Parental Experiences of Healthcare Education During Critical Illness

Ahmed Osman[1], Benjamin Cambers[2], Samantha Potter[3], Kim Sykes[3]

Corresponding author: Dr Ahmed Osman ahmed.osman8@nhs.net
Institution: 1. Paediatric Intensive Care Unit, The Children's Hospital at Westmead, Sydney, Australia, 2. Department of Anaesthesia, Dorset County Hospital, Dorchester, UK, 3. Paediatric Intensive Care Unit, University Hospital Southampton, Southampton, UK
Categories: Teachers/Trainers (including Faculty Development), Teaching and Learning, Postgraduate (including Speciality Training), Research in Health Professions Education

Received: 08/11/2018
Published: 10/01/2019

Abstract

Aim: To explore parental experiences and perceptions of healthcare education during critical childhood illness.

Methods: Thirty-one parents whose children participated in an educational project while in paediatric intensive care were given mixed qualitative and quantitative questionnaires regarding their involvement in education. Seven parents subsequently participated in semi-structured interviews. Inductive thematic analysis was used to interpret the data.

Results: 30/31 parents returned completed questionnaires (response rate 97%). Parents’ experiences were overwhelmingly positive. The main factor influencing participation was a sense of altruism. Parents reported unanticipated benefits, including increased understanding of their child's condition. All 30 parents would allow their child to be involved in education in the future.

Conclusions: Parents of critically ill children have an overwhelmingly positive attitude towards healthcare education, and all parents in this mixed-methods study would allow their children to participate in education in the future. Parents did not feel that their children’s critical condition affected their decision to participate, with the main driving factors being altruism and wanting to repay the staff for their care, as well as a recognition of the importance of healthcare education. Further research should focus on parental understanding of postgraduate education, and responses from parents who refuse consent for educational activities.

Keywords: Paediatric intensive care unit; parents; qualitative research; surveys and questionnaires; medical education; work-based teaching and learning.
Introduction

Education is continuously occurring in hospitals, at both undergraduate and postgraduate levels. Patients and their relatives are often involved in healthcare education, and there is an increasing drive towards making patients more actively involved in this area (Jha et al., 2009).

Several reports suggest high learner satisfaction with active involvement of real patients in adult specialties (Jha et al., 2009; Towle et al., 2010), as well as potential benefits to patients including increased self-esteem, increased knowledge of their own illness and satisfaction at being able to ‘give something back’ to their healthcare providers (Towle et al., 2010). However, there are fewer studies of patient involvement in paediatric education, particularly during critical illness.

In a cross-specialty study, Passaperuma et al. (2008) found that outpatient paediatric patients and relatives reported positive attitudes towards medical student involvement, as assessed by a Likert scale questionnaire. Sakata, McBride and Kimble (2010) administered similar questionnaires to parents of children in a burns outpatient clinic, and found that 99% of parents would allow medical students to be present, with 93% allowing students to physically interact with their child. Zeller et al. (2006) surveyed parents attending a paediatric outpatient clinic, and found that although parents had very limited understanding of the role of trainees, most were happy to have trainees involved in their child’s care, provided they were asked specifically. In an action research project, Spalding and Yardley (2016) found that children and parents attending a hospice were willing to help develop educational materials for medical students based on their own experiences. Pinnock et al. (2011) found that parents and children on an acute paediatric ward were willing to interact with medical students, provided they were asked for consent. They noted that most participants were motivated by altruism and a sense of responsibility, but that fear of pain or distress might cause them to decline participation.

To our knowledge, no prior studies have examined parents’ experiences and attitudes towards their children being involved in healthcare education during a period of critical illness, when parents might understandably be more reluctant for this to happen.

This mixed-methods quantitative and qualitative study aimed to explore parental experiences and perceptions of healthcare education while their children were admitted to a tertiary paediatric intensive care unit (PICU), as well as factors influencing their decision to participate.

