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## ORIGINAL ARTICLE

# Parents' experiences of palliative care decision-making in neonatal intensive care units: An interpretative phenomenological analysis

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## Abstract

**Aim:** This work explores the experiences and meaning attributed by parents who underwent the decision-making process of withholding and/or withdrawing life-sustaining treatment for their newborn.

**Methods:** Audio-recorded face-to-face interviews were led and analysed using interpretative phenomenological analysis. Eight families (seven mothers and five fathers) whose baby underwent withholding and/or withdrawing of life-sustaining treatment in three neonatal intensive care units from two regions in France were included.

**Results:** The findings reveal two paradoxes within the meaning-making process of parents: role ambivalence and choice ambiguity. We contend that these paradoxes, along with the need to mitigate uncertainty, form protective psychological mechanisms that enable parents to cope with the decision, maintain their parental identity and prevent decisional regret.

**Conclusion:** Role ambivalence and choice ambiguity should be considered when shared decision-making in the neonatal intensive care unit. Recognising and addressing these paradoxical beliefs is essential for informing parent support practices and professional recommendations, as well as add to ethical discussions pertaining to parental autonomy and physicians' rapport to uncertainty.

## KEYWORDS

decision-making, medical ethics, neonatal intensive care units, palliative care, parents, qualitative research, withholding treatment

## 1 | INTRODUCTION

Today, most deaths that occur in the Neonatal Intensive Care Unit (NICU) result from withholding or withdrawing life-sustaining

treatments.<sup>1</sup> However, neonatologists differ in how they involve parents in withholding or withdrawing life-sustaining treatment decision-making. For instance, Schouten et al.<sup>2</sup> report that neonatologists frequently seek parents' approval for their intended decision.

Abbreviation: NICU, Neonatal Intensive Care Unit

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Recommendations state that the physician guides the parents through the process of positioning themselves and supporting them.<sup>3</sup> In real-world settings, a French survey found that when withholding or withdrawing life-sustaining treatments was decided during a team meeting, but parents disagreed in favour of pursuing life-sustaining treatments, 69% of neonatologists think the implementation of *any* decision should be postponed. However, in this specific situation, only 35% believe that parents' opinions should be respected and life-sustaining treatments should therefore continue.<sup>4</sup> This situation reflects an inherent tension that current shared decision-making recommendations may not fully be effective in addressing. From a parental point of view, previous research has linked better mental health outcomes to parents feeling they actively participated in the decision-making process without bearing the full responsibility.<sup>5</sup> However, parental experiences are diverse and the issue seems laden with ambivalence, with both parents and physicians reporting feeling a sense of responsibility.<sup>6</sup> In their seminal paper, McHaffie and colleagues<sup>7</sup> asked:

Numerous publications advocate involving parents in decision making, but what happens in practice? Are parents really sharing decision making or are neonatologists practicing a form of benevolent paternalism? (...). Given the imbalance of power, experience, and authority, were (the parents) in reality deciding or is this an illusion created by the practices NICU teams have adopted?

This sensitive question remains true today and neonatologists still grapple with it. This gap between real-world experiences and recommendations suggests that 'something' is missing. However, existing contributions on the topic have focused on describing aspects such as conversational patterns and frequency of withholding or withdrawing life-sustaining treatments conversation initiation.<sup>8</sup> We aim to address questions such as: do current NICU decision-making dynamics lead to (an actual or perceived) minimisation of the *ethical* (as opposed to *medical*) component of life or death inherent to this decision? If so, what does this mean? To our knowledge, interpretative phenomenological analysis<sup>9</sup> has never been used to address this issue and is one of the most effective methods for addressing both psychological and philosophical aspects of a complex topic. As part of a larger research initiative investigating both medical and parental experiences of the decision-making process in the NICU, this study focuses specifically on the experiences of parents. We aimed to examine through the lens of interpretative phenomenological analysis how parents construct their experiences with regards to decisions related to withholding or withdrawing life-sustaining treatments in the NICU.

