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The neonatal intensive care unit (NICU) is a site of medical treatment for premature and critically ill infants. It is a space populated by medical teams and their patients, as well as parents and family. Each actor in this space negotiates providing and practicing care. In this paper, we step away from thinking about the NICU as only a space of medical care, instead, taking an anti-essentialist view, re-read care as multiple, while also troubling the community of care that undergirds it. Through an examination of the practice of kangaroo care (skin-to-skin holding), human milk production and feeding, as well as, practices related to contact/touch, we offer a portrait of the performance of the community of care in the space of the NICU. We argue that caring practices taking place in the NICU are multiple and co-produced, while simultaneously being subject to power and knowledge differentials between actors. Here we analyze the negotiations over the knowledge and practice of care(s) to open up the NICU as a particular community of care, and consider care as a both a joint accomplishment and a gatekeeping practice.

The stated primary function of the NICU is to medically treat critically ill infants. It is a space populated by medical teams and their patients, as well as parents and family. Each actor in this space negotiates providing and practicing care. In this paper, we step away from thinking about the NICU as only a space of medical care, instead, taking an anti-essentialist view, re-read care as multiple, while also troubling the community of care that undergirds it. Through an examination of the practice of kangaroo care (skin-to-skin holding), human milk production and feeding, as well as, practices related to contact/touch, we offer a portrait of the performance of the community of care in the space of the NICU. We argue that caring practices taking place in the NICU are multiple and co-produced, while simultaneously being subject to power and knowledge differentials between actors. Here we analyze the negotiations over the knowledge and practice of care(s) to open up the NICU as a particular community of care, and consider care as a both a joint accomplishment and a gatekeeping practice.

1. Introduction

The neonatal intensive care unit (NICU) is a space of multiplicity. It is a medical unit, a care space, a place for family, a workspace, a site for research and learning. It is sterile, it is messy. From the outside, the NICU looks the same throughout—incubators, monitors, machines, three patients to an alcove space, replicated over and over. Upon closer examination though, from the inside, the space of the NICU begins to take on character—signs with baby names, knitted and quilted blankets, a hospital gown, an old sweatshirt, a privacy screen. Difference. The stated primary function of the NICU is to medically treat critically ill and preterm infants, however, the character of treatment takes on multiple forms of care. Thinking about the differences in the NICU is helpful for considering the many forms that care takes in-place, and also for thinking beyond the NICU as a medical unit. As a site of “intensive care,” the NICU is characterized by acute illness and sometimes lengthy treatments. These treatments are developed and deployed by teams of medical professionals, including neonatologists, nurses, respiratory therapists, nutritionists, lactation consultants, and so on. Care is shaped by space and place (see: Milligan and Wiles, 2010), and is collectively co-produced. While medical care is of utmost importance, other forms of care happen alongside it and have dramatic influences on it. Parenting, feeding, skin-to-skin time, education, storytelling, and encouragement, all happen too. Thus, thinking about the NICU as a medical care unit is limiting and renders invisible the multiple and jointly enacted forms of care practice that occur in this space. We argue that an anti-essentialist take on care that is provided in a medical setting is needed to see and value the multiple forms that care takes.

The care labor that happens in this space could easily be regarded as a transaction, where staff are paid to provide medical care. Yet there is also volunteer and otherwise unpaid labor that is performed in this landscape, and so this consideration does not provide the kaleidoscopic view necessary to see the multiple forms that care takes. The labor that happens in the NICU cannot be fully supplied by the market. Many see medical care through a capitalocentric lens (Gibson-Graham, 2006) that divides care into binaries of paid/unpaid, public/private that neglects the co-production of care as a site of mutual aid accomplished by a collective of humans and non-humans (e.g. medical devices). However, there is much work on care that does not reify capitalism and instead makes the argument that a market-based view only captures a fraction of the care-work provided in this space. Moreover, this work decenters capitalism, placing it on a spectrum of exchanges.

In this paper we re-read the NICU to consider the multiple acts/practices of care that take place and argue that these acts of care are both a joint accomplishment of the community that comes together in the NICU and are part of a space where power over knowledge, training, and participation in care work unfolds in messy and uneven ways. The NICU is a key site of investigation as care takes on significant
complexity. Our case study concerns how communities of care create sites of parental engagement as well as gatekeeping practices related to providing contact and human milk. Specifically, we address the complicated character of three activities in the NICU: (1) overcoming barriers to the practice of skin-to-skin contact between parents and infants, (2) learning and providing positive touch when an infant cannot be held, and (3) the provision of human milk and the means of access to human milk. Medical care is already complex, however, the character of NICU care reflects the interconnectedness of parent/child bonding, if possible and desirable—the provision of mother’s own milk, medical treatment, and the cultivation of community. To conduct care in its multiplicity in the NICU, care must be part of a broader community that extends from the infant.

The NICU is not static as patients and families move through treatment and are discharged, nursing staff change shifts, and medical teams complete rounds. There is an ongoing production and reproduction of care as the community changes. In this paper, we argue that care is a practice that is shared by a community. This is a step away from discussions of the commodification of health + care, which focus on how care services have become privatized and care work relegated to a market relation; and that care can only be done in medical spaces by those with specific knowledge and training (cf. Gallagher, 2018; Green and Lawson, 2011; Healy, 2008; Henderson and Petersen, 2002). Many hospitals are operated as nonprofit entities, although the groups supplying them usually are for-profit—which is why considering the human (and other) care involved in health moves us toward an anti-essentialist view of medical treatment. This care takes place within, alongside, and outside of capitalist relations. To direct a reading of care as multiple in the next section of this paper, we create a foundation by discussing care-work and the practice of care in geographic thinking. Following this scaffolding, we turn to the context for the study and the methods in order to situate the site of the NICU and care. Building from this context and drawing on empirical work, we next consider the multiple forms of care in the NICU landscape. Finally, we make some concluding remarks about re-reading the NICU and how in investigating care as multiple we can continue to open up our thinking about the benefits and tensions that arise from enacting the processes and practices of care in a way that is attentive to difference in place.

