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## Mental health of parents with infants in NICU receiving cooling therapy for hypoxic-ischaemic encephalopathy

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### ABSTRACT

**Background:** Parents cuddling their babies during intensive care to promote parent-infant bonding is usual practice in the neonatal intensive care unit (NICU). However, babies undergoing cooling therapy and intensive care are not routinely offered parent-infant cuddles due to concerns of impacting the cooling process or intensive care. We developed the CoolCuddle intervention to enable parents to cuddle babies safely during cooling therapy. We investigated whether CoolCuddle impacted parent-infant bonding and parent's mental health.

**Methods:** We conducted parental interviews and compared mental health and bonding measures in two cohorts of parents; one with access to CoolCuddle and the other where CoolCuddle was not available.

**Results:** Ten tertiary NICUs in England and Wales from 2019 to 2023 were involved and 107 families. There were high levels of post-delivery depression amongst all parents. However, at discharge mothers in the CoolCuddle group had significantly less depression, lower EPDS scores, and higher MIBS scores (consistent with better mother-infant bonding) than those where CoolCuddle was not available. All measures appeared similar when re-measured at 8 weeks. Parents reported they were not ready to access psychological support or information whilst on NICU and stressed the need of mental health support following discharge, which was not offered or available.

**Conclusion:** The CoolCuddle intervention was associated with a lower prevalence of depression and enhanced bonding scores for mothers at discharge compared to those who did not cuddle their babies. Parents highlighted increased levels of postnatal depression following the sudden and traumatic admission of their infant to NICU after birth asphyxia.

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depression

## Introduction

Postnatal depression in parents with infants in neonatal units

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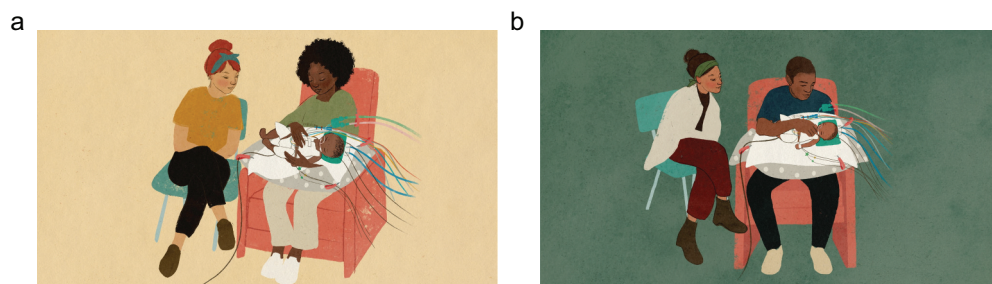
Mothers whose infants are admitted to neonatal units experience higher rates of mental health problems compared to the general perinatal population (Gong et al., 2023). Analysis of two UK population surveys confirms this and highlights the importance of routine, and repeated, mental health assessments and ongoing support for mothers of infants admitted to neonatal care (Gong et al., 2023). These parents are also at increased risk of developing perinatal post-traumatic stress disorder (PPTSD), and a study from the United States recommends routine screening for PPTSD and follow-up after discharge from the neonatal unit to mitigate risk (Malin et al., 2022).

Parents cuddling their babies soon after birth is the first step to develop physical and emotional bonding with their babies (Korja et al., 2008; Michelsson et al., 1996), which plays a key role in their later intellectual and emotional development (Malekpour, 2007; Sroufe, 2005). Consequently, parents cuddling their sick babies receiving intensive care are now standard in the neonatal intensive care unit (NICU) to promote parent infant bonding (Clarke et al., 2020; Flacking et al., 2012).

Hypoxic-ischaemic encephalopathy (HIE) is one of the leading causes of intellectual disability and costs the UK economy around £6 billion/year in health care and educational costs (Murray et al., 2012). More than 800 babies each year undergo cooling therapy over the first 4 days of life, in order to mitigate the brain injury occurring following HIE (Gale et al., 2018; Shipley et al., 2021), and currently their parents are not usually given the opportunity to have cuddles with their babies during this critical period. A national survey showed that 95% of NICUs do not permit parents to cuddle their babies during cooling and intensive care, due to concerns of warming the baby or dislodging breathing tubes or vascular catheters (Jordan et al., 2018). This impacts the mental health of parents (Laudi & Peeples, 2020), the development of parent-infant bonding, breastfeeding (Horsch et al., 2017; Thyagarajan et al., 2017), and potentially the intellectual development of these babies, who are already at a higher risk of developmental disabilities (Pappas et al., 2015, Lee-Kelland; Lee-Kelland et al., 2020).