## 2 | METHODS

### 2.1 | Study participants

This prospective pilot study was conducted at the three Neonatal Intensive Care Units in France (Artois and Métropole de Lille)

### Key notes

- This study addressed the gaps between current clinical and ethical guidelines by exploring the experiences of parents involved in decisions to withhold and/or withdraw life-sustaining treatments for their newborn.
- Parents' experiences of decision-making are structured around role ambivalence and choice ambiguity which serve as adaptive buffers against decisional regret and distressing feelings.
- Recognising and addressing these beliefs can inform parent support practices and professional recommendations and contribute to ethical discussions.

between April 2019 and May 2020. All parents whose infants underwent a decision to withhold or withdraw life-sustaining treatments during this period were identified ( $N=42$ ). Of these, 24 fit the study inclusion criteria (see [Table S1](#)), and 15 were successfully contacted. Oral and written consent were obtained from eight of these families, represented by seven mothers and five fathers, and semi-structured interviews were conducted. One interview was excluded from the analysis upon transcript review as the infant is alive and his mother did not mention end-of-life care. In accordance with the principles of interpretative phenomenological analysis, it is imperative that participants provide narratives pertaining to a shared experience. [Figure 1](#) depicts a flow diagram containing details of the recruitment process. The characteristics of each family are provided in [Table S2](#).

