey"	Thank you, we have changed the title on the manuscript.
<i>Associate Editor</i>	
Thank you for submitting this interesting manuscript on a very important topic in child health. I would like to request a number of amendments and clarifications to the manuscript - these are set out in the peer reviews and the attached document.	Thank you
I note that you attached a STROBE reporting checklist for cross-sectional observational studies - thank you. However, one of the reviewers has quite rightly requested the more appropriate CHERRIES reporting checklist for web surveys. I would like to ask you to align your reporting to CHERRIES as appropriate and enclose a completed checklist with your resubmission. My sincere apologies for the inconvenience here - this has brought to our attention that we need to review our author guidelines and update our website accordingly.	We have attached a completed CHERRIES checklist and included some additional details in the methods and appendices to align our reporting with this checklist.
<i>Reviewer 1</i>	
The authors have presented survey findings on a very important topic - training of care of children with a gastrostomy device. There are a few issues that would improve this paper prior to publication. 1. Please report the paper accord got the CHERRIES statement on online surveys.	We have attached a completed CHERRIES checklist and included some additional details in the methods and appendices to align our reporting with this checklist.
2. Introduction - please introduce the concept of the difference in training between parents and HCPs	We have added a few sentences to the final paragraph of the introduction to illustrate some of the differences between training for parents and HCPs:

	<p><i>"Many parents caring for children with complex medical needs develop substantial expertise over time.[6,9,10] However training for parents can be informal and highly variable [6,10,11]. This contrasts with training for healthcare professionals who receive years of university training, practice-based training and ongoing continuing professional development (CPD). Healthcare professionals typically also have on-site backup and support, whereas families are often home alone whilst carrying out medical tasks.[16]"</i></p>
<p>3. Methods - I was confused regarding the first qualitative survey - is this published elsewhere? If so reference here, if not and it is part of this study then full recruitment, analyses etc needs to be added here</p>	<p>The first survey will be published this summer in a PhD thesis and may be published later as a separate paper, however it is not currently published elsewhere. We have decided to reduce the description of this preliminary survey in this publication and leave it for a separate publication. We have removed Box 1 and just highlighted in the section on survey development that a preliminary survey informed the design of this survey:</p> <p><i>"The content of the survey was informed by findings from a preliminary qualitative survey with 50 families who performed a range of medical procedures, which highlighted parents' feelings of being scared and unprepared, the variability in experiences of training and the emotional demands on parents."</i></p>
<p>4. PPI statement is very generic - please add what the impact of the PPI was</p>	<p>Thank you, we have added the following additional information:</p> <p><i>"Two parents attended the research meetings from conception of the project, alongside a team of multidisciplinary healthcare professionals. The recruitment strategy was devised through consultation with our parent representatives. The parents completed the draft survey, which was then revised based on their feedback and feedback from clinicians. The recommendations from the survey were developed through meetings with parents and the healthcare professionals supporting the research."</i></p>
<p>5. what was the upper age of child to be included in this study?</p>	<p>We have added this information to the methods section:</p> <p><i>"The child needed to be under 25 years."</i></p>

<p>6. I am surprised that further information on the other needs of the children was not collected or reported. A child with an isolated gastrostomy is quite different to a child who is also ventilated etc</p>	<p>Yes in hindsight it would have been helpful to collect some more information on the level of medical complexity of the children or their diagnoses, or perhaps the length of stay in hospital before going home after surgery as this affects parents' experiences of training.</p> <p>When we developed our recruitment strategy we included a few different charities to capture different complexities of needs (e.g. Together for Short Lives who support children with life-limiting conditions who are likely to be more complex and deteriorate over time, and TOFS, who support children who often need feeding tubes often for a limited time early in childhood). We don't anticipate this would change the main finding (that experiences of training are highly variable and many parents feel unprepared to care for their child in the first few weeks at home), however we can see that the amount of time spent in hospital before discharge after gastrostomy surgery will likely affect parents' training experiences. This is partly illustrated by some of the quotes from parents e.g. in Box 1.</p> <p>We have added this as a limitation in the discussion section:</p> <p><i>"We also did not collect data on the children's diagnoses or the level of medical complexity, although we purposely advertised through charities that support children with a range of different diagnoses and levels of complexity."</i></p>
<p>7. 25% of the sample were excluded as the survey was incomplete - more information would be helpful here, surly part completed questionnaires would be useful for some of the questions?</p>	<p>We excluded any participants who did not complete all the quantitative questions and therefore included participants who had left some of the open-ended questions blank. We have now made this clearer in the methods section (page 6). The 25% excluded mostly just completed the first page or two of the survey. When we looked back at the data for these participants it did not add much to the findings.</p>
<p>8/ 43% of the children had a gastrostomy more than 5 years ago - comment on issues of recall bias needs to be addressed.</p>	<p>Thank you, we have added a comment to the limitations section:</p>

