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Personal Narrative

# Life with my baby in a neonatal intensive care unit: Embracing the Family Integrated Care model

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## Abstract

This paper is a personal narrative that describes the components of the Family Integrated Care Model in a neonatal intensive care unit in Canada. I begin by introducing the reader with a brief story of how my son came to be admitted into a NICU. Next, I discuss three aspects of the Family Integrated Care Model that I found to be most striking: medical rounds, "do-ups" and skin-to-skin contact. I also discuss how my immersion in this healthcare setting for three months was a form of autoethnographic fieldwork, as I experienced the NICU both as a parent and a health researcher. Finally, I outline two recommendations to the Family Integrated Care model that might prove to be useful for healthcare professionals in other NICUs to adopt.

## Keywords

Neonates, premature babies, parent roles, ethnography

## "Twenty-Seven and One"

Twenty-seven weeks into my pregnancy, my routine scan showed that my blood pressure was rapidly creeping up towards 200/100 and that my baby's growth had plummeted from the 57th to the 14th percentile. My obstetrician said to me: "I don't think you're going to be pregnant for much longer." Upon hearing these words, I felt my body buckle and collapse into a state of confusion. There was heaps of snow outside--not unusual for March in Toronto—winter's last hurrah. But this baby and I were supposed to share our June birthdays together. Instead, I was instructed to make my way as quickly as possible to another part of the hospital to get blood work done. When I arrived, with my chart in hand, a team of six nurses and physicians were waiting for me around a gurney in a room that seemed suspiciously large for just one patient. Ominous. They tried their best to keep my spirits up with cheerful "it's going to be ok" chatter, as they moved swiftly around me, puncturing my veins with butterfly needles to start a magnesium sulfate drip and then, inserting a catheter. I was being prepped for paramedics to transfer me to another hospital because this one was not equipped to admit babies with a gestational age of less than thirty weeks.

I was admitted into the Intensive Care Unit (ICU) at Wellsprings Hospital (a pseudonym) and was diagnosed with severe, asymptomatic preeclampsia. The only way to cure this pregnancy disease was to deliver the baby. After my blood was taken every six hours over the next two days, the doctors made the decision to deliver the baby via caesarian section to save us both, as my kidneys and liver were failing to function. Due to the symptoms of preeclampsia, my face had swollen and my eyes were temporarily sensitive to light; I decided to wear an Air Canada sleep mask to protect my eyes from the fluorescent lights above me as I lay on the operating table. Sadly, my sleep mask came at a price; I wasn't able to see the birth of my baby. According to my husband's report, our baby (a boy, we found out), was wrapped in a foil-like blanket and then loaded into a resuscitation isolette to be taken to the Neonatal Intensive Care Unit (NICU), on a different floor of the hospital. I remained in recovery for the next 48 hours, not knowing what the future would hold.

I entered the NICU later that day, whilst still in a wheelchair, as I was still very sore from surgery and was unable to walk. My husband wheeled me to the south end of the unit where our still un-named son was, in his incubator, his tiny, almost translucent browny-red body underneath a tangle of tubes and wires. He was intubated, and I could see his chest rapidly shaking from the force of the ventilator machine that was helping him breathe. I looked around his room and noticed a whiteboard on the wall that read: "Family Integrated Care: Teaching, Learning and Caring Together". The whiteboard was meant to convey basic information and messages for the baby's care team and for the parents. In this paper, I will share my experience of what it was like to be a parent in a NICU that employed a "family integrated care" (FiCare) model. I write this paper as both a parent and a health researcher.

## Family Integrated Care (FiCare)

What does FiCare mean? FiCare means that the baby's parents are expected to be actively involved in the care of their child during their stay in the NICU. Specifically, this model includes parents ". . . as an integral part of the NICU team so that they could provide active care for their infant, instead of being in a passive support role. During their participation in the FIC program, parents learned how to provide all care (except for intravenous fluid administration and medications) for their infants in the NICU, while the nurses became educators and coaches for the parents" (O'Brien, et al., p. 2, 2013). Simply put, this model meant that my husband and I were not "visitors", with accompanying visiting hours who would simply stay in the background and "watch" while our baby would receive care from healthcare professionals--*we* were part of our son's care team, on equal footing as the physicians, respiratory therapists, pharmacists and nurses. This fact came to life during medical rounds.

*Medical Rounds*

The staff neonatologist on duty for the next three weeks, Dr. Palmer (a pseudonym) was a good teacher. She encouraged my husband and I to take an active role in participating in medical rounds each morning by "presenting" our baby (now named Ezra), to the interdisciplinary team that would "check in" with each baby in the NICU at their bedsides every morning and evening. This interdisciplinary team typically comprised of the neonatologist, pharmacist, nutritionist, nurse practitioner, and oftentimes some kind of medical resident or fellow. Dr. Palmer taught my husband and I how to start our daily presentations at Ezra's bedside by saying something like this:

> *"Good morning, everyone. This is our son, Ezra. He was born at 27 and 1 and weighed 860 grams. He is now 3 days old and weighs 880 grams, up 20 grams from yesterday."*

We started our presentations conveying only his gestational age, corrected age and weight. As the days went by, Dr. Palmer encouraged us to "say more" to the team during rounds and not just recite his corrected age and weight. What else did we notice about Ezra? Was there anything out of the ordinary that we could see? How do *we* think he looks today? Dr. Palmer stressed to us that our opinions and observations mattered.

