Doctoral theses at NTNU, 2023:343

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Doctoral thesis

NTNU
Norwegian University of Science and Technology
Thesis for the Degree of
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Etikken rundt liv-og-død-beslutninger på levedyktighetsgrensa

Utvikling innen nyfødtmedisin har gitt oss muligheten til å redde barn som fødes flere måneder før fullgått svangerskap. Samtidig vet vi at både sårbarhet på sikt og behandlingsbyrde i nyfødtperioden øker jo tidligere i svangerskapet barnet fødes. Noen av de minste barna vil dø av komplikasjoner etter uker eller måneder med intensivbehandling, og noen vil overleve med skader som vil påvirke dem resten av livet. I ukene etter fødselen vet vi ikke hvilke barn som vil overleve til et godt liv. Dette reiser spørsmål om det alltid er riktig å starte livredning for de mest umodne barna, og har ført til at man snakker om en såkalt «gråsone», hvor fagfolk er usikre på om det er til barnets beste å starte livredning.

Hvem bør ta denne beslutningen for det enkelte barnet? Nyfødtleger har erfaring med å behandle for tidlig fødte barn, de har oversikt over ulike behandlingsvalg, og er vant til å fatte beslutninger. Men det er barnets foreldre som sammen med barnet skal leve videre med konsekvensene. Og når fagfolk er usikre på hva som er godt og rett, kan man hevde at det er barnets foreldre som bør eie beslutningen.

Målet for prosjektet var å belyse de etiske premissene for beslutninger på levedyktighetsgrensa. Vår arbeidshypotese var at det er etisk riktig at foreldre kan ta avgjørelsen om å forsøke livredning eller gå for lindrende behandling når barnet deres blir født i en etablert gråsone. Vi gjennomførte fokusgruppeintervju av ulike grupper helsepersonell som har erfaring med liv/død avgjørelser gjennom svangerskap og nyfødtperiode. Foreldre med ulike erfaringer etter ekstrem prematur fødsel og som hadde vært i samtale med barnelege om behandlingsvalg i forkant av fødsel ble intervjuet individuelt eller parvis.

Både helsepersonell (artikkel 1) og foreldre (artikkel 2) hadde innsigelser til hypotesen om at foreldre bør eie liv/død beslutninger for eget barn på levedyktighetsgrensa. Begge grupper mente at det ligger i foreldrerollen å kjempe for sitt barn, og foreldre i denne situasjonen kan hverken forventes å ha kunnskap, følelsesmessig stabilitet eller tid nok til å komme i posisjon til å ta en balansert beslutning. De uttrykte derfor at foreldre bør skjermes fra dette ansvaret, men helsepersonell bør ta foreldrenes syn inn i sine vurderinger. Flere av foreldrene beskrev at de hadde hatt et instinktivt ønske om å redde barnet sitt, selv om de i ettertid var i tvil til om dette hadde vært til barnets og familiens beste. Mange mente derfor at foreldrene bør beskyttes mot seg selv. Foreldreskapet er tuftet på ubetinget kjærlighet, som kan komme i konflikt med forventningen om at man skal kunne veie ulike hensyn opp mot hverandre for å utøve ansvarlig foreldreskap.

Samvalg har seilt opp som en gyllen middelvei. I stedet for å se på autonomi som formell selvbestemmelse hvor foreldrene skal ta valget alene, forstår man her autonomi som *myndiggjøring*, hvor foreldre og helsepersonell står i valget sammen. Målet er at beslutninger i gråsonen skal være basert på foreldrenes verdier, men at helsepersonell bærer ansvaret for prosessen og at beslutningen sånn sett er noe man står sammen om. I artikkel 3 presenteres et radikalt forslag for hvordan dette kan la seg gjøre når fødsel på levedyktighetsgrensa kommer brått på. I artikkel 4 går vi inn på autonomi-utfordringer når et umodent, men potensielt levedyktig foster er truet i mors mage.

I avhandlingen argumenterer jeg for at det er etisk riktig å gi foreldre mulighet til å delta i beslutninger som vil prege resten av deres liv når helsepersonells medisinske kunnskap ikke er tilstrekkelig for å slå fast hva som er rett og godt. Med god veiledning fra helsepersonell og tid til refleksjon, kan foreldre som står overfor liv/ død situasjoner på levedyktighetsgrensa gis forutsetninger for å kunne delta i disse eksistensielle beslutningene.

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‘Ok, stranger fetus-baby: I love you’

The ethics of life and death decisions at the border of viability

Advances in neonatal medicine have allowed us to rescue extremely preterm infants. However, both long-term vulnerability and the burden of treatment in the neonatal period increase with decreasing gestational age. Some of the most immature babies will die from complications after weeks or months of intensive care, and some will survive with major problems that will affect them for the rest of their lives. In the first weeks after birth we cannot know which infants will survive to a good life. This raises questions about the justification of life support when a baby is born at the limit of viability, and has led to a so-called ‘grey zone’, where professionals are unsure whether provision of life support is in the child's best interest.

Who should make such decision for the individual infant? Neonatologists have experience in treating premature babies, they have an overview of different treatment options, and are used to making decisions. However, it is the baby's parents who, together with the baby, must live with the consequences. When professionals are unsure of what is good and right, one can argue that the infant’s parents should be enabled to make the decision.

The aim of this project was to shed light on the ethical premises for decision-making at the border of viability. Our working hypothesis was that it is ethically sound for parents to make the decision of whether to provide life support or opt for palliative care when their baby is born in an established grey zone. We conducted focus group interviews with the different groups of clinicians dealing with life and death decisions throughout pregnancy and the neonatal period. Parents with different experiences after extremely premature birth, who had taken part in discussions about treatment choices before birth, were interviewed individually or as a couple.

Both clinicians (paper 1) and parents (paper 2) presented objections to the hypothesis that parents should own life and death decisions for their infant at the limit of viability. Several clinicians expressed that the parental role implies fighting for your child, and parents in this situation cannot be expected to have the knowledge, the emotional stability or enough time to be in a position to make a balanced decision. They therefore expressed that clinicians should take the parents' views into account, and shield the parents from decisional responsibility. Several of the parents described an '*instinct of saving'*, and expressed that clinicians should protect the infants against the parental push for treatment. Parenthood is founded on unconditional love, which can come into conflict with 'responsible parenting', where different considerations ought to be weighed and balanced.

Shared decision-making has emerged as a golden mean. Instead of seeing autonomy as formal self-determination where the parents have to make the choice all by themselves, autonomy is understood as empowerment, where parents and clinicians stand in the decision together. In paper 3, we present a radical proposal to support shared decision making when periviable birth occurs suddenly. In paper 4, we take a closer look at challenges of autonomy when an immature but potentially viable fetus is threatened in the mother's womb.

In the thesis, I argue that it is ethically sound to give parents the opportunity to participate in decisions that will affect the rest of their lives when medical knowledge is insufficient to determine what is right and good. With good guidance from clinicians and time for reflection, parents facing life and death situations at the border of viability can be enabled to participate in these existential decisions.

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Funding: The Department of Paediatrics, St. Olavs Hospital and The Liaison Committee for Education, Research and Innovation in Central Norway (Samarbeidsorganet).

This thesis has been found worthy of public defence for the degree of PhD in Medicine.

The public defence will take place in KBA on Friday the 20th of October, 2023, at 12.15 pm.

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Trondheim, September 2023

Janicke Syltern

An ethical judgment is not a quantitative calculation at root but an acknowledgement of responsibility for a relationship.

Donna Haraway

I believe in spectacles, but I think eyes necessary too.

John Stuart Mill

To Marita, Thea and Sara

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Paper I

Ursin, L., & Syltern, J. (2018). In the Best Interest of the. . .Parents: Norwegian Health Personnel on the Proper Role of Parents in Neonatal Decision-making. *Pediatrics*, *142*(Suppl 1), S567–S573. https://doi.org/10.1542/peds.2018-0478H

Paper II

Ursin, L., & Syltern, J. (2020). Protect us from ourselves: Balancing the parental instinct of saving. *Nursing ethics*, *27*(5), 1282–1296. https://doi.org/10.1177/0969733019871691

Paper III

Syltern, J., Ursin, L., Solberg, B., & Støen, R. (2022). Postponed Withholding: Balanced Decision-Making at the Margins of Viability. *The American journal of bioethics: AJOB*, *22*(11), 15–26. https://doi.org/10.1080/15265161.2021.1925777

Paper IV

Syltern, J., Ursin, L., Solberg, B., & Støen, R. Everybody wants to save the viable but dying fetus: why and how to support pregnant women's autonomy. Submitted.

Other papers published during the PhD

Syltern, J., Markestad, T., Saugstad, O. D., & Støen, R. (2018). NICU Dialects: Understanding Norwegian Practice Variation. *Pediatrics*, *142*(Suppl 1), S545–S551. https://doi.org/10.1542/peds.2018-0478E

Ursin, L., Syltern, J., & Lantos, J. D. (2018). Look to Scandinavia. *Pediatrics*, *142*(Suppl 1), S531–S532. https://doi.org/10.1542/peds.2018-0478B

Lantos, J. D., Saleem, S., Raza, F., Syltern, J., Khoo, E. J., Iyengar, A., Pais, P., Chinnappa, J., Lezama-Del Valle, P., & Kidszun, A. (2019). Clinical Ethics in Pediatrics: An International Perspective. *The Journal of clinical ethics*, *30*(1), 35–45.

Syltern, J., Ursin, L., Solberg, B., & Støen, R. (2022). Postponed Withholding: An Ethical Tool for Health Care Personnel to Empower Parents, *The American journal of bioethics: AJOB*, *22*(11), W1-W4, DOI: 10.1080/15265161.2022.2132316

Syltern, J., & Markestad, T. (2023). Norwegian paediatric residents surveyed on whether they would want life support for their own extremely preterm infant. *Acta paediatrica*, *112*(4), 645–646. https://doi.org/10.1111/apa.16631

Abbreviations and notes on terminology

GA: Gestational age

HCP: Health care personnel

HLHS: Hypoplastic left heart syndrome

NICU: Neonatal Intensive Care Unit

Level III NICU (‘Nivå 3c’): A NICU that provides critical care to all sick newborns, including the most immature

PPWH: ‘Postponed withholding’ (see paper 3)

Note on gestational age:

Gestational age is calculated based on the date of the last period, or estimated by ultrasound, with a level of uncertainty up to +/- 7 days. On average, pregnancy is expected to last approximately 280–283 days ($40^{+\,0\text{–}3}$ weeks). Premature (or preterm) birth is defined as babies born alive before 37 weeks of pregnancy are completed. In this thesis, I use the terminology 37 weeks gestation, (or simply ‘weeks’, or $37^{+0\text{–}6}$ (0–6 days as superscript). Extremely premature birth is defined as birth before 28 weeks (birth up to 27^{+6} weeks gestation).

1 Introduction

The title of this thesis was the words of a mother who had just given birth to her periviable infant. Prior to birth, she and her partner had a short deliberation with the obstetrician, and they had opted for palliative care: the prognosis was too gloomy. But when she shortly afterwards found herself holding her 'stranger fetus baby', she was overwhelmed. To her, the most important thing was to reassure her baby that she was loved. If she were to live only five minutes, those ought to be filled with love. 'She is viable – help her!' she remembered saying, frightened by her own words. How is the best way to help such a fellow, new human being – provide high-tech intensive care with the aim of survival, or provide comfort care during the short time she lives? The mother felt ambivalent.

Her reflection brings us to the core of this thesis: When a human life is threatened, even before it has been thrown into the world, barely having reached a state where survival is potentially achievable thanks to neonatal intensive care: what ought clinicians and parents see – and do? How can we know what is right, and what will be good for the new 'fetus baby', her family and the community in this particular situation?

This dilemma is raised by both extremely premature birth and threatening fetal demise after the point where the fetus can survive outside of the mother. To some, such questions will seem strange: 'as long as there is life, there is hope' – what better purpose for medical advances and technology than to save the life of the most vulnerable?

As a neonatologist, my training and position give me the possibility to provide complex medical care and life support. My overarching goal is to do good to babies and their families. Mostly, my moral intuitions tell me to pursue survival, that the pain we inflict on the infants is justified by the most essential of goals: existence itself. But there are other times when intuitions are less clear: a sense that my actions might lead to net suffering for both the baby and the parents. My intuitions may lean towards that this baby ought to receive comfort, and love, in the short period of life until she dies, rather than being exposed to the pain and burdens of alienating high-tech intensive care and highly uncertain outcome.

There are those who have provided us with rational arguments that support such intuitions. Life support procedures can do more harm than good: if there is practically no chance of success, life support will be futile and only cause harm. The duty of respect that we owe to our fellow humans, and the duty not to cause unjustified suffering will then outweigh our perceived duty to rescue. Other duties, and others interests may outweigh those of the infant. In some situations, the wise thing to do is to withhold life support and offer care and accompaniment. Many articles, papers and policy statements discuss in which situations we ought to forego life support and instead provide compassionate palliative care, allowing a patient to die with dignity. Complicating the case is also the much-disputed question about the fetus' moral status, and the significance of birth: should we regard the infant born at the limit of viability like any other baby, or more like an immature fetus, suddenly 'at the wrong place, at the wrong time'? This question may also relate to whether we face a duty to rescue a viable, but dying fetus when we have the means to do so.

As the scholarly quest for the Right and the Good is the domain of moral philosophy, I entered into a new world of concepts and ways of thinking. When moral philosophy is applied to dilemmas of modern medicine, we call it 'medical ethics'. Through my clinical work, and more thoroughly as part of the clinical ethical committee in our hospital, I have been exposed to clinical application of medical ethics, and its four most popular principles: autonomy, beneficence, non-maleficence and justice. Thanks to this project, I have been given the privilege to dig a little bit deeper. Abstract principles can be useful as guiding lights or rules of thumb, but may fall short when we are facing real-time, existential dilemmas. Aiming for the Right way, we must get into the situation. There is a choice to be made about the ethical starting point. We can consider different rules, obligations and duties and we can specify and balance potential conflicts. Alternatively, we can set up a calculation of benefits and risks. Another option is to pursue ‘human flourishing’, and aim to become wise persons through educating our emotions and practical reasoning. We can also choose a more pragmatic attitude, combining different approaches to find a way that ‘do the work’ in complex situations.

How and by whom should such decisions be made – is it our duty as clinicians due to our superior knowledge, clinical experience and practical wisdom to use our intuition, weigh the risks, and provide the answer? There are at least two lives that will be seriously affected by decisions made: the mother and the fetus-baby, in many cases also a second parent, in some siblings. As assisting doctors and nurses, we are also touched by the new relationships. It is a great privilege and deeply meaningful to be able to contribute with hope in the midst of despair, when parents fear losing their baby. But sometimes the hope we bring will be ambiguous.

In this thesis, I will try to give a good account of what such decisions implies. To those who opened this thesis hoping to find a clear and objective solution to this dilemma, I am sorry to say that I must disappoint you. To those of you who, like me, are wrestling with this question, or if you are just curious about how this dilemma can be looked at from different perspectives, I invite you to join my journey.

I will start by presenting the background scene from which this study emerged: how, from my point of view as a neonatologist in Trondheim, the medico-ethical debate played out, inevitably shaping my encounters with parents, their periviable fetuses/infants and colleagues. How have these question been framed in Norway over the last decades, as compared to other countries? Next, I will present the aims of the project, followed by a discussion of the methodology and a description of the method. I will then continue by briefly presenting the papers included in the thesis, and discuss what I see as potential implications of our work. Finally, I will conclude with some remarks about where to go from here.

I feel most privileged for the opportunity to be immersed in this project. The possibility to discuss this topic with leading bioethicists and clinicians from both Scandinavia, Europe and the US in a workshop at Tautra in 2017 was exceptionally rewarding and inspiring (Ursin et al., 2018). Perhaps even more valuable was the inclusion of different voices in this project, which gave us nuanced and rich descriptions and opportunities for vital dialogues. Together with theoretical input from the literature and philosophical studies done during this thesis, I am tempted to say that they have had a transformative impact on me, both as a doctor, and overall as a being-in-the-world. Starting out from a scientific, quantitative paradigm in search for objective parameters on which to build a guideline, I have been opened up to a qualitative paradigm with multiple perspectives and a broader understanding of how human beings conceive the world and how decisions unfold. Existential dilemmas, especially in the light of radical uncertainty, present an inherent ambiguity that is there not to be 'solved' – indeed, they are not solvable through medical technology or statistics, not even through abstract ethical principles. They are real challenges in our lives that we need to tackle: we have no other option but to face them, with all their hardship and complexity.

2 Background

A pregnant woman and her partner show up at the hospital very worried – halfway through the pregnancy, at 21 weeks gestation, they fear that something is terribly wrong. The message from the doctor is horrifying: the water has broken, and the labour could start at any time. If the baby is born now, there is no chance of survival. The mother tries to stay as calm as possible, pleading for her little daughter to stay inside – at nights in the hospital, any sensation from her abdomen raises the fear that labour has started, meaning that she is going to lose her baby. One week passes, nearly two.. The doctors now say that there may be hope, but the stakes are high: to have a chance of survival, life support will be needed for months, and risks of short and long-term complications and disability are high. As the days go by, the father gets more and more puzzled: how come that if they had been in Sweden, life support would have been an alternative already at 22 weeks gestation? And, even more worrying: at 23 weeks, does it matter which hospital you are admitted to, within Norway? Being a journalist, he starts investigating and finds that this actually might be the case. 'It is when I talk to the pediatricians who are in the middle of this that the different practices between the hospitals come forward, while the hospital managers are reluctant to admit that there are such differences,' he stated to a national newspaper (Langset, 2013). For these parents, the story has a happy ending. After spending ten weeks in what felt as a 'war zone, waiting for a strike in any moment', their daughter is born at 30 weeks gestation. After a few weeks at the Neonatal Unit, she can go home with her parents – a lovely, healthy girl.

This story sparked a public debate on acceptable differences in neonatal practice. The same year, The Perinatal Committee of the South-Eastern Norway Regional Health Authority urged the National Council for Priority Setting in Health Care (now decommissioned) to consider a revision of the 1998 guidelines. The reasons stated was *'unclear boundaries for when to start treating the infant in the event of extremely premature birth (..) currently no uniform practice regarding initiation of life support to the infants born at gestational age between 22 and 25 weeks (..) strong need for a new consensus in this area*' (National Council, 2014).

What is it about this situation that makes initiation of life support so controversial? Doctors, nurses, parents and bioethicists are struggling to come to an agreement on the right thing to do when an infant is born before 25 weeks gestation. Without life support, the baby will die. With life support, survival has become more likely during the last decades, but it comes at a price. Internationally, recommendations show wide variation for infants born between 22 and 25 weeks (Guillen et al., 2015). To get a feeling of where we are coming from, I will start by going back in time and look at how treatment strategies for extremely premature infants have developed in Norway.

2.1. Norwegian neonatology and the 1998 consensus report

The first neonatal ward in Norway opened in Oslo in 1957. Since then, Neonatal intensive care units (NICU) were established in all university hospitals. During the 1980s, the gestational age below which babies were not considered viable shifted downward from 28 weeks (Syltern et al., 2018). By 1998, it was 23 or 24 weeks, and this corresponds with a birth weight between 400 and 750 grams (Kvestad et al., 1999).

In parallel with the technological and medical advances, ethical controversies came forth (Hansen & Finne, 1995; Reigstad & Markestad, 2001). Should there be a lower gestational age limit for offering life support? How, and by whom should such decisions be made? To optimize the possibility for survival, there is a need for a coordinated, multidisciplinary effort. The question of whether to provide neonatal resuscitation is preceded by a number of obstetric decisions: timing of transfer to a level III NICU, administration of antenatal steroids for lung maturation, monitoring of the fetus, and the consideration of caesarean delivery. These decisions primarily affect the infant, parents and siblings, and involve obstetricians, maternal fetal specialists and neonatologists. They also have important implications for neonatal nurses, midwives and society as a whole.

In 1998, the Research Council of Norway (1999) organized a national consensus conference with the intention to 'promote good medical practice and fair prioritization in an area where professionals disagree or benefit is dubious'. The conference was organized by a multidisciplinary group of neonatologists from different Norwegian NICUs, psychologists, nurses, ethicists, and representatives from the Council. During the conference, they discussed the challenges of predicting sequelae and the burdens of treatment for both the infant and the family. Legal and ethical issues were analysed and they looked at international practice variation. Finally, a separate multidisciplinary consensus panel concluded on the consensus questions.

The primary focus was on establishing medical and ethical sound thresholds for initiation of life support. They recommended that treatment before 23 weeks gestation should be seen as futile and be considered experimental. Treatment at 23 and 24 weeks should be optional and based on the infant's vitality and the individual physician's judgement. From 25 weeks, life support should be considered standard of care, unless there were other major negative prognostic markers (table 1) (Miljeteig et al., 2007). The main message from the discussion was that both decisions of starting or withholding life support at birth, and stopping or withdrawing life support should be based on ethical deliberation that involves all affected parties.

Infants born after 25 completed weeks should usually receive life-saving treatment
Treating infants with gestational age less than 23 weeks is considered experimental and should only be initiated according to a research protocol approved by a research ethics committee and after obtaining informed consent from parents.
Treatment of infants born at 23–25 completed weeks should be assessed on an individual basis taking into account the child's vitality and the individual doctor's clinical judgement.
Decisions to withhold or withdraw treatment should be based on defined diagnostic and prognostic criteria, not on assessments of future quality of life. Methods for assessing quality of life lack sensitivity, and judgement of the quality of life of others is influenced by subjective opinions.
Based on discussions, each unit should establish procedures and guidelines which secure that all relevant considerations, included the parents' attitudes, are included in the decision-making process.

Table 1: The conclusions of the Norwegian Consensus Conference, 1998 (from Miljeteig et al., 2007, reproduced with permission)

Brinchmann and Vik (2005) comment that the parental role in the decision-making process was discussed, although the question of how and when the parents should be involved was not addressed in detail. It was stated that parents should participate, and their opinions should be given weight, but there should be no doubt that the physician carried the responsibility for the final decision. A clear argument for this was not given, and the authors suggest that there was likely a concern about late feelings of guilt and doubt on the part of the parents.

Since 1998, Norwegian health care personnel seem to have become more willing to provide life support at lower gestational age than recommended by the guideline. A questionnaire based study on changes in attitudes and practices over time in Norwegian obstetric and pediatric units in 2005 showed that the mean reported gestational age threshold for resuscitating infants had decreased by almost a week from 23^{+6} to 23^{+0} weeks since 1998 (Miljeteig et al., 2007). Physicians did not acknowledge this change, but 30% felt that decisions regarding provision of life support had become more difficult. Almost half of the responding physicians agreed with the statement that Norway was too liberal in providing life support to the most immature infants. At birth, more than 90% gave decisive weight to gestational age, followed by vitality (63%). Parents' attitudes were given decisive weight by 29% and some weight by 46%, while parents' ability to care was given far less weight (Miljeteig et al., 2007).

2.2 Is the 1998 consensus guideline obsolete? Current practices

In 2009, two University Hospitals in Oslo (Rikshospitalet and Ullevål sykehus) merged into one organization. The two institutions appeared to have a somewhat different approach to the provision of life support when faced with premature labour between 22 and 25 weeks gestation. After receiving the petition from the Perinatal Committee of the South-Eastern Norway to consider a revision of the 1998 guidelines, the National Council for Priority Setting in Health Care conducted a questionnaire study on current practices and local guidelines. This was sent to all 21 Neonatal Units and 40 Obstetric Units in Norway in 2015, and supplemented by data from the Norwegian Neonatal Network. Eight NICUs treated infants below 26 weeks. It seemed that these units could be divided into two categories: (1) Units mainly providing life support to all infants from 23^{+0} weeks gestation and (2) Units providing life support to all infants from 24^{+0} weeks, making an individual judgment of infants born at 23 weeks (National Council, 2017).

These findings are reflected in data from the Norwegian Neonatal Network: in the period 2009–2014, the proportion of live-born infants transferred to a NICU was nearly 97% at 24 weeks, 74% at 23 weeks and 19% at 22 weeks. During those years, only eight infants born at 22 weeks had been transferred to the NICU, all occurring in three of the eight NICUs in which life support to periviable infants was taking place. In conclusion, the grey-zone in Norway appear to have moved from 24 to 23 weeks; at 22 weeks treatment is still rarely offered, and at 24 weeks, treatment is normally started (Syltern et al., 2018).

The level of parental involvement in decision-making is largely unknown. Most units stated that parental wishes would be given decisive weight before 24 weeks gestation, but little is known about how they are involved. Concerns were raised about whether ‘parents receive neutral information about prognosis’ (National Council, 2017). The National Council recommended that the Norwegian Directorate of Health initiated a process with the aim to harmonize practice. So far, there has been no serious attempts of establishing a new national consensus.

2.3 Looking to Sweden and Denmark

2.3.1 ‘Proactive Swedish approach’

In Sweden, neonatal care started already in the 1950s, and close collaboration with US universities resulted in research innovation, such as the development of the porcine surfactant Curosurf by Curstedt et al., and the jet nasal continuous positive airway pressure system ‘Infant Flow’ by Moa et al. (Domellöf & Jonsson, 2018). During the 1960s and 1970s, the practical rule was to not provide active care to premature infants below 28 weeks gestation (or less than 1000 g), which was the legal definition of a viable fetus. During the 1980s, reports of survival up to 50% for infants below 28 weeks from some centers sparked high-profile debates in Swedish media on the ethics of life support to extremely premature infants.

The Swedish National Board of Health and Welfare organized in 1989 a national conference for neonatologists and obstetricians, discussing the perinatal management of extremely premature infants. No agreement was reached whether extremely premature infant in the range of 23 to 26 weeks gestation would benefit from initial intensive care, and further scientific studies were suggested. From 25 weeks, fetal interests should guide obstetric management, setting the limit for when pregnant women with threatening premature birth should be transferred to specialized centers (Domellöf & Jonsson, 2018). During the following decades, there were important regional differences in initial approach and survival rates, as first became evident in a national, population-based study of extremely premature infants born between the years 1985 and 1999, and confirmed in the prospective cohort study EXPRESS (The Extremely Premature in Sweden Study), performed between 2004–2007 (Fellman et al., 2009; Håkonsson et al., 2004).

Increasing survival rates at 22 and 23 weeks gestation in centers providing active care led up to a new consensus between Swedish obstetrician and neonatologists. In the 2016 guidelines, life support should be considered from 22^{+0} weeks, and is recommended from 23^{+0} weeks. Parents should receive information, and the neonatologist and the obstetrician should, ‘as far as possible, take into account the views of the parents’ (Domellöf et al., 2016). It is not clear to what extent the parents’ wishes should guide the decision. There are still differing opinions among neonatologists, ranging from a duty-based ethical standpoint that every premature infant should be offered life support (including at 21 weeks) regardless of parental wishes, to standpoints that infants born below 24 weeks should only be given life support if the parents demand so (Domellöf & Jonsson, 2018, p. S536). Neonatologist Strand Brodd even performed life support on aborted fetuses, stating that a ‘fetus that is expelled at week 22 is, in the legal sense, a child, and if I meet an acutely ill child, I want to help it (..) The child's rights take precedence over the mother's’ (Yllner, 2017). (Late abortion up to 22 weeks gestation is allowed in special cases in both Norway and Sweden, and since abortions this late may take time, the fetus can be expelled after 22 weeks gestation.) This caused intense public debate, and the National Board of Health and Welfare issued a consensus document in 2018 stating that neonatologists should not assist during abortion procedures; if midwives needed support, they should call for a gynaecologist (Bering, 2018).

2.3.2 ‘Family centered approach in Denmark’

Neonatal intensive care started in Copenhagen in 1965, and mechanical ventilation became standard of care for premature infants already in 1971 (Greisen & Henriksen, 2018). During the early eighties, doctors in Copenhagen started to push borders, providing full intensive care to infants born at 23 and 24 weeks gestation. The results were poor, and the nurses protested to these changes. After several multi-professional staff meetings, they changed to a minimally invasive approach, with an initial 24-hours wait-and-see period on nasal continuous positive airway pressure (CPAP) (Greisen & Henriksen, 2018).

Denmark is known for its family-oriented approach, with roots in a popular movement that challenged the technological approach to delivery, birth and neonatal intensive care already during the 1970s. A column published in a national newspaper in 1986 by a pair of parents also contributed to form the public opinion. They told the story of their premature daughter who ‘lived in a plastic box and died 4 ½ months later’ and claimed that ‘society should not have put all these resources on ‘before-lives’ (‘før-liv’):

‘Either we must take the decision-making out of the hands of physicians and say: After this or that limit we do not go further. Or the hospitals, with the physicians in front, must mount to their moral responsibility, not only for the single life, but for all those lives that are affected by what they have created’ (Ørum & Carstens in Politiken, 1996, as cited in Greisen & Henriksen, 2018, p. S542).

In 1990, a national consensus conference was organized with experts informing a lay panel, and the latter recommended not to offer life support below 25 or 26 weeks gestation. The process of decision-making with parents and support to families were central issues. In recent years, there has been a trend towards centralization of threatened premature labour at 22 and 23 weeks to enable better informed choice by parents and improved quality of care. These plans did not elicit much criticism or public discussion, and public opinion might have changed (Greisen & Henriksen, 2018). In 2018, Danish obstetrician and neonatologists agreed on consensus guidelines, where palliative approach is recommended at 22 weeks, shared decision-making with parents at 23 weeks and life support as standard of care from 24 weeks gestation (Christensen et al., 2018).

2.4 Europe and beyond

Guillen et al. (2015) performed a systematic review of international guidelines and found that most guidelines recommended comfort care at 22 weeks gestation and life support at 25 weeks. There was huge variation in recommendations for 23 and 24 weeks; these included comfort care, parental wishes or individualized approach at 23 weeks, and parental wishes, individualized approach and active care at 24 weeks gestation.