2. Care-full geographies

Feminist scholars consistently call for attention to care and care ethics within the academy, as well as academic research and writing. Yet, as Lawson noted, even though care is a critical component of human life it had remained on the margins of theory, heightening unequal relations along gender, race, and class lines (2009:210). Moreover, this marginalization neglects the role of the non-human and our earth others in relations of care. Care is brought to our attention by highlighting reproductive labor, such as social reproduction, relations of exchange, and affect, for example. It is an everyday practice that takes place in public, private and liminal spaces.1 Feminist geographers began to draw attention to an ethic of care as a basis for creating change and performing reflexive research. This work emphasized the gendered, and particularly the unpaid, aspects of care and drew from the early work of Tronto (1993), which argued against the narrow reading of care onto women’s bodies (cf. McDowell, 2004; Smith, 2005; Staeheli, 2003). This reading of care ethics comes from ideas about the “social character” of our being and thus should be linked up with the exceptional and the mundane of our everyday lives (Lawson, 2009; 210-211). It is a call not just to examine relations but also respond to spaces which, as part of neoliberal shifts have become ‘care-less’ (Lawson, 2009). As care begins to be conceptualized more broadly, some scholarship takes up care in its radical potential for re-reading spaces and relating to others.2

A relational approach to care allows for thinking outside of the individual, and places emphasis on what Atkinson et al. describe as the “mutual constitution of caring practices and caring spaces” (2011:565). This emphasis is tied to an ethic of care, which is built on practices that take into account those relationships, both human and non-human. An ethic of care is an attempt to democratize decision-making, labor in all its forms, and to distribute responsibility and benefits equitably. A deeper ethic of care is also reflexive, asking who benefits from the established relations of care and what forms of listening, advocating and allying can happen through the sharing of care practices. Care (in this guise) requires us to do the necessary labor to ‘survive well’ (Gibson-Graham et al., 2013). This includes care-giving, and also care-receiving where the care work (such as reproductive labor) that makes all work possible is illuminated (see de la Bellacasa, 2017). This revealing includes regarding the care provided by the non-human, for example, medical devices and machinery or ecosystems and clean air. Dombroski et al. (2018) discuss re-reading for “who cares” to think about the diverse actors involved in caring, which is collective and multiple. In considering care in its multiplicity, the visibility of the varied actors, relations, as well as, the practices and performances of care is increased. Reading care as multiple refocuses our gaze and can for example, upend the idea that care work is inextricably tied to capitalist relations (Morrow and Dombroski, 2015). This work is important in moving towards a “care-full” regime.

Drawing on Milligan and Wiles’ (2010) work on how care is shaped by place and space, we consider the care undertaken in the NICU as part of a community of care that is co-produced and multiple. Here they draw our attention to both the interpersonal relations between people and place—we would also add people-material relations—to see the spatial character that care takes on as it is practiced in place. There are structures that shape the experience and practice of care that range from where it is happening and who/what is providing it, to the layout or constraints of the physical space and the emotions that may (or not) permeate them. There are, as they note, “complex embodied and organizational spatialities that emerge from relations of care” (Milligan and Wiles, 2010: 740). Similar to our framing of care-full geographies, Milligan and Wiles identify “care-full” and “compassionate geographies” to enunciate an approach “informed by care” that can show the collective labor in the landscape (743). Here we note this distinction and expansion as “care-full” indicates, for our framing, a care that is abundant, multiple, and not confined to any one space. Ultimately, in considering an ethic of care, scholars can shape these “compassionate geographies,” however, how the care is negotiated pushes on the idea that care is inherently free from tension.

As noted in the introduction, this paper takes up care as multiple and the NICU as a site where the processes and practices of care are jointly shared and in some cases, contested. These are two distinct but interwoven theorizations that we use to push on the power dynamics often unrecognized in discussions of communities of care. To think through the liminal space of the NICU and the multiple and competing forms that the processes and practices of care takes creates an opportunity for opening up our theorizations of care.

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1 There is a well-established literature outside of geography on nursing and healthcare that is foundational in this line of thinking and which is increasingly drawing on spatial analysis to take a critical view (see: Andrews, 2016; Cheek, 2004; Halford and Leonard, 2006; Kingma, 2008; Sandelowski, 2002; Solberg and Way, 2007). We do not seek to replicate that work here; scholars interested in reading these more health-focused geographies onto NICU care provides an additional avenue for future examination.