### *The CoolCuddle intervention*

To enhance parent-infant bonding, parents' mental health, and optimise the development of infants cooled for HIE, we developed the CoolCuddle intervention (animation link:



**Figure 1.** CoolCuddle intervention for those in CoolCuddle studies: baby is wrapped up in a sheet with leads and tubes; then moved carefully from the cot by three staff members; placed on a pillow on parent's lap and unwrapped for up to 2 hours.

<https://youtu.be/ZVN83K0xp7g>; Figure 1(a,b)). CoolCuddle enables parents to cuddle their babies during cooling therapy and intensive care. This intervention was refined with 27 families cuddling their babies during cooling treatment: cumulatively over 115 h in 70 cuddle episodes (CoolCuddle 1 study). An experienced advanced neonatal nurse practitioner (ANNP) facilitated and monitored the cuddles along with neonatal nurses looking after the babies (Odd et al., 2021). ANNPs are senior nurses who work with neonatologists to deliver comprehensive medical and nursing care to newborn infants in acute settings; neonatal nurses only offer nursing care. Parents reported that cuddling during cooling helped them to bond with their babies and establish breastfeeding (Ingram et al., 2022). The mental health of mothers improved at 8 weeks postnatally. While the CoolCuddle intervention was developed predominantly in one city neonatal network, subsequently we carried out the CoolCuddle 2 study, where the intervention was rolled out to additional tertiary NICUs across the UK, using senior neonatal nurses to lead the intervention. In both CoolCuddle studies, we observed no adverse effects on the temperature during cooling and cardiorespiratory parameters or on intensive care.

In a third study (CoolBonding), we obtained data on postnatal depression and mother-infant bonding from a comparison group of parents of infants that were not cuddled during therapeutic hypothermia. In this paper, we collate the findings from across the three studies to examine the impact of CoolCuddle on parental mental health and parent-infant bonding.

## Methods

CoolCuddle 1 study was undertaken in two tertiary neonatal intensive care units (NICUs) in South-West England from October 2019 to December 2020 with 27 families. CoolCuddle 2 took place in six tertiary neonatal intensive care units in England with 36 families from April 2022 to August 2023. Across both studies, there were 140 cuddles, 90 involving mothers and 50 by fathers. For 70% of families (44), both mother and father were present in the NICU during cuddling. CoolBonding involved 47 families from four NICUs across England and Wales from May to December 2021.

Parents were eligible if their infants were born at  $\geq 35$  weeks gestation and undergoing TH using a servo-controlled cooling device and intensive care for HIE (BAPM, 2020), and they were approached, consented and recruited where appropriate by study personnel. We excluded infants who received considerable cardio-respiratory support (one or more of: high-frequency oscillation, mean airway pressure  $> 12$  cmH<sub>2</sub>O, inhaled nitric oxide for persistent pulmonary hypertension, oxygen requirement  $> 70\%$ , more than one chest drain, or  $\geq 3$  inotropes). Infants who had congenital anomalies or status epilepticus at the time of the cuddle, as well as families who lacked English proficiency to complete questionnaires, were also excluded. In the CoolCuddle studies, only one parent cuddled the baby during each cuddle, although the other parent may have been sitting by their side.

We compared the two cohorts where CoolCuddle was routinely delivered (CoolCuddle 1 and 2), with the comparison cohort (CoolBonding). Outcome measures in all three cohorts were derived from questionnaires given to the parents. We assessed maternal postnatal depression using the Edinburgh Postnatal Depression Scale (EPDS) (Cox et al., 1987), and maternal-infant bonding using the Mother-Infant

Bonding Scale (MIBS) (Taylor et al., 2005) at 1 week and 8 weeks postpartum. Fathers' attachment with their infants was assessed using the Paternal Postnatal Attachment Scale (PPAS) (Condon et al., 2008) at 8 weeks postpartum. EPDS  $\geq 13$  was defined as indicative of depression (Levis et al., 2020). Breastfeeding rates at 1 and 8 weeks postpartum were also collected. All questionnaires were sent by email using a secure REDCap hyperlink (Harris et al., 2009). Automatic reminder emails were sent one week later if a questionnaire had not been completed, and NICU staff contacted parents after two weeks to check they had received the link.