Each day I spent by Ezra's bedside I would watch him breathe and grow. Sometimes his eyes would open for a second and then close. Sometimes he would move his arm up above his head. Other times, he would place his hands over his mouth. These little movements gave me hope and were signs that he was getting stronger. About three weeks in to his stay at the NICU, I noticed that his belly button looked pink and slightly inflamed. He had an umbilical catheter to deliver nutrients to him through his navel and normally his navel was a neutral colour. But on one particular day, I thought it looked pink. I mentioned this to the nurse on duty and she said agreed with my observation and recommended that the neonatologist should have a look. It transpired that Ezra had developed omphalitis—an infection of the umbilical stump, which, if left untreated, could lead to sepsis. At that point, I remembered what Dr. Palmer had taught me—to be the best advocate for my baby that I could be, because I was at Ezra's bedside every day, all day. I was the one who noticed that his navel was a slightly different colour than the day before—a significant detail that a rotating crew of nurses might have missed. A long course of antibiotics was administered through a PICC line and the infection was cleared. When the rounds team came the next day, my presentation to the team went something like this:

> *"Good morning, everyone. This is Ezra. He was born at 27 and 1. He is now 30 and 4, 23 days old. He weighs 1240 grams, up 10 grams from yesterday. On the weekend I noticed his navel was pink and inflamed. Dr. _______ examined him yesterday and a PICC line was inserted to for him to receive a course of vancomycin and for omphalitis. Ezra will be on this course of antibiotics for the next seven days."*

I presented with confidence to the team, knowing that it was because of my observation that Ezra was treated quickly for this potentially serious infection. Generally speaking, my presentations became more detailed over time, often updating the team on Ezra's oxygen level, other medications he was on, amount of fluid intake he was receiving and my general impression of how much he was desatting on a given day. I also used rounds as times to advocate; on a few occasions, both my husband and I presented cases as to why we believed Ezra's oxygen level ought to be decreased. Participating in rounds is one of many examples of why the FiCare model works in favour of both the parents and the infants.

*Do-ups*

One of the daily routines that any new parent is faced with when having a baby is changing diapers. It's almost a rite of passage for first-time parents, and premature babies in a NICU are no exception! In the NICU, life is scheduled. That means the infants' diapers are changed every four hours and the FiCare model allows parents to do this kind of baby care during the "do-up" schedule. Do-ups involve three tasks. One: change your baby's diaper. How do you change your baby's diaper when he is inside an incubator? It's pretty simple. First, wash your hands. Second, get a new diaper ready from the supply drawer under the incubator (premature babies' diapers are about the size of a menstrual panty liner) and grab three or four wipes. Open both doors on the side of the incubator. Roll up your sleeves and reach in, one arm in each porthole (it feels humid in there!). Move the wires to the side, lift up your baby's legs and put the clean diaper underneath the one he is currently wearing. Undo the soiled diaper, wipe your baby's bottom and discard the diaper. Fasten the new diaper on. The second task in the do-up routine is to take your baby's temperature under his arm. This is done using a hospital-grade thermometer with removable probes. The nurse on duty then records his temperature into the baby's chart on the computer. The third and final task is to change the baby's blood-oxygen saturation probe from one foot to the other. The probe is kept in place using a sticky tensor bandage type material wrapped around the foot. It is easy to unwrap it and then place the probe part onto the sole of the baby's other foot and wrap the material around the foot to keep it in place. Done. Repeat these three tasks in four hours.

Do-ups were important parts of parents' routines. This time allowed me to handle my baby and feel connected to his care and wellbeing. My husband and I would both make sure that we were five minutes early at the bedside so that we could handle Ezra during do-ups because if there was a nurse on duty who didn't know us and we were a minute or two late, she might already get started with the do-up and we would miss our chance. Missing a do-up only happened two or three times but when it did, we felt like we missed a special part of the day. It is important to note here that most nurses knew that parents wanted to take advantage of this time to handle their baby and would coach parents on how to perform the tasks until it felt natural.

