Original Paper

Parents' Perspectives on the Use and Development of Predictive AI in Neonatology: Focus Group Study

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Abstract

Background: Predictive AI models, such as AI-generated early warning systems for detecting critical conditions, are being praised as promising applications in neonatology. Despite technological advancements in predictive AI, the integration of AI at the bedside remains challenging, and few AI technologies are currently integrated into routine neonatal care. A better understanding of the wishes and barriers of patients and, in the case of neonatal patients, their parents, is essential to bridge this gap. Yet, parental perspectives on the use of AI remain underexplored.

Objective: This study explored the perspectives of parents whose child had previously been admitted to a neonatal intensive care unit about the development and use of predictive AI in neonatal clinical settings.

Methods: We conducted 3 focus groups with 18 Dutch parents of children admitted to a neonatal intensive care unit to explore their views on AI in neonatal care. Participants were purposively recruited via a neonatology parent and patient organization. Discussions focused on predictive AI in acute settings and on AI to predict neurodevelopmental outcomes in later life. A reflexive thematic analysis of the focus group data was performed.

Results: Parents generally welcomed predictive AI as a supportive tool for the medical team, anticipating improvements in patient outcomes. AI for short-term predictions was especially appreciated, whereas longer-term predictions were received with some reservations. Overarching concerns regarding predictive AI systems included AI undermining parental intuition, overreliance on AI in decision-making, and undesirable ethical and psychological implications of long-term health predictions. Interestingly, in addition to predictive AI systems that support medical judgment, parents also hoped that other AI tools could be developed to better involve parental input in the decision-making process. Specifically, they envisioned applications that extend beyond clinical decision support to provide parents with information, emotional support, and tailored guidance on the right course of action.

Conclusions: Parental perspectives highlight both opportunities and challenges for predictive AI integration in neonatal care. Engaging parents in the design and implementation of AI informs the development of family-centered, ethically responsible AI solutions and may identify opportunities for developing parent-centered AI tools alongside systems designed to support clinicians.

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Introduction

Medical AI is attracting significant interest due to its potential to transform health care and improve patient outcomes. In recent years, the development of AI is expanding into neonatology, a subfield of pediatric medicine [1-6]. The neonatal intensive care unit (NICU) is an environment where infants are continuously and closely monitored, generating large amounts of data, from laboratory parameters to vital signs, offering potential for AI integration [3,7]. Predictive AI models, such as AI-generated early warning systems for detecting multiple critical conditions, are being especially praised as promising for neonatology [7]. Predictive models to gain clarity on short- and long-term outcomes for infants play a crucial role in guiding clinical decision-making and counseling parents [8]. Consequently, the development and application of predictive AI in neonatology have gained considerable interest in recent years [9].

Despite these promising technological advancements in AI, the integration of AI at the bedside remains challenging, and few AI technologies are currently integrated into routine care [10-12], including predictive AI in neonatal clinical care [3,4,9,13]. A better understanding of the wishes and barriers of those who will face AI at the bedside is critical for bridging this gap [14]. This includes the perspectives of patients and, in case of neonatal patients, their parents.

In pursuit of bridging this gap, significant attention has been devoted to understanding parents' perspectives on AI. Previous studies suggest that parents generally view the use of AI in pediatric clinical settings with cautious optimism [15-18], reporting a mix of expectations and concerns, including information access, diagnostic accuracy, overreliance, and the potential erosion of physicians' critical human skills [15-17,19]. In neonatology, the existing empirical research often focuses on AI in applied settings, such as AI-assisted pain monitoring [19,20]. Yet, in these studies, AI is considered in broad or generic terms, without distinguishing between its various applications. As a result, there is a lack of clarity and empirical insight specifically into parents' perspectives on predictive AI. Given the rapid technological advancements in predictive AI for neonatal practice, understanding how parents perceive such technologies is essential for the adequate and trusted implementation of AI [21].

Although AI in pediatric care is gaining attention, parents' perspectives, particularly in the NICU, remain largely unexplored. Regarding prognostic information, it is known that parents value concrete, honest, transparent, and hopeful information about their child's anticipated health outcomes [22,23]. Moreover, prior research suggests that a medical background, such as having experience as a health care professional, previous experience with illness, or familiarity with medical terminology, may be relevant for how parents participate in decision-making in neonatology [24,25]. Furthermore, a medical background may affect trust in AI systems among patients [21]. However, this has not yet been studied in the context of parental perspectives about AI. This study uniquely examines these perspectives across different levels of medical familiarity, providing novel insights into parent-AI interactions in neonatology. We conducted a focus group study in which we investigated Dutch parents' perspectives on the use of predictive AI in neonatal clinical settings, including parents with and without prior medical knowledge who had a newborn child admitted to a NICU.

Methods

To explore parents' perspectives on implementing predictive AI in neonatal clinical care and at the NICU, we conducted a focus group study. Focus groups are semistructured discussions in small groups where participants can share and compare experiences and explore various topics. This is especially valuable when discussing a complex and relatively new topic, such as AI in neonatal care [26,27].