2 See for example: Atkinson et al., 2011; Bartos, 2018; Diprose, 2017; Dombroski et al., 2018; Gallagher, 2018; Gibson-Graham et al., 2013; Hanrahan, 2020; Hanrahan and Smith, 2020; Healy, 2008, 2018; Henry, 2018; Jackson and Palmer, 2015; McEwan and Goodman, 2010; de la Bellacasa, 2017; Robinson, 2011; Wight and Boyer, 2018.
3. Context and methods

The data in this paper come from a larger project investigating the
practices of skin-to-skin contact, infant feeding, and access to human
milk that is ongoing. This phase of the project involved conducting
fieldwork in the specific space of the Neonatal Intensive Care Unit
(NICU) to ask questions about how care and feeding of infants in con-
cert with complex medical treatment is undertaken and to consider
alternatives. To better understand the context for NICU treatment we
developed and disseminated a national (U.S.) survey in 2017, with the
cooperation of breastfeeding coalitions to ask questions about parents’
experiences having infants who received NICU care. A key takeaway
from the survey was that parents have dramatically different experi-
ences across the United States (Clarke-Sather and Naylor, 2019; Naylor
and Clarke-Sather, 2020), signaling that landscapes of care in the NICU
are not homogenous. Building from that finding, data was gathered at
one specific NICU between 2018 and 2019. A contract between the
university and the hospital was established that specified the conditions
of the research and the role of the researchers and allowed for a one-
year research period. Two members of our research team undertook
hospital-based protection of human subjects training and became offi-
cial research assistants with the hospital for the 2018–2019 research
period.

The data analyzed in this paper draw on the survey results
(n = 150), over thirty hours of participant observation in the NICU, and
transcribed and coded interviews with NICU staff (n = 40) and birth
mothers (n = 35). Staff interviewees (n = 34) identified as White and
Black or African American and mothers interviewed (n = 11) ranged in
age from 18 to 34 and identified as White, Black or African American,
Hispanic, and Mixed (Black or African American and White). The dif-
ference in n values is a result of a request from the hospital not to
collect demographic information order to maintain respondent anon-
ymity at the start of the project and which was subsequently changed to
allow us to collect that data. Research in the NICU was conducted be-
tween May of 2018 and May of 2019, in cooperation with the neonatal
research office at the hospital. All interviewees were approached to
participate and consented by the hospital research office, the research
team did not conduct any recruitment. There were two approaches to
the NICU-based fieldwork, one researcher did an intense two-week
exclusive interview segment and the other researcher spent one day per
week in the NICU either interviewing participants or observing rounds
and NICU practices over the one-year research period. Throughout this
period we interviewed staff members, including nurses, neonatologists,
dieticians, lactation consultants, respiratory therapists, occupational
therapists, physical therapists, speech language pathologists, and milk
bank staff. We also had the opportunity to talk with birth-mothers over
the age of eighteen (no partners or adoptive parents have yet been in-
terviewed for this project) about their experiences while their infant(s)
were receiving NICU treatment.1 Interviews were structured and ap-
proved by the Institutional Review Boards of the university and the
hospital. Questions for staff and birth-mothers alike focused on three
main topics: skin-to-skin contact (also called kangaroo care), infant
feeding, and milk pumping in the space of the NICU. Interviews with
staff were conducted in offices and conference rooms at the hospital
that were available and reserved by the research office. Interviews with
mothers were conducted in these spaces and additionally outside of the
NICU in an available overnight room. The data were transcribed and
analyzed using the qualitative data analysis software NVivo and for the
purposes of this paper, data were coded using pre-determined codes
related to “care” and “treatment.” These codes were designed based on

survey data that suggested differences in how care and treatment were
practiced and perceived.

The partner hospital where research was conducted is located in the
Mid-Atlantic region in the United States and is in a state that received a
“C” score from the March of Dimes on their 2019 Premature Report
Card, which indicates a preterm birth rate of roughly 10%; this per-
centage compares to an “A” score of less than or equal to 8% and an “F”
score of greater than or equal to 11.5%. The March of Dimes reports
that the pre-term birth rate in the U.S. for 2018 was 9.9% overall (a “C”
on their scale). The March of Dimes is a non-profit organization focused
on the health of mothers and infants with specific attention to pre-
mature birth; their “report card” draws data on preterm birth rates from
the National Center for Health Statistics, 2018 final natality data and
grades are assigned by the March of Dimes Perinatal Data Center. Ac-
ccording to the U.S. Census, the Mid-Atlantic is characterized by greater
than average poverty levels and a majority white population (on average 63% in 2018).

The NICU at the selected partner hospital, which is a non-profit
organization, is located in a high-risk delivering hospital that offers
level three care for newborns.2 The space of the NICU at the hospital is
an open-space, climate controlled alcove nursery that has the possibility
of caring for up to fifty infants at one time. Each alcove can accom-
modate up to three infants and the equipment for their care. There are
two medical care teams headed by neonatologists and a trio of nurses
who provide, in shifts, round-the-clock care for infants. There is a
slider chair at each bedside, a space for parents to store items, and if desired, a
privacy screen (five or six are available and rotate around the NICU on
an as-needed basis). There are three lactation lounges if mothers ex-
pressing milk prefer a private place to do so and the NICU maintains a
milk bank to receive, process and store the milk of birth-mothers who
have infants being treated in the NICU. Three over-night rooms outside
of the medical treatment area are available for extended stays; these
rooms have a sleeper sofa, a private bathroom, and a television. Each
infant bed is equipped with a webcam that parents can access from an
application (called NicView) installe on their phone so that parents
can see their baby when not at the bedside. In addition there is a
children’s play area and a small kitchen with snacks available provided
by the Ronald McDonald House located outside the entrance to the
NICU.

Access to the NICU is restricted, although parents are allowed at any
time and are asked to remain with their infant while visiting the NICU.
Up to two approved visitors are allowed to be at the bedside during
regular visiting hours (9:00 am to 9:00 pm) as long as they are healthy
and have followed proper intake procedure, which includes receiving
an ID band from the front desk and following handwashing/scrubbing-
protocol prior to entry. Visitors, including parents are not allowed
any food or drink in the NICU and they must clean their mobile phones
with a provided wipe. Parents are encouraged to be present if and when
possible and to participate in routine care, such as temperature taking
and diaper changing, and to visit with the medical care team. The NICU
is a complex space, with many changing actors, that does not lend itself
to universals. Care in the NICU is multiple, it is indeed a joint e-
fort that is shared and maintained collectively.

