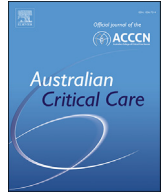




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## Research paper

# Creating a home with a critically ill child: A qualitative study exploring the experiences of parents of children admitted to paediatric critical care following treatment in neonatal care

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## ABSTRACT

**Background:** Survival of children with complex medical conditions has increased over time. Around 5% of children admitted to a neonatal unit (NNU) later have an admission to a paediatric intensive care unit (PICU) in early life. No work to date has explored the needs of parents who have a child admitted to both of these healthcare settings.

**Objective:** The overall aim of this study was to understand parents' experiences as they navigate the transition between admissions to the NNU and the PICU. This paper reports on one of the themes (creating a home) identified inductively from the dataset.

**Methods:** We used a qualitative research design using semistructured interviews with parents who had a child (or children) who had been admitted to neonatal care after birth and then subsequently were also admitted to a PICU. We recruited a national purposive sample of parents with experiences of having a child treated in an NNU before being admitted to the PICU. We undertook the interviews and transcribed them before taking a reflexive thematic analysis approach.

**Results:** A total of 15 mothers and three fathers, of 17 children, were interviewed between January and March 2022. 'We identified 'creating a home' as a key inductive theme with three subthemes: (i) developing parental roles; (ii) creating a physical home; and (iii) creating core memories.

**Conclusions:** There is a growing cohort of children living with chronic health conditions. In this work, we have explored how their parents establish a home whilst often spending significant periods within the public arena of intensive care. Families across settings need support from healthcare professionals to help them develop their role as parents, build a home, and to create memories together.

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## 1. Background

Globally, around 140 million children are born annually.<sup>1</sup> In the United Kingdom (UK), around one in seven babies is admitted for specialist neonatal care,<sup>2</sup> and some may have ongoing healthcare needs throughout early life and beyond. Many parents will begin to form identities for themselves as parents with the discovery of their pregnancy, the first scan, the first kick, or at another important milestone.<sup>3</sup> However, admissions to a neonatal unit (NNU) following delivery may disrupt the continuum of

parent–child bonding due to separation and disruption to the normal parenting experience.<sup>4</sup>

Following NNU discharge, if a child requires specialist care, this will usually be in a paediatric setting, with the sickest children cared for in a paediatric intensive care unit (PICU). Whilst PICUs are equipped to care for children into early adulthood, in the UK, over half of all admissions are children aged under 2 years.<sup>5</sup> Recent research has suggested that nearly half of PICU admissions of children aged under 2 years have previously been cared for in an NNU.<sup>6</sup>

NNUs and PICUs care for similarly young children, but aspects of care delivery differ, and moving between these services may feel overwhelming for parents.<sup>7</sup> Within an NNU, importance is placed

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on helping to establish and support the formation of new families, albeit in an acute healthcare setting.<sup>8,9</sup> By contrast, the case-mix in a PICU is much more heterogenous, concerning age and clinical condition, meaning that families will be at very different stages of their parenting journey (e.g., parents of young children physically next to parents of teenagers).

The impact of having to navigate the transition between admissions to the NNU and the PICU has received little attention.<sup>10</sup> Our research question was: “What are the experiences of parents who have a child needing neonatal care and paediatric intensive care?”. This paper focusses on one of the inductive themes that was identified from the findings, how parents construct and create a ‘home’, and the importance of this, across these diverse settings, and how this shapes their experiences of transitions across neonatal and paediatric critical care.

## 2. Methods

### 2.1. Study design

We used a qualitative research design using semistructured interviews with parents who had a child (or children) who had been admitted to the NNU and PICU. Our work followed a constructivist epistemology, where knowledge is generated through the interaction between the researcher and the researched,<sup>11</sup> and this shared experience aids the analysis and interpretation. We believe there is no single reality of the world and that all experiences are equally valid. Ethical approval was granted by the University of Leicester Medicine and Biological Sciences Research Ethics Committee (reference: 32037-ses26-ls:healthsciences).

### 2.2. Participants

We recruited a national purposive sample of parents with experiences of having a child treated in the NNU and PICU. Advertisements were shared by charities that support parents of sick children via social media, and parents contacted the study team to participate. These charities also provided a source of support, if required.