Recruitment

Participants were eligible if they were the parent or caregiver of a child who had been admitted to a NICU in the Netherlands, spoke Dutch, and were available on the date of the focus groups. Participants were purposively recruited via the neonatology parent and patient organization Care4Neo, which reached out to their members and community via newsletter, email, and social media. Interested participants self-selected to participate by providing their contact details through an online form, after which they were contacted by telephone by LS to receive additional information and the written consent form.

Data Collection

The data were collected during 3 online focus groups. The focus groups took place in April 2025 and were conducted via Microsoft Teams. Online interviews were chosen to facilitate participation by parents with young children, with previous research indicating that they produce results comparable to those of face-to-face focus groups [28,29]. To facilitate in-depth discussion on the hypothetical integration of predictive AI systems in neonatology, the focus groups initially examined current practices in neonatology and then concentrated on parents' perspectives on the hypothetical use of AI applications in such contexts. A semistructured topic list was used to facilitate an open discussion of relevant topics (Multimedia Appendix 1). At the start of the focus groups, LS introduced the topic in lay terms using a presentation designed by LS and JD, describing 2 examples of predictive AI models developed for use in the NICU, 1 model for early detection of late-onset sepsis [30] and 1 electroencephalography (EEG)-based tool for predicting long-term neurodevelopmental outcomes in extremely preterm infants [31]. The intended function and basic operation of the 2 AI models were described in accessible language, without intentionally or explicitly presenting potential benefits or risks to participants. These concrete examples were provided to give participants a shared and focused understanding of predictive AI in neonatology and to prevent the discussion from becoming overly broad or from referring to different types of AI technologies. LS facilitated the discussion to

ensure that all participants had an opportunity to contribute and intervened when necessary to balance participation. Each focus group lasted between 120 and 135 minutes.

All focus groups were audio-recorded and then transcribed verbatim. They were coded to ensure confidentiality, and identifying information was removed. The transcripts were then checked for accuracy and completeness by SR. The focus groups were conducted in Dutch, and quotations were translated semantically into English by LS and SR to preserve the meaning and richness of the original quotations [32]. As we used reflexive thematic analysis, our assessment of data sufficiency was based on the richness and relevance of the data, the depth of discussion, and the extent to which the research question could be meaningfully addressed through the dataset, rather than on a predefined saturation criterion. As such, we did consider information power insofar as we assessed the internal validity of the data and continuously ascertained that the level, quality, and variation of information we received were satisfactory [33].

The research team consisted of LS, KJ, JD, and SR. LS, KJ, and JD were trained and experienced in qualitative research and ethics of medical technology. SR was a medical student in the final year of her clinical rotations. All researchers were female, and none had clinical experience in neonatal care. None of the researchers had prior relationships with any of the participants. LS, KJ, and JD together developed the focus group design. The focus groups were moderated by LS, while JD took field notes and asked follow-up questions, and SR observed the sessions. The researchers' backgrounds and perspectives may have shaped the focus group discussions and interpretation of the data. Throughout data collection and analysis, the research team discussed their observations and interpretations while reflecting on the potential influence of their own academic and professional backgrounds and considered alternative interpretations of the data.

Data Analysis

A reflexive thematic analysis according to Braun and Clarke was performed using NVivo (version 15; Lumivero) [34-36]. Data selection and analysis occurred iteratively and followed a predominantly inductive approach, while also incorporating deductive elements as we followed predetermined study aims and primarily focused on perspectives regarding predictive systems in line with our initial topic list. Nevertheless, although the analysis was informed by the study aims and some anticipated distinctions, such as between short-term and long-term predictions, specific codes and themes initially and primarily emerged from the participants' perspectives as expressed in the focus group discussions. A first version of the codebook was developed by SR and LS, which was refined in conversation with KJ and JD. All transcripts were then coded independently by SR and LS. Coding and interpretation were then discussed within the research group (SR, LS, KJ, and JD), including differences in coding, with attention to the meaning of the text fragments in the context of the focus group discussions. Through these discussions, alternative perspectives on the emerging findings were considered, while the coding and interpretation of the data were jointly refined within the research group. Throughout the analysis, codes were adapted and additional codes were added when needed, a process that was always discussed with the entire research group. Finally, codes were organized into potential themes, and accompanying quotes were selected for each theme. The coding tree is available in Multimedia Appendix 2.

Data Statement

The data are presented in the form of themes supported by illustrative quotes from participants (Multimedia Appendix 3). The complete dataset is not publicly available due to the sensitive nature of the data, which is protected under Article 9 of the General Data Protection Regulation (GDPR).

