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Between 'fetal viability' and the 'viability of families': Decision-making for extremely premature infants in Spain

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ABSTRACT

Neonatal expertise and technologies have been perfected over the last decades, improving preterm infants' survival rates and allowing a gradual reduction in the gestational age limits of fetal viability. Using the concept of viability as a starting point, we analyze decision-making processes regarding extremely preterm newborns at the limits of viability. Drawing on extensive ethnographic fieldwork in a public hospital in Barcelona between March and November 2023, we examine the knowledge forms, rationalities and values that healthcare workers employ when guiding families in decisions about infants' viability. In this respect, we thoroughly analyze the actors involved and the extent of their agency. The findings point out that although neonatal decisions in Spain are embedded in an ethos of "individual responsible choice," they are in practice collectively produced and shaped by two main (sometimes conflicting) drivers: the perceived means of families to face the challenges posed by infants with high chances of severe sequelae (the 'viability of families'), and the preterm patients' perceived "will to live" ('fetal viability'). The study highlights how viability in this context needs to be understood within the structural socioeconomic constraints and struggles to make and raise families in Spain.

1. Introduction

> "It's not the same [to think of] prematurity at 23 weeks [of gestation] within a family of a teenage mother who didn't want the pregnancy, as in the case of a lady [*señora*] who has done I don't know how many IVF [cycles] … I think all these aspects must be considered when deciding what to do" (Natalia, neonatologist).

A birth is generally considered preterm when an infant is born before the due date calculated for a complete pregnancy, which is from 38 to 42 weeks of gestation according to the World Health Organization (2023). Before that, births are labeled as 'preterm' and classified into different categories depending on the gestational weeks (GWs). Extremely preterm babies, those born at less than 28 GWs, are the most challenging patients due to risks to their survival and the likelihood of both short- and long-term health issues.

Extremely preterm babies pose significant challenges regarding the decision of whether to offer active treatment or not after birth and the GWs at which they can be considered 'viable.' 'Viability' is defined by medical scholarship as the point from which a fetus is mature enough to potentially survive outside the womb, with or without external support (López Moratalla, 2011). Despite consensus on the definition of 'viability,' legislation and medical protocols worldwide establish the limit of viability at different GWs. The underlying reason is that 'viability' reaches far beyond biomedical considerations to include available medical resources and cultural norms and ideologies (Pignotti, 2009; Stanojevic, 2021). This aspect has led some scholars to conceptualize viability as a "cultural construction" (Morgan, 2002, 43).

As we demonstrate, while the existing medical guidelines on GWs and decision-making aim to provide clarity to healthcare workers and parents, these definitions and limits are in constant negotiation in gynecological wards and neonatal intensive care units (NICUs). The quotation highlighted above illustrates the complex interplay of reproductive trajectories, perceived desires, and the availability of resources, whether material or emotional, when determining action at the limits of viability.

We explore how professional decisions are made in the context of birth at the limits of viability in Spain, asking the following questions: What rationalities operate when informing and guiding parents who are facing the possibility of an extremely preterm birth? What actors have a say in this decision, and what logics underpin their perspectives? Moreover, what do their rationalities tell us about the politics of

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neonatal life and death within the Spanish context?

We engage with critical approaches to the notion of 'fetal viability' (Pignotti, 2009) as a purely medical assessment to highlight the collective and social nature of letting individuals in and out of society, which we argue constitute "acts of belonging" (Gammeltoft, 2014). We therefore argue that 'viability' cannot be disentangled from contextually specific social and cultural aspects and that a careful analysis of its different layers highlights broader social values, inequalities, and struggles at different levels.

2. Pregnancy and neonatal care regulations in Spain

Spain has undergone a paradigmatic shift in family formation patterns over the last decades. In less than 50 years, the country transitioned from having one of the highest total fertility rates in Europe (2.77 in 1978) to having one of the lowest (1.19 in 2024), reflecting a move from the "baby boom" era to what has been termed "structural infertility" (Briggs et al., 2012). This period has also seen a significant rise in average age at first-time motherhood, now among the highest in the world at 32.6 years (INE, 2022). Spain stands out as the European country with the highest proportion of women having children at age 40 or older, a rate that is double the European average (Eurostat, 2023).

While demographic transitions leading to a reduction in fertility rates are also observed worldwide, Spain's extreme situation is often attributed to a combination of factors. These include limited access to affordable housing, precarious employment conditions, high unemployment rates, and gender disparities in domestic work (San Román, 2020). The consequence is that when women achieve the "right conditions" to become mothers, they often need to turn to reproductive technologies (Alvarez and Marre, 2021), which increase the risk of preterm birth and other adverse neonatal outcomes (Fineman et al., 2023).

The structural struggles of the Spanish population to have children contrast with the country's position as one of the most liberal European countries regarding family formation options. Same-sex marriage was legalized in 2005, making Spain the third country in Europe to do so, and both national adoption and assisted reproduction techniques (except for surrogacy) are available regardless of sexual orientation and marital status. Notably, Spain has the second greatest number of international adoptions, only behind the United States (Briggs and Marre, 2009). Additionally, Spain has a highly developed private fertility industry, which performs over 160,000 assisted reproduction cycles annually, the highest number in the European Union (Spanish Fertility Society, 2021).