We took an inclusive approach, as memories can remain strong over time.<sup>12</sup> Parents were eligible if their child’s most recent PICU admission was in the last 10 years due to significant changes in care provision, characteristics of children, and outcomes in both neonatal and paediatric care beyond the past decade.<sup>13,14</sup> To minimise potential distress, we suggested their child should not currently be in the PICU. Consent was taken by completing a form and was reconfirmed verbally at the start of each interview.

### 2.3. Data collection

Parents were interviewed over Microsoft Teams or the telephone due to the COVID-19 pandemic. All interviews were conducted and transcribed by one author (SES), who had regular debriefs with another member of the team (NM) to reflect on the experience. SES is a cisgender child-free woman with several years of experience in paediatric epidemiology.

The topic guide drew on relevant literature and was further developed with our parent advisory group. Topics focussed on experiences in neonatal care; preparing for admission to the PICU; experiences in the PICU; transitions out of the PICU; returning home, and messages for healthcare professionals (topic guide in [Appendix 1](#)).

### 2.4. Analysis

Our analysis was led by SES who undertook the interviews and transcribed and rechecked them before taking a reflexive thematic analysis approach,<sup>15</sup> with the aid of NVivo software. In team meetings, differences of interpretation were discussed, and a consensually agreed set of analytic categories was developed. We identified five inductive themes from the data which included the following: navigating the healthcare service; the unseen work of parents; being in the wrong place; parental knowledge; and creating a home. The findings reported in this paper focus on creating a home as a key analytical theme.

We were guided by the principles of code and meaning saturation,<sup>16</sup> and focussing on our overall research question, our sample size was based on the ideas of data saturation, where we continued collecting data until no new meaningful information was gained.<sup>17</sup> We adhered to the COnsolidated criteria for REporting Qualitative research checklist.<sup>18</sup>

## 3. Results

A total of 15 mothers and three fathers of 17 children were interviewed between January and March 2022. General characteristics of the parents and children are provided in [Table 1](#).

Analysis focussed on the theme of creating a home. We identified three subthemes: developing parental roles; creating a physical home; and creating core memories, which together represented home as a unifying construct across the different settings ([Fig. 1](#)).

### 3.1. Theme 1: Developing parental roles

This theme reflects the complex way that the parenting role is established, developed and evolves. Being a parent has a vital role in feeling ‘at home’ and being able to live authentically, although it is complicated for parents of critically ill children both emotionally (e.g., being separated) and practically (e.g., their child’s care being delivered by healthcare professionals).

Most parents talked about the importance of involvement in day-to-day care in the NNU and PICU by providing cuddles, skin-to-skin contact, and being involved in care. This helps establish and develop the parenting role but was enabled or disabled by staff and affected by prior experiences in the NNU in terms of who could control access and interactions with their child, with one mother reflecting on breastfeeding in the NNU:

*“I was giving them little containers of expressed milk, and I was told he was getting it, but I wasn’t involved in it at all. so, it was all just like observing and not really being part of it, which was kind of weird when it’s your child.” (M002)*

Within NNU, participants reported often a higher level of breastfeeding support than in the PICU, where at times there “*weren’t things like the comfy chairs next to the bed*” (M001). A few mothers noted they could not breastfeed due to their child’s condition or that they needed additional support that was not provided.

One father reflected on struggling to identify his role in the NNU, thinking of himself as “*just dads in that environment*” (F002), and this differed from the PICU where he felt like their parenting role was clearer. Mothers potentially had a clearer role and identity in the NNU, and this was compounded by physical spaces such as the pumping room (a physical room to pump breast milk), where mothers could bond with other mothers.