Methods

Participants
Thirty-one parents whose children had previously been involved in an educational video project on our PICU (Cambers and Osman, 2018) were approached for this study. This group was chosen as a purposive sample of parents whose children had definitely been involved in healthcare education.

Data Collection
All parents were given an anonymous paper questionnaire to complete, which was returned via sealed envelope. The questionnaires contained both quantitative and free-text qualitative questions regarding involvement in healthcare education.

Seven parents were subsequently invited to participate in semi-structured interviews to explore their perceptions further. Four were parents of children who had been on PICU for more than one month, while the other three had
been on PICU for shorter periods. The interviews were digitally recorded and transcribed, with additional field notes taken at the time.

**Data Analysis**

The questionnaire results and interviews were electronically transcribed and anonymised; the transcripts were reviewed against the originals to ensure accuracy. The transcripts were analysed using inductive thematic analysis to identify, analyse and report patterns within the data (Braun and Clarke, 2006).

After familiarisation with the transcripts, initial codes were generated through line-by-line analysis of the data. These codes were created by dissecting the text into meaningful segments, related to the research question as well as to new insights generated through the initial familiarisation stage (Attride-Stirling, 2016). The codes were then reviewed, refined and rechecked with the original data, then grouped into potential themes. These resulting themes were again reviewed to ensure that they were representative of the coded extracts and the dataset as a whole.

**Study Approval**

The study was approved by the hospital research ethics committee and deemed exempt from formal research ethics approval. All participants were required to provide written informed consent, with interview participants providing separate consent for questionnaires and interviews.

**Results/Analysis**

**Results**

Thirty parents returned completed questionnaires; a response rate of 97% (30/31). All thirty-one parents (including the non-responder) had previously agreed for their child to be involved in the educational video project. Seven parents were approached to participate in semi-structured interviews, all of whom agreed and completed interviews.

**Quantitative data**

Quantitative results are summarised in Tables 1 and 2.

**Table 1. Quantitative Questionnaire Results**

| Question                                                                 | Yes (% ) | Not sure (%) | No (%) |
|--------------------------------------------------------------------------|----------|--------------|--------|
| Did you agree to your child being filmed?                                | 30 (100%)|              | 0 (0%) |
| Have you or your child ever been involved in healthcare education before?| 5 (17%)  | 5 (17%)      | 20 (67%) |
| Do you think your decision to participate was affected by your child's critical condition? | 0 (0%)  | 2 (7%)       | 28 (93%) |
Table 2. Likert Scale Results

| Question                                           | Definitely not (%) | Probably not (%) | Not sure (%) | Probably (%) | Definitely (%) |
|----------------------------------------------------|--------------------|------------------|--------------|--------------|----------------|
| Would you allow your child to be involved in education again? | 0 (0%)             | 0 (0%)           | 0 (0%)       | 5 (17%)      | 25 (83%)       |

Only 5 out of 30 parents (17%) were sure that they or their child had been previously involved in healthcare education. No parent felt that their child’s critical condition had any effect on their decision making, though 2 parents (7%) were not completely sure. All 30 responding parents said that they would probably (5/30) or definitely (25/30) allow their child to be involved in healthcare education in the future.

**Qualitative data**

The main themes generated from the questionnaires and interviews related to parental experiences of education and the perceived factors affecting their participation. Figure 1 illustrates the overall themes and subthemes generated.

**Figure 1: Themes and Subthemes**

Experiences of Education

*Previous experiences.* Most parents did not recall any prior involvement in healthcare education. Those that did report previous experiences mainly described interactions with undergraduate medical and nursing students, either informally at the bedside or more formally as part of observed clinical examinations. Two parents recalled student nurses being trained to perform practical procedures such as chest drain removal and intramuscular injections. Only
one parent gave an example of involvement in postgraduate education; this was related to their child’s participation in a practice clinical examination for postgraduate trainees.