4The regional focus is used to not disclose the name/location of the hospital
where the research was performed.

5The four distinct levels of infant care are: Level I, Well newborn nursery;
Level II, Special care nursery; Level III, Neonatal intensive-care unit (NICU);
Level IV, Regional neonatal intensive-care unit (Regional NICU).

1This terminology refers to the parent who gave birth to the infant and is
accurate for the study population, although we recognize that this phrase does
not fully capture experiences of trans parents who give birth, or adoptive
parents.
Care as multiple captures the social practices it is embedded in and makes visible mutual aid, belonging and exclusion. Here we think about care as a communal or joint practice, where the community is the semi-ephemeral group who participate in these acts of care. In this case, the community is made up of parents, NICU staff, NICU volunteers, milk donors, researchers and non-human actants, such as heart monitors, C-Pap machines, feeding tubes and bilirubin lights, for example (see Fig. 1). The NICU is a care-full space and to better understand care as multiple, here we draw on survey responses, interviews with parents and staff, as well as observation undertaken. In the following subsections we examine the practices of kangaroo care, medical “cares,” and care-work. The character of care and how it is ‘used’ is discussed to show how it is negotiated; our findings suggest that care in the NICU requires a community effort, yet power dynamics surrounding knowledge about and who can do care complicate participation in this community.

4.1. Kangaroo care

Kangaroo care refers to the practice of skin-to-skin holding of infants. It is an intimate method of holding a baby, where the care provider removes any clothing barrier from the waist up and the infant is, wearing only a diaper, placed on the bare chest. For NICU staff, the baby is, for the first time, in the hospital of course to be held. The nurses here understand the benefits and they understand that it is important to the families. Many nurses commented that they wanted parents to be able to comfort their babies and they often realized that parents did not know that they could hold their baby. As a result, there is a lot of information sharing, support, and education that goes into the practice of kangaroo care. In other interviews this experience was reiterated, for example another nurse offered: “I try to explain as much as I can the benefits especially to the parents who are like no, the baby’s too small to hold or I’m too scared to hold, and once they understand they are doing something good for their baby, then usually they want to and they usually once they do the skin-to-skin, they’re hooked.” On occasion, more encouragement is needed, such as in this story related by a nurse:

We try to offer as soon as the baby is able to and if there’s a parent that’s timid—one mom was, she was so scared to hold her baby. Then one day, she was all ready for it, but she got really nervous when she came in, I was like sit down, I’ve already got respiratory coming, like we’re doing this. And she—so she did, and her palms were sweating—it was kind of funny, but at the end of it she was so thankful and so it’s kind of just reassuring them, you’re not going to break him [her son], it’s ok. We’re all here, and um, I think that probably really meant a lot to her. So coming to them, I don’t know, giving them that little nudge cause she had never held him before, and I was like we’re doing it, let’s go!

A number of participants commented that this form of care required effort from everyone, but that ultimately, when it is done well, it creates a less-stressful environment for everyone. Again, care is a site of mutual aid and kangaroo care is a coordinated, co-created joint effort. One nurse emphasized this point saying: “when I saw a mom hold her baby for the first time and the baby was weeks old at this point with all the tubes, there were two nurses two respiratory therapists and the baby was on so many tubes, but the mom was so happy, how she felt when she held the baby, it makes me tear up.” Although many parents are initially afraid to hold their infants, nearly all participants ultimately found it to be a positive experience of care. When analyzing and coding interviews we found that many mothers used similar descriptions for talking about the joy of holding their babies. One mom said, “I have never been happier. I mean the fact that it’s in the hospital of course makes you upset but holding her [her daughter] you just forget about everything.” The often emotional response to the question of “How do you feel when you’re holding your baby in the hospital?” was consistent across all interviews and is also echoed by parents who took the 2017 survey, Fig. 2 captures the positive adjectives that participants used to describe how it felt to practice kangaroo care.6

6 For example, an infant who needs to be kept cooled, or who is undergoing phototherapy, or one who has an arterial line at the site of the umbilical cord.

7 The survey responses were recorded using Qualtrics and the data drawn on
In this figure, larger and repeated words represent those adjectives used most often to describe their experience. Moreover, mothers report feeling instrumental in improving the medical condition of their children through their continuous practice of kangaroo care. Many also feel that it is helpful for them as part of their recovery from a traumatizing birth experience and the anxiety of being separated from their newborn. One mom reported:

I feel kangaroo helps moms a lot, you know. It was hard leaving him [her son] every night and I felt good coming in every morning that was like my main goal, hope he’s having a good day so I can get to hold him, and be able, cause every time I held him I felt like I was protecting him, so I was looking for that, it’s a big impact, and I actually found out that not all NICUs have kangaroo, and I was like oh my god I can’t imagine being in that NICU.

Although kangaroo care is promoted at the partner hospital where interviews were conducted, it is not a universal practice among NICUs and many survey respondents reported not being offered the opportunity to do kangaroo care and in some cases being denied it when they requested it. In survey responses, we learned that many parents had to struggle, fighting against the staff to be able to practice kangaroo care with their infants. In response to the query about experiences with kangaroo care in the NICU respondents reported: “unnecessary delays,” “limited due to policy,” “staff doubtful and resistant,” “lack of privacy,” “cords and monitors made it difficult,” and “felt like I was messing up the schedule.” For some moms who answered the survey it became a battle to gain access to their babies. One participant who expressed a negative experience with NICU treatment claimed: “many times I asked, whose baby is it anyway?” Another stated that the staff “wouldn’t let me touch or feed baby.” Almost one-third of respondents (17 of 58) answering this open-ended survey question claimed that kangaroo care was either never offered or was discouraged.

