How Neonatologists Use Genetic Information

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Objective To delineate specific ways in which neonatologists integrate genetic information into their clinical decision making.

Study design We employed chart-stimulated recall, in which neonatologists described how they used genetic tests in specific patient cases, as well as semi-structured questioning about genetic information.

Results Based on 28 interviews with neonatologists, we document 6 uses of genetic information: making a diagnosis, categorizing/stereotyping as "genetic," informing prognosis, influencing treatment, informing goals of care, and supporting accountability. Both specific genetic diagnoses as well as a general categorization as "genetic" help neonatologists make sense of unusual clinical situations and calibrate their predictions about the future. Predictions, in turn, inform goals of care decisions, the timing of medical technology placement, and neonatologists' self-evaluations. Diagnoses rarely influence day-to-day treatment directly. Neonatologists assign great value to improved prognostication, but simultaneously feel a responsibility to ensure that genetic information is not applied in ways that are overly deterministic or reflect ableism.

Conclusions Frameworks for measuring successes and failures of genetic information in the neonatal intensive care unit need to be aligned with the ways neonatologists use this information. Understanding neonatologists' use creates opportunity to maximize benefit and reduce bias in applying this complex information. *(J Pediatr 2025;280:114508)*.

The neonatal intensive care unit (NICU) has become a proving ground for rapid genetic sequencing, given the prevalence of genetic disease,[1,2] high acuity, and inadequacy of prognostic data.[3,4] Opinions about this testing remain divided. Many experts anticipate that genetic testing will benefit medical decision making as results are available more quickly, and they aim to document changes in management as markers of success.[1,5-9] Other experts continue to caution that genetic information may produce harms.[10-12] Overall, neonatologists have reported general discomfort with applying genetic information to critical care decisions.[13,14]

Increasingly, this debate is viewed through the lens of assessing the utility of genetic testing. We and others have reported systematic reviews of measures of clinical utility used in studies of neonatal and pediatric genomic testing.[9,15] These reviews raise 3 concerns about how the utility of genetic testing is being assessed. First, most current utility measures only assess whether there were any changes in clinical care rather than assessing expected magnitude of benefit to the patient.[8] Second, utility studies and reports systematically overemphasize cases in which a genetic diagnosis leads to a targeted treatment, even while acknowledging that such changes are rare.[9,15] Finally, current utility measures fail to assess for harms, including faulty or biased application of genetic results.[9,12,15,16] This is of particular concern, as ethicists have long warned that genetic diagnoses may enable the perpetuation of ableist bias.[12] Our group demonstrated, in a controlled experiment, that neonatologists inappropriately applied uncertain genetic information and information portending future disability, with both types of information biasing them toward palliative care in a hypothetical context.[17]

To understand better the utility of genetic testing in neonatology, we sought to explore the various ways that neonatologists seek to use genetic information in making clinical decisions and whether the information in practice had utility or not. To do so, we employed chart-stimulated recall-based interviews to examine specific patient cases. Our study was conducted at a high-acuity, quaternary referral center with relatively abundant resources; patients in this setting would be expected to experience maximal beneficial utility from genetic testing.

Methods

Participants and Recruitment

The study was approved by the institutional review board and conducted in the NICU at the Children's Hospital of Philadelphia, a 103-bed level IV unit that

NICU	Neonatal intensive care unit

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serves a referral patient population. We obtained written consent from all participants. Through chart review, we identified neonatologists who had, within the last 2 weeks, received the result from broad genetic testing: a genome-based panel (the first-line test for most patients in our unit) or exome or genome sequencing. We ensured the patient had no additional genetic testing pending. By email, we recruited the neonatologist who had received the result, with regard to this specific patient they had cared for, purposively recruiting by result to include pathogenic results, negative results, and variants of uncertain significance. We also included a subset of neonatologists who had cared for patients whose parents declined recommended genetic testing. Though we selected the cases for chart review from our level IV NICU, most neonatologists also practice at our associated level III NICU.

