

# Protect us from ourselves: Balancing the parental instinct of saving

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## Abstract

**Background:** Neonatologists, legal experts and ethicists extensively discuss the ethical challenges of decision-making when a child is born at the limit of viability. The voices of parents are less heard in this discussion. In Norway, parents are actively shielded from the burden of decision-making responsibility. In an era of increasing patient autonomy, is this position still defensible?

**Research question:** In this article, we discuss the role of parents in neonatal decision-making, based on the following research question: Should parents decide whether to provide lifesaving treatment when their child is born at the limit of viability?

**Research design:** We conducted eight interviews with 12 parents, 4 individuals and 4 couples, all having experienced prenatal counselling at the limit of viability. The interviews took place at different university locations in Norway in the years 2014–2018.

**Ethical considerations:** All study participants gave their written informed consent. The Regional Committee for Medical Research Ethics approved the study.

**Findings:** We identified six main themes in parents' responses to the research question. Parents (1) experienced an emotional turmoil confronted with birth at the border of viability, (2) emphasized the importance of being involved in decision-making, (3) described and reflected on the need to balance the parental instinct of saving, (4) were concerned about the dilemmas involved in protecting the family, (5) were worried about the burden of overwhelming responsibility and (6) called for guideline relief.

**Conclusion:** The perceived parental instinct of saving the life of their child makes it hard for parents to step away from a call for 'everything to be done'. Involvement of an interprofessional periviability team drawing on the experiences and viewpoints of nurses and neonatologists in decision-making is needed to protect both infants and parents against undue parental push for treatment and enable parents to make good decisions regarding their child.

## Keywords

Ethics, extremely premature infants, life-and-death decisions, neonatal nursing, role of parents

## Introduction

In 2018, a television team from the Norwegian Broadcasting Corporation visited our regional neonatal intensive care unit (NICU). In the resulting television programme,<sup>1</sup> we meet Malin, who is going to give birth at the limit of viability. While the obstetricians are trying to stop the imminent birth, the neonatologist approach the question about treatment options that can be made. In her ears, it sounds like she is asking her, 'should we save your child?' and to her, it is 'the worst question you can get'.

From an ethical point of view, what kind of question is this? Is it a real question, or is it more of a test question to check whether the parents have understood the virtues of good parenting? If it is a test question, there is a correct and an incorrect answer. The correct answer then is, 'yes, of course'. For Malin, the question had just one possible answer. She felt that the question was horrible, but the decision-making was simple, and her answer was, 'of course you should save her'.

So, why pose the question? Let us rewind a bit and describe the situation: The first three critical months of pregnancy went well, and the ultrasound near the middle of pregnancy showed a healthy child. Everything is fine. Suddenly everything turned upside down: The mother's body starts preparing for birth all too soon, or the pregnancy must be interrupted to save the mother. The gestation is not much more than halfway, and the foetus will no longer be able to mature in the womb.

Rushing to the hospital, parents are typically thinking, 'what are we facing now – are we losing our child?' Once in the hospital, they learn that there might be hope for survival for their child-to-be, but that it will require extensive treatment, and there are no guarantees that this will lead to a long and healthy life. The odds of coping well depend on many factors, in particular the gestational age of the child. The lower the gestational age, the longer the need of intensive care and the greater the risk of death or survival with severe impairment. Despite the horror, Malin appreciated the question, as it made her realize the severity of the situation. However, should parents be the owner of such a decision?

## Background

There are several nuances and practice variations in neonatal medicine both between and within countries worldwide. Regarding treatment variations at the border of viability, some countries or regional units have policies of lifesaving treatment attempts as early as in the gestational age of 22 weeks, while others recommend comfort care as late as in week 24.<sup>2</sup>

In general, however, if an infant is born before the gestational age of 23 weeks, the chance of survival is regarded as so small that most NICUs worldwide will not attempt lifesaving treatment.<sup>3</sup> Standardization of the provision of lifesaving treatment at a lower gestational age than 23 weeks is not recommended here, based on a perceived undue high risk of burden of treatment followed by early death or serious long-term morbidity. After birth, the child is then often laid on the mother's breast and might breathe for some minutes before dying. However, only a few weeks later in gestation, the infant's chances of coping well are so much better that treatment is considered 'clearly beneficial', and there is no question whether to provide lifesaving treatment or not.