In the case of the partner hospital, kangaroo care is common and frequently offered. In one interview a nurse explained to a member of the research team that they sometimes have competitions between the staff called “kangaroo-athons” to see who can log the most hours of skin-to-skin contact time between their patients and parents. However, each case is different and sometimes nurses are hesitant to offer or assist with kangaroo care. In response to the question of “have you had skin-to-skin contact with your children?” one mother told us “yes, about a week ago, one nurse allowed me to hold them both [her twins] at the same time, which was the best experience ever” (emphasis added). We draw attention to the word “allowed” because the infant is the patient of the nurse, which can put them in conflict with the parent as it relates to prioritizing care. Although it can be a joint effort and a site of mutual aid, it can also be a gate-keeping space, where there is differentiated power over who can provide care. Indeed, paid care work (that done by specialists, such as nurses and neonatologists) illuminates a hierarchy of caregiving that is immediately imbued with power.

This tension came up in a number of interviews with staff. One nurse in particular had a lengthy discussion about nurse attitudes toward kangaroo care, and we draw from this interview extensively to illuminate the power struggles over care. When asked about whether “parents need assistance to do kangaroo care,” this nurse explained the different approaches in the NICU.

I say go ahead and hold them. ‘Cause, at home they would be holding them, and sometimes I’m like go ahead and hold your baby whenever you’re here, it’s fine with me, and it conflicts with people I work with because a lot of nurses that I work with are on a schedule. Babies are fed every few hours, they need to sleep between that. Whereas I’m—they’ll sleep better on their parent, I know they’re safe, they’re on their parent instead of just laying in a crib, so I’m all about parent holds them as long as they want to...but some nurses are no, the baby’s sleeping, don’t wake them up. I don’t know where that comes from…it’s a power trip, I’ve seen that too. Where they’re like you don’t wake up that baby, I’m like uh that’s their baby, how can you talk to them like that? So, I don’t know what backgrounds or what the nurses are coming from their home, but when they are here, they are the person in power of that baby. So does it make them feel better to say you can’t touch that baby? Probably. Is it right? Probably not, but is it what happens? Sometimes. ‘Cause I’ve heard it, I’ve heard nurses say to the mom don’t touch that baby, it’s not time. I was like, oh my god, I cringed inside…and that’s where people butt heads too, and then the nurses get more picky…the mom’s touching them too much. It’s a sick, sad cycle of weirdness. I don’t know how to explain it except that you know, the nurse is like this mom’s a pain, where in my head I’m like she’s being a mom, so how do you, what do you do with that? So that’s the problem. A nurse like me, as long as you want for as long as the baby’s saying they’re fine, and the baby’s tolerating—the babies don’t have a problem with it. It’s other nurses I’ve heard say, you can hold the baby for an hour a day and that drives me insane, because there’s no limit that that would be a minimum for me. I let the moms hold for as long as they can hold.

This nurse’s comments correlate strongly with other nurse responses about how they manage kangaroo care. Some mothers reported that it was not offered very much and suggested that they did not know to ask.
This kind of response from mothers was limited to only a few interviews, but interviews with nursing staff explain why some mothers felt this way.8

Some nurses explained just how labor intensive and time consuming it was to facilitate kangaroo care, citing the number of staff needed to move the baby, the lack of privacy or space to maneuver, or scheduling issues with post-partum staff if the birth-mom was still inpatient and also with outpatient moms traveling to the NICU. Each nurse discussed the complications with the materials and technology used in their joint effort to care such as, tubes, wires, and breathing equipment that posed a challenge and how as part of the process they had to be pinned in place or taped down. One nurse explained, “everyone has a job, one person holds this tube and we disconnect it, put baby on mom and reconnect it, it has to be quick, and then you’re taping it to mom. Somebody else is trailing all the wires around and you’re moving around, so you all have to be kind of one person.” Other nurses commented on the difficulty with the lines and keeping the baby’s head stable and how kangaroo care is concerning to the staff and so they try to control, limit, or combine it with routine medical care times. These concerns exemplify the tension in providing care as the nursing staff maintain a dominance over parents by having power over their babies.

Care technologies enable disembodied caring (Milligan, 2012), however, even the non-human caregivers, the medical equipment, can act as gatekeepers while simultaneously forming part of the collective/co-produced care. Medical devices form an important component of the medical care of infants, all neonatologists interviewed agreed that the vast improvements in technology over the past decade had made it possible not only to save infants born at increasingly early gestation with higher rates of survival, but also improve the overall health outcomes of premature infants.9 On one hand, machines enable life-saving care, on the other hand they are devices to be read by staff with expertise, which centers control over care. The medical technologies used assist nursing staff with making determinations about how a baby is “tolerating care.” Nursing staff listen for alarms, which signal negative changes to five core measures of vital signs: heart rate, respiratory rate, temperature, blood oxygenation levels, and blood pressure. In many cases, any change to one of these measures signals to a nurse that the baby is not tolerating care and can be used to defend decisions made about whether or not (and when) a parent can practice kangaroo care.

