

Original Article

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Wayfinding through the “ocean of the great unknown”: how lactating parents establish a direct breastfeeding relationship with an infant with critical CHD

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Abstract

Introduction: Lactating parents of infants hospitalised for critical congenital heart disease (CHD) face significant barriers to direct breastfeeding. While experiences of directly breastfeeding other hospitalised neonates have been described, studies including infants with critical CHD are scarce. There is no evidence-based standard of direct breastfeeding care for these infants, and substantial practice variation exists. **Aim:** To explain how direct breastfeeding is established with an infant hospitalised for critical CHD, from lactating parents’ perspectives. **Materials & Methods:** This study is a qualitative grounded dimensional analysis of interviews with 30 lactating parents of infants with critical CHD who directly breastfed within 3 years. Infants received care from 26 United States cardiac centres; 57% had single ventricle physiology. Analysis included open, axial, and selective coding; memoing; member checking; and explanatory matrices. **Results:** Findings were represented by a conceptual model, “Wayfinding through the ‘ocean of the great unknown’.” The core process of Wayfinding involved a nonlinear trajectory requiring immense persistence in navigating obstacles, occurring in a context of life-and-death consequences for the infant. Wayfinding was characterised by three subprocesses: navigating the relationship with the healthcare team; protecting the direct breastfeeding relationship; and doing the long, hard work. Primary influencing conditions included relentless concern about weight gain, the infant’s clinical course, and the parent’s previous direct breastfeeding experience. **Conclusions:** For parents, engaging in the Wayfinding process to establish direct breastfeeding was feasible and meaningful – though challenging. The conceptual model of Wayfinding explains how direct breastfeeding can be established and provides a framework for research and practice.

Infants with CHD often face challenges in developing oral feeding,¹ with feeding problems particularly common in critical congenital heart disease (CHD; i.e., requiring surgery <1 year of age). Approximately 44% of infants undergoing neonatal surgery for CHD do not meet expectations for oral feeding volume by hospital discharge and require feeding tube support at home.² Feeding challenges contribute to suboptimal direct breastfeeding prevalence in this population, with rates as low as 3.2% (exclusive) at 6 months.³ Emerging evidence demonstrates that human milk may be a “life-saving intervention”⁴ for infants with CHD due to lowered risk for necrotising enterocolitis⁵ – a devastating disease with 19–26% mortality in CHD.⁶ Providing human milk via direct breastfeeding reduces early human milk weaning in term and preterm infants,^{7,8} allows greater cardiorespiratory stability while feeding,⁹ offers personalised immunological benefits,^{10–12} and is preferred by most birthing persons.¹³ Furthermore, emerging research with very low birth weight infants has demonstrated that early direct breastfeeding is associated with quicker attainment of full oral feeding,¹⁴ potentially due to the infant-driven^{15,16} nature of direct breastfeeding experiences.

Lactating parents of hospitalised infants face barriers to direct breastfeeding.¹⁷ Experiences of direct breastfeeding for other vulnerable infants have been described,^{18–20} however, infants with critical CHD encounter unique challenges (e.g., volume restriction; lengthy fortification; historic breastfeeding discouragement) that may not be captured by this evidence. The only report focused on parents’ experiences breastfeeding infants with CHD is a 1998 informal survey²¹ including both critical and non-critical diagnoses. No studies examining the process of directly breastfeeding infants with critical CHD, from lactating parents’ perspectives, have been found. An understanding of this process is imperative, as there is no standard for evidence-based direct breastfeeding care in this population and substantial provider- and site-specific variation in feeding practice exists.^{22,23}

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Therefore, the aim of this study was to examine how lactating parents establish direct breastfeeding with an infant hospitalised for critical CHD. Improved understanding of this process may provide a theoretical foundation for interventions to improve the low rates of direct breastfeeding in this population.

Materials and Methods

A grounded dimensional analysis approach^{24–26} guided our inquiry into “what all is involved”²⁶ in the process of establishing direct breastfeeding, from lactating parents’ perspectives.

Definitions

For simplicity, we will refer to direct breastfeeding as “breast-feeding,” defined as human milk via a latch at the breast. We acknowledge that direct breastfeeding is not the only way to breast-feed²⁷ and that individuals may prefer other terms (i.e., chestfeeding). We will often refer to participants as “parents,” as not all identified as women/mothers.

Recruitment

Recruitment began in July 2021 with purposive sampling through a private social media group dedicated to breastfeeding children with CHD and an online CHD parent advocacy group, with administrator approvals. Eligibility criteria included parents of infants hospitalised postnatally for critical CHD who directly breastfed in any amount within the past three years,²⁸ were ≥ 18 , could read English, lived in the United States (U.S.), and had internet access. Individuals were excluded if the child died within two weeks postnatally. An online screening form confirmed eligibility and directed participants to a full description of the study. Interested participants completed informed written eConsent via REDCap.²⁹ High interest required us to pause recruitment after a few hours, with further purposive and snowball theoretical sampling as the study progressed.

Data collection and analysis

After consent, participants completed an online survey to collect demographics and basic feeding information (Supplementary File S1). This survey was followed by a face-to-face interview (45–120 minutes), conducted from July to November 2021 by the first author via video conference (i.e., Zoom). Participants received a \$50 gift card.

Consistent with the grounded dimensional analysis approach,^{24,25} an initial unstructured interview guide evolved into a semi-structured format based on emerging salient concepts (Supplementary File S2), facilitating constant comparison of concepts. Interviews were audio recorded and transcribed verbatim using NVivo (QSR International Pty Ltd., Release 1.6) for immediate analysis, with K.M.E. or N.M.S. verifying accuracy.

To explain the core process, analysis involved dimensionalising through open, axial, and selective coding^{24,25} using MaxQDA 2020 (VERBI Software, 2019). Two researchers independently coded interviews. Initial open coding often employed *in vivo* labels like “standing my ground” or “asking everyone I met.” Axial coding supported preliminary organisation of higher-order concepts and relationships. For example, the previously listed codes were grouped into the higher-order concept, “advocating.” Selective coding elaborated on patterns related to the core process while seeking out variation. Explanatory matrices²⁵ were created to

identify relationships between salient concepts. Analysis continued through theoretical saturation.³⁰

Study rigour was realised through multiple strategies. The research team had varied expertise (i.e., certified nurse-midwife, paediatric physical therapist, neonatal ICU nurse, critical CHD researchers). The first author has experiential perspective as a parent of an infant with critical CHD, which facilitated rapport with participants and allowed for a nuanced analysis of parents’ experiences. To mitigate potential bias and encourage alternative analytical perspectives, the full team met weekly for discussion and peer review. A transparent audit trail of memos and reflexive journals documented key decisions. Member checking was continuous, with later interviewees asked to reflect on concept salience.