Consent process. Parents described positive experiences of being asked to participate, including the consent process for video recording. They praised the "professional manner" of the staff and valued the "very friendly and free of pressure" approach to the consent process. Parents highlighted the importance of "clear explanations" and information on "how it will help others", as well as reassurance that they could "change [their] mind at any time". They also appreciated the staff assuring them that participation or non-participation would not "affect the way [their child] was cared for". A small number of parents did initially report being "a bit shocked" at being asked, but that after a thorough explanation they "felt completely comfortable."

Timing of consent was discussed, with parents generally unsure of the best time to discuss educational involvement. Most parents said that they would be happy to be asked at any time, and did not feel that their child’s critical condition had any effect on their decision to be involved in education. One parent summed up their opinion that staff will know the best time to approach:

"Obviously you know the situation of all the kids down there, so you wouldn’t ask at an inappropriate time... Obviously if our kid’s dying or on death's door, then that'd be really inappropriate..."

Overall, parents felt that a "good relationship with the staff" was important prior to the consent process, as it meant that they already knew and trusted the team, and this would also help the team know the best time to approach them.

Experience of this event. Parents’ experiences of participation in the educational video project were overwhelmingly positive. A small number of parents described initially feeling apprehensive, but were completely reassured after staff "talked [them] through everything that was going to happen, so [they] knew the process". Parents valued the opportunity to "stay and watch the filming process", and most parents described the atmosphere as "calm" and "friendly", which they found reassuring. Parents found the experience interesting, and welcomed the chance to "talk about something a bit different" from the usual intensive care discussions. No parent reported any negative experiences, even on direct questioning.

Future intentions. All of the parents stated that they would be agreeable to their child or another family member being involved in healthcare education in the future, "if it would help”. One parent did clarify that they would not wish to come back to hospital specifically for education purposes, but felt that they would be amenable to participating in education in the event of a further PICU admission.

Factors affecting participation
Child factors. Most parents felt that their child’s critical condition did not affect their decision to participate, though a small number thought that they might not have agreed if their child was deteriorating at the time of approach. Some parents did comment that their child’s critical condition made them more inclined to participate, as they understood that it was rare for health professionals to get an opportunity to see some of the procedures involved. Importantly, parents felt reassured that participation would not harm their child, so felt confident that "nothing negative could come from it".

Parents felt that the potential benefits to the children were related to the procedures performed, and that involvement in the education project would not "play a huge role in [their child’s] life”. It was noted, however, that the actual procedures "might have been performed better" due to the filming process. A number of parents also commented
that involvement in education was something that their children could "be proud of" when they were older.

**Parental factors.** The main parental factor identified that influenced decision making was their opinions on the importance of education in healthcare. A number of parents commented that healthcare professionals "have to learn somehow", and that they understood the need for on-the-job training. Some parents described previous positive experiences of education, which made them more predisposed to participate again.

Parents described some unanticipated benefits to themselves, which influenced their decision to participate in the education project. Being present for the filming process gave parents the opportunity to improve their own understanding of the procedures involved in their child's journey:

"I could actually watch what was going on, and it gave me a better understanding of what was going on, what people usually do, how they do it, instead of this vague idea of 'yeah, they're putting a line in'…"

One parent also commented that some of the videos may be useful for parents to learn relevant procedures themselves, such as changing a tracheostomy tube.

**Education/healthcare benefits.** Parents were enthusiastic about the potential educational benefits of the project for healthcare professionals and students. They were pleased that "people are going to learn from it", and that it could potentially "help a lot of students in the future". They described it as an opportunity to learn rare skills, and felt that the involvement of real patients was important:

"I feel that it is incredibly important for student/junior doctors/nurses to be able to gain "real life" experiences, rather than just textbook learning"

Parents suggested that the educational material created would also potentially have a positive effect on future healthcare, by improving the knowledge and skills of future students.

**Altruism/gratitude.** Parents saw participation in the project as an opportunity to repay the team caring for their child:

"We are very grateful for the care my son received and we felt this was giving a little something back"

They also reported being "happy to help" the staff, and pleased to be doing "a good thing". Many parents described the overall experience as positive due to feeling that their child could "help others", and that they were "making a difference to someone else's life".