Ethical Considerations

The study was performed in accordance with relevant guidelines and regulations. The research protocol was reviewed by the research quality control committee of the University Medical Center Utrecht and was deemed exempt from the Medical Research Involving Humans Act (*Wet medisch-wetenschappelijk onderzoek met mensen* [WMO]). Under Dutch law, studies are subject to the WMO when they involve medical-scientific research, and participants are subjected to procedures or required to follow a particular behavioral regimen [37]. As this study was considered non-WMO, formal approval by a Medical Research Ethics Committee was not required (research proposal number 23U-0364). Written consent was obtained from all participants prior to the start of the focus groups. A €25 (US $28.04 as of April 2025) voucher was offered as reimbursement for participation in this study. Participants were informed in the study information letter that participation was voluntary and that they could withdraw from the study at any time. The focus groups centered on hypothetical scenarios concerning the potential use of predictive AI in neonatal care and did not systematically address participants' own experiences of illness, distress, or loss related to neonatal care. This was also specifically explained by LS to each participant during an individual telephone call prior to the focus groups. Nevertheless, given the personal experiences of some participants, the moderator remained attentive to potential emotional responses during the discussions. The study design and reporting were in line with the COREQ (Consolidated Criteria for Reporting Qualitative Research) [38]. The COREQ checklist is provided in Checklist 1.

Results

Participant Characteristics

This study consisted of 3 focus groups with a total of 18 parents of children who had previously been admitted to a NICU in different parts of the Netherlands, comprising 7, 6, and 5 participants, respectively (Table 1). Most participants were female (n=16). Participants' educational levels varied from lower secondary or vocational education to academic master's degrees (n=9). One focus group consisted

exclusively of participants working in health care, including both clinical and nonclinical roles within health care organizations (n=5), while the participants in the other focus groups had other professions. All participants generally had some familiarity with AI through everyday or work-related contexts, although none reported professional experience with AI or clinical AI systems. All participants came from different families. All but one had 1 child with a history of NICU admission; 1 participant had 2 children who had been admitted to the NICU, born 2 years apart. The children of the participants were admitted for various reasons, and hospitalization ranged from a couple of days to several months. For some, this period was marked by relatively few setbacks, while the children of other parents faced serious complications.

In what follows, the perspectives of parents on the use of AI in neonatology and AI-generated predictions are outlined in three overarching themes: (1) parents' perspectives on AI-generated predictions in acute settings, (2) parents' perspectives on long-term AI-driven predictions in neonatology, and (3) AI and the parental role.

Table 1. Background characteristics of participants.

Characteristics	Values
Sex, n (%)	
Female	16 (88.9)
Male	2 (11.1)
Age (y), mean (SD; range)	36.8 (4.5; 30-47)
Highest level of education, n (%)	
Lower secondary/vocational	2 (11.1)
Upper secondary/vocational	4 (22.2)
Bachelor's degree (applied or academic)	3 (16.7)
Master's degree	9 (50.0)
Profession, n (%)	
Health care professionals	5 (27.8)
Other	13 (72.2)
Infants' reason for hospital admission, n (%)	
Prematurity	17 (94.4)
Asphyxia	1 (5.6)
Time since birth of their child (y), n (%)[a]	
0-1	4 (21.1)
≥1-2	4 (21.1)
≥2-4	5 (26.3)
≥4-8	6 (31.6)

[a]One parent reported 2 separate neonatal intensive care unit admissions for 2 children, which explains the additional denominator.

Theme 1: Parents' Perspectives on AI-Generated Predictions in Acute Settings

The Desire for Certainty, Not False Hope or Increased Stress

> *We were told over and over again: "We don't have a crystal ball, so we can't predict anything." (…) I really longed for more certainty, but that certainty was constantly taken away from me. Can AI actually provide more clarity about this? Or does it simply provide more information?* [Participant 1]

Many parents shared positive experiences with the neonatology care their child received, with some even mentioning these as a reason for joining the focus groups. At the same time, several parents also vividly remembered the fear they experienced when their child was admitted to the neonatology ward (quote 1a in Multimedia Appendix 3). As their fears were heightened by not knowing whether their child was at risk of adverse events, many expressed a wish for more certainty and hoped AI could support determining the likelihood that adverse events would occur, with the caveat that it should be ensured that the use of AI would not result in false hope (quote 1b in Multimedia Appendix 3) or undue stress (quote 1c in Multimedia Appendix 3). Some medically trained parents, for example, worried that predictions could result in more fear and questions for parents who do not know what they mean (quotes 1d and 1e in Multimedia Appendix 3). Nevertheless, when considering specific predictive AI tools, such as a sepsis tool, both medically trained and nonmedical respondents were enthusiastic, expecting these tools to provide certainty and predict adverse events earlier than a physician would (quote 1f in Multimedia Appendix 3). Moreover, some parents mentioned that they felt comforted by the idea that AI could, for instance, reduce the number of invasive treatments if a prediction resulted in treatment starting earlier (quote 1g in Multimedia Appendix 3). Also, many expected that AI-generated short-term predictions might reduce overtreatment with, for instance, antibiotics.

