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Exploring near death experiences with children post intensive care: A case series

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ABSTRACT

Near death experiences (NDEs) can occur during life-threatening events. In this article, we present preliminary findings from a case study series. We highlight experiences of children that are synchronous with the basic elements of near death experiences (NDEs) and discuss how children describe their own experiences. Children reported unsolicited NDE type experiences that included out of body experiences, bright lights, bedside visions, bi-location and visiting celestial places. The aim of the article is to show that children are an important research population for the study of near-death experiences. Children's near-death experiences are simple and carry transcendental features such as a peaceful darkness, a knowing awareness and time alterations. Children assign a subjective reality to their near-death experiences. Younger children may demonstrate a visual NDE semiosis which warrants further investigation. The aim of the article is to demonstrate the value for involving children in NDE research through participatory and creative research methods.

Introduction

Near Death Experience (NDE) research largely deals with adult populations.[1–7] In comparison, there is a scarcity of NDE research *with* children.[8–11] Recent guidelines for the study of recalled experiences of death[4] set out future directions for the study of NDEs. Parnia et al.[4] highlight a need for empirical and systematic studies of NDEs to address "a lack of overall research framework, as well as precise definitions and terminology" (2). The value of rigour and empiricism cannot be underestimated, especially for scientists who study phenomena considered implausible under materialism.[12] Yet, future studies of NDEs may warrant an interdisciplinary orientation to ensure certain groups, such as children, are not excluded from studies. Children have an epistemological authority over their own death and near-death experiences. For children to be meaningfully involved in scientific research, a case must be made for the validity of knowledge, often considered as merely "anecdotal" in NDE research.[13]

Most studies of children's NDEs are conducted retrospectively with adults recalling their childhood experiences. While there is evidence to suggest adults' memories carry a vivid epistemic authority,[11] children's NDEs reported retrospectively may be filtered through an adult overlay.[9] The same can apply to adult researchers working with children. Using participatory approaches such as co-interpretation,[14] rebalancing power relations[15] and art-based research methods, can support adult interpretations of children's experiences. Non-traditional and creative research methodologies are shown to be successful in exploring children's extra-sensory experiences in non-clinical contexts[13,16–19] and for involving children in NDE research in intensive care contexts, days after children have experienced death.[20]

In this article, we present preliminary findings from a case study series, extrapolated from a pilot study that explored extra sensory experiences of children in a paediatric post-intensive care unit in the United Kingdom.[20] Through the case series, we highlight experiences from participants that are synchronous with the basic elements of NDEs[2,4,21] and discuss how children theorize their own experiences. In our pilot study, children reported a range of experiences such as Out-of-body experiences (OBEs),[22] bi-location[23] and bedside visions.[21] The aim of the article is to demonstrate the value for involving children in NDE research through participatory and creative research methods.

NDEs, children and research

In the early eighties, Nancy Evans Bush[9] highlighted a paucity of NDE research with children, noting sparse evidence from children

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themselves, in favour of retrospective accounts of NDEs by adults. Little has changed since Bush's[9] evaluation of children's involvement in NDE research, with children's engagement still minimal in comparison with the extensive (and growing) literature on adult populations. Children may offer a validity over the nature of NDEs as universal, and as carrying some objective phenomena. For example, research studies on children's NDEs show how children see figures in NDEs that they do not recognise – but their parents do.[1,24] Children are shown to carry pre-linguistic and pre-conditioned knowledge around their NDEs.[25] Sunderland[26] suggests that researchers may miss the richness of younger children's experiences, as "even pre-linguistic children have later reported quite complex experiences" (93). Children's NDEs, according to Schröter-Kunhardt,[27] may evidence some form of universality across diverse populations, demonstrating how sociological, demographic or psychological variables do not influence the occurrence of NDEs. Furthermore, retrospective studies estimate that 58 % of children affected by life-threatening illnesses may have experienced an NDE, compared to 43 % of adults.[28] In this way, children are an important research population for the study of NDEs.