Cavolo et al. (2019) performed a systematic review looking at physicians' attitudes on resuscitation of extremely premature infants that included 34 articles from 27 different countries, and found that attitudes varied greatly for infants at 23 and 24 weeks gestation. At 22 weeks, most neonatologists would not provide life support, even on parental request. Still at 23 weeks, most physicians would not provide life support, and would accept parental request for palliative care. Focusing on Europe (with the exception of the Netherlands), the majority would provide life support at 24 weeks gestation. However, a significant proportion would accept a parental request for palliative care.

The Netherlands has been considered an outlier for ‘ its relatively high thresholds of initiating active care, its grey zone spanning 24 and 25, in which active management is determined by parental discretion, and a slight reluctance to provide active care in case of extreme prematurity’ (De Proost et al., 2021, p. 1). The different thresholds for resuscitation of extremely premature infants were reflected in an online survey distributed among neonatologists from UK, Sweden and the Netherlands (Wilkinson et al., 2018). The grey zone for most UK respondents was 23^{+0}–23^{+6} weeks gestation, compared to 22^{+0}–22^{+6} weeks in Sweden and 24^{+0}–25^{+6} weeks in the Netherlands. Of the Swedish respondents, 6% would provide resuscitation at any gestational age if the infant were born alive. There was wide variation in the prognosis that warranted life support or comfort care; 33% of Swedish respondents would be prepared to provide life support no matter how low the chance of survival, as compared to 6% of the Dutch respondents (Wilkinson et al., 2018).

In the US, there also seem to be a wide range of different approaches in different centers, from those who provide life support as default from 22 weeks gestation, to those who practice shared decision-making up to 26 weeks (Kaempf et al., 2016; Watkins et al., 2020).

How can we make sense of such variation, even in countries that are otherwise comparable, like the Scandinavian countries? I will start out presenting some medical facts before we go into further ethical considerations.

2.5 Prognosis and burdens

2.5.1 Survival

Survival is strongly related to gestational age, and it is also influenced by other known factors. The most recent Norwegian study was published in 2017, examining 1-year survival and rates of major neonatal morbidities among infants born at gestational age 22 to 26 weeks in 2013–2014 (NEPS 2; Stensvold et al., 2017). Survival was 35% at 23, 58% at 24 and 86% at 25 weeks gestation. The results were compared with the first Norwegian Extreme Prematurity Study (NEPS 1; Markestad et al., 2005), which followed the national cohort of extremely premature infants born in Norway during 1999–2000, and other contemporary studies. There was no significant change in survival rates. More infants born at 22 weeks received life support in the second period (from 2 infants in 1999–2000 to 5 infants in 2013–14) (table 2). Data on survival for the years 2018–2021 is shown in figure 1, provided by the Norwegian Neonatal Network.

In Sweden, survival rates among infants admitted for neonatal care have been steadily increasing between 2007 and 2018, as showed in a recent study, with national survival rates of 38% at 22 weeks gestation and 67% at 23 weeks (Lundgren et al., 2022).

Bell et al. (2022) looked at survival and 2-year outcome of extremely premature infants born in 19 academic centers in the US (NICHD) during 2013–2018. Survival was higher than in earlier cohorts: for actively treated infants, it was 30% at 22 weeks, 56% at 23 weeks, 71% at 24 weeks and 80% at 25 weeks gestation.

In a joint publication of survival rates for extremely premature infants in all Nordic countries born in 2021, differences were found in admission rates for infants born alive at 22–24 weeks of gestation (73% in Denmark, 80% in Finland, 67% in Iceland, 92% in Norway and 98% in Sweden) (Norman et al., 2023). The authors discuss that the lower rates in Denmark and Finland most likely reflect variations in attitudes and different guidelines on perinatal management at the border of viability. In contrast, live born infants at 25–27 and at 28–31 weeks gestation were almost universally admitted for neonatal care, in all regions. However, there were no statistically significant differences in survival rates among live born and admitted infants between regions and countries. The overall Nordic survival among live born infants was 58% at 22–24 weeks and 91% at 25–27 weeks gestation (Norman et al., 2023).

On request from the National Council, The Norwegian Knowledge Centre for the Health Services summarized international literature on recent gestational age specific prognosis on survival and neurodevelopmental outcome (Myrhaug et al., 2019). They found a strong correlation between gestational age and survival (table 2).

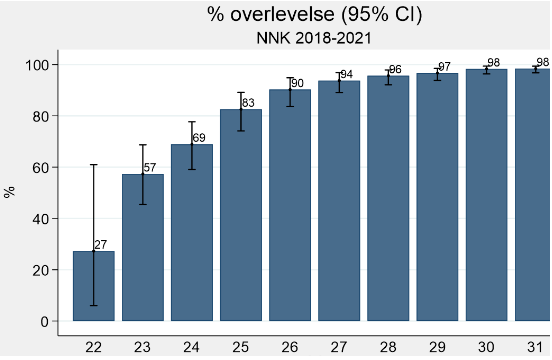


Figure 1. Proportion of Norwegian infants who survived to discharge by gestational age at birth 2018–2021 (Data from the Norwegian Neonatal Network).

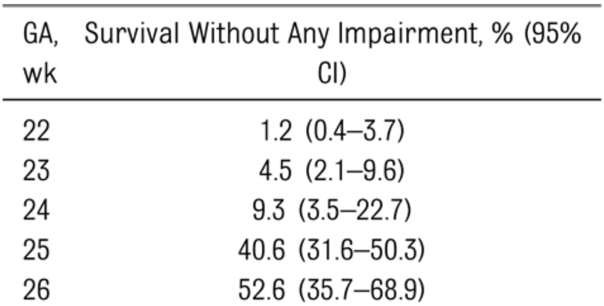
GA	***Review 2000-2016 N (%)***	***Norway 1999-2000 N (%)***	***Norway 2013-14 N (%)***	***Express Sweden 2004-2007 N (%)***	***Sweden 2016-2018 N (%)***	***EPICure 2 UK 2006 N (%)***	***NICHD (US) 2013-2018 N (%)***
22 weeks	98/285 (33)	0/2 (0)	3/5 (60)	5/51 (10)	31/82 (38)	3/19 (16)	60/200 (30)
23 weeks	516/1052 (48)	9/23 (39)	12/34 (35)	53/101 (53)	80/119 (67)	66/217 (29)	535/958 (56)
24 weeks	1255/1923 (68)	35/68 (60)	35/60 (58)	96/144 (67)		178/381 (47)	972/1362 (71)
25 weeks	73 %	55/69 (80)	59/69 (86)	167/205 (82)		346/498 (69)	1266/1584 (80)

Table 2. Survival rates of periviable infants admitted to NICU

* Survival to discharge:, NEPS, NICHD. Survival to one year: Express. (Ref: Myrhaug et al., 2019; Markestad et al., 2005; Stensvold et al., 2017; Fellmann et al., 2009; Lundgren et al., 2022:, Moore et al., 2012; Bell et al., 2022)

2.5.2 Survival – to what?

How is it possible to abstain from life support if there is 50% chance of survival at 23 weeks gestation, as seen in some studies? The short answer is that disability rate correlates with gestational age. The chance of survival without impairment if born alive, increased from 1.2% at 22 weeks to 52% at 26 weeks in the systematic review (table 3; Myrhaug et al., 2019).



GA, wk	Survival Without Any Impairment, % (95% CI)
22	1.2 (0.4–3.7)
23	4.5 (2.1–9.6)
24	9.3 (3.5–22.7)
25	40.6 (31.6–50.3)
26	52.6 (35.7–68.9)

Table 3. Chance of survival without any impairment for live-born infants (Myrhaug et al., 2019; reproduced with permission)

In the first national cohort from Norway (NEPS1), 75% of infants born at 23–25 weeks gestation who survived presented some disability at the age of 5 years, whereas this was found in 49% of those born at 26–27 weeks, and to a less severe degree (Leversen et al., 2012). At 11 years, and excluding those with intellectual disabilities, non-ambulatory cerebral palsy, blindness, and/or deafness, an increased risk of mental health problems and autism was found in the extremely premature cohort as compared with a reference group (Fevang et al., 2016). In the NEPS 2 study, more than half of the survivors experienced major neonatal morbidity (Stensvold et al., 2017).

Lundgren et al. (2022) found that the increased survival in Sweden lamentably did not show a concomitant reduction in neonatal morbidity. Thus, the absolute number of infants born before 24 weeks gestation who suffered from severe neonatal morbidity increased, and this may impact long-term outcomes. Long-term follow-up keeps showing high rates of both neurodevelopmental disorders (75%) and somatic diagnosis (88%) in children born before 24 weeks during 2007–2018 in Sweden, with high rates of both intellectual disability and autism spectrum disorders, and increasing with age (figure 3). Just over half received habilitation services (Morsing et al., 2022).

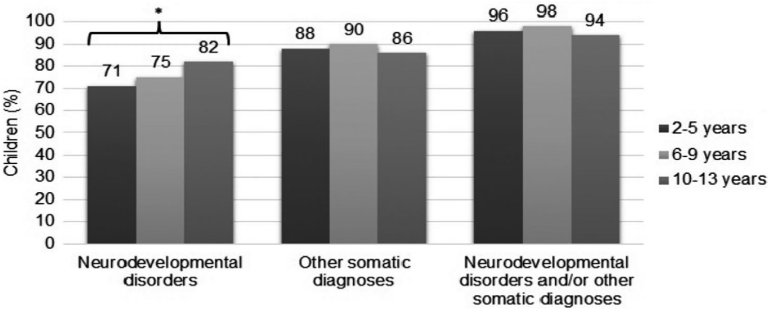


Figure 2. Percentage of Swedish children born before 24 weeks gestation with neurodevelopmental disorders, somatic diagnosis or combination of the two (Morsing et al., 2022; reproduced with permission).

Two prospective national cohort studies were conducted in the UK, including all infants born below 26 weeks gestation in 1995 and 2006 (EPICure and EPICure 2). Comparing outcome at 3 years for both cohorts, there was an increase in survival of babies admitted for neonatal care in the second period, from 39% in 1995 to 52% in 2006 (figure 4) (Moore et al., 2012). Survival without disability increased from 23% in 1995 to 34% in 2006, particularly for those born at gestational ages 24 and 25 weeks. At 11 years, no improvement in neurodevelopmental outcome was seen between the two cohorts (Marlow et al., 2020).

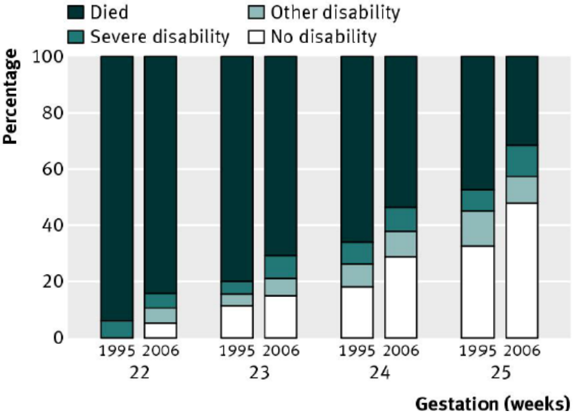


Figure 3. Changes in outcome for babies born at 22–25 weeks gestation or less in England in 1995 (EPICure) and 2006 (EPICure 2) cohorts (Moore et al., 2012, reproduced with permission).

Long-term follow-up shows that these effects persist, and may worsen over time. When survivors of the EPICure study were evaluated at 19 years of age, they found that the prevalence of intellectual impairment increased from 11 years into adulthood, and 60% had impairment in at least one neuro-psychological domain (O'Reilly et al., 2020). The proportion of participants with an intellectual impairment (IQ < 70) increased from 8% at 11 years to 15% at 19 years of age. It is noteworthy that in the follow-up of the EPICure cohort, the dropout rate was more than 50% at 19 years (study participants that declined to participate or did not show up for evaluation). Those who did not participate had lower mean IQ, higher disability score and came from lower socioeconomic backgrounds as recorded at 2.5, 6, and 11 years (O'Reilly et al., 2020). Evensen et al. (2022) have followed a cohort of infants born in Trondheim in 1986–88 with very low birth weight into adulthood (28 years). They found persistent influences on the brain, cognition, mental health, vision, pain, physical health, motor skills, general and social functioning, education and employment, as well as on health-related quality of life.

As a contrast to all the studies showing that ex-preemies have worse medical and mental health outcomes than their term-born peers, Saigal (2016) highlights that 'most studies suggest that a significant portion of former premature infants have made a reasonably successful transition into adulthood'. She sees the value of bringing in the perspectives of the former preemies, and their thoughts about their life and feelings for their future. She problematizes the use of 'quantitative approach', strongly held in neonatology and very useful for achieving better care through rigorous clinical trials, when looking at so-called 'quality of life' (QoL). As Wyatt wrote: 'QoL is not a biological variable in the same way as a serum sodium value, so it is logically incoherent to evaluate the unique and profoundly complex experience of an individual into a single score.' (Wyatt, 2005, as cited in Saigal, 2016, p. 580). She therefore argues in favour of qualitative studies and essays as a much richer and more candid source to relevant information. Regrettably, she states, 'some medical professionals continue to perceive these so-called 'soft' studies to be nebulous and unscientific'. In her book 'Preemie Voices' (2014), 41 adults who were born extremely premature between 1977 and 1982 in the US tell their stories, with their challenges and strengths. Some send a message to future parents: Elizabeth, who has cerebral palsy and learning difficulties writes, 'I urge you not to give up hope. Like me your baby is a fighter.' Jennifer writes, 'We learn to adapt to our issues, be it breathing, vision, motor skills, or other functions that most people take for granted. It is not as hard or depressing as some people think…so long as we have love from our families' (Saigal, 2016, p. 582).

Most of the adults participating in Saigal's book were born after 25–28 weeks gestation, not 22–24 weeks. They are survivors who master language, and who have the ability to take part in enjoyable activities. Norwegian nurse and bioethicist Berit Støre Brinchmann (1999) wrote a doctoral thesis on neonatal decision-making, where she interviewed both clinicians and parents who had experienced life and death decision-making in the NICU. As part of this work, she spent time with seven families who had been discharged home with their severely disabled child after months in the NICU. She found that they had an extremely tough life; some described their home as a prison. They described ambivalent feelings towards their children, at the same time love, but also hatred; happiness, but also pain and sadness. It is like 'living with a baby that never grows up' – a baby who just gets bigger, heavier and more difficult to handle, and to provide good care for (Brinchmann, 1999). As expressed by a mother:

> 'If only she could escape, if only we could escape. Why should I escape, I have given birth to her? She's my daughter. But at the same time I'm aware that if I have one more sleepless night, more sickness and washing to do, I just can't cope. It affects freedom and the like. We will never see her walk or go to school. There's a big sorrow inside us. It's there when we laugh and talk. It's there all the time, engraved independent of what's going on. The life of grief – or is it beyond grief? – that we live. (Brinchmann, 1999, p. 140).

At birth, there is a radical uncertainty of which of these realities the tiny, immature baby we have in front of us will meet, should he or she survive. Without life support, death is certain. What does life support entail at the border of viability?

2.5.3 Survival – at what cost?

The total burden of intensive care correlates strongly with immaturity, as seen with length of stay and the invasiveness of treatment. As an example, the median duration of mechanical ventilation in Sweden for a baby born at 22 weeks gestation was 54 days, as compared to 22 days for a baby born at 24 weeks, and 2 days or less for babies born between 25–31 weeks (Norman et al., 2022). Data from the Norwegian Neonatal Network show the same association: the surviving infant born at 22 weeks spent 45 days on the ventilator, as compared to an average of 10 days for those born at 26 weeks – if they were ever intubated (figure 4). An international study comparing days of hospitalization in different countries in the iNeo network (comprising 10 networks and NICUs from 11 high-resource countries from four continents), found that surviving babies born at 24 weeks stayed in the hospital for an average of 121 days, while the stay for a baby born at 26 weeks was 94 days (Seaton et al., 2021). Among the babies who died, the average stay was 7 and 9 days, respectively. In Sweden, the length of inpatient care for infants born at 22–23 weeks gestation during 2016–18 was more than five months (162–164 days), and mean age of discharge home was more than ten months (322–329 days), having a huge impact on family life (Lundgren et al., 2022).

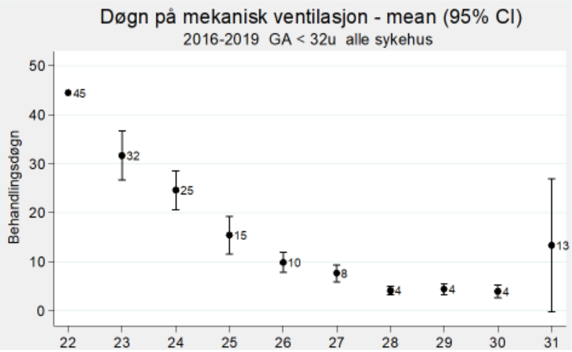


Figure 4. Days on mechanical ventilation in infants who survived to discharge by gestational age at birth 2016-2019 (Data from the Norwegian Neonatal Network).

As recent as 30 years ago, premature infants underwent major surgical procedures without analgesia during and after the operation – since they did not ‘tell’, they were thought not to feel pain. Research has shown that it is the other way around: painful stimuli reach the immature brain already by 20 to 24 weeks gestation, while regulatory mechanisms do not mature until beyond term, leaving the premature baby especially vulnerable to the damaging effects of pain (McPherson et al., 2020).

An infant on mechanical ventilation is exposed to many painful procedures every day. Cruz et al. (2016) performed a systematic review of painful procedures performed in neonates, and found that on an average, each neonate was exposed to 7.5-17.3 procedures per day during their first 14 days in a NICU. The most frequent procedures were heel lance, suctioning, venepuncture and insertion of peripheral venous catheter. Premature infants at the lowest gestational age, with very low birthweight and/or ventilation support experienced a higher number of painful procedures, and pain management was more inconsistent in these vulnerable neonates.

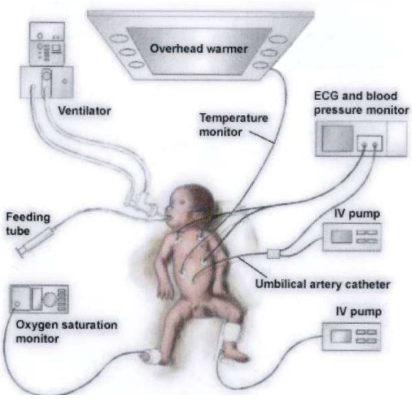


Figure 5. Standard intensive care for infants born at the border of viability (© 2019 Moore & Ding, The Ottawa Hospital modified with permission © 2011 Guillen & Kirpalani, reproduced with permission).

How can a premature infant cope with such a situation? Harris Williams tried to imagine how the premature baby lives this experience:

> The morning after the night when I was prematurely ejected from my mother's womb during a violent tempest . . . I awoke to find myself in many pieces, pinioned to the incubator floor, with my several senses separately trapped in distinct forms of torture: my eyes shut against the insufferable brightness, my mouth scorched by dryness, my skin scratched by roughness, the sensitive mucosae of my nose crudely pierced by foreign tubes . . . Only pain made any link between my senses so that I could recognise they were all functions of myself, me. (Williams, 1994, as cited in Green et al., 2016, p. 9).

Figure 6. Extremely premature baby born at 24 weeks gestation and receiving intensive care (© 2019 Moore & Ding, The Ottawa Hospital, reproduced with permission).

Nurses, in particular, have been drawing the attention to the burden of treatment since the early days of neonatology. They stand by the babies, and are those who inflict many of the prescribed procedures on the infants. Even as early as 1986, researchers reflected on the different roles of nurses and doctors, and how this affected their ways of relating to the baby:

> How often have I heard a neonatologist say, ‘I have to give this kid a chance to live. I have to give him an opportunity. The baby will decide for us’. A nurse, on the other hand, is more likely to say ‘I cannot stand to see this pain any longer. I cannot, in light of my own integrity, continue to inflict pain, and deny this baby the dignity of a human being in the process of dying’. (Gustaitis & Young, 1986, as cited in Green et al., 2016, p. 6).

At some point, the nurses find this difficult to bear. Green (2016) performed a study with questionnaires and semi-structured interviews of Australian nurses. One of the themes was ‘when caring and torturing become the same thing’. This is especially hard to accept when the perceived benefit of the care is dubious, as a nurse stated: ‘[The baby] should not be put through all the torture unless there is an absolute guarantee that they would be without. . . disabilities’ (Green et al., 2016, p. 6).

In addition to the badness of suffering in itself, it is also well documented that pain has adverse neurobiological impact on the premature brain, seen both on neuroimaging and neurobehavioral outcomes (McPherson et al., 2020). Pain management in neonates remains highly challenging, as pain medication may not always be effective and some have unacceptable side effects. There is wide variation in analgesia practices between NICUs and countries (Carbajal et al., 2015). A continuous effort is needed to limit painful procedures to a minimum, to support the infants and to provide evidence-based pain relief (Kristoffersen et al., 2019). Approaches like skin-to-skin contact and sucrose have shown positive effects (Johnston et al., 2017; Kristoffersen et al., 2018; Stevens et al., 2016). Strong collaboration between physicians, nurses and parents as active members of the team is needed to improve pain management (Balice-Bourgois et al., 2020).

Now we know a bit more about the possibility of survival, and what it entails for the infants and their families. However, the numbers and facts do not speak sufficiently clearly for themselves: different people have come to different conclusions to what one ought to do when a periviable baby is born. It does not make matters any easier that the prognosis for the individual infant is radically uncertain. The next step is to turn to medical ethics and see if we can find some clarification and guidance.

2.6 The role of ethical analysis in practical problems

The terms *morality* (from Latin: moralis) and *ethics* (from Greek: ethikos) are often used interchangeably to explain differences between right and wrong, good and bad/evil. Beauchamp and Childress refer to *morality* as the attitudes, values and norms about right and wrong, good and bad human conduct, which are so widely shared that they form a stable social compact (Beauchamp & Childress, 2013, p. 3). We learn about morality as we grow up, and continuously make instant moral assessments. Different groups and cultures develop specific moral codes and norms.

A central function of the critical discipline of ethics or moral philosophy is to investigate the underlying reasons or justifications for specific moral beliefs or moral codes. This is done through seeking *clarity* in the use of important terms, such as ‘quality of life’. Ethics requires *consistency* in the practical application of moral claims or values, and *coherence* in the defence of any moral framework, meaning that it must conform to other beliefs held to be true (Nuffield Council on Bioethics, 2006).

Developments in health sciences and biomedical technology have led to the development of specific ethical frameworks for biomedical ethics. The most influential is Beauchamp and Childress' 'Principles of Biomedical Ethics', published first in 1977, and developed successively into the 8th edition published in 2019. Much of the biomedical literature and frameworks for perinatal ethics are based on these principles. Beauchamp and Childress claim that their four clusters of moral principles, derived from common morality, form an especially suitable starting point as an analytical framework for biomedical ethics (Beauchamp & Childress, 2013, p.13):

(1) *Respect for autonomy*: a norm of respecting and supporting autonomous decisions

(2) *Nonmaleficence*: a norm of avoiding causation of harm

(3) *Beneficence*: a group of norms pertaining to relieving, lessening, or preventing harm and providing benefits and balancing benefits against risks and costs

(4) *Justice*: a group of norms for fairly distributing benefits, risks, and costs

In addition to the overarching principles, the framework encompasses several types of norms, including rules, rights and virtues. Most importantly, these principles, rules, obligations and rights are not rigid or absolute standards, but must be balanced and specified so that they can function in particular circumstances. Beauchamp and Childress accept the distinction between *prima facie* and *actual* obligations, as defined by W.D. Ross. A *prima facie* obligation must be fulfilled unless it conflicts with an equal or stronger obligation: 'the greatest balance' of right or wrong must be found in the particular situation. 'Agents can determine their *actual* obligations in such situations by examining the respective weights of competing prima facie obligations. What agents ought to do is, in the end, determined by what they ought to do all things considered' (Beauchamp & Childress, 2013, p. 15).

As the principles only provides a framework of norms, they need to be specified in order to achieve guidance that is more concrete. Specification is a process of reducing the indeterminacy of abstract norms and generating rules with action-guiding content, by 'spelling out where, when, why, how, by what means to whom, or by whom the action is to be done or avoided.

(Beauchamp & Childress, 2013, p. 17). For example, the norm that we are obligated to promote beneficence may not be very helpful without further specification in case of periviable birth, especially not for the neonatologist facing this situation at 2 am in the morning. Does beneficence point towards life support, as the only means to the goods of human life, or does it point towards allowing a good death?

To say that a problem or conflict is resolved or dissolved by specification is to say that norms have been made sufficiently determinate in content that, when cases fall under them, we know what ought to be done (Beauchamp & Childress, 2013, p. 19). Proposed specifications should be based on deliberative processes of reasoning. Beauchamp and Childress favour the model of ‘reflective equilibrium’, as proposed by Rawls, as a way of bringing principles, judgements and background theory into a state of equilibrium or harmony (Beauchamp & Childress, 2013, p. 404). The ‘considered judgements’ constitute the body of beliefs that are initially acceptable without argumentative support and come from all levels of moral thinking, ‘...from those about particular situations and intuitions through broad standards and first principles to formal and abstract conditions on moral conceptions’ (Rawls, 1971, as cited in Beauchamp & Childress, 2013, p. 405). Once a conflict is detected, the goal of reflective equilibrium is to match, prune and adjust the considered judgements, their specifications, and other beliefs to render them coherent. This pruning and adjusting of beliefs occur continually, as we cannot assume a completely and permanently stable equilibrium in our moral beliefs: finding out how to best live our lives and to support our fellow beings is a continuous work in progress. Which judgements and values should we take into consideration in the case of extremely premature birth?

2.7 Ethical considerations at the border of viability

Cavolo et al. (2020) conducted a systematic review of the argument-based literature on the ethics of resuscitation for extremely premature infants. They found that *best interest*, *autonomy*, *personhood* (*moral status)* and *justice* were the grounding concepts, and the arguments centred on in what cases life support for extremely premature infants was indicated, and who should make the decision. In the following, I will address some of the debate concerning these questions.

2.7.1 Best interest

The Norwegian guideline established that the primary concern in the decision of whether to provide life support at the border of viability was ‘the infant’s illness and life prospect’ (National Council, 2014). Since 1998, the principle of the child’s best interest has been strengthened in Norwegian law, as the UN Child convention was ratified in 2014. The Norwegian neonatologist Saugstad argues that this implies that ‘every newborn, regardless of gestational age, therefore has the right to be assessed beforehand in case a decision is made not to provide intensive care treatment’ (Saugstad & Stokkereit, 2016).

In the ethical concept of best interest, the principles of beneficence (clinicians’ obligation to pursue the infants’ good) and nonmaleficence (our obligation to avoid harm) are merged together. The goal is to choose the treatment option where benefits outweighs harms, in order to minimize both undertreatment and overtreatment of extremely premature infants (Leuthner, 2014).

Let us go back to our couple in the hospital, terrified with threatening premature birth at 21 weeks. Thanks to Google, they have immediate access to ‘miracle stories’: Lyla, born at 21 weeks gestation, weighing only 410 grams, is smiling to them from the website, looking like a healthy and happy four-year old girl (Pawlowski, 2017). However, despite anecdotally described survival at 21 weeks, the scientific consensus considers 22 weeks gestation as a more realistic limit of viability. As we expect the fetus at 21 weeks to be sentient, any pain caused by futile resuscitation would violate the principle of nonmaleficence. There is therefore general agreement that doctors will act unethically if they performe life support this early.

Five weeks later, at 26 weeks gestation, the situation is clearly different. Eight or nine out of ten premature infants born at this gestational age will survive, and the odds are on the infant’s side to survive without disability. The burden of treatment is not considered overwhelming; at birth, she will receive respiratory support through a nasal prong, be placed in an incubator and initially receive both intravenous and enteral nutrition. If things turn out well, she will soon be spending most of her day on her parents’ chest, receiving gentle care, her milk – and coffee! (caffeine mixture, to prevent breathing stops) through a nasogastric tube, becoming more mature and closer to a ‘normal baby’ as the weeks go by. We would expect her to have given her parents the ‘roller coaster’ feeling, scaring them with breathing stops, and they have learned that subtle signs can be warnings of potential life-threatening infections or other serious complications of prematurity. There are no guaranties, but still: the odds are on her side, and among neonatologists, there is likely to be universal agreement that life support at birth, given that the resources are available, is in her best interest.

In between those situations, at 23-24 weeks gestation, opinions may differ. The chance of survival is significantly lower; the road to get there is bumpier: numerous painful procedures are needed, complications both on short and long term are more likely, and the probability of eventually being able to live an independent life is lower. The moral intuitions of neonatologists are ambiguous: the outcome for the particular infant is genuinely uncertain. The stakes are high, not only for the infant, but also for the parents and siblings. The neonatologist's expressed, or internalised, opinions about the infant's best interest will depend on the weighting of the different stakes and values, and be shaped by both cultural and individual factors.

The best interest standard has been criticized for being both incoherent, unknowable, or overly individualistic (Leuthner, 2014). On the one hand, it is meant to be objective, and one is to ignore or negate all other interests except that of the infant's self-regarding interest. By doing this, it seems like we ought to hold parental and family interests up against the infant's interest, as if these were not interrelated. Following Beauchamp and Childress, a surrogate decision maker:

> ...must determine the highest probable net benefit among the available options, assigning different weights to interests the patient has in each option balanced against their inherent risks, burdens, or costs. The term *best* applies because of the surrogate's obligation to act beneficently by maximizing benefit through a comparative assessment that locates the highest probable net benefit. (Beauchamp & Childress, 2013, p. 228).

