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)	Ethical dilemmas in providing acute medical care at home for children: a survey of health professionals
AUTHORS	Bryant, Penelope

VERSION 1 – REVIEW

REVIEWER	Peter Flom Institution and Country: Peter Flom Consulting, USA Competing interests: None
REVIEW RETURNED	27-Oct-2019

GENERAL COMMENTS	I confine my remarks to statistical and methodological aspects of this paper. The general approach is fine but I have a couple issues to resolve before I can recommend publication. p. 5 lines 8-11 : If statistics are descriptive then p values and CIs should not be given. These are inherently inferential. lines 13-18 I would say that the clinical staff are the subjects here and I'm not sure why no ethics approval was required. p 6 Lines 41-43 Give the actual ORs, even if not signficant.

REVIEWER	Reviewer name: Kitty O'Hare Institution and Country: WakeMed Health and Hospitals, Raleigh, North Carolina, USA Competing interests: n/a
REVIEW RETURNED	04-Nov-2019

GENERAL COMMENTS	This is a very interesting study about the application of ethical principles to understanding home care treatment decisions in pediatric patients. However, I am concerned that the study design of public voting on ethical principles likely had a significant impact on participants' responses.

REVIEWER	Reviewer name: Leah Ratner Institution and Country: Boston Children's Hospital/ Brigham and Women's Hospital. Harvard University. Boston, MA. Competing interests: None
REVIEW RETURNED	17-Nov-2019

GENERAL COMMENTS	1. Methods: Did the "Ethical Dilemmas in HITH" session offer anything else to the participants including Continuing Medical Education credits? What was the demographics, professional backgrounds, ages of the participants? Did they all have prior experience working in paediatrics home-based care? That might inform their perspectives.

bmjpo: first published as 10.1136/bmjpo-2019-000590 on 6 February 2020. Downloaded from http://bmjpaedsopen.bmj.com/ on March 28, 2024 by guest. Protected by copyright.

	Results: Question 1. It would be helpful to define the role of the existing "home care pathway for CF" exacerbations, and specifically how the patient would then qualify for home hospital care, over the existing pathway.

REVIEWER	Reviewer name: Michael Rieder Institution and Country: University of Western Ontario Canada Institution and Country: University of Western Ontario Canada
REVIEW RETURNED	03-Dec-2019

GENERAL COMMENTS	This manuscript reports on a survey carried out at a Hospital-in-the Home conference and presents the views of care providers on the ethical acceptability of various situations involved in the home care of children. While one can ascertain the number of participants (84) is it possible for the authors to at least comment on the background and professional affiliation of those surveyed? Was there a preponderance of any particular type of care provider? The authors note some of the limitations of the study but perhaps this should be expanded. The participants were attendees at a meeting where home care of complex patients was the conference focus, and thus represent both a self-selected group and also a group who is most likely to be very comfortable with the clinical scenarios presented. It would be interesting as a follow up to see how a more widely diverse would respond to the scenarios presented.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Comments to the Author

I confine my remarks to statistical and methodological aspects of this paper. The general approach is fine but I have a couple issues to resolve before I can recommend publication.

Thank you and see below.

p. 5 lines 8-11 : If statistics are descriptive then p values and CIs should not be given. These are inherently inferential.

This is a fair point. The sentence in the Methods reads as though the statistics were only descriptive whereas they were also comparative. This phrase has therefore been changed to reflect that comparative statistics were also done, and for these tests of significance were included.

lines 13-18 I would say that the clinical staff are the subjects here and I'm not sure why no ethics approval was required.

The reason was 2-fold 1) the opinions belonged to the healthcare staff and were not associated or linked to the healthcare institution involved, did not involve clinical care, and were collated and anonymised; 2) the purpose of the session was clearly set out prior to starting and participants were

bmjpo: first published as 10.1136/bmjpo-2019-000590 on 6 February 2020. Downloaded from http://bmjpaedsopen.bmj.com/ on March 28, 2024 by guest. Protected by copyright.

offered the opportunity to leave, or stay but not participate without having to declare their non-participation – no ethical issues could therefore be identified. Ethics boards are institutionally-based and this survey was done at a conference with staff from multiple institutions across Australia. This has been clarified in the methods.

p 6 Lines 41-43 Give the actual ORs, even if not significant.

This has been amended as requested.