Spain also stands out for having one of the most liberal abortion laws in Europe. Organic Law 2/2010 on Sexual and Reproductive Health and the Voluntary Interruption of Pregnancy (Spanish Official State Gazette, 2010) establishes a limit of 14 weeks for voluntary interruption of pregnancy and 22 weeks for interruption in cases where "there is a serious life or health risk of the pregnant woman" or "a risk of serious anomalies in the fetus" (7). The same law states that the threshold of fetal viability is "around" the 22nd week of gestation. In this context, reproduction is constructed as a rational choice, governed by a moral regime that emphasizes individual responsibility for the outcomes of this decision (Alvarez and Marre, 2021). This state of affairs is the result of the liberal policies and feminist ideologies of Western societies, where the reproductive domain is understood as a space of autonomy in which individuals have the right to make their own choices (Christoffersen-Deb, 2012; Gammeltoft, 2014). Nevertheless, we sustain that in the NICU of our study, reproductive decisions concerning viability are collectively constructed, revealing that individuals under these circumstances are inevitably "tied into social worlds and obligations" (Gammeltoft, 2014, 16).

The analysis of our fieldwork data challenges the notions of 'choice' and 'individual responsibility' that are at the core of the neonatal politics of life and death in Spain. The neonatal medical protocols of the Spanish Society of Neonatology (SeNeo) establish that babies born between a gestational age of 23 GWs and one of 23 weeks and six days (23^0 and 23^6) are eligible for resuscitation and medical treatment after birth only with parental consent. Medical literature and practice usually refer to the range between 23^0 and 23^6 GWs as "the grey zone," due to the uncertainty of health outcomes at this GW (Seri and Evans, 2008; Wilkinson, 2016). Resuscitation is recommended for babies born at 24 GWs after an "individualized decision in reference centers, in the presence of good perinatal conditions and in consensus with the family" (Fernández Trisac, 2023, 57), and 'comfort care' alone—without resuscitation—is indicated for babies born before 23 GWs. To the best of our knowledge, there are no reports that explain the underlying reasons for the disparity between the Spanish law's criteria for fetal viability around 22 GWs and SeNeo protocol's recommendation of limiting interventions to 'comfort care' before 23 GWs.

Progress in obstetric and neonatal care has led to a gradual reduction in the gestational age limits of viability, from 28 weeks in the early 1990s to 22 weeks in some countries (Pescador et al., 2021). Nevertheless, reducing mortality without increasing morbidity remains a huge challenge (García-Muñoz et al., 2014). The health sequelae that extremely preterm infants may face in both the short and long terms underscore the importance of families' resources in coping with such difficulties. This factor is particularly salient in the Spanish context, where around 30% of children are classified as being at risk of poverty and social exclusion because of low household income (INE, 2023).

There are specialized public and private centers across Spain that support infant development. In the region of Catalonia, these structures are called Centers for Infant Development and Early Assistance (CDIAP), where professionals specializing in neurodevelopment, such as psychologists, physiotherapists, and speech therapists, follow children's development until they turn six. This service is offered to children with various developmental issues.

The Care of Children with Serious Illness subsidy (CUME) offers financial aid to parent(s) of preterm infants born before 32 GWs or under 1,500 g (Spanish Official State Gazette, Royal Decree 1148/2011). In these cases, one of the working parents, can reduce their working hours by between 50 and 99 percent with no salary reduction. Infants diagnosed with 65 percent or more disability may receive this subsidy until they turn 26. While these resources may help families of preterm babies, they are not always enough to cover their special needs, particularly in the mid and long term. For this reason, families often continue or reinforce professional follow-up of their infants' development in private centers, an additional support that not every family has the means to afford.

3. The contested nature of fetal viability

Since the creation of the first incubators in the 19th century, biotechnologies have enabled the emergence of specialized medical care that has resulted in the 'production' of two new types of patient: the fetal patient (Casper, 1992) and the preterm patient (Landzelius, 2006), both concepts inevitably associated with the sociotechnical notions of intra- and extrauterine life.

Birth, as a transformative process marking the transition from one social status to another, can be conceptualized as a rite of passage (Van Gennep, 1909). It symbolizes the individual's initial contact with society after crossing the threshold of the womb (Turner, 1969), while simultaneously signaling the transition of the birthing person into motherhood (Davis-Floyd, 2003). Extremely preterm birth 'alters' this transition between states when seen through this lens since—as Weir (2006) explains in her work on pregnancy and risk—an unsettling event during birth has the potential to completely transform the relation between intra- and extrauterine life. From this perspective, we argue that extremely preterm infants, especially those in the "grey zone" of viability, are suspended in a liminal space, where various social actors (clinicians and parents) negotiate their possibilities to overcome liminality and be incorporated into society (Navne and Svendsen, 2018b).