Mothers and fathers who had cuddled their cooled baby and consented to contact were invited for an interview by LB or JI (qualitative researchers) after they had completed their 8-week outcome questionnaires. Interviews took place online with those who agreed and gave informed consent between March and November 2020 for CoolCuddle 1 and January to August 2023 for CoolCuddle 2. Interview topic guides for parents were informed by the research literature, team discussions and input from our parent advisors, who were parents with experience of having a baby undergoing therapeutic hypothermia in NICU.

Demographics were collected on all infants, in all three studies, and included:

- Antenatal factors: mum and dad's ethnicity (white or other) and parental age at the time of the birth
- Neonatal factors: sex (male or female), birth weight, head circumference, gestational age at birth.
- Birth condition measures: HIE grade (Mild, Moderate, Severe), Apgar score at 10 min of age, lowest (worst) cord pH and Base Excess (BE)

All covariates were *a-priori* considered potential confounders.

### **Quantitative analysis**

Questionnaire data from the two cohorts of babies (CoolBonding and CoolCuddle1 and 2) were checked and harmonised between the three studies.

Initially, the demographics of the population were derived and compared between the two groups. Categorical variables were compared using the Chi<sup>2</sup> test, ordinal using the Mann-Whitney-U and continuous outcomes using a t-test. Summary outcome measures were also compared between the two exposure groups, using the same methodology as above.

Next, a univariable association between having a CoolCuddle and the exposure and maternal depression was derived using a logistic regression, random-effects model grouped around the site of care, to reduce the chance of clustering (Peters et al., 2003). This model was then adjusted for antenatal and neonatal confounders, with the variables being added to the model in these two groups. The model was repeated for the other binary outcomes (depression at 8 weeks), and an equivalent linear regression (for EPDS, MIBS and PPAS scores) models then derived. To reduce the risk of bias, a multiple imputation model, using chained equations was derived using all available exposure, outcome and covariate data (eTable 1), although imputed outcome measures were not included in the main analysis.

As sensitivity analyses, all analyses were repeated using complete case analysis methods (i.e. no imputed data), and then again, including imputed outcomes in addition to the covariates. Analysis was performed using Stata 17. All comparisons are two-sided; no *a-priori* cut-off for statistical significance was defined (Sterne & Davey Smith, 2001).

### Qualitative analysis

Trained qualitative researchers with extensive experience in evaluating health care services conducted the thematic data analysis. Interviews were recorded, transcribed verbatim by a professional transcription service and anonymised. Analysis of the data was an ongoing and iterative process using NVivo 11 software to organise and code the transcripts (QSR International Pty Ltd., 2018.) after each interview. Transcripts were initially coded by LB, and themes were generated (Braun & Clarke, 2006). Coding and candidate themes were discussed and developed with the lead qualitative researcher (JI) and the research group at regular intervals during data collection and analysis to achieve consensus. Interviews continued until data saturation was achieved, in that no new themes were arising from the data. The final themes were presented, discussed and endorsed by the study parent advisors.

### Ethics

CoolCuddle1 received Research Ethics Committee (REC) approval (19/NI/0143) and Health Research Authority (HRA) approval in August 2019. CoolCuddle2 received REC approval (22/NW/0141) and HRA approval in June 2022. CoolBonding study received REC and HRA approval (20/SS/0130) in December 2020.

### Results

Ten tertiary NICUs were involved in the studies with 60 families in the CoolCuddle studies and 47 in CoolBonding. Questionnaires were completed by 52 CoolCuddle families at 1 week, 45 at 8 weeks; and by 41 CoolBonding families at 1 week and 34 at 8 weeks (see Table 1).

