BMJ Paediatrics Open

High levels of parenting stress and trauma despite age-appropriate developmental outcomes following perinatal asphyxia: a cross-sectional observational study

Angela Sutterer-Verrelli,[1] Anna Katharina Georg,[2,3] Anja Riecker,[1] Veronique B Weiss,[1] Alexandra F Puchwein-Schwepcke,[4] Claudia Nussbaum [1]

To cite: Sutterer-Verrelli A, Georg AK, Riecker A, *et al*. High levels of parenting stress and trauma despite age-appropriate developmental outcomes following perinatal asphyxia: a cross-sectional observational study. *BMJ Paediatrics Open* 2026;**10**:e004976. doi:10.1136/bmjpo-2026-004976

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/bmjpo-2026-004976).

AS-V and AKG are joint first authors.

Received 20 May 2026
Accepted 17 July 2026

Check for updates

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For numbered affiliations see end of article.

Correspondence to Prof. Dr. Claudia Nussbaum; claudia.nussbaum@med.uni-muenchen.de

ABSTRACT

Objective To examine the association of perinatal asphyxia across mild to moderate hypoxic-ischaemic encephalopathy (HIE) severity levels and therapeutic hypothermia (TH) with child developmental outcomes and parenting stress and to explore parental trauma and psychosocial support.

Design Multicentre, cross-sectional, comparative observational study.

Setting Two university medical centres in Germany.

Participants Parents of children aged 1–5.5 years with a history of perinatal asphyxia treated with TH (n=58) or without TH (n=77), and unexposed control children (n=179).

Outcome measures Parents completed the Ages & Stages Questionnaire, Third Edition, and the Parenting Stress Index (PSI) for the primary outcome, and reported on birth-related trauma, psychosocial support and family planning decisions as exploratory secondary outcomes.

Results Most children showed age-appropriate developmental outcomes across all groups. In contrast, parents in both asphyxia groups reported elevated stress levels, with higher PSI scores in the TH group, particularly in the health, competence and attachment domains. Postnatal trauma was highly prevalent, affecting 88% of parents in the TH group, 73% in the non-TH group and 15% in controls. Psychosocial support was perceived as sufficient by only 20% of parents in the non-TH group, compared with 39% in the TH group. Birth-related trauma was a significant predictor of parental stress.

Conclusions Despite mostly age-appropriate development on screening, parental stress and trauma were highly prevalent regardless of HIE severity, and psychosocial support was markedly insufficient, particularly for families whose infants did not receive TH. These findings highlight the need for structured, accessible psychosocial support for all patient-families affected by perinatal asphyxia.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Perinatal asphyxia can cause neurodevelopmental impairment depending on the severity of associated hypoxic-ischaemic encephalopathy (HIE), and may negatively affect parental mental health and parent–infant bonding.

WHAT THIS STUDY ADDS

⇒ Parental stress and trauma remain high after perinatal asphyxia regardless of HIE severity or child developmental outcomes. Parents of children classified as only mildly affected particularly report insufficient psychosocial support during hospitalisation.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Psychological support should be offered to all patient-families following perinatal asphyxia, irrespective of HIE severity or treatment. Family-centred care models need to address parental mental health needs alongside neonatal care.

INTRODUCTION

Perinatal asphyxia can lead to multiorgan damage, with hypoxic-ischaemic encephalopathy (HIE) posing a major risk for long-term neurodevelopment.[1] The reported incidence of HIE ranges between 1 and 3 (–8) per 1000 live births in industrialised countries and up to 26 per 1000 in low- to middle-income countries.[2 3] Several large randomised controlled trials have shown the neuroprotective benefits of therapeutic hypothermia (TH) in neonates with HIE, involving whole-body cooling to 33–34°C or head cooling to 34–35°C for 48–72 hours[4 5] As a result, TH has become standard care for moderate to severe HIE.[6]

However, most neonates with HIE present with mild forms, for which management is not well established, and TH is not routinely recommended.[7] Emerging evidence suggests that mild HIE may still lead to developmental delays, concentration issues and learning disabilities, affecting both children and

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families.[8–10] Considerable variation exists in clinical practice regarding the longitudinal follow-up of neonates with HIE, particularly those with mild disease.

For parents, perinatal asphyxia and TH are traumatic and emotionally stressful experiences, potentially resulting in post-traumatic stress disorder (PTSD), negative emotions and impaired bonding.[11–13] Parents of neonatal intensive care unit (NICU)-treated infants frequently report adjustment difficulties, anxiety and postpartum depression[14 15] as well as more behavioural issues in their children, such as sleep disorders by age 3, compared with controls.[16] Furthermore, PTSD during the perinatal period may also impair long-term parent–child interactions and the child's development.[17] Available evidence therefore highlights the need for trauma-informed care, including clear and consistent communication, parental involvement and ongoing psychosocial support.[18]

To date, most research has focused on cases presenting with moderate to severe HIE treated with TH, leaving mild cases without TH under-represented. It remains unclear whether parents of infants with perinatal asphyxia who did not require TH face comparable levels of parenting stress, traumatic birth experiences and concerns regarding child developmental outcomes.