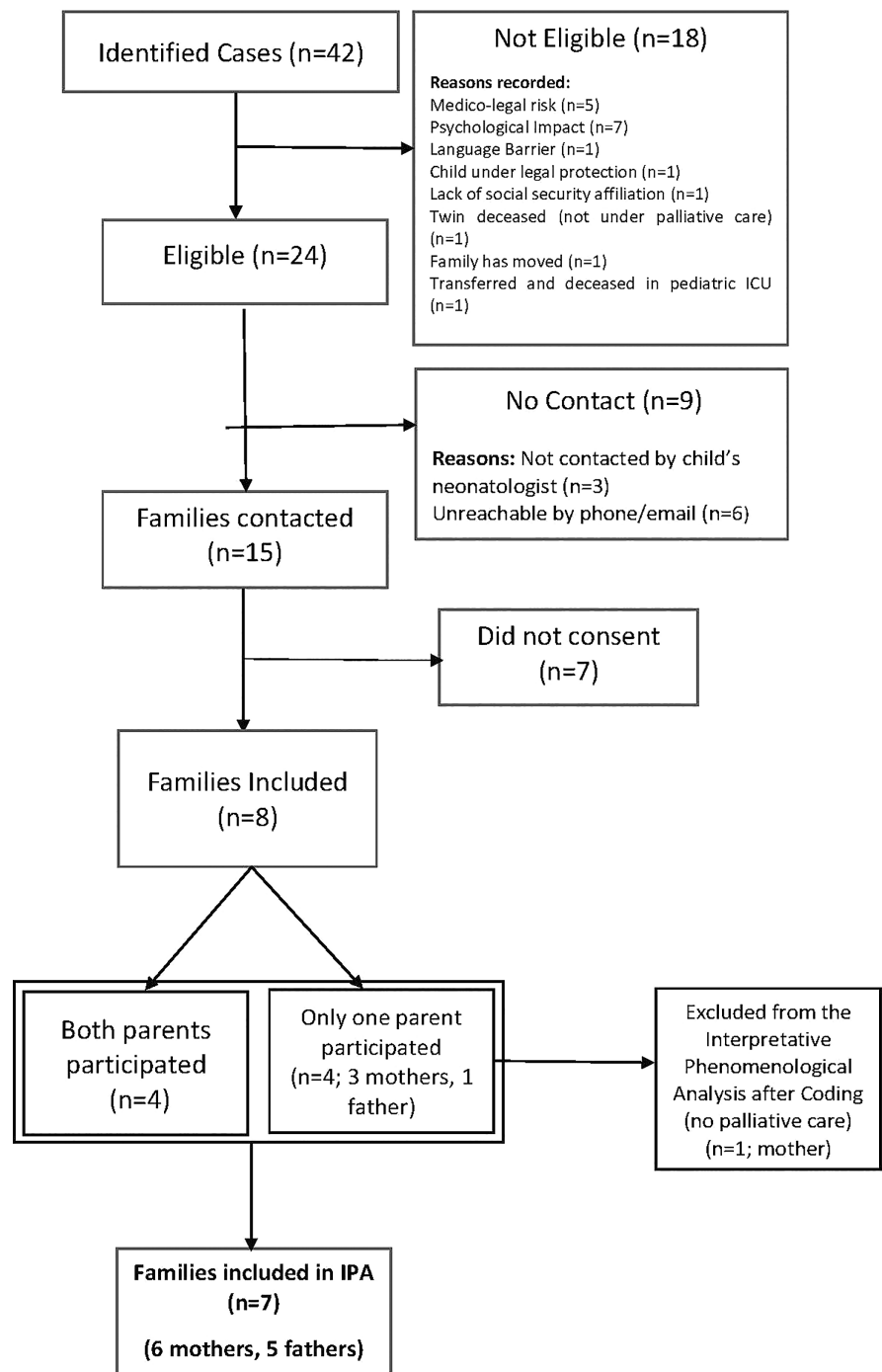
### 2.2 | Procedure

Eligible parents were contacted by the neonatologist who had overseen their infant's care, usually by telephone. The neonatologist explained the purpose of the study and sought oral agreement from the parent(s) to receive study documentation. Follow-up was conducted a minimum of 1 week after documentation was sent to enquire about willingness to participate. Individual or joint interviews were conducted based on parents' preferences. They were held throughout 2021 and 2022, 2 years ( $\pm 2$  months) after the decision to withhold or withdraw life-sustaining treatments for their baby and took place in a meeting room in the hospital where the participants' baby had been hospitalised. They were led by KSD, CP and SM who had no prior relationship with the participants.

### 2.3 | Analysis

The interviews' audio content was recorded and transcribed verbatim and NVIVO v12 was used for data management. The data were then analysed using interpretative phenomenological analysis<sup>9</sup>; this approach was chosen due to its suitability in achieving a deeper

**FIGURE 1** Flow diagram of the recruitment process.



understanding of the experiences of parents in such circumstances, as it seeks to make sense of how individuals comprehend their experiences without attempting to generalise human thought or behaviour (idiographic approach). The underlying phenomenological lens involves the researcher's attempt to understand the participant's interpretation of their experience through their experiential claims (double hermeneutics). This is why interpretative phenomenological analysis relies on only a small number of participants: an exhaustive examination and interpretation of the meaning-making process requires in-depth analysis of experiences that are homogeneous among participants.

The transcripts were thoroughly analysed one by one by KSD, and a table of codes was developed and refined as the analysis progressed. The themes were discussed with an experienced interpretative phenomenological analysis practitioner (KL) who supervised the study, and meetings took place regularly to monitor progress. The themes identified were then discussed with all the co-authors, and categories were modified in accordance with their comments. KSD continuously evaluated her subjectivity, through journaling, discussion with co-authors and interpretative phenomenological analysis supervision. This self-reflection aimed to accurately represent the participants' experiences and maintain the study's rigour and credibility.

### 3 | RESULTS

#### 3.1 | Group experiential themes

A preliminary step to interpretative phenomenological analysis is content analysis. This step consists of the identification and categorisation of elements present in all parental accounts. Eight group experiential themes that encapsulate the participants' experiences from pregnancy to the present day were captured. Further details as well as parental excerpts are presented in the supplementary material (Table S3).

The first theme focuses on the ambivalence and paradoxes that parents experience when making decisions about their child's end-of-life care in the NICU. Parents spoke of the importance of parental autonomy and responsibility in the decision-making process while acknowledging the role of medical professionals in making the final decision. The paradoxical thinking of parents is seen as a way of navigating the emotional difficulties of the situation. The second theme explores the journey that parents go through from the moment they make the difficult decision to withhold or withdraw life-sustaining treatments to the period after their child's passing. The theme highlights the emotional and practical support that parents receive from healthcare providers, the importance of rituals, rites and spirituality around death and dying, and the need for individualised support. It also emphasises the importance of providing clear and honest information about the prognosis, potential treatment options and end-of-life care to families. The third theme centres on the impact the death of their baby had on their lives, they speak of 'before' and 'after' and how they have changed as people and as parents. They recount the questions they asked themselves, and how they try to cope with grief. The strategies described include maintaining a connection with the lost child, seeking support, giving meaning to their experience and focusing on their other children. The fourth theme explores specificities of the hospitalisation of their child, including parental observations of the NICU environment and its impact on them. Parents discuss the characteristics of their baby's health and physical state and describe aspects of their baby's treatment, such as the use of tubes, incubators and ventilators. The theme focuses on the more technical and medical aspects of the baby's hospitalisation. The fifth theme focuses on the experiences and challenges faced by parents taking care of their baby in the NICU. Parents express the importance of providing caregiving in ways that are compatible with their baby's health and the NICU environment. The sixth theme describes the medical aspects of the parental experience from pregnancy to the death of their baby. It covers a range of practical and logistical aspects, including transportation and accommodation during hospitalisation and the mother's medical procedures. It provides insight into the more pragmatic aspects of their medical trajectory. The seventh theme focuses on the overwhelming emotional and psychological impact of having a newborn baby hospitalised in the NICU as well as losing their baby. The parents describe feelings of shock, anxiety and disbelief at the situation they find themselves in. They also discuss the challenges