Due to the lack of medical consensus and the variability across contexts, the notion of fetal viability itself has been argued to be a 'legal fiction' (Horn, 2020), defined as a "moveable threshold, determined by fetus-specific and external considerations, rather than a universal standard" (Halliday et al., 2023, 2). Similarly, Lynn Morgan (2002) relates the concept of viability to the notion of personhood. Arguing that (non) viability is associated with the social categories of person and non-person, she claims that both the acquisition of personhood and the definition of viability are cultural constructions.

Referenced first in medical writings as early as 1832, 'fetal viability' was defined as, "the capacity to sustain life, rather than the mere signs of this condition" (Dewees, 1832 cited in Pettker et al., 2023, 725). Since then, ideas about the starting point of life's sustainability have changed over time and across geographical contexts.

We engage with Gammeltoft's notion of reproductive choices as "acts of belonging" (2014), which refers to how individuals' moral decisions are shaped by the moral values of their communities. The work in Vietnam conducted by Gammeltoft highlights how reproductive decisions are collective acts, events influenced by institutional and social actors. Choice becomes "a matter of with whom [a person] belongs, a question of what demands are placed on him or her" (ibid., 20). In this context, Vietnamese health professionals consider themselves to be guiding parents toward a decision that protects them from having a severely disabled infant. This approach emerges from the view in Vietnam that infants' health and well-being is a common good to society. The concept of 'acts of belonging' helps us understand how decisions about fetal viability are intertwined with the broader view of reproduction as a 'responsible choice,' especially in the context of structural socioeconomic struggles for having and raising children in Spain. In this sense, negotiations about an infant's viability become an intersectional space in which actors "are always part of a larger constellation" (Svendsen, 2015, 180), where the intimate/personal and collective/social spheres merge.

Navne and Svendsen (2018b) observe how healthcare providers in Denmark decide on the viability of preterm infants. They show that the possibility of saving infants who may require lifelong, high-commitment care due to disabilities often leads clinicians to assess "parental qualities and abilities" (ibid., 15). These qualities and abilities are thought to be revealed through family stories—particularly those of reproductive hardship—and impact medical decision-making processes. Through the term 'careography' Navne and Svendsen (2018a) describe the complex interdependencies that take place at the NICU when making life-and-death decisions for extremely preterm infants. Unlike in Gammeltoft's (2014) context of study, the policies of the Danish state are based on the principles of patients' autonomy and informed consent, as also found in Spain (Spanish Official State Gazette, Law 41/2002). However, despite these political narratives, the researchers demonstrate how clinicians, parents, infants and relatives collectively navigate several spaces and temporalities when facing decisions about viability.

In Spain, the existing protocols state that parents of babies in the grey zone should have the final say on whether to offer resuscitation to their newborns at the moment of birth, becoming "moral pioneers" (Rapp, 1999) that must label their infants as 'viable' or 'not viable.' However, this decision becomes highly problematic for parents, who usually fear having a child with disabilities or serious health issues, as Christoffersen-Deb (2012) demonstrates in her study about viability in the United States. As we show, parents' struggles to make a decision often place professionals' guidance at the center of these situations. This guidance, in turn, reflects structural constraints within the Spanish context.

Nevertheless, these assessments do not rely only on parents' position within a particular reproductive politics. Instead, extremely preterm patients also play a role at birth through their actions, contributing to the negotiation of viability. The idea of the importance of newborns' actions was already present in ancient times, as Dasen (2011) explains in her analysis of rituals in ancient Greece and Rome when referencing the Greek physician Soranus (98–138 AD), who described the practice of scrutinizing newborns. Among other criteria, newborns were expected to "cry vigorously" as a sign of their suitability to be accepted into society. This example underscores the notion of respecting life when the infant "expresses" this will, a concept acknowledged in the contemporary legislation of countries such as England and Wales, where "the standard remains 'capable of being born alive,' suggesting that the fetus must be capable of displaying some legally recognizable life signs after being born" (Romanis, 2020, 11). Through her fieldwork in a NICU in Thailand, Seo (2016) makes a similar point in observing how both preterm babies' difficulties to survive and their will to live compels clinicians to care for them. Her conclusion is that newborns have a form of agency in the circuits of care, a concept that we further explore below. We consider how 'fetal viability' and the 'viability of families,' sometimes in tension with each other, are assessed in the Spanish ethos of making "responsible choices" amid a challenging social and economic landscape.

4. Methods

This study is part of a larger anthropological research project on the artificial placenta. This technology, currently at the animal trial phase, aims at "maintaining a preterm newborn as a fetus, and not as a neonate, in an intrauterine-like environment" (Eixarch et al., 2023, 2), involving the immersion of infants in synthetic amniotic fluid, with oxygenation and nourishment via the umbilical cord, as opposed to traditional incubator methods. The main users of the technology would be preterm babies at the limits of viability—around 23 GWs—with potential application for newborns starting at 21 GWs (Usuda et al., 2022). The goal of this larger project is to foresee potential clinical scenarios and key moments of tension in the possible future implementation of the artificial placenta in humans. To achieve this end, the authors are working on several lines of analysis which will materialize in different articles. One of the scenarios of interest is the decision-making process of whether to use this technology after an extremely preterm birth occurs, as well as the agency that the different actors involved would have in it. For this reason, in the current article, professionals' rationalities in life-and-death decisions are explored.