The majority of nurses interviewed talked about “clustered cares,” where the baby is receiving routine medical care that can then be combined with a period of kangaroo care, because the baby has already been disrupted and may be experiencing changes in heart rate or temperature, for example. Or, in other cases, nursing staff will make claims to the stability of the baby when limiting kangaroo care time, nurses might say ‘just once a day,’ or only for ‘one hour.’ Other nurses complained that parents made it difficult because they were under-prepared (in terms of clothing), or not having enough time, or asking at the “wrong time.” For example, a nurse commented that “we wouldn’t want to get the baby out an hour after we just did cares, we would want it closer to a care time.” Providing routine medical care makes changes in an infant’s vital signs and as a result, nurses try to limit the number of times a baby is “disrupted.” Staff reported that taking babies out of the incubators puts a lot of stress on them and so if they were going to take them out for kangaroo care it needed to be for at least an hour to justify the stress on the baby.10

One universal that cut across all interviews with NICU staff was that they always prioritized kangaroo care and any holding of the baby if medical care was going to be withdrawn. One nurse commented that “the rules just go out the door in that situation, we just let them hold if it’s looking like a case where they may withdraw care.” Another nurse echoed this statement, saying “…if we can barely do care without the baby becoming very unstable, we kind of offer kangaroo as um, like your baby is not going to make it, why don’t you hold your baby, as kind of a last, you know, just as a last offering of getting to do some care, like we know your baby is not going to make it, so why don’t you hold your baby and make the most of it.” Each member of staff discussed how kangaroo care was encouraged in these cases and demonstrated how care is still co-produced even in situations where a type of care (medical treatment) may be stopped, another exists to take its place. This practice shows a compassionate geography of co-produced care in the landscape of the NICU.

4.2. Medical “Cares”

In the NICU the typical medical procedures that happen every few hours are called “cares.” Nurses and parents talk about being involved in the “cares,” such as changing the infant’s diaper or taking their temperature. This is the site of cluster care that was described so often when discussing kangaroo care. When asked how many times a day parents can hold their infants, a nurse detailed the cluster care process: “we do cluster care where we try to get in and do everything at once so we don’t have to bother that baby again, because that baby’s job is to grow and stay warm, and maintain sugars and be able to breathe right.” However, when the cares are happening is the ideal time to get the parents involved. This involvement is one of the ways that the staff in the NICU attempt to include parents in the treatment processes and practices. These “cares” are taught with parents alongside, and overall the neonatologists reported that they felt the nurses did a great job of getting parents involved in cares. Diaper changes can be stressful, and so having a parent participating assists with making it more positive. One nurse noted that she likes parents to learn the signals, she related an experience of a baby “kicking out,” “they’re looking for a boundary, so why don’t you tuck their legs back in so they can feel where they are in space, give them a head cup, help bring their hands to their face.” These are all areas where the staff are educating parents and creating a community of care. It also makes visible a division in knowledge, where the staff have the training and knowledge and the parents are viewed as non-experts. Parents are often relegated to watching experts care for their infants in the NICU instead of being the center of care for their own infant(s), which may reduce the stress of the medical trauma on parents and positively influence infant health outcomes (Jiang et al., 2014).

Nevertheless, as noted by de la Bellacasa (2017) touch and being touched are preconditions for care. Staff, including nurses, neonatologists, and occupational therapists discussed the importance of helping parents feel comfortable with holding their babies, and providing education on how to touch the baby. As noted earlier, a common theme described by the nursing staff in response to questions specifically about kangaroo care was that parents are afraid to touch their babies. One nurse emphasized the education piece on their end, noting that “if the babies are tiny, they’re [the parents] are a little afraid to even just touch them, so it’s kind of just getting them to know that they’re not going to break their baby.” Moreover, occupational therapists work with parents on positive touch, one participant explained that they “teach them how to touch the baby and how not to touch the baby and explain why, you know, their neurosystem’s not developed, they don’t like it. And then

8 Moreover, “No data exist showing that being in an incubator is better than being in KC, making incubator use one of the most widely used non-evidence based practices in neonatal care” (Ludington-Hoe, 2011:6).
9 An area of further inquiry was brought to our attention in an interview with a neonatologist who indicated that the advances in in-vitro fertilization technologies were causing the premature and thus NICU census rate to increase as parents tended to have multiples (e.g. twins, triplets) and fewer full-term pregnancies as a result.
10 Intermittent Kangaroo Care is recommended to be practiced for a minimum of two hours to allow enough time for an infant to feed and sleep while being held (Charpak et al., 2005).
you explain why the babies are in the incubator, they can’t regulate heat, and then you say these are the stress signs, so you know, hiccup, heart rate drops, all that, just so they understand a preemie.” This positive touch and positioning of the infant is something that happens during kangaroo care as well, where babies are put in a position that emulates how they were situated in the womb. The staff work together to let parents know that they want them to be able to touch their babies, but they are foremost concerned with making it beneficial for the baby and so education on the “way that the baby likes to be touched” is an instrumental part of managing this care.

There is also education and support about what to bring (or not) to the NICU and what to wear so that they can best facilitate parental care. When prompted to describe this education, one nurse explained that they “tell them what they are allowed to bring, like boppy pillows and to wear a button down shirt so they can kangaroo their babies easier, we give them lockers out front for their personals, but of course everyone has to have their phone with them. Nobody comes in here without a phone!” There are also items that are not allowed and which constrict the ability of some parents to provide care. For example, absolutely no food or drink is allowed in the NICU. For nursing parents in particular this is a strain as expressing milk is a dehydrating process and so denying parents the opportunity to have even water in the NICU is a contradiction in care—breast- and chest-feeding parents need to be hydrated. One nurse expressed their exasperation with this rule, noting that the environment of the NICU was outright “uncomfortable,” and that parents should be able to bring in a snack and a drink and “just settle in for a couple hours.” However, if parents wish to eat or drink or use the facilities they must exit the NICU and to re-enter, they must go through the laborious process of scrubbing in, wiping down their phone, and etcetera, again.