Research shows children's NDEs to be similar to adult NDEs.[11,25,26] Conversely, PMH Atwater[8] signals differences between children's NDEs and adults identified in research conducted with 216 children and adults (retrospective accounts of NDEs in childhood). For example, Atwater[8] compares statistical data for adults and children, examining the types of experiences each group have. Initial experience is a loving nothingness or living darkness with 76 % of children and 20 % of adults experiencing this state. An unpleasant experience is an encounter with a threatening world, with children assigned a 3 % incident rate and adults 15 %. Pleasant experience is defined as a heaven-like scenario with deceased friends and family, with children showing a 19 % incident rate and adults 47 %. Transcendent experiences are defined as exposure to otherworldly dimensions beyond the individual's frame of reference, with 2 % of children experiencing this state and 18 % of adults. Van Lommel[29] notes "the fact that children experience NDEs only in genuinely life-threatening circumstances is at odds with the findings of research amongst adults; adults' fear of eminent death can sometimes trigger an NDE" (74). Morse[21] also highlights some differences between adult and child NDEs, noting how children have a different perception of death than adults, "their experiences are simple and reveal a core NDE that is universal to the human dying experience" (5, 1994).

Exploring NDEs with children in intensive care

NDE research with children shows profound changes carried across the life course in terms of intellect, sensitivities and attitudes, similar to adult populations.[8,10,21] Similarly, children diagnosed with PICS-p (post-intensive care syndrome in paediatrics), can be negatively affected into adulthood. PICS-p was coined to highlight the effect of both the cognitive and physical abilities of an individual who has received intensive care treatment.[30] Nearly half of long-term out-of-hospital cardiac arrest survivors show PICS-p after 12 months from a cardiac event. Experiences considered extrasensory, or delusional in clinical terms, feature largely in children with PICS-p and are often attributed to opiate-based medications whilst in intensive care.[31] It is unclear what the nature of these reported experiences are for children.[32] More research is needed into delirium with children in ICU contexts to demarcate delirium from naturally occurring experiences children have near death.[20]

Just as there is a paucity of research on children's NDES, similarly, definitions of PICS-p are defined from adult experiences, rather than children's. Differences highlighted for PICS-p include dependence on the family and health recovery level,[33] and exposure to death and dying.[34] Systematic studies of children's NDEs in a hospital context were carried out by Morse et al.,[10] across a ten-year period. Morse et al.[10] noted differences between children who required intubation and were given narcotics, and benzodiazepines, and children who survived cardiac arrest or coma, with the former group having no memories and the latter group reporting NDEs. Morse et al.'s[10] findings differ from our own, albeit a small study, that shows children who have been intubated and remain on post intensive care do have memories of their experiences.[20] The researchers observed how children can report strong memories through fragmented narrative segments that are disrupted and non-chronological.[20]

The pilot study

The pilot study applied arts-based research methods, involving drawing, painting, play and talking to gain insights into the lived experiences of children post-cardiac arrest. 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 in accordance with the ethical standards of the responsible committee on human experimentation with the Helsinki Declaration of 1975. All children and parents provided informed consent to take part in the pilot study. Recruitment started by screening potential patients. The total number of children who were initially screened as potential recruits was fourteen. However, during further assessment seven children were excluded due to significant brain damage rendering the child unable to comprehend the study aim. Seven children and families consented to participate, meaning all eligible children consented to take part. Females represented 5 (71 %). Table 1 outlines the primary cause for a cardiac arrest, 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 age was 12 years old, and the average length of stay in intensive care was 19 days (± 10 SD). The median number of interview episodes per participant was two, and the median length of interviews were 24 min (Table 1). Four (57 %) participants applied art (paint/ draw) 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. Two (28 %) participants had no memories of their time in intensive care. Once participants were recruited, prior to 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.

Procedure

A bedside play area was assembled providing participants with choices over research methods, which included paints and crayons, small world play, and a camera. The time of the research session was prebooked with the family and nursing team, the length of the session depended on the child (i.e., tiredness, willingness to participate etc.). The researchers framed interviews with a set of general questions related to the child's stay in intensive care. A second set of questions were used with children to explore any experiences which may have occurred during cardiac arrest, coma or medical procedures:

a) What happened before you fell asleep/lost consciousness?
b) What happened when you woke up?
c) What happened in between falling asleep/losing consciousness and waking up?

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.[35,36]

Data analysis

We approached data analysis through co-interpretation with children. Co-interpretation of data is a form of 'member-checking' for adult

Table 1
Case series table of participants.