Results

Participants

The sample included 30 parents representing 26 hospitals in 20 states. Sample characteristics can be found in Table 1. Primary critical CHD diagnoses are in Figure 1, with a majority single ventricle physiology ($n = 17$, 57%). Additional anomalies/syndromes were diagnosed in 27% of infants.

Wayfinding through the “ocean of the great unknown”

The core process of establishing direct breastfeeding with an infant hospitalised for critical CHD was one of Wayfinding through the “ocean of the great unknown” (04), with the conceptual model in Figure 2. Example quotations can be found in Table 2.

Wayfinding was a nonlinear process requiring immense persistence as parents became navigators of an unfamiliar journey conducted in a context of life-and-death consequences for the infant (Table 2.a). Parents continually observed, assessed, and course-corrected to determine the best path. Wayfinding was an active endeavour involving three core subprocesses: navigating the relationship with the healthcare team; protecting the direct breastfeeding relationship; and doing the long, hard work. These core subprocesses were impacted by three primary influencing conditions: concern about weight gain, the infant’s clinical course, and the parent’s previous breastfeeding experience.

The core subprocesses of Wayfinding were related and could occur concurrently. For example, when parents experienced feeding-related obstacles in navigating the relationship with the healthcare team, the need to protect the breastfeeding relationship was heightened. Engagement in these protective processes facilitated the work of breastfeeding, but sometimes strained the relationship with the healthcare team.

The primary consequence of Wayfinding was breastfeeding establishment. This establishment could result in positive consequences (e.g., pride) because of the parent’s perception of providing their infant with the best chance for optimal health. Some parents described mental health benefits (Table 2.b) or positive consequences for the infant’s physical health (e.g., weight gain, lack of illness, improved cardiorespiratory stability; Table 2.c). Nearly all parents described breastfeeding as allowing them to fulfil an important aspect of the relationship they had envisioned with their infant (Table 2.d).

Influencing conditions

Three primary influencing conditions impacted the Wayfinding process: concern about weight gain, the infant’s clinical course,

Table 1. Participant characteristics (N = 30).

Age	n (%)
20–29	6 (20)
30–39	20 (67)
40 or older	4 (13)
Gender	
Non-binary	1 (3)
Female	29 (97)
Race	
BIPOC	2 (7)
White	28 (93)
Ethnicity	
Hispanic	2 (7)
Non-Hispanic	28 (93)
Highest level of education	
High school/Vo-tech/Some college	6 (20)
College graduate	14 (47)
Any graduate school	10 (33)
Income	
< \$50,000	3 (10)
\$50,000–99,999	13 (43)
≥ \$100,000	12 (40)
Prefer not to say	2 (7)
U.S. region	
Midwest	11 (37)
Northeast	5 (17)
Southeast	5 (17)
West	5 (17)
Southwest	4 (13)
Previous DBF experience	
Yes	20 (67)
No	10 (33)
DBF duration^a	
0–2 months	3 (10)
3–6 months	10 (33)
7–11 months	4 (13)
12+ months	13 (43)
Other oral feeding routes used^b	
Bottle	27 (90)
Feeding tube	23 (77)
Oral care with human milk	19 (63)
Other	2 (7)

Abbreviations: BIPOC = Black, Indigenous, and people of colour; DBF = Direct breastfeeding; U.S. = United States; Vo-tech = Vocational or technical school.

^an = 10 currently directly breastfeeding

^bAt any time during the infant's life

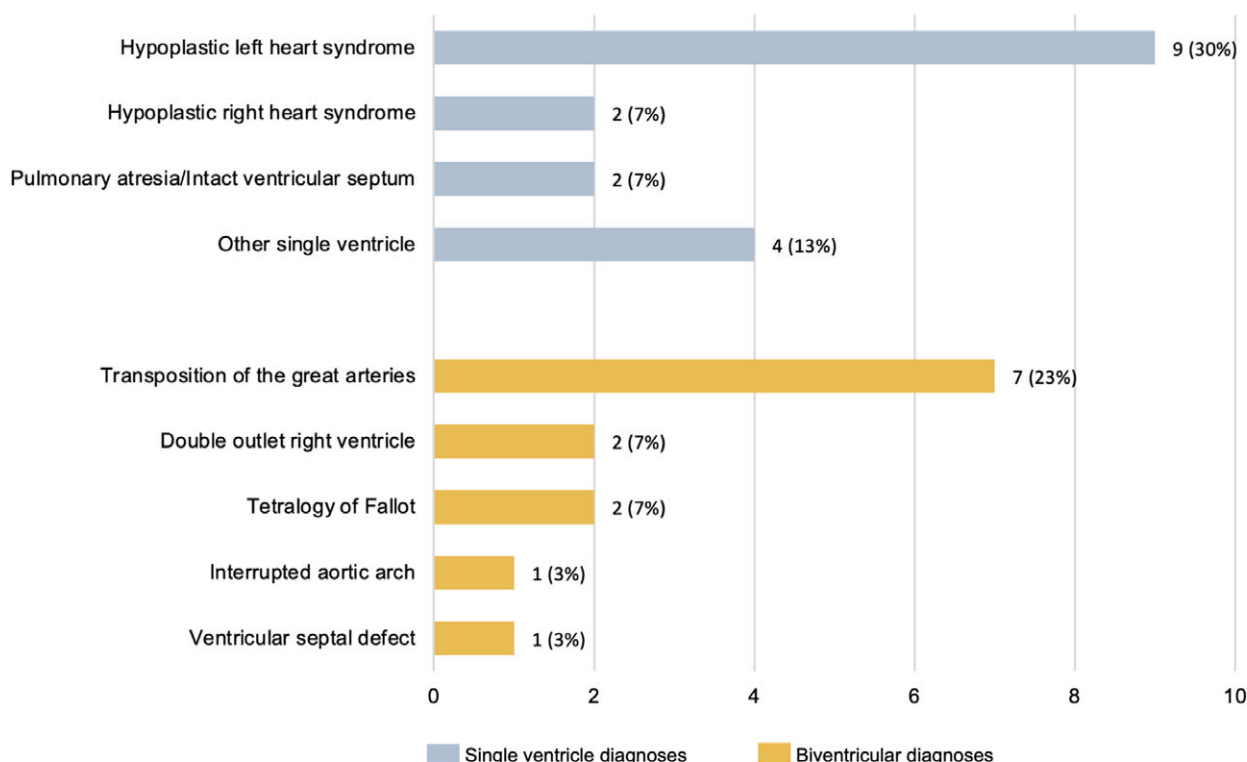
and previous breastfeeding experience. Concern about weight gain was ubiquitous, with many parents describing a single-minded healthcare team focus “all about the numbers” (02) both in the hospital and after discharge (Table 2.e). This concern about weight informed feeding protocols that often interfered with direct breastfeeding (Table 2.f) due to the healthcare team's perceived need to be, as one parent explained, “very specific and controlling on exactly how much [the infant] was getting in” (11).