of processing and coping with their emotions while caring for their child in the NICU and parenting their other children. The eighth theme covers the social interactions and support (or lack thereof) that parents encounter during and after their time in the NICU, including relationships with friends, family, colleagues and strangers. Parents navigate between wanting privacy and finding comfort in the presence of loved ones. They recount instances where interactions were difficult, leaving them feeling misunderstood and lonely. The theme also encompasses the impact on siblings, within the couple and the baby's other parent.

#### 3.2 | Interpretative accounts

Interpretative phenomenological analysis considers that people actively construct meaning from their experiences and allows us to focus on the meaning *parents have made and continue to make* of their experience with end-of-life decisions concerning their baby. Additionally, because these were retrospective interviews, more so than the informational content of the parental accounts, it is *how they construct meaning and how they remember having constructed meaning* to their experience, which was interpreted (i.e. double hermeneutics). The results of this analytical process are presented in this section, they suggest a paradoxical dynamic that encompasses two key questions: who decides and is it a decision?

The parents described the process as being guided by medical professionals who impart information about the baby's prognosis and future quality of life, ultimately leading them to realise that withholding or withdrawing life-sustaining treatments is the only option remaining. When asked if she felt it was her decision, Barbara answered 'Yes and no, actually, because they told us that they wouldn't push, and that's when he understood that it was, well, you know... yeah... So, basically, no, I didn't decide, they were the ones who made it happen slowly'. The idea that doctors and the medical team were the deciders is also reflected in Abigail's account, speaking about a conversation with her own mother who was questioning the decision to withhold or withdraw life-sustaining treatments: 'We explained to her and she said to me "Are you sure about making this decision?" but I said "ma, look!" "It's not me who says it, it's not me who's going to stop my son's care, it's.... They explained to me, as clear as A + B, that my child, he... He won't be able to have a life like other children and it will be too complicated for him."' For Abigail, it is the doctors, not she, who made the decision to withhold or withdraw life-sustaining treatments because her baby's future quality of life would be plagued by suffering and disability. This is coherent throughout the parental experiences; three main elements were identified as the rationale for their decision: the baby's future quality of life being incompatible with their views of a good life, not wanting their baby to suffer any longer and the trust and legitimacy of the medical team's competence and expertise. It is interesting to note that quality of life is expressed as something that is considered in relation to a norm, to *others*. A father, Edgar, also identifies

the decision as being made by the medical team: 'At one point, look, I trusted them, they explored all the possibilities, and at one point they saw that there was no possibility. They didn't hesitate. At one point they said stop, stop. That's when I understood that we had to stop'. Trust in the medical team's expertise seems necessary but insufficient: the parents also must feel convinced that there is no room left for doubts. Abigail uses the analogy 'as clear as A+B', which connotes a sense of definite certainty, akin to mathematical certainty. When Edgar explains that the doctors 'didn't hesitate', he is referring to his perceptions of certainty: hesitating is associated with being unsure or having doubts. Sometimes, it is the characteristics of the word choice rather than the meaning of the words that convey the gravity and the hopelessness of the child's future quality of life. David recounts a discussion with his daughter's neonatologist about her prognosis 'And then she said, she told us "your daughter is a vegetable. As of today, she has no capabilities. Blind, deaf...Blind, deaf...Vegetable. She will never be able to walk, never eat on her own. In fact, she will never be able to do anything."' The word 'vegetable', the repetition of 'blind, deaf', combined with words conveying a sense of definitiveness, such as 'never' and 'anything', seem to act as markers of the absence of any degree of doubt or uncertainty concerning her future.