Infants in the studies had different profiles of HIE, with those in the CoolBonding study mostly being moderate HIE, whereas the CoolCuddle infants had more severe (20%) and mild (18%) HIE ( $p = 0.040$ ) (Table 1). They were similar for sex, ethnicity (maternal and paternal), birthweight, head circumference, maternal and paternal age, gestation, cord pH, BE and Apgar score at 10 min (all comparisons  $p > 0.05$ ). Their milk feeding at discharge was similar across the studies ( $p = 0.118$ ). All infants in the CoolCuddle studies had a CoolCuddle while receiving TH (60/60), while 2/47 (4.3%) had some form of undescribed 'cuddle' in the CoolBonding study.

In the univariable analysis, mothers in the CoolCuddle studies had significantly lower EPDS scores (14 (9–19) vs 16 (12–21),  $p = 0.031$ ), less depression (27 (54.0% vs 30 (75.0%),  $p = 0.040$ ) and a better MIBS score (5 (1–7) vs 2 (0–5),  $p = 0.010$ ) than those in the CoolBonding study at discharge from the neonatal unit (Table 2). At 8 weeks, there were no differences in the scores for all these measures. Paternal scores for the PPAS at 8 weeks were also similar between the CoolCuddle and CoolBonding studies.

**Table 1.** Characteristics of the study population, split by their Cuddle status ( $n = 107$ ).

Characteristic	N	Coolbonding	CoolCuddle 1 and 2	p-value
Number		47	60	
Sex	101			0.180
Male		28 (68.3%)	33 (55.0%)	
Female		13 (31.7%)	27 (45.0%)	
Mum's Ethnicity	103			0.910
White		39 (90.7%)	53 (88.3%)	
Other		4 (9.0%)	7 (11.7%)	
HIE grade	97			0.040
Mild		2 (4.9%)	10 (17.9%)	
Moderate		35 (85.4%)	35 (62.%)	
Severe		4 (9.8%)	11 (19.6%)	
Dad's Ethnicity	78			0.616
White		23 (92.0%)	47 (88.7%)	
Other		2 (8.0%)	6 (11.3%)	
Birth Weight	101	3.501 (0.518)	3.312 (0.581)	0.0963
Head Circumference	82	35.0 (1.3)	34.4 (1.3)	0.0534
Dad's Age	78	34.0 (6.6)	31.0 (8.4)	0.1034
Mum's Age	100	31.5 (5.3)	29.6 (8.0)	0.1912
Gestation	100	39.7 (1.7)	39.0 (1.7)	0.0648
Cord pH	84	7.00 (0.15)	7.01 (0.15)	0.8740
BE	79	-12.71 (5.40)	-11.91 (8.79)	0.6683
Apgar@10 minutes	80	7 (5-7)	7 (4-7)	0.9182
Milk at Discharge	92			0.118
Mixed		9 (19.6%)	11 (23.9%)	
Breast		34 (73.9%)	26 (56.5%)	
Formula		3 (6.5%)	9 (19.6%)	
Cuddled	107	2 (4.3%)	60 (100.0%)	<0.001

**Table 2.** Outcome measures, split by their Cuddle status.

Characteristic	N	Coolbonding	CoolCuddle 1 and 2	p-value
Number		47	60	
D/C scores				
EPDS Score	90	16 (12-21)	14 (9-19)	0.031
EPDS=>13	90	30 (75.0%)	27 (54.0%)	0.040
MIBS	92	2 (0-5)	5 (1-7)	0.010
8wks scores				
EPDS Score	78	8 (4-15)	8 (4-13)	0.558
EPDS=>13	78	10 (30.3%)	11 (24.4%)	0.564
MIBS	79	2 (0-4)	3 (1-5)	0.071
PPAS	57			
Patience		32.6 (4.1)	33.2 (4.8)	0.601
Pleasure		27.9 (3.5)	27.6 (4.0)	0.762
Affection		18.7 (1.7)	19.0 (1.1)	0.502
Total		79.2 (7.4)	79.7 (8.9)	0.799

Measures are n (%), Median (IQR) or Mean (SD) as appropriate.