This study examined the association of HIE severity and exposure to TH with developmental outcomes in children aged 1–5.5 years and with parenting stress as the primary outcome. Exploratory secondary outcomes included parental traumatisation, psychosocial support received, family-planning decisions and potential confounders. Children with a history of perinatal asphyxia, managed with or without TH, were compared with controls without asphyxia.

The study addressed the following research questions:

1. Are HIE severity and exposure to TH associated with child developmental outcomes and parenting stress?
2. Are HIE severity and exposure to TH associated with traumatic birth experiences and psychosocial support received?

Our findings aim to support early intervention strategies and highlight the importance of psychological support for affected parents to identify at-risk families and promote overall family well-being.

METHODS

Study design and patient recruitment

This multicentre, cross-sectional, comparative observational study was conducted at the LMU University Hospital and the Heidelberg University Hospital. On ethical approval, children with perinatal asphyxia born between 2016 and 2021 were identified through a systematic search of hospital information systems using International Classification of Diseases (ICD) codes P21.0 (severe asphyxia), P21.1 (mild to moderate asphyxia) and P21.9 (unspecified asphyxia). As these codes may also capture infants with impaired postnatal adaptation (Apgar score ≤7) without true perinatal asphyxia, additional inclusion criteria were applied to confirm cases: minimal pH value ≤7.1 and/or base excess less than or equal to −12 mmol/L, gestational age ≥36+0 weeks, and admission to the NICU within 6 hours of birth. Exclusion criteria were absence of confirmed asphyxia, death before discharge, missing treatment data or lack of parental contact information. Eligible infants were categorised according to the HIE severity recorded in clinical routine based on modified Sarnat score and amplitude-integrated electroencephalography (aEEG) as having mild, moderate or severe HIE.[6] Infants diagnosed with severe HIE were excluded per ethics board request due to concerns about potential retraumatisation of families (figure 1). Consistent with current German treatment guidelines,[6] all neonates classified by Sarnat score as having moderate HIE in our study population received TH for 72 hours, whereas infants classified as having mild HIE did not receive TH. For the purposes of this study, infants with perinatal asphyxia were grouped according to treatment exposure as TH and non-TH groups because exposure to TH, including intensive technical monitoring and restrictions on parent–infant contact, may itself affect parental stress and traumatic birth experiences.

Controls were children from the same birth years without parent-reported perinatal asphyxia. Recruitment in Munich and Heidelberg, two large (>150 000 inhabitants) German cities, involved flyers in paediatric practices, childcare facilities and social media. Participants accessed the online survey via quick response (QR) code or URL. Parents selected the questionnaire according to the current age of the infant in months without providing details on the exact birthdate or other personal identifiers except for the sex of the child. When response rates were low, term-born children (2016–2021) without ICD-code P21*. diagnosis were randomly selected from hospital records starting mid-2022. Their parents were contacted by phone and sent study materials electronically on verbal consent.

Parental consent

For the asphyxia group, written informed parental consent was obtained. Eligible patients were assigned study numbers, and their parents were contacted by telephone. Following verbal consent, parents received the study information, the informed-consent form and the pseudonymised paper-based survey. Patient-related data and the survey responses were entered into the study database and analysed only after written informed consent had been returned. To assess potential participation bias, selected clinical data of eligible infants whose parents declined participation or did not return the consent form were collected retrospectively following additional approval by the institutional review board on the condition that all data were irreversibly anonymised before analysis.

For the control group, a waiver of written informed consent was granted by the institutional review board, as