At times, parents viewed this concern about weight gain as limited, unrealistic, or illegitimate (Table 2.g). Many parents described “fear and worry and chaos” (04) related to their infant's weight, with one parent explaining, “that fear . . . it was kind of instilled from them . . . placed by the doctors being so concerned with how much he was getting” (11). Some parents became “obsessed” (30) with their infant's weight gain and found that the intense focus on weight could negatively impact their mental health (Table 2.h) or cause tension between the parent and the healthcare team. One parent described frustration that the healthcare team would not honour her request to fortify her child's feedings with the high-fat cream from her own expressed milk: “They're like, no, there's no way for us to know how many calories [there are]. It's all very scientific for them” (08). In contrast, some healthcare teams allowed for more experimentation and flexibility in assessing the infant's weight status, which positively impacted the Wayfinding process (Table 2.i).

This concern about weight gain was sometimes related to the infant's clinical course. Infants with the same CHD diagnosis often have vastly different trajectories, and the clinical course was unpredictable in our sample. A few parents described feeling “lucky, because she has some pretty heavy diagnoses” (26). For one parent, this smooth clinical course was perceived to facilitate the Wayfinding process: “I was blessed when he was born. He did not need any direct intervention . . . I was able to establish a direct breastfeeding relationship with him right away” (06).

More commonly, parents reported a wide range of challenges related to clinical course that interfered with breastfeeding establishment and necessitated increased engagement in Wayfinding processes (Table 2.j & 2.k). Parents described experiences with cardiac arrest, extracorporeal membrane oxygenation, ventricular assist devices, heart transplants, emergency reoperation, chylothorax, paralysed vocal chords, failed swallow studies, hypoxic events requiring lengthy intubation, necrotising enterocolitis, intestinal malrotation, diaphragmatic paresis, reflux, hospital-acquired infection, hypotonia, genetic syndromes, and tongue ties. While many of these health challenges were life-threatening (Table 2.l), their impact on breastfeeding establishment varied. One parent whose infant was immediately intubated for several weeks after birth and developed post-surgical chylothorax reported that her infant latched perfectly at 7 weeks old. In contrast, another parent explained that “by the time he really got [breastfeeding], he was like a year old” (30).

Some parents reported that the healthcare team's prenatal perception of the severity of the infant's clinical course impacted their willingness to support the Wayfinding process at birth, which could conflict with parents' priorities for establishing a relationship with their new child (Table 2.m). Other institutions worked within the constraints of the clinical course to assist parents in initiating processes to facilitate breastfeeding establishment (Table 2.n).



Note: Diagnoses listed in this figure are considered the infant's primary cardiac diagnosis; many infants had multiple cardiac defects.

Figure 1. Primary cardiac diagnoses of participants' infants (N = 30).

The parent's previous breastfeeding experience also played a role, with one parent acknowledging that "having that previous experience ... gave me the confidence to know that we could do it" (26). Others did not feel that previous experience facilitated Wayfinding, as the process was different with a medically fragile infant. As another parent explained, "In some ways [experience] hurt because I did have hopes and I did have expectations (21)."

Subprocess: Navigating the relationship with the healthcare team

As a subprocess of Wayfinding, navigating the relationship with the healthcare team involved parents' efforts to sustain a working relationship with their infant's caregivers – not only as individuals, but as a collective system. Navigating the relationship with the healthcare team is central to Wayfinding, as most infants with critical CHD need multiple interventions and life-long follow up (Table 2.o). For parents, navigating this relationship entailed managing conflicting priorities between the healthcare team and the parent; assessing whether the parent and their infant were seen, heard, and valued by the healthcare team; and handling messages from the healthcare team.

Managing conflicting priorities. Parents perceived conflicting priorities when the healthcare team was focused primarily on the infant's survival: "hyperfocused on the diagnosis" (06) or "just there to do their job, check some things off" (25). While parents were concerned about their child's survival, they also considered quality of life in the present and long term (Table 2.p).

Many parents described a dawning understanding that breast-feeding – and by extension, the parent-infant relationship – was not a priority of the medical system (Table 2.q). While breast-feeding was typically not a healthcare team priority, it was described as a "very important wish" (21) for parents that was central to parental identity (Table 2.r). Some parents communicated with the healthcare team to try to overcome these conflicting priorities, while others disengaged (Table 2.s).

Assessing whether the parent and infant were seen, heard, and valued. Parents assessed the level to which the healthcare team saw, heard, and valued the parent and the infant. In some cases, the parent was invited into collaborative care. For these parents, navigating the relationship required less burden of time and energy. In contrast, some parents felt unseen, unheard, or actively marginalised (Table 2.t). One parent described feeling "like I did not matter as a human being" (19), while others perceived being "disrespected and traumatised" (04) or "looked down on ... judged ... for trying so hard [to breastfeed]" (24). Not feeling seen, heard, or valued by the healthcare team was emotionally taxing and prompted engagement in processes to protect breastfeeding, such as seeking knowledge or going against the healthcare team. Navigating the relationship with the healthcare team was more difficult when parents perceived their child being treated as a statistic – that the healthcare team "[did not] want to deviate" (08) from feeding protocols (Table 2.u). In contrast, navigating the relationship with the healthcare team required less energy when parents perceived that their child was viewed as an individual (Table 2.v).