Balancing Faith in AI-Generated Predictions and Parental Intuitions

> *She was maybe three or four weeks old and how could I know her already? How could my instincts have anything to say about her? Yet, that turned out to be the case, which strengthened me a lot. But will that be a kind of showdown between people seeing, feeling this, but the computer says that? That is a kind of balance.* [Participant 1]

Many parents emphasized the necessity of finding a balance between depending on short-term AI predictions and following parental intuitions in acute medical decision-making processes, as intuitions can be just as crucial for identifying warning signs. One respondent, for example, described how their parental instinct had been essential for identifying their child's pneumonia, and that the lack of monitoring alarms exemplified the necessity of not having ''blind faith'' in medical technology (quote 1h in Multimedia Appendix 3). Because parental intuitions were not always acted upon by medical professionals at the time, some parents worried that physicians might blindly follow AI instead of listening to parental input and that the use of AI could result in a ''tug-of-war'' between professionals and parents. Moreover, some parents worried that they themselves would lose faith in their parental intuition due to AI predictions; this worry was most pronounced among first-time parents. They argued that they already faced difficulties in trusting their parental intuition immediately after birth because of a lack of experience in parenting. They expressed that, as new parents of infants admitted to the NICU right after birth, trusting technological features to monitor their children's health felt more secure than following their own parental instincts. They were concerned that more sophisticated AI technologies could amplify this effect (quote 1i in Multimedia Appendix 3).

Nevertheless, when AI systems are integrated into the care process with the value of parental input in mind, some parents anticipated that AI could reinforce their parental intuition by providing neutral affirmation of their instinctive knowledge. For instance, 1 parent suggested that AI might help to ground their worries, which physicians could dismiss as being "overly anxious" (quote 1j in Multimedia Appendix 3), and another parent suggested that AI could help physicians act more quickly on parental instincts (quote 1k in Multimedia Appendix 3). Many thus hoped that AI might support them in their role as parents and make them a more "equal" partners in the parent-physician relationship.

Theme 2: Parents' Perspectives on Long-Term AI-Driven Predictions in Neonatology

Why Parents Do Not Always Want to Know Long-Term AI-Driven Predictions

> *A form of living loss could be created...What may never come?* [Participant 7]

The future of premature babies can be uncertain, and they face a risk of disabilities. Many parents mentioned conversations they have had with medical professionals about the future challenges of their child and what they could expect; some mentioned they had heard that their child might never walk or would probably be severely disabled (quotes 2a and 2b in Multimedia Appendix 3). When discussing the hypothetical use of long-term AI-driven predictions, parents questioned its value. They thought these predictions would probably be less accurate than short-term predictions, noting that contextual and environmental factors have a stronger impact on whether a child develops certain disabilities (quote 2c in Multimedia Appendix 3). They believed that whether a child will develop, for instance, neurodevelopmental challenges later in life, is multifactorial: it matters how parents raise their child, in what kind of environment the child lives, and whether parents receive adequate support. A few parents also argued that AI would have no additional value when the information it would provide would be comparable to that provided by physicians at present (quote 2d in Multimedia Appendix 3).

Several parents also noted that, hypothetically, knowing their young child might develop a serious condition would result in unnecessary distress for them. One parent called this "a living loss," reflecting anticipatory grief, perhaps unnecessarily, since the prediction may not come true (quote 2e in Multimedia Appendix 3). In addition, several parents wondered whether such predictions are in the child's best interest. For instance, they may lead parents or other people to treat the child differently, which may be harmful; one parent, for example, mentioned that if they were to receive the prediction that their child had a 70% chance of developing attention-deficit/hyperactivity disorder (ADHD), they might look at them differently (quotes 2f and 2g in Multimedia Appendix 3). Also, some parents indicated that they felt uneasy about knowing that their child might develop a condition for which there may be no suitable treatment. Moreover, some indicated that should AI provide long-term predictions about the health of their child, they would prefer *not* to receive this kind of information.

Conditions for Long-Term AI-Driven Predictions

> *You can worry about the worst, but maybe there's a small chance. (...) So I would like to link that to...Especially when you look to the future. It's nice to know that bandwidth, but also what is realistic? And the second is: what can you do yourself? What should you pay attention to? Because you...Certainly, at some point you also become detached from the hospital or further away from it.* [Participant 6]

Many respondents believed that hypothetical long-term AI-generated predictions should not be routinely incorporated into neonatology care and should be shared with caution. However, some parents saw value in such long-term predictions, for example, if they could inform actionable, timely decisions, such as choosing and initiating a specific

treatment (quote 2h in Multimedia Appendix 3). Currently, they are not always sure what actions they should take based on predictions, and that can lead to uncertainty, whereas knowing what to do with the information and when to act could provide parents with direction (quote 2i in Multimedia Appendix 3).

Some also mentioned that the value of long-term predictions depends on how health care professionals handle them (quote 2j in Multimedia Appendix 3). Some parents thought that they should be able to provide meaning to the numbers and statistics; how likely it is that their child will truly develop a certain condition and what this would mean for their roles as parents (quote 2k in Multimedia Appendix 3). Others thought that long-term predictions signaling a substantive risk should be accompanied by long-term support or a trajectory whereby health care professionals remain involved, helping parents to deal with early signs of a disability (quotes 2l and 2m in Multimedia Appendix 3).

