## Discussion paper

# Research with children in hospital: challenges and opportunities

#### **Abstract**

Qualitative research is highly valued as a means of understanding patients' experiences of illness and the healthcare system. When seeking to understand the healthcare experiences of children and young people, it is common to see parents and health professionals speaking on behalf of children, rather than children and young people representing themselves.

There are numerous challenges in undertaking research of any kind in a hospital setting, particularly when seeking the participation of children and young people. When qualitative research methods are proposed, children and young people are even more likely to be overlooked.

This article seeks to discuss the inequitable participation of children and young people in qualitative research conducted in a hospital setting. Challenges in undertaking research that acknowledges and values the voice of children are identified and critically examined to consider ways in which children and young people can more readily participate in sharing their own experiences of health and healthcare.

Keywords child-centred research, qualitative research, methodology, research ethics, challenges

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#### Introduction

Despite international efforts to promote the rights of children to be heard and to have a voice in their experience of health services, there remains a prevailing view of childhood that must be overcome. It originates in socially constructed ideologies that frame children as incapable and incomplete, of them 'becoming' (adult) rather than 'being'.<sup>1,2</sup> With regard

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to learning from their experiences, children and young people (from now on referred to as children) have been assumed to be incompetent, unreliable and lacking in expertise, and therefore being unable to inform decision-making or health services planning.<sup>3</sup> Until quite recently, research into matters of childhood has been concerned with the developmental acquisition of capabilities, with children being objects of investigation rather contributors to knowledge about themselves.<sup>4</sup>

Challenges in hearing children's views continue to exist and are well documented within healthcare services research.<sup>5</sup> Healthcare professionals and researchers are not immune to the socially and culturally constructed views of children's capacity.<sup>2</sup> Children can become marginalised throughout their healthcare experiences and their views may not always be taken seriously.<sup>6,7</sup> This has led to children experiencing 'epistemic injustice' in healthcare, where the reporting and interpretation of their experiences is seen as requiring much effort and resources, and their views and opinions not being given full credibility.<sup>8</sup>

The principle that children have a right to have their views heard and taken seriously was introduced by the United Nations Convention on the Rights of the Child (UNCRC) in 1989.9 Article 12 of the UNCRC addresses the issue of respecting children's views, stating that signatory parties shall "assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child".

Article 13 addresses the issue of children's right to freedom of expression, stating that this right "shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice". The UNCRC has significant implications for healthcare. In Europe and Australia for example 10,11, charters have been developed to support the principle that children and young people should have their views heard and taken seriously. The UNCRC has also given impetus to the development of research approaches that focus on including and valuing the vital contribution children can make to our understanding of their lives and experiences. The last 3 decades has therefore seen a growing shift in mindset, from one that views children as irrational and unreliable witnesses, to one that values children's voices as being integral to research about their lives.12 Despite this, significant challenges still exist when conducting research with children as participants, particularly in the hospital setting. Following principles from the UNCRC, qualitative research methodologies that focus on respecting and including children's voices have become increasingly popular.<sup>12-17</sup> Initially developed for education and social research, child-centred qualitative research is now often used to understand children's experiences of healthcare.<sup>18</sup>

This article will identify some of the challenges of including children's voices in healthcare research and provide suggestions as to how these challenges may be overcome. Child-centred qualitative research will be proposed as a methodology that offers potential to redress the often-limited voice of children in health research.

### Challenges in researching with children

It is widely recognised that understanding patient experiences of healthcare is vital to ensuring high quality services. 19,20 However, the views of parents and health professionals are often more readily sought when researching children's healthcare experiences. 1 The exclusion of children's voices from health research is partly due to the numerous challenges and barriers that researchers face. Parents' opinions are often obtained in proxy of their child's as there is an assumed match between a parent's and a child's view. This has led to the marginalisation of children's experiences and perceptions in research. The way we view children's experiences is influenced by pre-existing systems, societies and cultures. Unrassumptions that children are incapable of forming valid and reliable views on matters that concern them is largely socially constructed.