We draw on eight months of ethnographic fieldwork at a maternal and pediatric hospital in Barcelona and interviews with healthcare professionals from several institutions in the city. The hospital was a high-complexity quaternary care hospital that receives patients from the whole region of Catalonia and, in some cases, from other regions in Spain, or other countries.

A call for participation was made through various social media platforms and via the communication channels of the hospitals participating in the larger project. During fieldwork, participants were also recruited at the hospital, after they agreed to be introduced to the researchers. All parents included in the study had undergone a preterm birth from 34 GWs downwards. Interviews started in January 2023, and they are still ongoing. The observations at the hospital were conducted between March and November 2023. The method used was non-participant and based on the principles of the "shadowing" technique (Sclavi, 2014), consisting of following professionals during their daily routines and writing down the main events in a field diary.

Two ethics committees approved the study: one from the Autonomous University of Barcelona and one from the hospital where the research was carried out(kept anonymous for confidentiality purpose). All participants were provided oral and written information about the research goals prior to participation, and informed consent was obtained by handwriting or audio recording. The names and identifying details of infants, parents, and health professionals have been changed to preserve their confidentiality.

The first author led the research process, conducting the majority of observations, interviews, and data analysis. The second author contributed by conducting some interviews, participating in fieldwork and data analysis, and providing ongoing supervision. The third author facilitated access to the field, supplied research resources, and offered supervision of the fieldwork. The spaces observed included the NICU, follow-up consultations with children up to eight years old who had encountered pre-natal or post-natal issues, and specialized gynecological consultations of intrauterine growth restriction, threatened preterm labor, and fetal pathology. Finally, we conducted semi-structured interviews with parents of preterm babies and health professionals. The interviewed professionals numbered 55 and included neonatologists, neonatal nurses, gynecologists/obstetricians, and psycho-social workers from different healthcare institutions in Barcelona, and professionals working on the artificial placenta trial.

Specific interview scripts were used for each group of participants, and interviews were conducted online or in-person, depending on the availability of participants. We developed the scripts based on key topics identified in our review of the relevant literature. Most questions were open-ended and addressed aspects related to difficulties, fears, and expectations concerning preterm birth, personal and professional experiences in the NICU, relationships between health professionals and parents, and the factors impacting decision-making processes. The interviews were conducted in Spanish or Catalan and translated into English by the authors.

The interviews were audio recorded with a voice recorder or video recorded via the online meeting platform Teams.

5. Analysis

Interviews were transcribed using the software Sonix and later verified by the first author. Data analysis was conducted in Spanish and main analytical categories were created to delve into fieldwork material. First and second author independently analyzed data and discussed the results to ensure rigor. The software Dedoose was used to apply main and sub-categories using an inductive thematic analysis process (Strauss and Corbin, 1990) that resulted in the creation of a codebook to discern between anecdotal data and common patterns among participants. The more relevant categories were later analyzed in view of social theories concerning reproductive medicine and politics. The principal themes identified concerned the importance of families' socioeconomic aspects when caring for preterm infants (what we term the 'viability of families'), the illusion of GW calculations, parents' reproductive stories, and preterm babies' performance at birth.

5.1. Caring for the 'viability of families'

Health professionals often discussed the personal situation of families in the NICU. During the interviews, they expressed a strong sense of responsibility, recognizing that families of infants with serious health issues often lacked adequate social and economic support. This is the case not only in Spain, but also on a larger scale, where the care needs of disabled children are often not sufficiently supported by institutions (Gammeltoft, 2014). Factors such as parents' cultural and ethnic backgrounds, education levels, desire to have a child, and availability to care for their children were, from professionals' perspective, indicators of how prepared families were to "fight" for their infants. For this reason, we argue that the assessment of 'fetal viability' is intertwined with the assessment of the 'viability of families,' which we define as the perceived degree to which families can face the social and economic hardships involved in caring for extremely preterm infants, especially when social support is limited. Our analysis shows that these two forms of viability are often in tension.