Handling messages from the healthcare team. Parents synthesised numerous feeding-related messages from the healthcare

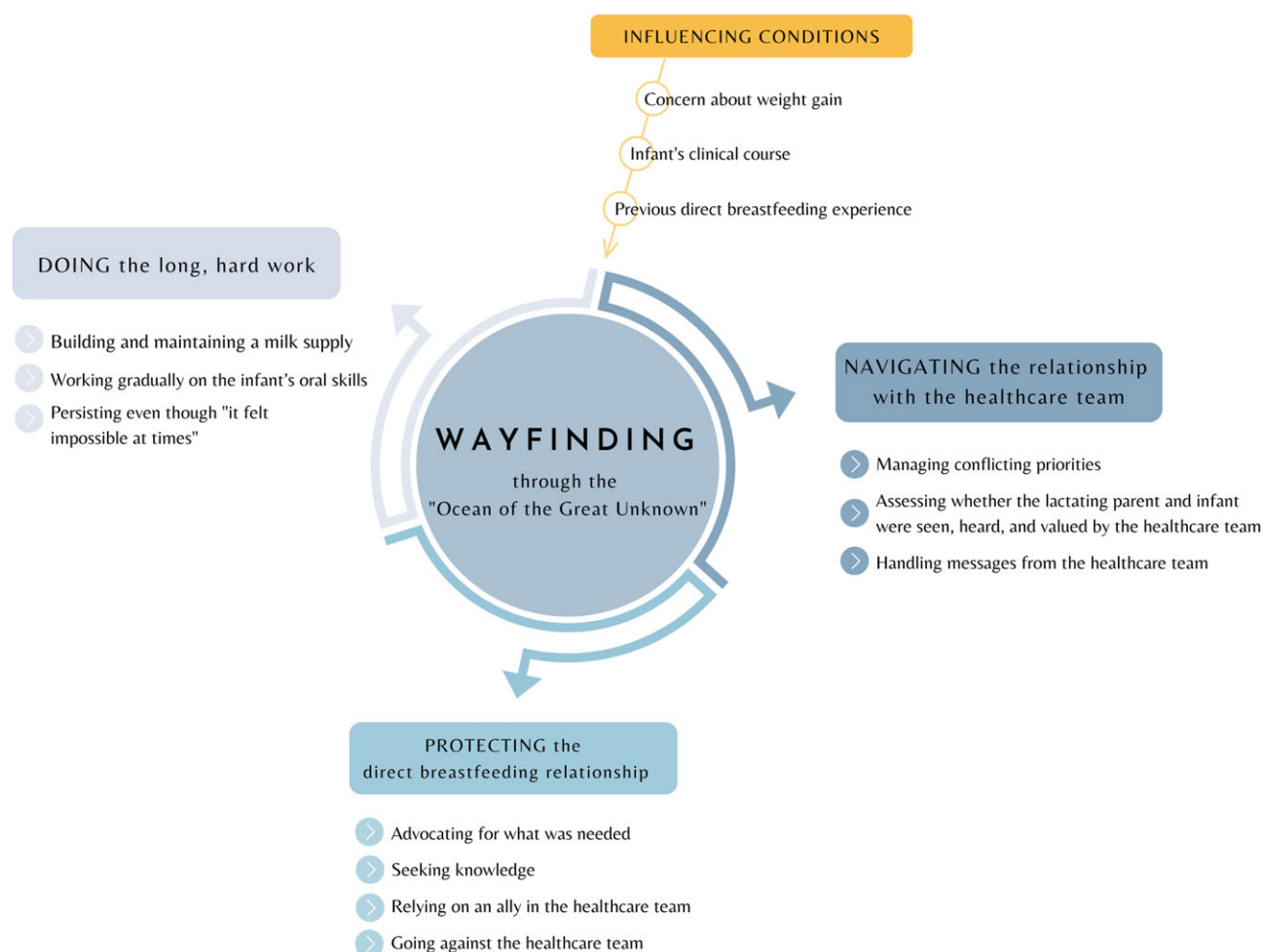


Figure 2. The conceptual model, “Wayfinding through the ‘ocean of the great unknown’,” explains how lactating parents establish a direct breastfeeding relationship with an infant with critical congenital heart disease.

team, constantly weighing what they were told against their own assessment and deciding how to proceed. Messages about breastfeeding were linked to concerns about infant weight, which were not always viewed as legitimate by parents. Most often, messages were perceived as negative or unsupportive of breastfeeding and were considered a barrier to parents’ feeding goals (Table 2.w). Common warnings included: “these babies just don’t exclusively breastfeed” (27) and “it’s easier for them to take a bottle” (05). Parents were often instructed to fortify feedings and permitted to offer the breast for “comfort” (11) or “pleasure” (19) rather than nutritional value. Such messages were perceived to be a “traditional mindset” (10), prompting many parents to engage in the protective process of seeking knowledge to verify what they were told (Table 2.x). Parents consistently described needing permission to breastfeed, with one parent recalling, “It was kind of like a three-parent household when we were in the hospital” (08). In extreme cases, any guise of parental authority over feeding was eradicated (Table 2.y).

While negative messages about breastfeeding dominated, some parents received positive messages of reassurance and encouragement. A few described institutions with unified support of breastfeeding, which was enough to mitigate other barriers (Table 2.z).

Subprocess: Protecting the direct breastfeeding relationship

Protecting the breastfeeding relationship involved parents’ efforts to ensure the opportunity to work toward breastfeeding by advocating for what was needed, seeking knowledge, relying on an ally in the healthcare team, and going against the healthcare team. All parents engaged in these protective processes, but the level of engagement varied. Parents experiencing a lack of healthcare support devoted much energy to protection, with going against the healthcare team a last resort.

Advocating for what was needed. All parents advocated to protect breastfeeding, which involved “standing your ground” (30) and “having a voice” (29). Parents often had to repeat their breastfeeding requests incessantly, before and after birth. When healthcare team support was low, parents recounted being “adamant” (17), “pushing” (10), and “fighting” (02; Table 2.aa). In unsupportive environments, language alluding to war was pervasive, with parents being “hypervigilant” (04) using research as “ammunition” (04) or a “best line of defence” (24), or fighting an “uphill battle” (26).

Advocating may have relied on social capital or privilege, as some parents discussed feeling “out of my league” (12) or “condescended to” (24; Table 2.bb). In other cases, advocating was made

Table 2. Example quotations describing the core process, subprocesses, and influencing conditions of “Wayfinding through the ‘ocean of the great unknown’.”