Theme 3: AI and the Parental Role

The Need for Clear and Transparent Communication With Parents, Including AI

> *You suddenly gave birth, are suddenly a parent and then... Little did we know about what to ask there.* [Participant 10]

Though several positive experiences were shared, the focus groups also revealed that the role parents play in medical decision-making in neonatology can be challenging. Parents, especially those with limited medical knowledge or experience, often felt that their input could be overlooked and that they were sometimes involved in medical decisions only days after they had been made by medical professionals. One respondent mentioned that "every week something unexpected happened" (quote 3a in Multimedia Appendix 3). Parents expressed that they imagined this would differ depending on, for instance, the hospital or the severity of the child's condition (quote 3b in Multimedia Appendix 3). Sometimes, parents described that their sense of involvement could be diminished when they were unable to be present during critical decision-making moments, as the mother was, for example, recovering from labor while their child remained in a hospital in a different location. One respondent expressed feeling helpless due to the distance from their child (quote 3c in Multimedia Appendix 3).

Just as many parents would have liked to consistently receive more information, they noted that this also applied to the use of AI. If AI were to be adopted in neonatology, most parents specifically expressed a desire to be informed about whether AI is used, what to expect, and the outputs of predictive AI, including in acute settings (quotes 3d and 3e in Multimedia Appendix 3), though a few respondents believed recommendations would be mostly relevant to medical professionals (quote 3f in Multimedia Appendix 3). Preferences regarding the timing of such information varied among parents: some thought the use of AI should be disclosed at the beginning of hospital admission, while others preferred to be informed once AI had influenced decision-making.

Moreover, when reflecting on their past experiences, parents often spontaneously mentioned hypothetical forms of AI that could support their role in medical decision-making in light of the challenges they had encountered, for example, moments of poor communication, uncertainty, or feelings of being overwhelmed. The next section outlines parents' perspectives on how AI could support their involvement.

AI Tools to Support Parental Involvement

> *During the first two weeks, we were really just standing on the sidelines, even though we really wanted to be involved in the care. But nothing really stuck in terms of knowledge. Fortunately, my mother is a medical specialist, and she really helped me: What questions do you ask? What are the consequences? And I think, because I was able to have those conversations, I could increasingly see myself as an equal partner. (...) And I think AI could play a role there too, because not everyone has a mother with that kind of network. But every parent deserves that.* [Participant 3]

Many parents mentioned that NICU admission can be overwhelming and that medical information may be difficult to follow or not available to them, and they sometimes felt hesitant to ask for additional information or clarification because of the busyness of the medical staff. Even though we did not specifically ask questions regarding AI beyond predictive systems, several parents mentioned that they wished that AI could play a role in providing guidance on what to expect during hospital admission through managing of expectations, for example, by providing a weekly timetable of planned treatments and procedures. This could help reduce feelings of uncertainty, "having no control," a lack of overview, or feeling overwhelmed (quote 3g in Multimedia Appendix 3).

Moreover, many parents described seeking support from health care professionals in their personal network or by searching for additional information online while their child was admitted to the NICU. Although several parents did not believe they should be involved in the continuous monitoring of their child, enabling their involvement in a more systematic way would be beneficial (quote 3h in Multimedia Appendix 3). Many believed that AI could improve communication and information provision, offering some of the guidance they had previously lacked or sought elsewhere. In this context, parents wished for AI to take on the form of a chatbot: always available, easy to consult, and capable of answering questions in an understandable manner. Some would use it to seek additional in-depth information, while others envisioned that AI would prepare questions for medical consultations or summarize the consultations afterward. One parent described how her mother, who was a medical specialist at the time, had fulfilled this role and hoped that AI could offer similar guidance to other parents as well (quote 3i in Multimedia Appendix 3).

When describing the role of AI, many parents were positive about AI "beside" them for practical and emotional support. Not being able to be with their child 24/7 was one of the most frequently mentioned barriers parents had experienced during NICU admission. In this context, parents envisioned different ways AI might offer emotional support. For some parents, the idea that AI would monitor their child would ease their mind (quote 3j in Multimedia Appendix 3). One parent voiced a wish to "check in" via AI to see how their child was doing. Another hypothetical example of potential emotional support was the ability to improve feelings of proximity via AI, for example, by playing parents' voices when they are not around. AI was also ascribed the role of practical support, for example, by tracking milk supply and notifying parents if the supply is low.

Furthermore, several parents hoped that AI could assist them in the period after discharge. During this phase, many parents felt overwhelmed and struggled to find appropriate care for their children. Parents envisioned that AI could help by providing more accurate forecasts about the future and consequently indicating available treatment options or even helping locate specialized services. One parent referred to this kind of support as a "railway guide," showing parents the way in the landscape of health care (quote 3k in Multimedia Appendix 3).