**Discussion**

This mixed-methods study has demonstrated that parents are willing to allow their children to participate in healthcare education during a period of critical illness, and that parents' experiences of education are overwhelmingly positive. Parents did not feel that their children's critical condition affected their decision to participate, and all parents reported that they would be happy to participate in education in the future. The main factors leading parents to agree to participate were a sense of altruism and wanting to repay the staff for their care, as well as a recognition of the importance of learning in healthcare. Parents also described some unanticipated benefits to themselves, such as increased knowledge and understanding of their child's condition.
Interestingly, although education is continuously occurring throughout our hospitals, most parents stated that they had not been involved in education before, with a significant proportion declaring that they were ‘not sure’. This suggests that healthcare professionals and students might not be explaining their roles clearly enough, and not seeking appropriate consent for education purposes. Another explanation may be that parents only considered undergraduate education when responding, discounting ongoing education for junior medical and nursing staff. This is a potential area for further study, especially as parents described informed consent as being a crucial part of healthcare education (Zeller et al., 2006; Pinnock et al., 2011).

This study supports the findings from other paediatric reports (Passaperuma et al., 2008; Sakata, McBride and Kimble, 2010; Pinnock et al., 2011; Spalding and Yardley, 2016), in that parents had positive attitudes towards healthcare education, and suggest that critical illness does not affect parents' willingness to participate. The motivating factors for parents are similar to those reported in other studies (Towle et al., 2010; Pinnock et al., 2011), with altruism and a sense of responsibility for education being primary drivers. The knowledge-related benefits to parents also support findings described in adult literature (Towle et al., 2010), and the lack of understanding of postgraduate healthcare training is similar to that seen by Zeller et al. (2006).

There are some limitations to the study. Although the researchers only approached parents when they were not directly involved in their care, they would have been known to them as members of the healthcare team. Despite being assured of their anonymity, it is possible that parents did not want to give negative feedback to their healthcare providers, potentially resulting in more positive feedback.

Furthermore, all parents in the study had agreed to participate in the educational video project, which may have resulted in a selection bias towards parents more predisposed to be favourable towards education. The study aim had been to recruit parents who declined to participate in the video project as well, but all parents approached for the video project agreed to participate. This is an interesting finding in itself, as it suggests that parents are likely to agree to participate in most education projects if asked. The high response rate for questionnaires and the 100% agreement to participate in interviews also supports this. Further research in parents who refuse participation would be useful to determine factors that stop them from consenting.

**Conclusion**

Parents of critically ill children have an overwhelmingly positive attitude towards healthcare education, and all parents in this mixed-methods study would be willing to allow their children to participate in education in the future. Parents did not feel that their children's critical condition affected their decision to participate, with the main driving factors being a sense of altruism and wanting to repay the staff for their care, as well as a recognition of the importance of learning in healthcare. Parents also described unanticipated benefits to themselves, such as increased knowledge and understanding of their child's condition. Further research should focus on parents' understanding of postgraduate healthcare education, and responses from parents who refuse consent for educational activities.

**Take Home Messages**

1. Parents have an overwhelmingly positive attitude towards healthcare education, even during periods of critical illness;
2. Their motivations include altruism and wanting to repay staff for their care;
3. Involvement in healthcare education may have unanticipated benefits for parents themselves;
4. Parents may not be always aware of when healthcare education is taking place, particularly in postgraduate education, and clinicians should make this clear to them.
Notes On Contributors

**Ahmed Osman** is a paediatric intensive care fellow at The Children's Hospital at Westmead, Sydney, Australia. ORCHID: [https://orcid.org/0000-0002-5879-9623](https://orcid.org/0000-0002-5879-9623)

**Benjamin Cambers** is an anaesthetic trainee at Dorset County Hospital, Dorchester, UK.

**Samantha Potter** is a paediatric intensive care trainee at University Hospital Southampton, Southampton, UK.

**Kim Sykes** is a paediatric intensive care consultant at University Hospital Southampton, Southampton, UK.

Acknowledgements

The authors would like to thank the staff and families involved in the educational video project that preceded this work, as well as all of the families who took part in this project.

