Title	A pilot study to explore children’s experiences of intensive care post-cardiac arrest using art-based participatory methods
Type	Article
URL	https://clok.uclan.ac.uk/id/eprint/56107/
DOI	https://doi.org/10.1177/13674935251355323
Date	2025
Citation	Thomas, Donna and O’Connor, Graeme (2025) A pilot study to explore children’s experiences of intensive care post-cardiac arrest using art-based participatory methods. Journal of Child Health Care. ISSN 1367-4935
Creators	Thomas, Donna and O’Connor, Graeme

Journal of
Child Health Care

A pilot study to explore children's experiences of intensive care post-cardiac arrest using art-based participatory methods

Journal:	*Journal of Child Health Care*
Manuscript ID	JCHC-2023-0157.R5
Manuscript Type:	Original Article
Keyword:	Children's Participation, Intensive Care, Paediatric
Abstract:	Children who have survived a cardiac arrest are at highest risk of long-term impairment, termed Post Intensive Care Syndrome (PICS). This study aimed to explore through participatory and creative methods, children and young people's (CYP) experiences post-cardiac arrest. Participatory research includes drawing, painting and small-world play. CYPs were recruited who had been admitted to intensive care post-cardiac arrest and had the cognitive and physical ability to talk, draw, paint, or play out their experiences. Seven CYPs and families consented to participate. The median number of interviews was two (IQR2,3), with a median interview length of 24 minutes (IQR15,65minutes). Themes that emerged: gratitude, distrust and extrasensory experiences. Four of the seven (57%) participants opted to paint or draw to convey their experiences. Two (28%) participants had no memories of their cardiac arrest or time in intensive care but used creative methods to express gratitude to the care team. Participatory research methods may be an effective way for CYPs to convey their experiences of intensive care. CYPs who have been critically ill have expressed a need to make sense of their experiences in intensive care. Healthcare professionals should be aware that these experiences may be deemed as extrasensory and require sensitive exploration.

A pilot study to explore children’s experiences of intensive care post-cardiac arrest using art-based participatory methods

Abstract

Children who have survived a cardiac arrest are at the highest risk of long-term impairment, collectively termed Post Intensive Care Syndrome (PICS). This study aimed to explore through participatory and creative methods, children and young people’s (CYP) experiences post-cardiac arrest intensive care. Participatory research includes drawing, painting and small-world play. CYPs were recruited who had been admitted to intensive care post-cardiac arrest and had the cognitive and physical ability to talk, draw, paint, or play out their experiences. Seven CYPs and families consented to participate. The median number of interviews was two (IQR2,3), with a median interview length of 24 minutes (IQR15,65minutes). Themes that emerged: gratitude, distrust and extrasensory experiences. Four of the seven (57%) participants opted to paint or draw to convey their experiences. Two (28%) participants had no memories of their cardiac arrest or time in intensive care but used creative methods to express gratitude to the care team. Participatory research methods may be an effective way for CYPs to convey their experiences of post cardiac arrest intensive care. CYPs who have been critically ill have expressed a need to make sense of their experiences in intensive care. Healthcare professionals should be aware that these experiences may be deemed as extrasensory and require sensitive exploration.

Keywords: Children’s Participation; paediatric; intensive care

Introduction

Children who have survived a cardiac arrest are at the highest risk of long-term impairment (Pinto et al., 2017). A decline in neurofunctional status occurs in up to a quarter of children requiring intensive care (Caprarola et al., 2017); of this cohort, children admitted who suffer out-of-hospital cardiac arrest have worse outcomes if they have a cardiac related primary diagnosis. having worse outcomes (Caprarola et al., 2017). In the adult and paediatric population there are approximately 60,000 out-of-hospital cardiac arrests are estimated to occur in the United Kingdom each year (Perkins and Cooke, 2012). Although a sustained return of spontaneous circulation can be initially established after resuscitation, many children do not survive to hospital discharge due to catastrophic brain injury (Topjian et al., 2019). Factors associated with survival and neurobehavioral function among children who are in a medically induced coma requiring mechanical ventilation post-cardiac arrest related to shorter duration of chest compressions, compressions not required at hospital arrival, fewer and epinephrine doses (Meert et al., 2016). The term Post Intensive Care Syndrome (PICS) has been coined to describe the effect of both the cognitive and physical abilities of an individual admitted to intensive care (Lopes-Júnior et al., 2018). Nearly half of long-term out-of-hospital cardiac arrest survivors have symptoms of PICS after 12 months from a cardiac arrest; These high numbers in the post-cardiac arrest population suggest greater emphasis on appropriate screening and treatment in this patient population (Viktorisson et al., 2019).

Definitions of PICS have emerged from adult experiences that may diverge from children’s experiences (Thomas, 2021). Differences highlighted for PICS in children include dependence on the family and health recovery level (Woodruff and Choong, 2021), and exposure to death and dying (Manning et al., 2017). Additionally, experiences considered extrasensory and delusional, feature largely in children with PICS and are often attributed to opiate-based medications whilst in intensive care (Colville et al., 2008). It is still unclear what the nature of these reported delusions is, in terms of experiences for children (Traube et al., 2017). Participatory research has the potential to explore anomalous experiences in children (Thomas, 2021).