Discussion

Principal Findings

Throughout the focus groups, it became evident that parents' past experiences in the NICU had a significant impact on how they viewed the potential of AI in neonatal care. That is, parents often discussed their perspectives about AI by sharing memories of how they had experienced neonatal care, and reflecting on the potential AI would have had on the ways in which care was provided. In line with parents' perspectives shaped by their past experiences, integrating predictive AI systems into neonatal clinical care was generally viewed positively. The hypothetical use of AI for short-term predictions was especially appreciated, whereas longer-term predictions were received with some reservation. A dominant theme across the literature on the use of AI in clinical settings was the envisioned role of AI as a supportive tool for the existing medical team, with adequate and continuous human oversight [15,19,20,39-42]. This envisioned role of AI was confirmed as desirable by the parents in our study, who, despite their enthusiasm about AI's potential for neonatal care, were adamant about the preservation of human expertise, oversight, and contact when AI is used.

In contrast to those with a medical background, parents without a medical background more frequently reported feeling insufficiently acknowledged or included by medical staff, sometimes accompanied by uncertainty about which questions were appropriate or necessary to ask. Nonetheless, no clear or consistent differences in perspectives about predictive AI in neonatology emerged from the focus groups, in contrast to earlier findings [21,24,25]. On the other hand, it elicited hopes regarding the development of AI systems that could support parents during the period in which their child receives neonatal care. That is, even though the focus groups were designed to specifically explore parents' perspectives on the use of predictive AI for clinical decision support, parents—particularly those who did not have a medical background themselves and did not have medical professionals in their social circle to call upon—frequently brought up other potential AI applications that could support them, such as AI-mediated communication tools and emotional support systems for parents. More broadly, they spontaneously suggested a range of functions that they envisioned AI could provide, although some of these would not necessarily require an AI application. For example, one suggestion was that a system could play recordings of parents' voices to their baby when they were unable to be present. While such a function could potentially be developed as a digital tool, it may not inherently require AI. This broad understanding of what AI could encompass for neonatology suggests that the participants' expectations may extend beyond applications for which AI is likely the most suitable technology.

Overall, this study gave rise to several overarching ethical considerations regarding predictive and general AI development and implementation in neonatal clinical care. These considerations are presented in Table 2. They include aspects specific to short-term or long-term predictions, as well as general considerations that apply more broadly to AI irrespective of the prediction timeframe or application. Specifically, these encompass ethical considerations regarding (1) the effects on parental intuition and uncertainty about the child's outcome, (2) actionability of a prediction or outcome, and (3) the need for ongoing parental support and engagement. We urge researchers, developers, clinicians, and other stakeholders to take these into account when they design, adopt, or use AI systems in neonatology. In what follows, we elaborate on and contextualize these essential ethical considerations stemming from the focus groups.

Table 2. Ethical considerations elicited by parents related to human-centered AI design and the implementation of predictive AI in neonatology.

Ethical consideration	Short-term prediction	Long-term prediction	Across prediction timeframes
Effects on parental intuition and uncertainty about child's outcome	Predictions regarding acute conditions may affect parents in their own parental intuition, which they consider important for their child's care	Parents might not want to know their child's prognosis, as they might treat their child differently because of it	Parents may worry about false hope or undue stress that knowing or not knowing health outcomes can bring

Ethical consideration	Short-term prediction	Long-term prediction	Across prediction timeframes
Actionability of a prediction or outcome	Parents may value information when acute predictions concern severe conditions with actionable treatment	Long-term predictions may mainly be appreciated when these are actionable and can be used to prevent adverse health outcomes of their children	AI systems may have an overly large impact on medical actions taken in care leading to potential under- and overtreatment
The need for ongoing parental support and engagement	Parents likely wish to be informed when AI is used, about what to expect, and to receive information about the output of predictive AI outputs in acute settings; yet, receiving excessive information may also induce stress among parents	Parents may need long-term support to help them adequately respond to a long-term prediction and provide the care their child needs	Actively engaging the perspectives of parents may help align AI systems with parents' needs and foster realistic expectations about AI in neonatal care, which may support parental trust in the care processes

Consider Concerns About Predictive Health Information During AI Design

In contrast to predictive AI in acute settings, parents expressed reservations about the hypothetical prospect of AI generating long-term predictions about their child's health. Their concerns centered on the inherent uncertainty underlying such predictions and the burdens these might impose, both presently and in the future, on their child and themselves as parents. Notably, these concerns seem to be related to the broader ethical and psychological issues associated with predictive health information. After all, similar arguments are found in debates surrounding genetic screening for adults, such as genetic screening for a predisposition to breast cancer (eg, "Do I want to be aware of this knowledge when it is uncertain whether I will actually develop the disease?") [43,44], or for Alzheimer disease (eg, "Do I want to know my risk if no effective treatment exists?") [45-47]. In these cases, the concerns reflect the same underlying ethical tension between the potential benefits of foreknowledge and the psychological and social burdens that such knowledge may impose.