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)	Experiences
1	Male	White Irish	13	Interstitial lung disease requiring lung transplant: respiratory arrest leading to cardiac arrest	24	Talking Art: Drawing	4 (140)	NDE, bedside visions, different worlds
2	Female	White British	5	Congenital heart disease post heart transplant: cardiac arrest	14	Play Art: Painting Film Directing	2 (90)	No reported NDE but drawing spirals similar with P_01
3	Female	British Pakistan	14	Septicaemia secondary to female genital mutilation: multiorgan failure leading to cardiac arrest	14	Talking	3 (45)	OBE, space, feeling of leaving earth and going home
4	Male	White British	16	Ischaemic Cardiomyopathy leading to cardiac arrest: heart transplant	17	Talking	1 (45)	Retrospective account 12 years, OBE during operation Experience of all-encompassing light after transplant
5	Female	Black African	16	Chronic kidney disease & transplant	10	Talking & Art	4(140)	Overwhelming love & gratitude/OBE
6	Male	White British	12	Dilated cardiomyopathy post-heart transplant: ventricular tachycardia leading to cardiac arrest	42	Talking	1 (20)	Terminated interview on request of child (due to stress re hospital and social circumstances)
7	Female	British Mixed	10	Dilated Cardiomyopathy post-heart transplant ventricular tachycardia leading to cardiac arrest	16	Art & talking	2(25)	Little memory but overwhelming sense of gratitude, repeated drawing of butterflies

researchers to test their interpretations against children's meanings and insights – and can avoid the limitations inherent when analysing data without participants insights.[37] In the pilot study, co-interpretation emerged at the point of children's creative representations, either through drawing and painting or play. Co-interpretation as a research practice can present numerous challenges for representation as the researchers endeavour to listen to children, and to understand and portray their experiences accurately.[38] We noted the active, fluid and embodied nature of co-interpretation with children. For example, we engaged in imaginative game play to support children to share their experiences, or our fingers would follow the squiggles and spirals produced by children in interviews.

Visual and embodied data (play) can afford a suspension of the researcher's preconceptions of familiar territory.[39] Co-interpretation of visual images with children requires an ethical reflexivity[40] and at times, a transpersonal reflexivity,[41] 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".[42] Children's images produced in research interviews provided "a shared focus for parallel or subsequent verbal discussion, or talk around image.[42,43] Thematic analysis was applied to the data set to identify any significant themes that may inform professional practice.

Extracting information from infants and very young children is challenging in NDE research, partly due to their under-developed language capacities. Discourses of the unsayable[44] can arise through different circumstances such as trauma and medical conditions. Developing creative research methods such as play or art can partly address this issue, affording a space for younger children to apply their own modes of representation in the research process.[13,17–20] For example, at times, squiggles and spirals can be co-interpreted with younger children in dialogue with researcher's interpretations and the wider literature.[17]

Fig 1 is a spiral squiggle that a young participant created as she told researchers how "she didn't know" what happened during her time in intensive care (see Table 1 patient 2). Fig 2 was drawn by a participant aged 12 years (Table 1 patient 1) who reported a near death experience which involved moving through 'spirals' towards a light. Analysing

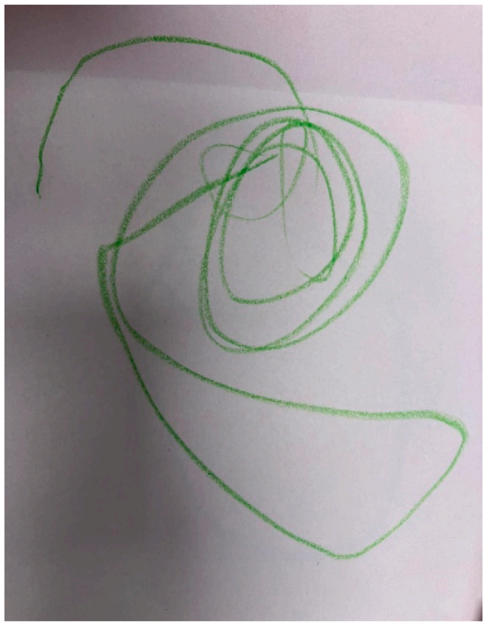

Fig 1. Age 6 "I don't know?".

these images using semiotics would entail reading these symbols (Fig. 1& 2) in relation to their wider system (images produced across the data set, then across wider literature and cultural cosmologies – author 1 2023). Fig 1 is also a spiral that shares similar contours with the spirals in Fig. 2– a representation of moving through spirals during death. We cannot claim Fig. 1 is representing the same experience but, we may again recognise the potentials for examining further, a visual NDE discourse of pre-linguistic and non-verbal children.[17,18]