	<p><i>"It is possible there are some issues of recall in parents who received their training a long time ago (43% of parents had more than 5 years' experience of caring for their child's gastrostomy)."</i></p>
<p>9. Is there any evidence that trainman has improved or change at all over time?</p>	<p>It would be really valuable to know where training has improved over time. We cannot fully answer this question from our dataset, however we did some further analyses exploring parents' confidence ratings and the numbers of years since surgery.</p> <p>We have added the following text to the results section of the manuscript:</p> <p><i>"It is difficult to say from the data whether the training parents receive has improved over time, however we did not find any evidence that parents' retrospective confidence ratings from the first week at home had changed over time: 40% of parents with less than a years' experience rated themselves as 'not at all confident' or 'slightly confident' in the first week at home, compared to 38% of parents with more than 5 years' experience. There was no statistically significant association between time since gastrostomy surgery and parents' ratings of confidence in the first week at home; $\chi^2(12, N=147) = 12.06, p = .44$. This suggests that parents' confidence in the first week at home has not improved over time.</i></p> <p><i>However as expected, there was evidence that parents' ratings of their current confidence (at the time of the survey) did improve with more years' experience: 46% of parents with less than a years' experience rated themselves as fully confident caring for their child's gastrostomy, compared to 89% of parents with more than 5 years' experience. A chi-squared test revealed a significant association between current confidence ratings and number of years since gastrostomy surgery; $\chi^2(9, N=147) = 17.54, p = .04$."</i></p> <p>One of the main findings of this survey is the variability in experiences of training, across time and between different regions.</p>

10. I think it is unusual to see such clear recommendations from a survey data only - I would urge some caution or reflection on these data.	<p>We have looked back at the recommendations and discussed them with our team. We have changed the language in this section of the discussion to ensure these recommendations are read as suggestions based on the survey data that need further testing, rather than clear recommendations.</p> <p>The recommendations have been developed based on discussion of the survey findings with our multidisciplinary stakeholder group- we have added some text to the discussion section to make this clear.</p>
<i>Reviewer 2</i>	
Congratulations on a clear and important paper on this topic.	Thank you
The lack of demographic data is unfortunate as I would be particularly interested in location of families.	Yes it would be helpful to know the location of families. We purposely recruited through national charities and Facebook support groups to reach families across the country.
It would be interesting to see if the medical team perception of training offered is different to the work as done as viewed by parents.	Yes we agree, it would also be useful to explore the views of professionals on how else training for families could be improved. We have added a sentence to the discussion on this: <i>"Future research is needed to understand healthcare professionals' views on training families and ideas for improvement, to compare against the findings from the families in this survey."</i>
It would also be really interesting to look at language barriers and cultural framing of feeding tubes as I suspect this varies considerably.	<p>Yes this is clearly something that needs more work. It is unlikely that we included any families in our sample who do not speak fluent English as the survey would not have been easily accessible to them. Further work is needed to look at what support these families need.</p> <p>We have added a sentence to the box of recommendations relevant to developing accessible training videos: <i>"The videos should be accessible to families who do not speak fluent English, and feature families from different cultural backgrounds"</i></p>

VERSION 2 – REVIEW

The paper was not sent for re-review

VERSION 2 – AUTHOR RESPONSE

Comment	Response
Main text	
I have made several comments about how you are referring to your study population – please see below.	Thanks, we've now used the term family carer as that is the term used in the inclusion criteria for the study.
This section will need to be tweaked based on my comments below.	Thank you, I've tweaked this section based on your comments later in the manuscript.
Please see comments below on your use of the term 'poor quality'	We have reworded this to clarify: "The training family carers report receiving to care for their child's gastrostomy varies considerably and often does not fully meet their needs."
Are you claiming that the training causes parents to feel anxious and under-confident? I don't think is what you are saying, please re-word carefully.	Thanks, I have reworded this to make it clearer. I have separated out the anxiety/under-confidence from the comments about training.
Please consider adding a little bit of context here – by 'the system' do you mean the NHS / UK context?	I've reworded this to make it clearer. I've removed the word 'system' and stated that this study uses UK data.
Could you reference this project?	I've added a reference to the website (OxSTaR) where resources from this project are hosted.
Thank you for clarifying the preliminary qualitative survey, which informed the content for the survey you are reporting here. Could you also please reference the unpublished preliminary qualitative survey?	I've added a referenced to my unpublished thesis.
Some of the information from your supp file 3 I think would enhance this section (word count allowing). Some of your supp 3 content is duplicated from your discussion, so I wonder what supp file 3 adds.	I have removed this file and added some of the information from supplementary file 3 to the main text.