One of the key ways that a caring community is created in the NICU is through support and mutual aid. As parents participate in the medical care, such as providing support for the nursing staff who are doing “cares” and through kangaroo care and the provision (when possible) of human milk, another site of care is found in making the NICU a care-full space. Mothers interviewed at the partner hospital agreed that they felt well supported and that if they needed anything that the staff would assist them. When discussing if clothing created a barrier to breastfeeding or pumping, one mother continued her narrative beyond dismissing the restriction, saying that she could not imagine not being able to breastfeed her baby. During observation in the NICU the cuddlers were often holding the neonatal abstinence syndrome babies—those babies going through addiction withdrawal from drugs they were exposed to prior to birth. Thus, there is a community of support that is formed in the NICU that facilitates care even if the caretaker changes.

Support for expressing milk is a key part of the range of care discussed in this paper. As discussed in more detail in the next section, expressing milk becomes a crucial component of how the lactating parent can participate in care. Most nurses talked about how important encouragement was for each parent, but especially for the parent expressing milk. One nurse commented: “I had a young mom a week ago, just like wow, look at your milk supply, it’s really good, it’s very fatty, and she just like perked up and was so excited that she was doing a good job. Like so you know you hit the person at the right time with the right comment, it just changes everything for ‘em.” For many moms, expressing milk was care that they alone could provide and contribute their own expertise—but interviews demonstrate that it is a complex community effort as well.

4.3. Care-work

In the NICU human milk is medicine and is considered a key part of medical care. It is an intervention that is recognized in clinical studies for being lifesaving as it reduces common and life-threatening medical issues in preterm infants (cf. Ahrami and Schanler, 2013; Arnold, 2008; Kantorowska et al., 2016; Montgomery et al., 2008; Vohr et al., 2006). Milk is a form of care that trespasses kangaroo care and medical care, where it forms part of the treatment plan and makes up the feeding component of “cares;” and caring, where it is a site of support, bonding, privacy, intimacy, and information sharing. While lifesaving, providing human milk also captures the everydayness of care, the seemingly simple act of providing food.

Milk cuts across care, and the provision of human milk is a form of

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11 Many neonatal abstinence syndrome (NAS) infants are treated in NICUs either for a monitoring of symptoms or treatment period. NAS infants may not communicate, eat, or sleep in an ordered manner (March of Dimes, 2017). NAS infants exhibit a range of different extreme symptoms (Kocherlakota, 2014) effecting the central nervous, gastrointestinal, respiratory, and autonomic systems (Pritham, 2013) and often have low birthweights (Patrick et al., 2015).
care work that is undertaken by those with lactating bodies. Care work, in all of its forms is demanding (Mol, 2008); it is an everyday and relational practice. Here, the lactating body is the starting point. The lactating parent, theoretically, has control of this form of care, however, it is mediated by medical care, and paid caregivers. Ultimately, human milk is controlled and distributed to nurses by the milk bank staff within the NICU, which limits parental involvement.

Most infants who are being treated in the NICU cannot feed at the breast or chest immediately or at all during their stay because they have not yet developed the suck-swallow-breathe coordination that is required. As a result, many are gavage fed, where a nastro-gastric tube that is placed in the nasal cavity carries milk or formula to the stomach. When a parent provides milk, it is disconnected through this process. The lactating parent expresses milk by hand or with the use of a human milk pump. It is through the provisioning of milk that most parents feel connected to their child and to their care (see Bower et al., 2017). It is a labor intensive, around-the-clock process and it becomes full-time care work for the lactating parent. In an interview with a mother who was pumping while working in a market-based, paid job she talked about the stigma associated with pumping at work and “extra breaks,” noting: “it’s not a relaxing thing, people be like, oh you get to take an extra break, like no, it’s not a break, trust me it’s work…it’s not a break whatsoever.” It is also, in many cases, expected as part of parental participation in the medical care of their baby. When answering a question about the averages observed of mothers’ breastfeeding or providing milk, a nurse related this difficulty for birth mothers. She explained, “they’re dealing with so much with the shock of being here, that the primary focus is on your baby, and I think that women need to feel empowered that by pumping their doing the hard work…so you can sit and look at your baby, but you can also pump milk. It’s a tangible thing that they can do.” And many mothers did discuss expressing milk as part of their job and as something they were compelled to do in order to parent their child. A mother noted that she was “not a doctor or a nurse” but that she “wanted to do something more, and you know, pumping was one of the things that helped me, you know, like I was helping because it was so important.” However, mothers relate the difficulty and the stress of pumping milk both in and out of the NICU. A mother explained: “pumping in the NICU was really hard. I tell the nurse, the pumping room sucks. I feel depressed going into the rooms because they were so tight. I did it because I had to for my little one and I wanted to, but they were just not the greatest to me.” Pumping was something that a lot of mothers needed help with and this was discussed by lactation consultants and parents alike, but not every mother received the same information and lactation consultants are not always available to work with mothers. In discussing how the consultations work, we learned that this group of staff are on a Monday–Friday, nine-to-five schedule, which does not always match up with parental visits to the NICU. One nurse described this conundrum: “a lot of moms are very overwhelmed and kind of in information overload and we’re asking them to pump every three hours, even through the night, they’re exhausted so that’s a lot. So it’s hard for a mom of a premature baby to establish milk supply…our LCs [lactation consultants] are awesome, they’re kind of a Monday through Friday though…” However, there is a concerted effort to make sure that every birth mother can gain access to a pump. Both labor and delivery as well as the NICU attempt to get mothers pumping within the first hour after delivery. However, as many preterm births are unexpected there can be complications with gaining access to and receiving training on using a pump. Additionally, the labor and delivery unit is in a different building than the NICU complicating efforts to bring in-patient mothers to their infant’s bedside. One nurse discussed the complicated character of this work as the birth mother is not their patient. “I think we tend to say, oh ‘we’re just caring for the baby, mom’s discharged now, she’s good.’ But you forget that she needs to still be taken care of so that she can provide milk, so you do need to check in with her….” As a result, it takes a community of people to assist mothers with expressing milk, a layering of care work that reverberates through the community of people caring for infants in the NICU. Notwithstanding this reality, once a birth mother is discharged the commodified healthcare system does not recognize them as a patient, which underscores the importance of valuing all forms of care work.