The perceptions related to the idea of families' viability were also evident during neonatology follow-up consultations conducted once babies were discharged from the hospital, as illustrated by the following example from the first author's fieldnotes:

> The neonatologist Mateo is visiting a baby girl born preterm. The baby is with her foster mother, with whom she has been living during the last four months. During the visit, Mateo informs the foster mother that the baby's biological mother tested positive for benzodiazepines and cannabis right after birth; this appears to be the first time the woman receives this information. "We usually test for drugs when we detect specific social situations," says the doctor without further explanation. The baby is now 11 months old, and the foster mother explains that while the child has been discharged from the CDIAP, she continues to take her to a private development center for ongoing medical follow-up. Mateo seems satisfied with the baby's health condition. He chats with the woman while exploring the baby and at one point asks about her husband's job. She replies that he is an "environmental consultant," to which Mateo responds, "I guess he has a university degree, right?" The woman confirms, and the doctor types this information into the computer. I start to wonder about the significance of this specific information, as Mateo often poses this question to parents. After the family leaves the room, in appreciation of the care the child is receiving, Mateo exclaims, "How lucky some children are!"

Setting aside the assumption that the baby is fortunate to be growing up with a foster mother due to drug abuse by her biological mother, the doctor's question about the foster father's level of education is noteworthy, and we observed the same topic being raised in other doctor-parent interactions. According to some professionals, there was a significant difference between parents with a higher education level—one deemed "appropriate for explaining certain things" (as described by a neonatal nurse)—and parents with a lower one. The parents' level of education, according to Gammeltoft (2014), is associated by clinicians with parents' 'awareness' of the importance of conducting certain medical procedures, such as fetal scans in Gammeltoft's case or specific infant care actions in our study. These differences also resonate with Ranya Rapp's study about genetic counseling for amniocentesis. As Rapp (1999) observes, the ability of patients to speak science influenced the information provided by counselors, resulting in "nonscience speakers [getting] less information than their more privileged pregnant peers" (66).

When health outcomes of extremely preterm babies are discussed by the medical team and the parents, they usually focus on the so-called "quality of life" of the child. This theme is also reflected in the SeNeo 2023 protocol, where "quality of life" is invoked in several sections as crucial to consider in medical decisions. However, the meaning of "quality of life" is not explained in the document. As the professionals told us, sequelae are not always easy to assess or predict, not only because of the high uncertainty of health outcomes of extremely preterm infants, but also because neonatologists often only see the babies while they are at the NICU and lack a follow-up perspective on patients' lives. As Rita (neonatal nurse) acknowledged, "You'll be there for a short, specific period of the baby's life, but the family will be present throughout their child's journey." The problems associated with this narrow perspective are already present in a 1990 article by the American neonatologist William Silverman, to which Sara, a neonatologist, referred when talking to us:

> "Silverman [1990] says, let's see, it's like treating a child in the hospital seems like a race. […] You invest a lot of resources to help the baby to get by. Then this child goes to a home where there might not be an elevator, or the family may not have income for whatever reasons, you name it, or the pediatrician who will see them, they have 40 other children to see that day […]. In the end, much of this is private support from families. So you say, as a common good for society, it might make more sense to provide resources so that the effort put into children has continuity in society instead of lowering the viability threshold. But well, it's a very complicated ethical question" (Sara, neonatologist).

Many health professionals we interviewed were mindful of the "complicated ethical question" derived from treating babies with high chances of sequelae when social support to raise them was scarce. As some of them regretted, however, their everyday work enabled them to take care of newborns mostly concentrating on survival and—at most—severe sequelae.

> "We help their children to get by, and we are giving parents a huge responsibility […] Sometimes [doctors] help a lot of children to get ahead, which poses a lot of dilemmas to us [the psycho-social team] because you see the suffering of the families. These families have to take care of a child that is an expense. I know it sounds very cold to talk about expenses, but it's real: Families have to eat, and they need money to live! Who takes care of these children? Once they leave the hospital, they [doctors] have saved this child, which means that their heart is beating and that they are alive […]. Too much responsibility is put on families. I think it's too much. And [there is] an issue with existing resources, which are not there … I really believe that society is not yet prepared for these medical advances" (Julia, psycho-social team).

The awareness that medical efforts might not have continuity in terms of social aid and support toward the children makes 'viability' a complex issue to assess for professionals. For this reason, as we show in the next sections, there are disparities in medical advice to different families, something that might also be seen as a way to prevent them from further suffering.

Our analysis challenges the discourses of individuality usually present in the Spanish reproductive context, in particular, and Euro-American societies, more generally. As Gammeltoft (2014) argues, an "overemphasis on individual choice" (ibid., 17) diverts attention from the collectivity that is certainly a part of reproductive decisions in Western societies. For this reason, we highlight the ways that interactions between professionals, parents, and infants turn the decision concerning viability into a collective act.