Data Collection

We employed chart-stimulated recall to begin all interviews. The interviewer reviewed medical charts prior to interviews and asked the interviewee to do the same, to refresh their memory about the specifics of the case. The interviewer prompted the neonatologist being interviewed to describe their use of genetic tests in the specific patient case. We chose to anchor interviews to specific patient cases to elicit concrete information about medical decision-making rather than generalizations and perceptions alone.[18] We then employed semi-structured questioning about genetic information more generally, inviting the neonatologist to discuss other cases that were similar or different to the subject of chart-stimulated recall. We developed the interview guide (**Figure 1**) using existing frameworks of utility and uncertainty for genetic medicine[9,19] and 2 pilot interviews. One author, who is a neonatologist with qualitative training, conducted all interviews in person or virtually; recordings were transcribed.

Data Analysis

We employed a constructivist grounded theory approach to data analysis.[20] Three authors collaboratively developed a codebook. Codes were primarily derived inductively from the data, although informed by the authors' research questions, prior work, extant literature, and clinical experience. The same 3 authors then independently double-coded all transcripts.[21] We assessed inter-rater reliability among coders at 3 timepoints, achieving k scores ranging from 0.80 to 0.89. Using constructivist grounded theory, we created and iteratively revised a conceptual model of the ways neonatologists use genetic information.[20] We identified codes most relevant to our research questions, synthesized them into broader themes, posited relationships between these themes to create a model that we agreed most usefully represented the data, and together reflected on its implications.

Introduction

- The NICU is a place full of questions and uncertainty. When you think about the big picture of caring for [first name], what questions seemed most important to answer?
- Many times, uncertainty relates to what the future will look like. What kinds of questions about [first name]'s future have seemed important in caring for this baby and family?
- *What information did you have, or did you try to get, to answer these questions?*
- *Were there any unanswered questions that were troubling about this case? The kind of things that you thought about after you left work or that kept you up at night.*
- *Now we're going to step back and for a couple minutes and talk about uncertainty more generally, not specific to this case.*
  - *Is uncertainty something you think about much in clinical practice, or talk to colleagues about?*
  - *In general, to you as a neonatologist, does uncertainty feel more like a good thing or a bad thing in clinical practice?*

Discussion of Genetic Testing (abbreviated if spontaneously discussed above)

- *Ok, now we're going to talk more specifically about genetic information in the case of [first name].*
- *What questions were you, or the neonatologist who ordered the genetics consult, hoping to answer with the genetic information?*
- *Did [first name]'s parents consent to the testing that was recommended?*

If consented to genetic testing:

- *What were the genetic test results?*
- *Was this genetic result helpful to you in taking care of [first name] and their family? How so?*
- *Was the result meaningful to this family? How so?*
- *Some people have told us genetic results answer some questions but turn up new ones. Did this genetic testing create any new questions?*
- *Did you feel like [first name]'s parents understood these results?*

If consented and received *positive* results:

- Was this genetic result helpful to you in taking care of [first name] and their family? How so?
- Was the result meaningful to this family? How so?
- Did the genetic result bring up any new questions?
- Did the genetic result, overall, increase or decrease your feeling like you knew how to take good care of this baby? Why?

If consented and received *negative* result:

- Was this genetic result helpful to you in taking care of [first name] and their family? How so?
- Was the negative result meaningful to this family? How so?
- Did the negative genetic result bring up any new questions?
- Did the negative genetic result, overall, increase or decrease your feeling like you knew how to take good care of this baby? Why?

If parent declined testing:

- *For what reasons do you think these parents decided not to proceed with genetic testing?*
- *Have you seen other parents decline genetic testing, and if so, are there any other reasons you've seen?*
- *Does it seem reasonable/acceptable for parents to decline?*

Genetic information, in general

Last, I will ask a couple questions about genetic testing more generally, not specific to this patient.

- *What questions are neonatologists usually trying to answer when they send genetic tests?*
- *Are the tests more often to help us make decisions for medical care or help parents deal with difficult experiences?*
- *Can you think of a case when the results answered questions just as we'd hoped they would?*
- *Can you think of a case where the results led to greater uncertainty or confusion?*
- *In general, in what situations is genetic information most helpful to neonatologists?*
- *In general, what are the greatest limitations of genetic testing?*

Figure 1. Neonatologist interview guide.