This claim seems highly demanding. On the other hand, if we allow parental and family interests and values to define the best interest, then we risk that it becomes too subjective. Kopelman (1997) has responded to this critique and argues that the best interest should be seen as a *standard of reasonableness*. She defends that the best interest standard, on the one hand, can be seen as 'an ideal to promote children's good or articulate our *prima facie* duties to them (..) Ideals can be like lighthouses when we are at sea, giving us perspectives and helping us steer our course' (Kopelman, 1997, p. 276–278). Seeing the infant's best interest as placing a *prima facie* duty on us means that even the best interest may yield to a more pressing duty. Other concerns, like what is possible, others' rights, needs and interests can affect what our actual duties are; we must weigh, balance or rank our conflicting *prima facie* duties; 'best interest' also becomes an *all-things-considered* obligation. In this way, the best interest standard becomes a standard of *reasonableness*, instructing us to choose wisely, and find the most acceptable of the available choices. Kopelman also claims that the best interest standard may serve as a threshold for intervention, to overrule parents. Here, she uses a two-step test: first, determine whether parents make acceptable decisions. If parents want to forego life support at 26–27 weeks gestation, we might find this non-acceptable and contrary to the best interest of the infant. Now, the second step, using the best interest standard as a standard of reasonableness, is to decide whether it is best for the child that we overrule the parents' decision: do we have the resources to provide good care to this infant, even if the parents no longer will take care of her?

When making treatment decisions for young children, she claims that 'decision-makers should have the best available information to assess [the infant's] immediate and long-term interests and set as their prima facie duty that option (or from among those options) that maximizes the infant's overall or long-term benefits and minimizes burdens. (...) Second, decision-makers should make choices [for the infant] that must at least meet a minimum threshold of acceptable care; what is at least good enough is usually judged in relation to what reasonable and informed persons of goodwill would regard as acceptable were they in that person's circumstances' (Kopelman, 2010, p. 26).

Two practical problems arise at the border of viability, (1) the opinions of well-informed and 'reasonable and informed persons of goodwill' differ, (2) There is no agreement on whether, or how much, the interests of others may weigh in when it comes to life and death decisions for infants. The first question has been 'solved' in bioethics by saying that when opinions among health care personnel vary, parents should be allowed to make the decision, referring to this as the 'zone of parental discretion' (Gillam et al., 2017). This was rejected in the Norwegian 1998 guideline, placing decision-making responsibility within the 'grey zone' on the physician. I will come back to this question in the next section.

Another issue is the delimitation of the 'grey zone'. Most guidelines, including the Norwegian, use gestational age-based thresholds. These have been criticized, both due to the uncertainty in the estimate of gestational age (+/- 7 days), and due to the ‘Cinderella-effect’, with a sudden change in approach at the stroke of midnight (Wilkinson et al., 2018). In addition, there has been an increasing focus on other factors that affect prognosis, like growth/weight, sex (girls do better), presence of infection and provision of antenatal steroids among others (Tyson et al., 2008). In recent years, prognosis-based guidelines have been published in both UK and Canada (Lemyre et al., 2016; Mactier et al., 2020).

The second question, regarding whose interests should count, is heatedly debated. Following up on the evidence of the importance of other prognostic factors than gestational age, Mercurio (2012) summarized the pressing ethical questions:

> As a result of the NICHD data, the conversation may eventually move from, ‘Below what gestational age is it acceptable not to resuscitate?’ to, ‘Below what chance of survival, or survival without severe disability, is it acceptable to resuscitate?’ The fundamental ethical questions, however, remains largely unchanged: Should parents and physicians consider the interests of the family, or should the decision be based solely on the interests of the child? How much choice should parents be given? At what point should physicians seek to overrule a parental decision? Should these questions be viewed differently for infants than for older children and adults? If so, what is the justification? (Mercurio, 2012, p. 849).

The Norwegian 1998 guideline stated that ‘consideration for the family must be given weight’. Inwald (2008) argues along this line in favour of taking into account the interests of others, particularly the interests of close family members when setting up a ‘best interest test’ for deciding whether to stop life support in a child. However, Norwegian lawyer Marianne Bahus argues together with bioethicist Reidun Førde:

> ‘In our opinion, parents’ and siblings’ personal preferences should not be taken into account in the consideration of the child’s best interests. Parents’ wishes are irrelevant. Emphasis on the child as an individual with his or her own preferences, interests and needs, establishes the basic fact that the final decision affects the child directly and at a different level from the one at which it affects parents and siblings. Parents and siblings may need social, practical or professional support as a consequence of the final decision, but their needs should not be included in the best interests test’ (Bahus & Førde, 2011, p. 543-44).

In this article, their primary concern is that doctors tend to comply with parents' requests for continued life support, even when doctors consider this to be against the child's best interest. Doctors should have the courage to seek legal support to withdraw life support against the parents' unreasonable wishes (Bahus & Førde, 2011).

One thing is our duty to stop 'futile' treatment, but are we allowed to withhold life support if parents see having this child as contrary to their interest, for instance to be able to fulfil their responsibility towards other children? Many authors argue in line with Inwald: 'complex situations sometimes occur in which the interests or parents, siblings, health professionals, and even society must also be considered' (Brudney & Lantos, 2014, p. S80). The Nuffield Council on Bioethics also recognized that 'Parents have interests and it is reasonable for these interests to be given some weight in any relevant deliberations about critical care decisions for a child who is, or who will become, severely ill' (Nuffield Council 2006, xvii, 10).

Groll (2014) sketched out four conceptual models for thinking about family interests. (1) The 'oxygen mask model', where family interests have instrumental value for the patient: parents must take care of themselves in order to be able to promote the child's best interest. With this in mind, we encourage parents to get sleep, go for walks and 'charge their batteries' during their stay in the NICU, for the best of their child. (2) The 'wide interest model' seen as a collapse of altruism and egoism. Ross draws the attention to how the well-being of family members is intertwined, and 'other-regarding activities become self-regarding activities, since part of my interests consist of my child doing well'; 'in doing well by my child I am doing well by myself'. (Ross, 1998, as cited in Groll, 2014 p. S83). Doing kangaroo-care, providing breast milk and supporting their infant during painful procedures can be seen from this perspective. (3) In the 'family interest' model, the family is seen as a unit; having corporate interests different from individual interests. Lindemann (2014) talks of the family as a 'nurturing and intrinsically valuable entity' that is not reducible to the interests and the contributions of its individual members. Paediatric illness may place strains on the family and can lead to decision-making that the patient-centered paradigm cannot accommodate: there can be a 'clash between healthcare ethics, which is patient-centered and individualistic, and the ethics of families, which is neither' (Lindemann, 2014, p. 102). From this perspective, it is thought-provoking that surveys among Norwegian pediatricians consider parents' ability to care as the least important consideration when making decisions about life support, with only cost ranging lower (Kvestad et al., 1999; Miljeteig et al., 2007). Finally, Groll argues for inviting parents to speak openly also within (4) the ‘direct model’, where each individual’s interests are allowed to be weighed directly, not as part of some other set of interests or as a part of a non-egoistic conception of interests. When it comes to how to weigh and balance in order to reach a conclusion, and whose interests should prevail, no simple equations can solve complex dilemmas. Groll points to a need to accept ambiguity. Where uncertainty is intrinsic, exact rules and systematicity may not be of much help. He suggests going back to Aristotle and practical wisdom: ‘for it is the mark of an educated person to look for precision in each kind of inquiry just to the extent that the nature of the subject allows it’ (Aristotle, as cited in Groll, 2014 p. S85).

Rhodes and Holzman (2014) challenge the *best interest* of the patient as a standard for surrogate decision-making, and promotes the *not unreasonable standard* for parental decisions: parental decisions should be respected unless they are deemed unreasonable. They claim that the best interest test is subjective, that it leads to intolerant and polarizing behaviour and that it is often vague and indeterminate. In addition to the failure to consider the interests of anyone but the patient, they point at the ease with which it can be massaged to induce a surrogate to accede to the health care team’s preferences. This is not very difficult to imagine. Norwegian neonatologist Trond Markestad also points at the fact that the decision is naturally made in the meeting between the parents and physicians, and holds that it should be made within borders that is accepted in the society (Markestad, 2022). He has hypothesized that the differences seen between Norwegian hospitals in the approach to life support to infants born at 23 weeks, may reflect that a choice is presented to parents as an ‘*opt-in’* or an ‘*opt-out’* opportunity, following the culture of each unit (or the individual doctor’s view). In some units, doctors tend to frame choices as: ‘we usually provide life support at 23 weeks gestation, but are willing to do otherwise if you insist’, in others as ‘we usually provide palliative care at 23 weeks gestation, but are willing to do otherwise if you strongly want us to’.

Leuthner (2014) points at the importance of how the best interest is determined. In the *expertise* model, doctors have a privileged position in determining the patient’s best interest, due to their medical knowledge and neutral emotional involvement that allow them to make ‘rational and objective' decisions. In his recommended *negotiated* model, parents and doctors work together to determine the infant's best interest and both can bring values into decision-making.

This leads us to the next concept: respect for autonomy. The infant is far from being autonomous, but many authors argue that parents are the legitimate surrogate decision-makers for extremely premature infants, and that within reasonable limits, parental autonomy should be respected (Lantos, 2018).

2.7.2 Parental autonomy

The emphasis on *autonomy* as opposed to medical paternalism started during the 1980s, as reflected in patient's rights movements and the change to informed consent standard from physician-based to patient-based. In the US, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recommended in 1982 that physicians should assess treatment options for seriously ill newborns as either *clearly beneficial* (agreement among clinicians that treatment provides net benefit), *futile* (no benefit) or *uncertain* (Sullivan & Cummings, 2020). When the benefit is considered uncertain, parents should be allowed to make decisions; whereas for treatment that is considered either clearly beneficial, or clearly harmful or futile, parents' wishes should be overridden. In this line, Mercurio and Cummings (2021) describe the dynamic *I-P-O spectrum* (figure 7). When we are faced with genuine uncertainty, or where reasonable people disagree on what to do, parents should be allowed to decide. Gillam et al. refer to this grey zone as the 'zone of parental discretion' (Gillam et al., 2017).

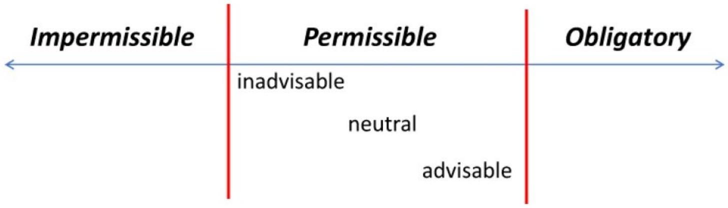


Figure 7. Ethical spectrum of treatment options: the I-P-O framework. In the zone of ethical permissibility, ethically permissible treatments range from inadvisable to neutral to advisable (Mercurio & Cummings, 2020, reproduced with permission).

In the ethical literature, many authors argue that parents are the legitimate surrogate decision-makers for the extremely premature infant and should be granted considerable autonomy (Cavolo et al., 2020). However, to make such decision, parents need to be 'truly autonomous': they need to have the ability to make decisions, to have a satisfactory understanding and to be free from conflicts of interests and controlling influences. Traditionally, there has been a focus on giving objective, complete and understandable information, explaining statistics of survival and disability and presenting available options. There are conflicting views of whether family outcomes should be presented as quality of life perspectives, or as suggested by Harrison, discussing the impact of a severely disabled child on the family (Cavolo et al., 2020). There is also a focus on value pluralism, and the need for physicians to be aware of their own values or 'biases'. The uncertainty of the outcome for each individual infant must be addressed. Over the last years, there has been a shift in the approach to decision-making. Previously, the doctor was expected to provide complete and objective information. Now, there is a call for *shared decision-making*, more focused on the process rather than the result, where doctors should help parents discern their own values and commitment, before making life-altering decisions (Lantos, 2018). In line with this, Leuthner's (2014) *negotiated model* received empirical support from research done in the UK. Marlow et al. (2020) analysed conversations between neonatologists and parents concerning limitation of life support for infants in the NICU, and found that 'making recommendations' or presenting a 'single-option choice' based on what the clinicians saw as the child's best interest led to misalignment and reduced opportunities for questions and collaboration. Providing options and allowing for shared discussion between clinicians and parents in order to achieve a shared conception led to an aligned approach, with fuller participation from parents in the decision-making process. I will come back to shared decision-making in the discussion.

There are considerable differences in European guidelines with respect to how parents are involved in life support decisions in extreme premature infants (Gallagher et al., 2014). A questionnaire study performed in 1996 as part of the EURONIC project, found that parents were not the ultimate decision-makers in life support decisions for periviable infants in any European country (De Leeuw et al., 2000, Cuttini et al., 1999). In some countries, like the UK, Germany and the Netherlands, answers pointed towards more explicit parental contribution to decision-making, while in France and Luxemburg, neonatologists stated that they alone made the decisions, but sounding out parental opinions and taking them into account.

Orfali (2004) compared the parental role in decision-making in France and the US by doing ethnographic fieldwork in a NICU in each country. Parental autonomy is the ethically and legally supported model in the US, while the French neonatologists defended medical paternalism. She concluded that parental involvement and the legal context played less role than the doctor's differential use of certainty and uncertainty in prognosis, and highlighted medical control over ethical dilemmas even in the context of autonomy. Whereas French doctors did not ask parents for permission to withdraw care, doctors in the US tended not to ask for permission to continue. As the worst risk in the eyes of the French neonatologist was letting a severely disabled child survive, they framed information in a paradigm of medical certainty. In the US, on the contrary, the worst risk was to withhold or withdraw life support from a child who could after all have a meaningful life, so they emphasized uncertainty. As a US neonatologist stated: 'It is harder to stop than continue and pretend we didn't know' (Orfali, 2004, p. 2020).

Numerous doctors and nurses may find the ultimate responsibility too great for families to carry, but several authors have found that many parents see such decision-making as a part of their parental responsibility (McHaffie et al., 2001; Moro et al., 2011; Sullivan et al., 2014). Icelandic parents of extremely premature infants claimed their right to participate in treatment decisions as 'emotional experts', but there was disagreement about parents' right to demand withdrawal of life support (Einarsdottir, 2009).

As part of her study on parental attitudes towards involvement in neonatal life and death decisions, Brinchmann interviewed 35 Norwegian parents who had experienced life and death decisions during their infant's NICU stay, focusing on postnatal decisions (Brinchmann et al., 2002).The majority were extremely premature infants who had developed postnatal complications, such as cerebral haemorrhage or infections. The parents expressed high levels of indecision and uncertainty, and thus felt ambivalence about participating in decision-making. Most parents would want their child to live 'no matter what', and would choose treatment at any cost, and feared that they would not be able to make the 'right' choice if they had been asked to participate. They highlighted the need for good information and communication through an individual approach, and the importance of being included. The authors concluded that parents agree that they should not have the final word in decisions concerning their infant's future life or death. Such a responsibility would put too heavy a burden on parents who lack the medical knowledge and the professional experience needed to make such a decision, and would likely lead to strong feelings of guilt. However, some of the parents pointed to the mother's right to decide before birth on equally serious and important choices, and highlighted that the parents are those who will live with the consequences of these choices. They know best what they will be able to cope with. After all, it is 'the parents' child', expressed as one of the themes in the study (Brinchmann et al., 2002).

The desire to protect Norwegian parents against the burden of decision-making was reiterated by neonatologist Ruud Hansen and Førde in 2016, who stated that many parents wish to be exempt from decisional responsibility in end-of-life decisions for their children (Hansen & Førde, 2016). Joolaei et al. (2017) interviewed neonatal nurses and doctors at one hospital in Norway and one in Sweden. Although the participants expressed that parents were much more included in decision-making in later years, many argued against parents making the decision – 'parents are at the mercy of our advice' (Joolaei et al., 2017, p. 10).

How does this resonate with the general trend towards increased patient autonomy, as reflected in the Norwegian Patients' Rights Act? Parents or other persons with parental responsibility are entitled to consent to health care for patients under 16 years of age, but with clear limitations: Parents cannot deny treatment which is clearly in the child's best interest, nor can they demand futile treatment. This is specified in a national guideline for decision-making when considering limitations of life-sustaining treatment (Norwegian Directorate of Health, 2013). The guideline states that parental values and opinions should play a larger role the more uncertain the medical professionals are on prognosis and on what is in the child's best interest. Still, it is unclear who has the final say in life support decisions. A close reading of the law suggests that parents, not doctors, are the legal decision-makers in cases where it is unclear whether life support or palliative care is in the best interest of the infant (Bahus, 2014, p. 130).

Norwegian professional guidelines have uniformly stated that in matters of life-and-death decisions the opinions of relatives must be heard, but the doctor is responsible for making the final decision – with one exception: infants born with the cardiac malformation called hypoplastic left heart syndrome (HLHS) (Vandvik & Førde, 2000). In Norway, this condition is known as ‘Lasse liten-syndromet’, after the first surviving Norwegian infant, Lasse, born in 1987 and flown to the US on day five of life for surgery (Petersen, 2021). Babies with this malformation die within few weeks after birth if left untreated. To survive, they will need several cardiac interventions or a heart transplant. Due to the burden of treatment and the high risk for death or disability, palliative care has been considered reasonable, and parents have been told that they must make the decision.

Vandvik & Førde (2000) performed an interview study of 20 mothers whose children were born with HLHS in the period 1990–96, 10 whose children survived the operations and 10 mothers who chose comfort care. They found that mothers who chose comfort care had more years of education, reported a ‘better childhood environment’ and had more often been employed in the healthcare services. Among the mothers that chose surgery, the main motive was that they perceived this as the only acceptable choice, while the motive for choosing comfort care in the other group was to prevent the child from suffering. In the latter, six women stated that parents should make this decision (despite being tough), while nine women who chose surgery stated either that ‘it was wrong or too painful to make such decision, or that the physicians should make the decision that all the HLHS children should have surgery’ (Vandvik & Førde 2000, p. 1131). Based on the interviews, the authors concluded that parents’ possibilities for making autonomous choices are limited due to lack of knowledge about long-term outcome, a state of shock and short time to deliberate. As autonomous decisions may be neither possible nor desirable for all parents, they propose the *care* perspective. This opens up for a focus on interconnectedness of needs, the role of emotions and social relationships, rather than individual rights and cost-benefit analysis. Clinicians willing to decide on behalf of the child should be guided by the parents’ preferences, resources and values (Vandvik & Førde, 2000).

Mercurio et al. (2008) have drawn attention to the fact that, although very different in nature and presentation, the medical prognosis regarding survival and neurodevelopmental outcome of an infant born with HLHS is quite similar to an infant born at 24 weeks gestation:

> Both diagnoses are fatal in the absence of aggressive medical intervention. Even with aggressive management, there is significant mortality associated with both of them. All survivors face a difficult and expensive hospital course. For each condition, there is significant morbidity, including neurologic morbidity, among many of the survivors. Finally, for both

diagnoses, some pediatricians have felt that aggressive medical or surgical care should be optional rather than obligatory, and parents should be given the option of providing palliative care (Mercurio et al., 2008, p. 186).

Even though the guidelines from the American Academy of Pediatrics recommends shared decision-making in the grey zone between 22^{+0} and 24^{+6} weeks gestation (Cummings et al., 2015), Mercurio et al. claimed that many neonatologists did not provide the option of palliative care at 24 weeks to parents. They argued that in order to respect the principle of justice, decision-making choices for parents should be similar, based on prognosis and burden of treatment, unless we identify a morally relevant difference between the groups.

What may count as a ‘morally relevant difference’? Within a utilitarian approach, the balance of harms and benefits would be relevant. If they are equal, then the thresholds for withholding treatment should also be the same - unless we consider them to be of different ‘worth’. Janvier et al. (2007) have argued that neonates in general, and premature babies in particular, are not treated according to the same criteria as other patients, and that they are subjected to systematic discrimination. They claim that this is due to the equivocal attribution of a lower ‘moral status’. What do we mean by moral status, and how does it affect the equation?

2.7.3 Moral status

Having moral status means that there are moral reasons or requirements, for one’s own sake, for how one is to be treated. In a weak sense, ‘moral status’ refers to a status or rank of moral importance, and in a strong sense, ‘moral status’ means to have *rights* (Beauchamp & Childress, 2013, p.62).

Who should be protected by moral norms, and given moral status? Vigorous debates are held on what status to give human eggs, fetuses, newborns and the mentally disabled amongst others. This has important implications for research, abortion rights and life support decisions. Many scholars believe that the issue of abortion depends on the clarification of the moral status of the fetus. Historically, some groups of human beings (slaves, women, racial groupings) and virtually all nonhuman animals have been treated as less than persons. Infanticide has been tolerated in many societies. Can moral theories help us find acceptable justifications for who we shall grant moral status, and will it help us ‘solve’ the issue of what we ‘owe’ to the extremely premature infant?

Full moral status, or personhood, provides the maximum level of protection and rights. All ‘paradigmatic humans’ are granted personhood: adults with relatively standard cognitive capacities for self-control, self-criticism, self-direction, and rational thought, and capable of moral thought and action (Warren, 1997). However, the grounds for this status are controversial, and this have direct implications for the moral status of fetuses and children. Multiple theories have been proposed. Some are based on properties: human properties/ specieship, cognitive capacities, and the potential to develop such properties; moral agency and sentience. Others are based on relationships: on the interest others with moral status take in them, or the relationships they have with them, or the capacity to be active participants in morally valuable relationships with others (Matthews & Mullin, 2023).

Beauchamp and Childress defend a multi-criteria account for moral status, based on a number of those different theories (Beauchamp & Childress, 2013, p.79). They accept that both being a human, having cognitive properties, moral agency and sentience are all sufficient criteria, but neither provides a necessary criterion which excludes all those who do not possess such trait. To harm a sentient being is to wrong them, and thus harm-causing actions are morally prohibited unless one has moral reasons sufficient to justify them. They reject that relationships per se affect moral status, as it does not address which kind of beings should have moral status. However, they acknowledge that certain relationships account for how one gains and loses specific rights or obligations.

So, what moral status should we ascribe to the fetus and to the premature neonate? An adult human being has developed gradually from the original embryo and passed phases as fetus, infant, child and adolescent before reaching adulthood. On the contrary, the assignment of human worth and rights is not gradual. There is no universal agreement on a milestone that confers particular levels of moral status. In relation to the moral permissibility of abortion, those who do not support full moral status from the moment of conception but oppose near-term abortions, need to find some morally relevant difference that arises somewhere in between. Watson (2018) describes different approaches to this question. There have been many attempts to link the attainment of a single-intrinsic property X (a biological feature like heartbeat, or lung development or brain development) to the condition that can be seen as being both necessary and sufficient for a fetus to achieve moral status that trumps the status of the woman carrying it (Watson, 2018, p. 146). The strength of single-intrinsic property theories is that they pin abortion limits to something tangible and secular. However, 'they are all vulnerable of 'scientism' critique: the fallacy of going from an 'is' to an 'ought', from scientific facts to moral values. Scientific inquiry supplies facts, whereas ethical inquiry is needed to supply meaning' (Watson, 2018, p. 145). (I will have a closer look at the is/ought and fact/value distinction in the methodology section). Still, some of these features have significant impact in both law and practice.

Viability, described as a realistic possibility of maintaining and nourishing a life outside the womb, is used in Norwegian law as the (near) absolute ban to abortion (Abortloven, 2021, § 2). However, viability is highly dependent on the available support at birth, and is therefore both unequal and constantly redefined by advancing technologies, which is problematic when used as a proxy for moral status.

The *emergence of consciousness* (around 23–25 weeks gestation) has been proposed as a promising candidate, as 'our accepted understandings of brain development appear more stable and less likely to change with time'. Supporters of the idea of fetal sentience as the criterion for personhood believe that 'this more scientific approach can be more easily accepted by all and truly provide a unified answer to the question of when one becomes a person.' (Dupont-Thibodeau & Janvier, 2016). Lagerkrantz claims that 'the capacity to be conscious can be regarded as the crucial sign of human life', and thus marks the point where fetus/infants should be 'shown the same respect as adult patients', and should have important implications for both abortions and obligatory provision of life support. (Lagerkrantz, 2014, p. 304).

Warren (1989) defends the moral significance of *birth*, as it marks the end of a unique relationship between the pregnant woman and the fetus, and the beginning of other relationships: the starting point of the infant's existence as a socially responsive member of a human community. Although sentient fetuses ought to be protected from harm, they do not yet have the cognitive capacities or the richly interactive social involvement typical of persons. She claims that 'there is room for only one person with full and equal rights inside a single human skin' (Warren, 1989, p. 63).

In the literature revised by Cavolo et al. (2020), most authors defended a drastic change of rights and obligations of stakeholders at birth. Only Rieder defended a gradual increase even after birth, and that NICU treatment could be compared to continuing the creative process, and thus involves creational rather than rescue ethics (Rieder, 2017). This is ethically relevant, as ‘saving reasons’ are symmetrical: benefits and harms are weighted equally, while ‘creative reasons’ are asymmetrical: the badness of future life counts against creating that life, whereas the goodness of a future life does not count in favour of creating that life (McMahan, 2009).

Tännsjö (2018) argues that moral theories can help us justify that the premature infant is morally exchangeable. Following *utilitarianism*, where we are all replaceable, *and moral rights theory*, where neonates are replaceable to the extent that they have not developed personhood, he sees the case for granting parents a veto right against life support for an infant with poor prognosis. It would be moral to allow, and even encourage parents to let go of their periviable infant and opt for a new pregnancy and, hopefully, have a healthy ‘replacement’ child.

Wilkinson (2011) defends permitting a slightly different threshold for allowing parents to choose to stop life support for a newborn, as compared with older children and adults. His ‘Threshold view’ is based on a well-being account, and since we cannot know what kind of life the infant will be facing, it may be worse to risk that an infant survives to a life not worth living, than to allow a newborn to die who would have a restricted life. The infant’s reduced awareness of his future, the great prognostic uncertainty and the long period before the extent of the infant’s impairment is known are reasons that can justify a slightly different threshold in the newborn. This may be especially relevant for those who, like the most immature infants, must face a heavy burden of treatment under the veil of uncertainty. It also allows for giving some weight to the interests of others, like parents and siblings.

Some authors inspired by virtue ethics, like Midgley and Hursthouse, argue that moral status accounts offer a superficially attractive but overly simplistic picture of how we ‘expand the circle of our concern’ – that such theories blind us to the range of features that are morally relevant in decision-making (Beauchamp & Childress, 2013, p. 90). Hursthouse (1991) provides a powerful critique of the scholarly debate on abortion, and claims that academic philosophers have entertained themselves with sophisticated debates on moral status, and missed out on the essential ‘familiar biological facts’. In their quest for a simple rule, the philosophical debate on abortion has lost touch with reality, where people live their lives as best they can, and where family relationships are among the deepest and strongest in our lives:

> The fact that the premature termination of a pregnancy is, in some sense, the cutting off of a new human life, and thereby, like the procreation of a new human life, connects with all our thoughts about human life and death, parenthood, and family relationships, must make it a serious matter. (..) Rather than solving the (unsolvable) metaphysical question of the fetus’ moral status, it is about having the right attitude: some abortions can be seen as ‘callous or light-minded’, while others might indicate and appropriate modesty or humility: it all depends on the circumstances of the situation (Hursthouse, 1991, p. 237,244).

Many accept that moral intuitions point towards a gradual increase in moral status during pregnancy; late abortions are generally seen as morally more problematic than early abortions, and the loss of a near-term fetus more tragic than a loss during the first weeks of pregnancy. From a virtue ethics perspective, this may indicate that stronger reasons are needed to morally justify abortion late in pregnancy. From a deontological or rights perspective, the quest for the ‘rights-giving property’ continues. However, considering all duties as *prima facie*, a so-called ‘fetal right to life’ may be overridden after due consideration of other duties, interests and rights. This is reflected in many laws, by permitting abortion throughout pregnancy if the woman’s life is threatened.

I am not convinced that the concept of moral status is of much help in the quest for good decisions when faced with periviable birth, or decisions to withhold or withdraw treatment in the NICU. Rather than being an issue of moral status, it is about taking into consideration what it actually entails, both for this particular infant and for his or her family. More or less moral status does not solve the issue of whether it will be best for the infant to die with dignity, or to go through burdensome treatment. Some authors argue that not providing the option of palliative care to the periviable infant is discriminatory, as an adult with such prognosis would be given the alternative to forego life support (Carter, 2022). A ‘sanctity of life’ doctrine does not necessarily point towards unconditional life support. Even the Catholic Church expresses that ‘the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome (...) The task of medicine is to care even when it cannot cure' (Ethical and Religious Directives for Catholic Health Care Services, as cited in Pierucci, 2019, p. 173). Trying to convince parents that they should let go of their infant because it has less 'worth' will probably be experienced as reckless and uncaring, paving the way for conflicts. Decisions of starting, withholding and withdrawing life support are better framed as acts of respect, and love, towards the infant, whose life is intertwined with those of his or her parents and siblings. Fetuses and infants should be cared for and treated respectfully. Their particular situation is different from that of an older child with established relationships, and this may justify a different approach, especially when facing a heavy burden of treatment with prognostic and moral uncertainty. In my opinion, life support should not compromise the dignity of the infant, and family interests deserves to be considered.

2.7.4 The vitality criterion

The Norwegian guideline stated that the individual assessment at birth for infants born between 23^{+0} and 24^{+6} weeks gestation was not solely dependent on the doctor's individual judgement which includes prognostic facts and taking into account parental views, but added one more: the child's *vitality.* Brinchmann (2000) found that the infant's 'spirit and vitality' was used as criteria in the NICU when clinicians assessed whether or not to discontinue life support. Staff often referred to some of the infants as being 'full of life', 'showing that they could make it'.

However, clinical assessment in the delivery room is not a good predictor of survival in extremely premature babies (Manley et al., 2010). Recent guidelines therefore suggest that when a prenatal decision is made, it should not be overturned by the infant's initial vitality (Mactier et al., 2020). When palliative care is chosen, parents should be made aware that the infant may show signs of life, by heartbeat, crying and moving. When a decision in favour of life support has been made, lack of 'vitality' at birth should not limit initial efforts. However, if the infant's heart rate does not respond to effective ventilation in few minutes, the prognosis worsens significantly (Haines et al., 2016).

Vitality, although subjective and not 'statistically significant' as a prognostic marker, might be seen as the infant's own will to fight and to reach out for support. Should we take this into the 'moral equation'? In practice, it is much easier to provide palliative care to a non-breathing, flaccid infant, than it is to withhold life support to a baby who is crying and radiating vitality. In the same sense, it is harder to stop life support once the baby is stabilised in the NICU, and relationships are strengthened. Are these perceived differences of moral significance, or are they simply psychological difficulties that we must combat?