Results

We focus on a case series to show how children: a) can rely on visual representation to share their NDE experiences; and b) highlight a range

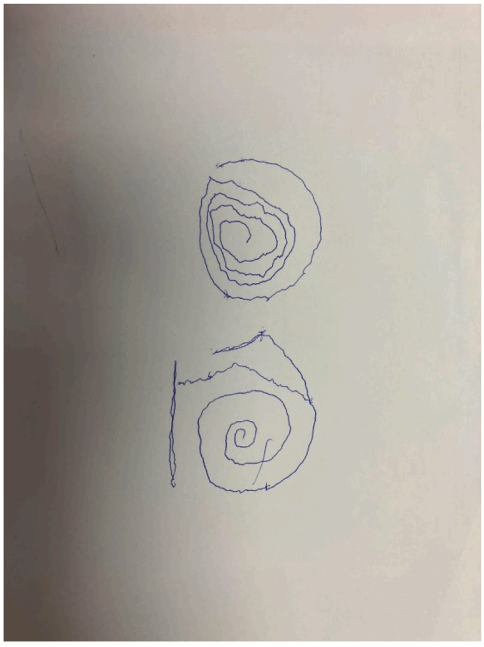

Fig 2. Age 12 "I moved through two spirals with a light at the end.

of experiences reported by children across the pilot study. For example, three children reported an OBE, a prototypical feature of NDEs.[45] One child aged 14 years (see Table 1 patient 3) described how she could leave her body at any time, a frightening experience as she was worried that if she did leave her body, she may not be able to return to it:

"I had to fight to keep within my body to stop floating away."

Aged 14 years

Jacob, aged 16 years (see Table 1 patient 4) reported two NDE type experiences, one a retrospective account of an out of body experience that occurred when he was 12 years (same intensive care unit) during a heart bypass:

"They put me to sleep for an operation but I was lying
there paralysed, and I could hear everything the doctors
and nurses were saying like "is everyone ready to stop this"
It's like I had this knowing what they were doing. It was like
I'd been taken up to a bird's eye view but I couldn't see only
hear and know. I was above just listening to everything. Even
though it happened four years ago, I remember everything
like it only happened yesterday, like a flashback"

Jacob 16 years

Jacob's mother reported how he had accurately described many aspects of the operation and what the doctors discussed despite being under anaesthetic. What is unusual about Jacob's OBE (when aged 12 years) is how he could not see. Jacob described knowing he was above his body in the operating theatre and could hear the doctors (and knew what procedures they were performing) but he had no vision. It was difficult for Jacob to verbally describe the experience of being above the operation and he was too tired to engage in the creative methods. Jacob described a sense of objective attention, what Albahari[46] notes as 'aperspectival witness consciousness'. Similarly, Ring & Cooper[47] refer to a similar state of consciousness as 'transcendental awareness' in their NDE studies with blind participants.

Spirals and lights

Harry was admitted to intensive care post bi-lateral lung transplant. During the transplant procedure Harry was transferred to cardio-pulmonary bypass for 2hours (no beating heart). Additionally, Harry had three cardiac arrests, one on the way to intensive care and twice on the ward. Harry received immediate cardio-pulmonary resuscitation during these episodes. An overview of Harry's medical details can be viewed in Table 1 (patient 1). Harry's mother witnessed these events and described her own fear that her son "would not make it". Primary carers of children can, at times, co-narrate children's NDE narratives, filling in details that children cannot remember. As Harry began to report his experience, the researchers noted long silences from Harry, a linguistic feature identified when children attempt to report a peak or mystical experience.[17] Harry began by describing a dark space, then a sensation of moving through spirals. Harry reported seeing a light, but then struggled to talk about his experience. At this point, the researchers invited Harry to represent his experience visually, initiating talk around image. Harry began to draw two spirals narrating his experience as he created the image. According to Harry, he moved through the first spiral, then continued to move through the second spiral. At the end of the second spiral was, what Harry describes as "a bright light" that he felt compelled to move towards (Fig. 3).