Results

Over a 6-month period in 2024, we interviewed 28 neonatologists (100% consent rate) to achieve thematic saturation (**Table I**). The average interview duration was 44 minutes. Neonatologists discussed 6 uses of genetic information (**Figure 2**, **Table II**). Both specific genetic diagnoses as well

Table I. Characteristics of participants

Category	n (%)
Neonatologist characteristics (n = 28)	
Gender	
Female	17 (61)
Male	11 (39)
Age, y	
30-39	12 (43)
40-49	6 (21)
50-59	6 (21)
60+	4 (14)
Race	
Asian	2 (7)
Black	1 (4)
White	25 (89)
Ethnicity	
Hispanic or Latino	1 (4)
Not Hispanic or Latino	27 (96)
Years in practice	
0-4	8 (29)
5-9	7 (25)
10-14	3 (11)
15-19	2 (7)
20+	8 (29)
Patient discussed	
Tests recommended* (n = 33)	
Exome	12 (34)
Genome	1 (3)
Genome-based panel	20 (57)
Test result† (n = 28)	
Decline testing	3 (11)
Pathogenic	15 (54)
Negative	4 (14)
Uncertain	6 (21)

Sample includes 28 neonatologists, who were interviewed regarding 28 different patient cases. *Displayed as percent of total tests represented. Several patients had multiple tests. Numbers include the type of test that had been recommended even if parents ultimately declined the test. †For stratified sampling and representing result, case was counted using most definitive result: positive > uncertain > negative > decline.

as the general categorization as "genetic" helped neonatologists prognosticate. Prognosis, in turn, informed treatment and goals of care. Genetic information was also used as part of neonatologists' self-evaluative processes, influencing accountability. Within each use, neonatologists reflected on information from their perspective as doctors making medical decisions and—with guidance and spontaneously—considered how the information affected parents. We provide subject identification numbers in parentheses following quotations.

Making a Diagnosis

When asked about the primary use of genetic tests, many neonatologists responded along the lines of, "We're trying to simply put a name on an observation" (26). Genetic conditions were frequently suspected when patient's findings were unusual, or their courses deviated from the expected. In part, the desire to name diagnoses was related to curiosity; "It's fascinating to know" (23). Neonatologists simultaneously acknowledged that intellectual curiosity should not be the primary driver for "finding answers" (25). They hoped providing a named diagnosis would relieve parents' uncertainty about etiology, described as "a really painful space to live in" (23). Neonatologists also felt that a genetic diagnosis made their job of counseling easier: "We can tailor what we're saying much better than having these big, broad strokes of like, well, it could be this or that" (23).

Categorizing as Genetic

Categorizing a condition as genetic in etiology also served purposes that were independent of the specific diagnosis. Genetic tests were often sent when a patient's presentation or course did not proceed as a neonatologist expected. When genetic diagnoses were made, neonatologists felt this gave patients license to be unusual. "This baby is not responding. This is acting a little odd. And now [the diagnosis] is putting the pieces together, and it's unifying what the neonatologist is seeing as not right, not working right" (14). Even if nothing was known about a novel genetic diagnosis, knowing that the etiology was genetic rather than "out of the blue" (5) often inspired relief. To some extent "genetic kids" (1) were considered one category, unified by having diagnosed genetic changes. Categorizing came with stereotyping, which clinicians discussed as both a useful function of genetic tests and a serious problem.

Informing Prognosis

Respondents considered informing prognosis to be one of the most important functions of genetic information.

