



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

Janicke Syltern, Lars Ursin, Berge Solberg & Ragnhild Støen

To cite this article: Janicke Syltern, Lars Ursin, Berge Solberg & Ragnhild Støen (2021): Postponed Withholding: Balanced Decision-Making at the Margins of Viability, The American Journal of Bioethics, DOI: [10.1080/15265161.2021.1925777](https://doi.org/10.1080/15265161.2021.1925777)

To link to this article: <https://doi.org/10.1080/15265161.2021.1925777>



© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC



Published online: 17 May 2021.



Submit your article to this journal [↗](#)



Article views: 335



View related articles [↗](#)



View Crossmark data [↗](#)

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

Janicke Syltern^{a,b} , Lars Ursin^c , Berge Solberg^c , and Ragnhild Støen^{a,b} 

^aNorwegian University of Science and Technology; ^bSt Olavs Hospital University Hospital in Trondheim; ^cThe Norwegian University of Science and Technology

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.

CONTACT Janicke Syltern  janicke.m.syltern@ntnu.no  Department of Clinical and Molecular Medicine, Norwegian University of Science and Technology, Trondheim 7491, Norway; Department of Neonatology, St Olavs Hospital University Hospital in Trondheim, Trondheim, 7006, Norway.

© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

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 significantly¹. 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.

¹Recent 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).

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).

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 defensible—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

²The 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: <ul style="list-style-type: none"> • Prenatal steroids, transfer • Mode of delivery • Life support or comfort care at birth 	Information Shared decision-making: <ul style="list-style-type: none"> • 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 pre-natal 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 pre-term 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.

ACKNOWLEDGMENTS

Thanks to the editor and four anonymous reviewers of AJOB for very valuable comments and suggestions that significantly improved this article. Thanks also to Håkon

Bergseng, consultant neonatologist at St. Olavs Hospital, for valuable contributions.

DISCLOSURE STATEMENT

Dr. Syltern, Associate Professor Ursin, Prof. Solberg and Prof. Støen have significantly participated in the development, preparation, and revision of this manuscript. None of the authors has personal or scientific conflicts of interest. They all agreed to the final version of this paper.

FUNDING

This work was supported by grants from St. Olavs Hospital, Trondheim, Norway and The Liaison Committee between the Central Norway Regional Health Authority and the Norwegian University of Science and Technology, Trondheim, Norway [SO: 90278900b].

ORCID

Janicke Syltern  <http://orcid.org/0000-0001-8858-3025>

Lars Ursin  <http://orcid.org/0000-0001-5892-2823>

Berge Solberg  <http://orcid.org/0000-0001-6434-082X>

Ragnhild Støen  <http://orcid.org/0000-0001-8814-0451>

REFERENCES

- Brecht, M., and D. J. C. Wilkinson. 2015. The outcome of treatment limitation discussions in newborns with brain injury. *Archives of Disease in Childhood – Fetal and Neonatal Edition* 100 (2):F155–F60. doi:10.1136/archdis-child-2014-307399.
- Brinchmann, B. S., R. Forde, and P. Nortvedt. 2002. What matters to the parents? A qualitative study of parents' experiences with life-and-death decisions concerning their premature infants. *Nursing Ethics* 9 (4):388–404. doi:10.1191/0969733002ne523oa.
- Brunkhorst, J., J. Weiner, and J. Lantos. 2014. Infants of borderline viability: The ethics of delivery room care. *Seminars in Fetal and Neonatal Medicine* 19 (5):290–5. doi:10.1016/j.siny.2014.08.001.
- Cavolo, A., B. Dierckx De Casterle, G. Naulaers, and C. Gastmans. 2020. Ethics of resuscitation for extremely premature infants: A systematic review of argument-based literature. *Journal of Medical Ethics* XX:XX–XX. doi:10.1136/medethics-2020-106102.
- Chang, D., J. Parrish, N. Kamangar, et al. 2019. Time-limited trials among critically ill patients with advanced medical illnesses to reduce nonbeneficial intensive care unit treatments: Protocol for a multicenter quality improvement study. *JMIR Research Protocols* 8 (11): e16301. doi:10.2196/16301.
- Chung, G. S., J. D. Yoon, K. A. Rasinski, and F. A. Curlin. 2016. Us physicians' opinions about distinctions between withdrawing and withholding life-sustaining treatment. *Journal of Religion and Health* 55 (5):1596–606. doi:10.1007/s10943-015-0171-x.