5.2. *Medical considerations and the illusion of gestational week calculations*

Medical and parental decision-making with infants at the limits of viability is a complex matter that healthcare providers argue exceed strictly medical considerations. During our fieldwork, when an extremely preterm birth was anticipated, and if there was enough time, numerous conversations took place at the birthing hospital between the parents and the medical team. In order to give the baby the "best chances of survival" at birth, as expressed by healthcare workers, two doses of corticosteroids are usually administered to the pregnant person before labor to enable fetal lung maturation (McGoldrick et al., 2020). As we show, GW dating has significant implications in these treatment recommendations, an aspect that led some neonatologists to doubt the precision of the GW calculation when it came to deciding about a baby's viability:

> "We every so often clash with the gynos … They say, 'Don't mature babies [that is, don't administer corticosteroids] before the 23rd [week].' I mean, are you sure that this pregnant woman … ? 22.6, 22.5 … Sometimes, the gestational age is not completely accurate. If this baby doesn't get matured properly and is born in their 23rd week, you'll call me in to resuscitate them. Gosh, give them corticoids, then. What I mean is that, perhaps, should there be a really peculiar case of 22 + 6, what is the difference between 22 + 6 and 23? When was the child conceived? How would I know? If it's 23:30 or midnight, am I to resuscitate the baby if it's born half an hour later [but not otherwise]?" (Amelia, neonatologist).

As Amelia describes, the fact that gestational age is not always an exact calculation means that it is necessary to consider other aspects when deciding whether to provide corticoids or resuscitation to a newborn. Unlike the account by Christoffersen-Deb (2012) at a U.S. hospital where babies turning 24 weeks at midnight become officially viable and gain the right to be treated medically, the context of our research suggests that GWs are taken as a flexible category, especially by neonatologists. Amid these ambiguous calculations and uncertainties, the medical opinion was often permeable to the family reproductive story, desires, and possibilities, expressed in the next example through the language of "commitment."

> "I do remember at least two or three cases where children were around 22 weeks old, and say, we don't know if they are 22 + 3, 22 + 6 or 23 + 1, because the gestational age calculations are not 100% accurate. If the family is totally committed to giving the child a chance, whether because it has been very hard to conceive, or whatever other reasons and values in play, we must have that flexibility. And the other way around too, if the parents are absolutely sure that they don't want to take on any risks [that they will have a child with severe health complications], we can't say, 'No, no, we'll always keep fighting for the baby'" (Almudena, neonatologist).

This idea of "commitment" relates to the concept of the "imperative of family life" by Navne and Svendsen (2018b). In the same way as in the Danish NICU, perceived parental qualities and abilities are considered indicators of parents' will to care for a potentially disabled child, the notion of "commitment" became a benchmark for the 'viability of families' in our fieldwork. In this sense, not only parents' educational level and economic resources were considered when assessing this kind of viability. According to neonatal professionals, factors such as spending a lot of time with their children at the NICU, demonstrating a strong desire to have a child, and revealing good organizational skills (which would be important for ensuring their attendance at follow-up appointments) were all positively regarded.

5.3. *Perspectives about families and their reproductive stories as a pathway for medical advice*

Uncertainty is a predominant element when an extremely preterm birth is anticipated. As observed during our fieldwork with a case of a 23 GW threatened preterm labor (a possible birth at the limits of viability), conversations between health professionals and parents mostly revolved around whether to provide active medical care once the baby was born. On that day, we ran into Amelia, who explained to us that the mother had been admitted three days earlier and was about to have a spontaneous delivery. According to Amelia, the patient and her partner did not want to decide whether active medical treatment should be provided to the baby after birth. When the mother was admitted to the hospital, she was around 22 GWs, and both parents were aware of the baby's non-viability. However, by the 23rd week they didn't know what to do.

After this conversation, the authors went to the gynecology intensive care unit and asked Valeria, a gynecologist, if it was possible to ask for consent to the patient and her partner to be present during the conversations with doctors (which had been approved by the ethics committees). She replied that the situation was too sensitive for us to be present, but provided more details:

> "When they [babies] are in the grey zone it has to be them [the parents] who decide if they wish to resuscitate the baby or not […] [However] they [the parents] don't want to decide for themselves, they would prefer to get to the point where we would tell them that it is legally compulsory to resuscitate the baby."

As Valeria also shared with us, the parents had inquired about the likelihood of their baby being healthy in the long term. However, at that stage, the doctors lacked the necessary information to provide an answer. To get more insight into the situation, we met the hospital's psychologist who was supporting the couple. She reported:

> "The parents are too focused on the decision about their baby's resuscitation, but that's not the decision to be made. […] I have worked with them on the idea that it's not solely a medical decision, but rather a decision based on their life values, which may be wanting a child with the highest possible quality of life, and, if doctors consider that a procedure at that particular moment will not lead to this, then, the decision comes out on its own' […] We should not ask them, 'What is your decision?' Rather 'What factors do you want the medical team to use in making a decision?'"

A few days later, we were told that the baby had died immediately after birth. As these conversations show, while the act of resuscitating a baby at the limits of viability should be based on parents' decisions, according to the existing protocols, the struggles they faced in deciding made crucial the guidance and mediation of doctors.

Through our observations and interviews, it was clear that the transmission of information in these situations was highly dependent on the personal approach of the professional dealing with the parents:

> "We are somewhat biased by our own perspectives on the situation. Some [professionals] are more concerned about the risks than others because, based on the same information, you can focus more on the risk of damage or on survival rates, you know? […] So depending on the pediatrician assigned to the case, the patient will have one type of explanation or another" (Carlota, gynecologist).