Core process/ Subprocess	Example quotation
Core process: Wayfinding through the “ocean of the great unknown”	
a.	<i>I felt like I'd been thrown into this ocean of the great unknown. I just wanted my baby to be ok and I wanted the [healthcare] team to tell me what to do ... In the beginning of our adventures we're so fixated on: Please, someone give me a map showing me the way out of this ... Where do I go? What do I do? (04)</i>
b.	<i>Mentally, [breastfeeding] helped me, then I can be better for [my baby]. (09)</i>
c.	<i>[Breastfeeding] dramatically impacted [my daughter's] health in ways that I hope we will have a better understanding of after more research comes out. (04)</i>
d.	<i>Breastfeeding is the one thing I could hold on to, of these dreams I had for this baby. (12)</i>
Influencing conditions	
e.	<i>Their main concern was weight gain. They would have been totally fine just NG feeding her ... they just wanted the number of the weight at the end of the day. I don't think they cared about a lot of the other things, which ... I have worked in a hospital, I get it, you want to check off a box. But for me, [feeding] was more than that. And I was just like, I'm going to nurse. (27)</i>
f.	<i>We switched to some different doctors, and the first thing they said at rounds was “Let's start fortifying the milk.” And I was like, why? He's gaining well ... That's going to make things complicated – because he's directly breastfeeding – if we have to fortify and give him bottles. Why change if he's already doing well? (25)</i>
g.	<i>[The healthcare team] want[s] these kids to gain so much weight, and I'm not going for that ... I'm small, and my husband is small ... Pumping him full of calories, I felt like was just going to prolong needing an NG tube because then he's going to get on this curve where he's in the 50th percentile and he's not going to be able to maintain that if, genetically, he's in the 10th. (03)</i>
h.	<i>It was almost like PTSD ... I needed to know how many ounces went in her ... I think having that pressure of wanting to [breastfeed] your child and being scared that your child's not going to be gaining weight, then you're going to have to go to more appointments and [do] more formula feeds – which she didn't handle too well ... It's just ... yeah, it's a lot. (16)</i>
i.	<i>In the interstage [between surgeries], they wanted to make sure he was gaining weight. So they were a little bit hesitant to allow me to [breastfeed] exclusively, which is why I said, let's try it for a week ... We wanted to work with them. I didn't want to put my foot down and say we will do this ... But as soon as they saw his weight gain being exclusively breastfed, they were not concerned at all. (15)</i>
j.	<i>When she had surgery at three days old, they had to leave her chest open. She was unconscious for a week ... It took three times of going into the into the OR before they could close her. So during that time, it's impossible [to breastfeed]. And then after they did the wash out the last time, it created chylothorax which put [breastfeeding] off for another six weeks. (08)</i>
k.	<i>We've had two different times where he could not medically breastfeed. The first time was after his Norwood [surgery] ... his suck, swallow, breathe was uncoordinated. So that's when we had his G-tube placed and I was pumping because he didn't pass the swallow study ... And right before the swallow study ... he went into cardiac arrest and was on ECMO ... And at about two months old, he finally could latch. And then after the Glenn [surgery], he got chylothorax. So we couldn't latch again for a couple of weeks. (09)</i>
l.	<i>After her second surgery they were finally trying to get her to take some fluids and food, and she ended up aspirating and her oxygen dropped down into the 30s and she went completely blue. And I was like, this is it. This is where my kid dies. (16)</i>
m.	<i>I asked for delayed cord cut and clamp multiple times, and I'd been told repeatedly: We'll do what we can, but we don't like to see babies dying. And I said, that's great. But I have a [neonatal resuscitation program] certification and I'm going to be watching for respiratory effort, color ... and if she's fine, I want her left on me. Just for a minute. Just give us 60 seconds. Her prognosis was very poor, very poor. And so that minute mattered. It mattered a great deal. (04)</i>
n.	<i>They call it the golden hour right after birth. So it was important to me to make sure he got colostrum. I knew because he has HLHS that they were going to whisk him off to the NICU ... So I hand expressed the colostrum ... and they put him by my bedside so I could say goodbye. And I asked, can I give him a little bit of colostrum? And they said, yeah, that should be fine. (17)</i>
Subprocess: Navigating the relationship with the healthcare team	
o.	<i>You have to work with these doctors every week. I mean, every week we have a video visit with them. And then once a month we go in for an echo and meet with the dietician and the speech therapist and all these people ... and they're telling me what's best for her. (08)</i>
p.	<i>The cardiologist, a surgeon, is just thinking of getting them to surgery. But this child is hopefully going to have a whole life after the surgery that I want to prepare for ... We didn't know if he was going to make it through these surgeries. So it was really important for me to have the bonding that I wanted to have with him. I didn't want to have regrets that I didn't have the time I wanted with him because I got stampeded by the agenda of someone that's just looking at the one next step. (03)</i>
q.	<i>[The healthcare team's] primary concern is to preserve the function of the human body. So a lot gets lost in that process. (19)</i>
r.	<i>[This parent described learning that breastfeeding would not be allowed after birth as “the last straw”]: I'm thinking, I can't do anything to take care of this baby. In fact, if I try to take care of this baby, he's going to die ... This is the one thing I'm supposed to be able to do, is take care of my baby. And one of the big things is feeding ... It was like, “Well, I would like to be able to feed this baby.” [Mimicking healthcare team response]: “OK, we'll get to it when we get to it.” (21)</i>

(Continued)

Table 2. (Continued)