2.7.5 The ethics of withholding and withdrawing

Withdrawing (stopping) life support is often perceived as psychologically more difficult than withholding (not starting) life support at birth, for both parents and clinicians (Leuthner, 2014). However, the Nuffield Council stated that:

> (...) there are no good reasons to draw a moral distinction between withholding or withdrawing treatment, provided these actions are motivated in each case by an assessment of the best interests of the baby. Either would be an acceptable course of action depending on the circumstances of each case (Nuffield council, 2006, xvii, 11).

This is also stated in the Norwegian national guideline for decision-making when considering limitations of life-sustaining treatment (Norwegian Directorate of Health, 2013). The so-called *equivalence thesis* claims that although to stop life support may feel differently than not starting, there is no morally relevant difference (Wilkinson & Savulesco, 2014). Others have argued that there are crucial differences between withholding and withdrawing, in terms of autonomy, responsibility, and the status of the treatment (Ursin, 2019). This is discussed further in paper 3 and in the response to peer comments, see appendix.

Internationally, there is huge variation in resistance against stopping life support (Helenius et al, 2019). There is little published data about how such processes are carried out in Norway. A retrospective study of all infants who died in the NICU in Trondheim in the period 1990–99, found that in most infants (65%), death was preceded by a decision to withdraw (Syvertsen & Bratlid, 2004). This was the case in 83/113 (74%) of the premature infants who died, while 23/113 (20%) died despite maximum therapeutic effort. The authors stated that parents were involved and agreed with the decisions in the vast majority of cases, although little is known of their role in the decision-making process. Hagen and Hansen (2004) found that at Rikshospitalet in Oslo, the proportion of deaths following a decision to withdraw life support rose from 23% in 1987–88 to 64% in 1997–98. The study did not identify the final decision-maker, but the authors stated that the prevailing attitude was that the attending physician carried the final responsibility. The parents were asked to 'give their opinion about the physician's decision to withhold or withdraw life support for their infant'. A questionnaire study of Norwegian pediatricians found that the most relevant considerations for withdrawing life support in extremely premature infants were, ranked in decreasing order; risk of severe disabilities and future quality of life, followed by risk of suffering for the child and parents' attitudes towards treatment (Miljeteig et al., 2007).

2.7.6 Distributive justice: Economic and societal cost

Neonatal intensive care, like most modern health care, carries significant economic costs. However, even at low gestational age, it is often regarded as more cost-effective than intensive care for older patients, as survivors live a long time after discharge, spreading high initial costs out over a lifetime (Hayden & Wilkinson, 2017). The 1998 Norwegian guideline stated that the primary consideration was the infant's prognosis, and that family interests should be given some weight, whereas societal concerns could not be given weight in a particular case. There is much to discuss regarding distributive justice in neonatology on a global level, as done by Ingrid Miljeteig in her doctoral thesis looking at bedside rationing in an Indian NICU (Miljeteig et al., 2010). I will not go into that discussion, although I want to emphasise that I find it much needed and highly relevant.

However, survival is one thing, flourishing is another. What responsibility does society have to promote well-being in those who face various challenges – should not the state provide optimum support from 'incubator to grave'? Caring for a severely disabled child can involve complex medical care 24/7 in their home, placing a huge burden on the family. Thanks to a strong welfare state, Norwegian families receive economic support, home care and special education. However, as these resources are limited also in Norway, it is difficult to provide an optimum level of support for surviving infants and their families during childhood. In a recent newspaper column titled 'The child wave that nobody talks about', representatives from the organization 'Løvemammaene' ('*Lionmothers*'), claimed that 'If the state is not prepared to look after and treat children with illness and functional variation in an equal and dignified way, then they must stop rescuing them' (Lindgren & Ramberg, 2023). Saugstad has used his voice in Norwegian public debate to favour life support for infants born at 22 weeks (or any gestational age), comparing our duty to rescue these infants with the one we face confronted with a 50-year old with cardiac arrest, or a child with cancer (Jahren, 2014). However, he is also concerned about the perceived lack of support to families:

> I experience being called by desperate parents who live in municipalities that do not take responsibility for following up on their children. Then I can feel co-responsible. If we are actually going to treat extremely premature children, which I have advocated, both the children and their parents must get the help and support they need from the municipality for as long as there is a need (Aarli-Grøndalen, 2018).

2.8 How to make sense of different approaches

I have now presented different ways of approaching life and death decisions at the border of viability, or perhaps better expressed as the 'margins of neonatal survival and good health' (Kaempf et al, 2018). The scientific data are universally available, and the ethical debate takes place internationally. Still, strategies and public discussions vary between different countries, even those sharing similar values and political systems, like the Scandinavian countries. How can we make sense of this?

One way would be pointing at differences in moral reasoning, as done by my supervisor Lars Ursin (2018). In Sweden, appeal to moral foundations, either as universal rights, or as a utilitarian calculus, might facilitate a sound, unchanging set of moral principles. This can be used to tell right from wrong in every situation, and thus turning guidelines into powerful tools. The Norwegian focus on the 'best interest' of the infant tend to inherit the vagueness and ambivalence of the concept, facilitating inconsistent practice. In Denmark, the focus on the misery and hardship on both child and family leads to an ethics of responsibility. This traduces into a culture where the family is seen as the core unit, and parents are supported both as decision-makers and recipients of care.

Another way can be looking at cultural differences, as done by my co-supervisor Berge Solberg (2018). He argues that rather than being the result of individual disagreement due to different ethical reasoning among leading doctors in the three Scandinavian countries, the differences between the countries may have a cultural explanation. By shifting focus from premature infants to the practice of prenatal diagnosis, which involves a larger number of people and is more well known in the public discourse, he is able to come up with a tentative cultural explanation. From the public discourse on prenatal diagnosis, what shines through in Denmark is the 'paradigm of choice': women should be granted vast autonomy in prenatal choices, as universal access to screening of Down syndrome. In Norway, the discourse of prenatal diagnosis was a 'battlefield'. Many saw screening for Down syndrome as an abuse that would lead to a 'sorting society', and warned against ending up with 'Danish conditions'. In Sweden, the ethical dimensions of prenatal diagnostic were downplayed, placing practical reasons and scientific facts in the foreground. Solberg sees a resonance with the particular cultural characteristics of the three countries: whereas freedom and liberalism are highly valued in Denmark, consensus and politeness are important Swedish values. A plea for scientific facts, rather than an ethical debate therefore work well for the Swedes. In Norway, independence, individualism and opposition play a more prominent role, paving the way for the tolerance of heated debate and certain variations in practice.

In the same landscape of cultural and legal comparison, Verhagen (2018) compared the policies at the border of viability between the Scandinavian countries and the Netherlands, and identified three topics related to decision-making at the beginning and at the end of life. (1) In the Netherlands, there has been a consistent, conservative approach against life support at early gestational ages, informed by public debate and discussions among professionals. (2) There is also a consistent, high rate of deaths in the NICU following withholding or withdrawal of treatment (93-98 %), accompanied by universal involvement of parents in the decisions, without seeing much conflict. (3) Dutch neonatologists have a legal possibility of deliberate ending of life in a newborn with hopeless and unbearable suffering, through the nationwide adoption of the Groningen Protocol in 2005. This is justified by the principle of 'beneficence, parental determination, responsibility, and compassion or care', and points towards the recognition of quality of life and quality of dying as leading goals of care in Dutch NICUs. Looking at general cultural traits that can explain such remarkably different approach, Verhagen points at a history of tolerance and a culture of making taboo subjects discussable and preferring transparency over secrecy. *Accountability* is another central value (a 'Calvinistic' duty): if it becomes clear that the outcome of NICU treatments might involve a damaged quality of life (suffering), not only withdrawal but also *continuation* of life support demands justification. Verhagen sums up:

> We were taught that neonatologists carry the full responsibility for the suffering of patients and families if the outcome of NICU treatment is poor. And so, this is what many of us teach our residents today. The strong focus on responsibility might explain, at least partly, why Dutch neonatologists have remained rather conservative in their approach with regard to the active treatment of infants who are at the limits of viability (Verhagen 2018, p. s588).

3 Aims

The main goal of this project was to provide insight into and clarify the ethical premises surrounding life and death decisions at the border of viability in our setting, and thereby contribute to better decision-making. We aimed for a rich understanding of the phenomena, searching to challenge both theoretical assumptions and our own preconceived ideas, in order to promote fresh ethical thoughts on the following topics and hypothesis:

Life support decision-making at the border of viability: how, and by whom?

1. Should we enable parents to make the final decision?
2. What is the best way to provide support to the involved persons?
3. The ‘child’s best interest’ at the border of viability and relation to other’s interests
4. Implications of moral status and the notion of gradualism

We chose to approach these questions through two working hypotheses:

1- *Parental authority/ responsibility*: It is ethically sound for parents to make the decision on whether to provide palliative care or life support within an established grey zone.

2- *Gradualism*: The moral status of the fetus is not the same as the born child’s, and the premature infant has not the same status as a term baby.

Based on information provided by the interviewees, we decided to include decision-making when faced with a dying, viable fetus.

4 Method and methodological discussion

One thing is a chart to understand

Navigating a ship is something else

From a book on politics one may learn to reason

To rule a country, however,

More is required.

Ludvig Holberg (2004) *The Political Tinker*

(In Brinkmann & Kvale 2018, p. 160)

In the preparative phase of this project, we put forward the following working hypothesis: *It is ethically sound for parents to make the decision on whether to provide palliative care or to make a treatment trial within an established grey zone*. Several considerations led us to this hypothesis. Decision-making in the grey zone involves more than medical knowledge. Having a child is the decision of the parents, and it seems fair that their interests should prevail over any non-medical interests of clinicians. The parents are the authority in promoting the interests of the child, and in protecting the child from conflicting interest. Having a child is essentially to create a family, and the parents will live with the long-term consequences of the decision. They can consider the effect on the life of siblings and their own willingness to commit to the burden of care. Our impression is that this is also the prevailing view in the bioethical literature. Following the principles of biomedical ethics, when the child's best interest is inconclusive, what remains is 'respect for parental autonomy'.

But is it ***feasible*** for parents to make such a decision? As a neonatologist, I struggle with this question. In my encounters with pregnant women and their partners facing this tragic situation, it feels better to adopt a caring attitude, assuring them that we know what is best, and that we will treat their baby accordingly. Exposing them to (our) doubts about whether it is best for their baby to die or to start life support will in most cases increase the emotional distress. Asking parents whether they want life support to be started will in many cases be answered with 'yes, of course', leaving open the question if they have a 'reasonable' understanding of what that implies, even if information is given. On the one hand, we risk causing harm to the parents, rather than showing 'respect for autonomy'. In my impression, the attitude in the Norwegian perinatal milieu is that parents should be protected against the burden of the decision, more out of psychological concerns than from a sound ethical foundation.

The question of feasibility is relevant to applied ethics. It was also recognized by Kant, and the claim that 'ought-implies-can' (referred to as Kant's law), refers to that our moral obligations are limited by what we are able to do (Spielthenner, 2017). In modern times, Flanagan made a call for psychological realism: 'Make sure that when constructing a moral theory or projecting a moral idea that the character, decision processing, and behaviour prescribed are possible, or are perceived to be possible, for creatures like us.' (Flanagan, 1991, as quoted in Molevijk & Widdershoven, 2012, p. 449). With an aim of improving clinical practice, we must be aware of what make beings like us change behaviour. Rational reasoning and bioethical principles might fall short: it rather seems to primarily be an experiential and context bound process (Molewijk & Widdershoven, 2012, p. 449). Exploring the feasibility of parental autonomy in our context is therefore essential to our project.

Showing the normative aspects of science, technology or organisation is important here, and Førde makes a strong call for paying more attention to organisational issues. How healthcare services are organized may influence the quality of health care and the possibility to comply with societal ideals much more than ethical guidelines (Førde, 2012). Agledahl et al. (2011) found that medical decisions are taken within a complicated medical system, where the health care is a product of multiple decisions done by different people, making it difficult to comply with the principle of showing respect for the patient's autonomy. The focus on the value of autonomy as showing respect thereby risks deceiving both clinicians and patients. Simply eliciting a life-altering, high-stakes choice of whether to provide life support to one's child without assuring that the conditions for autonomy are in place might be cruel, making both parents, physicians and the child worse off. What does it mean for parents to be 'truly' autonomous in such decision? To get a better grip on the desirability, or even the possibility of promoting parental autonomy in our context, we saw a need for empirical input.

4.1 Integrated empirical ethics and thick descriptions

Empirical data has been used in normative ethics for several reasons; it may help to better inform normative conclusions, by describing facts relevant to normative arguments, and testing whether norms are followed. Careful descriptions of cases may serve as springboard for substantial normative discussions, and ethics can benefit from 'thick descriptions' provided by narrative and care-based approaches, where interpersonal dynamics and emotions are shown (Sugarman & Sulmasy, p. 11).

The interest in bringing empirical insight into ethical analysis has steadily grown over the last decades, in part as a response to social science critique of philosophical bioethics and its need to become more contextually aware and more grounded in the realities of lived experience (Davies & Dunn, 2015). Førde (2012) claims that since medial practice has become extremely potent, complicated and invasive, there is a need for increased awareness about the importance of value issues for good choices, good interventions, and good communication with patients or next of kin. However, clinicians often regard ethicists as 'people who don't know anything about the real world, who don't care that they know so little, who produces literature that is difficult to relate to and understand, and whose advices are of little use in clinical practice' (Førde, 2012, p. 518). She calls for 'empirical ethics' as a bridge between ethics and medical practice, a bridge necessary to improve clinical practice. Musschenga has in the same vein argued for the need for improved context-sensitivity of ethics: 'if ethics indeed intends not only to prescribe actions, but also to actually guide actions, a turn to empirical ethics is inevitable (Musschenga, 2005, p. 486).

Molewijk et al. (2004) argues in favour of what they call 'integrated empirical ethics': close, even intense, collaboration between ethicists and those performing the empirical study, traditionally done by social scientists. Here, moral theory and empirical data are integrated in order to ‘reach a normative conclusion with respect to a specific moral practice’ (Molewijk et al., 2004). In our case, the moral practice is how to approach decision-making when faced with periviable birth or threatening fetal demise. A ‘prescriptive conclusion’ means stating what ought to be done: making moral recommendations, for instance in form of guidelines or rules aiming to improve practice, or even proposing changes to a normative theory (Huxtable & Ives, 2019). While some argue in favour of ‘strong cooperation’ where ethicists themselves get involved in collecting empirical data, with truly interdisciplinary and not simply multidisciplinary work (‘to better understand each other’s techniques and pitfalls’), others argue in favour of showing ‘respect for autonomy and boundaries’ of different disciplines (Molewijk et al., 2004; Sugarman & Sulmasy, 2010).

The term ‘empirical ethics’ is used to describe a broad range of studies that combine empirical research and moral reasoning. While the value of integrating empirical insight into applied ethics seems to be uncontroversial, there has been an ongoing debate on what should count as empirical ethics, and what standards empirical ethics research should meet (Ives et al., 2018; Carter, 2018; Cribb, 2018; Dunn et al., 2018). Traditionally, ethicists focus on what ought to be done (the normative), while social science has focused on describing phenomena. How to mix those two disciplines in an activity that cannot be characterized as either wholly normative or wholly descriptive has caused much discussion. Aiming to improve quality standards and transparency, a European consensus document was published in 2018, stating that empirical ethics should address a normative issue, ‘combining empirical methods with explicit and robust ethical arguments’ (Ives et al., 2018). Others are less strict on placing the boundaries, and include studies that describes and analyses actual conducts, moral opinions, facts relevant to normative arguments and identification of moral issues that have escaped the attention of ethicists and in general aspects that enhances the context-sensitivity, making ethical norms more realistic (deVries & Gordijn, 2009; Førde, 2012).

Although social scientists are those who traditionally have performed qualitative research, this method has also become popular among health care personnel. General practitioner Kirsti Malterud (2001, 2022) has been a key figure in promoting qualitative medical research in Norway. She urges physicians to make use of our position of knowing, close to the experiences of individuals patients and everyday context, and enter into the field of qualitative research as a way of searching for meaningful answers. A basic understanding of the theoretical backdrop is needed, although the aim is not ‘to convert into (substandard) social scientists or philosophers’ (Malterud, 2016, p. 121). Our unique point of departure for knowledge development can make an important difference for both patients and clinicians and improve practice (Malterud, 2022).

One of the central challenges for empirical ethics centres on *ontological* and *epistemological* questions connected to the fact-value distinction, and how an empirical ‘is’ can inform a normative ‘ought’ claim. These concepts are essential both for empirical ethics and as a theoretical background for qualitative research in general (Malterud, 2016; Braun & Clarke, 2022; Ives et al., 2018). I will first go into the ‘meta-ethical fallacies’, before digging a bit deeper into onto-epistemological theory relevant for our research.

4.2 Meta-ethical challenges: the is/ought, fact/value, and the naturalistic fallacy

In the field of ethics, *moral ontology* studies the nature and substance of morality: are moral values objectively real and independent of the person making the judgement? *Moral epistemology* studies the nature of moral knowledge and how we can obtain knowledge about what is right and wrong (i.e. through reasons or intuitions) (Ives et al., 2018). The views one has on these questions lead to different *metaethical positions* (sets of beliefs about the nature of moral claims and how one can have knowledge about right or wrong).

Depending on the metaethical position, there can be different views on important issues, and this can easily lead to conflicts about the validity of different claims. In empirical ethics, there are (at least) four traditional distinctions at stake: (1) theory and practice, (2) fact and value, (3) expert ethics and lay knowledge and (4) descriptive activities and normative analysis (Molewijk & Widdershoven, 2012). While some deny a fundamental distinction between descriptive and normative discourse, others see a clear distinction, imposing barriers to the use of empirical data in normative ethics in order not to violate ‘Hume’s thesis’: *No-Ought-From-Is* (Spielthenner, 2017).

Coming from the world of medicine, my impression is that this is not a notion that we are used to problematise. The goals of day-to-day medicine are usually framed as saving lives and curing illness. Showing for instance that certain drug or procedure has a significant positive life-prolonging or curative effect, is easily considered a self-evident proof of what ought to be done. The burden of proof belongs to those who claim that this *ought* do not derive from the scientifically proved *is* (i.e. too expensive, burden outweighs the benefit, the patient refuses it: *are we sure that he is aware of his own interests, and can we trust him to make such decision?*). Following this logic, the solution to the dilemma at the border of viability has been looked for in more and better statistics: if we just manage to get all the 'is's', then the 'ought's' will follow. Forcing us to clarify the status of the premises is therefore a useful philosophical exercise in medicine (what do we consider as *goods* in this specific situation?). I will therefore go into this in some depth.

Spielthenner (2017) claims that there are many modes of ethical reasoning that allow for substantial use of empirical data, and sees Hume's thesis as an important tool for clarifying ethical reasoning in normative ethics, rather than being a barrier. Although sometimes confused with the is/ought distinction, he claims that the *fact-value distinction* represents a broad issue of how the factual is related to the evaluative, which depends on one's meta-ethical position (more about this in the following sections). On the contrary, the is/ought distinction is a logical statement, which only implies that *purely normative* conclusions cannot follow from *purely descriptive* sentences, and this may help us to be clearer on the premises. Spielthenner cites some examples that are relevant to this project.

First, as an example of straightforward use of empirical data – can empirical research be used in generating ethical principles? Kon (2009) found that patients commonly want others to share in the burdens of decision-making. Adding this to the normative principle that medical decisions should be made in a way that respects patients' preferences, a subordinate principle come up: patients who do not want to make decisions alone should not be abandoned to their own autonomy. Second, moral reasoning that seems to breach Hume's rule can rather be examples of 'elliptical reasoning' (incomplete reasoning) or 'hybrid reasoning' (statements which are both descriptive and normative). In everyday conversation, such shortcuts in moral reasoning are used more often than complete reasoning, taking some background moral assumptions for granted (Spielthenner, 2017). An example is found in McHaffie et al.'s study on the role of parental autonomy in life support decisions for neonates. They stated: 'the majority of parents want to be included in decision making about treatment limitation, and they appear to have the capacity to take on the role of final arbiters without adverse sequelae' (McHaffie et al., 2001 p. 108). The following conclusion was that parents ought to be given the opportunity to make the decision, which could be seen as a fallacious is/ought reasoning. However, it might be more plausible to think that the authors assumed the normative rule that parents who want to be included in life and death decisions for their infants and have the capacity to do so should be allowed to be included; *respect for parental autonomy* is the implicit normative premise. Premises can also be evaluative: 'parents should not be allowed to visit their hospitalized children because the children get upset'. To escape from the is/ought fallacy, we must assume that to get upset is (sufficiently) bad to deny parents and children of being together – and for some decades, this was considered a valid statement.

These two examples of elliptical reasoning show how Hume's thesis can promote laying bare what is tacitly assumed, and enable a debate on the soundness of the now explicit premises (i.e. should parents have a say in withholding life support at birth?). Examples of hybrid reasoning are 'drawing multiple blood tests causes anaemia and should therefore be avoided when we can', 'limiting parental visits to the hospital causes stress, and should therefore be avoided'. Reason-giving is normative and hence, there is no gap to be bridged between the empirical and normative (we take for granted the badness of anaemia and stress). However, the burden of proof lays on the author, to show that at least one of the premises is hybrid and making explicit the normative content, so that it can be subjected to critical scrutiny (Spielthenner, 2017).

The *naturalistic fallacy* is also related to and sometimes confused with the is/ought problem. In G.E. Moore´s view, normative notions like 'good' or 'right' are not definable in terms of descriptive notions, and if you do so, you will be committing the naturalistic fallacy (Spielthenner 2017). According to Moore, 'good' cannot by defined as 'desired' or 'pleasure' or 'loved by God', nor 'right' as 'approved by community' (Moore, 1903). Moore argues that if one defines good as pleasant, then the question 'This object is pleasant, but is it also good?' would not be open, where in fact it is. Most philosophers reject both Moore's view of good as a non-natural property and the soundness of the open-question argument, but many still maintain that it is a fallacy to identify the moral predicate *good* with natural (or metaphysical) predicates (de Vries, & Gordijn, 2009). In our project, we are not trying to define good *as such* (which would be committing the naturalistic fallacy), but we are searching for criteria that can be considered to point towards what a good decision or decision-making process may look like. We then ought to explain how we define good in this context. Some alternatives could be 'what produces less harm', taking into account both emotional stress and decisional regret, or 'what shows respect for life, or respect for autonomy', or 'what leads to highest level of human flourishing', or a pragmatic combination of different alternatives that is considered to work well in a given context.

The challenges to integrate the empirical and the normative in empirical ethics have resulted in numerous attempts to provide bridging methodology, to stay clear of the 'is/ought', 'fact/value' and 'naturalistic' fallacies. A systematic review of ethics publications which used empirical research to answer normative questions identified 33 publications, and *32* distinct different methodologies that somehow tried to 'integrate' the empirical and the normative (Davies et al., 2015). Wangmo and Provoost (2017) surveyed more than 200 bioethics researchers and found that the most used bridging methodologies were (wide) reflective equilibrium and reflective balancing. Interestingly, many respondents reported the use of methods that are not designed for carrying out the integration of the normative and the empirical. When empirical ethics is used to develop moral theories and principles there are especially strong reasons to critically reflect, and to seek firm ground to integrate the normative and the empirical (Mihailov et al., 2022).

Many of my colleagues combine medical practice with research, and traditionally, medical research has been synonymous with *quantitative methods*, featuring analysis by statistical calculations and objectivity, standardization, and generalization as research criteria (Malterud, 2022). However, 'not everything that can be counted counts and not everything that counts can be counted' (Cameron, 1963, p. 13). We considered that the relevant empirical input for our study required interactive dialogue within a research setting, and for me this meant that I needed to enter into the world of qualitative research. Within qualitative research, there is a call to be conscious about meta-theoretical positions and the implications for the approach to research in general, and specifically, how this ought to affect choices of methodology (Braun & Clarke, 2022; Malterud, 2016). During the project, I have come to realise how strong grip the positivist paradigm has on the medical discourse and how it affects what is considered to be valid knowledge and valid representations of the world. I will therefore embark on another theoretical overview before I enter into our study.

4.3 From (post)positivism to ‘entangled ethico-onto-epistemology’

4.3.1 The relevance of ontology and epistemology in qualitative research

Broadly speaking, ontological questions concern the nature of substance and reality: what exists/ is real. Epistemological questions relate to knowledge: what it is possible to know, and meaningful ways of knowing (Braun & Clarke, 2022, p. 166). Major assumptions on worldview and knowledge can work together as unitary packages of ontology and epistemology (‘O&E’), which Kuhn named *paradigms (*Kuhn et al., 1962). Within a *positivist paradigm*, knowledge is objective and empirically verifiable (‘value-neutral scientific facts’, with low p-values and small confidence intervals as key quality indicators), in opposition to subjective, unverifiable knowledge. Now, Malterud claims that to do qualitative research ‘for a researcher raised in a biomedical tradition, the positivist ontological and epistemological idea of a stable and unified reality, where objective facts are waiting to be identified, must be defeated’ (Malterud, 2016). Qualitative research is generally situated in an *interpretative paradigm* where notions about human experiences in context is recognised from different subject positions. Intersubjectivity and transparency are key values, and Malterud highlights *relevance, validity, and reflexivity* as relevant metacriteria, rather than objectivity or reliability (Malterud 2016).

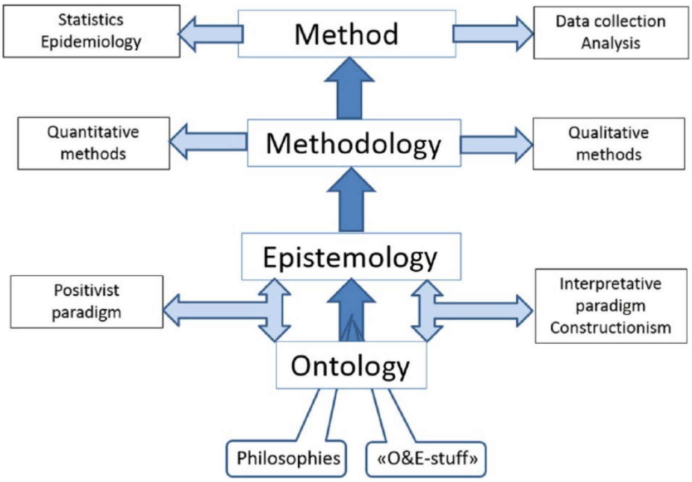


Figure 8. Associations between philosophy, ontology, epistemology, paradigms, methodology and method. (Malterud, 2016. © SAGE Publications. Reproduced with permission).

Braun and Clark provide a comprehensible introduction to these rather challenging concepts (Braun & Clarke, 2022, p. 7). They show how qualitative studies can be performed within a quantitative, (post-)positivist paradigm (‘small q’), focused on recording and understanding singular situations. Here, the impartial researcher seeks generalizable understanding, with the aim to avoid bias and subjectivity, and contributes with his or her stepping-stone piece of knowledge towards the goal of complete understanding. However, within a qualitative, non-positivist paradigm (‘Big Q’), the focus is on understanding and interpretation of ‘situated practices’. The subjective, reflexive researcher searches in-depth understanding that can become a part of a rich tapestry of meanings. Trying to develop what Braun and Clarke call *qualitative sensibility* to perform reflexive research means developing an interest in *process and meaning* over *cause and effect*, and to tolerate uncertainty. This includes the ability to reflect on dominant assumptions in one’s own context, to take a critical and questioning approach to life and knowledge as well as not being seduced by the idea of a singular truth to be discovered (Braun & Clarke, 2022, p. 7).

Within the Big Q paradigm, there are different orientations of qualitative research underpinned by ontological and epistemological positions and theory of language. (Braun and Clarke, 2022, p. 159). Within the *experiential* orientation, the focus is on meaning and experience; to ‘give voice’ to the ‘rich tapestry’ of people’s lives. Language is seen as a tool for communicating meaning, and interpretation seeks to stay close to the participants’ voices, using a *hermeneutics of empathy*, searching to understand and make sense of their statements. This was one of our aims when talking to parents: to hear their story and how they assigned meaning to what they had gone through. Brinkmann & Kvale use the metaphor of the *miner* who unearths nuggets of knowledge, preferably uncontaminated by the miner (Brinkmann & Kvale 2018, p. 20). If the nuggets are seen as objective, real data, we move within a quantitative paradigm; seeing the nuggets as subjective, authentic meaning align with a phenomenological, qualitative paradigm. The miner metaphor also describes Socrates’s pursuit of already existing philosophical truths and to Freud’s quest for hidden meanings buried in the unconscious (Brinkmann & Kvale, 2018).

‘Critical’ qualitative approaches are concerned with meaning-making, as construction and negotiation, interrogating patterns of meaning and the effects and implications of these. Language is seen as an integral part of the way truth and reality are put together, as symbolic, powerful, and active rather than neutral and passive. A *hermeneutics of suspicion* informs critical research, interrogating and asking critical questions of the meanings in the data, drawing more heavily on the researcher's theoretical resources (Braun and Clarke, 2022, p. 160). As the project developed, I came closer to understand the value of Brinkmann & Kvale's *traveller* metaphor: the researcher that embarks on a journey to a distant country, wandering through the landscape and talking to people, encouraging them to tell the stories of their lived world. Through interpretations, the traveller unfolds the possible meanings of the narratives he or she brings back to home audiences. Most importantly: 'The journey might even be transformative for the traveller, instigating a process of reflection that leads the traveller to new ways of self-understanding, as well as uncovering previously taken-for-granted values and customs in the traveller's home country.' (Brinkmann & Kvale, 2018, p. 20). In this project, I experienced a process of doing and being immersed in the interviews, combined with on-going ethical dilemmas in clinical practice, and the possibility to reflect academically on this topic. This has had a significant impact on my understanding of both the construction of meaning and the activity and aim of research.