Between these gestational ages, and considering other relevant factors like sex and birth weight, there is a grey zone – a grey zone between not starting and always starting lifesaving treatment, and

between lack of hope and lots of hope. In the grey zone, we need good answers to tricky questions: Should we initiate intensive care, knowing that the chance of coping well is small? How small is 'too small'? Is our provision of lifesaving treatment in the best interests of the child? Facing these questions, the views of health personnel diverge. This might be the case because we face an ethical dilemma that we cannot solve with medical knowledge alone.

To approach the dilemmas and reach sound decisions, it thus seems natural to turn to the family. Family members are, after all, the ones who will care for the child and live with the consequences of the decision. The family might have special considerations influencing the choice. They might see this as their only chance to have children and have a particularly strong desire to become parents. Alternatively, the family might already consist of children with special needs, requiring extensive support from the parents, and additional burdens of care is more than the family can handle. Some parents might also find it unacceptable to expose their immature baby to the suffering of NICU treatment for a long time, knowing that the outcomes are uncertain.

These are weighty reasons for asking parents whether we should try to save their infant, and several international guidelines leave the decision in this grey zone to the parents. The Norwegian guidelines, however, explicitly state that parents are actively shielded from the burden of responsibility.<sup>4</sup> In the NICU, healthcare professionals (HCP) have the responsibility to facilitate the involvement of parents in decisionmaking, and there is a growing literature on how to communicate with and involve parents in a way that make it possible for them to reach decisions in line with their values. Shared decision-making seen as value clarification where the doctor is aware of his role as a choice architect requires skills far beyond simply asking what the parents prefer in an extreme situation like this.<sup>5</sup> However, is it right, advisable, desirable – or even defensible – to ask parents to answer such a question, even if the decision-making process is ideal? What does it mean for a parent to feel responsible for the suffering of your child or to know that you have denied your child the chance to survive? Or, is facing and tackling such a question just one of the tough calls that parenthood includes and that might make parents grow stronger?<sup>6</sup>

There are several possible and reported views on the question of the proper role of parents in decisionmaking at birth at the limit of viability. In the articles of our edited 2018 issue of *Pediatrics*, the current regional and global differences in approaches to parental involvement – as part of the practice variations mentioned above – became striking.<sup>7</sup> How parents are involved in decision-making seems to be a matter of culture and cultural differences, differences not only between countries but also within countries – between units.<sup>4</sup>

Such cultural differences might be problematic from the viewpoint of equal treatment and access to healthcare. One way to attempt at 'solving' this problem is simply to ask, 'who is right?' Is it HCP that (1) leave the responsibility for decision-making with the parents, permitting parents to make choices according to their values; (2) make the decision themselves; or (3) enable some kind of shared decision-making?

We mentioned some central arguments for the first view above, and parental autonomy can in addition be seen as ethically and legally imperative in the universal move from HCP paternalism to patient autonomy in modern healthcare. In this perspective, it would be illegitimate not to leave the ultimate decision and the responsibility with the parents.

However, who is the patient? Defendants of the second view will argue that neonatal decision-making is all about medical assessments of the benefit or futility of treatment options for the premature child, like for all other patients. Of course, as we can observe from the current international differences in policies and practices, this would not by itself lead to equal treatment. A strategy to arrive at equal treatment, however, would be to make a radical move: We could hold that we should as a standard provide lifesaving treatment at birth at any gestational age, even at the very low end, in line with what we would do for any other patient whose life is at risk. Supporters of this view can recur to the UN Convention on the Rights of the Child, which states that every child has the inherent right to life. Based on this view, there is no room for parental decision-making, as there is no ethical grey zone in neonatal care – at most a medical assessment of avoiding futile treatment. Thus, any contribution from the parents is restricted to adding information relevant to the medical assessment done by the HCP.

Proponents of the third view hold that there indeed is an ethical grey zone in neonatal care and argue that parents play an important role in the decision-making – but that it is too demanding to leave such a decision with the parents. Parents should be informed and involved, but ultimately share the burden of decision-making with the HCP, and can also choose to leave the decision entirely to the HCP.

## **Research question**

In this article, we discuss the role of parents in neonatal decision-making, based on the following research question: *Should parents decide whether to provide lifesaving treatment when their child is born at the limit of viability?* This question is central to our larger study on ethical challenges of decision-making for periviable neonates. The aim of the larger study is to bring forth experiences and reflections of parents and HCP, in order to provide nuanced and clear descriptions of what is at stake in decision-making for babies born at the limit of viability. These descriptions should enrich the current ethical reflection of HCP, parents, and policy makers.