Regarding newborn screening, for instance, screening for rare genetic diseases or prognostic screening for neurodevelopmental conditions, similar concerns have been echoed [22,48]. Although parents may certainly express enthusiasm about the potential of prognostic tests and may strongly desire such prognostic information [49-51], hesitancy when such information concerns their own child is also highlighted [22]. Consistent with the perspectives of parents in our study, worries about the potential loss of hope or the risk of stigmatization have previously been cited as reasons why predictive health information can be perceived as challenging [22]. Difficulties in obtaining adequate informed consent, the psychological burden on families, the emotional distress that may arise for young children who are aware of an untreatable condition, and broader ethical considerations such as the child's right to informational self-determination (eg, the child's right to an open future) all contribute to this challenge [48,50,52,53].

Throughout the broader debate on predictive health information, the urgency to continuously assess the psychological and social impact is consistently voiced; especially when it concerns minors, who are assumed to be particularly vulnerable [43,52,54]. When contemplating the use of predictive AI, particularly regarding a child's health later in life, similar concerns should not be overlooked.

Develop AI Systems to Support Parents in Neonatology

The provision of information about anything related to the care of their children was one of the most pressing concerns among parents in our study. Interestingly, such a need or desire to be informed is similar to what is known from other studies of parental or patient perspectives on AI in pediatric medicine and radiology [15,16,20,42]. Yet, while the parents in our study expressed a clear desire to be informed about the use of predictive AI in the care of their child, many also indicated that receiving excessive information could lead to unnecessary stress. This apparent tension between wanting to be informed and avoiding information overload is consistent with previous empirical findings on parental perspectives about AI specifically within NICU settings [20]. Moreover, discrepancies between standard practices of information provision and the actual needs of parents, as well as between the development of prognostic models and what parents prioritize, appear to be particularly pronounced in the field of neonatology [8,55]. These insights underscore the need to further investigate, should AI be routinely integrated into neonatal care, how tailored communication strategies may best meet the needs of parents during an already overwhelming and vulnerable time.

Moreover, while the aim of the study was to gain insight into parents' perspectives about predictive AI, parents also envisioned other ways in which AI could be designed for and implemented in neonatology, even though these were not demonstrated uses for AI systems. Notably, many of their envisioned applications differ significantly from current AI development in neonatal settings. A systematic review on the use of AI in the NICU and the pediatric intensive care unit [4] shows that many of the included AI models are currently geared toward supporting the medical team, with their intended use mostly being the prediction of diseases and mortality among infants. While parents acknowledged the importance of these applications in our study, they also imagined AI supporting them directly in their parental role, particularly when they did not have medical knowledge to draw upon. This included being a constant source of information and emotional support, providing tailor-made

suggestions for finding appropriate care for their child, and integrating parental intuition to improve the quality of neonatal care. While these envisioned applications of AI do not yet align with the current clinical reality, they are in line with arguments in the theoretical debate on improving trustworthy and adequate AI integration in clinical settings [56]. Actively engaging the perspectives of patients and carers ought to result in more realistic expectations about AI, improved trust in AI, and better designed AI solutions.

In addition, although the current capabilities of AI in clinical neonatology do not yet encompass all of the roles envisioned by the parents in our study, their perspectives and expectations nonetheless shed light on areas of care in which they perceive opportunities for additional support or involvement. These perspectives thus offer valuable insights into parents' wishes at the neonatal bedside, some of which may require improvement regardless of whether AI is the best solution. For the development, implementation, and governance of AI in neonatal care, these findings highlight the importance of starting by identifying meaningful needs and opportunities for support among relevant stakeholders. Parents' perspectives may thus help to identify not only which AI systems and functionalities are desired but also where other forms of support may be appropriate or even more suitable for neonatology.

Strengths, Limitations, and Recommendations

This study provides empirical insights into parental perspectives on AI integration at the neonatal bedside. Parents are a group that has thus far been relatively overlooked in the literature on AI in neonatal clinical settings, yet their perspectives are of critical importance for successful AI implementation. This study thereby adds valuable practical insights to the substantial theoretical debate, contributing to improved implementation of AI in neonatal clinical settings.

Although the participants in our study had diverse occupational backgrounds and levels of education, the sample was relatively homogeneous with an overrepresentation of female parents, parents of children admitted to the NICU due to prematurity, and parents whose highest educational level was either a bachelor's or a master's degree. These characteristics may have influenced participants' perspectives on the hypothetical use of AI in neonatal clinical settings, as parental perspectives may vary according to factors such as gender or education [18,57,58]. The extent to which these participant characteristics influenced our results could not, however, be investigated in our study. Importantly, these groups were not excluded a priori from participation. Despite our efforts to recruit a diverse sample, we found that some groups, including fathers and parents with lower educational attainment, were more difficult to reach and engage in the study. Nonetheless, the transferability of our findings to more diverse groups of NICU parents, including fathers, parents with different educational backgrounds, and parents of children admitted for other neonatal conditions, should be considered with caution.

Moreover, we recruited participants for this study via the social media channels and mailing list of the parent and patient advocacy organization, Care4Neo. The perspectives of parents who follow these social media channels and receive the newsletter of this organization may differ from the perspectives of parents who do not. They may, for instance, be more informed and more engaged or critical. A study on the potential biases of recruitment via social media versus hospital-based recruitment in adolescent and youth cancer survivors found that participants recruited via social media were significantly more likely to be White and to report a more negative mood and more negative illness perceptions [59]. To the best of our knowledge, similar studies have not been carried out in neonatology. However, it should be considered that recruitment via Care4Neo may have introduced selection bias, as the resulting study population may not have been fully representative of the broader population, potentially influencing our findings [60].