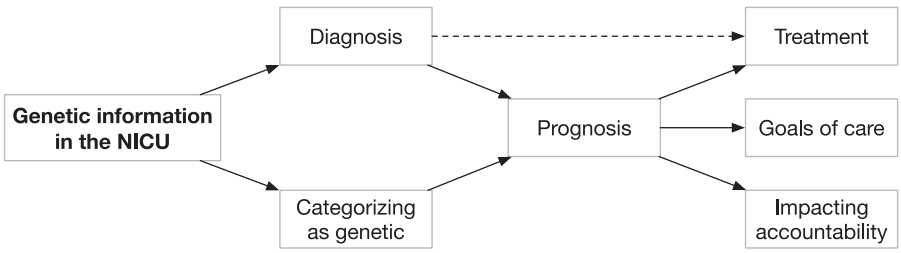

Figure 2. Conceptual model of neonatologists' 6 uses of genetic information. Both specific genetic diagnoses as well as the general categorization as "genetic" help neonatologists prognosticate. Prognosis, in turn, informs goals of care and timing of medical technology placement. Diagnosis only rarely informs treatment directly (*dotted arrow*). Genetic information is also used as part of neonatologists' self-evaluative processes, influencing accountability.

Table II. Supportive quotes for the 6 uses of genetic information

Use	Supportive quotes with summary of central point
Making a diagnosis	*Satisfies curiosity*: "It's fascinating to know" (23).
	Facilitates counseling: "We can tailor what we're saying much better than having these big, broad strokes of like, well, it could be this or that" (23).
Categorizing as genetic	*License to be unusual*: "This baby is not responding. This is acting a little odd. And now [the diagnosis] is putting the pieces together, and it's unifying what the neonatologist is seeing as not right, not working right" (14).
Informing prognosis	*Fills gap in prognostication*: "We've explored babies inside out and have really figured out what we're dealing with right then and there and now. The one thing that we can't tell you is kind of what direction that you're going. That's the X factor. If you do have positive genetic testing, [it] could really help with figuring it out" (1).
	Limitations in prognosticating: "You look into the literature, and you start to find sometimes this happens, and sometimes that happens…You don't look at any of it and say, 'oh, that's who he is.' So, it's provided a lot of confusion for the family and for the providers… sometimes the response to that confusion is to sweep it under the rug and forget about it" (13).
Influencing treatment	*Separate from day-to-day treatment*: "We treat the babies in front of us, with or without genetic testing. And because we're an ICU, we're treating them based on ICU issues, acute respiratory failure, and blood pressure issues. We don't need a genetic diagnosis to treat those things" (12).
	Concern about overreliance: "We just have to treat the patient that's in front of us, no matter what the genetic information says or doesn't say" (20).
	Concern about therapeutic misconceptions of parents: "Because [doctors] make a big fuss about the diagnosis and then the parents believe that that's going to answer all their questions …And then [the genetic result] comes, and it doesn't" (27).
	Hopeful about future treatment implications: "We feel like at some point we're going to unlock the genetic code maybe and be able to provide precision care and gene therapy… Maybe someday we will, maybe someday we won't" (20).
Impacting goals of care	*Informs goals of care*: "the first question [for genetic testing] was, is this something lethal?" (36).
	Concern information may be misapplied or simplify complex decisions: "I still struggle with it because… [the surgeons] said 'no' because of all the things that we've essentially known about the patient. But they didn't say *definitively* no until they got a genetic diagnosis—that didn't change much about the patient, at least for me" (21).
Impacting accountability	*Part of being thorough*: "We're trained to find answers" (26).
	Diffuse sense of responsibility: "It's almost a way of blaming the patient. Yeah, well, you would have done okay, except for your genes…We couldn't help you" (28).

"We've explored babies inside out and have really figured out what we're dealing with right then and there and now. The one thing that we can't tell you is kind of what direction that you're going. That's the X factor. If you do have positive genetic testing, [it] could really help with figuring it out" (1).

Neonatologists wanted to know about children's long-term prognoses, especially neurodevelopmental outcomes, which they often felt ill-equipped to predict. Genetic information left them "armed with factual information rather than guesses" (23). In a few cases, a genetic diagnosis offered "good news" (7). For example, one child with severe dysmorphic features was found to have a genetic condition associated with typical neurodevelopment. More often, genetic diagnoses heralded future disability. Even without information specific to the diagnosis, "So many [genetic diagnoses] are associated with a developmental delay that whenever you're dealing with a 'genetic kid,' you always kind of have those worries in the long-term" (1). Long-term prognosis could in turn inform short-term care by providing a "roadmap" (27), enabling neonatologists to pursue medical technology earlier for infants who were expected to have long-term difficulties.