In the regression model, adjusting for the clustering in the unit of recruitment, unadjusted results were similar to the those seen in [Table 2](#), with evidence of lower EPDS scores (OR 0.42 (0.18–0.99)) and higher MIBS scores (OR 0.37 (0.18–0.79)) at discharge for infants in the CoolCuddle studies vs the CoolBonding infants, but less evidence of an association with a high EPDS score (OR 0.47 (0.20–1.12)) ([Table 3](#)). The association with EPDS score attenuated in the adjusted models (adjusted for antenatal factors: OR 0.43 (0.17–1.09) and adjusted for antenatal, neonatal and birth condition measures: OR 0.43 (0.17–1.09)), but there remained a lower risk of a low MIBS score (adjusted for antenatal factors: OR 0.42 (0.19–0.94), and adjusted for antenatal, neonatal and birth

**Table 3.** Association between CoolCuddle 1 and 2 and coolbonding infants and measures of parental mental health and bonding.

Measure	Summary Measures	N	Unadjusted	Adjusted for Antenatal Factors*	Adjusted for Antenatal* and Neonatal Factors**
Number					
D/C scores					
EPDS Score	OR (95% CI)	90	0.42 (0.18 to 0.99)	0.43 (0.17 to 1.09)	0.43 (0.17 to 1.09)
EPDS=>13	OR (95% CI)	90	0.47 (0.20 to 1.12)	0.46 (0.14 to 1.54)	0.46 (0.15 to 1.43)
MIBS	OR (95% CI)	92	0.37 (0.18 to 0.79)	0.42 (0.19 to 0.94)	0.38 (0.16 to 0.90)
8wks scores					
EPDS Score	OR (95% CI)	78	0.79 (0.36 to 1.73)	0.73 (0.30 to 1.76)	0.85 (0.31 to 2.35)
EPDS=>13	OR (95% CI)	78	0.57 (0.19 to 1.71)	0.44 (0.11 to 1.78)	0.34 (0.04 to 3.11)
MIBS	OR (95% CI)	79	0.48 (0.22 to 1.06)	0.43 (0.18 to 1.02)	0.48 (0.18 to 1.29)
PPAS					
Patience	Mean difference (95% CI)	57	0.66 (-1.92 to 3.23)	-0.64 (-3.15 to 1.88)	-0.39 (-2.66 to 1.88)
Pleasure	Mean difference (95% CI)		-0.44 (-2.61 to 1.73)	-1.14 (-3.39 to 1.10)	-1.11 (-3.25 to 1.02)
Affection	Mean difference (95% CI)		0.27 (-0.49 to 1.02)	0.05 (-0.82 to 0.93)	0.05 (-0.81 to 0.91)
Total	Mean difference (95% CI)		0.41 (-4.37 to 5.19)	-1.71 (-6.56 to 3.13)	-1.45 (-5.76 to 2.86)

condition measures: OR 0.38 (0.16–0.90). There was no association between any 8 weeks scores and the study the infant was in, for any of the models.

Similar, but less precise measures were seen in the complete case analysis results, with little evidence of an association in any of the adjusted models (the unadjusted model is identical to the main analysis) (eTable 2). In the fully imputed model (also imputing outcome measures), point estimates, and interpretation remained compatible to the main analysis.

A total of 32 and 25 paternal EPDS measures were returned in the CoolBonding study at discharge and 8 weeks, respectively, with very high scores of 27 (25–29) at discharge and 5 (2–8) at 8 weeks. All the fathers had a score above 12 ( $n = 32$ ) at discharge, while only 1/25 had a high score at 8 weeks. In comparison, the maternal scores in the CoolBonding study were 16 (12–21) and 8 (4–15), with 27 (67.5%) and 9 (27.3%) having high scores, at discharge and 8 weeks, respectively.