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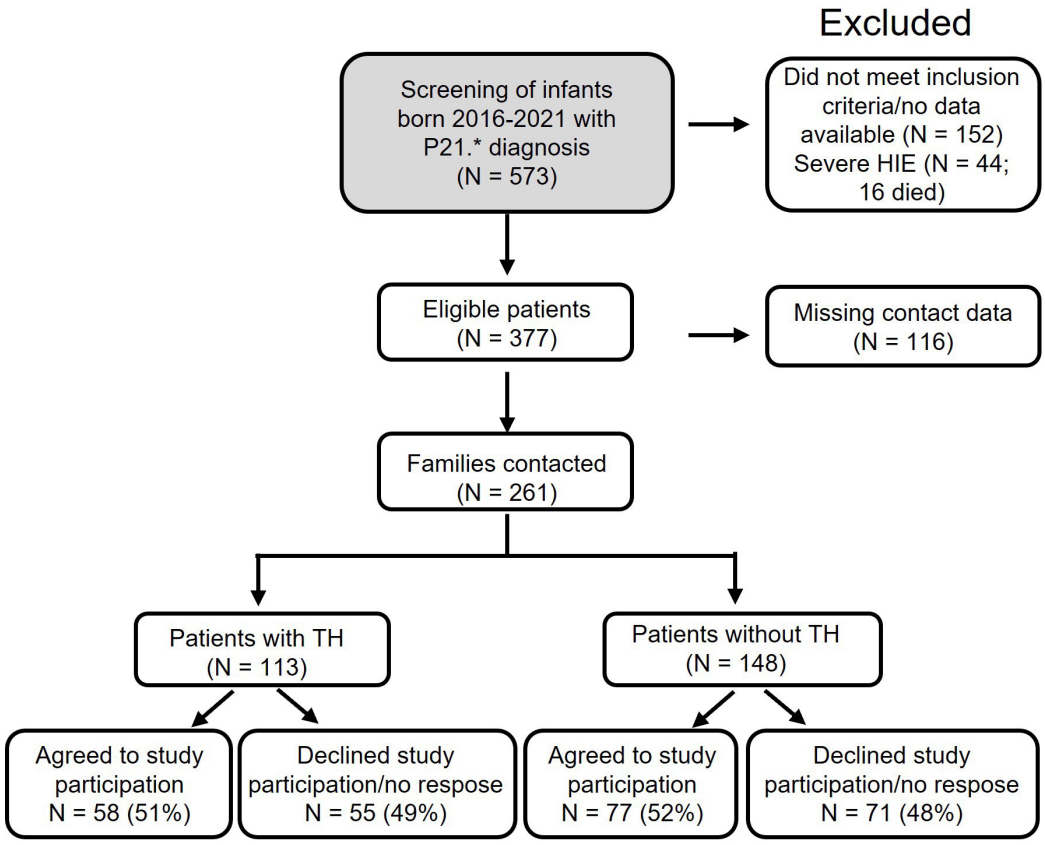


Figure 1 Flow diagram of study participants in the asphyxia groups *incl ICD-codes P21.0; P21.1; P21.9. Additional inclusion criteria: min pH <7.1 and/or base excess less than or equal to −12 mmol/L, gestational age >36+0 weeks and age at admission <6 hours. Cases with severe HIE were excluded due to Ethical Board request. HIE, hypoxic-ischaemic encephalopathy; TH, therapeutic hypothermia.

the questionnaire was fully anonymous and no personally identifiable data were collected.

Survey design and evaluation

The survey assessed developmental outcomes, parenting stress, trauma perception and possible confounding factors, which were grouped into three parts:

1. Demographic and health data: questions covered the child's sex, age, birth details, anthropometrics, parental age, education, occupation, living conditions, siblings, preventive check-ups, developmental assessments and special needs.
   Trauma experience and psychological support were assessed on a 5-point Likert scale (see online supplemental methods). Furthermore, parents were asked about the impact of their experiences surrounding birth and the early postnatal period on family planning decisions (see online supplemental ImPACS questionnaire _part 1).
2. Developmental screening: the Ages & Stages Questionnaire, third edition (ASQ-3), screens developmental delays in children aged 2–66 months.[19] It has been validated in various patient groups and shows good psychometric properties (Cronbach's alpha 0.51–0.87; test–retest reliability 92%; sensitivity 86.1%, specificity 85.6%). Parents assess their child's abilities across communication, motor skills, problem-solving and social competence using six items per domain. Scores (10=yes, 5=sometimes, 0=notyet) are totalled and compared with age-specific cutoffs. Up to two missing items per domain may be imputed by assigning the average value of the remaining items in the respective category (online supplemental table 1A). The German translation was created using forward- and backward-translation at the Institute for Psychosocial Prevention, University Hospital Heidelberg. It is used clinically but not yet formally validated.
3. Parenting stress: the German version of the Parenting Stress Index (PSI)[20] for ages 1–6 assesses the subjectively experienced current stress and demand related to parenting and is a validated and widely used questionnaire. Only the parent domain was used. Missing items were not imputed (online supplemental table 1B). Each subscale includes four items rated on a 5-point Likert scale. Subscale scores were transcribed according to the user manual and summed for a total score. In this study, the PSI showed strong internal consistency (Cronbach's α=0.91; subscales: 0.69–0.83). *T*-scores (mean=50, SD=10) were used to interpret stress levels: *T*-score ≥60 = elevated stress; *T*-score ≥70 = clinically significant stress. Stanine scores were used for subcategories: 1–3=below average, 4–6=average, 7–9=above average.

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Patient-families and the public were not involved in the design, conduct, reporting, or dissemination plans of this study.

Statistical analysis

Sample size was estimated ASQ-3 comparisons across three groups, including pairwise comparisons between the two patient groups. Based on published normative SDs of 10–12 points,[21] a moderate effect size (Cohen's d=0.6; approximately 6–7 ASQ points), α=0.05 and 80% power, 45 participants per patient group were required. A shared control group of approximately 90 patients was targeted for the comparison of developmental outcomes. For PSI *T*-scores (mean 50, SD 10), this sample size provides 80% power to detect a 0.6 SD difference (approximately six points) between groups.