As Carlota pointed out, by referring to the risk of damage or the chance of survival, the same information can be provided in different ways, resulting in more pessimistic or optimistic views. However, regardless of the personal style of professionals, it became clear that a range of other contextual elements also had an impact—such as the family's reproductive history—when informing and guiding decision-making processes.

> "If [the patient] is 42 years old, [has undergone] seven IVF cycles or, I don't know, has endured three fetal deaths, these influence the decision-making process. So the patient's history and records do carry some value. Maybe not so much in the decision-making, as the expectant mother will have the final say, but perhaps in how we talk [to the patient]" (Victoria, gynecologist specialized in preterm birth).

As these quotations show, previous conception difficulties, miscarriages, and/or fetal loss are elements that play a significant role in informing and guiding families. In particular, advanced maternal age and the use of assisted reproductive technologies were often mentioned by professionals as increasingly common situations at the hospital, caused by the insertion of women into the job market and their difficulties to reach an economically stable position. Furthermore, more or less explicitly formulated by healthcare providers, perceptions regarding the mothers' caregiving abilities, alongside the family's socioeconomic status, were also considered.

> "[We had] a very young mother with substance abuse problems. Her daughter was born at the 23rd week and survived barely six days. I thought, 'This woman has seen her 23-week-old baby being fully wired to the life-support system, being constantly jabbed, suffering from sepsis and full of fungi. Wouldn't it have been better for her [the mother] to say goodbye to her baby in the delivery room, more calmly?' This mother was ravaged, devastated. A 23-year-old child [*niña*]; I often get mad [about these things]" (Julia, psycho-social team).

Julia highlights the fact that the mother was "very young" and had a drug-dependence problem to question the need for her to endure the hardship of the situation. In her narrative, there is also an implicit idea that there may be no point in resuscitating extremely preterm babies when mothers are perceived as unready to care for their children or do not have the tools to overcome the challenging emotional circumstances these situations might pose. Similarly, in many professionals' accounts, the idea of a wanted pregnancy versus an "accidental" one arose as an indicator of whether the family would "go all in" [*ir a por todas*]. This was the case of Leticia, who was admitted to the hospital due to the threat of preterm labor at 27 GWs. When Alicia, a neonatologist, visited her in the gynecological ICU, Alicia asked if the pregnancy had been "accidental or planned." Leticia seemed confused about what to answer, and Leticia's mother responded that Leticia "had known for a while that she wanted to be a mother." Alicia seemed pleased with this response and concluded, "That's really good, it means you're going to fight for your child." As Han (2013) notes, the "wantedness" of a pregnancy is usually positively perceived by medical professionals, who may even consider it as a guarantee that the pregnant person will avoid behaviors that may endanger the fetus, such as smoking or consuming alcohol.

Social class imaginaries emerged in medical professionals' perceptions of who should "fight" for their children. However, there was also a care logic in their discourses. Healthcare professionals were often concerned about the family's socioeconomic means when considering the amount of material resources that extremely preterm babies with high chances of severe sequelae might need after hospitalization. Nevertheless, in specific situations, the significance of the 'viability of families' in medical decision-making processes was overridden by the babies' 'performance' at birth, as we address in the next section.

5.4. Babies' performance at birth: looking for 'signs of vitality'

Despite the importance of families' reproductive stories and socioeconomic contexts in the assessment of professionals, an element of tension was identified among their discourses. On one occasion at the NICU, when discussing decision-making at the limits of viability with a neonatologist, we referred to a baby's parents as "patients," considering the whole unit as being taken care of by the medical team. The doctor politely interrupted us to clarify: "The patient is the baby, not the family. It's confusing for us [the medical team] to talk in terms of patients when we're referring to parents." As this neonatologist stated, and we observed at the NICU, the baby was always at the center of neonatologists' professional practice and narratives. This centrality was particularly salient when births occurred at the limits of viability, where the baby's 'signs of vitality' were crucial in deciding the treatment that would follow:

> "When a 23-week-old baby is [to be] born, we talk to the family. Usually, we tell them that they [the baby] will be given a chance, that's to say, well, we'll see how it goes and if they show any signs of vitality, we'll try to help them" (Alicia, neonatologist).

As illustrated in the quotation above, far from being considered passive actors, newborns at the limits of viability are expected to demonstrate their viability. Guidelines for assessing newborns emphasize specific indicators of viability. For example, the Apgar test evaluates newborns 1 min and 5 min after birth by checking their skin color, heart rate, breathing effort, and muscle tone. Likewise, SeNeo guidelines state, "Newborns must have all four limbs flexed; demonstrate alertness after tactile, acoustic or light stimuli; exhibit good passive and active muscle tone; respond vigorously to stimuli; and cry energetically" (8). Professionals often glossed these traits as the baby being "vigorous," and they highlighted that they would not engage in actively ending the life of a "vigorous" infant, regardless of other considerations, such as GW or parents' views and values.