4.3.2 Embodied existence and conditioned freedom

Merleau-Ponty (2012) pointed out the fact that we exist as *bodies*, always-already situated in the world, and that *perception* is primary. He argued that we become a reflexive subject through bodily interaction with the world and our fellow beings. He offered an account of perceptual *ambiguity* as a lived, embodied experience, drawing on the famous Gestalt images such as 'duck / rabbit' or 'old woman / young woman' where the same images produce two disparate perceptual experiences, depending on our focus (figure 9 and 10).

Merleau-Ponty claimed that this also goes for our ordinary perceptions at a much larger scale: perceptions are always dynamic, produced by our ongoing, embodied interactions with our environment, and they can always be organized in more than one way, depending on what we see as *figure* and what we consider as indeterminate *background* (Weiss, 2012). This engaged, embodied subjectivity is not detachable from social relationships and historical situation. As human cognition requires a body and the body a position in space, our experience is necessarily perspectival and therefore incomplete:

> True reflection presents me to myself, not as idle and inaccessible subjectivity, but as identical to my presence in the world and to others, such as I currently bring it into being: I am everything that I see and I am an intersubjective field, not in spite of my body and my historical situation, but rather by being this body and this situation and by being, through them, everything else (Merleau-Ponty & Landes, 2012, p. 478).

To consider whether we can expect parents to be able to make autonomous choices at the border of viability, we must be aware of situational possibilities. Merleau-Ponty also pointed out how traces of previous choices will leave sedimentation in the subject, and thus affect the probability of how one will respond (Merleau-Ponty & Landes, 2012, p. 467). This kind of insight may be more readily at hand in the clinical setting than at the moral philosopher's table; considering that a 'field of freedom' is not available to some patients or parents may serve to justify paternalistic and caring attitudes. Freedom for Merleau-Ponty will always be found in the exchange between the subject and its situation, in mediated action. Freedom 'must have a field, that is, it must have some privileged possibilities or realities that tend to be preserved in being' (Merleau-Ponty & Landes, 2012, p.462).

Figure 9. Duck or rabbit? Flegende Blätter, 1892. (Image credit: Public domain)

Figure 10. 'My Wife and My Mother-in-Law' (Image credit: Public domain)

What is the relevance of this for our dilemma? On the one hand, our embodied existence points towards the need for a broader understanding and dialogue: our medical viewpoint is but one limited perspective. What we see, as neonatologists in a high-tech environment, when a fetus-baby is expelled at 25 weeks' gestation is quite different from what a midwife in a poor rural setting can ‘see’. Medical possibilities shape realities and provide hope. On the other hand, accepting that freedom is dependent upon a field, urges us to avoid dichotomies: a freedom that is conditioned is not absent freedom, but the sensitivity to context must be acknowledged.

4.3.3 Ecological thinking and the ethics of ‘mattering’

Doucet (2018) describes how feminist contributions to epistemology have challenged the so-called neutrality of the investigation and researcher distance from its objects. Central philosophers are Haraway and her concept of *situated knowledge* and Code’s concept of *epistemic responsibility*. While the former draw attention to the fact that all knowledge and knowledge-making processes are constituted by the standpoints of both the researcher and the researched, the latter issues from a concept of knowledge-making as a creative process emerging through dialogue between various authoritative ‘knowers’, situated within particular social and historical contexts. ‘Knowers’ are not individuals, but science and epistemic communities, and there is an entanglement of ethical and political values, which plays a legitimate normative role. 'Knowledge claims arises in specific circumstances and have real consequences’ (Rouse 2009, as cited in Doucet, 2018, p. 76).

As a deepening of her concept of epistemic responsibility, Code launched ‘ecological thinking’, emphasising the intraconnections between epistemology, ontology, ethics, science and politics, arguing that we are not just making knowledges but ‘*reconfiguring worlds*’ (Code, 2006, in Doucet, 2018, p. 79). In short, ecological thinking means emphasising ‘a process of becoming’ (Bennett, 2010, as cited in Doucet, 2018, p. 79). Ecological thinking ‘offers a conceptual frame within which to construct a responsive-responsible theory of knowledge and subjectivity’, wherein researchers are responsive to, and responsible for, their participation in and accounting of unfolding worlds and dialogically constituted narratives (Code, 2006, as cited in Doucet 2018, p. 80). Epistemic responsibility is about being accountable to the evidence. Code does not oppose ‘scientific progress’, but being responsible might mean moving at a slow phase, to be able to evaluate the world that unfolds (Doucet, 2018).

Going back to the situation that inspired the title of this thesis – the mother with her fetus-baby in her arms. The choices for what have been defined as relevant knowledge to seek, like developing technologies capable of saving human lives at this stage of development have ontological consequences: it converts an inviable fetus into a viable baby. The situation is transformed from being predetermined, to a situation of different possibilities where a choice must be made. In this way, technologies reconfigure responsibilities for death and dying in fetuses and infants (Adrian, 2020).

Techno-anthropologist Stine Adrian's son Klemens died at three weeks of age, 24 hours after being diagnosed with hypoplastic left heart syndrome (HLHS). While mourning her son, she starts looking at how responsibilities are perceived, and finds a need to challenge the understanding of ethics and responsibility that emphasises the 'autonomous subject in control' (Adrian, 2020). Looking at other stories of fetuses and infants with HLHS with different trajectories, she finds that outcomes are unpredictable, as bodies are uncontrollable: 'technology neither enables quick fixes nor control outcomes. Instead, the diagnostic and surgical technologies enable more paths to follow and more choices to make' (Adrian, 2020, p. 13). Despite the complexity of these situations, decision-making and responsibility are still often perceived as held by a single, autonomous subject.

Adrian draws on Haraway and Barad's theoretical understandings of how we can conceptualise technology. Technologies are seen as 'material-discursive': ethics and technologies are entangled, and questions of who is responsible and how responsibility emerge matter. According to Barad, knowledge making is a 'deeper set of relational entanglements where relations between the researcher and the researched unfold together, not as 'independently existing objects' but rather as a 'phenomenon in their ongoing materialization' (Barad, 2007, as cited in Doucet, 2018, p.80). She describes the process of knowing the material world as 'intra-action' rather than interaction. In doing so, she emphasises that agency is not an attribute—something that one isolated subject has—but rather is the involvement in the iterative practices that constitute materiality. The wordplay on 'matter' that runs through 'new materialism' points to the inseparability of science, ontology, epistemology, and ethics. 'Our practices *matter* both in the sense of making a difference and in the sense of being involved in the configuring and reconfiguring of the material world' (Crasnow, 2020).

Barad uses the case of ultrasound technology during pregnancy to illustrate her argument. She argues that the 'ontological understandings of both ultrasound technology and the fetus it helps to visualise, make a material difference to the fetus, the mother, the medical profession, abortion debates, science, politics, the law and much more' (Barad, 2007, as cited in Mauthner, 2018, p. 53). Ultrasound technology is generally seen as an innocent tool for viewing the fetus. However, it enacts the fetus as an autonomous, free-floating, self-contained subject that is separate from the mother, and as an ontological given, independently of the ultrasound. Barad rejects the innocence of the ontological understanding of the fetus, the ultrasound, and the relation between them, as it makes possible the constitution of the fetus as a moral and legal subject, which in turn has bearing on abortion policy. Others have pointed out that ultrasound enables a relationship between the physician and the fetus, making possible a reduction of the pregnant woman into a 'fetal container' (Edvardson et al., 2015; Lyerly et al., 2008). On the other hand, ultrasound is welcomed by many pregnant women as a way of strengthening their relationship to the fetus. There has been an ongoing debate among feminist philosophers since the appearance of ultrasound technology whether it poses a threat or an opportunity to women (Petchesky, 1987). From the perspective of those who oppose abortion on the grounds of the fetus's right to life, ultrasound is equally ambivalent. On the one hand, it serves to strengthen the notion of the fetus as an individual, but on the other hand, it permits the detection of 'defective fetuses', that may lead to late abortions and the notion of a 'sorting society'.

Barad names her relational ontology *agential realism*, where ethics, knowing and being are intertwined. 'Agential realism' calls on ultrasound technology to account for its own non-innocence and for its own non-innocent ontological effects on the world, in order to become an ethical practice. (Mauthner, 2018). A new perspective on research is therefore needed, and Barad introduces the concept of *diffractive practices*. While *reflexivity* involves researchers accounting for cultural influences on knowledge production systems and objects of knowledge, *diffractive practices* involve practices accounting for their own ontological existence, their ontological assumptions, and the ontological entities they help bring into being. So, while reflexivity is an epistemological practice where epistemological agency, accountability and responsibility is located to human researchers, diffraction is an 'onto-epistemological' practice that locates ontological agency, accountability and responsibility *with the practices themselves* (Mauthner, 2018, p. 53). Over the last three decades, research in this field has received different labels, i.e. 'ELSA' or 'ELSI' (Ethical, Legal and Social Aspects/Implications of science and technology) and 'RRI' (Responsible Research and Innovation) (Zwart et al., 2014).

In line with this, virtue ethics can provide guidance to researchers. Carpenter (2018) draws on Macfarlane's virtue-based framework for researchers, emphasising some virtues that are essential for different phases of a research project: courage, respectfulness, resoluteness, sincerity, humility, and reflexivity. Others are friendliness, social responsibility, and creativity, and most importantly: integrity, comprising both knowledge, experience, honesty, and fairness (Carpenter, 2018).

I discovered Macfarlane's work through Carpenter just recently, so I cannot claim to have followed his methodology. However, the perspective of virtue ethics as a promising approach to difficult dilemmas at the border of viability has been present during the whole project. We have aspired for virtue, aiming for a result that can contribute to fruitful discussions, with a goal of improving practice.

Slowly, I feel that the 'positivist' grip has loosened a bit, and I have ended up with a different and more nuanced understanding of what knowledge entails. During the journey, different interpretative perspectives have opened themselves, and hopefully this has led to meaningful insight shared in the papers. Sometimes it has felt scary for a novice like me to work within a transdisciplinary field without a prefixed, established method. My aim for the next sections is to present how we performed our research, and what we actually did during the different phases. Drawing on recommendations from several authors, I will try to provide a comprehensive picture of how we carried out our work and the choices that we made (Molewijk & Widdershoven, 2012; Ives et al., 2018).

4.3.4 The ethics of qualitative interviews: 'craft and episteme'

The interview is a powerful method of producing knowledge of the human situation, and historical interview studies have contributed to change ways of understanding the human situation and of managing human behaviour throughout the twentieth century. Carol Gilligan's interview study 'In a different voice', showing different patterns of moral reasoning in girls and women, sparked a feminist revolution in moral philosophy, giving raise to both feminist and care ethics (Shafer-Landau, 2013, p. 690). Brinkmann & Kvale (2018) point at both Freud's psychoanalytic theory and Piaget's theory of child development as examples of interpreted knowledge that emerged from interviews.

Trough conversations, one can get some understanding of other's view on the world. A research interview can also be seen as an 'inter-view', where knowledge is constructed in inter-action between the interviewer and the interviewee (Brinkmann & Kvale, 2018, p. 2). They see the interview study research less as a *method* following explicit rules than pragmatically as a *craft*. The quality of knowledge produced through the interview rests upon the subject matter knowledge and the craftsmanship of the interviewer: 'The proficient craftsman does not focus on the methods but on the task – in Heidegger's famous analysis of craftwork it is not the hammer the carpenter focuses on, but the wood and the table to be built.' (Brinkmann & Kvale 2018, p. 55). The knowledge is constructed through the opening to other life worlds, aiming for understanding, interpretation and/or constructing meaning. Interviews can be undertaken from a specific position ('phenomenological', focusing on understanding, 'hermeneutical' with focus on interpretation or as 'postmodern' meaning-construction), or from a more pragmatic position, drawing on several methods and motivated by being relevant for human practice.

Important research ethical issues must be handled. Although most interviews are performed in a friendly manner, there is inevitably a power asymmetry. The interviewer sets the agenda, asks questions and has monopoly on interpretation. As an attempt to reduce this power asymmetry, collaborative interviewing can be undertaken, where the subjects also are invited to ask questions, and to discuss and interpret meaning (Brinkmann & Kvale 2018, p. 19). Flyvbjerg has characterised social science used to pose value-rational questions as *phronetic social science* (Flybjerg, 2001, in Brinkmann 2007, p. 1128). A 'socratic' attitude, with intersubjective recognition of the Other as a responsible and accountable agent may well be a precondition which enables her/him to act as such, whereas a caring, therapeutic attitude may promote vulnerable selves, unable to take action as accountable citizens. In such epistemic interviews, much of the analysis is in principle carried out *in* the conversation, with the accountable respondents involved. Brinkmann argues that this may improve the quality of analysis and create more interesting interviews (Brinkmann, 2007, p. 1136).

In our project, the combination of an 'insider' and an 'outsider' perspective was actively engaged. There is a substantial literature on the pros and cons of 'insider research' (Toy-Cronin, 2018). Advantages include greater access, understanding, rapport, and the possibility to bring about change in clinical practice. Among disadvantages mentioned are lack of critical distance, subjectivity, and bias. However, the insider-outsider dichotomy can lead to oversimplification, as the positioning relative to participants is described as rather complex, fluid, and multi-dimensional (Toy-Cronin, 2018).

4.4 Our methodological approach

Brinkmann & Kvale (2018) emphasises a pragmatic approach when embarking on a journey to learn how to do qualitative research interviews. 'Moving from interview research as methodological rule-following, with method as a truth guarantee, to research as craft, where craftsmanship is learned through practice, and with the value of the knowledge produced as the key quality criterion (Brinkmann & Kvale, 2018, p. 164). Such a pragmatic approach involves a move from philosophical legitimation to the practical effects of knowledge. Relevant pragmatic questions are whether the interview-produced knowledge is useful to our purpose, and whether it is valuable, insightful, and beneficial.

I will start out by describing the overall shape of the project following a 'landscaping' metaphor, using the framework 'mapping, framing, shaping' proposed by Huxtable and Ives (2019). Having a sense of where we were and what we wanted to achieve, as neonatologists and ethicists with an urge to contribute to better decision-making at the border of viability, we needed a good plan for our project. This is not to say that the project has followed a strictly linear process. Rather, we have been going back and forth between different stages during the whole project, which still, luckily, is a work in progress.

4.4.1 Mapping

This project started out in 2014. Together with two ethicists (Lars Ursin/ LU and Berge Solberg/ BS) and my superior at the department of neonatology, Ragnhild Støen/ RS, we formed the research group 'Premethics'. LU, BS and RS had been collaborating in a theoretical project looking at 'ethical foundations for parental decision-making in treatment decisions' since 2010, where LU had a 50 % position as a researcher in the period 2012-2017.

In this first phase, the aim was to survey and get a sense of the terrain, to create a 'map' that would help us navigate and plan (Huxtable & Ives, 2019). We needed to understand the 'state of the art' to specify gaps in the literature, and to get a grip on what was actually going on in our setting. Working in the field and having conversations with colleagues throughout the country gave us a privileged starting point. As insiders, we have greater access, but we still need to be aware of the pitfalls of 'insider research'.

We drew from international bioethical literature and had a special focus on Norwegian studies and the on-going public debate. Important contributions came from the (now decommissioned) Norwegian Council for Quality Improvement and Priority Setting, who discussed the topic 'Treatment and follow-up of extremely premature infants' during the period 2014 to 2017. The paper 'NICU dialects: Understanding Norwegian practice variation' was written in collaboration with experienced neonatologists from different Norwegian NICUs, and contains the synopsis of this first mapping phase, as presented in the Background section (Syltern et al., 2018).

4.4.2 Framing

The ethicists' (LU and BS) motivation to join this collaboration was a desire to seek an understanding of how this issue was experienced (or 'framed by') the lived experience of different stakeholders, starting out with neonatologists (RS and JS). To get a broader understanding with multiple perspectives, it was clear that input was needed from other stakeholders with relevant experience and different perspectives. Drawing on LU's and BS's experience in empirical research, all four participated in the design and planning of the qualitative study. Our aim was on the one hand exploratory, looking for experiences with life-and-death decisions throughout pregnancy and periviable birth. We also wanted to 'test' our hypothesis through dialogue: should parents be the final decision-makers in life support decisions for periviable fetus-babies? We therefore searched input from both health care personnel and parents who had experienced periviable life support decision-making, and considered research interviews best suited for our purpose. This was based on numerous reasons and aims: to increase context-sensitivity, to enrich descriptions of conduct; unveil relevant facts, moral opinions, reasoning patterns and to get a grip on how organization of health care may impact decision-making in our context. We also wanted the possibility to dig into, and have the possibility to discuss, the different *reasons* stakeholders held to be valid in this setting.

We sought inspiration from *epistemic interviews* based on Socratic dialogue, with an aim to 'take advantage of the knowledge-producing potentials inherent in human conversations' (Brinkmann 2007, p. 1116). This gives the possibility to explore the strength of different moral intuitions, and to see whether they are altered or not by potential counterarguments. In this dialogical encounter with different stakeholders and persons with relevant experience, we wanted to bring forth and discuss different reasons for action or ways of being, and we sought the opportunity to be challenged and to challenge moral assumptions. In this way, we could start the knowledge-making as a normative exploration during the interview with the intention of seeing each other as equals. By going from a *spectator* to a *participant* position in the interview setting, we wanted to facilitate a dialogue about reasons for believes, and their justification.

As a neonatologist, being a physician made me an insider in some groups, and working in the NICU an insider in others. It was revealing for me to see how much of an outsider I was in the meetings with other related health care personnel groups. However, I felt that the combination of a skilled 'craftsman' leading the interviews, with extensive knowledge in moral philosophy and applied ethics, and a physician, with relevant clinical experience as co-interviewer, contributed to rich conversations.

4.4.3 Ethical considerations

Recruitment of experienced parents had to be done with much care. Inclusion criteria was having experienced prenatal counselling between 23 and 25 weeks gestation at Trondheim University Hospital, Norway. Exclusion criteria was the lack of clearly documented conversation with a neonatologist before birth, where different approaches had been discussed, since this was the central experience we were looking for. I therefore checked the mother's patient record prior to sending out invitation, in line with the ethics committee approval. As we also wanted to include birth where palliative care was chosen, we wanted to be sure that parents had been involved, and that a neonatologist had been present at birth. This was important to prevent unnecessary harm, in the sense of changing the 'ontological premises' of what they had gone through. If the situation had been defined as stillbirth, with no discussion about the possibility of life support, we saw that an invitation to a study like ours could be seen as reckless and risked causing harm.

The research ethics committee first claimed that our study was not concerned with new knowledge about health care, and therefore fell outside the law requiring ethical approval as such. Upon insistence from our part, REC central considered our proposal and approved our application (2015/208/REK Midt).

4.4.4 Recruitment and interview: Focus group interviews with health care personnel

To gain insight from different groups of health care personnel with experience from ethically challenging situations during pregnancy and the periviable period, we chose the design of focus group interviews. Focus group methodology is particularly well suited to bring out the reflections of people that share experiences and challenges, especially on subjects that are underarticulated, sensitive, and lack positions grounded in comprehensive public debate. Group interaction may facilitate the expression of viewpoints that are usually not accessible (Brinkmann & Kvale, 2018).

An important aspect of our study was to compare the perspectives of health care personnel throughout the period of pregnancy and periviability, including the fetal and perinatal perspective. St. Olavs Hospital as the seat of the Norwegian National Center for Fetal Medicine was seen as well suited for our study. We invited midwives, specialists in maternal-fetal medicine, obstetricians, neonatologists, and neonatology nurses at St. Olavs Hospital to share their experiences and join in reflections. Recruitment was made through letters and e-mails with initial information of the project, and we aimed to include clinicians with different level of experience, age and gender. Those who responded got additional information about how the interviews were planned. All study participants gave their written informed consent.

All focus groups interviews took place at St. Olavs Hospital in Trondheim, Norway during 2014-2017. All were led by LU, with me as co-moderator in the groups with neonatal nurses, midwives, obstetricians, mother-fetal specialists, and BS as co-moderator in the group consisting of my neonatologist colleagues. The group meetings lasted for 1.5 to 2 hours, and each group consisted of 4 to 5 professionals, 22 in total.

The group conversations were primarily between the participants on themes successively introduced by the moderator from a semi structured interview guide. The guide was used to cover the same themes in all groups, with adapted wording of questions to fit the group. The main questions of the interview guide are presented in table 4, and our main goal was to bring forward experiences with ethically challenging decisions during pregnancy and birth and the parent's role in the decision-making process (interview guides included in appendix). All interviews were audiotaped.

Interview guide

1. Could you tell us about a situation where health care personnel and parents were confronted with an ethically challenging decision?
2. Do you have experience from decision-making on termination of pregnancy?
3. How would you describe the role of the parents in decision-making concerning extremely prematurely born babies?
4. When a baby is born extremely premature; which factors and whose interests are relevant for making a decision regarding life-saving treatment?
5. Should the responsibility for the final decision regarding life-saving treatment rest with the parents?

Table 4. Main questions of the interview guide with health care personnel.

4.4.5 Recruitment and interview: Individual/ pair interviews with parents

As the overarching goal of this project was to explore the parental role in life support decisions, to include parents with relevant experience was key. We wanted to hear about their experiences during this life-altering event, and their reasoned views on how they saw the proper role for parents in this situation. Importantly, we wanted to engage in a dialogue about our hypothesis: that it is ethically sound for parents to make the decision of whether to provide life support at birth in an established grey zone. We also wanted their thoughts on what they would have found helpful in such process, and their views on how health care personnel best could support parents in this situation.

We expected our topic to be highly emotional to parents, requiring special safeguards in all phases from recruitment, interviewing and up to reporting. Psychological support was available after the interviews upon request, this was not solicited by any of the participants.

We aimed to include parents whose experiences covered the broadest range of possible outcomes: life-saving treatment resulting in a healthy child, life-saving treatment with survival of a child with different degrees of disability, and death in the Neonatal Intensive Care Unit. In addition, we also wanted to recruit parents where palliative care had been chosen, and the baby had died in the delivery room. Strategic recruitment was therefore chosen, and we aimed for 8-10 interviews.

After checking that requirements were met, I sent a letter of invitation with information about the project, where participants were provided with e-mail and phone numbers of both LU and me. Only one letter was sent to each parent. The parents had to contact us actively by text message, mail or email to be included. All study participants gave their written informed consent, and we informed about their right to withdraw at any point.

We ended up with eight interviews of 12 parents performed in the years 2014-2018 and included in paper 2. Time passed between birth and the interviews ranged from one to thirteen years (mean 5,5 years, median 3,5 years). As the project has been progressing, we have performed another six interviews in the period 2020-2022 (in total 14 interviews with 21 parents).

The interviews took place at different university locations in Norway and lasted from 70 to 120 min. LU performed all eight interviews, and I participated as a co-interviewer in the six interviews performed in Trondheim. All interviews were audiotaped. First, LU invited the parents to tell their story freely from the start of their pregnancy. Using 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 (table 5). The first part of the interviews was primarily descriptive, while the main part was a conversation with a goal of probing normative positions and seek advice on how to support parents. I adopted a rather passive role, 'downplaying' my role as a neonatologist. However, it felt useful to have the possibility to clarify and offer explanations when requested by the parents. 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. We also invited parents into deliberation about the parental role. Notably, I felt that the fear of my presence being a hindrance for parents to express criticisms and concerns did not strike.

Interview guide

1. Could you tell us about your experience with extreme premature birth?
2. Could you describe how you related to the fetus 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?

Table 5. Main questions of the interview guide with parents

4.4.6 Transcription

I transcribed all interviews, initially strict verbatim, and as I gained more confidence and experience, I progressively traduced slightly from oral to written language (Brinkmann & Kvale, 2018, p. 106). I thereby got the possibility to listen carefully a second time, both to the groups of clinicians, and to what the parents had said, how they had lived those moments, and their message to us as care providers. I had met some of the parents in the NICU, while others had their NICU stay before I started in Trondheim. The contrast between the understanding I had gained as a doctor, and the reflections when we could sit down and talk at large, in calm waters and more like equals, was an eye-opening experience. My impression was that the parents openly shared their thoughts with us during the interviews. This may not be surprising; taking their time and effort to share such life-altering experiences would probably be perceived as wasted if they had not transmitted a sincere and important message. They shared both positive and negative experiences, and their perceptions on both human factors and organizational issues. Finally, they also got an opportunity to share what they had found frustrating during their stay in the NICU, as well as an opportunity to express gratitude.

Although as a physician, I am aware of the power asymmetry in the doctor-patient relationship, I was still struck by how much greater it is than in the researcher-subject relation. The need to protect oneself in the midst of a crisis added to the power asymmetry can be a potent barrier to the articulation of feelings and thoughts. Some of the stories were heart breaking, and being present, transcribing and further analysing these stories had a transformative effect on me.

4.4.7 Analysis

Being a newcomer in this field, I first approached the topic through books in addition to the discussions within the team (Kvale & Brinkmann, 2009, Malterud, 2011, 2012). As an apprentice, transcription was an important learning tool. In 2016, I undertook a PhD course in qualitative research methods, focusing on a method frequently used in medical research in Norway: ‘systematic text condensation’. This is a method developed by Malterud as a strategy for qualitative analysis, ‘offering for the novice researcher a process of intersubjectivity, reflexivity and feasibility’ (Malterud, 2012, p.802). After reading the transcripts, I started out coding the manuscripts manually with an inductive approach, trying to start out from the data with an open mind (aiming at ‘phenomenological bracketing’) and find patterns, which resulted in themes. However, while reading and re-reading, and picking the best quotes was rewarding and meaningful, we did not find it fruitful to go further with phenomenological approach. Our resulting approach can be described as follows:

1) Analysis started during the interviews with the epistemic approach, engaging with the participant in normative reasoning, and during debrief immediately after the interview.

2) After transcribing the interview, LU and I read and re-read the interview, writing a synopsis focusing on the normative aspects that were central to this study. We also included and interpreted descriptions, where we saw potential to increase context-sensitivity, to enrich descriptions of conduct, relevant facts, moral opinions, reasoning patterns and to get a grip on

how organization of health care may affect decision-making. We selected illustrative/ best quotes.

3) The resulting 3-5 pages synopsis was sent to the participants with the aim of continuing the process of shared 'meaning-making' started during the interviews. We also encouraged participants to share reflections and thoughts that had come up after the interviews. Answers were included in further analysis (only one parent answered at length).

4) Both inductive (finding themes) and deductive (testing our hypothesis) approaches were used. We also practiced reading and re-reading combined with theoretical reflection several times during the project.

4.4.8 Validation: Objectivity, validity, and generalization

Objectivity is an ambiguous term. In our project, we aim for both objectivity and validity through performing well-crafted research. Objectivity can also be seen as 'allowing the object to object' (Latour, 2000, as cited in Brinkmann & Kvale, 2018, p. 141). Latour argues that if social scientists wanted to become objective, they should, as natural scientists do, seek the rare or extreme situations where their objects have maximum possibilities of protesting against what the researchers say about them – where the objects are allowed to raise questions in their own terms and not in the researcher's terms. By asking explicitly our participants to express their opinion on our hypothesis, we got plenty objections – they expressed their reasons and engaged in reciprocal criticism during the interviews. To *validate* means both to check, to question and to theorise, and hopefully this will lead to powerful knowledge claims, standing in their own rights (Brinkmann & Kvale, 2018, p. 143). It can be tested through communicative validity: by probing it in an appropriate community. Pragmatic validity involves a move from philosophical legitimation to the practical effects of knowledge and to its generalisation: is our project capable of bringing about a change in behaviour, to improve clinical practice? This takes us further down to the third and last point after mapping and framing: can we go on to propose modification to the terrain.

4.4.9 Shaping

In the final steps of an empirical ethics project, time has come to (re)shape the terrain, informed by our findings that has come out of our ‘mapping’ and ‘framing’ work. Following Huxtable & Ives:

> (...) armed with intimate understanding and knowledge of the terrain, the designer can now build a vision for what s/he wants, and explain why certain features have to be in certain places – sometimes for aesthetic reasons, sometimes for pragmatic reasons, and oftentimes aimed at an artful blending of the two (Huxtable & Ives 2019, p. 3).

If the empirical work is considered primarily to be of descriptive character, there will be a need for a bridging methodology to hook up with the normative, theoretical reasoning. Having employed a normative approach in our empirical work, and not pretending to have arrived at a final normative conclusion but rather seeing our work as a means to continue the dialogue, our approach might be closer to an interpretative method of ‘pragmatic hermeneutics’, as for instance ‘responsive evaluation’ with stakeholders (Molewijk et al., 2004).

Locally, a desired side effect of these interviews was to increase the level of reflection and discussion among clinicians of the questions raised by this project. Such effect did occur, but it also taught me that a continuous effort is required to maintain this dialogue.

To reach a wider audience and engage in further societal dialogue, we have published in a local newspaper and written a blog on paper 3, and organised a multidisciplinary national conference on shared decision-making at the border of viability (Samvalgskonferansen i Nyfødtmedisin, 2022).

5 The papers: A brief presentation

Paper 1: In the best interest of the… parents: Norwegian health personnel on the proper role of parents in neonatal decision-making

In this paper, we present the results from the focus group interviews with the different groups of health care personnel dealing with life and death decisions throughout pregnancy and birth, performed in Trondheim in the period 2014-2017. Our participants did not embrace our working hypothesis. They expressed that parents were expected to fight for their child, and they should not have to live with the burden of a decision to start or withhold life support. Parents lack required time and emotional stability to process information. Nor do they have the vital experience of what life support for a periviable infant entails. Couples may have conflicting views, adding strains to the traumatic situation. Combined with the cultural expectancy that 'good parents fight for their child', they are not in a position to make balanced decisions. They should therefore be spared for bearing the burden of responsibility and for possible future decisional regret – '*they should rather be angry with me than being angry with themselves for the rest of their lives*', as one of the neonatologists stated. The general attitude of our groups was that parents should have a say, and be included in a thorough information and decision-making process. The doctor, or the health care team, however, should make the final decision, due to their superior knowledge and a less restrained normative role, which enables them to weigh interests of both parents and the child. The decision should be informed by the viewpoints and values of the parents, without making it explicit, fitting into a model of decision-making termed as '*Patient Preference-Satisfaction Paternalism'* by Sandman and Munthe (2009).