Another limitation is the hypothetical nature of the discussions during the focus groups. We asked the parents in our study about their perspectives on the hypothetical scenario of predictive AI being used in neonatal clinical settings, in which parents often retrospectively linked their perspectives to how they received care during the hospital admission of their own child. Consequently, the findings should be interpreted as parents' anticipated perceptions and expectations of predictive AI, which may differ from their responses when encountering or relying on such technologies during an actual NICU admission. In particular, the acute and emotionally demanding circumstances surrounding NICU care may shape how parents perceive AI systems in practice. Also, it is common for parents' priorities and values to change over time, for instance, through processes of reappraisal and sense-making [61]. What parents reported retrospectively might therefore not fully represent parents' perspectives at the time their child is admitted to the hospital.

Also, the framing of the AI scenarios may have influenced participants' responses. Although the scenarios were presented descriptively and in accessible language, the acute prediction scenario explicitly highlighted the possibility of earlier detection, which may have contributed to more positive perceptions of the acute predictive AI.

Furthermore, during the focus groups, it became clear that parents whose child had experienced prolonged and severe complications in the NICU often expressed different perspectives compared with those whose child had a shorter and less critical stay. Specific experiences of parents, marked by, for instance, the severity of their child's condition, may matter for what is deemed important in clinical decision-making [62]. However, within the limits of the non-WMO agreement, information about the children's health, condition, or duration of admission could not be collected prior to the focus groups. Therefore, we were unable to systematically investigate these potential differences. Future research could benefit from organizing focus groups with deliberate homogeneity to explore how factors such as education level or severity of the child's condition might influence parental perceptions and outcomes more precisely.

Moreover, the focus groups were conducted in Dutch, the analysis was conducted using the Dutch transcripts, translation occurred after the themes were developed, and excerpts of the interviews were translated into English to serve as illustrative quotes. While two researchers reviewed the translations of the themes and quotes to assess whether their meaning was adequately preserved, some nuances or intended meanings may have been lost in translation.

Conclusions

Parents of children who were admitted to the NICU consider the hypothetical use of predictive AI as a tool with significant potential to support both clinical care and their own roles, especially in acute settings. Their perspectives also highlight critical ethical, psychological, and practical considerations. While they expected that AI might improve access to information, support decision-making, and empower parental intuition, they also expressed that reliance on AI might risk undermining parental agency, amplify power imbalances, and create an emotional burden, particularly regarding long-term health predictions. Engaging parents in the design and implementation of predictive AI in neonatal care is essential to ensure that these tools align with their wishes, respect their insights, and mitigate potential harms. Ultimately, incorporating parental perspectives can guide the development and implementation of AI solutions in ways that support trust, shared decision-making, and family-centered neonatal care.

Generative AI Use

The authors declare the use of generative AI in the research and writing process. According to the GAIDeT taxonomy (2025), the following tasks were delegated to generative AI tools under full human supervision: quote translation and editing. The GenAI tool used was OpenAI. Responsibility for the final manuscript lies entirely with the authors. GenAI tools are not listed as authors and do not bear responsibility for the final outcomes.

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Data Availability

The data are presented in the form of themes supported by illustrative quotes from participants (Multimedia Appendix 3). The complete dataset is not publicly available due to the sensitive nature of the data, which is protected under Article 9 of the General Data Protection Regulation (GDPR).

Authors' Contributions

Conceptualization: LS, MB, KJ, JD
Data collection: LS, SR, JD
Data analysis: LS, SR, KJ, JD
Funding acquisition: KJ
Investigation: LS, SR, JD
Methodology: LS, SR, KJ, JD
Project administration: KJ
Recruitment: LS, SAO-B
Supervision: MB, KJ, JD
Visualization: LS
Writing – original draft: LS
Writing – review and editing: LS, SR, SAO-B, MB, KJ, JD

Conflicts of Interest

LS is employed at the Royal Dutch Medical Association (RDMA). Views presented in this article are not linked to the RDMA. The other authors declare no conflicts of interest.

Multimedia Appendix 1

Topic list.
[DOCX File (Microsoft Word File), 22 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Coding tree.
[DOCX File (Microsoft Word File), 28 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Illustrative quotes.
[DOCX File (Microsoft Word File), 27 KB-Multimedia Appendix 3]

Checklist 1

COREQ checklist.
[PDF File (Adobe File), 317 KB-Checklist 1]

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Abbreviations

ADHD: attention-deficit/hyperactivity disorder
COREQ: Consolidated Criteria for Reporting Qualitative Research
EEG: electroencephalography
GDPR: General Data Protection Regulation
NICU: neonatal intensive care unit
WMO: Medical Research Involving Humans Act (Wet medisch-wetenschappelijk onderzoek met mensen)

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