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Cover Page Footnote

Author's note: James, although your life was short, it was full of purpose. This article is associated with the Innovation & Technology lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_InnovTech

A home for us and a womb for her: Living the Family Integrated Care model in a Danish NICU

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Abstract

Family Integrated Care (FICare) has been widely adopted in Denmark as a framework for caring for infants in the Neonatal Intensive Care Unit (NICU), enabling parents to take on an active role in the care of their infant, while the NICU staff takes on a more supporting and educating role when possible. The purpose of this paper is to provide an autoethnographic account describing the personal experience of living in a NICU with a preterm infant for the duration of 76 days from the perspective of a first-time mother. The autoethnographic method provides the reader with a detailed description of the experience of a mother caring for her preterm baby under the conditions of living fulltime in the NICU and allows for an exploration of specific challenges related to the FICare model as it is practiced in the Danish public healthcare system. The article discusses specific challenges of the FICare model related to parental isolation as well as parent-healthcare staff interdependence and highlights reflections on its implementation that may prove valuable for healthcare professionals in the NICU setting to consider further.

Keywords

Autoethnography, FICare, prematurity, neonatology

FICare in Denmark

Parenting a preterm infant raises a number of complex questions. Among them are considerations regarding the role of the parents in the care for and treatment of their own child, as well as which approaches to take in order to best ensure a healthy attachment and relationship between parents and infant during this difficult and distressing time. Since it is already known that preterm birth and experiences in the NICU disrupt early parent-infant relationships and induce parental psychosocial distress,¹ one such attempt at answering these challenging and difficult questions regarding the parent's role in the NICU has been the conceptualization of the FICare model.

FICare is an extension of the principles of Family Centered Care² and is one of the first pragmatic approaches to enable parents to become partnering caregivers within the NICU setting. Within a Danish context, the goal of FICare is for the parents to perform all basic care related tasks, such as feeding, comfort, positioning, measuring temperature, diaper changes and bed baths. In the beginning, the care tasks are carried out with the help of nursing staff, but within days, parents are expected to carry out this work independently.³ Although the inspiration for FICare originates from lower resource settings where families provide care out of necessity rather than choice,⁴ this approach has been adapted within NICUs by FICare teams in countries such as Canada, Australia, New Zealand, Denmark, Norway, Sweden and the UK with the aim of improving outcomes for both the

parents and the infant.⁵ The enhanced outcomes resulting from the use of the FICare model include improved weight gain, reduced parental stress and shorter length of stay in addition to increasing parental self-efficacy and sense of confidence in relation to caring for a fragile preterm infant once the family leaves the hospital.⁶ The FICare model is, however, implemented in different degrees across the above-mentioned countries depending on factors such as access to resources and limitations to the physical space available in the NICU. Thus, different hospitals have varying resources at hand to fulfill all aspects of the FICare model. At the hospital where my family and I had our NICU experience, the FICare approach had been comprehensively adopted to the degree that the parent(s) would live full-time in the NICU in a single or two-family room with their preterm infant for the full duration of the infant's NICU stay.⁷ However, other hospitals in Denmark do not have the option to offer live-in facilities for both parents.

Known barriers to implementation of FICare

Research has already shown that realizing the FICare model has proved to be challenging for NICU staff. The clinical barriers to the FICare model are already well researched and understood, and include limited resources and space, a strong existing professional culture among the NICU staff, existing hospital policies and procedures incompatible with FICare, as well as fixed professional routines that prove challenging to change.⁸ However, the

parental perspective on the FICare model and potential barriers related to the parental experience from a social science perspective remain underexplored.⁹⁻¹¹ This article will therefore use autoethnographic empirical material to shed much needed light on this gap in order to analyze two points of contention related to living within the FICare model as a parent for an extended period of time.