I do not see any further information about closed Facebook groups in supplementary file 2.	I have removed the supplementary file relating to recruitment and sampling and added some additional information to this section of the main text.
Please highlight this in the sampling section of your methods.	This sentence has been moved from the discussion to this section on sampling.
How do you know? Would it be more accurate to state that you encouraged participants to share the survey with friends and family (i.e. snowball sampling)? Although I could not see that stated in the participant information.	We didn't encourage snowball sampling but in the question 'where did you hear about the survey' a small number of parents mentioned other families/friends. This is now added to the main text and to the checklist.
How do you know? Would it be more accurate to state that you encouraged participants to share the survey with friends and family (i.e. snowball sampling)? Although I could not see that stated in the participant information.	We did not encourage families to share it, however there was an optional box for where families heard about the survey, and a small number of families indicated they had heard about the survey through a friend or family member. I will make this clear in the supplementary file and remove this from the main text.
I think this would be a helpful place to state that 'fully complete' was defined as viewing all pages of the survey and completing all the quantitative questions at a minimum.	Thanks, definition is now added to the text.
You variously use the terms family, parent, participants, carers etc. It would be helpful to be more consistent, where possible. For example, here I think it would be helpful to say that Table 1 gives more detail about the participants.	Ok, I agree that 'participant' is the best term to use here for the table. The inclusion criteria states 'family carers' so I have now used this term throughout rather than parents, as technically they are not all parents.
Please review as total is 99%	I've double checked this and the percentages are correct. I've used the values rounded to the nearest whole number, so that's why they add up to 99% and not 100%, it's not a mistake.
Perhaps worth briefly clarifying that child may have had more than one device (I assume, based on these numbers)	Yes this is correct, I have clarified this in the table.
Just to make the point again, you refer to 'parents' here, but 3% of participants were not parents. It would be helpful to say 'participants' or 'respondents' I think.	Thank you, I have ensured we use the word participants throughout the results section, or family carers where appropriate.

<p>This section is about experiences of initial training.</p> <p>Please ensure that all these results relate specifically to initial training, including Box 1.</p> <p>It may also be worth clarifying what you are meaning by 'initial'.</p> <p>Or, if these results are about variability of both initial and ongoing training, please clarify.</p>	<p>Yes good point, this section summaries participants descriptions of their training in the open-ended box early on in the survey. I have changed the subtitle accordingly.</p>
<p>Another sub-heading for this section would be helpful. It seems that you have moved from 'experiences of (initial?) training' to a new section (or perhaps two new sections) about confidence and changes over time – please clarify and restructure as needed.</p>	<p>Thanks I agree this would be helpful, I have added a subtitle here,</p>
<p>I have suggested some changes here to aid understanding – I hope I have correctly interpreted what you are saying?</p>	<p>Thank you, yes this is the correct interpretation,</p>
<p>Please arrange for a thorough proofread before resubmission, particularly with regards to use of apostrophes, commas, consistency of use of colons etc.</p>	<p>Thank you, we have now proof read the paper carefully.</p>
<p>Please remind us what you mean by 'experienced' participants here – how was this defined?</p> <p>Otherwise, this could be interpreted as only 10% of your participants saying definitely yes to further training, which I don't think you are saying.</p>	<p>This data reports on all participants- the majority of whom are fairly experienced at the time of completing the survey. I have clarified in the text.</p>
<p>Can I draw your attention to our author guidance and suggested structure for a discussion section (below), I think this would enhance how you have set out your discussion.</p> <p>Discussion: we recommend, but do not insist, that the discussion section is no longer than five paragraphs and follows this overall structure (you do not need to use these as subheadings): a statement</p>	<p>Thank you, we have rearranged the discussion to reflect this broad structure with a summary of the main findings, followed by strengths and weaknesses of the study and in relation to the literature, and then implications for clinical practice and finally future research and development.</p>