Participatory research approaches involve methodology viewed as ‘non-traditional’ and include but are not limited to drawing or painting and small world play (Brown et al., 2020). Art-based research is one such method, demonstrating a shift in values in terms of what constitutes knowledge and affording opportunities for children to be involved in research (Punch, 2002; Satchwell et al, 2022; Thomas, 2023). Using art-based approaches with children in research is considered to enable more accurate representations of children’s experiences (Umoquit et al, 2011), to unmask social influences on children’s identities (McLaughlin & Coleman-Fountain, 2018), or to devolve power to children in research (Kindon et al, 2007). Art as a research method has the potential to highlight the embodiment of experience for children (Woodyer, 2008) or can be used as a communication tool (Liebenberg, 2009). Participatory methods can be an effective way to involve children in research who have been unwell or have impaired cognition, in a meaningful way (Boydell et al., 2012). Traditional research approaches in a clinical context have the potential to exclude vulnerable patient groups from research – including children. Qualitative art-based methods with responsive interviewing technique proved to be an effective method to explore psychosocial well-being of childhood survivors of critical illness - survivors revealed uncertainties in their stories as they recalled their critical care event, exposure to death and dying; talking about extreme physical vulnerability provoked anxieties, mediating between different social worlds and identities (Manning et al., 2017).

Participatory research generates knowledge based on the experience of the child, rather than starting from a professional understanding of the phenomenon under investigation (Grant, 2016). Participatory research enables and enhances the types of information produced around other circumstantial factors that may impact PICS (Tierney et al., 2022). Importantly, children carry authority over their own experiences and life stories. Knowledge generated from participatory studies is shown to enhance professional learning and practice (Freire et al., 2022).

The literature concerned with involving children in post-intensive care research is sparse, revealing an absence of children’s experiences and views in studies that define PICS. A review by Menzies et al (2017), highlighted both the lack of research involving children in intensive care and the need to develop participatory research approaches to explore the experiences of children in these settings (Menzies et al., 2016). A previous study that used participatory research with children in a hospital context worked well, engaging children in research to express their experiences around care and support (Wu and Cree, 2022). Therefore, for this pilot study, we focused on children who are at greatest risk of developing PICS (children post-cardiac arrest) to explore the usefulness of participatory methods as a platform for children to describe their lived experiences.

Aim

To explore and describe children's experiences of intensive care post cardiac arrest.

Materials and Methods

The study design applied participatory research and creative methods, involving drawing, painting, play and talking to gain insight into the self-reported lived experience. The timeframe of children’s experience encompassed the point of cardiac arrest to their discharge from intensive care. Ethical approval was granted by the Health Research Authority and Health and Care Research Wales on 19th July 2022 – reference: 316532 22/SC/0185. Recruitment procedures were followed by the ethical standards of the responsible committee on human experimentation with the Helsinki Declaration of 1975.

Population

Participants were recruited from a tertiary paediatric intensive care unit. Participants were eligible for inclusion if: aged four to 16 years old; children who had been admitted to intensive care due to an in or out of hospital cardiac arrest requiring chest compressions for ≥2 minutes, and required mechanical ventilation after return of spontaneous circulation - defined as a return of a perfusing heart rhythm accompanied by the presence of a palpable central pulse from a spontaneous perfusing heart rhythm (Topjian et al., 2019); post-extubation children with the cognitive ability to understand the aim of the study, which may include non-verbal communication due to vocal cord palsy but sufficient motor skills to draw, paint, or play; or communicate verbally but lacked motor skills to draw, paint, or play. Participants were excluded if their cognitive function was impaired to the extent that the child was unable to grasp the study aim. The cognitive function and ability of the child to understand and participate in the study were assessed by the research team and parents.

Once participants were recruited, before each planned interview the researchers and ward clinical psychologist coordinated diaries to ensure the clinical psychologist was available in the unlikely event a child becomes distressed about an experience of intensive care. The clinical psychologist was not required during any of the interviews.

Steering Group

A Steering Group of young people was established at University of Central Lancashire. The seven young people (age range 12-16 years old) who attended the steering groups had hospital experiences and long-term medical conditions. Other members of the Steering Group included an independent researcher based at University of Lancashire, along with the two researchers involved in the pilot study (GOC and DT). The first meeting aimed to share information about the proposed study and discussions around co-designing the protocol. The second meeting involved checking the clarity of patient/ parent information sheets and proposed delivery/ set up of creative methods. The final meeting involved interpreting the images produced by the children/ young people from the study.

Data Collection

A bedside play area was assembled with the option to access different participatory research methods including art materials (paints and crayons), small world play (including hospital beds and park swings/ slides), and an instant photo camera. A communication board and communication cards were available to help children with limited language skills. The communication board/ cards use photos, symbols, or illustrations to aid communication. Children can gesture and point to images to communicate. The length of the session depended on the child (i.e., tiredness, willingness to participate, etc.). Interviews with participants were recorded using a video recorder, enabling information from research methods such as play to be documented to allow researchers to focus on the activity with the child (Sparrman, 2005; Carter and Ford, 2013).

The researchers applied semi-structured questions with the participants while they played/ drew (Adapted from (Foster and Whitehead, 2018).

1. What was good about being in intensive care?
2. What was bad about being in intensive care?
3. Do you remember why you were admitted to intensive care?

4. What or who helped you before you were in intensive care?
5. Please tell me about your drawing.
6. Is there anything else you would like to add?

Data analysis

To provide a platform for centralising children's narratives data collection methods included participant observation, interviews and conversations with CYP participants (Tindall, 2009). Both co-interpretation and thematic analysis were adopted to allow for a comprehensive assessment of CYPs' lived experiences. Co-interpretation of data is a form of 'member-checking' for adult researchers to test their interpretations against children's meanings and can avoid the limitations inherent when analysing data without participants' insights (Lavari, 2018).

In this pilot study, co-interpretation emerged at the point of CYP's creative representations, either through drawing, painting and/or play. Co-interpretation as a research practice can present challenges for representation as the researchers' endeavour to listen to children and to understand and portray their experiences accurately (Tathum-Fashnu, 2022). We noted the active, fluid and embodied nature of co-interpretation with CYP. For example, we engaged in imaginative gameplay to support children in sharing their experiences, or our fingers would follow the squiggles and tunnels produced by children in interviews. Images were analysed to identify any significant features, for example, patterns and colours, which may appear consistent across children's artwork (Kindon et al., 2007).