**Table 1**  
Characteristics of parents interviewed and their child or children.

Identifier*	Age at the time of interview	Time since PICU experience at the time of interview	Occupation	Sex of child	Information about the child or children who had been admitted to the NNU and PICU
F001	31–40 years	~4 years	Government worker	Boy	Born very preterm and admitted to the PICU as an emergency with a respiratory condition.
F002	41–50 years	~4 years	Healthcare professional	Girl	Born very preterm and admitted to the PICU as an emergency with a respiratory condition. (Partner of M014 (interviewed separately).
F003	Not known	<1 year	Not known	Boy	Born with a heart condition requiring planned PICU admission, following surgery. Partner of M012 (interviewed separately).
M001	31–40 years	~3 years	Healthcare professional	Girl	Born very preterm and admitted to the PICU as an emergency with a respiratory condition.
M002	41–50 years	~2 years	Civil engineer	Boy	Born with a heart condition requiring a planned PICU admission, following surgery and a subsequent emergency admission for a neurological condition.
M003	Over 50 years	~10 years	Government worker	Girl	Born with a heart condition requiring a planned PICU admission, following surgery
M004	20–30 years	~2 years	Carer for her child	Boy	Born with a genetic syndrome which includes a heart condition requiring planned admission to the PICU, following surgery.
M005	31–40 years	~4 years	Scientist	Girl	Born with a heart condition that was not diagnosed antenatally and required a planned admission to the PICU, following surgery.
M006	31–40 years	~8 years	N/K	Girl	Born very preterm and admitted to the PICU as an emergency with a respiratory condition where she died aged 1 year.
M007	N/K	~2 years	N/K	Boy	Respiratory difficulties after birth led to long-term tracheostomy that required planned PICU admission to be reversed.
M008	N/K	~3 years	N/K	Girl	Born very preterm and admitted to the PICU as an emergency with a respiratory condition.
M009	Over 50 years	~8 years	N/K	Boy (one of triplets)	Born very preterm and planned admission to the PICU with a neurological condition.
M010	41–50 years	~7 years	Carer for her child	Boy	Born very preterm and with a cardiac condition. Planned transfers between PICU and neonatal care before continuing care in the PICU.
M011	41–50 years	<1 year	Healthcare professional	Boy	Born late preterm and experienced respiratory difficulties and admitted to the PICU with suspected infection as an emergency.
M012	Not known	<1 year	Not known	Boy	Born with a heart condition requiring planned PICU admission, following surgery. Partner of F003 (interviewed separately).
M013	31–40 years	~2 years	Healthcare professional	Boy and girl	Girl was born very preterm and was admitted to the PICU as an emergency with a respiratory condition. Boy had an undetected cardiac condition and a planned admission to the PICU, following surgery.
M014	41–50 years	~4 years	Banker	Girl	Born very preterm and admitted to the PICU with a respiratory condition as an emergency. (Partner of F002 (interviewed separately))
M015	Not known	<1 year	Not known	Boy	Born very preterm and planned transfer directly from neonatal care to the PICU for ongoing respiratory support.

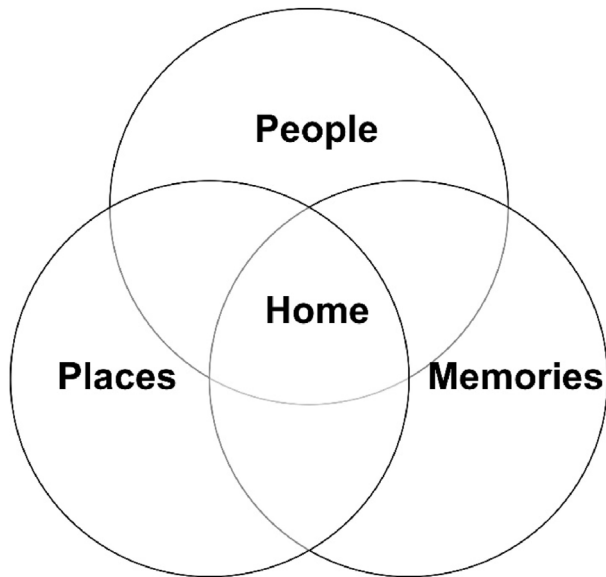
\*F denotes a father and M denotes a mother.

\*One mother interviewed about two children who were both admitted to NNU and PICU at different times. Abbreviations: NNU: neonatal unit; PICU: paediatric intensive care unit.

Fathers could be a go-between for their sick child in the NNU and their unwell partner (sometimes unwell in the postpartum period, e.g., recovering from surgery) being cared for elsewhere, who also wanted updates on their child, leading to feelings of conflict about who needed them more. However, generally in the PICU, their partner was not unwell, and they could focus on their child together: “we’re together in this; we’re doing this much more so than it did in NICU times” (F002).

Parenting in the PICU was more of a shared experience between both parents as they were more established in their parenting roles. Some parents talked about having more difficult conversations in

the PICU together, e.g., discussing whilst in the parent hospital accommodation what would happen if their child’s condition deteriorated or they died. This was reflected in their feelings about the physical environment; during PICU admissions, families were often provided with family accommodation to stay nearby, and one father reflected on how this enabled them to cope better with the situation, whereas in the NNU, most families would return to their own home. Conversely, for others, there was enforced physical separation in the PICU similar to the separation experienced by fathers in the NNU, e.g., one partner having to work or pandemic visiting restrictions.