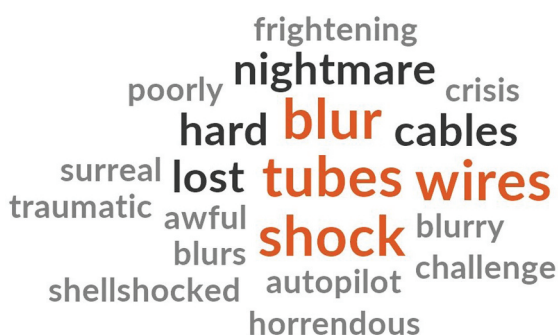
### Qualitative interviews

Of the 60 families enrolled in the CoolCuddle studies, in CoolCuddle1, 21 parents were interviewed from 11 families (11 mothers, 10 fathers); in CoolCuddle2, 17 parents were interviewed from 11 families (11 mothers, 6 fathers). Four fathers did not respond to contact about an interview, and one did not take part in a CoolCuddle. Family demographics are shown in Table 4. All infant weights were similar to the average UK birth weight, all were singletons, eight were first babies and two babies were born pre-term (before 37 weeks' gestation).



**Table 4.** Demographic details of the CoolCuddle study families interviewed.

Demographic	CC1	CC2
	11 families (21 parents)	11 families (17 parents)
<b>Infant characteristics</b>		
Baby sex	3 female (27%); 8 male (73%)	6 female (54%), 5 male (46%)
Mean Gestational age	39.3 weeks (36.6 – 41)	38.9 weeks (range 35.4 – 41.7)
Mean birth weight	3.41 kg (range 2.83 – 3.84 kg)	3.51 kg (range 2.39 – 4.87 kg)
<b>Maternal characteristics</b>		
Maternal parity	4 primiparous, 7 multiparous	4 primiparous, 7 multiparous
Mean maternal age	33.2 years	32.4 years
Ethnicity	1 non-white, 10 white; 4 non-English 1st language	11 white; 1 non-English 1st language

**Figure 2.** Word cloud showing words frequently used by parents to describe their childbirth experience.

Comments from the studies reflect some important parental mental health issues following the traumatic events around the birth (see [Figure 2](#)), whilst their baby was in NICU being cooled, and after they were discharged home.

Babies did not stay long in the unit after cooling therapy was completed, and stays were short as they focussed on the cooling therapy (typically 7–12 days including cooling; mean 9.7 days in total). Four sub-themes were identified from the parental mental health theme: *trauma and access to support while on NICU; lack of continuity of care; processing trauma and support needs post-discharge; parents needs may vary*. Illustrative quotes are anonymised with IDs for each family and whether spoken by mother or father.

### **Trauma and access to support while on NICU**

Parents felt that they were not always ready to access support or information, such as counselling or a BLISS charity pack ([www.bliss.org.uk/](http://www.bliss.org.uk/)) whilst on NICU as the experience had been such a huge and traumatic shock for them both and each parent had experienced the traumatic event differently.

It was nice being able to see him hold her [during CoolCuddle], because the last time he held her he thought she was dead. So for him to hold her was more emotional, because I was conscious of the fact that [husband] was, he was just plain worried . . . So did feel better once [husband] had held her as well, because I just needed his bad memories to be replaced with something good. (#13 mother)

I don't know if you'd be able to take anything on board to be honest, at that point it's very difficult isn't it. There's so much running through your head that you can't really think about anything. (#17 father)

### ***Lack of continuity of care***

Families highlighted that the transfer back to their home hospital or to home was often quite disjointed and there was a lack of continuity of care. This led to them having upsetting visits and phone calls with health professionals and having to explain their story repeatedly to doctors and others involved in their care.

What is a little bit frustrating is that every doctor you're having to explain things to, that can be a bit upsetting, and that upsets [partner] having to re go through it all again and again... (#19 father)

it might have been the health visitor, or somebody, and the baby was in hospital, so she tried to come a couple of times, and she left me a voicemail to say are you going to be home at any point, I was coming to weigh the baby? . . . . No, she's in NICU, she's not at home, she's poorly. (#15 mother)

### ***Processing trauma and support needs post discharge***

They emphasised the need of support for them following discharge, which was not always offered or available. They continued to process their traumatic experience at home and despite being part of a couple, parents often processed the trauma as an individual. Some said that they had not yet discussed what had happened between themselves, possibly because they were at different stages in coping with it. Parents reflected that having some form of counselling session might help them deal with the trauma experienced.