Core process/ Subprocess	Example quotation
s.	<i>I don't want to argue. I'm not interested, and I don't have the energy or capacity for it ... I'm gonna feed him how I want to feed him. (19)</i>
t.	<i>[The cardiologist] said, "My clinical gut tells me that [human milk] is not safe." And I said, "Well, my motherly gut tells me that's what's best." You know, what's the difference? But at the end of the day, it was either my kid doesn't eat that day or I give her formula ... I definitely felt dismissed. (24)</i>
u.	<i>When people start saying, "Our policy is ..." we have to have a much bigger discussion. Because my baby is not a protocol, and neither is our family. (03)</i>
v.	<i>We never felt like they were treating him as an HLHS baby in a box. We always felt like they were treating him as [infant's name] ... treating him as a child, not as a condition. (15)</i>
w.	<i>One doctor stopped me in the elevator and said ... "You're exclusively breastfeeding? ... That never happens! You know that, right?" ... I wanted to say, well, actually, it does happen, you just don't know about it. Maybe if you stop saying that – "this never happens" – maybe it would start happening more. (25)</i>
x.	<i>I'm a nurse, and was a certified lactation counselor ... Even so, my knowledge base did not prepare me for things I was being told that were not evidence based. The primary one was that the work of breastfeeding is going to be too much for her. We need to start with bottles ... And I bought that hook, line, and sinker until I started looking into it. (04)</i>
y.	<i>The head cardiologist actually told me that breast milk was going to be bad for my baby ... Nobody else agreed with him. But since he was the head cardiologist and the director, it was his choice. So I started doing my own research, finding peer-reviewed journal articles ... and found that it was good for her. And I came to him with this information and he still forced formula for two weeks. And then I switched it once she was no longer under his care. (24)</i>
z.	<i>I don't think I had even vocalized that I wanted to [breastfeed] ... If they had said she needed fortification, I would have said, sure. But they came with breastfeeding first ... They wanted to make sure that I had that connection and they were going to help me as much as they could. (23)</i>
Subprocess: Protecting the direct breastfeeding relationship	
aa.	<i>I demanded: By tonight, if I don't have permission to breastfeed, she will be getting oral care with colostrum. I will be getting second opinions – this has gone on long enough ... She's fine – she's on room air. If she can handle the 19 TootSweet [sucrose] containers that are in her trash can right now, she's fine for colostrum and oral care. (04)</i>
bb.	<i>I'm just [seen as] a woman. I'm JUST a mom. And it was like I didn't know [anything], because I was just a mom. (24)</i>
cc.	<i>I always feel like my opinion is valued, even though I'm just the mom here. (12)</i>
dd.	<i>Our complex care doctor is very much like, I know you're on all those [social media] groups, why don't you get on there and see what other people have done? I love that because he recognizes that he has limitations in what he knows. (12)</i>
ee.	<i>To have people tell you that breastfeeding doesn't usually happen ... is really discouraging. But then to go on a Facebook group and see a bunch of moms say: "I have a three-year-old girl with HLHS and she's still breastfeeding ..." and to see that experience over and over again ... helped me know that ... I'm fighting for something that IS, that HAS happened for other people. (25)</i>
ff.	<i>[Parent acknowledging an occupational therapist as her ally]: [She] was the only reason that my baby was allowed to latch after her first surgery, because she pushed and pushed ... There wasn't any medical reason for her not to latch ... it was opinion of the cardiologist. I was about ready to hide behind a curtain and do it myself. But thankfully, I had allies in the hospital to advocate for me and my baby. (24)</i>
gg.	<i>[Parent with postnatal diagnosis]: [The doctor] comes in and sees I'm pumping and she's like, why are we feeding this baby bottles? ... She actually went out, grabbed the cardiologist, brought him in and was like, why? ... This is an experienced mom who has breastfed before and this baby latched after birth – we should let her try. (23)</i>
hh.	<i>[Parent whose hospital team only permitted non-nutritive latching]: My [home] cardiologist [during the interstage period] saw how tired I was from the constant pumping ... "This whole pump and comfort nurse," she said, "that's absurd. Just feed your baby." And it wasn't until I had her in my corner that I felt like I was allowed. (26)</i>
ii.	<i>[At home], they had us on a formula that was making her really, really sick. And we were telling them ... they were like, just keep doing it. And finally me and my husband decided, we're not doing this ... You don't see her in pain. You don't wake up in the middle of the night to her face completely blue. You aren't here. So we're doing complete breast. (08)</i>
jj.	<i>I had already popped my boob in his mouth anyway, when no one was looking. Like "hmmph that's MY baby," as opposed to just talking to me about how many ounces of fortified feeds he's going to have every day ... You've prepped me for mostly the worst of the possible, and so if this kiddo is going to pass out, or die ... then I'm going to put my boob in his mouth, because that's what would make me happy. And then I'll ask you about it later. (19)</i>
Subprocess: Doing the long, hard work	
kk.	<i>I remember explaining to one of the rounding teams: It's really hard to produce milk without a child. Without actively touching, holding, connecting, bonding, feeling ... The milk I'm producing is filled with tears as opposed to being filled with joy. (19)</i>

(Continued)

Table 2. (Continued)

Core process/ Subprocess	Example quotation
ll.	<i>I probably wouldn't have been able to maintain pumping. It was ultimately too draining ... long term, I know that I wouldn't have been able to give him breast milk as long as I have, because I've been able to just directly nurse. (26)</i>
mm.	<i>It was literally like [the nurses] were holding your hand. You could tell that they cared, that they knew that you were in pain and that this one little moment [latching] can change your whole perspective. [Speaking through tears] ... I had a really hard time wanting to bond with my child because ... if I fully invest into this child right now and then they're taken from me, I don't know how I'm going to be able to move on with my life. But once you take that leap of ... [the baby] feeding from you ... it's an eye opener. It's a game changer for sure. (16)</i>
nn.	<i>It's not fair how hard we have to fight. I'm a nurse and I had breastfeeding experience and I was misled in so many ways ... It would have been really easy to walk away and hide in the bathroom that first time that I was given the chance and it would have been really easy to keep feeding her TootSweets [sucrose]. Breastfeeding is the harder thing to do. And I think the most unfortunate part of it is that without adequate support and education, it's an impossibility. (04)</i>
oo.	<i>I wouldn't be here if I hadn't pushed because I was at the point of quitting. I had mastitis and clogged ducts ... And [baby] was in surgery at the time and I was pumping and I couldn't get it all out. I nearly gave up at that point. But then I went into my daughter's room ... and her chest was opened still, and she's not giving up, she's going through way more than I'm complaining about. It put things in perspective for me. (08)</i>

Abbreviations: ECMO = extracorporeal membrane oxygenation; G-tube = gastrostomy tube; HLHS = hypoplastic left heart syndrome; NG = nasogastric; NICU = neonatal intensive care unit; OR = operating room; PTSD = post-traumatic stress disorder.

easier by a non-hierarchical relationship with the healthcare team (Table 2.cc). In those supportive healthcare systems, the burden of advocating was shifted away from the parent, although it was never completely absent.

Seeking knowledge. To protect breastfeeding, many parents sought knowledge to fill perceived gaps in understanding. This often occurred as a response to problems during the subprocess of doing the long, hard work (e.g., transitioning from tube feeding), or as a response to the subprocess of navigating the relationship, if messages about breastfeeding elicited distrust.

Knowledge was sought from academic research or – most often – from other parents of infants with CHD via social media. Many parents viewed social media as a shadow healthcare system, filling critical knowledge gaps. One parent was invited to share this knowledge with their healthcare team, which was a positive contributor to this relationship (Table 2.dd). The process of seeking knowledge supported persistence in the Wayfinding process and provided expectations for the journey (Table 2.ee).

