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## The ethics of family integrated care in the NICU: Improving care for families without causing harm

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### ARTICLE INFO

### ABSTRACT

The philosophy of care in Neonatal Intensive care Units (NICU) has changed with increasing integration of families. We examined parents' and clinicians' perspective about Family Integrated Care (FiCare) in our quaternary NICU. We found that parents and clinicians reported many benefits for families. They were all enthusiastic about FiCare for non-medical items such as changing diapers and skin-to-skin care; for more medical items, such as presenting at rounds, being present during resuscitation or procedures, most physicians wished for more parental involvement, more than other professionals, even parents. All parents described how FiCare benefited them, had empowered them, helped them feel like parents and become a family; but several parents, who could not participate as much or did not want to assume clinical roles, reported feeling guilty. Having a flexible, yet transparent FiCare philosophy is key, as opposed to having homogeneous goals. For example, an aim to have all parents present at rounds in a quality improvement initiative can cause harm to some families. We suggest how to ethically improve FiCare in the best interest of families while minimizing harms. It is important for FiCare not to be "Family Imposed Care." Optimizing FiCare can only be done when parents' priorities guide our actions, while also keeping in mind clinicians' perspectives and respecting the reality of each NICU.

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Abbreviations: NICU, Neonatal Intensive Care Unit; FiCare, Family Integrated Care; LOS, Length of Stay

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Over the last decades, the philosophy of care has changed in the NICU: it is hard to imagine that not long ago, parents were not allowed to visit their children or were expected to view them through windows or had limited visiting times. With the advent of “patient-centered” care, there were fewer restrictions; the importance of putting the whole family at the center of care was finally recognized.<sup>1</sup> Family-centered care has led to unrestricted visitation as now the norm for parents, and often for other family members. A systematic review of studies of family-centered care, including randomized trials prior to 2018, found 23 trials that were designed to investigate impacts of changes in NICU care<sup>2</sup> on parental stress. They found some evidence that family-centered care initiatives had an impact in decreasing maternal stress or anxiety. In particular, frequent skin-to-skin contact was the most effective intervention. The exact role of the family remains variable between NICUs. Family-integrated care (FiCare) refers to several initiatives involving integration of parents into the care team in a more intense and complete fashion, transferring some (or almost all, in some units) aspects of care from the medical team to the parents. Many units in Nordic countries have been leaders in this area, with NICUs even being designed to accommodate mothers immediately post-partum.<sup>3</sup>

Such initiatives often require a training period for the parents<sup>4</sup> and nurses,<sup>5</sup> often a minimum time commitment per day, which may be 3<sup>6</sup>, 6<sup>4</sup>, 8<sup>7</sup> or even 24<sup>3</sup> hours, and are designed to permit parents to perform tasks which were traditionally restricted to nursing or respiratory therapy staff.<sup>8</sup> Such tasks include the administration of some, usually oral, medications, adjustment of oxygen concentrations, checking intravenous sites, participating in medical rounds rather than just observing them, bathing and positioning the infant, and writing in the official medical chart or in a parallel document.

### Ethical issues in FiCare

When a neonatal team wishes to implement an initiative, it is usual to review the literature. However, the evidence demonstrating benefits of many aspects of FiCare is limited. Infants in FiCare studies have usually been larger preterm infants, on non-invasive respiratory support or no support,<sup>4</sup> or have been in level 2 nurseries.<sup>3</sup> Furthermore, the role of the family in some comparison groups has been extremely limited, such as one where they had no visitation, with video calls allowed 3 times a week.<sup>6</sup> How to ethically review the evidence is vital, considering non-participating parents. The empiric evidence for many of the features of FiCare is based on one randomized trial with some design flaws.<sup>4</sup> The included parents in the intervention NICUs of that trial did have a slightly lower stress and anxiety scores than parents in control units after 21 days of the trial intervention. Whether there are other benefits, and whether the reductions in stress and anxiety persist for longer and into their lives after discharge is unknown. One criticism of the major FiCare trial<sup>10</sup> was that the parents who were included in the intervention group were only those who were able to commit to being present for at least 6 hours each day during the daytime, thus significantly limiting

generalizability<sup>4</sup>. The parents who need the most support to find their role in the NICU are those who are unable to spend so much time there, i.e. those who did not meet inclusion criteria and did not participate. It has already been demonstrated that parental presence is associated with shorter length of stay (LOS).<sup>3,9</sup> Such data are, however, mostly based on observational studies which also have inherent biases; parents who can spend a longer time at the bedside (those who have the financial resources to take leave from work, two parent households, car owners, no drug or alcohol abuse issues, etc.) are also those, statistically, where children have better outcomes.

The limited amount of high-quality empirical evidence is, in part, because it is difficult, when practices become ingrained, to randomize families to practices which seem self-evidently substandard. For example, in some centres it would be impossible to randomize some parents to be prevented from sleeping in the unit next to their baby or adjusting oxygen levels. For example, in Uppsala, families of extremely preterm infants as early as 22 weeks are integrated in the care of their infants very early on, and their clinical outcomes are exceptional.<sup>11</sup> On the other hand, other units, such as the Iowa unit in the US, have comparable exceptional outcomes without parents sleeping in the unit and adjusting oxygen levels.<sup>12</sup> These countries are also very different. Is the Uppsala model transposable to the US? Social factors, such as parental leave, accommodations for breastfeeding, socialized healthcare, government subsidies, even the value of the minimum wage, will have an impact on the feasibility of FiCare initiatives and the outcomes of sick neonates.