Visual and embodied data (play) can afford a suspension of the researcher's preconceptions of familiar territory (Manney, 2010). Co-interpretation of visual images with children requires an ethical reflexivity (Warin, 2010) and at times, a transpersonal reflexivity (Thomas, 2022) when experiences reported by children go beyond typical ideas of personhood, space and time. The researchers afforded spaces in research interviews for children to agree, adopt, reject and contest researchers' interpretations of their experiences. Children's images were centralised in co-interpretation, "circumventing the initial need for language spontaneously capturing the texture of an experience" (Boden et al, 2018). Children's images produced in research interviews provided "a shared focus for parallel or subsequent verbal discussion or talk around image (Rollins, 2005).

Thematic analysis was applied to the data set through transcription to identify any significant themes. The first step in analysing video data was to transcribe the audio into text, which was completed manually. Video data was also used to capture the visual and non-verbal cues of participants, such as facial expressions and gestures. Extracted data was coded by assigning categories to different segments of the video, highlighting important or interesting observations.

Steering Group Data Analysis

The Steering Group was facilitated by an independent researcher from the University of Central Lancashire. A semi-structured focus group topic guide was used to explore initial reactions to paintings and drawings. Thematic analysis was applied to the audio recording data set through transcription to identify any themes that emerged from the patient involvement focus group (Skukauskaite et al., 2022).

Statistical analysis

Normally distributed continuous variables relating to age (years) and length of stay in intensive care (days) are expressed as means, ± standard deviations (SD), while medians and interquartile ranges (IQR) are used to describe the range of non-normal distributions including number of interviews and duration of interview (minutes).

Findings

The total number of CYPs who were initially screened as potential recruits was fourteen. However, during further assessment by the research team, seven CYPs were excluded due to significant brain damage rendering the child unable to comprehend the study aim. The remaining seven CYPs and families consented to participate in the study. The median age of CYP was 12 years old (IQR 9, 15), and the average length of stay in intensive care was 19 days (± 10 SD). The commonest cause for admission to intensive care was due to an underlying heart defect, which accounted for 3 (43%) participants (Table 1).

The median number of interview episodes per CYP was two (IQR 2, 3), and the median length of interviews was 24 minutes (IQR 15, 65) (Table 1). Four (57%) CYPs applied art (painting/drawing) to convey their time in intensive care. The drawings were either completed while the interviews were taking place or collected the following morning after the first interview.

Themes identified from participatory research methods:

Gratitude

The CYP reported a positive experience of intensive care, which was depicted in the drawings of butterflies and a rainbow (Figures 1 and 2). Although two CYPs had no memories of their cardiac arrest or time in intensive care, they expressed their gratitude to the care team using creative methods. CYP-Two wrote a thank you letter which valued the care they had received from nursing staff. Figure 3 is an example of multimodality (image with text) used to represent the CYP's experience of intensive care and emphasise gratitude towards nursing staff.

Relationships with staff were important for children, with nurses highlighted by four CYPs positively. Conversely, one younger participant evaluated doctors as "horrible" (age 6 years). When explored further, this description of doctors was linked to issues of rapport and trust.

Distrust

The researchers noted how CYP-Three became distrustful of our research intentions and misinterpreted the play research process as a distraction to taking blood, a technique often employed in paediatrics (Oulton et al., 2018). However, after reassurance and encouragement to play the researchers noticed she showed interest in taking control of the video recorder. This initiated an adaption to the participatory research methods and the researchers invited CYP-Three to be the 'director' of the play session, in which she guided the researchers to act out her own experiences, using the play items. Once the researchers had gained her trust, she then engaged in small-world play and painting.

CYP-One looked awkward and self-conscious about sharing his story, which we later attributed to the nature of his extrasensory experiences. This feeling of distrust towards the researchers was compounded by the presence of his younger brother who was also in the hospital room and voiced his concern that the brother would mock him. CYP-One's parents were extremely supportive, encouraging him to share his experiences, while distracting his younger brother with a games console.

Extrasensory Experiences

Extrasensory perception involves awareness of information about events external to the self not gained through the senses and not deducible from previous experience (Branković M, 2019). Three of the seven (42%) CYPs reported an example of extrasensory experiences, indicating that these experiences could be a significant aspect of a child's intensive care journey post-cardiac arrest. CYP-Seven described how she felt she could leave her body at any time, which was a frightening experience as she was worried that if she did leave her body, she might not be able to return to it.

"I had to fight to keep within my body to stop floating away." (CYP-Seven)

CYP-One began to recall his experience verbally, yet his narrative became disjointed, due to a lack of linguistic resources available to him. At this point, the researchers invited him to represent his experience visually. CYP-One drew two circular patterns (Figure 4) that were like spirals or tunnels, describing the sensation of moving through a spiral tunnel that split off into two other tunnels from which a light could be seen at the end. The experience was ineffable, lacking any referential with the social and physical world. CYP-One managed to draw a very simplistic version of what he experienced. A similar spiral tunnel was drawn by Participant Three, but the researchers were unable to get any verbal details about this drawing.