The larger study comprises interviews with parents and HCP with experience from ethically challenging situations during pregnancy and periviability. Experiences, views and reflections of parents and HCP other than doctors are underrepresented in the literature. In addition to interviews with parents, we moderated five focus group interviews with separate groups of HCP: neonatal nurses, midwives, obstetricians, mother–foetal specialists and neonatologists. In all the interviews, we focused on experiences and considerations in situations where life and death decisions had to be made. One of the central study hypotheses was, ‘It is ethically sound that parents make the final decision on whether to provide palliative care or a trial of treatment within the established decisional grey zone’. This hypothesis was motivated by the considerations mentioned above and based on years of reflection as part of NICU experience, national and international debate and ethics research. We introduced the hypothesis in some form in all the interviews with parents and HCP, for the parents as question 5 of the semi-structured interview guide.

As reported in a previous paper, our HCP participants did not embrace our hypothesis.<sup>8</sup> They thought that parents should have a say and be included in a thorough informational and decision-making process. Regarding the final decision, however, the view of the HCP was that parents were not in a position to make a balanced decision. Thus, the doctor or the team of HCP should make the final

decision. In our interviews with the parents, they echoed the views of the HCP to a large degree, but with interesting variations and disagreements, as we will see in the 'Findings' section of this article.

## Research design

We conducted eight interviews with parents as part of our study. Twelve parents took part in these interviews, as individuals or couples. The interviews took place at different university locations in Norway in the years 2014–2018 and lasted from 70 to 120 min. The language of the interviews was Norwegian or English.

The inclusion criterion for parents was having experienced prenatal counselling at the limit of viability at Trondheim University Hospital, Norway. The sample of parents were recruited strategically, to bring out experiences with as diverse outcomes as possible. We aimed to include parents with experience from active treatment that resulted in healthy child, parents with experience from active treatment and survival with severe impairment, and parents with experience from active or palliative treatment where the neonate died in the delivery room or in the NICU.

The vulnerability of the potential participants required great care in recruiting to and carrying out the study, and only one of the couples who opted for palliative care chose to participate. We nevertheless succeeded in meeting our recruitment aims, making parental experiences of parents that rarely surface in feature or academic articles to be voiced through our study. See Table 1 for an overview of the experienced child outcomes of our participants.

In our dynamic interview guide, we followed up on central ethical and legal questions regarding parental roles and authority in neonatal decision-making, as these questions are played out in policy documents and guidelines, in discussions among HCP and in academic literature. Of special importance were questions concerning distribution of decision-making responsibility between HCP and parents, and the significance of the interests of parents and siblings in decision-making regarding the periviable baby. See Table 2 for the main questions of our interview guide.

The interview guide consists of a combination of open-ended questions where interviewees described their experiences at length and more pointed questions asking for parents' considerations regarding the issues. We moderated the interviews according to an adjusted model of the epistemic interview,<sup>9</sup> sensitive to both emergent ethical descriptions and considerations responding to direct questions and interventions.

The research group analysed the transcriptions of each interview to find emergent ethical themes and identify responses. Based on this analysis, we made a summary of the transcribed interview and sent the summary to the interviewed parents for comments. Comments were then included in the analysis. In this article, we present findings from one of the central ethical themes identified in the process of revisiting the transcriptions for iterated analysis and discussion in the research group. Quotes from interviews in Norwegian were translated to English by the authors in a manner that reflects the actual wording used by the participants.

**Table 1.** Overview of interviewed parents and child outcomes.

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Four interviews with both parents, four with mothers  
Birth at GA 23–24 weeks, one at GA 34 weeks (threatening birth at GA 22 weeks)  
Initial care: Nine trials of treatment, one palliative care  
Outcomes:  
- Survivors with none, mild and severe impairment  
- Death in the delivery room, in the NICU and in early childhood

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GA: gestational age; NICU: neonatal intensive care unit.