In the text below, I will describe the events and experiences that stand out to me as important during my pregnancy and birth, as well as the ensuing 76 days spent in the NICU with my daughter and husband. I do so in an attempt to add nuance to the existing body of knowledge on FICare in a NICU setting by providing a personal parental perspective. Along the way, I present two points of contentions that I think are worth unpacking further in order to unfold what it means to take part in the FICare approach as a parent. The article suggests that the presented themes of parental isolation and clinical interdependence could be considered more carefully when putting the FICare model into practice by offering a discussion of the two topics.

Autoethnography: Giving voice to the personal experience

Autoethnography is a useful qualitative research method that presents and analyzes lived experiences. It is a particular approach that autoethnography researchers Ellis and Bochner define as “[...]a genre of writing that displays multiple layers of consciousness, connecting the personal to the cultural.”⁹ Emerging from postmodern philosophy, where traditional methods and research are questioned, autoethnography is a somewhat underestimated, yet valuable, form of inquiry that invites the reader to reflect on and empathize with the experiences presented. Autoethnographic text can stretch from poetry, personal essays, novels, across performative texts to more classical academic genres, but common for them all, is the author’s explicit and critically reflective presence in the text.¹⁰

My own training as an educational anthropologist has taught me to always keep notes and record observations about conversations, events, and experiences that seem important – even in my personal life. The account that follows is thus autoethnographic, in the sense that it addresses certain aspects of my personal NICU experience that have become noticeable and interesting to me by virtue of my particular position as a mother of a premature child. It is an attempt to tell a story of premature birth and motherhood as I see it, from where I now stand, with the aim of writing about and analyzing a particular personal experience, that is nonetheless relevant for others to gain insight into. Although there are challenges of both representation, balance and ethics to consider when engaging with the autoethnographic method, I agree with

Ellis who emphasizes that the main criterion to consider is that “[...] autoethnography itself is an ethical practice.”¹¹

Writing autoethnographically thus involves being ethical and truthful about the experiences described, but also accepting the personal narrative as a legitimate way into a critical analysis. Making use of the autoethnographic method thus means that I, as the author, will be visible throughout the text, since autoethnography “[...] exists in the intersection between fieldwork, biography and emotion,”¹² and since this methodology is more than merely self-reflection, it makes it possible to use my personal experience as a catalyst for asking complex questions that challenge the existing consensus on the topic of family integrated care.¹³

It is, however, important to note that for me to become able to convey my own experiences in the critically reflective way that autoethnography necessitates, has taken time. I have repeatedly attempted to write this article over the course of the last five and a half years, but only now has it become possible for me to portray my own experience in a way that would make sense to others than myself. Meanwhile, this time has allowed other phenomena to emerge as empirically and analytically relevant to me along the way. While the first years were filled with a profound sense of loss, losing a normal and healthy pregnancy and starting life as a family in such a traumatic and difficult way, this now takes up less space in my memories of my daughter’s first months and allows for other events and experiences to capture my attention – and these are what the reader will be presented with below.

7 hours: Deliver now. URGENTLY.

Intrauterine growth restricting (IUGR), meaning that our unborn baby was smaller than expected, had been haunting our pregnancy since midway through my second trimester. The underlying cause of IUGR can be many, ranging from maternal causes related to diabetes, cardiopulmonary disease, malnutrition and drug use, across fetal causes, such as genetic diseases and fetal infections to placental causes, often related to placental insufficiency.¹⁴ With no other noteworthy symptoms accompanied the IUGR condition, our prenatal care team was struggling to understand exactly what the underlying cause of my IUGR was. Nonetheless, a couple of days before Christmas of 2014, I woke up in the middle of the night with a sharp upper right-side abdominal pain and a blood pressure of 180/90. I was 28 weeks pregnant at the time and our baby, Edith, was delivered by emergency C-section the following morning due to severe and rapidly developing HELLP, which is a potentially life-threatening complication of preeclampsia. Seven hours was what I got from that sharp upper right abdominal pain that woke me up in the middle of the night until the time I was lying on the operating table. Seven hours for me and my unborn

child's life to be in danger and for the doctors and nurses to save us. Seven blessed and brutal hours that are forever held in my heart as our lives changed forever.