Within this, seemingly paradoxically, parents also express that they are the ultimate decision makers: 'It's not the doctors who make the decisions, it's us who have to say yes or no; we stop or we don't stop' (George). Another explains 'it's up to us to choose, but we basically only have a single choice' (Catherine). This dynamic shows that the parents, despite acknowledging that their choice was limited, still characterised the decision-making process as a conscious decision, perhaps as a means of fulfilling their role as parents and aligning with societal norms and values of parental autonomy and responsibility. Parents employed imperative verbs with remarkable consistency when describing the decision to withhold or withdraw life-sustaining treatments. They all speak at some point of 'having to' make the decision, suggesting inevitability and lack of alternatives: 'It is a possibility that is impossible... We understood that, that we have to...uh, I don't know how to say it, but we have to accompany her until the end. That's the possibility that remains' (Catherine). Understandably, parents had a hard time articulating ideas related directly to the decision leading to the baby's death. For instance, the use of euphemistic phrases such as 'accompany her until the end' makes it possible for the parents to psychologically survive this extreme situation as it is compatible with parental role representations and might help protect them against subsequent feelings of guilt. Indeed, being able to fulfil their parental role of supporting and taking care of their child transpires through the entire decision-making process. The paradox lies within the fact that despite acknowledging that there is only one choice, deciding to withhold or withdraw life-sustaining treatments was consistently considered a conscious and deliberative process, rather than resulting from a predetermined outcome.

## 4 | DISCUSSION

To our knowledge, this study is the first to use a phenomenological approach to explore parents' decision-making process regarding palliative care for their babies. Findings show the deliberation process is characterised by two contradictory pairs of beliefs: role ambivalence and what we call 'choice ambiguity'. Within this experiential construct, the need for medical expertise and certainty are two criteria for the decision to withhold or withdraw life-sustaining treatments to be psychologically and morally acceptable.

Decisional regret refers to the combination of (a) believing that selecting a different option would have resulted in a more favourable result, and (b) feeling accountable for making that particular choice.<sup>10</sup> We argue that choice ambiguity and role ambivalence, respectively, address these two components of decisional regret to form a robust adaptive psychological strategy protecting parents' mental health outcomes. Parents might not consciously be aware of the contradictory nature of their beliefs, and they may also serve to protect their senses of moral coherence and parental self. A preliminary attempt at a visual presentation of this hypothesis can be found in [Figure S1](#).

As for neonatologists, role ambivalence is in tension with the concept of parental autonomy *stricto sensu*, and choice ambiguity is in tension with both the medical uncertainties inherent to neonatology as well as the fact that withholding or withdrawing life-sustaining treatments is an *ethical*, as well as a medical, decision. It is possible that, within this context, the tension expressed by neonatologists might result from an intuitive perception of incompatibility between, on the one hand, addressing parents' emotional needs and protecting their mental health, and on the other, clearly translating degrees of uncertainty and the ethical components of the decision to withhold or withdraw life-sustaining treatments.<sup>11</sup>

When asked about the relational dynamics within the decision-making process, parents were consistently ambivalent about *who* made the decision (i.e. role ambivalence). This ambivalence might serve to alleviate the emotional burden of having to make a decision that ultimately results in the death of their baby, without relinquishing their parental role and values. Both legally and socially, it is considered that parents are accountable for the decisions surrounding their children and that this is an *essential component of what it means to be a parent*. Holding onto this might be integral to parents maintaining their sense of coherence and parental self all the while avoiding a 'moral schism'.<sup>12</sup>

The second pair of beliefs involves holding two opposing views: that the decision to withhold or withdraw life-sustaining treatments is an authentic choice made by the parents, but that it also is *not* an authentic choice because of the lack of alternatives. One way of understanding this can be through the distinction made in the field of ethics between agency (i.e. where individuals are able to make decisions and have moral responsibility for them) and assent (i.e. where individuals agree or give permission for something to happen). On an individual level, holding these two beliefs as simultaneously true might be a subconscious way for