Peter Flom

Reviewer: 2

This is a very interesting study about the application of ethical principles to understanding home care treatment decisions in pediatric patients.

Thank you.

However, I am concerned that the study design of public voting on ethical principles likely had a significant impact on participants' responses.

Although this is acknowledged in the limitations, it is an important point, so how this was mitigated has been clarified in the Methods and it has also been further expanded in the limitations section.

Reviewer: 3

1. Methods: Did the "Ethical Dilemmas in HITH" session offer anything else to the participants including Continuing Medical Education credits?

No – there was no other incentive to attend except the joy of participating and learning.

What was the demographics, professional backgrounds, ages of the participants?

The conference participants were predominantly Australian between the ages of 25 and 65 years. Their professional background was all in healthcare and all in home care, with 70% nursing, 20% allied health (predominantly physiotherapy) and 10% medical. This information has been added to the Results.

Did they all have prior experience working in paediatrics home-based care? That might inform their perspectives.

Yes to home-based care, but no to paediatric home-based care, which almost certainly informed their perspectives. While the impact of their home-care experience on their answers has been discussed in comparison to those without such experience, the lack of paediatric experience has not. This has therefore been added to the Discussion.

Results:

Question 1. It would be helpful to define the role of the existing "home care pathway for CF" exacerbations, and specifically how the patient would then qualify for home hospital care, over the existing pathway.

bmjpo: first published as 10.1136/bmjpo-2019-000590 on 6 February 2020. Downloaded from http://bmjpaedsopen.bmj.com/ on March 28, 2024 by guest. Protected by copyright.

This was not clear in the manuscript as the intent of the question was to espouse a classical situation in which an adolescent would qualify for the current home care pathway ie that this is an accepted, existing and therefore most likely ethical practice, to provide the basis for considering alterations to the situation and therefore challenges to what might be considered ethical. This has now been explained in the Results.

Reviewer: 4

This manuscript reports on a survey carried out at a Hospital-in-the Home conference and presents the views of care providers on the ethical acceptability of various situations involved in the home care of children.

While one can ascertain the number of participants (84) is it possible for the authors to at least comment on the background and professional affiliation of those surveyed? Was there a preponderance of any particular type of care provider?

Yes, this has also been requested by Reviewer 3 and has been provided at the start of the Results.

The authors note some of the limitations of the study but perhaps this should be expanded. The participants were attendees at a meeting where home care of complex patients was the conference focus, and thus represent both a self-selected group and also a group who is most likely to be very comfortable with the clinical scenarios presented. It would be interesting as a follow up to see how a more widely diverse would respond to the scenarios presented.

This is true and has been acknowledged in the limitations and the likelihood of different responses by different participants. We have expanded on how the make-up of participants in this type of study might impact on results further in the Discussion.

VERSION 2 – REVIEW

REVIEWER	Reviewer name: Leah Ratner Institution and Country: Boston Children's Hospital Competing interests: None
REVIEW RETURNED	04-Jan-2020

GENERAL COMMENTS	Please mention if there are current home care IV infusion services available to patients to be compared to Hospital-In-The-Home. Interesting article with good insight to complicated ethical dilemmas in paediatrics and home -based care.

REVIEWER	Reviewer name: Dr Michael Rieder Institution and Country: University of Western Ontario Canada Competing interests: None
REVIEW RETURNED	13-Jan-2020

GENERAL COMMENTS	The authors have addressed the concerns of this reviewer

VERSION 2 – AUTHOR RESPONSE

Reviewer: 1

bmjpo: first published as 10.1136/bmjpo-2019-000590 on 6 February 2020. Downloaded from http://bmjpaedsopen.bmj.com/ on March 28, 2024 by guest. Protected by copyright.

Please mention if there are current home care IV infusion services available to patients to be compared to Hospital-In-The-Home. Interesting article with good insight to complicated ethical dilemmas in paediatrics and home-based care.

Thank you. There are no IV infusion services for comparison in paediatric homecare in Australia or New Zealand. All services are offered through the model of nurses visiting the home. The main difference between service provision is the source of funding (community/hospital/private insurance). A comment about this has been added to the discussion.

Reviewer: 2

The authors have addressed the concerns of this reviewer

Thank you.

bmjpo: first published as 10.1136/bmjpo-2019-000590 on 6 February 2020. Downloaded from http://bmjpaedsopen.bmj.com/ on March 28, 2024 by guest. Protected by copyright.