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Celebration in the Face of Trauma: Supporting NICU Families through Compassionate Facility Design

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ABSTRACT

For families, the modern NICU is a place of both trauma and celebration. In order to support families through these types of experiences, NICUs should be designed to encourage family reunification and presence, facilitate psychosocial support, address/minimize sensory impact, offer social connection, and enable positive framing and revisioning of NICU parental experiences. Design teams must also consider how the NICU becomes an educational space for families, and ensure that the lessons parents learn there will serve them and their children well in the future. "*The opposite of a fact is falsehood, but the opposite of one profound truth may very well be another profound truth*," – Niels Bohr.

Before a Neonatal Intensive Care Unit becomes an actual place, it exists as an idea. It is an idea held in the minds of those who will design it and who will work there. It is not, however, an idea in the mind of those babies and families who will begin their stories there. Most parents, before entering an NICU for the first time, have never even considered what it might be like. Yet these perspectives are crucial. Babies and parents are the ones whose lives will be sent in one direction or another, for better or for worse, by what happens to them in the NICU. When embarking on a discussion of how the design of an NICU can support families, it is best to spend some time understanding what the NICU means to families, and what they will need from the space. These needs can be extrapolated into a set of design goals, which if adhered to will ensure the space supports those who rely on it most.

The NICU to Families

A central truth related to the idea of a modern NICU is that it is a place of trauma.[1] Many NICU parents leave the NICU with mental health issues[2] either caused or exacerbated by what happens to them there. The emerging concept of "trauma informed care" is a transformative one,[3] and the truth that it is intended to address is the type referenced by physicist Niels Bohr in our opening quote. What then, would be the opposing profound truth that we should consider?

As much as the NICU is a place of trauma, it is also a place of celebration. It is a place where babies and families are (we hope) surrounded by compassionate care, and, with the support of that care, overcome obstacle after obstacle. The first touch of a parent's hand, the first taste of a mother's milk, the first unassisted breaths – these all happen in an NICU. By supporting parents in celebration of these milestones, we can arguably alleviate or transform some of the trauma they have experienced, and help them reframe NICU events in a more positive way.[4] Our goal in the NICU should not just be to send home healthy babies, but to send home healthy and functional families, who are ready and able to deal with whatever the future will hold.[5]

If these two apparently opposing characteristics can co-exist in an NICU, if it can be simultaneously a place of trauma and a place of celebration, then we need to think about what the activities, processes and policies are that relate to each of these, and make sure that both identities are equally supported by the design of the space.

Embedded in this discussion will be another central contradiction that lies at the heart of the NICU. If your baby's first days are in the NICU, that is where you will learn your first lessons about being a parent to that particular child. While many of these lessons will be useful in the future, an equal number will not only be unhelpful but potentially damaging.[6] When we consider the NICU as a place of trauma and a place of celebration, we acknowledge that it is also a place of learning. We need to be explicit about what types of learning need to occur there, and thoughtful about how spaces can support this essential learning. this essential learning. Additionally, we need to think about how to help parents un-learn the damaging lessons inflicted on them by the surroundings and the situation, and support them as they transition from a highly medicalized environment to home.[7]

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The NICU as a Place of Trauma

"*If I smell the hand sanitizer or hear the sound of alarms going off, I am instantly back in the NICU. My heart starts racing and I feel like I'm going to be sick. My kid is 5 now and great, and I still feel this way. I don't think it will ever go away.*"

[– NICU graduate mother]

It is undeniable that the NICU is a challenging environment for both babies and families, and a growing body of research looks to quantify and describe the nature of its impact. Experts in developmental care[8] and trauma-informed infant care[9] are examining how NICU environments and practices can either deepen or ameliorate the trauma that care can inflict on an infant. A related but equally important direction of investigation seeks to understand the impact of NICU care models on a parent and/or family.[10] What does prolonged physical separation of mother/parent and infant do to attachment?[11] What advantages to both baby and parent can be created by facilitating parental presence?[12] What supports do parents need to either lessen or potentially nullify the traumatic impact of hospitalization?[13]

If we create a set of goals that we believe will serve to lessen the traumatic impact of hospitalization, we can then turn to a discussion of how design can support each of these goals.