The following few days continue to be a blur to me. I remained in the intensive care unit (ICU) until I was stable, while my daughter was cared for in the NICU. I do not have a continuous stream of memories from those couple of days; however, fractions remain. I remember being scared and alone – thinking that I was going to die. I remember asking to be taken to see my daughter because of that fear but being denied. Once I stabilized I was finally discharged, and my husband and I were moved to a room in the NICU ward. At this point our daughter was not yet stable enough to stay in the room with us. She had to stay in a room adjacent to the nurses' station for the purpose of close monitoring. Upon my discharge from the ICU, my husband had significantly more experience caring for our daughter than I did, since he had spent full days with her for the duration of that time. He knew the names of all the nurses and doctors. He knew how to feed her with a syringe and a feeding tube. He had already spent countless hours skin to skin with her, and when he did, he knew what monitoring alarms to worry about and which to ignore. I, on the other hand, was starting from scratch, and had to catch up with my husband, learning what it means to be a mother in this highly unfamiliar setting.

A home for us and a womb for her – creating an intimate space

My husband and I knew that we would be staying in the hospital for a considerable amount of time, so we put some effort into preparing our room in the NICU for when our daughter would become stable enough to stay with us. My husband and I moved the two single hospital beds together and found an extra duvet to fill the crack in the middle between the beds, creating a makeshift double bed. He found an old CD player in a storage room, for us to play a CD with calming instrumental music. He asked for a table and chairs so that we could eat our meals in the room rather than having to leave our daughter in order to eat in the cafeteria. He hung post-it notes with encouraging messages from family and friends, and a note on the door instructing visitors to keep calm and quiet while in the room. He hung sheets over the windows to keep the light from getting in, because we wanted to simulate, not only a home for us, but also, a womb for our daughter – even though this hospital room on the 10th floor was neither. We wanted it to be quiet and dark, with as little interference as possible. We wanted to be self-reliant when it came to our daughter's round-the-clock basic care needs, such as feeding, washing and changing. We wanted it to be our home for the time being, where visitors, such as family, friends, nurses and doctors could drop by from time to time, but where the three of us were the main occupants. We created an intimate space, which,

despite the fact that our daughter was still not fully recognizable as a human being, resembling a frail bird chick more than a baby, firmly placed her into a family structure – our family. We were full of hope during this time, and eager to do everything right in order for our daughter to have the best odds possible. We wanted to be able to do something, contribute to our daughter's recovery somehow, in order to rid us of this overwhelming feeling of helplessness – and FICare allowed us to do just that. Little did we know how exhausting and isolating this experience would also become over the course of the 76 days living in this home and womb.

The first contention: Laboring alone

A couple of days before my husband returned to work after his two-week paternity leave, our daughter could finally move into the room with us. We were several doors from the nurses' station now, which meant that the medical staff were optimistic about her stability and progress. Her incubator was placed right next to our bed, and a new routine could start to emerge and settle on us.

Although back at work, my husband still lived in the hospital with us, but left every morning at 7 am only to return in the evening. Every morning he would leave us after helping me set up skin-to-skin. I made sure to have gone to the bathroom, pumped milk, and fixed myself some breakfast, while he prepared her feeding tube with milk and the morning meds. As he kissed us goodbye, I was in the hospital bed with our daughter on my chest, feeding her milk through her GI tube. I remember these days as being dark and quite still - winter days in Denmark are short with little sunlight, due to our northern geographical location, and we would only turn on artificial lighting in the room for the daily rounds or when a nurse would pop by to check up on us. A CD entitled *Musique* was on repeat, and the sounds still resonates in my mind and brings me back to a distinct and complicated feeling of comfort, safety and utter sadness. Comfort and safety because I knew our family was exactly where we needed to be to ensure my daughter's health and safety – sadness because this place and this experience was the last thing I wanted for us and her.