of the principal findings; strengths and weaknesses of the study; strengths and weaknesses in relation to other studies, discussing important differences in results; the meaning of the study: possible explanations and implications for clinicians and policymakers; and unanswered questions and future research. Avoid stating 'This is the first study...'	
Please re-word this to more accurately align with the type of data you collected. For example, would it be more accurate to say that the training is sometimes experienced as unhelpful or of limited value. 'Is of poor quality' suggests that you have been able to assess the quality in a more structured and objective way, which is not the case (and was not your aim).	Ok thanks this is a good point. I've tried to reword this to reflect that these are parents' reported experiences.
It would be helpful to re-write this section so that it summarises the key finding from each of your results sections above. Currently,	Thank you we have now done this, following the order of the results section.
I am conscious that you have not discussed your results in the context of the wider literature – this would be helpful.	We have added some references to the wider literature under the section 'implications for the design of services'. There is limited literature available on parents' experiences of caring for their child's gastrostomy but we have references a few key studies which related to training.
I am struggling slightly with your structure here – could you possibly set out more explicitly the key strengths and limitations?	Yes, I have separated this out now into a short paragraph on strengths and a short paragraph on limitations.
<p>I think this should come much earlier in this section and should frame how you present your recommendations.</p> <p>Are all your recommendations based on your group's discussions of the survey results?</p> <p>Some of your recommendations sound very definitive (e.g. training 'ought') and I</p>	We have discussed this and decided to change the language in the box to be more tentative. These recommendations are based on our group's discussions of the survey results and I've tried to make this clearer in the text.

think this all needs to be explicitly grounded in your group's recommendations and/or framed as slightly more tentative given the scale and limitations of your survey.	
Please explain what you mean by emotional needs	Thanks I have added some examples here: "such as recognising parental anxiety and fears and discussing the potential impact of a gastrostomy on daily life"
<p>I think this should come much earlier in this section and should frame how you present your recommendations.</p> <p>Are all your recommendations based on your group's discussions of the survey results?</p> <p>Some of your recommendations sound very definitive (e.g. training 'ought') and I think this all needs to be explicitly grounded in your group's recommendations and/or framed as slightly more tentative given the scale and limitations of your survey.</p>	We have discussed this and decided to change the language in the box to be more tentative. These recommendations are based on our group's discussions of the survey results and I've tried to make this clearer in the text.
<p>I'm not sure this is in the right section.</p> <p>Also, could this work somehow be referenced, so the reader knows where to go with any questions or if they are interested in these videos.</p> <p>Any plans for evaluation of these videos?</p>	Thank you, we have decided to add the reference to the website where the videos and further information about the programme are hosted and stated in the text that the videos are currently being evaluated by families and healthcare professionals.
I am struggling slightly with your structure here – could you possibly set out more explicitly the key strengths and limitations?	Yes, we have separated this out now into a short paragraph on strengths and a short paragraph on limitations.
Are you able to say this, based on your data? My impression is that your participants have experience of different types of services, which is slightly different.	The point we wanted to make here is that parents were recruited through national organisations (charities support groups etc.) rather than from one or two hospitals or community teams, so it's unlikely our findings are specific to a particular region or service. We've stated this in the strengths section.

I think it would be helpful to emphasise this – it is not possible (as opposed to ‘difficult’) to know how selection bias played out in your study, and I assume we know little about the total population here. These results are almost certainly not representative, which you touch on by saying you did not collect key sociodemographic data.	Thank you, I’ve made this point at the start of the limitations paragraph to emphasise its importance.
Please highlight this in the sampling section of your methods.	Thanks I have added this in to the sample sections of the methods
This does not relate to the strengths and weaknesses of your study. As per our suggested structure for discussion sections, a separate section on unanswered questions and future research would be helpful. Reviewer 2 made several useful suggestions for unanswered questions and future research. These correspond with your point that: “We did not collect demographic data on the families so cannot tell the socio-economic, health literacy or ethnicity of families”	Thank you, we’ve added a separate section on unanswered questions and future research incorporating in some of reviewer 2’s comments.
Please see comment above	Thanks, I’ve reworded this to make it clearer
This is beginning to go beyond the scope of what you can conclude based on your results. For example, many of your recommendations sound like they would involve substantial time and resources – perhaps necessarily given the complexity and level of risk here.	Ok I’ve deleted the reference to substantial staff time and support and we have made clear these are suggestions based on discussions with our multidisciplinary group on the survey data.
I think this goes beyond the scope of your study and sticks out as a general and slightly irrelevant point here.	Ok I’ve deleted this point.
Checklist	
You mention purposive sampling in your text	We have clarified this and added some extra information on this to the sampling section of the main text.
Please highlight this in the sampling section of your methods.	This sentence has been moved from the discussion to this section on sampling.
Could email addresses/personal details be linked to responses? Were GDPR requirements upheld?	In our approved ethics applications to the university we stated that: “participants will be asked to leave their email address to

	receive an e-giftcard as a thank you. They will be informed that their email address will be deleted from our records once they have received their e-giftcard, unless they have consented to leave their email address with us to receive a summary of the findings, or to be contacted about participating in future studies.” I have clarified this in the text.
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