Normality was assessed using the Shapiro-Wilk test. Depending on distribution, group comparisons used ANOVA or Kruskal-Wallis tests with Dunn's post hoc testing; TH versus non-TH comparisons used t-tests or Wilcoxon tests. Frequencies were compared using χ^2 tests. Associations were examined with linear regression for continuous outcomes and ordinal logistic regression for ordinal outcomes. GraphPad Prism V.8, R (V.4.4.0) and STATA V.15 were used for analysis and visualisation. Significance was set at $p<0.05$.

During data analysis, we noted a discrepancy in response coding between the electronic (control) and paper-based (asphyxia) form. In the online version, parents rated PSI responses directly as a numerical value from 1 to 5, rather than selecting descriptive response options in which 1 indicates strong agreement and 5 indicates minimal agreement. Although this was explained at the beginning of the survey, the lack of repeated clarification may have led to systematic response errors and, critically, to systematic differences compared with the paper–pencil format used in the clinical groups. Due to these concerns about data validity, control group PSI data were excluded from further analysis to preserve study integrity.

RESULTS

Sample description

Figure 1 depicts the recruitment process for the asphyxia groups. After exclusion of infants who did not fulfil the inclusion criteria, had severe HIE, died before discharge, or were lacking clinical and/or contact information, a total of 261 families were contacted (113 TH group and 148 non-TH group). Participation rate was comparable between both asphyxia groups, with 51% (n=58) in the TH group and 52% (n=77) in the non-TH group. In the control group, 180 families completed the questionnaire; one case was excluded due to a reported syndrome disorder with neurological impairment.

Table 1 summarises clinical and sociodemographic data of study groups. The sex and age distribution of children across all study groups was comparable, while birth modes differed significantly. As expected, children in the TH group differed significantly from children in the non-TH group in APGAR values, minimum pH values and length of NICU stay, and a higher proportion was transferred from another hospital. We also observed significant group differences in parental participation and education level. Within the asphyxia groups, we found no significant differences in clinical parameters between children whose parents agreed to study participation versus those who did not or did not respond (online supplemental table 2).

ASQ scores

Overall, the distribution of ASQ-3 scores was similar across study groups, with the only significant difference seen for gross motor skills between the non-TH group and the control group (table 2). In total, 4% of children in the non-TH group, 10% in the TH group and 12% in the control group scored below the age-specific cut-off in one of the five subcategories, and 4%, 3% and 5%, respectively, scored below the cut-off in ≥2 categories (ns). Taken together, these neurodevelopmental screening results point towards a largely age-appropriate development in the majority of children in our cohort irrespective of group allocation. Health data reported by parents revealed that 41% of children in the TH group had received special support in the past, mostly physiotherapy, as compared with 25% in the non-TH group and 13% in the control group.

Parenting stress

Parents in the TH group reported significantly higher total stress scores than those in the non-TH group (median (IQR): 57 (12) vs 54 (14); figure 2A). Noteworthy, *T*-scores were rather high in both groups, with 29% in the non-TH and 40% in the TH group exceeding the threshold of 60, indicating elevated stress compared with normative samples (figure 2B). Subscale scores for 'health', 'competence' and 'attachment' were significantly higher in the TH group (figure 2C).

A comparison with the control group was not possible due to concerns about data validity; thus, the research question on differences in parenting stress could not be addressed.

To assess the influence of demographic confounders on parenting stress,[22] we conducted secondary exploratory analyses. Independent variables included treatment group, child/parent age, education level, parental working hours, siblings and survey respondent (online supplemental table 3). None of these factors significantly predicted PSI T-scores, whereas group affiliation (TH) remained a significant predictor.

Exploratory analyses: trauma, psychosocial support and family planning

Parents in both asphyxia groups reported significantly more trauma than controls, both during birth and in the days after birth (table 3). Notably, about 73% of non-TH parents experienced the first days as traumatic despite no

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Table 1 Clinical and sociodemographic characteristics of study groups