It is not always the case that milk can be provided by a birth mother and in some cases donor human milk is prescribed. Donor milk use is common in NICU settings and in this case it is purchased by the hospital for infants with prescriptions. Donations of milk are made by lactating parents who may have an oversupply or in some cases by bereaved parents who are expressing milk or donating stored milk as part of coping with the loss of an infant. When discussing policies around donor milk, one nurse discussed bereavement donation and how she uses her own story as part of counseling parents through loss. She explained:

I was just talking to a mom last week—about donating due to bereavement, and milk donation is something very near and dear to my heart because I donated after I had my first baby and it was in a bereavement situation, so having that option given to families that they can do something tangible in memory of their child is huge, I think.

This form of care work is performed at the site of the body (Carroll, 2015) and is a form of communal support as the donor may or may not have any relation to the infant. Boyer (2010) describes disembodied milk, whether mother’s own milk or donor, as a way to ‘care at a distance.’ The NICU always prioritizes mother’s own milk, but when it is not possible and donor milk is, it is part of the education on breastfeeding and the value of human milk. When discussing infant feeding protocols in the NICU, one nurse related the tensions in infant feeding to me, noting that “just giving formula once in the hospital totally changes mom’s perspective because we basically showed them this is okay cause we’re doing it in the hospital, and so by using donor breastmilk we’re showing her that this is so important that we’re using donor milk to help you.” However, donor human milk is also a site of tension in the NICU as the prohibitive cost of providing it to infants means that there is a weight requirement and only very low birthweight (1500 g or less) infants are prescribed donor milk. On this basis, access to milk is in some cases exclusionary, one nurse confirmed this noting “it’s something I don’t think we could probably provide to every baby both from a cost perspective and just from having the actual [financial] resources to do so.” Care in this case is unevenly distributed. It additionally demonstrates the pressure on birth-mothers to pump and provide milk as uncompensated laborers in order to realize better infant health outcomes for their infants (or in case of bereavement others’). This is a moment where the logics of capital compete with the co-production of care.

5. Concluding Remarks

In this paper we have argued that care is multiple and competing. Care labor, whether remunerated or not, provided by actants or actors is an essential part of life and living.12 Taking an anti-essentialist approach to regarding care in the NICU reveals this reality. Simultaneously it shows that the provision of care is not straightforward and so in taking this anti-essentialist view, we have ‘troubled’ care, assessing its practice and performance in multiple forms.

In the case of the NICU the subject of care is not limited to the infant receiving medical treatment. Parents and extended families are also

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12 We would like to note that this paper was revised during shelter-in-place orders in our home states stemming from the COVID-19 pandemic; in this context we want to reiterate the importance of all forms of care and honor the labor of those people and actants who/that protected the lives of so many people.
givers and receivers of care. Care is managed and maintained, offered and provided, distributed and withheld within this space. The landscape of the NICU appears to be set up for medical care—machines and paid staff working around the clock, but NICU care is best accomplished collectively in this space. Looking at a diverse logics and practice of givers and receivers of care. Care is managed and maintained, or stagnates to reduce the time of hospital stays—but the co-production of care outside of capital proceeds.

Being a participant in care for the parents is crucial but it cannot always take place because of power dynamics; moreover, the focus on medical care by practitioners simultaneously enhances and limits opportunities for members of this community to provide or participate in care. However, efforts to get parents to contribute to “cares” and seeing that when the parents are providing positive touch and creating a safe place for their baby the baby’s rights are improved, the provision of care becomes community-based. At the same time, the schedule of “cares” can inhibit other forms of care, such as kangaroo care and are also a way that they are broken up by time and space. Complicating all of these situations is the issue that parents cannot always be present as part of the caring community, and in some cases, for birth mothers in particular, they might not be able to provide care for their infant due to their own medical treatment or condition.

Finally, we reiterate that this community of care is comprised of participatory labor and it is evident that NICU care is a joint effort. Simultaneously, despite this compassionate geography of care, tensions exist in what ultimately is a complex space where care is multiple and negotiated by actors with differing levels of power. Care is shaped by this place, but also is part of shaping the NICU. If we are to be attentive to care-full geographies, we must recognize and value the multiple diverse actors provisioning care and the limits and expectations put upon all actors in the NICU space.

CRediT authorship contribution statement

Lindsay Naylor: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Visualization, Supervision, Project administration.
Abigail Clarke-Sather: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - review & editing, Visualization, Supervision, Project administration.
Michael Weber: Formal analysis, Writing - review & editing.

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