Reunification of Baby and Mother/Parent

"*The worst part of the experience was the day I left the hospital and my baby stayed there. I spent the next three months feeling like I was cut in half.*"

[– NICU graduate mother]

In most modern NICUs, it is routine for mother and baby to be separated after birth, sometimes for several hours or more. While there is a general acknowledgement of the value (both physiological and psychological) of keeping the mother/baby dyad together after birth,[14] the assumption has been that the medical state of the preterm newborn precludes this, and that separation is necessary in order to assess and treat the newborn appropriately. Ongoing patterns of separation become reinforced because of a lack of proper facilities; parental presence may be encouraged but lack of facilities or acceptable accommodation make it practically difficult for parents to be present in the ways they might choose. These patterns of separation can have lasting negative consequences on attachment and infant/parent mental health.[15]

However, units like that at Karolinska University Hospital in Sweden have been challenging assumptions about any unfortunate necessity of separation by enabling couplet care from birth onwards. They do this by holding up the understanding of the inseparable dyad as a core concept of their care, and designing their facilities to accommodate this. By creating units and rooms for babies that are also designed to welcome parents, they remove practical obstacles to parental presence.[16]

For hospitals who are redesigning their facilities, the Karolinska model can be an inspiration; for units who must make existing spaces work, it can be demoralizing. However, many examples exist of units where goals of family reunification have been achieved within constrained spaces and with limited resources. By focusing on solving discreet problems related to access and accommodation, a unit can overcome barriers to parental presence without extensive renovation. In the Family Integrated Care (FICare) pilot study at Mount Sinai in Toronto, shared rooms with beds for sleeping were made available on the same floor as the NICU, which made it possible for parents to spend more hours with their infants.[17] In the NICU at Salem Health, Oregon, the unit experimented with bringing a bed for the parents into the baby's bed space; this action made it easier for parents to be present and also helped parents spend extended hours providing skin to skin care for their infants.[18]

Enabling skin to skin care is one of the great advantages of supporting parental presence; the many benefits of skin to skin care for both baby and parent are well documented and need no reiteration here.[19] Units who wish to make it possible for parents to spend many hours engaging in skin to skin care need to support this practice by making it as comfortable as possible, either by investing in and creating space for beds as in the Salem model, or figuring out the most comfortable model that can be incorporated into their existing space. It should be noted that skin to skin care is only one of many vital activities that parents can participate in if their presence becomes normalized; parents can participate in rounds, perform many baby care tasks, read to their infants and become more responsive to their baby's cues if they are routinely present at their baby's bedside.[20]

In essence, if a unit wishes to support parent and child reunification with design, reunification needs to be a core value in the design process. Processes and spaces should be designed to accommodate parental presence as an expected norm. Design teams need to seek answers for questions such as: where will the first contact between parent and baby happen? How soon after birth can significant physical contact occur between parent and baby? After giving birth, how will mothers be connected with their babies? Can parents be with their babies 24/7? Where will parents perform skin to skin care? The answers to each of these questions need to position the needs of the infant/family as either more important than or equal to the requirements of the system.

Keep Essential Services Close

"*I knew I had to do things like take care of myself but I just couldn't. I couldn't do anything that took me away from my baby. I didn't go see my doctor for 5 months. It was hard enough to leave him for 10 minutes to go eat, let alone go for any.*"

[– NICU graduate mother]

One central contradiction of the NICU that can inflict hardship on families is that a preterm or medicalized birth causes trauma for the entire family, but in many facilities the only "official" recipient of the majority of clinical services or care in the NICU is the infant. While there may be support services for family members available via other clinical relationships (such as through a family doctor or counselor), accessing those services usually requires the parent or family member to make and coordinate separate appointments. In practice, while many NICU parents are open to the idea of receiving help and support, and also recognize the importance of self-care, they are unwilling to leave their infant for the amount of time it would take to access services in another location. There is also a tension between the messages given to NICU parents; one powerful message is that parents need to be present to support their infants, and another is that parents need to take care of themselves appropriately. One way of resolving the tension between these two messages is to ensure that key services are accessible to families within the NICU.

Each unit will have a different conception of what resources are essential, and this conception will be derived from what services are generally available within that particular system and which are most requested by families. A list of essential services/spaces could include (but are not limited to): specialized mental health support, emergency health care, and social work services.[21]

Create Safe, Private and Comfortable Spaces

"*One of the hardest parts for me was going through the toughest time in my life in front of so many people. I never felt good showing emotions because there were always people around.*"

[– NICU graduate father]

In both open bay units and in single-patient room units, parents often report feeling "like we're on stage" because of the high numbers