	Non-TH group n=77	TH group n=58	Control n=179	P value
Gestational age at birth (days)	281 (272–286)	280.5 (272–286)	na	0.46
Duration of NICU admission (days)	4 (2–4)	9 (7–11)	na	**<0.0001**
Infants transferred after birth	22 (29%)	28 (48%)	na	**0.012**
APGAR 5'/10'	7 (6–8)/8 (7–9)	6 (4–7)/7 (5–8)	na	**<0.0001**
Min pH value	7.01 (6.95–7.07)	6.91 (6.88–6.98)	**na**	**<0.0001**
Base excess	−13.75 (−17.03 to −9.75)	−15.85 (−18.35 to −12)	na	0.72
Gender of child (m)	44 (57%)	31 (54%)	91 (51%)	0.67
Age of child at survey completion (months)	29 (1–44)	30 (21–48)	30 (19–47)	0.43
Who is completing the survey				**0.0001***†
Both parents	25 (34%)	21 (37%)	10 (6%)	
Mother	45 (61%)	33 (58%)	157 (88%)	
Father	4 (5%)	3 (5%)	12 (7%)	
Mean age of mother (years)	35.5 (4.3)	36.6 (5.1)	36.0 (5.0)	0.39
Mean age of father (years)	37.3	39.3	38.0	0.21
Mother native German speaker	64 (84%)	50 (86%)	155 (87%)	0.49
Father native German speaker	68 (90%)	47 (81%)	156 (87%)	0.48
Maternal level of education				**0.023**†
Vocational training or apprenticeship	20 (26.0%)	19 (33%)	26 (15%)	
German high-school diploma/vocational baccalaureate	6 (8%)	6 (10%)	18 (10%)	
University degree	49 (64%)	29 (50%)	129 (72%)	
Other school degree/education	2 (3%)	4 (7%)	6 (3%)	
Paternal level of education				0.71
Vocational training or apprenticeship	17 (22%)	16 (28%)	32 (18%)	
German high school diploma/vocational baccalaureate	6 (8%)	5 (9%)	12 (7%)	
University degree	47 (62%)	34 (59%)	125 (69%)	
Other school degree/education	6 (8%)	3 (5%)	10 (6%)	
Mode of birth				**<0.0001***†‡
Spontaneous vaginal birth in the hospital§	42 (50%)	16 (26%)	110 (62%)	
Caesarean section¶	19 (23%)	29 (47%)	51 (29%)	
Vacuum/forceps	20 (23%)	15 (24%)	15 (8%)	
Birth centre/ home birth	3 (4%)	2 (3%)	2 (1%)	
Presence of siblings	31 (40%)	31 (53%)	104 (58%)	**0.029***

Data are presented as median (IQR) or as counts (%). Between-group comparisons of continuous variables were performed using the Kruskal-Wallis test. Categorical variables were compared using the χ^2 test. In case of overall significance, post hoc pairwise comparisons were conducted. Significant p-values are marked in bold.
*Non-TH group versus control.
†TH group versus control.
‡Non-TH group versus TH group.
§Cumulative counts across the different birth-mode categories exceed the total group sizes in the asphyxia groups because some births were double-reported as both spontaneous vaginal deliveries in hospital and vacuum/forceps deliveries (non-TH group: n =7, TH group: n =4).
¶Including emergency caesarean section.
NICU, neonatal intensive care unit; TH, therapeutic hypothermia.

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Table 2 Overview of ASQ-3 values across study groups

	Non-TH group (n=77)	TH group (n=58)	Control (n=179)	
	Median (IQR)	Median (IQR)	Median (IQR)	P value
Communication	50 (17.5)	52.5 (16.25)	55 (20)	0.903
Gross motor	60 (27.5)	55 (10)	55 (10)	**0.0215***
Fine motor	55 (12.5)	55 (15)	55 (15)	0.480
Problem solving	50 (15)	55 (15)	55 (15)	0.674
Personal social	50 (20)	55 (12)	54 (15)	0.275

Data are presented as median (IQR). Study groups were compared with the Kruskal-Wallis test. Dunn's multiple comparison test was employed for post hoc analysis.
*Non-TH group versus control.
ASQ-3, Ages & Stages Questionnaire, third edition; TH, therapeutic hypothermia.

significant HIE, TH or prolonged NICU stay. Belonging to the asphyxia group remained independently associated with greater birth-related and early postpartum trauma after adjustment for mode of delivery, postnatal transfer and length of NICU stay, all of which differed significantly between the groups. The association was strongest in the TH group (online supplemental table 4A and B). Caesarean section, including emergency caesarean section, as well as vacuum/forceps delivery, were also independently associated with higher trauma (online supplemental table 4A). Weaker associations were seen for length of NICU stay with birth-related trauma, and outborn status with postpartum trauma (online supplemental table 4B).