When questioned whether this was a dream, CYP-One became adamant that it was not, legitimating his experience with another memory that was corroborated by his parents:

"I was in bed, awake, the doctor was right next to me, and we talked, then when I looked to the side of the bed, there was a girl dressed in black and white, she was kind and smiled, and said you have a very bright future. She had weird old clothes on - I remember she was in old clothes like old black and white pictures." (CYP-One)

Of note, the message received from the young girl gave CYP- One hope, which supported his continued well-being in recovery. CYP-One welcomed an opportunity to share his experiences, as they had been a large aspect of his intensive care journey. CYP-One continued to share other extrasensory experiences, such as being in two places at the same time:

"I was having a dream, but it was different from a dream, it felt different from when I was in bed, it felt like the room was different. I felt at one point everything was made of stone and I was in a different room, it felt and looked like Romeness, you know Rome it felt like that." (CYP-One)

Incidentally, the family has never been to Italy or Rome, highlighting how his experience was non-referential to past experiences.

Findings from Steering Group

The CYP were invited to respond to general questions about the pictures with the understanding that the children had suffered a cardiac arrest and required intensive care. We recognise that these findings from the steering group are based on a discussion with a small group of young people all of whom have experienced being unwell in hospital and the views expressed are not fully representative of the service user population. From the qualitative data transcripts, the findings were derived thematically as follows:

- Sense of travel and movement: the spiral drawings were described as a never-ending staircase, increasing speed as you ascend the stairs but were not perceived as being traumatic.

- Transition: Travel and freedom were also mentioned to describe the butterfly painting. One member mentioned the butterflies represented a transition (caterpillar to a butterfly).
- Hope: the butterflies were perceived positively within the group using hope and calmness to describe the painting, especially in regard to the purple colouring used in the background colours used in the butterfly painting.

Discussion

This study aimed to explore through participatory research methods, observation and talk, children's experiences of intensive care, post-cardiac arrest. Our findings demonstrate that participatory methods were a useful tool for involving CYPs who had been admitted to intensive care. Importantly, CYPs who do have memories, especially extrasensory experiences found it difficult to make sense of and articulate their lived experience. Additionally, CYP who do not have memories of their time in intensive care still felt the need to express their gratitude to staff through participatory methods.

In this study, art (drawing and painting) and play items that mirrored the hospital environment, enabled children to develop a narrative around their experiences of intensive care. Art is gaining popularity as a participatory research method as it affords opportunities for younger children, and children without a voice, to participate in research (Eisner, 2008). Eisner (2008) notes the importance of art research methodology for capturing experience that can transcend usual ways of reporting experience. Co-interpreting art data with children and families carries special importance, especially as adult researchers can sometimes distort or misconstrue what children are trying to convey through their artistic representations.

Play methods work well when involving younger children in research (Jäger, 2013; Thomas, 2022). Children are 'experts and researchers', within their play activities and play worlds (Burke, 2008). Researching visual data with children, especially when there is little talk around images, can raise issues for a shared understanding of what children are trying to convey (Valencia Mazzanti and Freeman, 2022). A study by Herrup et al (2019) suggested a channel for children to convey their experiences of intensive care was to incorporate a picture diary. The team concluded that in a paediatric critical care setting a memory diary is feasible and perceived as beneficial by families of critically ill children. However, future studies are needed to better understand if intensive care diaries can be utilised by children and may objectively improve psychological outcomes of the child (Herrup et al., 2019).

Trust and rapport were significant aspects of the study, requiring multiple visits to build a relationship with the child. This fundamental element of participatory research with children has been highlighted by Solomon, (2014) who states constructing research relationships that dismantle the traditional child-researcher divide and therefore may warrant multiple visits. Moreover, multiple short visits may be more appropriate for children who are post intensive care, and find longer interviews difficult to manage (Christensen and Prout, 2002). However, intensive care healthcare professionals and researchers must be mindful to maintain some boundaries around establishing relationships to mitigate transference of patients' dependency due to high levels of vulnerability, which is reportedly carried by nurses in the intensive care unit (Maartmann-Moe et al., 2021).

Of the three CYPs who shared their extrasensory experiences, two provided a detailed account of what they remembered. Families and CYP's appreciated the platform and opportunity to share, not only their experience, but also their cultural understandings of experiences expressed by their child. The ethos of participatory methods is to privilege the meanings, definitions, and insights of participants around their own experiences (Cardeña et al., 2014). Little is known about how children experience post-intensive care, especially in relation to extrasensory experiences (Sansone et al., 2022). Extrasensory experiences are used to describe cognitive and physical experiences that go beyond usual ideas of personhood, time and space (Holly et al., 2018), including psychotic-like experiences (Laurens et al., 2012) or exceptional experiences (Cardeña et al., 2014). Critically ill and dying children have reported seeing entities that others cannot which is referred to as death-related extrasensory experience (Ethier, 2005). Additionally, tunnel-like visions are reported extensively across clinical studies with adults who have had a near-death experience (van Lommel et al., 2001).

Although only one of our participants was reluctant and guarded to share his experience, it is documented that children generally express a reluctance to verbally narrate their extrasensory experiences, which tend to have little referential points with the social world and physical environment (Thomas, 2023). Extrasensory experiences expose children to stigma and humiliation, rendering the child too afraid to share their experience, even when provided with a safe platform to do so (Thomas, 2023; Parnia et al., 2022). Children, at times, can represent unexplainable extrasensory experiences as dreams, as dreams are socially acceptable events (McLaughlin and Coleman-Fountain, 2018).

In the context of intensive care, extrasensory experiences are usually classified as delirium, with characteristics of agitation, disorientation, hallucinations, inattention, and sleep-wake cycle disturbances (Holly et al., 2018). Of note, neuroprotective management will form part of post-cardiac arrest care and includes normothermia , along with sedatives and analgesics; all of which can induce delirium (Moler et al., 2015). There are numerous theoretical and practical considerations related to the possible negative impact of anaesthetic agents on neurotoxicity and delirium. Intensive care delirium is a nonspecific, potentially preventable, and often reversible disorder of impaired cognition, which results from various causes in ICU patients (Arumugam et al., 2017). For appropriate management of delirium, early identification and risk factor assessment are most important (Topjian et al., 2019). Multidisciplinary collaboration and standardised care can enhance the recognition of delirium. To minimize risk factors to detect delirium and initiate appropriate treatment intervention, the validated delirium bedside screening tools should be implemented daily as routine practice by the ICU team (Arumugam et al., 2017) Without routine screening for PICS, these children are likely to be left underdiagnosed (Traube et al., 2017).