> "Below viability, it's not usual [to practice resuscitation], unless the baby is born vigorous. I mean, unless I would have to cover their mouth so that they would die! If the baby is vigorous at birth—and there are cases like that—then you have to carry on" (Yolanda, neonatal nurse).

Similarly, Rent et al. (2022) show how in Ghana and Ethiopia health professionals claimed to feel obliged to resuscitate every infant born with "signs of life" since they felt troubled by the individual responsibility of deciding which babies should live or die, another element that demonstrates the collective nature of viability decisions. Kyra Landzelius (2006) further exemplifies this by showing how the reputation of neonatology was built on the basis of the "preemie's reputation" (672), highlighting that this medical specialty was developed as the rescuer of this kind of patients. The author argues that neonatology "ontologically invent[ed] the preterm baby as a technological innovation, a scientific subject, medical patient, cyborg being" (Landzelius, 2006, 672). From this perspective, newborns' 'signs of vitality' can be analyzed taking an actor-network theory approach. According to Latour (2005), if we let go of the notion that an action is "intentional," we can embrace the idea that "anything that does modify a state of affairs by making a difference is an actor" (ibid., 71). Thus, newborns can be considered 'actants' whose actions, even if not conscious or intentional, influence the decisions made by health professionals.

The importance of showing 'signs of vitality' poses the question of the real chances for parents to discuss the concerns they usually have about possible sequelae. Consensus among professionals that a preterm baby had a chance of survival seemed to outweigh the perspectives of parents or even the 'viability of families.' In these situations, the significance of the 'neonatal patient' was at its highest, aligning with professionals' definitions of 'fetal viability.'

6. Conclusions

We have addressed the elements considered by health care professionals when deciding on the viability of extremely preterm infants in Spain. Through the concept of "grey zone", used to describe infants at the limits of viability, we have analyzed how viability is a 'legal fiction' (Horn, 2020) that results from a collective negotiation culturally, socially, and politically situated (Morgan, 2002). A complex entanglement of considerations mediates the great uncertainty surrounding the health outcomes of extremely preterm infants. The specificities of the Spanish context, defined by the widespread use of reproductive technologies, advanced maternal age, and structural challenges for families to raise children, play a central role in assessing the families' possibilities and suitability to care for extremely preterm infants. Considering the analysis by Navne and Svendsen (2018a; 2018b) on the interdependencies taking place at the limits of viability, we have expanded the concept of viability to preterm infants' performance at birth. In this sense, we demonstrate that the 'signs of life' exhibited by newborns in specific situations prevail over other factors.

We applied Tine Gammeltoft's (2014) concept of reproductive choices as "acts of belonging," to argue that viability is a negotiation among various actors with different degrees of influence, who draw on individual and collective stratified values and forms of knowledge. This entanglement reveals that while reproduction in Spain is framed in the ethos of individual responsible choices, as is usually the case in Euro-American societies, in the neonatal context these decisions become collective acts, shaped by structural socioeconomic constraints, the realities of public resources, and preterm infants' perceived agency. We therefore coined the term 'viability of families,' to describe healthcare professionals' perceptions of families' socioeconomic constraints, desire for a child, and commitment to taking care of an infant with high chances of sequelae.

This study represents the first anthropological examination on neonatal decisions regarding preterm birth in Spain. Beyond the specificities of this social context, our analysis provides crucial insights for understanding the current dynamics and future directions in preterm birth care, strongly shaped by discourses of disability (Christoffersen-Deb, 2012) as well as a contextual ethos of making "responsible reproductive choices", notwithstanding influenced by the preterm babies' "signs of vitality".

7. Strengths and limitations

The main strength of this study lies in the possibility of conducting fieldwork in a hospital setting. The long-term presence of the first author in the field was especially relevant to building relationships of trust with parents and professionals, resulting in a better understanding of the subject of study. The impossibility to observe births at the limits of viability remains a limitation of this study. Due to the sensitivity of the dynamics involved, the medical team deemed inappropriate that researchers asked for consent to parents. Lastly, as agreed with the ethics committees, the authors could not take notes in front of patients during observations. This may have entailed some biases or incompleteness in fieldnotes.

CRediT authorship contribution statement

Paula Martone: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Anna Molas:** Writing – review & editing, Validation, Supervision, Investigation, Formal analysis, Conceptualization. **Diana Marre:** Writing – review & editing, Validation, Supervision, Project administration, Funding acquisition, Data curation.

Ethics approval

Two ethics committees approved the study: one from the Autonomous University of Barcelona and another from the hospital where the research was carried out.

All participants were provided oral and written information about the research goals prior to participation, and informed consent was obtained by handwriting or audio recording. The names and identifying details of infants, parents, and health professionals have been changed to preserve their confidentiality.

Studies in humans and animals

All procedures were performed in compliance with relevant laws and institutional guidelines and have been approved by two different institutional committees, with reference number: CEEAH 6020.

Furthermore, the privacy rights of human subjects have been observed and informed consent was obtained for research with human subjects.

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Data availability

The data that has been used is confidential.

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