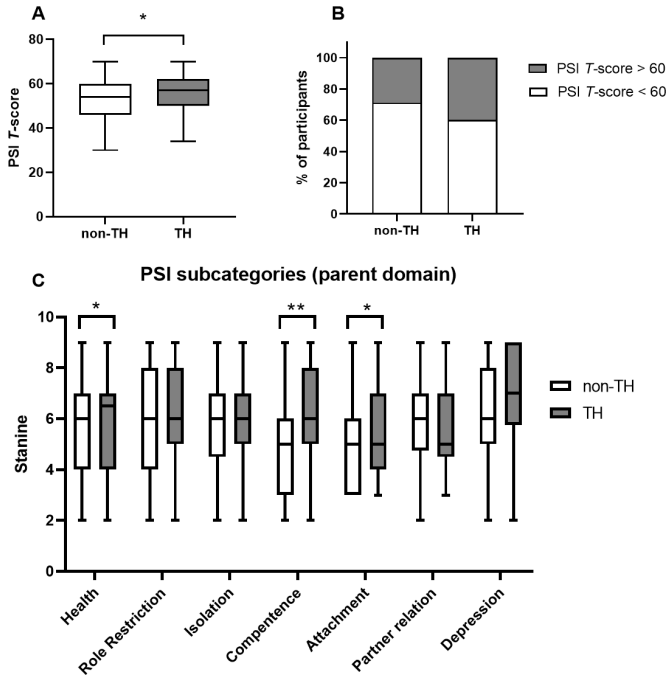


Figure 2 PSI-scores in the TH and non-TH groups. (A) PSI *T*-score was significantly higher in the TH versus non-TH group; p-value = 0.039. (B) Percentage of parents with elevated stress score (>60, indicating >1 SD). (C) Subcategories of the PSI scores were evaluated with stanine scores of 7, 8 or 9 indicating a value above average. Wilcoxon-test: *p<0.05, **p<0.01. PSI, Parenting Stress Index; TH, therapeutic hypothermia.

The non-TH group reported significantly less psychosocial support during hospitalisation than the TH group (table 3), with only 20% of parents considering support sufficient, compared with about 40% in the TH group; likewise, 32% of non-TH versus 58% of TH parents found it helpful. In controls, only 4% received in-hospital support. By contrast, support after discharge was high across all groups, likely reflecting widespread postpartum midwife care in Germany. These findings indicate that even without TH or prolonged NICU admission, non-TH families experience substantial distress and particularly lack adequate support during this critical period.

When asked about the impact of birth experiences on their family planning, 28% of the TH group reported having decided against further children and 17% were undecided. Among non-TH parents, about 20% were undecided, and 12% had decided against further children. Perceived trauma during and after birth was associated with deciding against further children, whereas study group, child and parental age, and parental education were not (online supplemental table 5).

Finally, given the significant differences in reported trauma among asphyxia groups, we examined its relationship with PSI scores (table 4). When trauma was included as an independent variable, it significantly predicted PSI *T*-scores, whereas asphyxia group affiliation no longer did. This suggests that trauma may partly account for the association between group affiliation and parenting stress, with higher trauma associated with greater stress regardless of group. The association remained significant after adjusting for birth mode, outborn status and NICU stay (online supplemental table 6).

DISCUSSION

This study aimed to improve understanding of how perinatal asphyxia across varying HIE severity, including cases requiring TH and those not treated with TH, affects child

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Table 3 Comparison of parental trauma perception and psychosocial support across study groups

	Non-TH group (n=77)	TH group (n=58)	Control (n=179)	P value
I experienced the birth of my child as traumatic				**<0.0001**
Strongly disagree/disagree	24 (31%)	9 (16%)	131 (73%)	
Neither agree nor disagree	6 (8%)	4 (7%)	15 (8%)	
Strongly agree/agree	47 (61%)	45 (78%)	32 (18%)	
I experienced the first days following the birth of my child as traumatic				**<0.0001**
Strongly disagree/disagree	20 (26%)	2 (3%)	138 (77%)	
Neither agree nor disagree	1 (1%)	5 (9%)	15 (8%)	
Strongly agree/agree	56 (73%)	51 (88%)	26 (15%)	
Did you have psychosocial support				
During hospital admission	12 (16%)	31 (54%)	7 (4%)	**<0.001**
After discharge*	56 (73%)	35 (60%)	128 (72%)	0.22
I received sufficient psychological support after birth and in the first days of life				**0.0022**
Strongly disagree/disagree	47 (72%)	30 (54%)	70 (45%)	
Neither agree nor disagree	5 (8%)	4 (7%)	27 (17%)	
Strongly agree/agree	13 (20%)	22 (39%)	58 (37%)	
I found the psychological support after birth and in the first days of life helpful				**<0.0001**
Strongly disagree/disagree	26 (59%)	14 (33%)	38 (35%)	
Neutral/neither agree nor disagree	4 (9%)	4 (9%)	19 (17%)	
Strongly agree/agree	14 (32%)	25 (58%)	52 (48%)	
Based on our experiences around birth and in the first days of life, we decided against having another child				**<0.001**
Disagree	49 (64%)	32 (55%)	159 (89%)	
Still undecided	18 (24%)	10 (17%)	14 (8%)	
Agree	9 (12%)	16 (28%)	6 (3%)	

Data are presented as n-numbers and %. χ^2 test was used for group comparison.
*Including support by postpartum midwife.
TH, therapeutic hypothermia.