I stayed this way for as long as I could – usually until 11.30 am. Then, another bathroom break, pumping milk, some lunch, a quick shower, followed by another round of skin-to-skin that would last until around 5 pm. As soon as my husband arrived back from work he would take over and do skin-to-skin until 9 or 10 pm while I fed him dinner with a spoon on the bed. Our daughter would then spend the nights in her incubator, with us sleeping next to her. We fed her every three hours, and I pumped milk for each feeding to have as many fresh feedings as possible. This was the routine that we quickly adapted to and, in many ways, relied on to structure and make sense of this strange

life we had been given. The routine was only to be interrupted by occasional eye exams, blood work, brain scans, tube changes and other minor medical procedures that required help from nurses, doctors and lab technicians. During this time, I realized that once a premature baby has stabilized, the work that goes into caring for such a child is extremely monotonous and repetitive, requiring a great deal of both perseverance and patience from everyone involved.

This stage of our hospital stay was characterized by slow progress as well as minor setbacks. *“Being in the NICU is a journey of two steps forward and one step back,”* the nurse, Marie, explained to me. The nurse’s explanation of the typical NICU progression brings me to my first point of contention when living the FICare model as a parent. Because although normal infancy progresses according to well-known milestones, the development of the NICU infant is different. This difference is not without significance, not only for the child itself, but also for the parents.

As time passed, our NICU routine described above did not only become everyday life for us, helping our daughter develop and manage the inevitable setbacks, but in many ways, this routine also became a very isolating experience, especially for me as a mother staying behind while my husband returned to work. I never left the hospital during those 76 days of admission, and it became increasingly difficult for me to connect with my network of friends and family that came to visit. Trying to explain this difficult journey that we had been thrust into seemed way too much work for me at the time, and the more I gave up on conveying my experience to others, the stronger the sense of isolation became. Often, visits from friends and family seemed to challenge and interrupt the strict routine that we had become so dependent on, and we would frequently question whether the visits were worth this disturbance. Yet, saying no to, or postponing visits, developed into a bittersweet cycle, that on the one hand enhanced my sense of isolation, while at the same time ensuring that all my energy was spent where it was most needed – caring for our daughter. Instead, I found myself spending a lot of time reaching out to other preemie families around the world on social media – reading their stories in exchange for telling them mine. It was easy, relatable, convenient and without particular commitment.

Nonetheless, in the eyes of the NICU staff, this isolation did not register. Our commitment to caring for our daughter so independently was repeatedly praised and appeared to contrast other typical reactions among parents. *“A lot of people have a really hard time taking on the role as parents in a NICU setting,”* Lene, a nurse who cared for us frequently, told me. She continued: *“(…) we see it all the time – that parents find it difficult to care for their child here. Sometimes it is because they are scared of becoming too emotionally attached in*

the event that their baby might not make it, other times they are just too nervous and anxious about making mistakes and hurting their baby.” Involving the parents was a challenge for the nurses, and while much of the existing research on the FICare barriers has highlighted the rigid work cultures and professional practices of the NICU staff as a limitation to the implementation of FICare,¹ the nurse in the above quote points out a more overlooked challenge. In order for the NICU staff to be able to involve the parents in the care of their child, there must be a parent willing and able to get involved. In the eyes of the doctors and nurses in the NICU we had achieved a great level of independence from them in relation to caring for our daughter’s daily needs, and we were therefore viewed as a good example of the FICare model working in practice.

During mornings rounds, our routine was emphasized as beneficial to our daughter’s progress and development, and new nurses were brought in to hear about our experience of life in the NICU. But while our NICU stay was an example of FICare working in practice, my experience of isolation continued to be overlooked. I felt profoundly different than those of my peers that had also become parents around the same time as us, and I was convinced that we did not share any of the same experiences of parenthood. In many ways, it is a sense of difference that persists even to this day.