Bibliography/References

Attride-Stirling, J. (2016) ‘Thematic networks: an analytic tool for qualitative research’, *Qualitative Research*. 3rd edn, 1(3), pp. 385–405. [https://doi.org/10.1177/146879410100100307](https://doi.org/10.1177/146879410100100307)

Braun, V. and Clarke, V. (2006) ‘Using thematic analysis in psychology’, *Qualitative Research in Psychology*, 3(2), pp. 77–101. [https://doi.org/10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)

Cambers, B. and Osman, A. (2018) ‘Abstract P-047’, *Pediatric Critical Care Medicine*, 19(6S), p. 63. [https://doi.org/10.1097/01.pcc.0000537504.56293.a3](https://doi.org/10.1097/01.pcc.0000537504.56293.a3)

Jha, V., Quinton, N. D., Bekker, H. L. and Roberts, T. E. (2009) ‘Strategies and interventions for the involvement of real patients in medical education: a systematic review’, *Medical education*. Blackwell Publishing Ltd, 43(1), pp. 10–20. [https://doi.org/10.1111/j.1365-2923.2008.03244.x](https://doi.org/10.1111/j.1365-2923.2008.03244.x)

Passaperuma, K., Higgins, J., Power, S. and Taylor, T. (2008) ‘Do patients' comfort levels and attitudes regarding medical student involvement vary across specialties?’, *Medical teacher*, 30(1), pp. 48–54. [https://doi.org/10.1080/01421590701753443](https://doi.org/10.1080/01421590701753443)

Pinnock, R., Weller, J., Shulruf, B., Jones, R., *et al.* (2011) ‘Why parents and children consent to become involved in medical student teaching’, *Journal of Paediatrics and Child Health*. Wiley/Blackwell (10.1111), 47(4), pp. 204–210. [https://doi.org/10.1111/j.1440-1754.2010.01937.x](https://doi.org/10.1111/j.1440-1754.2010.01937.x)

Sakata, S., McBride, C. A. and Kimble, R. M. (2010) ‘Parent attitudes towards medical student attendance and interaction in the paediatric burns outpatient clinic’, *Burns*. 36(3), pp. 418–421. [https://doi.org/10.1016/j.burns.2009.05.019](https://doi.org/10.1016/j.burns.2009.05.019)

Spalding, J. and Yardley, S. (2016) ""The nice thing about doctors is that you can sometimes get a day off school": an action research study to bring lived experiences from children, parents and hospice staff into medical students' preparation for practice", *BMJ Supportive & Palliative Care*. BMJ Supportive & Palliative Care, 6(4), pp. 459–464. [https://doi.org/10.1136/bmjspcare-2015-001080](https://doi.org/10.1136/bmjspcare-2015-001080)
Towle, A., Bainbridge, L., Godolphin, W., Katz, A., et al. (2010) ‘Active patient involvement in the education of health professionals’, Medical education. Blackwell Publishing Ltd, 44(1), pp. 64–74.  
https://doi.org/10.1111/j.1365-2923.2009.03530.x

Zeller, M., Perruzza, E., Austin, L., Vohra, S., et al. (2006) ‘Parental understanding of the role of trainees in the ophthalmic care of their children’, Ophthalmology, 113(12), pp. 2292–2297.  
https://doi.org/10.1016/j.ophtha.2006.06.019

Appendices

None.

Declarations

The author has declared that there are no conflicts of interest.

This has been published under Creative Commons "CC BY 4.0" (https://creativecommons.org/licenses/by-sa/4.0/)

Ethics Statement

The study was reviewed by the University Hospital Southampton NHS Trust Research Ethics Committee and deemed exempt from formal research ethics approval.

External Funding

This paper has not had any External Funding

AMEE MedEdPublish: rapid, post-publication, peer-reviewed papers on healthcare professions’ education. For more information please visit www.mededpublish.org or contact mededpublish@dundee.ac.uk.