When we challenged the groups with arguments that favoured giving decision-making power to the parents, there were some movement in the groups. The nurses argued that for parents to be entrusted decision-making responsibility, they should be empowered through a thorough process and supported by psychologists.

Paper 2: Protect us from ourselves: balancing the parental instinct of saving in neonatal decision-making

Here we present the results after discussing our working hypothesis and the role of parents in neonatal decision-making during eight interviews with twelve parents, all having experienced prenatal counselling at the limit of viability. The themes echoed to a large degree the statements of the clinicians. The emotional turmoil precludes the ability to digest information. The parents emphasised the importance of being involved in the decisions, and described at the same time ambiguity. The parents described an '*instinct of saving'* that easily makes hope overshadow the potential negative effects for the infant and for the family, precluding the possibility for 'balanced' decision-making. During the interviews, the parents expressed ambivalence both towards their role in decision-making, and towards the provision of life support at the border of viability. Those who had been through NICU treatment felt that their children had been exposed to tough treatment and significant suffering. The parents saw the role of clinicians to protect the infants against the parental push for treatment, and to help parents balance the ideal of showing *unconditional parental love* with the ideal or logic of *responsible parenting*. Following the logic of responsible parenting, parents should be invited into the decision-making space. Some of the parents had experienced decision to forego life support as responsible acts of love, to protect their infant and/or the family. However, parents should also be allowed to cling to the logic of unconditional love, and to fulfil the ideal of good parenting by making it clear that clinicians are the ones who ultimately take the responsibility.

To achieve the balance of conflicting logics in play, clinicians must make it possible for parents to exercise the parental ideals involved without compromising the best interests of the child: parents should not be cornered into situations where they are asked to decide whether 'everything should be done'. Strict guidelines could be helpful for parents and clinicians, preventing both decisional regret and the need to blame others. We concluded that given the interdependence of parents and clinicians in life support decisions, a flexible rather than a consistent and universal approach to parental roles and responsibilities is warranted. 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 clinicians inform and involve the parents.

Paper 3: Postponed withholding: Balanced decision-making at the margins of viability

In this paper, we explored the possibility to empower parents, so that they together with clinicians, in a shared decision-making model, could reach sound decisions in the ethical grey zone at the margins of viability. We questioned whether the set-up of the decision-making process promotes or obstructs the realization of the ideal of parental involvement, and pointed towards several obstacles to balanced decision-making: the treatment imperative, the instinct of saving, and the logic of unconditional parental love. Based on this analysis, we argued that we need to consider changes in the choice architecture in the grey zone. We specifically address cases where there is not enough time for proper prenatal counselling, and proposed an approach named *postponed withholding* ('PPWH').

Postponed withholding aims at balancing the external forces interfering with parental autonomy and empower parents as decision-makers. To realize this aim, postponed withholding includes two default actions in the event of birth at the margin of viability: (1) life support at birth, *unless* parents have had enough time prenatally to make a well-reflected decision for palliative care. After a period of time (in the paper, one week is proposed as a reasonable time frame), and after a shared deliberation with clinicians and parents, (2) life support will be stopped allowing for natural death, unless parents explicitly opt for continuation of life support.

In this way, parents are given time to deliberate on the one hand, at the same time as the initiation of life support at birth is seen as *non-directive*: life support at birth is the only reversible action, and thus, is defined as a *non-decision*. In other words, the aim of postponed withholding is to make parental decision-making possible by giving them time to deliberate, without at the same time removing the possibility of choice, since a decision to start life-support may be extremely difficult to undo. To visualise the process, we present, and follow the hypothetical case of Mina, born at 23 weeks gestation, only a few hours after her mother was admitted to the hospital.

Paper 4: Everybody wants to save the viable but dying fetus: why and how to support pregnant women’s autonomy

How should clinicians act when faced with a viable, but dying, premature fetus? In this paper, we argue that rather than merely focusing on fetal interests, we need to look closely at all relevant features, and empower the pregnant woman so that she can participate in the weighing of risks before any decision, or even a clear recommendation, is made. We claim that existing medial guidelines and two profiled ethical frameworks put substantial weight on rescuing viable fetuses, and fail to guide clinicians accurately. To accomplish balanced decision-making, we need to rethink the current practice of decision-making in maternity care.

With the development of ultrasound technology, the fetus is envisioned as an independently floating, full-fledged baby. The framing of the dilemma as an opposition between fetal beneficence and the pregnant woman’s (bodily) autonomy may have negative effects on the communication with, and care for, the pregnant woman. Although the autonomy of the pregnant woman is not violated in terms of compulsion, we question whether there is sufficient decision-making space for her to consider both fetal rescue and perinatal palliative care as acceptable choices. We identify several obstacles to the pregnant woman’s autonomy, as the ‘instinct of saving’ in both clinicians and parents, and the societal pressure on pregnant women. We argue that responsible decision-making implies acknowledging the existential ambiguity in such decisions, and a need to carefully consider relevant features before deciding upon fetal rescue. Saving the fetus requires, (1) performing a caesarean section on the pregnant woman, (2) need for neonatal intensive care of variable duration and intensity for the premature baby, as well as (3) a risk of physical and cognitive impairments for the child. Considering both medical and ethical uncertainty, practical wisdom is crucial for facilitating the pregnant woman’s autonomy when faced with a dying fetus. Insight from relational perspectives on autonomy, clinical practice, and own empirical research point towards the need for clinicians and potential parents to embrace ambiguity and engage in shared decision-making processes. Clinicians face a special duty to support autonomy and empower pregnant women to make authentic choices through a relation built on trust, transparency, and respect. We present three cases, with the aim of contributing to further discussions about how to meet these challenges in the clinical encounter.

6 Discussion

6.1 Shared Decision-Making

Acknowledging the shortcomings of both paternalism and unbridled autonomy, ‘shared decision-making’ has become the ideal when facing complex choices (Lantos, 2021). The concept of shared decision-making appeared in the research literature with the landmark paper of Charles et al. (1997) ‘Shared Decision making in the medical encounter: what does it mean? (Or: it takes at least two to tango)’. The concept of autonomy is heavily influenced by philosophers like Kant and John Rawls, who focus strongly on reasons and universality, where moral decisions ideally should not be influenced by the particularities of the specific situation, desires nor emotions. Some shared decision-making models have drawn on feminist perspectives on autonomy, where atomistic conceptions of the self are rejected and autonomy is no longer perceived as the will of an isolated, abstract reasoner, operating in a vacuum unaffected by social relationships and emotions (Stoljar, 2022). Feminist philosophers reject the claim that agents ought to be self-sufficient, and rather stress the importance of social relationships of care. The feminist reconceptualizations of the notion of autonomy are called ‘relational autonomy’. On the one hand, this term denies that autonomy requires self-sufficiency: autonomy is compatible with standing in and valuing significant family and other social relationships. On the other hand, ‘relational’ also emphasises that persons are not metaphysically isolated, but socially and historically embedded and shaped by factors like gender and class (Stoljar, 2022).

The development of autonomy may be hampered by restrictive or oppressive relationships, or enhanced by positive relationships that provides role models, self-trust and self-confidence. We need significant others to articulate values and to reflect on which to give precedence. Autonomy needs neither to be seen as hyper-rational; emotions and desires, as well as imagination may constitute valid forms of reflection on values of concern (Stoljar, 2022).

To qualify as shared decision-making, there are some central elements that needs to be made explicit. Stiggelbout et al. (2015) distinguish four steps: (1) acknowledging that a decision is to be made, and that the patient's opinion is important, (2) explaining the options, with their pros and cons, (3) deliberation on the patient's needs and preferences (value clarification/ articulation); (4) discuss the patient's decision role preference, make or defer the decision, and discuss possible follow-up. Shared decision-making is particularly relevant for preference-sensitive decisions, and is expected to improve clinician-patient relationships, decisions and outcomes. Despite being advocated for ethical reasons for over 40 years, it is still not widely implemented in clinical practice, and educational efforts focusing on skills, knowledge and attitudes are warranted (Stiggelbout, 2015).

The Dutch PreCo study (Prenatal Counselling in extreme prematurity) provided important insight into the preferences of Dutch parents and professionals in prenatal counselling at the limit of viability. Talking to professionals, Geurtzen et al. (2017) found a need to improve the understanding of shared decision-making. Professionals saw unclear language, directive counselling, information overload, and an immediate delivery as barriers for parents to perceive that there is a choice to be made, and that they could participate. The Dutch parents stated that they wanted information as soon as possible, delivered in an empathetic and honest style, and for various reasons, they needed more than one conversation (Geurtzen et al., 2019). Like the parents in our study, the Dutch parents also differed in their preferred role in decision-making: some wanted an advice, other wanted to decide for themselves and some wanted doctors to decide. They stated that it was important to highlight that there is no right and wrong decision (Geurtzen et al., 2019). In a survey of Dutch parents and clinicians performed after prenatal counselling, both parents and physicians reported high levels of perceived shared decision-making (Geurtzen et al., 2021).

Belgian neonatologists described life support decisions for periviable infants as both consensus-based, gestational age-based, contextualised, progressive, and shared (Cavolo et al., 2022). Consensus was desired both at a broad level, within and between units, and expressed in guidelines. For particular cases, consensus should be achieved with parents, but also within the extended care team. In some units, gestational age thresholds were applied strictly, while others had a more flexible approach. Decisions were contextualized, considering both infant-related factors (growth, infections, malformations etc), parent-related (like the mother's gynecological history and stakes related to the possibility for offspring) and the aspect of time. A lack of time for counselling, like when the mother arrived in labor, was perceived as 'a hindrance to an informed decision-making, which, in turn, was often perceived as a hindrance to an ethical decision-making' (Cavolo, 2022, p.8). All participants saw the need to involve parents in decisions, as the care for the mother may be directly affected (i.e. decisions to perform caesarean section on fetal indication), and the parents well-being may be influenced by the decisions made. Most (14/20) acknowledged parents' right to make decisions for their children. Parents' wishes were among the most valued factors considered in the decision-making, especially within the 'grey zone', due to the high clinical and ethical uncertainty. Doctors tended to follow parents' requests even when they disagreed with it, being vulnerable to moral stress when they felt that they acted against what they saw as the infant's best interest, in order to respect parental autonomy (Cavolo et al., 2021). Outside the grey zone, physicians were viewed as the main decision-makers. This means that although parents' wishes were still considered, counselling was more directive and the final decision was made by the physician.

The argument that parents need to be protected from the decisional burden to avoid harm does not seem to receive empirical support when a model of shared decision-making is applied. Studies have shown that higher levels of shared decision-making have been associated with lower grief scores compared to paternalistic or informed decision-making, and to lower decisional conflict (Caeymaex et al., 2013; Soltys et al., 2020; Geurtzen et al., 2021). Decisional conflict following shared decision-making has been described as low in several studies, and may be lowered by using decision-aids (Geurtzen et al., 2021; Tucker Edmonds et al., 2019; Moore et al., 2017). In the same setting, decisional regret for prenatal life support decision-making has also been reported as low in several studies (Geurtzen et al., 2017, 2021; Tucker Edmonds et al., 2019).

6.2 Reflections on our study

In our interview study, we found a shared conception among many clinicians and parents that clinicians were better positioned to make responsible decisions to protect the interests of both infants and families. The main concern which was raised, especially from parents, was parental push for treatment based on an ‘instinct of saving’.

This seems to be at odds with my personal perception that the drive to save lives has been strengthened over the last years. At conferences and in neonatal journals, colleagues present statistics showing improved survival at increasingly lower gestational ages. As technological development and medical research provide better tools, I feel the temptation to come to rescue – as stated by one of the nurses: ‘*our job is to save lives*’. Parental autonomy and parents’ wish for treatment in the grey zone is used as justification in the bioethical literature. However, in counselling, my experience is that it requires much more time and communicative effort to reach a joint decision with parents to opt for palliative care. The language of ‘giving a chance’ and ‘hope’ is tremendously more persuasive than ‘letting die’. The parents in our interview whose children suffered from the burden of treatment, and especially if they had survived with severe disability, raised critical questions about what parents should be allowed to ‘opt’ for.

Looking at national statistics, both fetal demise and neonatal deaths have been halved over the last two decades, as the numbers from 2001 and 2021 indicate: late fetal deaths down from 4.2 to 2.0/1000, perinatal mortality from 6.5 to 3.1/1000, and neonatal mortality from 2.8 to 1.4/ 1000 (Statistics Norway, 2023). Such improvement in perinatal care may suggest that clinicians are less habituated to see death as an acceptable outcome, strengthening an ‘urge to rescue’ on behalf of the clinicians, both in the case of viable fetuses and periviable infants.

However, pediatricians and nurses seem less eager to rescue their own, hypothetical periviable infant when asked in questionnaire studies. Whereas 9 out of 10 Norwegian pediatricians would provide life support to an infant born at 24 weeks, only 6 out of 10 would want treatment for their own infant (Hagen et al., 2012). Among Australian nurses, 23 of 24 experienced neonatal nurses would not want life support for their hypothetical infant (or grandchild) if born before 25 weeks gestation (Green et al., 2018). In Norway, 92% of infants born alive at 22–24 weeks are transferred to neonatal intensive care (Norman et al., 2023). We found that none of the

Norwegian pediatric residents surveyed wanted life support for own infant at 23 weeks, and most were negative or not sure at 24 weeks (Syltern & Markestad, 2023). This trend is also found in real life: in the Norwegian study on infants born with the cardiac malformation HLHS, 5 out of 10 mothers who chose palliative care were employed in health care, compared to only 1 out of 10 mothers who chose life-saving surgery (Vandvik & Førde, 2000).

In our interviews with clinicians, the groups brought up the rare cases where parents did not want life support. These were emotionally challenging for the clinicians. Midwives reflected on the difficulty of deciding when the *fetus/baby becomes a patient in its own right*. Obstetricians talked about the difficulty of being empathetic towards pregnant women who wanted late abortion facing minor malformations like a cleft lip and palate, or who did not want to save their dying, preterm fetus when the clinicians felt that the prospects were reasonably good. Neonatal nurses expressed that it was difficult for clinicians to stop life support, and that societal expectations made it difficult for parents to open up to the doctors about conflicting feelings once life support had been started: '*you are not allowed to say that you do not want this child*'. Parents interviewed later in the project spoke about their 'prohibited' thoughts, about ambiguity towards the prospect of survival. To speak openly about this was difficult: '*will they report me to Child welfare services'*?

Time constraints, lack of knowledge, burden of responsibility and the impossibility of understanding what life support in the neonatal intensive care unit entails were arguments given by the parents against being responsible for prenatal life support decisions. Taking this insight back into our medical practice, we tried to be more conscious about opening up for life support decisions within a shared and supported model. We experienced that parents needed time and repeated conversations, and there were differences in how actively they wanted to participate. However, some parents clearly appreciated the possibility to share their thoughts with us. Some chose, after careful reflection, to forego life support for relatively stable extremely premature babies with serious, but not catastrophic complications where we considered life support to be 'optional' due to uncertain prognosis. These parents also showed deep affection and love towards their baby, and expressed gratefulness towards the treatment team for being included in these existential dilemmas.

Parents need support, time and space for reflection to enable a well-balanced decision. This comes at a cost: ambiguity is unsettling, and maintaining the decision-making space open makes it difficult to steer the situation. In the interviews, the midwives stated that the lack of a clear decision was extremely stressing, and once a decision was made, the calm descended in the delivery room. In the NICU, we saw the need for a clear plan during the ‘interlude’, to avoid that life support is given in a half-hearted manner. Knowing that the decision is in the making, in a thorough and meaningful manner, can make it easier to go ‘all-in’ and provide optimum treatment.

We aimed for a decision making model that could compensate for the forces observed in our setting, and raised the proposal of *postponed withholding*. When possible, we argue for a thorough prenatal counselling process where parents can choose palliative care at birth. However, in the case of rapid birth, we saw the need to start life support to enable shared decision-making with parents, and at the same time counterbalance the strong driving forces towards continuing life support. By seeing life support as conditional, something that should be stopped after a period of time if a joint decision to continue is not explicitly made, our hypothesis was that this would ‘force’ clinicians to take shared decision-making seriously. Parents need to be invited into the decision-making space as equal partners, ideally through multidisciplinary support. Our aim was not to make the decision easier, but to promote ethical decision-making, and to empower parents so that they could participate in a manner that is proportional to the impact such decisions will have on their lives.

The concept of postponed withholding was presented as a target article in American Journal of Bioethics, and we received vigorous, well-articulated and constructive opposition and some support from international colleagues. Opposition came in very different directions, and reflection made it obvious to me that any proposal must be context-sensitive. *Postponed withholding* may be redundant in a setting where there are less driving forces towards life support (Cavolo, 2022). In another cultural setting, with different driving forces, our proposal risks being terribly cruel (Anani et al., 2022). As a worst case scenario, imagine a marginalised, low-resource family who has experienced discrimination, who 'sees' that their vulnerable and loved baby is being used as a ‘practice dummy’ during a week. Not feeling included nor empowered, they lack the force of raising their voice, and end up seeing their baby being sentenced to death by the doctors – their baby is no longer worthy of care and attention. Such situation is totally opposed to our model. I must emphasize that within *postponed withholding*, the goal of establishing a trusting relationship is paramount, as are the virtues of respect, compassion and kindness. You can find our response to the commentaries as an appendix.

One of the premises that we felt strengthened the claim that parents should be permitted to make life and death decisions for their 'fetus-babies', is that our society grants the opportunity to pregnant woman to do so, close to the limit of viability. However, during the interviews, both obstetricians and midwives expressed that pregnant women presumably wanted to be relieved of the decisional burden. In line with this, the maternal fetal specialists felt that it was their responsibility to make decisions of whether to rescue a viable, but dying fetus. This motivated the exploration of alternative approaches in paper 4.

Framing decisions as a conflict between parental autonomy and medical authority (legitimised by the concept of best interest) may not be a fruitful way of promoting shared deliberation and wise decisions. The application of principles and the exercise of achieving a resolution through balanced equilibrium may promote complex and rewarding academic discussions, but it might not be the best mean to solve the inherent ambiguity of real-life existential dilemmas. The primacy of reason over emotions when facing difficult decisions, as expressed by both some parents and clinicians during the interviews, is neither universally accepted. 'Detached ethics' or philosophers' confidence that reflection in the 'cool hour' yields better understanding has received critique from pragmatist philosophers. According to cognitive science, emotions help us to focus on normatively relevant features of urgent problems. Thus, contrary to the thought that having practical stakes in the outcome biases moral thinking, lacking stakes risks making moral reasoning irresponsible and unaccountable to those to whom the outcomes matter (Anderson, 2015).

To enable responsive and responsible ways of meeting ambiguous existential dilemmas, so-called 'bottom-up' approaches to ethical dilemmas might provide useful tools. Among these are feminist and care ethics, narrative ethics, pragmatist ethics and even existentialist ethics. Kaempf and Moore (2023) have recently proposed *dialogics and pragmatism* as a mean to promote understanding between physicians and bioethicists on life support decisions for extremely preterm infants, a way to *nurture a more collective consciousness*. *Dialogics* highlights that solutions to complex ethical issues cannot be entirely rational, objective, nor satisfactory to all. It recognises that language and information exchange affect us in multiple directions; 'we modify words and data as continual interactions, each of us biased, culture-influenced, but not necessarily fixed in sentiment and position' (Kaempf & Moore, 2023, p. 2). As Merleau-Ponty (2012) argued, our modes of responding to new situations are conditioned by the world in which we are immersed and by previous experiences, yet we still retain a certain amount of freedom. *Dialogics* supports *pragmatism*, where truth and validity is shown by 'experiments in living': 'We act in accordance with new moral principles, and see whether doing so solves the problem we wanted it to solve, better than the old principles, with side effects we can live with' (Anderson, 2015).

Humans tell stories to make sense of the world. Stories can open up for nuanced and complex views, but stories can also be dysfunctional and overly simplistic. Stories have the potential to embrace the wisdom found in both principlism and casuistry, and are essential to virtue ethics (Brody & Clark, 2014). Patients tell us their stories, and we reformulate their stories in patient records. What do we define as worthy of focusing on, being part of the 'figure', and what is pushed back into the 'background', judged as irrelevant? Reducing the story into mere factual data, escaping from uncertainty and ambiguity, may suit evidence based medicine and pave the way for a paternalistic approach. Through a good conversation, parents and doctors can agree on the best option, as presented by the clinician. But to use practical wisdom means taking one step further, where doctors and parents *co-interpret* and *co-construct* the judgement, and 'get the story right' through good and fitting interpretation, where both 'medical facts' and existential values are articulated and evaluated (Schultz & Flasher, 2011). During the stream of conversation and discourse, a decision may arise: agency becomes relational.

This calls for a notion of shared decision-making where power is actively shared, and values are co-articulated. Galasinski et al. (2023) see the conditions for shared decision-making as a matter of *epistemic justice.* Epistemic *injustice* refers to unjust communication, as when some stories are judged as less worthy than others, or they are simply silenced. Added to the power imbalance in the medical encounter and the prominent influence of evidence based medicine, they see a strong need for empowerment of patients to achieve a goal of shared decision-making. By their definition, shared decision-making is only '*initiated when a clinician explicitly suspends their* *communicative dominance and, in particular, their interactional advantage and offers patients an equal communicative role in their interaction'* (Galasinski et al., 2023, p. 3*)*. To reach this goal, they see various implications for clinical practices: (1) Clinical training must go beyond the development of communication skills and focus more on an understanding of healthcare as a set of social practices. (2) A stronger relationship between medicine and humanities and the social sciences is suggested: 'it is only through the insight from outside medicine that it can fully understand how it sets up its relationship with the patient' (3) Justice, equity, and agency is at core of shared decision-making.

Drawing on social sciences, Navne and Svendsen (2018) described the making of life and death decisions for extremely preterm infants as a complex process of '*careography',* rather than the balance of best interest and parental autonomy. Doing ethnographic fieldwork in the neonatal intensive care unit at Rigshospitalet in Copenhagen, Navne found that decisions were better described as *relational*, where multiples moves, spaces, temporalities and actors were involved. Many of those were staged, timed and coordinated by clinicians. She observed that in this situation, clinicians care for five different objects: care for the infant, care for the parents, care for staff, care for other infants and care for society. Is it desirable to empower parents in order to become a more active partner in this dance?

In a scoping review of the literature on prenatal counselling at the limit of viability, De Proost et al. (2022) found that the prevailing topics are parental values, uncertainty, shared decision-making and emotions. Emotions are sometimes seen as obstacles to 'reasoned' decision-making, but may also constitutes the driving force in the decision-making process. Personalisation seems to be the trend: prognosis vary, parents differ, both in informational needs and decisional preferences, so counselling must adjust accordingly. What values can we expect parents to bring into decision-making? A literature review found that many parents were concerned about long-term outcome, in terms of disabilities, medical complications and quality of life (de Boer et al., 2023). This was also a primary concern among some of the parents in our interviews, especially among those whose children suffered from severe disability. Some parents focus more on survival, others on protecting their baby against the burden of treatment. Long-term impact on the family was seen as important also by parents in our interviews: '*their lives also matter'*. In the same review, the values 'hope, responsibility, 'giving a chance' and 'wanting the best for the infant' were also mentioned by several of 'our' parents, whereas 'spirituality and 'everything done' did not arise in our interviews. In our published interviews, none of the parents had previous experience with birth at the border of viability. In later interviews, we saw that this changed perspectives dramatically. Parents with heavy burden of care expressed vividly that they did not want life support in case of extremely preterm birth in subsequent pregnancies, stating that the first time one encounter such situation, it is not possible to imagine what the infant must go through, nor the potential consequences for the family.

6.3 Implications for practice and the role of guidelines

In this project, we have advocated for the need for national policies to assure 'consistency'. Inconsistencies can be seen (1) in the involvement of parents in life support decisions, and (2) in the limits of the 'grey zone': when life support is considered *optional*, as opposed to obligatory or harmful.

There seem to be good empirical support for sharing decisions. This implies that rather than taking over the burden, we should provide support. Instead of saying: '*It is difficult for you to decide what to do, so let me decide*', our starting position should be to acknowledge the difficult situation: '*I imagine you would prefer to not be in this difficult position, but you are, and I am here to inform and support you*' (Kaempf & Moore, 2023, p. 5). Guidelines can provide guidance on the decision-making process. Geurzten et al. (2023) found that shared decision-making was the preferred model in a recent survey of Dutch perinatal health care professionals. Most preferred equal emphasis on both life support and palliative care, although some variation in preferences was observed.

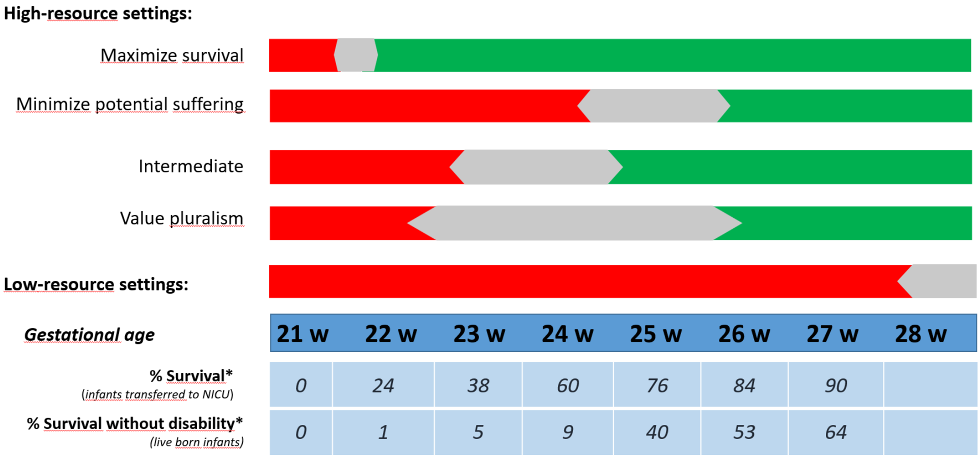
Starting out on this project, I questioned the validity of the perceived limits of the grey zone. Is it ethically justifiable to limit parental input to life support decision only to 23 weeks gestation, with no option of life support to a baby at 22^{+5} weeks with favourable risk factors, and 'obligatory' life support at 24^{+2} weeks despite unfavourable risk factors, and despite assumingly presenting similar, or even worse, prognosis?

In response to accusations of 'gestational ageism' (Wilkinson, 2012), the range of gestational age included in periviability guidelines seems to have broadened. In the UK, the guidelines issued by the Nuffield council (2006) recommended palliative care at 22 weeks, shared decision-making at 23 weeks and life support at 24 weeks. The BAPM framework (Mactier et al., 2020) adds other factors, and the range of gestational ages included is now 22 to 26 weeks. The ‘grey zone’ has shifted towards 22 weeks gestation if favourable risk factors are present, and life support is recommended for some babies at 23 weeks and most from 24 weeks. A shift in the reported lower threshold for resuscitation is seen in the UK after the publication of the framework, with greater acceptance of active treatment for infants below 23 weeks gestation (Di Stefano et al., 2021). The Ottawa guideline is similarly a prognosis-based guideline developed with heavy involvement of stakeholders and a strong research focus (Lemyre et al., 2016). Shared decision-making is recommended for gestational age 22 to 25 weeks, and is supported by meticulously developed decision-aids (Mardian et al., 2022). Both the guideline and the decision-aids are publicly available on their website, where you can find some of the illustrations from the background section of this thesis.

How do parents respond to a wider range? In Ottawa, Ding et al. (2023) observed that most parents counselled in a shared decision-making model opted for life support. Even at 22 weeks, this was the case for 14 out of 20 parents. In Portland, Kaempf et al. (2016) reported their 18-year experience with a guideline where life support was not offered at 22 weeks, with shared decision-making between 23 to 25 weeks, recommending palliative care at 23 weeks and life support at 25 weeks. They found that 37% of the parents opted for life support at 23 weeks, against the advice given in the guideline. At 24 weeks, one out of four chose palliative care, and at 25 weeks only 4% opted for palliative care (life support usually recommended). These findings seem to indicate that although a few parents opt for palliative care at the upper end of the grey zone, the trend is towards parental push for life support in the lower end.

Against the trend towards life support at lower gestational ages, Verwej et al. (2022) found that Dutch clinicians in perinatal care preferred the same limits as in the existing guideline: 24^{+0} weeks as the lower limit, and 26^{+0} weeks as the upper limit. The model preferred was a ‘gestational-aged-based-plus’ guideline, with possibilities for some personalisation. Most interestingly, de Proost et al. (2023) also interviewed Dutch adults born prematurely between 24-30 weeks’ gestation at birth about their guideline preferences. They agreed that a guideline was necessary, and all participants favoured a guideline based upon multiple prognostic factors beyond gestational age. They also stressed the importance of involving families in decision-making, and taking their care needs seriously.

What boundaries should we aim at? From an ethical standpoint, we have argued for a wide periviable grey zone. However, the boundaries should be determined by relevant stakeholders, not only by neonatologists and obstetricians, and established through a transparent, consistent and open process, preferably on a national level (Syltern et al., 2022). Despite being suggested by the former National Council of Priorities in Health in 2017, no further moves have been made in Norway to establish a new consensus.



Gestational age	21 w	22 w	23 w	24 w	25 w	26 w	27 w	28 w
% Survival* (*infants transferred to NICU*)	*0*	*24*	*38*	*60*	*76*	*84*	*90*	
% Survival without disability* (*live born infants*)	*0*	*1*	*5*	*9*	*40*	*53*	*64*	

QoL: Quality of life. NICU: Nenonatal intensive care.
*Myrhaug et al, 2019

Figure 10. Models of boundaries in the ‘grey zone’ for life support provision in extremely preterm birth

Figure 10 attempts to illustrate different models of grey zone boundaries. In Norway, I perceive to be within an ‘intermediate’, and rather narrow grey zone (23 weeks gestation, with some flexibility and room for personalisation). What would the consequences of a national process be, and do ‘we’ want to be bound by national guidelines? Will the Norwegian society choose to go in the direction of our neighbour Sweden and the UK, and provide more life support at 22 weeks gestation? The parents in our interview did not argue for lowering the threshold for starting life support. On the contrary, some argued for raising the lower threshold to 25 weeks, since it is difficult for parents to forego an option of life support: clinging to hope can have devastating effects on the family. Is it desirable to move towards a Dutch position in Norway? Verhagen (2022) also sees the possibility of discussing the boundaries of the grey zone 'with the parents as part of the continuous evaluations in the NICU, and establish/ accept them as a part of individualized care' (Verhagen, 2022, p. 2).