My experience in the NICU point to an important insight about parental isolation, which could be considered more carefully when applying the FICare model within the NICU setting. Although there is a need for a certain level of isolation in order to achieve the calm and focused environment necessary to care for a premature infant, this isolation can also take a great toll on the parents and complicate a successful transition out of the NICU and back to the family home and larger family and social network. Yet, for the NICU staff, the FICare model *remained* a meaningful way of working within an extremely sensitive professional field. *“This is a rewarding, but also very difficult job,”* Prisha, an experienced NICU nurse explained. *“It is so rewarding when you see these resilient babies pull through despite all odds, but it is also extremely difficult to care for other people’s sick and dying children every day.”*

It is undoubtedly difficult to care for a sick and frail infant regardless of whether you are the parent or the hospital staff, and the emotional labor, a term coined by social psychologist, Hochschild,¹⁵ and later interpreted within the professional field of nursing by Smith,¹⁶ as the process of inducing or suppressing feelings in order to make people feel cared for and safe, was a pivotal part of the nurses daily professional practice here. With the aim of FICare to transition the care of the infant from the staff to the parents, part of this challenging emotional labor was lifted from the shoulders of the staff; but from there, it did not just disappear – it was in turn placed on me as a parent.

During this challenging time, I was left laboring through the highly ambivalent feelings that NICU nurses face every day. These are feelings of optimism, fear, disappointment, joy, anger and love, but I did so without the safety net of professional knowledge or experience to draw on. I argue that within the development of the FICare model, this aspect needs more careful consideration. Involving parents in the care of a sick infant is not a straightforward task, and although a parent may very well want to be deeply involved, it is an emotional undertaking that requires professional support along the way.

The second contention: Between self-reliance and dependence

Time passed in the NICU, and our daughter slowly but surely grew and developed. As we came closer to her original due date, nurses started working with me on the transition from feeding via a GI-tube to breastfeeding. During the previous 60 days or so, I had seen nurses and doctors increase the amount of milk in every feeding, filling her small stomach to the point that it affected her ability to breath and be comfortable. I had seen them add protein to her milk in an effort to achieve an acceptable weight gain, yet none of it ever really seemed to completely satisfy their expectations. Until this point, feeding was not a bodily experience of latching to my breast or laying in my arms. Instead, we had been taught a very mechanical and technical approach to feeding our daughter: pumping with a machine, timestamping the milk and storing it correctly in the fridge or freezer, ensuring that her stomach was empty before starting a new feed by pulling back on the GI-tube with a syringe, filling the syringe with milk and medicine, pushing it into her tiny little tummy within 20 minutes and putting a warm towel on her belly afterwards to ease the pain related to digestion. I had become an expert in this approach, and it relieved my own anxiety to know exactly how much milk she was given and when. However, with the transition to breastfeeding, we were deprived of this mechanical, yet reassuring, approach and instead asked to rely on a new feeding practice.

I did my best to take on this new role of a breastfeeding mother, and I loved cuddling my daughter in my arm and doing something for her that no one else could, but the anxiety got to me over time. I felt blindfolded, never really knowing if she got enough milk, or whether she stopped feeding because she was full or merely too tired to go on. This unpleasant feeling ultimately got in the way of me truly enjoying these special moments, which led me to seeing bottle feeding as a good alternative for me and her. However, I could tell that the nurses were highly invested in having me breastfeed, and I therefore had to gather courage to speak up and tell them how I truly felt - that I would actually prefer to pump and feed my daughter with a bottle. I figured that as long as she was given my milk, full of important antibodies and hormones, it did not

matter the route. But the nurses did not accept my proposal. *“You need to give it time. [...] it is always difficult in the beginning.”* The independence and self-reliance that I had previously established in relation to the NICU staff was suddenly undermined, and I reluctantly continued to stick with the breastfeeding routine, because I did not have the support of the staff to make a different decision. One evening I finally broke down, and a new nurse on the floor, who had herself chosen to bottle feed her first child, saw me. She took me to the storage room and showed me where to find the bottles. She taught me how to clean them correctly and sat with me as I gave my daughter her first bottle.