Neonatologists frequently reflected about the impact of prognostic information on parents, expressing ambivalence about whether this information was helpful or welcome. On one hand, "It's helpful for parents to know what to expect for their child, to know that their child is going to need more support… to maybe not expect their child to do things on the same timeframe that we would expect a kid to do without a genetic diagnosis" (9). Conversely, a genetic diagnosis "closes the book early in life…This is what the baby has, and there's no doubt about that, and these are the likely things that are going to happen. So, it closes that door of hope" (14). Therefore, "some [parents] like uncertainty…They have more hope that things will get better because we don't really know what's wrong" (14).

One of the most frequently cited limitations of genetic information was prognostic uncertainty. Many genetic changes are associated with poorly defined or wide-ranging neurodevelopmental outcomes: "You look into the literature, and you start to find sometimes this happens, and sometimes that happens…You don't look at any of it and say, 'oh, that's who he is.' So, it's provided a lot of confusion for the family and for the providers… sometimes the response to that confusion is to sweep it under the rug and forget about it" (13). Many discussed growing prognostic uncertainty with technologic progress. "Now, we're getting finer details…we don't know what it means…If you told me a baby had Williams syndrome, I know what it is. …Now you're telling me he has a 'GTTB' deletion. What does that mean? I know genetically what it means, but I don't know exactly what it means" (27). Many felt that we were at a "pain point" (27), of being able to obtain more information but not always knowing its implications. "How do you cover that gap? You sort of have to exist in it a little bit and get through it" (27).

Influencing Treatment

Neonatologists could recall few cases where genetic tests were sent to inform specific treatment questions. In one patient, the genetic etiology of lymphatic dysfunction informed use of an experimental medication. Neonatologists more often noted that genetic syndromes may prompt screening for additional

associated risks or inform parents' reproductive risks, though these were typically conveyed as ancillary benefits. Most of the time, neonatologists emphasized that seeking a genetic diagnosis was, and should be, separate from day-to-day intensive care: "We treat the babies in front of us, with or without genetic testing. And because we're an ICU, we're treating them based on ICU issues, acute respiratory failure, and blood pressure issues. We don't need a genetic diagnosis to treat those things" (12). In large part, this was because there are so rarely ways to alter the genetic problem itself: "You can find out that this is from some genetic condition, but it doesn't change that the kid can't breathe on their own, or it doesn't change that the kid can't eat" (11).

Neonatologists worried that overdependence on genetic information could cloud decision making or create false expectations for families. "We just have to treat the patient that's in front of us, no matter what the genetic information says or doesn't say" (20). Another cautioned that neonatologists could become "psychologically reliant" (23) on genetic information, overlooking what they knew based on a child's clinical presentation. In particular, older, more experienced clinicians voiced concerns that younger neonatologists were overly dependent on genetic information. For example, one young neonatologist deferred tracheostomy placement to wait for genetic results, while an older clinician felt the child's presentation was evidence enough to proceed. Furthermore, neonatologists worried they could create false expectations for parents about the ways in which a genetic diagnosis would improve a child's outcome. "Because [doctors] make a big fuss about the diagnosis and then the parents believe that that's going to answer all their questions …And then [the genetic result] comes, and it doesn't" (27).

Neonatologists were hopeful that in the future genetic information would more directly influence outcomes but were unsure about the likelihood of that eventuality. "We feel like at some point we're going to unlock the genetic code maybe and be able to provide precision care and gene therapy… Maybe someday we will, maybe someday we won't" (20).