Our Steering Group served as a valuable addition to this pilot study. The consultation and participation of the young people significantly contributed to our research, providing a unique viewpoint that was not considered by the researchers. This was especially evident regarding discussion around correlation between colour and feelings (hope and calmness). Additionally, input from the Steering Group proved to be useful concerning co-designing of the creative methods, as it was a member of the Steering Group who suggested incorporating a hospital small-world play set, to help participants communicate their time and experience of intensive care. Rouncefield-Swales A. et al, (2021) state that careful decisions need to be made to ensure that patient involvement is suited to the context, setting and focus so that the desired impacts are achieved. When involving CYP with patient and public involvement it is essential to be guided by the CYP themselves regarding the level, purpose and impact of involvement (Rouncefield-Swales A et al, (2021).

The findings from our study provide a novel narrative of CYP's post cardiac arrest, intensive care experience. The amount of data gathered was informative, containing rich descriptions and variations, which made it possible to achieve a deeper understanding of the wider impact of intensive care and the utility of participatory research methods in this complex cohort. For CYPs who had memories of intensive care, especially extrasensory memories, when provided with an opportunity and safe platform to share, they do. Therefore, the aetiology of delirium or extrasensory experiences is irrelevant - the point is that CYPs are having experiences and families have expressed a need to address and discuss them. Not taking children's visions seriously is reported as contributing to feelings of fear, anger or distress in patients who have been in intensive care (Maartmann-Moe et al., 2021). Although, two CYP reported no memory from intensive care they still strongly felt the need to express their gratitude to the care team, which was expressed through participatory methods (drawings and writing). Our pilot study has shown that participatory research methods provide a platform for CYPs to express either their memories or gratitude for their time in intensive care and warrants further exploration and expansion to other high-risk PICS groups (long-term intensive care patients).

Strengths and Limitations

A strength of this pilot study was the successful incorporation of our young person 'Patient Involvement Steering Group', which provided another perspective for co-design and co-interpretation of CYP's paintings and drawings. Additionally, interviews with the CYP research participants provided insight for our follow-up study regarding time commitment required to build a rapport with children. Although all our participants in this pilot study were verbal, we identified the potential limitation of incorporating a communication board for this type of study when describing extrasensory experiences for non-verbal cognitively appropriate recruits.

Implications for practice

Healthcare professionals are increasingly aware of critical illness sequelae and how they affect both the patient and family (Watson et al., 2018). Healthcare professionals need to identify children who are at risk of developing PICS, which may be better understood and readily identified by healthcare professionals by exploring lived experiences of children with PICS. Healthcare professionals should be mindful and receptive to children who may wish to convey their experiences. A novel, simplistic, and comprehensive surveillance tool can aid healthcare professionals in the early detection and intervention of PICS, which may enhance rehabilitation and optimise long-term outcomes and recovery (Manning et al., 2017). This pilot study highlights the potential need to further explore critical illness extrasensory experiences and potential need to develop and validate a bedside tool for healthcare professionals to detect and manage extrasensory experiences.

Conclusions

Participatory research methods may be an effective way for CYPs to convey their experiences of intensive care post cardiac arrest. CYPs who have been critically ill have expressed a need to make sense of their experiences from their time in intensive care. Healthcare professionals should be aware that these experiences may be deemed as extrasensory and require sensitive exploration. Future research should expand to include other high-risk groups of PICS to provide a platform for families and CYPs to share their memories and gratitude from their time in intensive care.

References

Arumugam S, El-Menyar A, Al-Hassani A, et al. (2017) Delirium in the Intensive Care Unit. *J Emerg Trauma Shock* 10: 37-46.

Boydell K, Gladstone BM, Volpe T, et al. (2012) The Production and Dissemination of Knowledge: A Scoping Review of Arts-Based Health Research. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* 13.https://www.qualitative-research.net/index.php/fqs/article/view/1711.

Branković M. Who Believes in ESP: Cognitive and Motivational Determinants of the Belief in Extra-Sensory Perception. Eur J Psychol. 2019 Feb 28;15(1):120-139. doi: 10.5964/ejop.v15i1.1689. PMID: 30915177; PMCID: PMC6396695.

Brown A, Spencer R, McIsaac J-L, et al. (2020) Drawing Out Their Stories: A Scoping Review of Participatory Visual Research Methods With Newcomer Children. *International Journal of Qualitative Methods* 19: 1609406920933394.https://journals.sagepub.com/doi/abs/10.1177/1609406920933394.

Burke C. (2008) ‘Play in focus’: Children’s visual voice in participative research. *Doing Visual Research with Children and Young People* 1st Edition; Routledge

https://doi.org/10.1038/nri2316.

Caprarola SD, Kudchadkar SR and Bembea MM. (2017) Neurologic Outcomes Following Care in the Pediatric Intensive Care Unit. *Curr Treat Options Pediatr* 3: 193-207.

Cardeña E, Krippner S and Lynn SJ. (2014) Anomalous experiences: An integrative summary. *Varieties of anomalous experience: Examining the scientific evidence, 2nd ed.* Washington, DC, US: American Psychological Association, 409-426.

Carter B and Ford K. (2013) Researching children's health experiences: The place for participatory, child-centred, arts-based approaches. *Res Nurs Health* 36: 95-107.