Harry reported feeling calm in the dark space before moving through the spirals. Witnessing a bright light is a common feature of adult and child near death experiences. Often in adult NDE research, a scale is used to determine and measure features of an NDE experience (see NDE scale, [48,49] for example, "did you feel surrounded by a brilliant light".[45,48] Harry's mention of the light was unsolicited, as the researchers did not use an NDE measurement scale with children (footnote 1). We wanted to explore what would emerge from children prior to introducing any measurement scales. Bush[9] analysed 15 unsolicited retrospective accounts of adults who reported their childhood NDEs, concluding that light is the single most-noted feature of the NDEs, appearing in 65 % of accounts. Jacob (aged 16 years) also reported being with a bright light (see Table 1, participant 4):

"I could see a bright white light it was every
where in the room, it was just everywhere. But I had my
eyes closed, I couldn't see the actual room or people, but
I could feel people around me…it felt like my eyes were open
but they weren't. There was just this bright light everywhere,
it felt like it was ages (being in the light) but it wasn't"

Jacob 16 years

Jacob also made references to time distortion, another common feature of NDEs. Aiysha, aged 14 years, reported a similar time distortion during an episode of organ shutdown (see Table 1, participant 5).

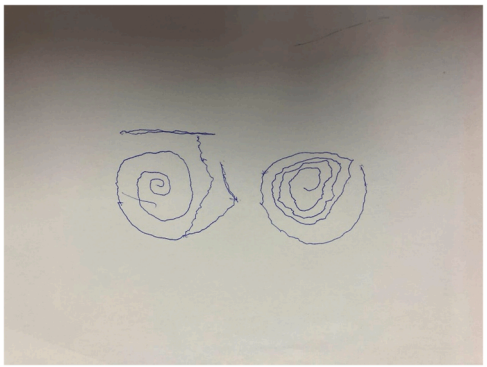

Fig 3. Spiral and bright lights.

"I had this feeling I was going home it was calm and

peaceful and felt like a long time but it wasn't"

Aishya, aged 16 years

Cities of light

Harry reported memories from a second death experience that occurred on the ICU. Harry had gone into cardiac arrest. Harry's mother reported the chaos around her son's bed, describing a scene of doctors working on her son's resuscitation. For Harry, he described being in another place:

"I was in a place, a hall, and behind me was stairs going up

and someone standing in front of me"

"I felt like at one point it felt like everything was made of

stone at one point […] and like I was in a different room,

I felt dizzy, it looked like a Romeness, you know Rome it felt

like that (like a colosseum)"

Moody[3] notes elements of near death experiences that are not as common as, for example, moving through tunnels and experiencing lights. One uncommon NDE feature identified by Moody is when individuals encounter 'cities of light', a reference to visiting other realms while experiencing death.[50] Osis & Haraldsson[51] examined 100 cases of terminally ill patients who had glimpsed other modes of existence and found "that one-third of cases were clearly perceptions of this-world places and objects, while the other two-thirds were concerned with otherworldly matters…symbolic architectural structures comprised of 5 % of the cases"[50], pp). The Roman-likeness Harry described was a landscape of light with large white columns. We asked Harry and his parents if they had visited Rome or other places with columns, which they stated they had not. Van Lommel et al.'s[7] prospective NDE study in the Netherlands also found that 29 % of participants had the perception of a celestial landscape.

Bedside visions

Harry also reported bedside visions while near death:

"I was in bed, but I didn't wake up, it was kind of erm the doctor was

right next to me and we talked to him for a second then when I looked

to the side of the bed, there was black and white and a girl and she said

I have a very bright future [..,] she had weird old clothes"

Moore & Pate[52] note differences between deathbed visions and NDEs, for example, deathbed experiencers are not undergoing clinical death at the time of the vision but in a terminal state where their death may be approaching in minutes, hours, days or weeks. Harry described a "knowing" or a strong sense of feeling as if he was going to die. The vision appears to be a response to Harry's sense of approaching death (Harry stated that he knew he was going to die). Harry did die and was resuscitated three times and experienced this vision between his second and third cardiac arrest. Despite "most professionals discounting these accounts as the last wisps of life – states of confusion – and thus anecdotes"[52], 81), for Harry the extra sensory experience brings reassurance, hope and potential healing effects.[16]

Harry's mother reported that Harry told her he had seen "lots of dead people around his bed" when he was revived and two other occasions shortly after his cardiac arrest.

"When I close my eyes I felt like there's someone next to me

right next to me even though there's no one there"

"When I close my eyes feels like someone is pushing me in bed"

Harry reported feeling "strange" and uncomfortable about his interactions with unseen presences days after his cardiac arrest. Harry's experiences of this nature where still occurring at the time of interview (1 week after his lung transplant). Greyson[53] notes how NDE experiencers can report paranormal or extra sensory experiences, especially people who had paranormal experiences prior to their NDE. Greyson[53] suggests near death experiencers may retroactively interpret past experiences as paranormal. We did not ask questions about children's experiences prior to their NDEs however, we noted the cultural influences present in Harry's parents' narratives. Harry's family are from the gypsy/traveller community with distinct and long-standing cultural beliefs around the supernatural, with Catholic influences. For Harry's mother, her son experienced the other side, supported by angels or guides who ensured her son returned to heal.