**Fig. 1.** The meaning of home: an interaction of the people, the place, and the memories.

In the PICU, some parents found they were actively discouraged from participating in their child's care, whereas others were not encouraged as in the NNU. They felt as if they needed *permission* to be a parent. Sometimes this was explicit, e.g., staff asking them to leave because it was night-time (*"I actually had very disapproving comments from both consultant and nurses when I came down in the middle of the night to see her. Bearing in mind I was awake because I was expressing anyway so ..."* M001) or *"they would kick you out the ward for some reason or other with no idea as to when you'd be allowed back in."* (F003) or discouraging parents from touching or cuddling their children. It could also be implicit due to the environment, e.g., no comfortable chairs at the bedside.

### 3.2. Theme 2: Creating a physical home

Leaving their child in the hospital was often a painful experience, exacerbated by physical reminders such as a decorated nursery and an empty cot. This was particularly acute when their child was in the NNU as most did not have access to parent hospital accommodation (more routinely available on-site with the PICU). Therefore, they would return home to the *"emptiness of the house"* (M014) without their child and be left wondering what to do since they were often establishing their role as new parents, but there was no child to parent. This went against a very powerful visceral need:

*"Obviously your body is telling you 'I am a Mum' and then they are saying 'right just leave your baby, you'll be fine.'" (M010)*

Others left their child in the NNU or PICU in attempts to get rest, and some felt they were judged for that: *"I would always go home at night ... and I got the feeling sometime that [PICU staff] wasn't that happy that I was going home"* (M009). Some parents did not want their first night together to be in a hospital so did not stay overnight: *"I was trying to latch on to something that was normal, you know like other people get to take their child home for the first night"* (M004).

Parents became familiar with the support around them and relied on healthcare professionals and machines to indicate the wellbeing of their child. For some, this transition to home with their child for the first or subsequent time and this shifting of

responsibility could be overwhelming: *"he was just put in your hands like that's you, go and be a parent now in your own home"* (F001). Some parents, particularly those with long hospital stays, needed support to prepare for discharge home from the PICU, and staff worked to develop their confidence, e.g., by encouraging the families to take short trips off the ward: *"we'd like you to take him to the park, and then we'd like you to bring him back ..."* (M010), whereas others felt ready to be together.

The parents in our study noted the different physical locations that were negotiated and adapted to create a sense of home and safety and security. At home, they would adapt the physical space to create a place that felt safe for them and their child, and sometimes, resembled the hospital setting. In hospital, they would adapt the setting to try and add a sense of homeliness and personalisation.

In both settings, healthcare equipment was sometimes a source of anxiety, with some parents finding it hard not to fixate on monitors. Some tried to adapt the hospital environment to feel homely, e.g., by bringing in toys, although this was sometimes met with disapproval by staff: *"I walked in with the play gym and a little chair [to PICU]! I think they thought I was a bit crazy"* (M006). On discharge, having medical equipment at home was a worry for some, but for others, a way of remaining in control, e.g., helping monitor oxygen levels so they knew when to ask for help: *"My limit was 90% sats, and if it got to there, then I would put the oxygen on him and take him to Accident and Emergency"* (M009).

Other parents were not provided with equipment, but they brought items for themselves, such as apnoea mats and video monitors, to facilitate feeling safe. Sometimes, they were reluctant to give up these items as they provided reassurance. Some found having medical equipment in their homes disruptive and attempted to mitigate this, e.g., moving their child into another room so they were not disturbed by the monitors. Some parents did not want any equipment, perhaps indicating their desire for a normal family life at home: *"we had normal monitor where we listen to her"* (M014).

Despite the medical equipment that could support safe care at home, some parents found the transition difficult. After the loss of control and consequent disempowerment they felt about their parenting role, to suddenly be responsible for their child sometimes felt overwhelming: *"to suddenly be at home with this four-pound baby, with no monitors and just 'there we go, use your eyes to keep him alive!' I found really hard"* (M011). However, over time, they became confident at home, and as their child got older, they felt empowered to recognise when their child was unwell.

Unfortunately, the reason some families came home without a child was because their child had died, although sometimes the life and home they had created in the PICU, and the time they had been together, had been marked with happy moments and was missed: *"after the experience, we both really missed being at the hospital. We missed our routine that we had there ... In our mind, it's where she grew up, and we always say the staff there were her family"* (M006).