**Table 2.** Main questions of the dynamic interview guide.

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1. Could you tell us about your experience with extreme premature birth?
  2. Could you describe how you related to the foetus during pregnancy?
  3. Facing birth at the limit of viability calls for a decision on whether to attempt lifesaving treatment or to provide palliative care. The role of the parents in making this decision remains unclear. Did you feel that you were given a scope of action, and if so, how did you experience that?
  4. When an infant is born extremely premature, which factors and whose interests are relevant for making a decision regarding lifesaving treatment?
  5. When a decision is made at the limit of viability:
    - A. Should the parents be enabled to make the decision?
    - B. Should the parents have the final word in making this decision?
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## Ethical considerations

The research group consisted of two medical doctors working at the NICU at Trondheim University Hospital and two ethicists working at the Norwegian University of Science and Technology, Norway. Two members of the research group took part in the interviews with parents. L.U. moderated all interviews, while J.S. took part as a secretary in six interviews and transcribed all the interviews verbatim.

Doing research close to a researcher's own practice can lead to bias in both what and how the informants discuss the interview questions. It might also lead to biased interpretations and analyses by the researchers. On the contrary, the insider perspective enables susceptibility to nuances in questions and analysis that otherwise would be unattainable. The combination of an insider and an outsider perspective in our interdisciplinary research group was actively engaged to avoid bias and reach nuanced and robust descriptions of parents' views. Potential participants were identified from the neonatal and maternal ward registers and contacted by letter. They had to contact the researchers actively by text message, mail or email to be included. All study participants gave their written informed consent. The study was approved by the Regional Committee for Medical Research Ethics.

While we conducted the interviews with healthcare personnel as focus groups, we avoided this methodology for the parental interviews due to the sensitivity of the topics and the diversity of outcomes. We offered psychological support after the interviews in case of stressful reactions. This was not solicited by any of the participants. In order to protect the privacy of the participants, their names have been replaced with letters in the transcripts, and the children's outcomes are neither detailed nor correlated with the participant identification.

**Table 3.** Main theme findings from the interviews.

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1. Birth at the limit of viability experienced as an emotional turmoil
  2. The importance of being involved in decision-making
  3. Descriptions of and reflections on the need to balance the instinct of saving
  4. The dilemmas involved in protecting the family
  5. The burden of overwhelming responsibility
  6. The call for guideline relief
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## Findings

One of the main themes of the study, focused in question 5 of the interview guide, is whether parents should be enabled to make the decision – and have the final word in making this decision – when a decision is made at the limit of viability. In answering this question, but in fact to a much larger degree in recounting their experiences in the beginning of the interviews, parents had several descriptions and considerations pertinent to the theme. In Table 3, we summarize the main theme findings from our interviews with the parents.

### *The emotional turmoil*

In their response to the opening question of the interviews, parents invariably described their experiences with extremely premature birth in terms of an emotional turmoil. For most of the parents, the turmoil was aggravated by the birth being a sudden and completely unexpected event. The parents found themselves in a quite unfamiliar situation and were unprepared for the tragic decisions that had to be made. In this situation, they lacked the time and emotional stability to be informed, reflect and contribute in a reasoned way to decision-making:

In the beginning, it happened very, very fast, and psychologically we were not prepared for any of this. You are not prepared to take these decisions, you have no clue in the moment. We had read some of the facts, but at the time, it happened so incredibly quickly, and you don't have any time to evaluate or reflect. You just come, you react, you go on adrenaline, and there's a lot of shock, and a lot of adrenaline, and you're not in a state to make any big decision, and you don't have the information. (Father 4)

Some parents stated that despite the time pressure, their unpreparedness and emotional instability, they were able to reason that periviable birth would give their child a starting point that to them was unacceptable:

We were in a state of shock but were given the possibility to make decisions more or less on our own. That was difficult, but we very much agreed that this was not the kind of life we wanted for our daughter. (Mother 5)

This view contrasted with the views of those of our interviewees who had experienced their child surviving to receive NICU treatment and to live on. Looking back, they stated that given their later parental experiences, they had not been in a position to understand what was at stake when their child was born:

Parents should not have a say at the time of birth. Because, as a parent, you have no clue. You can read as much as you want while you're pregnant, prepare yourself for giving birth at 24 weeks, but in my opinion an inexperienced parent is unable to have anything to do with decision-making at birth. (Mother 1)

### ***The importance of being involved***

All parents thought it was important to be informed about the situation and of different ways of dealing with it. They also united in thinking that parents should be involved and consulted in decision-making regarding treatment options. However, the views of the parents differed regarding the nature of parental involvement. Parents with children who died at or soon after birth tended to be more positive about heavy parental involvement in the decision-making than parents with children who survived and lived on. The latter were quite clear that the nature of parental involvement should be restricted to being informed and informing the HCP:

Information is important regardless of what decision you reach. It is important that the medical doctor is brave enough to stand up for his/ her decision, and can explain the reasons to the parents. (Mother 2)

Some parents experienced that it was unclear how actively they should take part in the decision-making, why they were asked to state their views and what kind of weight their statements had. They felt that involving the parents mainly was a way of making them feel included, informed and respected. This involvement ran the risk of being misunderstood by parents as an invitation actually to make decisions:

I think that we are asked as a way to feel included and informed, and not just run over. It's tricky if this is misunderstood as really asking for us to decide, because I do not think we should be deciding anything, in the early phase. (Mother 1)

As mentioned, parents who lack the experience of seeing their periviable born children growing up tended to be more positive to parental decision-making in the NICU. They also emphasized the therapeutic effect of taking part in the decision-making process, in order to reconcile oneself with the outcome:

I would have reacted if I had learned that there was a decision to be made, and that I was not consulted. (Mother 5)



If there is a decision to be made, you want to be involved. (Father 5)

But what if we would have wanted active treatment, and the outcome had been bad, what would we be thinking now? (Mother 5)

I am happy that we were involved, and got the opportunity to reflect on the decision (Father 5)

It is important to be listened to, in a way, that what we have to say makes a difference (Mother 5)

According to the interviewees, the framing of the situation had a huge impact on what is conceived as right and wrong regarding the role of parents. How parents are asked to contribute is decisive for their expectations towards the decision-making process, and consequently for their satisfaction with the process. Again, the intention of asking the parents can be ambiguous: Is it more a matter of HCP getting input to their decision-making process and of showing respect for the parents, or are the parents actually asked to make decisions?

I have changed my mind now, but at the time I was a hundred percent sure that if the child had survived it would have been no problem, and I would have been very happy with it. I would have been enormously frustrated if I had been invited to say what I wanted, with the understanding that my opinion was important, but that my opinion in the end was overruled by the HCP. [ . . . ] If parents are offered the possibility to voice their opinion, their opinion must matter, but it should also be made very clear to the parents that they can leave the decision to the HCP. (Mother 8)

### ***Balancing the instinct of saving***

As described above, the parents describe the emotional turmoil as strong, for some so strong that it is incompatible with taking part in decision-making. Others still find it possible and crucial to have a say in these decisions. Another troubling aspect of the situation that was emphasized by the parents is the making of decisions on life and death *at the moment of giving life* to a child:

It's hard, because when you have a child in your tummy, you want to have that child. Everything in your body tells you that you are going to have a child, that after the pregnancy you are going to become a mother. You experience that the survival instinct when you are pregnant, and the protection instinct after birth, is so strong that it is difficult in the situation. It's something completely different to discuss or think about the decision-making outside of the situation, and you would have gotten completely different answers if you just asked people in a survey about their views on saving preemies. I do not know how long it took me to arrive at a more nuanced view, because for a long time I just wanted to have my baby, no matter what. (Mother 8)

Based on their experiences, parents were very concerned that it should be the duty of HCP to balance the parental instinct of saving:

Even if the parents have tried for ten years, and then they get a preemie, it should not matter. [ . . . ] Someone must say stop, for the sake of the children, because they feel all the treatment, all the needles in their bodies. I fight for the authority of the doctor, because to be the mother of a child that asks, 'Why did you let me go through all that', that is my biggest fear, because he remembers. His body remembers things, and that is horrible. (Mother 2)

Thinking back, parents were troubled by the combination of being driven by an instinct to save and, at the same time, being ignorant of the realities of the treatment regime that might be awaiting their premature child:

I was not able to think about the treatment they had to go through in the NICU, even if they were stuck with needles every day. My daughter is so sensitive now [ . . . ] but at the time, I did not think about how she experienced it. (Mother 1)

Parents express a concern not only to take irrational decisions because of the emotional turmoil, but moreover that their decision systematically will err on the side of fighting for lifesaving treatment. The instinct of saving the child is not adapted to the particular situation they are in, when a child is born at the limit of viability:

When you are in the middle of the situation, you are not able to make a decision or understand what you are doing, it is the HCP that are able to see how bad it is, and how bad it can turn out to be. In the situation – I just wanted to say that we have to try everything [ . . . ] now, based on our experience, I am not in doubt; parents need guidance. (Mother 7)