- Cuttini, M., M. Rebagliato, P. Bortoli, G. Hansen, R. de Leeuw, S. Lenoir, J. Persson, M. Reid, M. Schroell, U. de Vonderweid, et al. 1999. Parental visiting, communication, and participation in ethical decisions: A comparison of neonatal unit policies in Europe. *Archives of Disease in Childhood – Fetal and Neonatal Edition* 81 (2):F84–F90. doi:10.1136/fn.81.2.F84.
- Diekema, D. S. 2004. Parental refusals of medical treatment: The harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics* 25 (4):243–64. doi:10.1007/s11017-004-3146-6.
- Domellof, E., A. M. Johansson, A. Farooqi, M. Domellof, and L. Ronnqvist. 2020. Risk for behavioral problems independent of cognitive functioning in children born at low gestational ages. *Frontiers in Pediatrics* 8:311. doi:10.3389.
- Einarsdottir, J. 2009. Emotional experts: Parents' views on end-of-life decisions for preterm infants in Iceland. *Medical Anthropology Quarterly* 23 (1):34–50. doi:10.1111/j.1548-1387.2009.01036.
- Emmerich, N., and B. Gordijn. 2019. Beyond the equivalence thesis: How to think about the ethics of withdrawing and withholding life-saving medical treatment. *Theoretical Medicine and Bioethics* 40 (1):21–41. doi:10.1007/s11017-019-09478-9.
- Feltman, D. M., H. Du, and S. R. Leuthner. 2012. Survey of neonatologists' attitudes toward limiting life-sustaining treatments in the neonatal intensive care unit. *Journal of Perinatology* 32 (11):886–92. doi:10.1038/jp.2011.186.
- Gallagher, K., J. Martin, M. Keller, and N. Marlow. 2014. European variation in decision-making and parental involvement during preterm birth. *Archives of Disease in Childhood – Fetal and Neonatal Edition* 99 (3):F245–F49. doi:10.1136/archdischild-2013-305191.
- Gillam, L., D. Wilkinson, V. Xafis, and D. Isaacs. 2017. Decision-making at the borderline of viability: Who should decide and on what basis? *Journal of Paediatrics and Child Health* 53 (2):105–11. doi:10.1111/jpc.13423.
- Gomez-Virseda, C., Y. De Maeseneer, and C. Gastmans. 2019. Relational autonomy: What does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC Medical Ethics* 20 (1):76. doi:10.1186/s12910-019-0417-3.
- Hagen, E. M., Ø. B. Therkelsen, R. Førde, O. Aasland, A. Janvier, and T. W. R. Hansen. 2012. Challenges in reconciling best interest and parental exercise of autonomy in pediatric life-or-death situations. *The Journal of Pediatrics* 161 (1):146–51. doi:10.1016/j.jpeds.2012.01.017.
- Hintz, S. R., B. R. Vohr, C. M. Bann, H. G. Taylor, A. Das, K. E. Gustafson, K. Yolton, V. E. Watson, J. Lowe, M. E. DeAnda, et al. 2018. Preterm neuroimaging and school-age cognitive outcomes. *Pediatrics* 142 (1):e20174058. doi:10.1542/peds.2017-4058.
- Hofmann, B. 2002. Is there a technological imperative in health care? *International Journal of Technology Assessment in Health Care* 18 (3):675–89. doi:10.1017/S0266462302000491.
- Humikowski, C. A. 2012. Confession. *Archives of Pediatrics and Adolescent Medicine* 166 (7):593–4. doi:10.1001/archpediatrics.2012.28.
- Janvier, A., K. L. Bauer, and J. D. Lantos. 2007. Are newborns morally different from older children? *Theoretical Medicine and Bioethics* 28 (5):413–25. doi:10.1007/s11017-007-9052-y.