In general, breastfeeding support is a high priority in Danish NICUs,¹⁷ and it felt like establishing a breastfeeding routine with my daughter was considered a final solidification of the success of the FICare approach for many members of the NICU staff. We were under the impression that the great work that my husband and I had done in terms of taking on the day-to-day care of our daughter would not be complete without this final step. In many ways, I identified with the frustration and feeling of defeat when it came to giving up on the idea that I would be exclusively breastfeeding my daughter, but I was nonetheless surprised by the lack understanding for my independent and well thought-through decision to continue to pump instead. So close to the end of our stay in the NICU, where our self-reliance and confidence as parents capable of caring for our own child should be at its highest, we found ourselves with an unfamiliar feeling of losing that self-reliance and instead experiencing an unfamiliar feeling of subservience.

I argue that giving the parents a central role within the NICU and in relation to the care of the infant patient challenges the relations of power between parents and staff in subtle but significant ways. In this instance, the nurses' ambition of having me breastfeed diverged with the fundamental aim of FICare creating independent and self-reliant parents confident in knowing what is best for their child and themselves. However, this example of choices related to breastfeeding highlights a much more fundamental challenge found in the NICU: the balancing act of caring for the infant shared across parents and staff.

While the FICare model advocates for an early transition of day-to-day care from staff to parents, the example of my desire to bottle feed my daughter and the ensuing dilemmas related to authority and power, illustrates the need for this to be an ongoing conversation between parents and staff instead. The parents' ability, strength and resources to care for their child will surely differ over the timespan of a lengthy hospital stay like ours. An ongoing discussion would allow for different types of factors, such as the nurses' professional knowledge of the importance of a strong and close emotional attachment between parents

and child and the parents' emotional and physical resources to be that primary care person, to play an equal role in deciding who is responsible for the care needed. But more importantly, this conversation needs to be ongoing, since parents that have initially been evaluated as resourceful and capable of taking on the primary care role might become drained of those resources over time in the same way that parents originally evaluated as less resourceful might grow capable, over time, to take on the role as primary care giver.

Concluding remarks

This autoethnographic description of our time in the NICU is meant to offer an understanding of the parental perspective of FICare as it is implemented and practiced in a Danish context. It adds an emotional and deeply personal perspective that contributes with new knowledge to existing research with the potential of contributing to the continued development of the FICare model, both in Denmark and abroad. My recommendations for the FICare model are in no way exhaustive, since the specific research method applied here provides deep insights that are not easily generalized to other contexts; however, some insights originating from my experiences are worth exploring further.

Firstly, I argue that parental isolation can play a significant role for parents in the NICU and cause psychosocial distress, not only for the duration of the hospital stay, but also after the challenging transition out of the hospital and into the home. This isolation becomes particularly problematic when parents are left to work through the many and conflicting feelings related to having a premature baby alone. Here, the potential of online communities for learning about prematurity and sharing experiences with other parents in similar situations should be explored in more detail. Also, more needs to be understood about that transition and appropriate ways of activating the parents' extended network of family and friends in order to prevent that particular experience from persisting long-term.

Secondly, I argue that rather than transitioning the responsibility of the day-to-day care from the NICU staff to the parents at a given point in time, this division of labor needs to be a continued, respectful and open conversation that takes into account both the professional knowledge of the NICU staff as well as the emotional and physical state and resourcefulness of the parents throughout the hospital stay.

Lastly, this article also aims at showing how autoethnography can help to advance the understanding of how to care for a preterm infant in the hospital and in what ways to work together with the family to do so. There is a tendency in Danish society to consider preterm

infancy as something that a child just needs to 'grow' out of, but my hope is for even more ethnographic descriptions of the experience of becoming parents to a preterm infant in the hospital, but also beyond the hospital setting, to shed additional light on this particular way of coming into the world and the long-term consequences that it might have.

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