Christensen PIA and Prout A. (2002) Working with Ethical Symmetry in Social Research with Children. *Childhood* 9: 477-497.https://doi.org/10.1177/0907568202009004007.

Colville G, Kerry S and Pierce C. (2008) Children's factual and delusional memories of intensive care. *Am J Respir Crit Care Med* 177: 976-982.

Eisner. (2008) Art and knowledge. *Handbook of the arts in qualitative research: Perspectives, methodologies, examples and issues. Los Angeles: Sages Publications.* 8: 3-12.https://doi.org/10.1371/journal.pone.0082963.

Engström Å, Grip K and Hamrén M. (2009) Experiences of intensive care unit diaries: ‘touching a tender wound’. *Nursing in Critical Care* 14: 61-67.https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1478-5153.2008.00312.x.

Ethier AM. (2005) Continuing Education Credit Article: Death-Related Sensory Experiences. *Journal of Pediatric Oncology Nursing* 22: 104-111.https://journals.sagepub.com/doi/abs/10.1177/1043454204273735.

Foster M and Whitehead L. (2018) Using drawings to understand the child’s experience of child-centred care on admission to a paediatric high dependency unit. *Journal of Child Health Care* 23: 102-117.https://doi.org/10.1177/1367493518778389.

Freire K, Pope R, Jeffrey K, et al. (2022) Engaging with Children and Adolescents: A Systematic Review of Participatory Methods and Approaches in Research Informing the Development of Health Resources and Interventions. *Adolescent Research Review*.https://doi.org/10.1007/s40894-022-00181-w.

Grant T. (2016) Participatory Research with Children and Young People: Using Visual, Creative, Diagram, and Written Techniques. In: Evans R, Holt L and Skelton T (eds) *Methodological Approaches.* Singapore: Springer Singapore, 1-25.

Herrup EA, Wieczorek B and Kudchadkar SR. (2019) Feasibility and Perceptions of PICU Diaries. *Pediatr Crit Care Med* 20: e83-e90.

Holly C, Porter S, Echevarria M, et al. (2018) CE: Original Research: Recognizing Delirium in Hospitalized Children: A Systematic Review of the Evidence on Risk Factors and Characteristics. *Am J Nurs* 118: 24-36.

Jäger J. (2013) Facilitating children's views of therapy: An analysis of the use of play-based techniques to evaluate clinical practice. *Clinical Child Psychology and Psychiatry* 18: 411-428.https://journals.sagepub.com/doi/abs/10.1177/1359104512455816.

Kindon S, Pain R and Kesby M. (2007) Participatory action research approach and methods: connecting people, participation and place. *Routledge. Routledge studies in human geography. London* December.

Laurens KR, Hobbs MJ, Sunderland M, et al. (2012) Psychotic-like experiences in a community sample of 8000 children aged 9 to 11 years: an item response theory analysis. *Psychol Med* 42: 1495-1506.

Lopes-Júnior LC, Rosa M and Lima RAG. (2018) Psychological and Psychiatric Outcomes Following PICU Admission: A Systematic Review of Cohort Studies. *Pediatr Crit Care Med* 19: e58-e67.

Maartmann-Moe CC, Solberg MT, Larsen MH, et al. (2021) Patients' memories from intensive care unit: A qualitative systematic review. *Nurs Open* 8: 2221-2234.

Manning JC, Hemingway P and Redsell SA. (2017) Stories of survival: Children's narratives of psychosocial well-being following paediatric critical illness or injury. *J Child Health Care* 21: 236-252.

Manning JC, Pinto NP, Rennick JE, et al. (2018) Conceptualizing Post Intensive Care Syndrome in Children-The PICS-p Framework. *Pediatr Crit Care Med* 19: 298-300.

McLaughlin J and Coleman-Fountain E. (2018) Pursuit of ordinariness: Dynamics of conforming and resisting in disabled young people's embodied practices. In Disability, normalcy, and the everyday 61-81.https://doi.org/10.1177/14614456211001607.

Meert KL, Telford R, Holubkov R, et al. (2016) Pediatric Out-of-Hospital Cardiac Arrest Characteristics and Their Association With Survival and Neurobehavioral Outcome. *Pediatr Crit Care Med* 17: e543-e550.

Menzies JC, Morris KP, Duncan HP, et al. (2016) Patient and public involvement in Paediatric Intensive Care research: considerations, challenges and facilitating factors. *Research Involvement and Engagement* 2: 32.https://doi.org/10.1186/s40900-016-0046-7.

Moler FW, Silverstein FS, Holubkov R, et al. (2015) Therapeutic hypothermia after out-of-hospital cardiac arrest in children. *N Engl J Med* 372: 1898-1908.

Oulton K, Oldrieve N, Bayliss J, et al. (2018) Using participatory and creative research methods to develop and pilot an informative game for preparing children for blood tests. *Arts & Health* 10: 227-240.https://doi.org/10.1080/17533015.2017.1392329.

Parnia S, Post SG, Lee MT, et al. (2022) Guidelines and standards for the study of death and recalled experiences of death—a multidisciplinary consensus statement and proposed future directions. *Annals of the New York Academy of Sciences* 1511: 5-21.https://nyaspubs.onlinelibrary.wiley.com/doi/abs/10.1111/nyas.14740.

Perkins GD and Cooke MW. (2012) Variability in cardiac arrest survival: the NHS Ambulance Service Quality Indicators. *Emerg Med J* 29: 3-5.

Pinto NP, Rhinesmith EW, Kim TY, et al. (2017) Long-Term Function After Pediatric Critical Illness: Results From the Survivor Outcomes Study. *Pediatr Crit Care Med* 18: e122-e130.