- Kaempf, J. W., N. Kockler, and M. W. Tomlinson. 2018. Shared decision-making, value pluralism and the zone of parental discretion. *Acta Paediatrica* 107 (2):206–8. doi:10.1111/apa.13971.
- Kaempf, J., M. Morris, E. Steffen, L. Wang, and M. Dunn. 2021. Continued improvement in morbidity reduction in extremely premature infants. *Archives of Disease in Childhood: Fetal and Neonatal Edition* 106: 265–270.
- Kochen, E. M., F. Jenken, P. A. Boelen, L.M.A. Deben, J.C. Fahner, A. van den Hoogen, S.C.C.M. Teunissen, K. Geleijns, M.C. Kars. 2020. When a child dies: A systematic review of well-defined parent-focused bereavement interventions and their alignment with grief- and loss theories. *BMC Palliative Care* 19 (1):28. doi:10.1186/s12904-020-0529-z.
- Kopelman, L. M. 1997. The best-interests standard as threshold, ideal, and standard of reasonableness. *Journal of Medicine and Philosophy* 22 (3):271–89. doi:10.1093/jmp/22.3.271.
- Krick, J. A., J. S. Hogue, T. R. Reese, and M. A. Studer. 2020. Uncertainty: An uncomfortable companion to decision-making for infants. *Pediatrics* 146 (Supplement 1): S13–s17. nodoi:10.1542/peds.2020-0818E.
- Lam, H. S., S. P. S. Wong, F. Y. B. Liu, H. L. Wong, T. F. Fok, and P. C. Ng. 2009. Attitudes toward neonatal intensive care treatment of preterm infants with a high risk of developing long-term disabilities. *Pediatrics* 123 (6):1501–8. doi:10.1542/peds.2008-2061.
- Lantos, J. D. 2018. Ethical problems in decision making in the neonatal ICU. *New England Journal of Medicine* 379 (19):1851–60. doi:10.1056/NEJMra1801063.
- Lemyre, B., T. Daboval, S. Dunn, M. Kekewich, G. Jones, D. Wang, M. Mason-Ward, and G. P. Moore. 2016. Shared decision making for infants born at the threshold of viability: A prognosis-based guideline. *Journal of Perinatology* 36 (7):503–9. doi:10.1038/jp.2016.81.
- Leuthner, S. R. 2014. Borderline viability controversies in caring for the extremely premature infant. *Clinics in Perinatology* 41 (4):799–814. doi:10.1016/j.clp.2014.08.005.
- Mactier, H., S. E. Bates, T. Johnston, C. Lee-Davey, N. Marlow, K. Mulley, L. K. Smith, M. To, and D. Wilkinson. 2020. Perinatal management of extreme preterm birth before 27 weeks of gestation: A framework for practice. *Archives of Disease in Childhood – Fetal and Neonatal Edition* 105 (3):232–9. doi:10.1136/archdischild-2019-318402.
- Marlow, N., C. Shaw, K. Connabeer, N. Aladangady, K. Gallagher, and P. Drew. 2021. End-of-life decisions in neonatal care: A conversation analytical study. *Archives of Disease in Childhood – Fetal and Neonatal Edition* 106 (2):184–319544. doi:10.1136/archdischild-2020-319544.
- Mchaffie, H. E., I. A. Laing, M. Parker, and J. Mcmillan. 2001. Deciding for imperilled newborns: Medical authority or parental autonomy? *Journal of Medical Ethics* 27 (2):104–9. doi:10.1136/jme.27.2.104.
- McMahan, J. 2009. Asymmetries in the morality of causing people to exist. In *Harming future persons*, eds Roberts, MA and Wasserman, DT, 49–68. Dordrecht: Springer Netherlands.