*Skin-to-skin*

Mounting research has shown that infants who experience skin-to-skin contact with their caregivers while in the NICU show increased weight gain, stabilization of physiological functions and promoting caregiver-infant attachment. The FiCare model at Wellsprings was designed for parents to hold their infants for prolonged periods of time. The NICU at Wellsprings is a new, revamped facility where each baby has their own private, 3-walled pod-like room with a reclining chair and padded bench. I would normally hold Ezra in the late afternoon and would alert the nurse on duty when I was ready. Gowns were available for moms and dads to wear during skin-to-skin time. I would remove my shirt, put on the gown and get comfortable on the reclining chair. The nurse would then open the incubator and carefully place Ezra, with all his tubes and wires attached of course, tummy side down, on my chest. It was always difficult to get a good look at Ezra's face and head because he was wearing a CPAP mask attached to a cap-like bonnet on his head. But I could *feel* him—light as a baby bird, his skin delicate like crinkly writing paper. He would wriggle around slowly for an hour or two on my chest but sometimes he would stay still, only to look up at me occasionally. During our time together, I would just let my mind wander and enjoy the sensation of his body on mine. Two months later when Ezra had gained enough weight to be moved out of the incubator and into a crib and also strong enough to try to breastfeed, I would play him music on my iPhone during our time together, usually Francois Couperin's Keyboard Music, Volume 1. I chose this music because of the simple melodies and train-like momentum that is unique to the Baroque style.

## The "Incidental Ethnographer"

For ninety days I was immersed in this healthcare setting. Once Ezra was stable and improving each day, I began to worry less. I had found a "rhythm" in the NICU that started in the morning and ended at the end of most people's workdays. I felt I was doing a job I loved—going to the hospital to take care of my son, working alongside people I enjoyed spending time with—the nurses (especially Ezra's primary nurse), respiratory therapists, social workers and of course, the other parents. I then started to feel like an ethnographer again—a type of qualitative research method that was my training in graduate school. During these three months, I imbibed the culture and knew that I also played an active role in creating it. I observed details such as how nurses would change shifts and what they would talk about during the "handover"; I took photographs of Ezra's bed space and his nametags. I grew accustomed to all the beeps and bells produced by the machines that kept these babies alive. A NICU soundtrack. I gained a sense of the major conversation themes that were talked about amongst the mothers in the milk pump room—how tired they were, how much weight their baby had gained or lost, how many days their baby was (still) intubated for, when they thought their baby might be discharged. I collected artifacts that were markers of Ezra's care in the NICU: old pacifiers, a fresh preemie diaper, his CPAP bonnets, the swaths of cloth for Ezra's incubator with my and my husband's scent on them, and notes that our primary nurse would leave for us to find in the mornings when she would finish her night shift. I wrote in a journal most days and my journal entries were sometimes notes I took during meetings with doctors and during the many "parenting a preemie" classes that I attended. But mostly, my journal pages were filled with little letters to Ezra. All of these pieces of evidence of my time in the NICU with Ezra were pieces of a story, an incidental period of "data collection" to describe a *culture*. The culture of the NICU in my experience was one that aimed to facilitate close bonds between parents and their babies and for the FiCare model to work towards providing parents with the knowledge and skills they need to contribute in a meaningful way to the care of their child.

## Recommendations

The Family Integrated Care model[1] was an unprecedented part of being a parent of a premature baby. I was not prepared for my baby to arrive so early. There were no warning signs (such as experiencing contractions or going into labour), in my case; hence, no "Googling" was done in advance to arm me with information and facts about having a baby at twenty-seven weeks. The FiCare model mitigated this dilemma by positioning parents to be advocates for their babies from the outset. In practice, I felt its effects daily, which helped tremendously, given Ezra's rocky start and the shock of it all, starting with medical rounds each morning, engaging in do-ups and ending my day with skin-to-skin contact with Ezra.

The first recommendation I would make is for healthcare team members to interact with dads in a more deliberate way that recognizes their knowledge and enthusiasm for caring for their baby. I remember one healthcare professional said to me, "You know your baby best." This was not true in my case. My husband knew just as much about Ezra as I did; however, it is easy to rely on stereotypes of fathers playing a support role while mothers "do the work". On another occasion, one nurse assumed that my husband would not want to be changing diapers and thus went ahead with Ezra's do-up without him. We both would have preferred if all healthcare professionals would give fathers the same quality of attention and eye contact as they would give mothers. I do acknowledge that oftentimes fathers do not have the opportunity to spend as much time with their babies in the NICU as mothers do; nevertheless when they *are* at the bedside, they still deserve the title of "parent expert" in order for the FiCare model to take advantage of the lived experience and knowledge produced by *both* parents.

Finally, a word about medical rounds. I was lucky that the neonatologist on staff when Ezra was first admitted to the NICU, Dr. Palmer, was committed to providing parents with the guidance they needed to participate in medical rounds. Given my career in academia and my husband's career in a management training company, presenting at rounds came relatively easy to us. I would suggest that to make rounds more accessible to all parents, a teaching and learning session with videos from "veteran parents" and accompanying role plays for current NICU parents to practice, would help to demystify the act of presenting at rounds as well as give parents the confidence to take on an even stronger advocacy role.

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