Rollins JA. (2005) Tell me about it: drawing as a communication tool for children with cancer. *J Pediatr Oncol Nurs* 22: 203-221.

Rouncefield-Swales A, Harris J, Carter B, Bray L, Bewley T, Martin R (2021) Children and young people's contributions to public involvement and engagement activities in health-related research: A scoping review. PLoS ONE 16(6): e0252774. https://doi.org/10.1371/journal.pone.0252774

Sansone V, Cancani F, Gagliardi C, et al. (2022) Narrative diaries in the paediatric intensive care unit: A thematic analysis. *Nursing in Critical Care* 27: 45-54.https://onlinelibrary.wiley.com/doi/abs/10.1111/nicc.12680.

Skukauskaite A, Yilmazli Trout I and Robinson KA. (2022) Deepening reflexivity through art in learning qualitative research. *Qualitative Research* 22: 403-420.https://journals.sagepub.com/doi/abs/10.1177/1468794120985676.

Solomon CR. (2014) "I feel like a rock star": Fatherhood for stay-at-home fathers. *Fathering: A Journal of Theory, Research, and Practice about Men as Fathers* 12: 52-70.

Sparrman A. (2005) Video recording as interaction: participant observation of children's everyday life. *Qualitative Research in Psychology* 2: 241-255.https://doi.org/10.1191/1478088705qp041oa.

Thomas D. (2021) A participatory research study to explore the healing potential of children's anomalous experiences. *Explore (NY)*.

Thomas D. (2022) Postmaterial Participatory Research: Exploring the nature of self with children. *International Journal for Transformative Research* 9: 6-17.https://doi.org/10.2478/ijtr-2022-0002.

Thomas D. (2023) Playing in the Field: Exploring the nature and emergence of extrasensory experiences with children. *Journal of Parapsychology* 86 829-832.http://www.sciencedirect.com/science/article/pii/S1876034117300576.

Tierney E, Rodriguez L, Kennan D, et al. (2022) Children's participation in practice: comparing the views of managers and practitioners in an early intervention and prevention programme. *Journal of Children's Services* 17: 73-93.https://doi.org/10.1108/JCS-04-2021-0014.

Tindall L. (2009) J.A. Smith, P. Flower and M. Larkin (2009), Interpretative Phenomenological Analysis: Theory, Method and Research. *Qualitative Research in Psychology* 6: 346-347.https://doi.org/10.1080/14780880903340091.

Topjian AA, de Caen A, Wainwright MS, et al. (2019) Pediatric Post-Cardiac Arrest Care: A Scientific Statement From the American Heart Association. *Circulation* 140: e194-e233.

Traube C, Silver G, Gerber LM, et al. (2017) Delirium and Mortality in Critically Ill Children: Epidemiology and Outcomes of Pediatric Delirium. *Crit Care Med* 45: 891-898.

Tress EE, Kochanek PM, Saladino RA, et al. (2010) Cardiac arrest in children. *J Emerg Trauma Shock* 3: 267-272.

Valencia Mazzanti C and Freeman M. (2022) The borders of theory: Towards an artful ontology of knowing in qualitative research. *Qualitative Research* 0: 14687941221096595.https://journals.sagepub.com/doi/abs/10.1177/14687941221096595.

van Lommel P, van Wees R, Meyers V, et al. (2001) Near-death experience in survivors of cardiac arrest: a prospective study in the Netherlands. *Lancet* 358: 2039-2045.

Viktorisson A, Sunnerhagen KS, Johansson D, et al. (2019) One-year longitudinal study of psychological distress and self-assessed health in survivors of out-of-hospital cardiac arrest. *BMJ Open*, 9. (accessed 2019/07//).http://europepmc.org/abstract/MED/31272987

https://doi.org/10.1136/bmjopen-2019-029756

https://europepmc.org/articles/PMC6615909

https://europepmc.org/articles/PMC6615909?pdf=render.

Watson RS, Choong K, Colville G, et al. (2018) Life after Critical Illness in Children-Toward an Understanding of Pediatric Post-intensive Care Syndrome. *J Pediatr* 198: 16-24.

Woodruff AG and Choong K. (2021) Long-Term Outcomes and the Post-Intensive Care Syndrome in Critically Ill Children: A North American Perspective. *Children (Basel, Switzerland)* 8: 254.https://pubmed.ncbi.nlm.nih.gov/33805106

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8064072/.

Wu S and Cree VE. (2022) Research with children in rural China: Reflecting on the process. *Qualitative Social Work* 21: 897-913.https://journals.sagepub.com/doi/abs/10.1177/14733250211031959.

Table 1. Participant characteristics, cause of cardiac arrest and overview of interviews

Figure 1. Participant 5, painting of butterflies

Figure 2. Participant 2, drawing of a rainbow

Figure 3. Participant 2, thank you letter to the intensive care nurses

Figure 4. Participant 1, drawings of tunnels he travelled through

Table 1. Children's characteristics, cause of cardiac arrest and overview of interviews

Participant	Gender	Culture	Age (Years)	Underlying diagnosis and reason for cardiac arrest	Number of days in intensive care	Participatory methods adopted by child	Number of sessions (total time- minutes)	Themes from interviews
1	Male	White Irish	13	Interstitial lung disease requiring lung transplant: respiratory arrest leading to cardiac arrest	24	Talking Art: Drawing	4 (140)	Distrust Extrasensory
2	Female	British Black African	15	Chronic kidney disease requiring kidney transplant: Hyperkalaemia-related cardiac arrest	10	Talking Art: Drawing Writing	2 (30)	Gratitude
3	Female	White British	5	Congenital heart disease post heart transplant: cardiac arrest	14	Play Art: Painting Film Directing	2 (90)	Distrust Extrasensory
4	Male	White British	12	Dilated cardiomyopathy post-heart transplant: ventricular tachycardia leading to cardiac arrest	12	Talking	2 (20)	Distrust Gratitude
5	Female	British Mixed	10	Dilated Cardiomyopathy post-heart transplant ventricular tachycardia leading to cardiac arrest	16	Art: Painting	2 (25)	Gratitude
6	Female	White British	9	Cerebral vascular accident: respiratory arrest leading to cardiac arrest	42	Talking	1 (20)	Gratitude
7	Female	British Pakistan	16	Septicaemia secondary to female genital mutilation: multiorgan failure leading to cardiac arrest	14	Talking	3 (45)	Distrust Extrasensory