development and parenting stress during early childhood, and to explore associations with trauma experience, psychosocial support and family planning. Evidence on long-term developmental outcomes in infants with mild HIE who do not receive TH under current guidelines remains limited. We chose the ASQ as a developmental screening tool because it is easy to administer and does not require families to attend an in-person clinic visit. This approach reduced participant burden and facilitated developmental follow-up in a geographically dispersed cohort. In our study population, ASQ-3 results indicated predominantly age-appropriate developmental trajectories across all groups. Although this may partly reflect limitations of the non-validated German ASQ-3 version, it is consistent with the parent-reported health assessments by their paediatrician. Importantly, normal or near-normal global development in early childhood may not exclude circumscribed, domain-specific neurodevelopmental weaknesses. Finder *et al* reported significantly lower Bayley-III cognitive composite scores in children aged 2–3 years with mild HIE at birth who had not undergone TH compared with healthy controls, although average scores remained within the broadly

Table 4 Association of trauma and asphyxia group with PSI T-score

PSI *T*-score (dependent variable) n=135		
Predictors	**β**	**P value**
TH group*	2.4	0.139
Trauma†	**−1.4**	**0.018**

*Non-TH group as reference.
†Negative β coefficients reflect the questionnaire format, where lower scores indicate greater trauma.
PSI, Parenting Stress Index; TH, therapeutic hypothermia.

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normal range.[9] We want to acknowledge that the ASQ-3 may be insufficiently sensitive to subtle cognitive or behavioural impairments.[23] Our cohort likely had a lower risk profile because infants with severe HIE were excluded. Since cognitive dysfunction may emerge only later in life, longitudinal follow-up remains warranted even in mildly affected or initially normally developing children.[24] Unexpectedly, a slightly higher proportion of controls scored below the gross motor cut-off. However, the lack of validated normative data for the German ASQ-3 translation limits interpretation. Rautava *et al* found that 14% of healthy-born children showed long-term illness or developmental delay by age 3,[16] indicating that concerns may also arise among initially healthy infants. It must be emphasised that direct, specialist-administered assessments using validated, age-appropriate instruments, such as the Bayley Scales or the Wechsler Preschool and Primary Scale of Intelligence (WPPSI-IV), would be required to characterise neurodevelopmental outcomes more comprehensively.

This study also identified a significant association between self-reported parental trauma and parenting stress measured by the PSI. Both TH and non-TH parents showed high stress levels, with TH parents scoring significantly higher in the domains of health, competence and attachment. Feelings of reduced competence often begin after traumatic delivery and may be intensified by NICU stays, during which parents commonly report helplessness and detachment.[25 26] A meta-analysis of 53 studies across diverse healthcare settings, including middle-income countries, identified disruption of the parental role as the leading source of NICU-related stress.[27] In Rwanda, about half of mothers of 287 NICU-treated neonates, 34% with HIE, screened positive for poor mental health 24–47 months later.[28] Maternal mental health was associated with childhood disability and socioeconomic adversity rather than the neonatal diagnosis itself. These findings suggest that NICU-related parental distress is not confined to a particular healthcare system or determined solely by the infant's initial diagnosis. Separation during NICU care can disrupt bonding and have lasting effects on parent–child relationships. Our findings suggest that attachment difficulties may persist years after the initial trauma. Perceived maternal stress has also been linked to altered infant EEG,[29] and family stress can negatively affect child quality of life, particularly when maternal well-being and parental competence are impaired.[30] Elevated parenting stress is a risk factor for emotional and behavioural problems in children and may contribute to reciprocal effects across development.[31] PTSD symptoms in parents may also emerge later, underscoring the need for ongoing psychological support.[13 32] Overall, parents who experience birth-related trauma appear to face long-term risk of elevated parenting stress, with TH families at particularly high risk.

A striking finding in our exploratory analyses was the high prevalence of parent-reported trauma in both TH and non-TH groups. Roughly two-thirds of non-TH parents reported birth and early postpartum days as traumatic, paralleling TH group figures, despite less intensive interventions and usually only short NICU stays. This expands qualitative research results reporting high levels of traumatisation among parents of children treated with TH and advocating trauma-informed care to better support affected patient-families.[18 33] Notably, 72% of parents in the non-TH group reported inadequate psychological care, compared with more frequent but still insufficient support in the TH group. Thus, families of infants with mild HIE may face a particular support gap. Rapid clinical recovery may lead to underestimation of the potentially traumatic impact on parents. Neonatal research and follow-up have historically focused on preterm infants and more severe diagnoses. As a result, the needs of families affected by mild HIE may remain under-recognised. This may be further compounded for patient-families from marginalised communities, whose experiences and needs remain under-represented in neonatal research.