Informing Goals of Care

Goals of care decisions represented a concrete way in which the prognostic implications of genetic diagnoses affected immediate NICU care. When neonatologists were asked, "Can you think of a case where genetic information answered a question just as we had hoped?" a majority cited goals of care decisions. Neonatologists felt that genetic information could be of great benefit because it "helps families come to peace with a really sick baby and redirecting care" (16) and helps neonatologists and families "make decisions together" (14). Genetic diagnosis could provide a sense of "closure" (9).

Applying genetic information to goals of care decisions also incited concerns that information about disability could be applied in biased ways. One questioned, "Do we have a right to know everything about a person?… Can we predict what college they're going to?… Are they going to be schizophrenic? It's like, well, that is good to know but maybe it's not good to know" (28). She worried this predictive information could lead a neonatologist to say, for example, "We're not going to put you on extracorporeal membrane oxygenation because now we have data that when you're 10, you're going to have leukemia, and die" (28). Neonatologists also pointed out that genetic diagnoses could be used to simplify multifactorial decisions about goals of care in problematic ways. For example, several discussed the case of a patient recently denied cardiac surgery: "I still struggle with it because… [the surgeons] said "no" because of all the things that we've essentially known about the patient. But they didn't say *definitively* no until they got a genetic diagnosis—that didn't change much about the patient, at least for me" (21). Neonatologists advised thoroughness, with each other and with families, about the many factors included in goals of care decisions.

Influencing Accountability

Genetic information served a role in neonatologists' self-evaluative processes. First, sending genetic tests was part of being thorough. In intensive care units, the unknown signals potential danger. Intensivists are trained to respond to uncertainty by seeking information; "we're trained to find answers" (26). Sending genetic tests was often part of a larger effort not to "miss anything" (7). Genetic tests helped clinicians feel they had done due diligence: "Even if it's negative, it's a box checked" (22). If a genetic etiology was uncovered, this reassured clinicians alternate etiologies, for example infection, with potential treatments.

Second, genetic diagnoses could diffuse neonatologists' sense of responsibility for bad outcomes. If a specific genetic diagnosis portended a poor prognosis, "it makes [neonatologists] feel better. Sounds terrible. It makes us feel better if the patient doesn't survive that they had this terrible diagnosis, and it wasn't something that could have been fixed" (12). Some comments suggested that bad outcomes were attributed to genetic diagnoses as a general category, rather than specific prognostic associations. Perhaps in response to the emotional difficulty of working with very sick infants, "It's almost a way of blaming the patient. Yeah, well, you would have done okay, except for your genes…We couldn't help you" (28).

Neonatologists simultaneously were aware that genetic information could be used to stereotype and felt responsible for reducing bias. "They have variant blah, blah, blah. Nobody even knows what it means, but it's in their sign out and in their one-liner…You expect less of them" (15). Yet, "the certainty is around 'you have the genetic difference,' but then what comes next is individual to that person…This is a genetic condition, but this child is not going to be defined by this, right?" (4). Neonatologists felt they were responsible for mitigating bias—being the "dictators of uncertainty" (22). One resolved, "That's our job, to not make the label bigger than the child" (11).

Discussion

Based on chart-stimulated interviews, we have documented 6 ways in which neonatologists use genetic information. Both

specific genetic diagnoses and general categorization as "genetic" help neonatologists make sense of unusual clinical situations and calibrate their predictions about the future. Predictions in turn inform timing of decisions about medical technology and factor into goals of care decisions. Overall, neonatologists indicated that they wanted genetic information. They simultaneously reflected their struggle to ensure the information was applied soundly given prognostic imprecision and the potential for biased interpretation, particularly related to disability. Several aspects of these findings warrant further discussion.

The uses of genetic tests that neonatologists report highlight flaws in current measures of the utility of genetic medicine in the NICU. A focus on changes in management has created the illusion that genetic information is routinely improving medical outcomes.[7,22-24] However, even in this study's setting, with ample access to geneticists, subspecialty services, and any available intervention, genetic information only rarely leads to targeted treatments. Instead, neonatologists report that genetic information does not—and should not—change day-to-day intensive care, in most cases.[25] Instead, genetic information most often informs prognosis in ways that are valued, but unlikely to change children's short-term outcomes, outside of goals of care decisions. At the same time, some of the most important successes of genetic tests from neonatologists' perspective would not meet the threshold of utility in current frameworks. For instance, when neonatologists know a disease is genetic, they can stop looking for alternate etiologies. Neonatologists find counseling easier when they can discuss a genetic diagnosis rather than an unnamed constellation of symptoms, even when little is known about the diagnosis.