### 3.3. Theme 3: Creating core memories

The parental role developed and was facilitated by the conscious reflection on key 'normal' memories of special occasions that these families shared, from the first cuddle to birthdays and Christmas. These moments and memories, necessarily given the disruption of the hospital admission(s), took place in different locations for these families; at home, in the NNU, and in the PICU. This was acute in the NNU as they were often experiencing or hoping to experience a number of particular 'firsts' with their child, e.g., first cuddle.

Parents had challenges in creating initial memories together due to the health condition of their child or miscommunication with staff. Some parents spoke about not having the chance to give their child an initial cuddle after birth: *"I really struggled because they*

took her away straight away, and I wasn't even able to hold her, so that was really horrible [cries]" (M003).

Other parents went a long time without having that initial cuddle due to miscommunication between teams: "I think he was about 3 weeks in, and I said in the end 'can I just have a cuddle? Is that ok?' and she went 'oh haven't you had a hug with him (M010). For some parents, being faced with the reality of what had happened brought the realisation that they would not have the homecoming they expected, and this could lead to feelings of resentment: "I'm a decent guy. Why is this happening to me?" (F001).

Some families tried to celebrate special occasions such as the child's first Christmas in the PICU, even if these happened in the hospital, thereby regaining control of the situation they were in (M003). Others felt that special occasions exacerbated the reality of their situation:

*"I remember coming home for the first time after giving birth to [my son]. We drove home and came into the house because it was still post-Christmas. The Christmas tree was still up, so we kept that up for a month after, and no one would take it down."* (M015)

For some, special dates gave key points to aim for "my hope was to get home for Christmas" (M015), whereas for some people, they tried to reclaim special moments by adapting the place they were in to create memorable moments together. For example, one mother experienced her first Mother's Day in the NNU, and her partner decorated the cot using surgical gloves as balloons to give her some aspect of normality and an experience of being a normal new mother (M014). Another mother talked about making her daughter's first birthday in the PICU a happy memory:

*"She had her first birthday in ICU actually. I've got pictures of her cause she's there on her CPAP. She was on, you know the full-face mask; she was on that an awful lot. I don't think she went back onto the nasal CPAP; it was a full-face one, and there's a picture of her with a party dress on and a hat and she's smiling"* (M006).

#### 4. Discussion

Survival of babies with neonatal complications such as those born preterm or with serious congenital anomalies has increased,<sup>13,19</sup> leading to a potential increase in children living with lifelong conditions. In this work, we identified how home featured in parents' narratives about their experiences of the NNU and PICU. To our knowledge, this is the first study to report on the experiences of parents who have specifically experienced neonatal and paediatric intensive care, although there may be a degree of overlap here with the early experiences of parents of children with lifelong conditions, since many of this cohort spend time in both intensive care settings.<sup>20–22</sup>

We identified how parents found it hard to claim and retain the parent role. This aligns with previous research, where mothers of preterm babies struggle to transition to motherhood<sup>23</sup> and fathers have difficulty transitioning to fatherhood due to minimal physical contact, lack of involvement, and unexpected start to their child's life.<sup>24</sup> We were able to explore their experiences as they developed through their child's admissions to the NNU and PICU. Efforts are made by NNU staff to encourage bonding such as via close physical contact (e.g., skin-to-skin cuddles)<sup>25</sup> and the importance of feeling like an "ordinary family".<sup>26</sup> However, the support to develop their parent role was sometimes lacking in the PICU setting, with more restrictive visiting, particularly at night-time or by the discouragement of cuddles. Whilst for some unstable babies and children it may be unsafe to offer cuddles, there is increased evidence that kangaroo care (skin-to-skin contact between a baby and parent)<sup>27</sup> improves outcomes.