He's parked it and put it aside sort of thing, and just going through the motions of being a young parent, and focusing our time on [baby] etc. So in all fairness, no we haven't actually really spoken about it. But giving him time I'm sure he will. (#16 mother)

... we don't really speak about it, and I've not really processed it, he [partner] thinks it's all going to come to an abrupt head at some point. But at the moment I just don't really ... But talking about it now, even to you, it feels good to be able to talk about it ... talking about it now doesn't make me feel depressed or anything like that, or anxious. I just choose not to really talk about it, because it was such a traumatic time, and at the end of the day we both might not have been there, and so that's why I don't talk about it. (#15 mother)

I think there isn't enough follow-up support for parents in general, and like I said I'm a strong minded person that I don't really let things get to me... from a mental health perspective I would say [partner] she struggles with it, ... I don't think she's processed it, ... She has never been followed up to have an assessment and how are you feeling, do you know what I mean? So no, I don't think there is anything. (#15 father)

There were ongoing investigations about the birth and continued anxiety about the health of their baby, including worry about milestones and possible seizures which could occur. Some babies were readmitted to hospital, and other medical conditions were diagnosed.

I do think mentally things are a lot harder later on, because I think initially it's more just like you're quite relieved that they're still alive and that they're getting better and things, and you celebrate much smaller stuff. But then when you're home and you're starting to worry about the future and whether things are normal, and you don't have people around you telling that everything is okay every day, I think that's probably when it's a bit harder. (#18 mother)

I am still going to see the mental health nurse service, and I've got quite a bit of support with that ... the hospital did an investigation into what happened in [baby]'s birth. It has been on the phone, but I'm getting some face to face support now, which is good... I think I am getting a good level of support, and I think that does help a lot. (#17 mother)

### *Parents' needs may vary [in terms of therapeutic approach]*

When discussing the type of support that they would need, parents suggested that needs may vary in terms of therapy, but they would prefer a tailored personal session as HIE is quite different from other infant conditions experienced in NICU. They would appreciate talking to parents who had gone through a similar situation to provide reassurance and positive feedback and also wanted to help other parents in the future. Others suggested that time rather than therapy would heal and help them come to terms with the traumatic experience.

It's not necessarily me as a person that I'm wanting to change, it's my understanding of what's happened and me being able to deal with that... But in hindsight to be honest I feel given time, I think it's going to be a time thing rather than a therapy thing for us. (#16 mother)

I did join some Facebook group for babies who had HIE... it was just lots of very traumatic stories about the birth of children who were doing very poorly... so looking at the information I found about it, a lot that was around babies that either die or who had been very severely brain injured... it's the sort of condition that if you're researching things what you will find is very, very bleak... (#17 mother)

## **Discussion**

The CoolCuddle and Coolbonding studies have highlighted the raised levels of post-delivery depression amongst parents after their baby is admitted to NICU to receive therapeutic hypothermia to treat HIE. However, mothers who had been involved in a CoolCuddle with their cooled baby had significantly less initial depression, lower EPDS scores and higher MIBS scores consistent with better mother-infant bonding when discharged from NICU than those in the CoolBonding study, where CoolCuddle was not available. The levels of depression suffered by the families after this point are unclear in this work, but by 8 weeks postpartum both groups had similar and lower levels of depression. How the profile differed between the two groups was not measured in this work. However, while improved, about 25–30% of these mothers, in both groups, still had measures consistent with postnatal depression at 8 weeks postpartum. The threshold we used on the EPDS score captures moderate depression, and it is known that moderate postnatal depression is associated with childhood adverse outcomes including behavioural difficulties. Further persistent and severe postnatal depression could have substantial impact on childhood development affecting the behavioural and educational attainment and mental health of children (Netsi et al., 2018). However, the impact of this

on the development of these particularly vulnerable infants, and how the postnatal depression evolves moving forward, in parents of infants with HIE, remains unclear.

In the non-cuddling (Coolbonding) study, we also measured depression levels in fathers at discharge, and these too were extremely high, indicating a concerning level of mental health distress in the fathers. It is likely that fathers being exposed to dual adverse experiences of their partner having a traumatic delivery and their baby suffering brain injury requiring intensive care may be related to their higher postnatal depression scores at discharge from the neonatal unit. Interestingly, when their babies were 8 weeks old, fathers postnatal depression scores declined, and their attachment score with their babies appeared stable. It is possible that fathers may experience more post-traumatic stress disorders, as reported in this population of fathers with babies who had HIE, which we were unable to capture with the postnatal depression or attachment scales utilised in this work (Horsch et al., 2017).