Relying on an ally in the healthcare team. At times, breastfeeding was protected when parents relied on an ally who was part of their infant's primary cardiac healthcare team. This ally took action to help the parent achieve their breastfeeding goals, often in contrast to institutional culture or policies (Table 2.ff). Some allies were in positions of power (e.g., surgeon, cardiologist, physician) and could set the institutional tone. For parents who experienced this top-down support, the burden of protecting breastfeeding was lifted (Table 2.gg). In contrast, when parents encountered an unsupportive healthcare team, an ally sometimes helped the parent in going against feeding directives (Table 2.hh). Allyship increased parents' perception that they were seen, heard, and valued; facilitated the relationship with the healthcare team; and supported parents in doing the long, hard work of establishing breastfeeding.

Going against the healthcare team. Protecting the breastfeeding relationship sometimes involved parents going against feeding-related directives. Parents took this action in response to the healthcare team's persistent reluctance to support breastfeeding in a way that was acceptable to the parent (Table 2.ii). While some parents communicated their decision to change the feeding plan, it was more common for parents to hide what they

were doing, not wanting to “rock the boat” (27). For some parents, taking things into their own hands was described as a reclaiming of parental autonomy (Table 2.jj). While going against the healthcare team was not a comfortable process, some parents were willing to strain the relationship with the team to do what they determined was best for their infants.

Subprocess: Doing the long, hard work

Doing the long, hard work involved parents' physical and technical efforts to establish breastfeeding with their child while moving through challenges related to hospitalisation, neonatal surgery, and cardiac physiology. This entailed building and maintaining a milk supply, gradually working on the infant's oral skills, and persisting even though “it felt impossible at times” (04). The need to engage in this subprocess could be facilitated by the healthcare team and influenced by previous breastfeeding experience or a smooth clinical course.

Building and maintaining a milk supply. Building and maintaining a milk supply was considered critical to the possibility of breastfeeding, as early parent-infant separation interrupted the breastfeeding trajectory (Table 2.kk). Most parents described pumping immediately after birth and around the clock. In contrast, one parent blindsided by a postnatal diagnosis explained, “[Pumping] wasn't something I was even thinking about at that point, because I just wanted her to live” (23). Parents recognised that pumping was necessary and one thing they could do for their baby. However, pumping was described as “dreadful” (12), “exhausting” (26), “disappointing” (14), and “the worst” (12). Many parents found extended pumping unsustainable, particularly in the context of their child's significant medical needs (Table 2.ll).

Gradually working on the infant's oral skills. Parents described gradually working on the infant's oral skills in hopes of breastfeeding. This process can be considered multi-staged technical work (i.e., illness-related work that can be addressed by common clinical interventions).³¹ Parents used some or all of the following strategies: oral care with human milk while the baby was *nil per os* (npo), pacifiers to stimulate sucking, skin-to-skin contact, non-nutritive latching at an empty breast, nipple shields, assessment and assistance by feeding specialists, slow

incorporation of nutritive breastfeeding, and pre- and post-breastfeeding weights to track volume (i.e., test weights). The infant's first latch at the breast was universally described as pivotal. This first latch could be facilitated by the healthcare team (Table 2.mm), which positively impacted the subprocess of navigating the relationship.

Persisting even though “it felt impossible at times.” Doing the long, hard work of establishing a milk supply and building infant oral skills required persistence and strength. Parents described a “roller coaster journey” (09) that could be “stressful” (07), “grueling” (08), and “frustrating” (25). Many parents reported wanting to give up at times (Table 2.nn), but drawing strength from their infant's resilience (Table 2.oo). For these parents, persisting in doing the long, hard work ultimately led to breastfeeding establishment. However, the process looked different than parents had envisioned and they needed to adapt to changing circumstances by, as one parent explained, “holding hopes and dreams with an open hand” (12).

Discussion

This study addresses a critical knowledge gap as the first in-depth examination of the process of establishing direct breastfeeding with an infant with critical CHD, from parents' perspectives. The findings reveal that, while challenging, breastfeeding is feasible, meaningful, and consequential.

The Wayfinding process aligns with previous work in other neonatal populations. Demirci et al.'s³² theoretical model of late preterm breastfeeding describes a “volatile and labour-intensive” process, echoing the Wayfinding subprocess of doing the long, hard work. Many strategies described by parents to do this long, hard work align with Spatz's³³ 10 steps for promoting and protecting breastfeeding for vulnerable infants (e.g., pumping early and often, non-nutritive latching, test weighing).

However, the primary issues described by Demirci and colleagues (e.g., suck-swallow coordination, snacking behaviour)³² are different than those affecting infants with critical CHD (e.g., neonatal surgery, extensive time npo, volume restriction, lengthy fortification).³⁴ Jones et al.³⁵ have identified numerous factors that contribute to disruptions in feeding development for infants with critical CHD, including cardiac physiology, necrotising enterocolitis, gastroesophageal reflux disease, surgical intervention, sedation and medication, chylothorax, respiratory support, neurodevelopment, genetic syndromes, a noxious feeding environment, nerve paralysis/paresis, and dysphagia. All of these disruptions were described by our sample as part of the influencing condition of the infant's clinical course, often resulting in increased engagement in Wayfinding processes to protect the breastfeeding relationship. Furthermore, the critical nature of critical CHD results in a looming threat of life-and-death consequences, which does not dissipate after discharge. While other vulnerable neonates may also experience post-discharge health concerns, the parents in this study reported infant health challenges and multiple surgeries that could extend the Wayfinding process well into the first year.

It is notable that 57% of the infants in this sample had single ventricle physiology, considered the most severe form of critical CHD with high risk for oral feeding problems.³⁶ Previous literature reporting breastfeeding for infants with single ventricle CHD is limited to one case study,³⁷ and many parents in our sample received messages that breastfeeding would not be possible. In the case study, breastfeeding was described as a challenging process necessitating a strong relationship between the parent and the

healthcare team.³⁷ Our study expands upon this previous finding, demonstrating that breastfeeding an infant hospitalised for critical CHD can occur without cohesive healthcare team support, although the parental burden is substantial.

Our findings reveal that parents often felt compelled to seek support outside of the healthcare system or go against feeding directives, and suggest that few U.S. cardiac centres prioritise families' breastfeeding goals. Concerningly, some parents described being actively misinformed by their healthcare team, receiving messages that human milk is not safe for infants with critical CHD or that breastfeeding is more work for these infants than bottle feeding. These types of statements conflict with available evidence, which demonstrates that exclusive human milk feeding confers benefits including a reduced risk of necrotising enterocolitis in this population⁵ and that, as the American Heart Association explains in its online patient education, “the ‘work’ of breastfeeding is actually less than the work of bottle feeding.”³⁸ Especially considering that infant feeding holds deep moral and relational meaning for parents, it is ethically objectionable for healthcare teams to dissuade families from pursuing human milk or breastfeeding goals based on opinions that contradict previous evidence.