### ***The burden of overwhelming responsibility***

As described in the introduction, parents find it hard to be left with the responsibility to decide on life and death of their own child. It seemed unreasonable to most of our interviewees to demand of parents to make such a decision. In the situation, they lack the required knowledge and should not risk having to live with the awareness that they – maybe out of ignorance or fear – ended their child's life or with knowing that they requested lifesaving treatment that resulted in a life of suffering:

I didn't want to have a bad conscience afterwards. What if we had said that we wanted everything to be done, and then the child turned out to be very sick? (Mother 2)

And, vice versa, what if we had said that they should not save him, and then we learned that he could have been a healthy boy. (Father 2)

It would have been much worse if I had told them not to save him, and then later risk having a neighbor boy born at the same gestational age, doing just fine. (Mother 1)

The lack of knowledge makes it unreasonable to ask parents to take the full responsibility for decision-making, because their decision can turn out to be very wrong. Moreover, regardless of the outcome of the decision, parents in addition express that it is in principle wrong to place parents in a situation where they have to decide on the best interests and the intertwined fate of themselves and their own child, and live with the responsibility for this decision for the rest of their life:

We don't have the basis to make such a decision on behalf of the child, whether he should get the possibility to live or not, maybe to live a life with severe disabilities. [. . .] And, how could I have looked my own child in the eyes and said that, yes, I made the decision out of my own interests? (Mother 2)

### ***Protecting the family***

When asked question 4 of the interview guide, 'which factors and whose interests are relevant for making a decision regarding life-saving treatment?' the major concern of the parents was the best interests of the child. They were hesitant to say that the interests of the parents and the family should weigh heavily in the decision-making:

I have thought about the question: how far should we go? I met a child a bit later that survived with very severe cerebral palsy. Aware, able to communicate, but her body did not work. Beautiful girl, but with enormous assistance needs, always. Meeting her, I thought of how my life would have been if my girl had survived, and survived because I told them to save her no matter what, and ending up severely disabled as the girl I met. How would that be, for the sake of the child, for the family, and for myself. Of course, I know that once you're in the situation, you are able to handle it, and you love your child and you receive a lot of happiness in return. Still, I did not find it easy to bear the responsibility for such decision. (Mother 8)

The parents point out that there is a difference between saying that once you have the child, you will love it regardless of any difficulties and saying that putting the child and the family in that situation in the first place is the right thing to do:

The lives of those that get the child, their lives also matter. I know that my life would have been very different if my son was still alive. Perhaps it wouldn't be possible to go to work, or to ever have time on your own. If you get to choose as a parent, you would never say that it is not worth it. However, if someone else could make the decision for you, and decrease the risk of ending up in such situation, it would be easier for people to live with, I think. (Mother 1)

There is a difference between saying that the child and the parents will be brave and show resilience once a decision is made and saying that the parents should be brave and make the decision themselves. It is, for instance, possible to agree on the former and have different views on the latter.

Another aspect of concern regarding protection of family interests was whether parents should be shielded from possible detrimental effects of the decision-making process as such, and not just from living with the long-term outcome of the decision-making. If parents are left with the responsibility to make the decision, and they strongly disagree, this can potentially ruin their relationship and the family. This might have negative consequences for all the family members and damage their ability to care for the child:

That's a dilemma, if the parents have different views. (Mother 8)

You must take into consideration that the parents might differ in their opinions. I was reluctant, but when the father wanted lifesaving treatment, I felt that I could not say no, and that kind of dynamic is important to acknowledge. (Mother 3)

### ***The call for guideline relief***

At the end of the interviews, several parents voiced that considering all the complications regarding who should have the final say in NICU decision-making, a solution would be to go by strict rules. Life-and-death decisions in the NICU are simply too hard for both parents and HCP to make and be responsible for, so there should be guidelines to follow. Such guidelines, if made on a national level, would also secure equal policies between the NICUs:

If you have a strict set of rules, you do not have to go through all that, and you have no reason to think about whose decision it was. (Mother 1)

As quoted above, when you give birth, there is a deep bodily and emotional instinct to save the baby. Moreover, if the baby dies, the parents describe their experience of trying to find someone to blame for making a wrong decision or clinical judgement. A way to counter the challenge of irrational decision-making by parents and block the possibility of blaming the HCP in this situation is to enter into a Ulysses pact, and tie parents and HCP to the mast by imposing strict and detailed guidelines:

There should be a line, and that line must be followed strictly! (Mother 2)

## **Discussion**

This study brings forth important new aspects in the experiences and reflections of parents. Our study complements findings of previous studies by going deep into the reasons why parents voice ambivalence on the issue of parental decision-making.<sup>10</sup> Such ambivalence is found in previous studies on parental involvement in end-of-life decisions in neonatology, their descriptions of the emotional turmoil of experiencing premature birth, and the bearable or unbearable burden of overwhelming

responsibility.<sup>11</sup> Previous studies have also indicated that parents are ambiguous regarding their active participation in the decision-making process, even though they want to be included somehow.<sup>12</sup> In our interviews, we have given the parents the opportunity to expand on the considerations that lead to their ambivalence.