Figure 1. CYP 5, painting of butterflies

92x68mm (150 x 150 DPI)

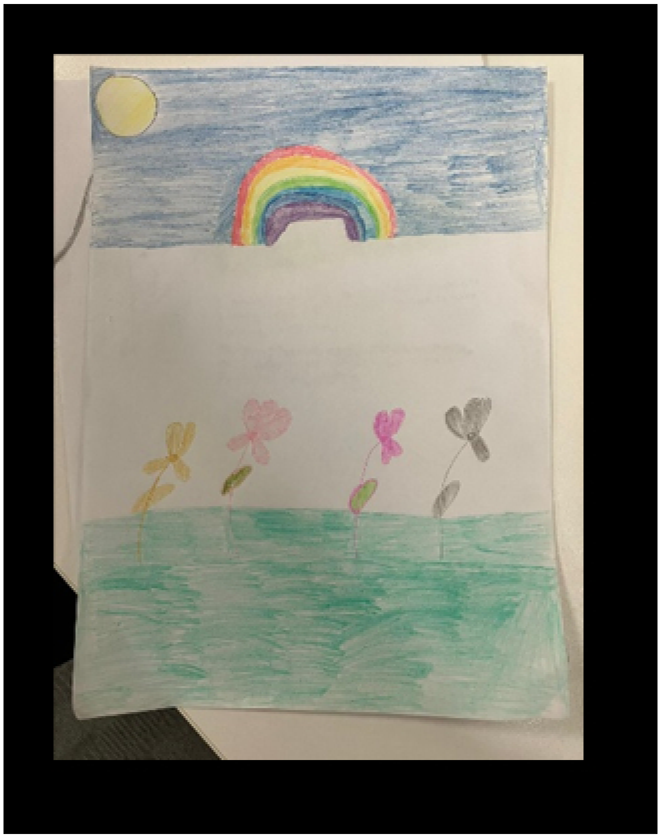
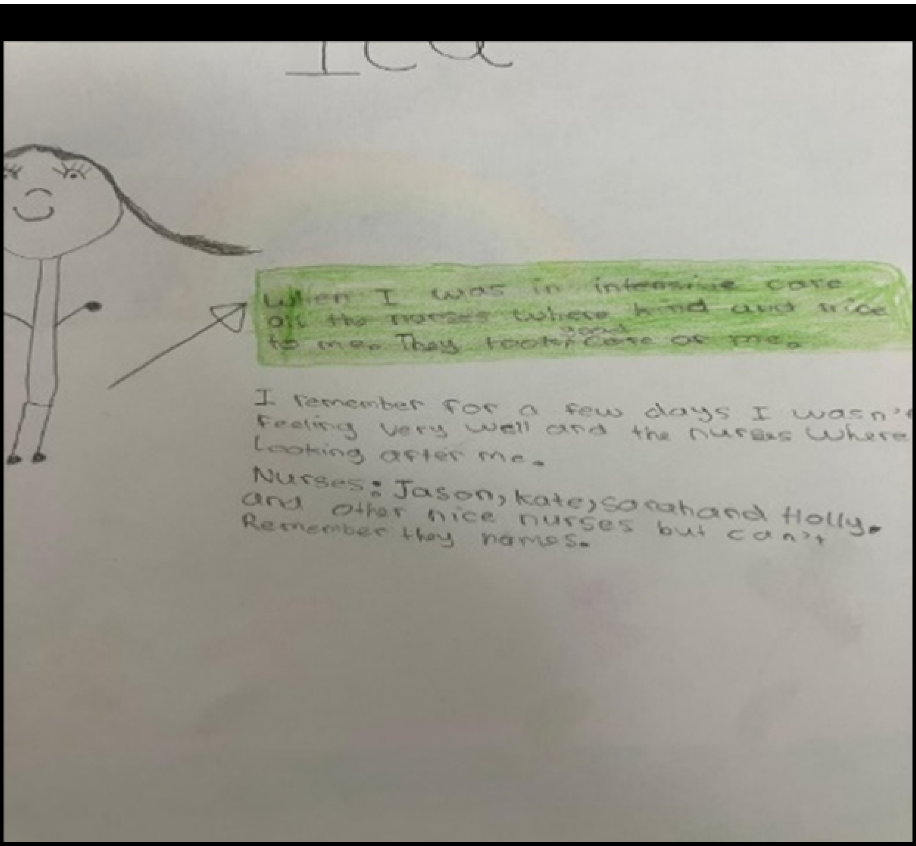


Figure 2. CYP 2, drawing of a rainbow

55x70mm (150 x 150 DPI)



ICu

When I was in intensive care all the nurses where kind and nice to me. They took good care of me.

I remember for a few days I wasn' feeling very well and the nurses where looking after me.

Nurses: Jason, kate, Sarah and Holly.
and other nice nurses but can't
Remember they names.

Figure 3. CYP 2, thank you letter to the intensive care nurses

114x102mm (150 x 150 DPI)

Figure 4. CYP 1, drawings of tunnels he travelled through

76x78mm (150 x 150 DPI)