The interviews with parents described some important issues following the sudden and traumatic admission of their infant to NICU following birth asphyxia, with several stressing the need of extensive mental health support following discharge. Other studies have reviewed mental health problems experienced by parents with infants in NICU. A case-control study in 2020 in the US assessed the effects of the diagnosis of neonatal encephalopathy and subsequent separation on rates of maternal postpartum depression (PPD) as compared to other hospitalised infants (Laudi & Peeples, 2020). They concluded that mothers of infants with HIE are at high risk for PPD, which may be related to TH interfering with maternal – infant bonding. They recommended continued universal depression screening for these parents and investigation of new methods to reduce stress and improve the bonding experience during and after TH.

Gong et al. (2023) reported the higher prevalence of postnatal mental health problems in mothers of infants admitted to NICU compared to those not admitted to NICU 6 months after giving birth in the UK. A review by Roque et al. (2017) on the mental health of all parents with infants in the NICU concluded that ongoing assessment of the mental health of parents should be part of routine NICU care with culturally appropriate policies and services in place to respond to their mental health needs.

A review of interventions that have been implemented in NICU to support parents describes staff-based support such as wellness rounds and education in developmental care, as well as parental-based support including cognitive-behavioural therapy and home visitation programmes (Bernardo et al., 2021). They conclude that interventions should use a multidisciplinary approach involving NICU staff, social workers, spiritual/religious representatives, specialists in developmental care, and psychiatrists/psychologists to help support families and facilitate the transition to the home. Future efforts should include raising awareness of the psychological stresses of NICU parents and encouraging the development of programmes to provide parents with psychological support.

### *Strengths and limitations*

This is the largest study of parents of infants with HIE undergoing TH, with over half of them receiving a new CoolCuddle intervention. We report on the associations between postpartum depression and taking part in a CoolCuddle. The sites were based across

England and Wales (10 in total). Thirty-eight parents (both mothers and fathers) were interviewed from two CoolCuddle studies, and they gave vivid accounts of their mental health challenges following their infants' traumatic birth.

Limitations include that only 107 infants were included in the data collection process, but this spanned several years as this is a relatively rare condition. We did not measure paternal depression at discharge for those in the CoolCuddle studies and also did not have an intermediate time point between 1 and 8 weeks or later time point and the impact of the parents' depression and bonding on childhood development, but these would be useful data to collect in future studies.

## Conclusions

The CoolCuddle intervention for cooled infants was associated with lower prevalence of depression and enhanced bonding scores for mothers at discharge compared to those who did not cuddle their babies. Parents highlighted increased levels of parental depression following the sudden and traumatic admission of their infant to NICU with HIE. Many were not always ready to access support or information whilst on NICU and stressed the need of mental health support following discharge. We suggest that future efforts should include raising awareness of the psychological stresses of NICU parents and encouraging the development of programmes to provide parents with psychological support.

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## Authors' contributions

EC, DO & JI contributed to the conception of this work; DO conducted the statistical analysis; LB and JI the qualitative data collection and analysis; LB and JI interpreted the qualitative data and discussed findings with EC and DO; JI drafted the manuscript with contributions from all authors. All authors have approved the submitted version of the manuscript.

## Consent for publication

Consent for publication of quotes was included in the online consent form.

## Data sharing

Additional quantitative data that support the findings of this study have been included in the supplementary file. The data set is available from corresponding author on a reasonable request. The qualitative data are not publicly available to protect the anonymity of participants but are available from the corresponding author upon reasonable request.

## Ethics approval and consent to participate

CoolCuddle1 received Research Ethics Committee (REC) approval (19/NI/0143) and Health Research Authority (HRA) approval in August 2019. CoolCuddle2 received REC approval (22/NW/0141) and HRA approval in June 2022. Coolbonding study received REC and HRA approval (20/SS/0130) in December 2020. Participants completed online consent forms on a REDCap database.

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