Neonatologists' accounts also highlight potential downsides of genetic testing, adding weight to long-standing concerns and introducing new issues. First, genetic information may be interpreted as more certain than data justify, leading to misapplication.[26] This finding is in line with work from other medical specialties demonstrating that doctors often ascribe too much meaning to medical information, particularly if they have had a role in obtaining the information.[27,28] Neonatologists extend this concern in wondering if they may become "psychologically reliant" on genetic information, discounting their clinical intuition. This possibility is particularly concerning since neonatologists report difficulty interpreting genetic results.[14] In our unit, neonatologists and geneticists disclose genetic results to families together, and geneticists remain available as questions arise, so misunderstanding may be a greater risk in units with fewer genetics resources. Second, information about expected disability in the future may be applied to neonatal care in ways that reflect stereotyping and ableism.[12] Unjustified genetic determinism has been documented throughout medicine.[29-33] Third, neonatologists' perception that parents may not want genetic information, and in particular negative prognoses which "close the book," are inconsistent with several parent interview studies that have dismissed such concerns.[34-39] The discrepancy may reflect neonatologists' own trepidation around the technology, or their unique vantage on parents who decline interview or are not forthcoming about their reservations. Neonatologists, the very doctors who are to be applying genetic information in the NICU, have a major stake in defining success and highlighting risks, second only to parents.

Future research can build on the findings of this qualitative study in 2 different dimensions. First, a lateral dimension, seeking to understand how these findings vary across different settings, such as NICUs with different levels of patient acuity or of resource availability, or across diverse patient groups, could be done with further qualitative comparative research or with quantitative approaches based on standardized questionnaires or objective outcome measures. Second, given that much of the utility of genetic information hinges on the value of prognosis, longitudinal study of patients over time, ideally for years beyond the NICU hospitalization, will be necessary to evaluate whether the purported benefits of genetic-information-based prognoses do indeed benefit patients and their families.

Our study design has both strengths and limitations. We engaged neonatologists in discussion of specific patient cases, a technique shown to improve accuracy of reporting,[18,40] and had a high consent and participation rate. That this study took place at a single, tertiary referral center is both a strength and limitation. Our center has ample access to genetics experts and sends genetic tests on a high proportion of the complex patient population. Although this means our findings may not be representative of all institutions currently, our study sample provides an opportunity to consider the forefront of genetic technology. An additional limitation is that interviews were conducted by a neonatologist who practices at this site. This may have introduced interviewer bias yet may also have allowed interviewees to be candid and explain complex clinical reasoning.

In conclusion, our findings emphasize the need for more robust thinking about genetic testing utility and disutility in clinical practice and, for patients and families, their lived experiences over time. Understanding how neonatologists use genetic information creates opportunities to maximize benefit and ensure that genetic information is applied soundly to clinical care. Frameworks for measuring successes and failures of genetic information in the NICU need to be aligned with neonatologists' uses. ■

CRediT authorship contribution statement

Katharine Press Callahan: Writing – review & editing, Writing – original draft, Visualization, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Rebecca Mueller:** Writing – review & editing, Project administration, Investigation, Formal analysis. **Steven Joffe:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Cara Skraban:** Writing – review & editing, Formal analysis. **Nancy B. Spinner:** Writing – review & editing, Formal analysis. **Karen Crew:** Project administration, Formal analysis, Data curation. **K. Taylor Wild:** Writing – review & editing, Formal

analysis. **Justin T. Clapp:** Writing – review & editing, Methodology, Formal analysis. **Chris Feudtner:** Writing – review & editing, Methodology, Formal analysis, Conceptualization.

Declaration of Competing Interest

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Data Statement

Data sharing statement available at www.jpeds.com.

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