Rather than consistency and justice based on gestational age or strict prognosis thresholds, my emphasis has been evolving towards promoting what I now have learned to call *epistemic justice*. Guidelines or frameworks for joint decision-making in neonatology and pediatrics should be seen as crucial tools to help clinicians enter into processes and relationships that empower parents.

6.4 Limitations

When we started out this project, we intended to include several hospitals, to get a sense of the national differences. This did not happen, and the 'transferability' of the results may therefore be considered limited. Input from different hospitals could have given us more perspectives. At the same time, it is important to stress that the aim of our study was not primarily to describe the preconceived opinions of Norwegian clinicians or parents in general. We do not pretend to have revealed the inner thoughts and values of a 'representative sample' of Norwegian parents and clinicians. Due to financial and time constraints, this is lamentably still pending, and represents an opportunity for future research.

6.5 Concluding remarks

MacIntyre stated that 'I can only answer the question 'What am I to do?' if I can answer the prior question 'Of what story or stories do I find myself a part?'' (MacIntyre, 1985, p. 216). In this thesis, I have been telling my story of how I try to make sense of the expanding possibilities of neonatal intensive care. I have tried to give a good account for how these decisions can be understood in order to approach the question of what we should do in the delivery room.

Different stories could be told by those who see suffering as inherent to human existence and technology as a gift that we should use to promote life. Someone with a strong affinity towards a perspective of rights, whether it is the infant’s right to life, or the parents' rights to make decisions, would probably tell yet another story. I have also thrown myself into deep water by articulating proposals for how we should live responsibly with our expanding possibilities. Lastly, I want to express my gratitude to all those of you who have contributed to the conversations that have made this thesis possible. I look forward to continuing the dialogue.

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Paper III

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Postponed Withholding: Balanced Decision-Making at the Margins of Viability

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ABSTRACT

Advances in neonatology have led to improved survival for periviable infants. Immaturity still carries a high risk of short- and long-term harms, and uncertainty turns provision of life support into an ethical dilemma. Shared decision-making with parents has gained ground. However, the need to start immediate life support and the ensuing difficulty of withdrawing treatment stands in tension with the possibility of a fair decision-making process. Both the parental "instinct of saving" and "withdrawal resistance" involved can preclude shared decision-making. To help health care personnel and empower parents, we propose a novel approach labeled "postponed withholding." In the absence of a prenatal advance directive, life support is started at birth, followed by planned redirection to palliative care after one week, unless parents, after a thorough counseling process, actively ask for continued life support. Despite the emotional challenges, this approach can facilitate ethically balanced decision-making processes in the gray zone.

KEYWORDS
Children and families; decision-making; end-of-life issues; pediatrics: neonatology; professional-patient relationship

INTRODUCTION

Many families owe a debt of gratitude to neonatal intensive care units (NICUs) for their baby's survival and good health. Outcomes for premature babies continue to improve, in terms of both survival and short-term morbidity (Kaempf et al. 2021; Rysavy et al. 2020). Nevertheless, the risks of mortality and disability for premature babies are persistent and significant. This means that at birth, a dilemma arises on whether to start life support. In many cases, it is unclear what constitutes the best approach, both from a medical and an ethical perspective.

Being more than a medical question, there are strong reasons to involve parents in the decision-making process. In our experience, few parents are ready to take decisive part in decisions when facing imminent periviable birth. And, once life support is started, it may be hard to withdraw (Chung et al. 2016; Feltman, Du, and Leuthner 2012). Given this situation, how can we facilitate real and balanced shared decision-making in the NICU?

In this paper, we put forward the approach of "postponed withholding" (PPWH) to address this question. The basic idea of this approach is, firstly, to regard the provision of life support at birth as a *non-decision*. Secondly, after a thorough counseling process within a shared decision-making model, further provision of life support should depend on *active* parental request for continuation. We believe that this change in the NICU choice architecture will contribute to empowering parents and enable them to act based on their situation and values.

We start by introducing the basis of the medical and ethical uncertainty in decision-making at the margins of viability, and the resulting "gray zone." We move on to discuss the challenges of shared decision-making, before we introduce the PPWH-approach to address these challenges. Finally, we proceed to a critical discussion of our proposal. To illustrate the dilemmas we are facing, we will follow a hypothetical family and their baby "Mina" in the NICU.

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The Gray Zone

Helen came to the hospital with her husband Peter, presenting symptoms of threatened preterm labor at GA 23 + 4 weeks. She had become pregnant while on contraceptives, and had 3 children aged 3, 5 and 9 years. 3 hours later, Mina was born. Due to a rapid delivery, there was no possibility for proper prenatal counseling.

Advances in medical technology and improved practice over the last decades have permitted survival of extremely immature babies. Survival has been published as early as 21 weeks of gestation, improving rapidly from around 7% of live births at 22 weeks to 90% at 27 weeks (Myrhaug et al. 2019). Most ex-preemies live good lives (Saigal 2016), but infants born before 26 weeks of gestation still present high mortality and significant long-term complications, including impaired neurodevelopmental outcome and psychological and behavioral problems (Domellof et al. 2020; Myrhaug et al. 2019; O'Reilly et al. 2020).

The risk for adverse outcomes is strongly correlated with lower gestational age, but multiple other factors can also influence outcome significantly[1]. Recent models show huge variation in estimated probability of survival amongst actively treated infants, ranging from less than 10% to more than 60% for infants born at both 22 and 23 weeks of gestation (Rysavy et al. 2020). Mina's individual prognosis is impossible to predict with certainty and will continue to be uncertain for a long time: no specific assessment during the first weeks or months has shown ability to accurately predict the outcome for a given individual survivor. The outcome for each infant and family will remain essentially uncertain for years, and decision-making will continue to be ethically challenging (Hintz et al. 2018; Wong et al. 2016).

Extremely preterm infants are dependent on initial life-support to survive, and intensive care with technological support is required for months, in some cases for years, having a huge impact on family life. Due to the considerable physical, emotional, relational and financial risks for both the infant and the family, the decision of whether to start life support must respond to both clinical and ethical concerns, and a certain "gray zone" at the margins of viability seems unavoidable (Gillam et al. 2017; Leuthner 2014).

How, and by whom, should the gray zone be defined? The boundaries of the gray zone will depend on the current state of medical technology and the resources available. However, gray zone limits also depend on cultural, social and religious factors. This is reflected in the varying boundaries of the gray zone between high-income countries, as defined by when medical life support is either considered mandatory (upper limit of gray zone) or not recommended (lower limit). In Europe, there is little consensus on how active interventions after birth at 22–25 weeks of gestation should be managed (Gallagher et al. 2014).

In recent years, the use of gestational age to define the gray zone has been criticized, and newly published guidelines and frameworks from Canada and the UK have switched to prognosis-based limits: risk of death and major disability (Lemyre et al. 2016; Mactier et al. 2020). However, this has not solved the dilemma of how to define the gray zone: we still need to agree on how much risk should define the lower and upper limits. In the Canadian guideline, the upper limit (where intensive care is considered to be in the best interest of the infant, and hence, standard of care) is defined as less than 25% risk of death or survival with unacceptable severe impairment, whereas in the BAPM framework from the UK, less than 50% risk would lead to the same conclusion. How we define the exact limits of the gray zone thus comes down to a value-based question.

From an ethical point of view, the child's best interest guides decisions in pediatrics (Lantos 2018), and this is also the most important criterion for extremely preterm infants (Cavolo et al. 2020). However, the "best interest" of an infant born at the margins of viability can be extremely difficult to determine, and will therefore depend on perceptions and values of the proxy decision-makers. How can we weigh up the pros and cons for Mina? In order to survive, she will need months of intensive care and be exposed to many painful procedures, and we do not know how her quality of life will eventually turn out. On the other hand, it is difficult to claim that death is clearly in her best interest (Brunkhorst, Weiner, and Lantos 2014). Another challenge is determining how much weight we should give to the interests of others, like the family (Leuthner 2014).

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[1] Recent studies have shown that not just risk of death, but also risk of impairment is strongly associated with decreasing GA, challenging the view that GA is not a good predictor of long-term outcome (Myrhaug 2019). In a recent systematic review presented by professor Kaempf at Hot Topics in Neonatology (Washington, December 2020), improved survival seemed to be accompanied by improved long-term outcome for extremely premature babies born at GA 25 and 26 weeks, but sadly not for the most immature babies born at GA 22 to 24 weeks. The total burden of intensive care treatment also relates strongly to immaturity. As an example, the median duration of mechanical ventilation in Sweden for a baby born at GA 22 weeks was 47 days, whereas one out of three babies born at GA 26 weeks were never intubated, with a 2-day median duration of mechanical ventilation for those who were. (Norman, oral presentation at Hot Topics in Neonatology, Washington, December 2020).

Is periviable birth, where the infant is suddenly "in the wrong place at the wrong time," in a different ethical situation than other emergencies later in pregnancy and childhood? Some authors argue that preterm infants are systematically discriminated due to what is seen as the equivocal use of a lower moral status (Janvier, Bauer, and Lantos 2007), while others question whether we are taking over creation rather than saving babies at the margins of viability (Rieder 2017). This is ethically relevant, as "saving reasons" are symmetrical: benefits and harms are weighted equally, while "creative reasons" are asymmetrical: The badness of future life counts against creating that life, whereas the goodness of a future life does not count in favor of creating that life (McMahan 2009).

We are among those who consider that the prognostic and moral uncertainty, the great impact on interests of others, and the parental right to make decisions about their pregnancy and children, point toward a wide gray zone at the margins of viability (Krick et al. 2020; Wilkinson 2011). To be ethically robust, however, the gray zone should not be determined by individual doctors or NICU staff. The definition and boundaries of the periviable gray zone within a society should be consistent and transparent, and should be determined by relevant stakeholders through an open process, preferably on a national level.

For the purposes of this paper, we do not need an exact definition of the gray zone. In the following, we will discuss decision-making within any established gray zone. We will focus on the parents' role as decision-makers, and on how both parents and health care personnel (HCP) can be supported in these difficult life-and-death decisions.

MAKING DECISIONS IN THE GRAY ZONE

> *Mina appeared vital at birth and was stabilized on noninvasive ventilation and surfactant administration through a tracheal catheter. Her skin appeared immature, and she had transitory electrolyte disturbances during the first days of life. After 2 days, she was intubated due to apneas, and bilateral grade II intraventricular hemorrhage (IVH) was found, which progressed to grade III on one side. The parents stayed in the NICU around the clock and participated in the care.*

When treatment is clearly beneficial, the baby's right to treatment outweighs the parents' rights to make medical decisions for their baby. But how, and by whom, should decisions be made when the best interests of the baby are not clear? Ethicists in the US have been deferring to parental choices for decades. John Lantos summed up the ethical boundaries neatly (Lantos 2018): "We try to do what is best for children (Kopelman 1997). If we are not certain what is best, we try to do what causes the least harm (Diekema 2004). These principles lead to clear conclusions in most cases. When they do not, parents are empowered to make decisions (Gillam et al. 2017)."

But is it right, advisable, desirable—or even defendable—to ask parents like Mina's to be responsible for life-and-death decisions for their child? What does it mean for parents to feel responsible for the suffering of their child or to know that they have denied their child a chance to survive?

Views are conflicting in the empirical literature on the question of parents as the ultimate decision-makers in the NICU. Several authors have found that most parents see such decision-making as a part of their parental responsibility (Mchaffie et al. 2001; Moro et al. 2011; Sullivan, Monagle, and Gillam 2014). By contrast, a 20-year old Norwegian study found that many parents of preterm infants expressed an unwillingness to make life-and death decisions (Brinchmann, Forde, and Nortvedt 2002). Icelandic parents of extremely preterm infants claimed their right to participate in treatment decisions as "emotional experts," but there was disagreement about parents' right to demand withdrawal of life support (Einarsdottir 2009). In a recent study, we found persistent skepticism among both parents and HCP toward the idea of parents being the ultimate decision-makers. The general attitude of both groups was that parents should have a say and be included, but that the lack of necessary knowledge, experience, time, emotional stability and possible disagreement within the couple all point against placing the decision with the parents (Ursin and Syltern 2018, 2020).

Mirroring this, studies show considerable cultural differences in how actively doctors are expected to involve parents in decision-making in the gray zone. A European study from 1999 found that European neonatologists did not leave the decision to parents (Cuttini et al. 1999), and this finding was confirmed in a systematic review published in 2014 (Gallagher et al. 2014). In line with increased focus on patient-centered decisions in general, a survey conducted in Germany, Austria and Switzerland showed an increase in the involvement of parents in such decision-making from 18% in 1996–1997 to 49% in 2016 (Schneider et al. 2019).

There are several reasons for deferring the decision to parents within a defined gray zone. Having a child is the decision of the parents, and it seems fair that their interests should prevail over the preferences and potential interests of HCP. The parents are the authority in promoting the interests of the child and in protecting the child from conflicting interests. The parents will live with the long-term consequences of the decision, and they can best consider the effects on the life of siblings and their own willingness to commit to the burden of care. These concerns all point to the parents as the legitimate owners of decisions in the established gray zone.

For parents to become competent decision-makers, they must process the medical facts, acknowledge the ethical complexity, understand the implications for the infant and the family, and be able to comprehend the consequences of different options. They need to clarify their goals, values and priorities within their own context and circumstances. The two parents can have different views and values and might process information at a different pace. Both will face emotional and psychological hardship, and the mother can be physically affected by pregnancy-related illness.

To facilitate a fair decision-making process, time is essential to enable unprepared parents to take part. In Mina's case, the mother was in active labor at arrival, and there was no possibility for a proper shared decision-making process. Without life support, Mina would have died, precluding parental participation. Hence, initiation of life support was the only reversible action.

Most couples just want to be good parents, and suddenly they are placed between a rock and a hard place: while mourning the loss of their healthy pregnancy, they must choose between letting their baby die or opt for life support, with all the risks it entails. They need to unite the *logic of unconditional parental love* with the *logic of responsible parenting* (Ursin and Syltern 2020). Should "unconditional love" lead to choose life support, accepting a possible future burden of care for oneself, or does it point toward sparing their baby from suffering, and willingly face deep grief due to the loss of a child?

Parental push for initial life support might represent an autonomous, well-reflected decision based on a deep parental understanding of the situation. Their push can also come as an instinctive reaction: the *instinct of saving*. In interviews with parents, we found that parents emphasize the need to be "protected from themselves," in order to attenuate the immediate and problematic impact of the parental instinct of saving when their child is born at the border of viability (Ursin and Syltern 2020). Some parents claimed that HCP ought to protect parents against this immediate instinct, based on HCP's knowledge about the hardship for both the child and the family. The influence of social media can also fortify the primary instinct of saving, offering easy access to "miracle" stories, and the many narratives of heroic parents fighting for their baby might further reinforce the primary instinct of saving (Rozier et al. 2020).

SHARED DECISION-MAKING: EMPOWERING PARENTS

Through several conversations during the first week, within a shared decision-making approach, Helen and Peter were given support and information about the moral dilemmas and Mina's uncertain prognosis. They expressed ambiguity: they hoped for survival and a good life for her but were concerned about future disability. The doctors and nurses caring for her felt that further life support was dependent on parental wishes; all agreed that both continuing and withdrawing life support were justifiable decisions, and strived to communicate that to the parents.

Inexperienced NICU-parents are completely dependent on the support and influence of HCP. The goal should not just be to help parents understand their child's situation and prognosis, but also the meaning of the choices they face. This represents a move from a more individualistic understanding of autonomy, defined as the ability to make individual, fully informed and independent decisions, toward a model of relational autonomy, where decision-making is made in consultation with and in consideration of others (Walter and Ross 2014).

In *shared decision-making*, autonomy should not only be protected from unsolicited pressure but should also be actively promoted; family members and HCP can contribute to the development of the decision-making capacity of parents by presenting new possibilities, giving emotional support and removing social barriers (Gomez-Virseda, De Maeseneer, and Gastmans 2019). Values, perceptions and aims can be shared and still be considered as the agent's own, and parents can rely on trusted intimates and health care personnel, both for guidance and even to defer decision-making to them (Lantos 2018). For shared decision-making to succeed, parents are completely dependent on the doctor's willingness and capability to let them come into a position where they can participate decisively. *Empowerment* is indispensable for true parental autonomy in this setting. A goal of empowering parents will direct health personnel to their ethical task of creating autonomous parents: parents who are able to cope, control, find meaning, make decisions and achieve family well-being.

Poor communication skills are a challenge for proper parental involvement. A recent US study showed that when physicians were uncertain about outcomes, they presumed that families shared their goals for the child and initiated life-sustaining treatments, without discussing alternative treatment goals (Richards et al. 2018). Studies looking at specific decision-making situations found that many parents felt decisions were made by doctors, whereas doctors in the same situations felt they were made by parents (Cavolo et al. 2020). For instance, parents who state that they want their child "to be given a chance," may feel that they have left the decision with the doctor, whereas doctors may misinterpret this statement as "the parents want everything done."

Making recommendations based on the perceived best interest of the infant may at best lead to passive parental acceptance, and at its worst to misalignment between doctors and parents (e.g., "so you're telling me to kill my baby") (Marlow et al. 2021). Strategies that encourage joint decision-making, such as looking together at different options, may lead to better parent engagement and less misalignment between the conversational partners.

There is increasing focus on how doctors can fulfill their ethical responsibilities toward parents faced with "impossible" choices. In order to enable parents to make decisions in line with their values, their circumstances, their needs, the desires of others they love, and their hopes for the future, the focus has shifted from the result of the decision-making process to the decision-making process itself. This has led to a paradigm shift in the understanding of what shared decision-making is and should be, urging physicians to become ethically conscious of their role as "choice architects" (Lantos 2018).

Interestingly, questionnaire studies have shown that HCP are more reluctant to treat their own hypothetical periviable infant than the infant of others (Hagen et al. 2012). One explanation could be that doctors are biased, and that they judge the quality of life of disabled children as being worse than parents do (Lam et al. 2009). Another explanation might be that HCP stand in a more privileged position, with a deeper understanding of the moral dilemmas and better knowledge about the options and consequences of the decisions made. This raises a central question: How can doctors enable parents to step closer to such a privileged position?

TOWARD A BALANCED DECISION-MAKING PROCESS: POSTPONED WITHHOLDING

In their effort to include parents in decision-making, HCP must be aware that parental wishes expressed in the delivery room or shortly after the delivery of their extremely premature infant may represent instinctive reactions. Without life support, the infant will die. A *trial of therapy* gives a chance of survival and the opportunity to tailor the decision-making process to the family's need. Unfortunately, prognostication remains highly uncertain despite clinical and ultrasound assessments during the first weeks and months, and for parents it may be extremely difficult to ask for, or even consent to, withdrawal of life support (Leuthner 2014).

In other words, we arrive at the dilemma of needing to start life support in order to permit a proper decision-making process on the one hand, at the same time as this by default leads to continuation of intensive care unless serious complications occur, thus effectively removing the intended possibility of decision-making.

Is it possible to escape from this dilemma? Is there a way to reach an Aristotelian golden mean, where parental decision-making is acknowledged and facilitated, and the psychological treatment imperative is avoided? Our proposal is that in the absence of enough time prenatally to elaborate a well-reflected prenatal advance directive,[2] life support at birth should be started in order to allow parents to participate in the decision-making. However, we need to make an effort to see this action as a "non-decision," and as the only option to maintain the gray zone's inherent window of opportunity for one week.

At the end of the week, one possible default option would be to continue life support unless serious complications occur. Another option is a formal meeting for planned shared decision-making, without any default. However, to compensate for the forces that arise from the instinct of saving and the withdrawal resistance (*see* next section), we propose that the default action for infants, who still fall within the limits of the gray zone, should be to redirect to compassionate care after one week, unless the parents

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[2] The time frame for elaborating a prenatal advance directive needs to be individualized. Some well-prepared parents will know what is right for them upon arrival at the hospital while others may need several days.

Table 1. Core elements of PPWH compared to the traditional approach.

	Traditional approach	Postponed withholding (PPWH)
Threatening birth in defined gray-zone	Information Shared decision-making: • Prenatal steroids, transfer • Mode of delivery • Life support or comfort care at birth	Information Shared decision-making: • Prenatal steroids, transfer • Mode of delivery • Level of life support postponed until parents are sufficiently prepared
At birth	Decision at the discretion of attending neonatologist, based on best interest of infant and informed by parental wishes	Trial of life support as a **non-decision** (should not surpass "harm threshold") Comfort care possible if proper prenatal shared decision-making process
In the NICU	Parental participation in care. Decision-making at the discretion of the neonatologist. Emotional and spiritual support. "Attachment imperative." Life support continues unless complications occur. Withdrawal often require parental assent/consent	Parental participation in care, memory-making. Active counseling Emotional and spiritual support Room for attachment and hope, but also for detachment and hopelessness If infant still within defined gray-zone at 1 week of age: Withdrawal of life support unless parents explicitly ask for continuation of life support

explicitly request to continue intensive care. This would be the best out of three imperfect options, and we label this approach *postponed withholding.*

The practice of postponed withholding—*the PPWH-approach*—aims to balance the external forces interfering with parental autonomy and empower parents in the shared decision-making process. Parents should not be placed in a situation where the set-up of the NICU and expectations of their parental role precludes their opportunity to act in line with their own life project. The clearly communicated default of intensive care withdrawal after one week should make the initial life support non-decisive: the decision of whether to opt for intensive care or not is still to be made, it has not already been made. Withholding is still an option, not just withdrawal. The withholding of life support is not decided against, but postponed.

The Ethics of Withholding Versus Withdrawing Practices

Even though withdrawal and withholding have been regarded as ethically equivalent in ethical literature and guidelines, studies show that HCP find it more difficult to withdraw than to withhold treatment (Ursin 2019a). This difference between withholding and withdrawing treatment is often explained as a psychological effect and referred to in terms such as "withdrawal aversion": a non-rational preference for withholding treatment over withdrawing treatment (Wilkinson, Butcherine, and Savulescu 2019).

However, this *psychological* explanation has been criticized by both physicians and ethicists, arguing that there are *ethically* relevant differences between withholding and withdrawing treatment (Chung et al. 2016; Ursin 2019a). In the NICU, the ethics of saving versus creating points toward such a difference. The option to withhold life-saving treatment at birth can be regarded as belonging to a "window of opportunity," where the decision not to initiate life support is justifiable. By contrast, the option to withdraw life support some days later, even within a gray zone and even if the medical situation is more or less the same, can be regarded as unjustifiable.

Why? Because a treatment and care relationship has been initiated, parents might hold that the ethics of *creating* a life (not to opt for life support at birth can be justifiable) has changed to the obligations of *saving* a life (not to uphold life support for the born child is unjustifiable) (Rieder 2017). Thus, to make withdrawal—and consequently parental decision-making—ethically possible in the special situation of periviable birth, it must be clearly communicated to parents from the start that by not opposing the initiation of life support at birth they do not thereby close the window of opportunity: they still have the option of postponed withholding.

Talking of "postponed withholding" may appear to be mere moral newspeak, having no impact on the moral realities. This is not so. Postponed withholding implies an ethically significant change in NICU *practice* (Emmerich and Gordijn 2019; Ursin 2019b) [Table 1]. This change of practice is a way to clarify the ethical situation in the gray zone, where different courses of action are equally justifiable. This change is not just a matter of moral psychology, for instance "making it easier to withdraw," since the aim of PPWH is not to make it psychologically easier to withdraw treatment. The change is a matter of ethics, making it clear that starting life support at birth is not to make an ethically irreversible decision, but to enable well-reflected ethical decision-making.

Acknowledging that the difference between withholding and withdrawing can be of ethical importance, we name the ethical difficulty of withdrawing treatment once started *withdrawal resistance*. At the border of viability, withdrawal resistance can potentially lead to both under- and overtreatment. Undertreatment may result from fear of having to bear the responsibility for the future life of the infant and family, leading to a decision of not initiating life-support at birth. Overtreatment can arise due to the hardship of withdrawing treatment; continuing treatment can easily become the default and the consequence of a "non-decision."

Some parents feel that explicitly consenting to withdrawal of care is giving up on, or even killing, their child (Humikowski 2012). If the default action is to stop life support, there will be no need to force parents to consent. Postponed withholding gives parents the time to receive guidance from different perspectives and the opportunity to reflect and deliberate. Thus, withholding life support after some time rather than withholding treatment at birth will provide the parents an opportunity to cope with the situation in a meaningful way for them.

Default options are sometimes used as "nudges"; an approach to steer people in a particular direction for their own good (Schmidt and Engelen 2020). The intention of PPWH is not to nudge, but to strengthen volitional autonomy. The aim is to counteract the forces that immediately come into play when faced with the possible loss of a desired baby, and to give parents time to reflect on their goals and values. At the same time, we secure equity by starting life support for infants in the gray zone, making shared decision-making possible.

Postponed Withholding in Practice

In the setting, the treatment team felt that continuing life support was easier than withdrawing, as there was still a possibility for survival with minor disability, which was clearly communicated to the parents. In order to make it possible for parents to opt out of life support, they were asked if they would protest if the treatment team made a proposal (not a recommendation) to stop life support. They stated that they would be comfortable with such a decision. After baptism with grandparents and siblings present, treatment goal was redirected to palliative care. Mina was extubated on her mother's chest at 10 days of life, and died peacefully within 2 hours.

At birth, the immaturity of Mina's vital organs will lead to death within minutes or hours. If palliative care is chosen, her fetal aspect can promote emotional acceptance of a natural, even inevitable, death. However, thanks to technology and improvements in neonatal intensive care, we know that a chance for survival may exist. The NICU team can start respiratory support, intravenous nutrition and keep her warm in the incubator, treating her as gently as possible to try to minimize the risk of complications. This is the only potentially reversible action for Mina at birth.

After one week, Mina's prognosis is still highly uncertain; she may die from complications due to extreme immaturity, survive with severe impairment or survive with only mild impairment. Signs of brain damage or bleeds on cerebral ultrasound during the first days often serve as a trigger to start conversations with parents about treatment limitations (Brecht and Wilkinson 2015; Sheehan et al. 2017). However, even in the absence of such findings, it is ethically problematic to exclude parents from the continuous process of decision-making, which is inherent in the continued provision of intensive care in the gray zone.

Inevitably, both the emotional and psychological situation changes as time passes, and so do the actions required to reverse the initial life support. To allow a "natural death" in the NICU for Mina, the endotracheal tube needed to be actively pulled out, and parents and HCP could observe how Mina would gradually shift from a warm and active preterm baby, to become a cold and eventually dead baby on her mother's chest. Psychologically, it might have been easier for the parents if life support had never been initiated. For HCP, it might have felt easier to continue life support as long as there was hope for an acceptable outcome. The parents felt the risks for their family were too high, and their decision of not asking for further life support prevailed.

In order to enable parental decision-making, life support and optimum care should be provided in the NICU during the first week, and the counseling process with parents can either start, as in Mina's case, or continue if started prenatally. The parents will get to know their premature infant, see how treatment is carried out and how the infant responds. In addition to being counseled in a relational way by the infant's treatment team, the parents would benefit from psychological and spiritual support, allowing them to explore as a couple how to cope with the situation. This could help them to focus on the possible long-term consequences for both the child and the family, and to understand the moral meaning of the choices they face.

During this week, no decision is forced upon them. During and after initial resuscitation, the treatment team must continuously assess whether life support continues to be within the limits of the gray zone, or if it has fallen below a harm level due to serious complications and thus ought to be discontinued. If the infant dies, there will be no decisional burden for the parents to bear. While in the NICU, memory-making will take place (pictures, visits from extended family, rituals at parental discretion), acknowledging the infant's place in the family narrative, all of which may lessen the burden of bereavement if the baby dies (Kochen et al. 2020).

A planned redirection of care will encourage HCP even more to involve parents and help them clarify the ethical dilemmas and shared responsibility created by technological opportunities at the beginning of life. By the end of the first week, the parents should be better prepared to participate in the shared decision-making process for their child. If they decide to leave the decision with the treatment team, we propose that the default for an infant in the gray zone should be to redirect to palliative care. If the infant presents a better prognosis than predicted and no longer is considered to be within the established gray zone, redirection of care would no longer be an option.

Critical Discussion of the PPWH-Approach

There are several challenges to the proposed PPWH approach and its implementation. In this section, we will discuss some of these challenges.

First, is the PPWH-approach just old wine in a new bottle? How does this approach differ from already proposed or established practices? In many aspects, the proposed PPWH-approach resembles time-limited trials (TLT) in adult intensive care units. TLT is an agreement to initiate all necessary treatments or treatments with clearly delineated limitations for a certain period, in order to gain a more realistic understanding of the patient's chances for a meaningful recovery or to ascertain the patient's wishes and values (Vink et al. 2018). TLT typically applies for patients with limited reserves and quality of life, where the benefits of intensive care treatment are uncertain. The aim is to promote effective dialogue, develop consensus in decision-making and set rational boundaries to treatments based on patients' goals of care (Chang et al. 2019).

An important difference between TLT and PPWH is the special situation of the infant at the margins of viability, where the infant's interests are so profoundly dependent on and intertwined with those of the parents. In addition, when there is no time for prenatal counseling, life support at birth is the only way to ensure parental involvement in the decision.

PPWH shares similarities with other NICU approaches. Conditional offer of treatment is the basis for a "trial of therapy": the opportunity to withhold or withdraw life support tailored to the needs of the family and child (Myers, Andrews, and Meadow 2018). PPWH in a way resembles "life on approval" as described in Dutch national guidelines, which requires withdrawal of life support when facing a grim prognosis (Willems, Verhagen, and Van Wijlick 2014). PPWH is also a kind of "defined treatment period" in prescribing an active decision to reinstitute life support after a set period (Wilkinson, Butcherine, and Savulescu 2019).