parents to cope with the emotionally intense situation with which they are faced. In general, the more medical uncertainty within a given situation, the more the decision-making process involves moral reasoning and not purely medical criteria. The experiential mitigation of medical uncertainty might therefore be necessary for cognitive avoidance of the 'life and death' (i.e. the moral) component of the decision to withhold or withdraw life-sustaining treatments and a prerequisite to the prevention of moral schism. As for how this uncertainty is mitigated, one possible explanation lies within the notion of implicit normativity. Implicit normativity is 'the presence of unstated or taken-for-granted assumptions about what is good and bad, right or wrong, required or not required'.<sup>13</sup> In the parents' experiences, the mitigation of uncertainty is made possible because norms and values concerning the child's best interest are implicitly considered to be shared both by the parents and neonatologists. However, scholarly work in the field of bioethics has shown that implicit normativity plays a role in masking and containing potential ethical uncertainty.<sup>14</sup> This further supports the hypothesis that the decision-making process is experienced 'within the framework of medicine and not ethics'.<sup>15</sup> Finally, the way parents in our study experienced conversations with doctors can be considered in terms of 'informed nondissent decision-making', which is an approach that falls on the physician-driven side of the shared decision-making continuum.<sup>16</sup> This approach seeks parental adherence rather than a decision, without depriving parents of their role and all the while allowing them to align their self-representation with moral and normative constraints. This is in-line with the findings discussed in the introduction concerning the difficulties of implementing shared decision-making in NICU end-of-life decisions.<sup>2</sup>

The strengths of our study lie in the in-depth exploration of the experiences and perspectives of a small group of parents through interpretative phenomenological analysis methodology. Findings offer a preliminary understanding of a coping mechanism not previously explored (see Section 4 and Figure S1). However, the study was limited to parents adhering to the proposed treatment plan (withholding or withdrawing life-sustaining treatments), excluding those who opposed it. These parents could provide valuable insights as their experiences may differ significantly. Furthermore, in this study, parents were given the choice between being interviewed alone or with the other parent. This choice was made from an ethical point of view as, given the nature of the topic addressed, the study team considered some parents might want to have the other parent present during the interview (for emotional support or other needs). This limits the validity of our findings, however, as individual interviews might provide different content and would be a more methodologically robust option. Additionally, self-selection and cultural biases limit the external validity of our findings. Future research is needed to inform current recommendations in ways that are compatible with real-life settings. They should consider cultural aspects and employing mixed methods. Moreover, subsequent research should consider investigating the potential links between neonatologists' attitudes concerning shared decision-making and parental autonomy/

involvement, their efforts aimed at alleviating parental distress and their rapport with uncertainty.

## 5 | CONCLUSION

Our study suggests that the parental decision-making process regarding withholding or withdrawing life-sustaining treatments concerning their baby entails a complex coping mechanism characterised by role ambivalence and choice ambiguity. This way of experiencing the decision might protect parents against decisional regret and complicated grief as well as preserve their sense of parental self. It might also serve to alleviate acute psychological distress during the decision-making process itself. Further research is needed to (1) validate the findings discussed in this paper, (2) determine the potential implications on long-term mental health outcomes for parents and (3) examine the impact of parental needs for role ambivalence and choice ambiguity on neonatologists' attitudes towards decision-making and uncertainty. This would help fill particularly important practical and theoretical gaps linked to evolutions in conceptions of parental autonomy and share decision-making models in the NICU.

## AUTHOR CONTRIBUTIONS

**Kelly Saint Denny:** Investigation; writing – original draft; methodology; validation; writing – review and editing; software; formal analysis; data curation; conceptualization. **Kristopher Lamore:** Methodology; validation; writing – review and editing; supervision; data curation; formal analysis. **Jean-Louis Nandrino:** Methodology; validation; writing – review and editing; supervision; resources. **Sabine Rethore:** Conceptualization; resources. **Charlotte Prieur:** Conceptualization; investigation; data curation. **Sebastien Mur:** Conceptualization; investigation; funding acquisition; project administration; resources. **Laurent Storme:** Conceptualization; funding acquisition; writing – review and editing; project administration; supervision; resources.

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## CONFLICT OF INTEREST STATEMENT

The authors have no competing interests to report.

## DATA AVAILABILITY STATEMENT

The transcripts of the full parental interviews that were collected and qualitatively analysed in the current study are not available for confidentiality reasons. The redacted transcripts that were used and analysed as part of the current study can be made available by the corresponding author upon reasonable request.

## ETHICS STATEMENT

Prior to undertaking the study, the research was registered on the Clinical Trials website under the number NCT04619901, and ethical clearance was obtained from the Comité de Protection des Personnes SUD-MEDITERRANEE III (CPP, 2018.09.01ter\_18.07.04.52256). All aspects were in compliance with the regulations of the French National Commission on Computer Technology and Freedom (CNIL). Additionally, approval was obtained from each participating hospital prior to the initiation of the study.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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