These deficits are concerning, especially given that a significant proportion of parents decided against further pregnancies, or remained undecided. Importantly, our cohort included only mildly to moderately affected children without overt neurodevelopmental impairments at the time of study assessment. These findings echo Heringhaus *et al*, who showed lasting emotional impact of asphyxia and TH-treatment on parents despite absence of long-term injuries.[11] Parents may not be ready to accept support during hospitalisation, underscoring the need for continued psychological care postdischarge.[34] Programmes supporting parent–infant bonding during NICU care such as the Cool Cuddle initiative have shown promise,[35] improving maternal mood and bonding outcomes.[34] Expanding such programmes to broader NICU populations could improve family psychological health. After discharge, patient-families should be connected with follow-up services, alongside regular contact and low-threshold psychological support, to identify difficulties early and prevent post-traumatic stress reactions. Structured peer support, delivered in collaboration with patient organisations, may provide a scalable, low-cost complement to clinical care. These measures should be available to all families in need, regardless of HIE severity, to strengthen trauma-informed care and reduce long-term burden.

Limitations and strengths

This study has several limitations. The lack of family involvement in the study design may have limited our ability to identify and capture outcomes and experiences that are most relevant to affected parents. Future studies should actively involve patient-families in defining research questions, outcomes and interpretation. The control group was a convenience sample, subject to participation bias and limiting generalisability. Control parents had higher educational levels, and most surveys were completed by mothers, possibly skewing results. The

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ASQ-3 is based on subjective parent reports and lacks validation in German, potentially limiting sensitivity for subtle deficits. Further, the assessment of trauma related to birth and the early postpartum period was not based on validated questionnaires and may be subject to retrospective bias. Future studies should use validated instruments and longitudinal designs.

Due to the exclusion of the control group from the PSI analyses as a result of a suspected systematic error, it was not possible to put the values observed in the asphyxia groups into perspective; however, as the German version of the PSI has been validated and normed, a direct comparison with a control group is not strictly required for interpreting the results.

Nonetheless, the study's strengths include use of standardised questionnaires, a control group for developmental comparisons, differentiation by HIE severity and a robust sample size. These factors enhance reliability and provide a strong foundation for future research.

CONCLUSION

This study provides evidence that experiencing perinatal asphyxia with mild-to-moderate HIE is associated with high levels of parenting stress and traumatisation during early childhood despite largely reassuring child developmental outcomes. These associations appeared to be largely independent of TH treatment. We also identified a gap in the psychosocial support available to families of children with mild HIE who did not undergo TH. Our results underscore the importance of addressing psychological and developmental needs of families affected by perinatal asphyxia, irrespective of TH status and extending beyond the immediate postnatal period. Supporting families in processing their experiences and rebuilding confidence in family planning is essential for mitigating the long-term psychological impact of perinatal asphyxia.

Author affiliations
[1]Div of Neonatology, Department of Pediatrics, Dr von Hauner Children's Hospital, LMU Medizin, LMU University Hospital, Ludwig-Maximilians-Universität München, Munich, Germany
[2]Clinical Psychology and Psychotherapy of Childhood and Adolescence, Department of Psychology, University of Tuebingen, Tübingen, Germany
[3]Institute for Psychosocial Prevention, Heidelberg University Hospital, Heidelberg, Germany
[4]Department of Pediatric Neurology and Developmental Medicine, University Children's Hospital Basel, UKBB, Basel, Switzerland

Acknowledgements We would like to thank Martina v. Poblotzki for valuable advice on the survey design, Andreas Nathrath and Nino Kipiani for assistance with the recruitment of the control group, and all participating parents and children for their contribution to this study.

Contributors AS-V recruited patients, collected clinical and survey data, analysed and interpreted the data, and wrote the manuscript. AKG provided the German translation of the ASQ-3 and resources, assisted in the recruitment of controls, analysed and interpreted the data, and wrote the manuscript. AR designed the survey, contributed to patient recruitment, interpreted the data and revised the manuscript. VBW was responsible for digitising the survey, collecting data and contributed to patient recruitment. AFP-S performed statistical analyses, interpreted the data and revised the manuscript. CN designed the study and the survey, provided resources, supervised the recruitment of patients and controls, analysed and interpreted the data, and wrote the manuscript. CN is the guarantor and accepts full responsibility for the finished work and the conduct of the study. ChatGPT (OpenAI) was used exclusively for language editing and text shortening. It was not used to generate scientific content, analyses, interpretations, conclusions or references. All edits were critically reviewed by the authors, who remain fully responsible for the manuscript.

Funding CN received funding from the MOMENTE programme of the Medical Faculty of the Ludwig-Maximilians-Universität München to finance a student assistant who supported recruitment and the creation of the online questionnaire.

Competing interests No, there are no competing interests.

Patient and public involvement Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Ethikkommission bei der Medizinischen Fakultät Ludwig-Maximilians-Universität München (project No 21-0115) and registered with the German Registry of Clinical Studies (DRKS000252253). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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ORCID iD
Claudia Nussbaum https://orcid.org/0000-0003-4414-6717

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