Numerous challenges in researching with children have been identified and were personally experienced during my own PhD study, which I will provide reflection on throughout this article. Issues concerning ethics, governance, gaining and maintaining access, consent, engaging children in research, and the representation of children's voices have all been reported in the literature.<sup>22,26-29</sup>

#### **Ethics processes**

Assumptions regarding the role of children in research frequently exist among the adult members of human research ethics committees. Children are often viewed as vulnerable, with researchers having the potential to cause harm to the child.<sup>23</sup> While every effort should be made to ensure safety

and reduce harm, this protectionist perspective means that ethics committees take a very cautious approach which is often at odds with the child's rights to participate and have their views heard. This can often impede the research process.<sup>22</sup>

Although children and young people are able to consent for medical treatment independently of their parents once they are deemed to possess sufficient understanding and competency (Gillick vs West Norfolk and Wisbech AHA, 1985), the issue of their consenting to involvement in research is less clear.29 For example, the ethics and research governance process for my own study took several months, due in part to a lack of agreement about the required age of consent for research participation. This resulted in several amendments to the original proposal. Healthcare ethics committees will generally take a conservative approach; therefore, whilst always considering the need for methodological rigour and lowest possible risk, applications should allow for flexibility in the research design.28 Alternative plans for recruitment or data collection in the ethics application may mitigate the need for repeated amendments.

#### Access and recruitment

Many researchers experience profound difficulty in recruiting children to studies, with the process being time-consuming and often resulting in little or no success.<sup>22,29</sup> It took 2 years to recruit 20 children to my own study, a fact that must be considered in research plans and timelines. Self-referrals sought through posters and flyers is a popular research recruitment method; however is not necessarily successful for the recruitment of children, even when advertising materials are distributed widely.<sup>29</sup> The use of age-appropriate and visually appealing advertising material, face-to-face recruitment in clinics and hospital wards, snowball sampling, and recruitment through health professionals should be all be considered. Importantly, building variability into recruitment methods may also avoid the need for amendments to ethics applications and further time delays.

This combined approach to recruitment benefits from the identification of a research champion who is known to stakeholders and is physically 'on the ground' at the chosen site to coordinate and drive the process. Researchers who are not known to the organisation can be awarded 'outsider' status<sup>22</sup>, a position that is incongruous with the "simultaneous negotiations and building of relationships on many fronts" required to gain access to children and young people.

While access may be positively influenced by pre-existing relationships, multiple levels of individuals, groups or organisations act as gatekeepers between the researcher and research participants. When children are so unwell as to need hospitalisation, multiple levels of gatekeepers can actively assist, or obstruct, the process of accessing people for research.<sup>22,26</sup> While it is both appropriate and necessary that health professionals protect children in their care, gatekeeping is not only challenging but time consuming when researching in the hospital environment.<sup>22,28,31</sup> The need to negotiate with multiple adults before accessing and recruiting children to research studies is again well documented in the literature.<sup>22,26,28,31</sup>

My own experience was of several hospital personnel – including executive managers (directors of nursing and hospital general manager), head of clinical governance unit, heads of department, medical staff, nurse unit managers, registered nurses and child life therapists – that needed to be consulted with in order to access and recruit children to my study. Health professionals are busy people and will make up their own minds as to whether the research activities add to or compete with their workload. Recruiting children for a study may not be high on their working day list of priorities and so understanding hospital and health professionals' priorities is essential.

In addition to factors that may disengage health professionals such as intrusion, privacy and work disruption, the study must generally meet the needs of the organisation. Offering research evidence that is useful to practice will more likely result in approval and cooperation. Researchers may need to pay a 'fee' which could include assisting service development, helping with development of staff skills, or political representation.<sup>26</sup> It is important to identify and develop an effective relationship with those in positions of influence to ensure their full understanding of the process and the relevance of your research.

Other studies have noted how gatekeepers may select children to whom the researcher is given access, thereby 'cherry- picking' or censoring potential participants.<sup>29,33</sup> This may be out of a desire to protect children under their care, assumptions around children's competency to be involved in research<sup>29</sup>, the result of considering risks after hearing children's perspectives about their healthcare experiences<sup>23</sup>, or may even be due to their own competing research agendas. Health research is dominated by a scientific paradigm and qualitative research can be given lower priority or be seen as less valid.<sup>22</sup>

Negotiating with and gaining consent from parents is often the last step before inviting a child to take part in a study. Researchers are dependent on parents to pass on information about research studies to children<sup>28</sup> who may be reluctant to consent if participation is perceived as an added burden or stress for themselves or their sick child. For example, it was not uncommon for parents in my own study to refuse consent before they had consulted with their child. Parents naturally want to protect their children<sup>28</sup>; however, parental gatekeeping may also restrict children's rights to participate and have a say on matters that are of concern to them.<sup>33</sup> Clearly explaining how the research aims to further understand the experiences of children and allowing time for thinking and questioning may help overcome parental concerns.