The parents of our study in addition bring in novel considerations, different from those emphasized in previous studies. Of particular importance here are their considerations regarding the impact of the instinct of saving and the dilemmas involved in protecting the family. These considerations are particularly interesting regarding the following questions: (1) whether a uniform and universal stipulation of parental responsibility indeed should be an ideal, and (2) how the main aim of HCP involvement in neonatal decision-making should be understood.

Both questions connect with our central study hypothesis, namely that parents should make the decision on whether to provide palliative care or active treatment when their child is born in the grey zone. As stated in the 'Background' section, this hypothesis was motivated by the general move from paternalism to patient autonomy in healthcare and the known national and international differences in the role of parents in decision-making. Seen from the viewpoint of equal treatment and access to healthcare, such differences are problematic.

One way to solve this problem of justice is to arrive at and justify a universal policy of the rights and responsibilities of parents in grey zone decision-making.<sup>13</sup> There are three main options available for such a universal policy: Parents can be given the responsibility to decide, HCP can take the responsibility for making the decision, or there can be a kind of shared decision-making between parents and HCP.

Previous studies of the views of parents on this issue report opposing findings. In a Norwegian study from 2002, parents did not want to be decision-makers,<sup>14</sup> whereas in similar studies performed in Scotland and Canada at the same time, parents saw decision-making as a part of their parental responsibility.<sup>15,16</sup> This discrepancy was backed by a contemporary cross-cultural study of parental involvement in decision-making in French and US NICUs that showed notable cultural differences of expectations and responsibilities.<sup>17</sup> These international differences are still present and reported.<sup>18</sup>

A central consideration voiced by the parents of our study is the problematic impact of 'the instinct of saving'. To attenuate the problematic impact of the instinct of saving when their child is born at the border of viability, parents emphasize the need to be 'protected from themselves'.

The instinct of saving is intimately related to the parental ideal of receiving the child as a gift, to show unconditional parental love regardless of the characteristics of the child and to care for the child in any situation. Taken in a straightforward way, the ideal compels parents to fight for their child in all kinds of situations. Good parents do not pause to ask whether they should help their child in an emergency, based on an assessment of uncertain future risks and benefits. Good parents never decide against helping their child. Good parents do not abandon their child because they might have to offer extra care. Good parents love their child regardless of whether it has or acquires a handicap. How does this ideal of good parenting fare in the NICU? The prognosis of the individual child born at the border of viability is uncertain. At the same time, the high risks of unwanted short- and long-term outcomes at a statistical level are well known. These risks of bad outcomes are due to the child being born extremely prematurely, where it becomes unclear whether we are 'saving' or 'creating' a child if we intervene with life-sustaining treatment.<sup>19</sup>

In this situation, it is possible for parents to act from an imperative to save the life of one's child regardless of the consequences. Parents who push for treatment and state that they 'want everything done', however, run a twofold risk. First, they risk not promoting the best interests of the child. Disregarding the known risks of suffering in the NICU and bad long-term outcomes can in effect be to place the interests of the parents above the interests of the child. Thus, the circumstances can make a parental push for life-saving treatment go against the child's best interests. To protect the child from undue harm, parents have to control the instinct of saving and situate the ideal of good parenting. (To protect the child from undue parental push for lifesaving treatment might even need a stronger legal backing.)

Second, they risk not protecting the interests of the family. The impact of the possible burden of care on the lives of siblings and their own lives might be disregarded. This is a bit paradoxical, as leaving decision-making to the parents is thought to be a way to secure that not only the short-term perspective of the NICU period but also the long-term perspective of the future life with the family is taken into consideration. Moreover, parental push for treatment risks ruining the relationship of the parents, both because the mother and father might disagree on the decision and because the burden of care over time puts a too heavy strain on their family life.