Our findings point to a clear gap in practice in which families are not receiving evidence-based, family-centred breastfeeding care, which is in line with previous work demonstrating a lack of consensus about best practices for breastfeeding in this population.²³ While research focused on breastfeeding for infants with critical CHD is sparse, previous literature describes relevant clinical practices that support breastfeeding for other vulnerable neonatal populations. These practices include prenatal lactation care with feeding specialists; frequent, continuous skin-to-skin contact; oral care with colostrum; direct breastfeeding for the first oral feed (vs. bottle feeding); non-nutritive oral practice at the breast; using test weights to measure direct breastfeeding volume; specialised training for hospital staff; and evidence-based feeding policies that are clearly communicated to families.^{39–42} Studies testing the safety and feasibility of these practices for infants with critical CHD are emerging,^{43,44} but more research is needed to determine whether these practices can effectively increase the low rates of breastfeeding in this population.

Furthermore, there is a growing interest in individualised, family-centred developmental care as a way to counteract the negative impact of the hospital environment for infants with critical CHD and their families.⁴⁵ This approach advocates cue-based, developmentally appropriate infant care; supports parental engagement in caregiving processes; and has potential to improve breastfeeding outcomes through neuroprotective practices such as skin-to-skin care⁴⁶ and infant-driven feeding.⁴⁷ Unfortunately, as in the case of the parent who perceived the healthcare team as primarily concerned with “preserv[ing] the function of the human body” (19), many of the participants in this study described dismissive, inflexible hospital environments that operated in stark contrast to developmental care principles. Our findings suggest that there is a clear opportunity for improvement in individualised, family-centred developmental care in U.S. cardiac centres.

For parents in our sample, a perceived lack of support for feeding goals could result in impaired mental health. Clinically concerning symptoms of depression, anxiety, and traumatic stress for parents in this population have been well described^{48,49} and an additional burden related to infant feeding can exacerbate this distress, as highlighted by previous qualitative research.^{50,51} The link between feeding challenges and parents' distress might be

due in part to parental role alteration (i.e., a perceived inability to provide care or comfort for the infant), which has been associated with increased anxiety and depression in parents of infants hospitalised for critical CHD.^{52,53} Considering that feeding is a critical aspect of care and direct breastfeeding an empowering way to comfort an infant with critical CHD, our findings demonstrate missed opportunities to support parents' mental health during a tumultuous time.

It is important to note that parents in our sample experienced varying degrees of difficulty in establishing breastfeeding with their infant suggesting that, for some, breastfeeding may be more feasible than previously understood. Our findings indicate that healthcare providers should merge clinical experience with individualised assessment, resist the default assumption of considering breastfeeding too difficult for this population, critically examine the evidence behind unit breastfeeding policies, intentionally address institutional barriers to breastfeeding, and work collaboratively with parents to support feeding goals.

Considering the critical lack of evidence about breastfeeding in this population,²³ there is an urgent need for future research to identify clinically appropriate support for breastfeeding from prenatal diagnosis through the first year of life. The conceptual model of Wayfinding highlights opportunities for research and practice change. Future translational research is needed to develop and test comprehensive, family-centred interventions that facilitate breastfeeding for infants with critical CHD. Such interventions should provide evidence-based lactation care, adapted to the specific needs of this population, to aid parents in doing the long, hard work; should span the prenatal and postnatal timeframe to facilitate clear, consistent messaging from the healthcare team; should empower parents to advocate for their feeding goals; and should acknowledge that infant feeding can be deeply meaningful in the midst of a highly traumatic family experience. Effective, accessible interventions are critically needed to increase the low rates of breastfeeding in this population and have the potential to improve infant and family outcomes.

Future research should also examine the impact of breastfeeding on these outcomes for infants with critical CHD and the potential mechanisms to explain differences in outcomes, particularly as participants in our study observed physical and developmental benefits for their infants related to breastfeeding that are not well understood in infants with critical CHD. As one example, research into the interaction between human milk, direct breastfeeding, and the infant microbiome is beginning to emerge, with a particular focus on preterm populations.⁵⁴ Direct breastfeeding has been shown to confer unique immunological benefits,^{10,11} and is a reliable means of delivering bioactive immunological properties directly to the infant without risk of alterations related to milk storage and handling that could denature these delicate structures.⁵⁵ However, to our knowledge, there has been little investigation into the relationship between direct breastfeeding and the microbiome of infants with critical CHD. A better understanding of the relationship between breastfeeding and an infant's health and development could support clear, consistent healthcare team-parent communication, thereby facilitating navigation of the relationship with the healthcare team.

Future work should also focus on the influencing condition of concern about weight gain, particularly as ubiquitous fortification and stringent feeding protocols were perceived to interfere with breastfeeding establishment in our sample. We recommend future research on the development and testing of alternative fortification strategies⁵⁶ for infants with critical CHD, which could include

targeted fortification⁵⁷ or fortification "shots" provided as medication via after breastfeeding – a practice used by some Danish neonatal ICUs (Ragnhild Måstrup, PhD, e-mail communication, March 2021). Advanced statistical methods could support the development of risk prediction models to help identify infants with critical CHD who are at low risk for growth failure and may not need immediate postoperative or post-discharge fortification.

Limitations

The primary study limitation is a sample that was majority white, college educated, and financially resourced. Sample demographics might reflect the impact of structural racism and social determinants of health (SDoH), as there are well-documented disparities in human milk and breastfeeding rates for vulnerable infants associated with racism⁵⁸ and socioeconomic status.¹⁰ Although parents in our sample reported variance in SDoH, findings cannot be generalised to all populations. There is a clear need for research to determine the impact of SDoH on feeding for infants with critical CHD. Additional limitations could include the cross-sectional design with retrospective explanation of a temporal process reliant on participant recall; the potential for self-selection bias; or recruitment from selected online sites.

Conclusion

The findings in this study are a step toward addressing the knowledge gap about direct breastfeeding for infants with critical CHD. The conceptual model of Wayfinding explains how breastfeeding can be established with these infants. Future work is needed to implement family-centred interventions that support parents' feeding goals, with potential to increase the current low rates of direct breastfeeding in this population and improve infant and family health.

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S1047951122003808>

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