#### Practical and organisational challenges

The short length of stay of acutely unwell children has been identified as a barrier to recruiting hospitalised children.<sup>31</sup> For my own study, the average length of stay for many children was less than 2 days, offering only a small window of opportunity between the child being too unwell to participate and being discharged. Interviewing children at home following discharge may be preferable for families and this eventuality should be included into the initial ethics application to prevent

delays. Other practical challenges are those shared by many researchers recruiting hospitalised participants: limited access due to infection control procedures; patients being away from the ward due to surgery, x-rays and other testing; prioritising time for treatment and caring activities; and limited space in which to undertake research activities. The child's daily healthcare needs must always be the priority.<sup>22,31</sup> Planning to visit wards after business hours and at weekends may reduce the likelihood of children being engaged with other health professionals or undergoing testing or treatment in other departments. In addition, private, accessible spaces for data collection are usually at a minimum during busy times and interviewing children at the bedside is unlikely to meet conditions for privacy and confidentiality.

# Child-centred qualitative research: putting children at the centre of research

Whilst barriers and challenges cannot always be prevented, using research methodologies that focus on putting children at the centre of the research process can help ensure their perspectives are central to all research activities and can provide the researcher with strong arguments for children's inclusion in healthcare research.

Our social worlds are pre-existing systems that are stratified and marked with inequalities. Our way of seeing the world in which we live is taught to us by pre-existing systems, societies and cultures.<sup>24</sup> What we see as knowledge and facts are social constructs, artefacts of socially mediated discourses that are governed by normative rules and historically and culturally situated.<sup>34</sup> Our way of knowing about children has been influenced by these societies and cultures, and this 'knowing' is often taken for granted and goes unchallenged. Social constructivist research methodologies are interested in individual stories within these social systems and aim to generate understanding of the lived experience of those whose voices often go unheard due to social inequalities. Child-centred qualitative research is one such methodology which aims to place children at the centre of research about them. It draws on the principles of the UNCRC to provide a philosophical foundation that supports children's rights to have their views heard and taken seriously.35

A key concept of child-centred qualitative research is the notion of a child versus a child's perspective. A child perspective is one in which adults have opinions about children's experiences, whereas a child's perspective is when children are given the opportunity to speak for themselves.<sup>21,36</sup> Child-centred qualitative research replaces the discourse of protection and nurturing of children, with the rights of children to self-determination, as human beings with unique, valid and reliable knowledge and with the right to participation being a social obligation. Child-centred qualitative research also places responsibility on adults to provide children with the opportunities to have their voices heard by creating safe, inclusive and engaging ways for children to do so and honours the principles of Article 12 of the UNCRC to provide the best possible source of knowledge about children's lives.37 Children are not only invited to contribute to the collection of data but also to participate at different stages throughout the research process. This includes identifying research questions, choosing methods, collecting data and

analysing and interpreting the results.  $^{38}$  Participation can occur anywhere between inception and completion of the study.  $^{39}$ 

The pragmatic issues of undertaking child-centred research often need to be balanced with concerns of methodological rigour<sup>27</sup> with flexibility in design. Children not only participate in the generation of data, but are viewed as partners (rather than simply objects) in the research process.<sup>38</sup> Participation is not an 'all or nothing' phenomenon and can mean different things to different individuals.<sup>40,41</sup> Children may or may not choose to participate. What is more important is that children act upon their own desires, not on the desires of adults, and therefore participation is less about the techniques and methods used and more about the philosophy or methodological 'attitude' taken<sup>40,42</sup>, with an understanding that being child-centred means that children are at the centre of all thinking in the research process, as well as at the centre of health professional practice.<sup>18</sup>

Child-centred qualitative methodologies often use art-based methods in data collection. <sup>18,43</sup> These methods are a way of facilitating engagement with children, allowing for communication and the interpretation of their own experiences using activities that are familiar, fun, accessible and 'child-driven'. Techniques may include drawing, storytelling, poem writing, photography, video making, puppetry, collage, games, poster-making and mapping. <sup>44</sup> These methods do not preclude the use of other more traditional methods of data collection – for example interviews – as art-based techniques can supplement these. Maintaining flexibility and having alternate data collection methods available are important when undertaking child-centred qualitative research, as different methods suit different children. <sup>31</sup>

Choosing methods that support child-friendly approaches and recognise inequalities in power between children and adults is also essential. Taking the 'least adult approach' builds trust relationships<sup>45</sup>, supports child-led research and enables the researcher to embrace the 'messy' process of listening to children's voices.<sup>46</sup> Interviews should be flexible enough to allow children to talk about issues that are important to them yet structured enough to steer children back to the topic when required. Expecting diversions at interview prepares the researcher to embrace these as a part of the data collection process.