To qualify as PPWH, however, it is essential that doctors and parents see the initial life support as a non-decision, followed by a period of time in the NICU where HCP engage with parents in an active process to pursue parental empowerment before a decision is made. Several forces need to be counterbalanced to accomplish this, not just the instinct of saving on behalf of parents. Another force is the continuous comparison of survival statistics between NICUs that may lead to a "benchmarking effect," making doctors favor continuation of life support in the gray zone. The technology itself can also become a self-perpetuating force, referred to as the "technological imperative" (Hofmann 2002).

The PPWH approach thus entails that, in the absence of an explicit parental request to continue life support, the default should be redirection to palliative care. In this way, both parents and the treatment team have to acknowledge that there is a choice to be made and the parental right to actively take part in that decision. If parents and the treatment team together agree that further life support should continue, they can decide whether it should be as a period of time-limited treatment or as maximum beneficial treatment.

Second, if NICUs introduce postponed withholding at the margins of viability in the sense described here, are they then expressing that the lives of these preterm babies are not worth living? In our view, they are not. What they *are* expressing is that no medical doctor has the expertise to say whether the benefits outweigh the harms. Postponed withholding, as the default position, is then backed up by two ethical concerns: first, that postponed withholding is ethically acceptable due to the harm-benefit-balance and second, that it empowers those who actually own the decision to make better decisions.

Third, the huge emotional burden on parents and the possible perceived inability to reach a sound decision may be one of the most obvious challenges. The decisions to be made are extremely high-stakes and life altering, so it is no surprise if many parents prefer not to bear the burden. However, as parents are ethically entitled to take part in these decisions, we should strive to position them to participate, despite the inherent difficulties.

We are not implying that this approach will ease the decision. Our goal is not to aim for the easiest way out, but to strive for an ethical and fair decision-making process, where parents are empowered to act in line with their life project.

Moreover, in many countries, parents are presented with similar "impossible decisions" in other contexts. When a fetal anomaly is detected halfway through a desired pregnancy, and terminating the pregnancy is an option, HCP's role switches to that of counselor. Society has placed the decisional power with the mother. Medical authority retreats; no doctor is entitled to take on the decisional burden.

A second trimester abortion places the responsibility of ending the life of the fetus on the woman. For some, it is not even an option, while for others it can be seen as a self-sacrifice on behalf of the mother, to protect both the unborn child and the family from suffering (Risoy and Sirnes 2015). Some parents choose to terminate the pregnancy, and others opt for palliative care after birth, even if the prognosis is better than for preterm infants born at 23 weeks of gestation (Mercurio, Peterec, and Weeks 2008). Others opt for maximum beneficial treatment. Although there are fundamental differences between the abortion situation and the extremely premature birth situation (that we cannot elaborate on here), the take-home message is that when reasonable people disagree about the right action and doctors are not in a privileged position to make the decision, parental values should be given a possibility to prevail. Value pluralism should be actively promoted and accepted within the established limits (Kaempf, Kockler, and Tomlinson 2018).

Fourth, introducing the postponed-withholding concept may lead to more infants receiving initial life support, and potentially more needless suffering. However, this is justified by both the medical and moral uncertainty: our objective is to permit parents to grasp the situation before any irreversible action is taken. The burden of intensive care will be of limited duration, and many parents who suffer a loss in the NICU, express their gratitude for the days they got to spend with their baby. The initial treatment is complex and requires great skill, and by facilitating practice of technical procedures and teamwork in the NICU-team, this approach might contribute to optimize care and improve outcomes for those who continue on life support. This may potentially reduce the total amount of suffering for the group of periviable infants as a whole.

Fifth, the PPWH-approach may induce emotional distress in clinicians, both for placing the burden on parents and for acting against what they may see as the child's best interests. Moral distress, the anguish experienced when clinicians are prevented from acting in accordance with their own moral judgment, is most commonly described in situations where HCP, typically nurses, feel that a patient is receiving disproportionate care ("doing too much") (Prentice et al. 2020). On the other hand, a default leading to withdrawal of respiratory support from an otherwise stable one-week old extremely immature baby might be difficult to unite with the strong imperative to save lives experienced by many neonatologists.

Moral distress may arise from tensions between personal values and the professional obligation to respect parents as decision-makers for their child. When a decision legitimately remains within the gray zone, parental values should prevail over a doctor's possible "instinct of saving." HCP who believe that the child is being harmed must be supported in their ongoing provision of care of both the infant and the family, and the potential costs and burdens to the clinician must be acknowledged. A stronger focus on the high degree of prognostic uncertainty may help doctors to feel more comfortable accepting parental decisions that differ from what they would professionally recommend (Krick et al. 2020). Attention to factors that can build moral resilience and an ethical climate characterized by self-reflection and constructive dialogue should be promoted (Prentice et al. 2018).

Postponed withholding does not solve the need for prenatal counseling and support in the decision-making process. Decisions concerning mode of delivery (vaginal or C-section), when to start antenatal steroids and whether to transfer to a hospital with a tertiary NICU must be addressed as soon as threatened birth is recognized. Comfort care at birth will still be an option for well-informed parents.

Lastly, does postponed withholding place parents in an inhumane situation? With their vulnerable and beloved infant in the incubator, will they have any other option but to choose continuation of life support and thus feel responsible if the outcome, as they see it, turns out to be bad? Laura Navne, a Danish anthropologist, may give us a hint of an answer. Doing fieldwork in a Danish NICU, she observed that even the shortest and smallest life was articulated and enacted by HCP as a morally valuable person that parents are encouraged to relate and attach to. At the same time, however, not all lives were considered by the HCP as worth saving or worth living. Periviable birth created a "maybe-life," but there was no such thing as a "maybe-parent" (Navne, Svendsen, and Gammeltoft 2018).

Attachment is imperative in the NICU, but Navne asks if we perhaps should be more coherent and balanced in our approach and make more room for detachment and hopelessness when receiving children who arrive much earlier than expected. To offer optimal initial life support, giving parents time for responsible and balanced decision-making, and presenting withholding as the default option can be a step in that direction. Moreover, if parents have been given room for detachment, doubt and the default policy of PPWH, and they still want to go all in, the decision-making process itself may promote resilience and acceptance of the outcome for the child and the family.

CONCLUSION

In neonatal care, we need transparent, consistent, documented, published and clearly communicated gray zones and decision-making processes that can accurately meet the dilemmas that modern technology entails. Within the gray zone, the acceptance of value pluralism points toward a responsible shared decision-making approach. We should empower parents and enable them to address both the short and long-term interests of the child and family and to act according to their own values and circumstances. Given a caring relationship with the treatment team and access to accurate written information, physiological and spiritual support and time for parents to reflect, we believe the postponed-withholding approach can help HCP and parents to reach robust and balanced decisions for infants born at the margins of viability.

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Paper IV

This paper is awaiting publication and is not included

Appendix

Postponed withholding:

An ethical tool for health care personnel to empower parents

Syltern, J., Ursin, L., Solberg, B., & Støen, R. (2022). Postponed Withholding: An Ethical Tool for Health Care Personnel to Empower Parents, *The American journal of bioethics: AJOB*, *22*(11), W1-W4, DOI: 10.1080/15265161.2022.2132316

We are grateful for our peers' comments on our target article (Syltern et al 2021), and welcome their valuable suggestions and challenges. A special thanks to Tissington for sharing reflections based on his personal experience, providing invaluable insight (Tissington, 2022). Reading the comments, it strikes us that there is a general agreement about shared decision making as the model of choice when faced with ethical uncertainty about whether to start, and continue, life support in the gray zone of periviability. To support parents faced with the tragic choice of letting their baby die, or to expose their baby to the burden of NICU treatment, inevitably involving hundreds of painful procedures and followed by uncertain outcome, we must act wisely. We do not believe that our framework will make the decision easy, maybe not even easier. Our aim is to foster ethically sound decision-making.

In the comments, we found elements that can enrich our model, as well as substantial misinterpretations. We appreciate the opportunity to provide further clarification by responding to some of the criticisms, and to show why *postponed withholding* is more than a euphemism.

Several commentators mentioned the need to improve shared decision-making processes, and the aim of the postponed withholding (PPWH) approach is to provide clearer ethical guidance to health care personnel (HCP). Any framework, ours included, can be misused in the absence of good will. As empathetically pointed out by Kaempf, the ultimate goal of our framework is in line with the quote from Philippa Foot: an 'attempt to connect good reasoning to goodness' (Kaempf and Dirksen 2022). However, reasoning is not enough. In order to help parents in the midst of despair, we need to truly see and pay attention to their individual needs. As the philosopher Iris Murdoch pointed out: 'I can only choose within the world I can see' (Murdoch 1971). She puts forward the need for just and loving *attention,* aiming for an unselfish, unbiased and world-disclosing perception. This is essential to our framework: most parents do not have any fixed values that are ready to be applied on situations like these. They will have to *articulate* those values in a close dialogue with HCP, in order to provide what the philosopher Charles Taylor has called 'a horizon of significance', under which self-choice becomes important. This is why we believe that 'informed nondissent', as proposed by Kon may be problematic, if not accompanied by sufficient decisional space. It does not *per se* guide HCP to empower parents to participate in shared decision-making

(Kon and Kon 2022). Actually, PPWH is set up to be an ethically balanced ‘informed nondissent’, aiming to assure that parents are sufficiently empowered before any irreversible decision is made.

Amongst others, De Proost and Kukora claim that our model discounts parents’ wishes in the antenatal encounter, and thus undermines trust (De Proost et al 2022, Kukora and Laventahl 2022). Our model does support parents who want to forego life support at birth.[1] However, since *time* is essential to the articulation of wishes and values in the midst of a shock, we must avoid rushing decisions. Seeing life support at birth as a *non-decision* gives room for an open process. To achieve the goal of empowering parents, we advocate for strengthening the prenatal counselling process by starting a continuous process of building partnership as soon as threatening periviable birth is diagnosed. We see the value of using Patient Decision Aids (PDA), and appreciate the overview provided by Pope (Pope 2022). By using PDAs to inform both about medical facts and to present the ethical dimensions, we can help parents understand the moral meaning of the choices they face. Value clarifications may guide parents through different and unknown moral landscapes, as these topics are not very present in the public debate.

The definition of the *gray zone* was beyond of the scope of our article.[2] When Gillam and Prentice ask us to address the comparative weight we should give to child-focused and parent-focused considerations, this is also an invitation to dig deeper into the gray (Gillam and Prentice 2022). Our assumption in the paper was that the gray zone is gray, because medicine cannot decide upon the best interest of the child. Since the parents have no more intimate insight into their child’s best interest than HCP at this early point in life, this leads us to put considerable weight on parent-focused considerations. However, these focuses are intimately linked: most parents will give heavy weight to their parental obligations, and thus consider what they see as a good (enough) life for their baby. On the other hand, Janvier and Barrington’s focus on ‘not discriminating’ preterm babies, will lead to a narrow gray zone or probably no gray zone at all, which again means that parent-focused considerations loose moral weight (Janvier and Barrington 2022). We acknowledge that this is a challenging ethical debate, but the argument in our paper is put forward on the premise that ‘we’ accept a gray zone. Having read the peer commentaries, it seems to us that almost all the other peers accept this premise.

There will always be a need for *responsible framing* of options, as Mercurio reminds us (Mercurio 2022): what is ethically impermissible, what is permissible and what is obligatory? If life support treatment (LST) can be considered optional, HCP should support and empower parents to participate in decision-

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[1] Parents who feel prepared to make that decision together with HCP, should definitively be given the opportunity to forego life support at birth, and be assured that this is within what a good and loving parent would do, the same goes if they express that they want a trial of life support. As stated in our article, the time needed is highly individual: ‘some well-prepared parents will know what is right for them upon arrival at the hospital while others may need several days’. Some may never want to make such decision, but hand it over to HCP.

[2] We reiterate that the definition and boundaries of the periviable gray zone within a society should be consistent and transparent, and should be determined by relevant stakeholders through an open process.

making. We support that this is a zone of parental discretion (ZPD), where we should accept the uncertainty and the plurality of values and hopes. However, when reasonable people of good will agree that LST is clearly harmful for the infant, this is no longer within the ZPD. According to Gillam and Prentice, here is 'where the real heat lies' (Gillam and Prentice 2022). We argue that by being transparent, supportive and deferring decision-making until the parents have had some time to reflect, there is better hope for achieving a relation based on trust, where it will be possible to support parents and help them come to terms with the situation. Likewise, if there is a general agreement that the future prognosis and expected burden of treatment is such that LST is clearly in the infant's best interest, there is no longer an option to stop LST.

We proposed one week as a guiding time frame, to give room for several conversations, reflection and a minimum of recovery time for the mother. As pointed out both in our article and in several comments, for an infant born towards the upper limit of ZPD, the window of opportunity may close in 24-48 hours. We need to be transparent with the parents about this from the start, as highlighted by Wilkinson (Wilkinson 2022). Frameworks must be flexible: we ought to see them as helpful tools, not obstacles to best possible clinical care. We certainly reject any treatment plan that suggests less than optimal clinical care for the infant. What is important is to see decisions about life sustaining treatment as a *process*. HCP must be in charge of the situation, providing information and guidance tailored to the individual family's need, and there may also be room for different degrees of directiveness.

Anani infers that our framework will exacerbate mistrust in the most vulnerable families (Anani et al. 2022). We appreciate this emphasis on an important dimension that we did not specifically address; the need to put an extra effort into supporting low-resource and minority families, striving towards equity. Building trust is paramount in our model, which implies meeting parents with respect and an unbiased attitude. Although studies may show that 'BIPOC mothers are more accepting of treatment and morbidities', we should be careful not to assume that a specific family in a specific situation hold such opinion. Further, offering all our technological capabilities and personal effort to save the premature children in minority families, does not seem like a good way of compensating for previous atrocities. In our view, NICU care can be potentially harmful, and the best way to care for minority families, in particular, is to make them aware of that, empower them and involve them in the decision-making.

While we agree with Carter that starting life support at birth is not morally neutral (though we have never advocated, nor stated in our target article, that all periviable babies should be resuscitated), we argue that *not starting life support when you have the means to do so* is equally morally charged (Carter 2022). Most parents have already bonded with their fetus-baby during months, and even a short life after birth may have an immense value for parents. This might give them the opportunity to come to terms with the situation, and to navigate between different hopes. Do they want to pursue hope for survival, or hope for minimizing suffering for their child? Perhaps giving a little time and empathetic support is enough to transform the initial, all-consuming hope for survival, to hope for some valuable moments of 'embodied parenthood' (Abraham and Hendriks 2017). In our opinion, this goal sufficiently justifies initiation of life support at birth. Creating memories, getting to hold their baby and co-creating a sense of family in an alienating NICU-setting, and acknowledging different manifestations of grief caused by the abrupt ending of the pregnancy may be a source of resilience for the parents (Abraham and Hendriks 2017). The moral stress on HCP caused by the potential temporality of the relation with the infant must be acknowledged and met, but the primary relation between parents and child must prevail: if the infant is still in the gray zone, the parents must be acknowledged as the rightful decision-makers.

Why do we insist on the term *postponed withholding*? PPWH differs for instance from deferred decision-making, as it requires an explicit request from the parents to continue LST. Within PPWH, HCP are obligated to see the initial LST as a *non-decision*, to empower parents and to maintain the decisional space open for a reasonable time. Parents will get time to articulate their values, and while many will pursue survival, some may not. By presenting different moral landscapes and being transparent about what the gray zone implies, our aim is to 'embrace the gray' (to use Cavolo's words), and move power from the individual *doctor* to the individual *family*. The huge variation in resistance against stopping LST is seen in the range of critique from our peers: Cavolo states that Belgian doctors find withdrawing of LST ethically preferable to withholding, while Carter claims that withdrawing carries significant moral weight, and is 'nothing like withholding LST at birth' (Carter 2022, Cavolo 2022).

What about parents who do not want to 'become empowered' and make such difficult decisions? There are probably a lot of them, and maybe our model can be accused of being naïvely rationalistic. As Lantos puts is, is there anything rational with letting your baby die? (Lantos 2022). We do not have all the answers, but we will insist that our approach is less harmful than merely letting the technological imperative govern. Perhaps Murdoch, pointing at 'Refined Love', rather than Reason or Freedom as the best candidate in our search for moral goodness, can help when facing tragic choices? (Murdoch 1971). As expressed by a mother:

> *'I did not experience this moment as a freedom but rather as a responsibility of course because this baby cannot decide for herself. We are her parents and we should make this decision. And we should decide what is best for our baby. Now in retrospect, I regard that as a great act of love. But in those hours, I thought I would die. But you do not die and you go on and you have to decide.' (Hendriks and Abraham, 2017).*

Our framework must definitively be judged by its power to connect, to illuminate, to explain and to make new and fruitful places for reflection when faced with new moral dilemmas. Our aim is to help parents and HCP to navigate the rugged shores of good parenting at the limit of viability. We thank all the commentators for their contributions toward this aim.

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Forespørsel om intervju til foreldre (første henvendelse)

Vi henvender oss til dere for å spørre om dere vil stille opp på intervju som ledd i en forskningsstudie hvor vi ønsker å se nærmere på hva som skjer når et barn blir født ekstremt prematurt, helt på grensen av levedyktighet. På grunn av behandlingsbyrde og risiko for død og varige skader hos de minste barna, er det mye diskusjon om hvor man skal sette grensen for behandling. Ulike sykehus har litt ulik praksis med tanke på hvordan beslutningene om behandling tas. På bakgrunn av de mange erfaringene dere har vært gjennom som foreldre til Adrian tror vi at deres bidrag vil være svært verdifullt, og vil kunne bidra til at denne studien får betydning for hvordan vi som helsepersonell møter foreldre i en sårbar fase.

Studien inngår i et forskningsprosjekt som har som formål å kartlegge erfaringer fra foreldre og ulike faggrupper, slik at vi kan stå bedre rustet til å ta gode beslutninger. Vi ønsker derfor å utføre intervju av foreldre som har erfaringer med ekstrem prematur fødsel. Et annet ledd i studien er fokusgruppeintervju med helsepersonell som har erfaringer med liv-død-beslutninger gjennom svangerskap og fødsel. I intervjuene vil vi gi anledning til å reflektere over temaet for forskningsprosjektet. Dette temaet vil kunne oppleves som forholdsvis følsomt. Deltagelse i studien forutsetter ingen forkunnskaper innenfor etikk, og vil i stor grad dreie seg om egne erfaringer og refleksjoner ut fra disse.

Formålet med dette forskningsprosjektet er å kartlegge erfaringer fra foreldre og ulike faggrupper, slik at vi kan stå bedre rustet til å ta gode beslutninger. Vi ønsker derfor å utføre intervju av foreldre som har erfaringer med ekstrem prematur fødsel. Et annet ledd i studien er fokusgruppeintervju med helsepersonell som har erfaringer med liv-død-beslutninger gjennom svangerskap og fødsel. I intervjuene vil vi gi anledning til å reflektere over temaet for forskningsprosjektet. Vi har forståelse for at dette temaet vil kunne oppleves som følsomt. Deltagelse i studien forutsetter ingen forkunnskaper innenfor etikk, og vil i stor grad dreie seg om egne erfaringer og refleksjoner ut fra disse.

Dette prosjektet er et samarbeidsprosjekt mellom nyfødtmedisinere ved St. Olavs Hospital, ved nyfødtlege Janicke Syltern og seksjonsoverlege Ragnhild Støen, og forskere innenfor medisinsk etikk ved NTNU, ved forsker Lars Ursin og professor Berge Solberg

Hva er bakgrunn for vår henvendelse til dere?
Vi ønsker å høre om deres erfaringer fra svangerskap, fødsel og fram til i dag. Dere kan enten intervjues sammen eller hver for dere, en eller begge.

Slik foregår intervjuet: Intervjuet blir ledet av etiker Lars Ursin og nyfødtlege Janicke Syltern. De øvrige i forskergruppa vil ikke være tilstede, men ha tilgang til en anonymisert utskrift av diskusjonen. Om det er ønskelig, kan intervjuet gjennomføres uten nyfødtlege tilstede. Intervjuet kan skje på NTNU eller annet sted etter ønske. Telefonintervju er også en mulighet. Lydopptakene vil bli skrevet ut i de nærmeste dagene etter at samtalene har funnet sted. Det vil ikke bli gjengitt navn på utskriften, for å sikre deltakernes anonymitet. Så snart prosjektet er avsluttet, vil lydopptakene bli slettet. I mellomtiden oppbevares de i låste arkivskap ved Institutt for samfunnsmedisin, NTNU.

Bruken av materialet: Informasjonen fra intervjuet vil bli analysert med tanke på publisering i form av vitenskapelige artikler, presentasjon på konferanser, i undervisning og andre offentlige sammenhenger. All formidling er basert på at det ikke skal være mulig å gjenkjenne enkeltindivider, og forskerne i prosjektet er underlagt taushetsplikt. Lydopptakene vil bli slettet ved prosjektslutt.

Deltagelse er frivillig
Vi håper du har anledning til å sette av et par timer en dag i løpet av de nærmeste ukene for å la deg intervjue. Deltakelse i studien er frivillig, basert på at du gir ditt skriftlige samtykke til å delta. Du kan når som helst trekke deg fra studien uten å måtte begrunne dette. . Dersom dere ønsker å la dere intervjue eller har spørsmål vedrørende denne henvendelsen ber vi dere om sende en e-post eller sms med e-postadresse til Lars Ursin (lars.ursin@ntnu.no; mobil 979 53 910) eller Janicke Syltern (janicke.marita.syltern@stolav.no; mobil 957 96 160), så vil vi kontakte dere.

St. Olavs Hospital, dato
Med vennlig hilsen
Janicke Syltern

Intervju i forbindelse med forskningsprosjektet *'Etiske utfordringer ved livets begynnelse: Beslutningsprosesser rundt livreddende behandling av ekstremt premature'*

Vi vil herved bekrefte dato, tid og sted for intervjuet:

Dato:

Tid:

Sted

Adresse:

Dette intervjuet vil være del av en forskningsstudie hvor vi ønsker å se nærmere på hva som skjer når et barn blir født ekstremt prematurt, helt på grensen av levedyktighet. Det finnes ingen absolutt grense for levedyktighet. Jo tidligere i svangerskapet et barn fødes, jo tyngre vil behandlingsbyrden forventes å være både for den premature og foreldrene, og risikoen for død og alvorlige senskader for barnet vil være økt. Dette har ført til variasjon i behandlingspraksis i Norge og internasjonalt. Når et barn blir født på grensen til levedyktighet må en beslutning tas om det er riktig å forsøke omfattende behandling. Hvem som skal ta denne avgjørelsen og på bakgrunn av hva er fortsatt etisk utfordrende.

I prosjektet 'Etiske utfordringer i livets begynnelse: Beslutningsprosesser rundt livreddende behandling av ekstremt premature' ønsker vi å utføre intervju av foreldre som har erfaringer med ekstrem prematur fødsel. Et annet ledd i studien er fokusgruppeintervju med helsepersonell som har erfaringer med liv-død-beslutninger gjennom svangerskap og fødsel. Formålet med studien er å kartlegge erfaringer fra foreldre og ulike faggrupper, slik at vi kan stå bedre rustet til å ta gode beslutninger.

Dette prosjektet er et samarbeidsprosjekt mellom nyfødtmedisinere ved St. Olavs Hospital, ved nyfødtlege Janicke Syltern og seksjonsoverlege Ragnhild Støen, og forskere innenfor medisinsk etikk ved NTNU, ved forsker Lars Ursin og professor Berge Solberg. Intervjuet blir ledet av etiker Lars Ursin og nyfødtlege Janicke Syltern. De øvrige i forskergruppa vil ikke være tilstede, men ha tilgang til en anonymisert utskrift av diskusjonen. Lydopptakene vil bli skrevet ut i de nærmeste dagene etter at samtalene har funnet sted. Det vil ikke bli gjengitt navn på utskriften, for å sikre deltakernes anonymitet. Så snart prosjektet er avsluttet, vil lydopptakene bli slettet. I mellomtiden oppbevares de i låste arkivskap ved Institutt for samfunnsmedisin, NTNU.

I intervjuet ønsker vi å høre om deres erfaringer fra gjennomlevd ekstremt for tidlig fødsel. Vi ønsker også å høre om hvordan dere opplevde relasjonen til barnet gjennom svangerskapet og hvilke erfaringer dere gjorde dere i møtet med helsepersonell. Et sentralt spørsmål vil være om dere hadde en opplevelse av at det foregikk en beslutningsprosess rundt grad av behandling og i hvilken grad dere var med på denne. Er man i en slik situasjon i stand til å ta gode beslutninger? Hva ville dere ta hensyn til om dere skulle ta en slik beslutning?

Deltakelse i studien er frivillig, basert på deres skriftlige samtykke til å delta. Du kan når som helst trekke deg fra studien uten å måtte begrunne dette. Dersom du har noen spørsmål før vi møtes eller du av en eller annen grunn blir forhindret i å møte er det bare å ta kontakt med Janicke Syltern, telefon 957 96160.

Etiske utfordringer ved livets begynnelse:
Beslutningsprosesser rundt livreddende behandling av ekstremt premature

Intervjuguide foreldre

Innledning: Presentasjon av forskerne og studien (bakgrunn og mål).
Oppfølgingsspørsmål/stikkord er satt i hakeparantes.

1. Kan dere fortelle om deres erfaring dere fikk et barn midtveis i svangerskapet?

[Svangerskapet; om det var noe spesielt – da du ble lagt inn med truende prematur fødsel og senere fødsel – nyfødtperiode og videre]

2. Kan dere beskrive relasjonen dere følte til fosteret gjennom svangerskapet?

[Endret det seg underveis? Endret det seg da det ble klart at det ville bli født altfor tidlig?]

3. Ved ekstrem prematur fødsel må en avgjørelse om det skal gjøres et forsøk på livreddende behandling eller om man kun skal gi lindrende behandling. Om foreldre bør ha handlingsrom og evt omfanget av dette er ikke klart.

Opplevde dere at det var et handlingsrom, og i så fall, hvordan opplevde dere dette?

4. Når beslutning om behandling tas ved ekstrem prematur fødsel:

***Hva og hvem* dreide denne avgjørelse seg om for dere, eller hva tenker dere er relevant?**

[Komplikasjoner og ubehag for barnet? Livskvalitet - på kort og lang sikt? Barnets verdighet? De særskilte etiske forpliktelsene ovenfor mennesker en skaper: Betydningen av å være født på grensen til levedyktighet/å stå ved livets begynnelse/mangelen på levd liv/foreldres reproduktive frihet.]

[Familiens beste? Barnets beste? Hvem er best egnet til å sette seg inn i barnets sted/avgjøre hva som er til barnets beste: Helsepersonell med erfaring og profesjonsetiske forpliktelser (medisinsk vs. etisk vurdering), eller foreldrene med følelsesmessig engasjement og livsvarige foreldreforpliktelser?]

6. Når beslutning om behandling tas ved ekstrem prematur fødsel:
- Bør foreldrene settes i stand til å ta den endelige beslutningen?
- Er en slik beslutning egentlig foreldrenes ansvar?

På hvilken måte ville du ønsket å få støtte og informasjon til å være med på en beslutning?

- Fakta og sannsynlig utkomme nøytralt framlagt, ta beslutning selv
- Følge legens anbefaling – implisitt samtykke
- Hjelp til å utforske egne verdier; helsepersonellets verdier; felles beslutning

Intervjuguide helsepersonell

Innledning: Presentasjon av forskerne og studien (bakgrunn og mål).

1. Kan du fortelle om en situasjon som har påvirket deg, hvor helsepersonell og vordende foreldre sto ovenfor et vanskelig etisk valg?

2. Foreldre har et visst handlingsrom i forhold til svangerskapsavslutning.

- Har du erfaringer fra situasjoner hvor omfanget av dette handlingsrommet, og hvilke hensyn som bør spille inn, har vært uklart?

- Kan du gi eksempler på reelle valg foreldre har blitt stilt overfor?

Foreldre har et visst handlingsrom for liv-død beslutninger for fosteret gjennom svangerskapet, som fri abort fram til uke 12 og terminering ved alvorlige tilstander hos foster fram til uke 22.

Kan du fortelle om erfaringer med foreldre som har stått i slike beslutninger?

[Hvilke hensyn har man vektlagt? Har du refleksjoner angående hva som former dette handlingsrommet for ulike foreldre og i ulike situasjoner? Hvordan bør man som helsepersonell ivareta foreldrenes og fosterets/barnets interesser?]

3. Ved ekstrem prematur fødsel må en avgjørelse om initial resuscitering eller palliativ behandling tas. Hvilket handlingsrom foreldrene her bør ha, er ikke klart.

Hvordan vil du beskrive foreldrenes handlingsrom ved fødsel av et ekstremt prematurt barn ved din avdeling?

[F.eks: I hvor stor grad er de medbestemmende på forløsningsmetode?]

4. Når beslutning om behandling tas ved ekstrem prematur fødsel: *Hva og hvem* dreier en slik avgjørelse seg om?

[Gi gjerne eksempler fra samtaler med foreldre. Hva diskuteres med mor? 12Hva: Komplikasjoner og ubehag for barnet? Livskvalitet - på kort og lang sikt? Barnets verdighet? De særskilte etiske forpliktelsene ovenfor mennesker en skaper: Betydningen av å være født på grensen til levedyktighet/å stå ved livets begynnelse/mangelen på levd liv/foreldres reproduktive frihet. Hvem: Familiens beste? Barnets beste? Hva om disse synes å være i konflikt? Hvem er best egnet til å sette seg inn i barnets sted/avgjøre hva som er til barnets beste: Helsepersonell med erfaring og profesjonsetiske forpliktelser (medisinsk vs. etisk vurdering), eller foreldrene med følelsesmessig engasjement og livsvarige foreldreforpliktelser?]

5. Når beslutning om behandling tas ved ekstrem prematur fødsel:

Bør *foreldrene* være de som tar den endelige avgjørelsen?

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