Summary

The participatory and creative research methods used with children in the pilot study are embryonic but show great potential for involving children in NDE research. There are challenges and limitations for situated and creative research in the ICU with younger children. For example, analytical issues for the researchers can ensue with creative data, especially when working with abstract symbols and images.[13,19,20] A stronger case needs to be made for the role of semiotics as a robust method for interpreting children's abstract or 'out of this world images' in NDE research.[20] Children may initiate new and novel ways for reporting near death experiences that may be applied with various vulnerable groups (including adults) in research.

Interviews are prone to disruption by medical professionals who come to administer care to the children. This can disrupt the flow of an interview that is already subject to fragmentations, discontinuities and silences. The timing of interviews may present issues for children's memories when they are still recovering or close to their death experiences. Follow up interviews with children may be required to investigate their experiences further – a protocol that will be included in further studies. Morse et al.[10] describe returning to children 2 years after hospitalisation and finding children have more memories and confidence to share their experiences.

Children in the pilot study reported their experiences as "real", assigning a subjective reality to their extra sensory experiences. Clinical professionals can attribute extra sensory experiences, such as NDEs, OBEs and bedside visions to medication. Patients 1 & 3 (see Table 1) were administered ketamine. Classical etiologies ascribed to NDEs in the literature, such as cerebral anoxia, hypoglycemia, use of ketamine and psychological reactions are examined in the NDE literature.[1,7,29,54] For example, Lopez et al.[54] cite the case of a healthy child who had a spontaneous NDE during an uncomplicated surgery with no use of Ketamine. Van Lommel[29] notes how small quantities of ketamine causes frightful and bizarre images rather than features of typical NDEs.

Children in the study show features of transcendental experiences such as a knowing awareness, time expansion and feelings of peace. These findings correlate with studies which explore peak and mystical experiences with children in non-clinical and clinical contexts.[17] PMH Atwater's statistical data shows 76 % of children, compared with 20 % of adults, experience a realm of loving nothingness or a living darkness. Children who reported NDE type experiences in the pilot study referred to being in a darkness but experiencing peace, or a sense of "home". Children's NDE's reported in the study were simple compared to the rich experiential narratives reported by adults.

The pilot study only includes a small number of children and does not carry an equal representation of younger children. We fully acknowledge that data from such a small number of children cannot substantiate definitive claims that most children have similar NDE-type experiences.

Further research is needed to establish any similarities/differences between younger and older children, children from various cultural backgrounds and with a variety of clinical and environmental experiences. The aim for the pilot was to examine the usefulness of creative and participatory research methods with children and identify any 'extra-sensory experiences' children may have. In some ways, having no fixed research agenda to identify NDEs, may add to the authenticity of children's experiences (we didn't ask about NDEs directly) - but we recognise the need to a) involve greater numbers of children, and b) follow up with children several months/years following their NDE experiences. Our future study will focus largely on younger children's experiences near death.

The pilot study has been successful for showing the value for involving children in NDE research, and for highlighting the importance for applying a range of research methodologies.[18] Children from various cultural backgrounds (gypsy/traveller, Asian-heritage, white-secular, black-heritage) reported unsolicited NDE experiences, without prior knowledge of near-death experiences. These findings may correlate with claims made about the nature of NDEs as universal.[1,24] Children's extra sensory experiences in clinical and non-clinical contexts continue to challenge materialism which carries hegemony over research practice, clinical practice and mainstream institutions.[17,18,20]

NDE research with children changes the parameters for enquiry. For example, children tend to have no prior knowledge of NDE's or have not been exposed to experiences which may influence the phenomenal content of their NDE's. Children's representation of their NDEs (and similar transcendental experiences) embody symbology that may transcend time, histories and culture with similar signs located across various cultural cosmologies.[13,17–19] Moreover, very young children have not yet formulated a fixed worldview, nor do they have clear ideas about life and death. Children's NDEs significantly contribute towards addressing some of the key questions which motivate NDE research, such as "what happens when we die" and "what does it mean to be human"?

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