Whatever research methods are used, the authentic representation of children's voices is the main consideration, and clarity on the meaning of a child versus child's perspective is paramount.<sup>21</sup> As children's voices are often dominated by those of adults, data analysis should not take an interpretive approach. This can result in data being explained through an adult lens.<sup>47</sup> Descriptive approaches like qualitative content analysis<sup>48</sup> are appropriate to mitigating this risk. Involving children in the process of data interpretation will also ensure the creation of findings that reflect the perspectives of children, not the adult interpretations of those perspectives.<sup>35</sup>

#### Discussion

Child-centred qualitative research is based on a philosophy that credits children with having both the ability and the right to contribute to research on their own terms. This approach

requires a shift in thinking about children as objects of investigation, to children as active beings in the research process<sup>4</sup>. Despite progress in recent years, strong socially and historically constructed concepts of childhood still exist and children continue to be viewed as lacking the emotional or cognitive maturity to speak for themselves and as being in need of protection from the harsh realities of the adult world<sup>25</sup>.

There is a powerful risk-averse discourse surrounding contemporary childhood<sup>49</sup> and this becomes starkly evident during the research process. Issues of gatekeeping and the requirement for all children and young people under the age of 18 years to gain parental consent for their decisions are particularly grounded in the ethical positioning that children are vulnerable and research is potentially dangerous.<sup>23</sup> Balancing the legal rights of parents with the rights of children to have a voice in matters that concern them can be difficult and potentially threaten the participation of children and young people in healthcare research.22 The blanket requirement of parental consent for all children under 18 years fails to recognise children's capacity to contribute<sup>33</sup>, often denies them a voice, and adds another layer of gatekeeping to a process that already requires the navigation of multiple levels. The requirement for all children and young people in my own study to obtain parental consent was a compromise to the research design that challenged one of the basic principles of child-centred qualitative research.

Overall, the fundamental tensions between Article 3 and 12 of the UNCRC, the rights to protection and participation, create real challenges for researchers working with children where "the discourse of child vulnerability competes with the discourse of child participation and involvement".<sup>23</sup> A 'thin red line' exists between care and control which, whilst masquerading as being in a child's best interest, can act as a form of restraint on children's right to a voice.<sup>49</sup> Children's best interests should always be the primary consideration whilst undertaking research activities, but this should not be at the expense of their views and experiences being excluded.

Researching with children can be challenging and this can be considerably increased in the hospital setting. This may explain why so little research is undertaken with this cohort.<sup>22</sup> Healthcare ethics committees are generally risk-averse, often requiring the researcher to reach compromises that may ultimately necessitate altering the research design.<sup>22</sup> Childcentred qualitative research acknowledges the difficulties of researching with children<sup>50</sup> and the need for flexibility.<sup>27</sup> Careful pre-emptive planning is required, with adaptability built into the research design so the methodological integrity of the study is not compromised. While seeking to empower and collaborate with children, it should not be assumed that greater levels of participation in the research process are necessarily more inclusive and empowering.<sup>13</sup> What makes child-centred research participatory is the social relations and value given to co-producing knowledge.51

#### Conclusion

The challenges in undertaking child-centred qualitative research need to be considered when embarking on research that is for and with children. These challenges, which

include issues of access, gatekeeping, ethics processes, organisational and practical difficulties, ultimately impact upon the researcher's ability to undertake research with children and young people. This is particularly true when researching in the hospital setting and may be the reason why so little research about hospitalised children's experiences is undertaken. Understanding these challenges encourages child-focused researchers to pre-emptively plan and formulate ways of working with, through and around them in order to hear and value children's own accounts of their healthcare experiences. Flexibility in the research design is paramount, as is the premise that children are indeed competent at telling their own stories, that those stories are worthy of being heard, and that barriers can be overcome. Adopting child-centred research methodologies ensures that processes are firmly focused on the rights of children to contribute to research and their ability to do this on their own terms.

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#### Conflict of interest

The authors declare no conflicts of interest.

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