To facilitate the development of the parenting role and the sense of the feeling of home, the hospital can become a negotiated space, where home meets hospital. The PICU is a space that has been described, negatively, as transforming children into patients and parents into visitors.<sup>28</sup> Staff can become gatekeepers, with parents having to prove that they have the skills for the nursing staff to involve them in care.<sup>29</sup> In our work, some parents found the physical environment unwelcoming, e.g., no comfortable chairs at the bedside or at times were unable to visit their child (e.g., discouraged from being on the unit at nighttime). Parents talked about trying to bring familiarity (e.g., toys) into the hospital environment, sometimes to the disapproval of staff with little explanation, to promote normal activities such as play. Similarly, sometimes home became more similar to a hospital, and when they were discharged, some parents tried to replicate aspects of the hospital at home to feel safe, e.g., buying oxygen saturation monitors. In a similar group of children, those living with technology-dependency, parents felt as their home was being taken away from them and that adaptations needed to be codesigned.<sup>30</sup>

Home is more than just a physical location, and for many of us, it is the place where we will experience and anchor key childhood memories of our own families. Likewise, for new families, these early developmental moments (e.g., first bath) form core memories of their child's early life. However, for parents of critically ill children, these memories may take place within the medical setting rather than at home, forging an important attachment to the hospital setting by association. Memory-making has been recognised as vital in PICU settings, particularly when children may not survive.<sup>31</sup> Likewise, some research has indicated that keeping diaries of time in the PICU may be beneficial in helping cope with the experience.<sup>32</sup> Memory making is particularly important for families of young and newborn children, and they should and are still enabled to experience and mark these moments.

##### 4.1. Recommendations for practice

From our work, it is evident that parents value and need support from staff within the PICU to develop their roles and identities. As such, health professionals need to be cognisant of the significant impact and influence they can have in enabling a support that transcends the PICU environment, team approach/models of care, professional/parents communication, and activities. Recognising parents will differ according to their prior experiences and needs, it is fundamental that parents and staff work together to broker understanding and negotiate roles to ensure these needs are met.

Moreover, from this study, parents identified the importance of communicating needs and support (such as important milestones and moments) during the transition of care between one setting/hospital to another. This highlights the importance of cross-specialism communication and orientation, which goes beyond the clinical/medical plan of care and involves a holistic and family-centred approach to transitional care. Teams within both NNU and PICU could collaborate in relation to skills training and communication needs of parents. For example, for children at high risk of needing the PICU after the NNU, the family could be introduced by the neonatal team to the paediatric team before neonatal discharge.

It is important for intensive care settings to recognise that families are establishing, and consolidating, their home together. Parents and the wider family are key and active care partners, as described in other work, bond together as "one inseparable unit".<sup>33,27</sup> Local unit policies need to reflect the interrelated nature of the family unit, an example of this support is to consider accommodating 24/7 "visiting" (although parents are never visitors) from families. Furthermore, PICUs could usefully consider providing more training for both staff and families in bonding and

early parenting, which needs to be enabled through an appropriate physical environment where these activities can occur (e.g., pumping facilities, comfortable chairs/beds next to their child).

#### 4.2. Limitations

Although our study added to knowledge on a topic on which little is known, it was not without limitations. We recruited parents via charities, and this is likely to have impacted on the diversity of the sample of parents who chose to engage in this work. We intentionally recruited parents with a range of experiences in the NNU and PICU to capture the diversity of these environments, but there may be differences that would have been more apparent by focussing on particular subgroups of children and families, such as those with particular conditions or who were born very prematurely. We did not consider if the families had other siblings at home or the care pathway that had resulted in a PICU admission (e.g., a direct transfer from the NNU or an admission from home to the PICU), although we had families with a range of experiences. Future work may wish to consider these subgroups further.

#### 5. Conclusions

The cohort of children who have been admitted to the NNU and PICU reflects the increasing population of children living with chronic health conditions and those acquiring morbidity during their hospital stay.<sup>34</sup> We explored how their parents establish a home whilst often spending significant periods in intensive care. We demonstrated that, for this population, home is a social construct of people, a physical place and the memories that are cocreated within each setting. This experience was sometimes different for fathers and mothers, and it can be difficult for these families to leave intensive care and adapt to life physically at home. Families across settings need support from healthcare professionals to help them develop their role as parents, build a home, and to create memories together.

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#### Credit authorship contribution statement

Sarah Seaton: conceptualisation; analysis; writing original draft, and funding acquisition. Joseph Manning: validation and writing, reviewing and editing. Gillian Colville: validation and writing, reviewing and editing. Nicola Mackintosh: validation and writing, reviewing and editing, and supervision.

#### Conflict of interest

None declared.

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For the purpose of open access, the author has applied a Creative Commons Attribution license (CC BY) to any author-accepted manuscript version arising from this submission.

#### Data availability

Not available.

#### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.aucc.2024.07.082>.

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