- Mercurio, M. R., S. M. Peterec, and B. Weeks. 2008. Hypoplastic left heart syndrome, extreme prematurity, comfort care only, and the principle of justice. *Pediatrics* 122 (1):186–9. doi:10.1542/peds.2008-0143.
- Moro, T., K. Kavanaugh, T. A. Savage, M. R. Reyes, R. E. Kimura, and R. Bhat. 2011. Parent decision making for life support for extremely premature infants: From the prenatal through end-of-life period. *Journal of Perinatal & Neonatal Nursing* 25 (1):52–60. doi:10.1097/JPN.0b013e31820377e5.
- Myers, P., B. Andrews, and W. Meadow. 2018. Opportunities and difficulties for counseling at the margins of viability. *Seminars in Fetal and Neonatal Medicine* 23 (1):30–4. doi:10.1016/j.siny.2017.11.001.
- Myrhaug, H. T., K. G. Brurberg, L. Hov, and T. Markestad. 2019. Survival and impairment of extremely premature infants: A meta-analysis. *Pediatrics* 143 (2):e20180933. doi:10.1542/peds.2018-0933.
- Navne, L. E., M. N. Svendsen, and T. M. Gammeltoft. 2018. The attachment imperative: Parental experiences of relation-making in a danish neonatal intensive care unit. *Medical Anthropology Quarterly* 32 (1):120–37. doi:10.1111/maq.12412.
- O'Reilly, H., S. Johnson, Y. Y. Ni, D. Wolke, and N. Marlow. 2020. Neuropsychological outcomes at 19 years of age following extremely preterm birth. *Pediatrics* 145 (2):e20192087. doi:10.1542/peds.2019-2087.
- Prentice, T. M., L. Gillam, P. G. Davis, and A. Janvier. 2018. The use and misuse of moral distress in neonatology. *Seminars in Fetal and Neonatal Medicine* 23 (1): 39–43. doi:10.1016/j.siny.2017.09.007.
- Prentice, T. M., L. Gillam, A. Janvier, and P. G. Davis. 2020. How should neonatal clinicians act in the presence of moral distress? *Archives of Disease in Childhood – Fetal and Neonatal Edition* 105 (4):348–9. doi:10.1136/archdischild-2019-317895.
- Richards, C. A., H. Starks, M. R. O'Connor, E. Bourget, R. M. Hays, and A. Z. Doorenbos. 2018. Physicians perceptions of shared decision-making in neonatal and pediatric critical care. *American Journal of Hospice and Palliative Medicine* 35 (4):669–76. doi:10.1177/1049909117734843.
- Rieder, T. N. 2017. Saving or creating: Which are we doing when we resuscitate extremely preterm infants? *The American Journal of Bioethics* 17 (8):4–12. doi:10.1080/15265161.2017.1340988.
- Risoy, S. M., and T. Sirnes. 2015. The decision: Relations to oneself, authority and vulnerability in the field of selective abortion. *Biosocieties* 10 (3):317–40. doi:10.1057/biosoc.2014.39.
- Rozier, M. D., C. E. Willison, R. R. Anspach, et al. 2020. Paradoxes of professional autonomy: A qualitative study of U.S. Neonatologists from 1978-2017. *Sociology of Health and Illness* 42 (8):1821–1836. doi:10.1111/1467-9566.13169.
- Rysavy, M. A., J. D. Horbar, E. F. Bell, L. Li, L. T. Greenberg, J. E. Tyson, R. M. Patel, W. A. Carlo, N. E. Younge, C. E. Green, et al. 2020. Assessment of an updated neonatal research network extremely preterm birth outcome model in the vermont oxford network. *JAMA Pediatrics* 174 (5):e196294. doi:10.1001/jamapediatrics.2019.6294.
- Saigal, S. 2016. In their own words: Life at adulthood after very premature birth. *Seminars in Perinatology* 40 (8): 578–83. doi:10.1053/j.semperi.2016.09.010.
- Schmidt, A. T., and B. Engelen. 2020. The ethics of nudging: An overview. *Philosophy Compass* 15 (4):12658. doi:10.1111/phc3.12658.
- Schneider, K., B. Metze, C. Buhrer, M. Cuttini, and L. Garten. 2019. End-of-life decisions 20 years after euronc: Neonatologists' self-reported practices, attitudes, and treatment choices in germany, switzerland, and austria. *Journal of Pediatrics* 207:154–60. doi:10.1016/j.jpeds.2018.12.064.
- Sheehan, J. W., M. Pritchard, R. J. Heyne, L. S. Brown, M. A. Jaleel, W. D. Engle, P. J. Burchfield, and L. P. Brion. 2017. Severe intraventricular hemorrhage and withdrawal of support in preterm infants. *Journal of Perinatology* 37 (4):441–7. doi:10.1038/jp.2016.233.
- Sullivan, J., P. Monagle, and L. Gillam. 2014. What parents want from doctors in end-of-life decision-making for children. *Archives of Disease in Childhood* 99 (3):216–20. doi:10.1136/archdischild-2013-304249.
- Ursin, L. 2019a. Withholding and withdrawing life-sustaining treatment: Ethically equivalent? *The American Journal of Bioethics* 19 (3):10–20. doi:10.1080/15265161.2018.1561961.
- Ursin, L. 2019b. Withholding versus withdrawing treatment: Why medical guidelines should omit “theoretical equivalence”. *The American Journal of Bioethics* 19 (6): W5–W9. doi:10.1080/15265161.2019.1607920.
- Ursin, L., J. Syltern. 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–S73. doi:10.1542/peds.2018-0478H.
- Ursin, L., and J. Syltern. 2020. Protect us from ourselves: Balancing the parental instinct of saving. *Nursing Ethics* 27 (5):1282–96. doi:10.1177/0969733019871691.
- Vink, E. E., E. Azoulay, A. Caplan, E. J. O. Kompanje, and J. Bakker. 2018. Time-limited trial of intensive care treatment: An overview of current literature. *Intensive Care Medicine* 44 (9):1369–77. doi:10.1007/s00134-018-5339-x.
- Walter, J. K., and L. F. Ross. 2014. Relational autonomy: Moving beyond the limits of isolated individualism. *Pediatrics* 133 (Supplement):S16–S23. doi:10.1542/peds.2013-3608D.
- Wilkinson, D. J. 2011. A life worth giving? The threshold for permissible withdrawal of life support from disabled newborn infants. *The American Journal of Bioethics* 11 (2):20–32. doi:10.1080/15265161.2010.540060.
- Wilkinson, D., E. Butcherine, and J. Savulescu. 2019. Withdrawal aversion and the equivalence test. *The American Journal of Bioethics* 19 (3):21–8. doi:10.1080/15265161.2019.1574465.
- Willems, D. L., A. A. Verhagen, and E. Van Wijlick. 2014. Infants' best interests in end-of-life care for newborns. *Pediatrics* 134 (4):e1163–e1168. doi:10.1542/peds.2014-0780.
- Wong, H. S., S. Santhakumaran, F. M. Cowan, N. Modi, and G. Medicines For Neonates Investigator. 2016. Developmental assessments in preterm children: A meta-analysis. *Pediatrics* 138 (2):e20160251. doi:10.1542/peds.2016-0251.