To give parents the responsibility for decision-making posits a 'logic of responsible parenting' alongside a 'logic of unconditional love'. A weighty reason to introduce the logic of responsible parenting is to hold that decision-making in the grey zone concerns ethics as well as medicine. This makes it wrong to leave the decision with the HCP and right to leave it with the guardians of the child, namely the parents. The logic of responsible parenting thus instigates autonomous parental decision-making to promote the best interests of the child.

The logic of unconditional love, by contrast, instigates unconditional protection of the child from death and unconditional acceptance of any future burdens of care. Making choices by weighing risks against benefits is alien to this logic. The ideal of unconditional parental love removes the grey zone by removing the ground for ethical dilemmas, leaving only the medical assessments of fruitful versus futile treatment. Alternatively, the ethical dilemmas of the grey zone are acknowledged, but as the logic of unconditional love prevents parents from taking proper account of the best interests of the child in decision-making, the ethical assessments involved also have to be left with the HCP.

To reconcile these logics, the parents interviewed in our study (echoing our HCP study) advocate a hybrid approach to parental involvement in decision-making in the grey zone. In accordance with the logic of responsible parenting, parents should be included in the ethical assessments involved and given the opportunity to take part in decision-making. In accordance with the logic of unconditional love, parents should be allowed to adhere to this logic and fulfil the ideal of good parenting by making it clear that HCP – not the parents – are the ones who ultimately make the medico-ethical assessments and take the responsibility.

The hybrid approach resolves a tension in the statements of the parents in our study. The parents emphasize both the importance of being involved in and at the same time not being left with the decision. Rather than voicing incoherent views, the parents manage to accomplish a balancing of the conflicting logics in play. To achieve this balance, it is decisive that HCP understand and make it possible for parents to exercise the parental ideals involved without compromising the best interests of the child.

Thus, when their child is born extremely prematurely, parents should be shielded by HCP from being placed in a position or having to make decisions that is incompatible with the ideas of good parenting. It is important not to corner parents into situations where they are asked to decide whether everything should be done to save their child. In the NICU, parents might be pushed to claim excessive treatment leading to undue suffering of the child, at odds with the interests of the child, the interests of the parents and the interests of the family.

The responsibility of HCP to avoid this is acknowledged in recent interviews done with HCP in Norway and Sweden by Joolaei et al.,<sup>20</sup> and in England by Birchley.<sup>21</sup> To fulfil this task, HCP can employ their experience with the decision-making situation and the outcomes of the decisions that are made.<sup>22</sup> To bring in the care perspective and unique experiences of nurses is of particular importance to make decisions based on a comprehensive assessment of the situation.<sup>23–26</sup> A challenge for HCP is their relatively short-term experience with the extremely premature children: Once out of the NICU, they might never see the child again. Given their responsibility in the decision-making process, NICU HCP should aim to complement their knowledge of the future life of children born at the border of viability.

## **Conclusion**

A central question in this article was whether a uniform and universal stipulation of parental responsibility indeed should be an ideal. An affirmative answer was presupposed by our main research question. But our findings questioned this presupposition. The findings pointed to another way of posing the question of uniform and universal norms: Why do cultural variations in neonatal decision-making occur between units and countries – and should we strive to level them out?

Given that HCP take part in the responsibility for grey zone decision-making, which involves both medical and ethical assessments, there should be national policies to ensure a consistent approach. Otherwise, parents would risk ending up with different decisions depending on the values of the HCP at their local NICU.

On the contrary, the interdependence of parents and HCP in decision-making questions the presupposition that we should strive to arrive at uniform and universal parental roles and responsibilities. Parents can play different roles in decision-making processes that promote the best interests of the child and the family. The optimal parental role will depend on personal and cultural factors, as well as the way in which HCP inform and involve the parents.

It is nevertheless desirable to enable parents to make and own decisions regarding their child.<sup>27</sup> More knowledge is needed about how counselling processes in the NICU can give a less restrained parental role and more parental involvement in decision-making. According to the new paradigm of choice architecture, this implies not merely giving comprehensive and adequate information about the consequences of the options available but enforces the importance of a caring relationship.<sup>5</sup> HCP should initiate and be attentive to the development of new skills to help parents understand the choices involved, clarify their own values and together make good decisions.

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## Author contributions

LU and JS conceptualized and designed the study, collected data, conducted the transcript analyses, and reviewed and revised the manuscript; JS transcribed the interviews; LU selected and translated the quotes from the interviews, and drafted the manuscript with substantial input from JS.

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