Thankfully, we have come a long way in caring for parents and families as a whole and most NICUs want to develop or improve FiCare. An important ethical question is whether some FiCare initiatives can be a burden or create harm in some families. None of the studies have examined the perspectives of parents who were excluded (not “FiCare group” participants) because they did not satisfy inclusion criteria. Several quality control initiatives (QI) have even developed aims such as “all parents present at rounds”, with QI goals of reaching 80% of all parents as an optimal clinical outcome. At first sight, this might seem admirable, but we should also question: what time of the day do rounds occur? Can a mother who has to bring her other children to school participate? What if the father is working 2 jobs? What if these parents do not feel comfortable speaking in public? Does pressure -real or felt- to be present at a particular time of day or perform a specific task create harm for those who are unable/unwilling to do so or who have limited language proficiency? One response may be, that if we train parents well enough and support them, they will be able to. But this is an incomplete answer without parental perspectives. Both the first and last author of this paper are neonatologists who also had the experience of caring for their 24-week daughter in “their” NICU, where parents were integrated from an early stage. Only one of them wanted to present at rounds and perform medical interventions, such as tube feeding, but it was not because the other was unable to do so, this did not feel like tasks a parent should do.<sup>13</sup> Pushing the analogy further, they could have provided extreme FiCare, performing intubations and LPs. This seems ridiculous, surely parents should never do that, even if they

are neonatologists! But in some NICUs, parents with no medical background are expected to engage in tube feedings and round presentations, with much less training. FiCare initiatives should take into account the desires of the parents, their individual capacities, experiences, cultural backgrounds, and availability, and should be able to evolve during the sometimes prolonged stay of NICU families.

The philosophy and layout of the unit is also important. Some initiatives will be applied very differently in an open bay NICU compared to a single room NICU, where parents may often be alone with their babies. Many clinicians are also resistant to change when a model seems to work well for them. Resistance to FiCare has been documented<sup>14</sup> but the literature about it is scarce. Because FiCare has been presented as the new goal to reach, lukewarm perspectives are not popular and may be labelled as “non-parent friendly”. Nurses are profoundly involved in the care of sick infants; it is important that their voices be heard and that FiCare develops in a way which supports their expertise. Changes that are imposed without accounting for the perspectives of parents and clinicians are unlikely to be successful. There are other ethical examples where the clinician field and philosophies have changed quickly without adequate parental perspectives. As an example, paternalistic decision making was the reality 50 years ago, important ethical advances replaced this by informed consent, which then evolved into shared decision-making, which has greatly improved the care of families. However, rigid adherence to shared decision-making without considering the views and cultural backgrounds of the parents can lead to harms. Some families want recommendations about the best course to take, that clinicians are now often reluctant to give;<sup>15</sup> other families do not wish to share some decisions.<sup>16</sup> The objective should be personalized or titrated care. For the FiCare philosophy, adapting to parents as well as clinicians and the reality of the NICU, with sequential changes to increase benefits while decreasing harms.

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### Improving FiCare: a local QI initiative

In 2012, we were invited to be part of a study where outcomes of children would be examined with FiCare or with “usual” care.<sup>17</sup> The inclusion criteria for parents in the intervention group was them to commit to be in the NICU for > 6 hours per day. We considered participation as a medical team and asked the PAF (Family Partnership team, including 24 parents at the time<sup>18</sup>) to reflect on our participation. This sparked questions about our protocols, as many FiCare aspects described in the study were already in place: inclusion of parents at rounds, presence of parents was permitted during interventions such as resuscitation, intubation, lumbar puncture, and vaccination. It became quickly clear that members of the PAF team—even our “veteran” resource parents—disagreed about optimal FiCare: such as whether we should aim to include all parents in tube feedings or whether parents should be permitted to change oxygen concentrations. Ethical considerations raised were numerous: such as security, responsibility, and guilt for parents who may not want or be able to participate. In the end, we declined to participate in that study, instead embarking on a quality improvement (QI) initiative. The reality of our

NICU is the following: in Quebec, neonatology is regionalized, health care is universal (socialized), parental leave is one year. The CHU Sainte-Justine NICU is the largest mother-child NICU in Canada (level 4), with 75 beds and 30-35 dedicated to intensive care (about 1000 admissions a year). Before initiating our QI project, we first assessed the needs and perspectives of parents and professionals regarding FiCare. Our aim was to develop and optimize FiCare with goals that were identified by the whole team (including parents) and adjusted to the reality of the NICU.

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### Needs assessment

In 2016, over a two-month period, we surveyed all groups of full-time clinicians who worked in our unit as well as two groups of parents; 1) parents of all children who were hospitalized in the NICU for more than one month and 2) all parents attending the Neonatal follow-up clinic (one parent was asked to participate for each child). We asked participants their opinions regarding a list of potential items (see Appendix): 1. At the present time, can parents (item), if they wish to?"; 2. "IDEALLY, should parents be able to (item)?"; they were invited to justify their comments in an open-ended fashion and were all asked how family integrated care could be optimized in the NICU. Quantitative data were analyzed using descriptive statistics; open-ended questions were analyzed using thematic analysis. Themes and sub-themes were rigorously defined by two independent investigators (a resource parent and a clinician). Two independent investigators coded all the data. Discrepancies were resolved by involving another investigator. This QI questionnaire survey was approved by the Research Ethics Committee and all participants consented.

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### Survey results

During the research period, 332 participants were recruited (79% response rate): 240 healthcare professionals and 92 parents. The providers proportionally represented all health care professionals in the NICU: nurses, neonatologists, fellows, residents, nurses, respiratory therapists, social workers, psychologists, pharmacists, nutritionists, physiotherapists, clerks, chaplains etc. In total, 92 parents participated: 48 families of hospitalized children and 44 parents who participated at follow-up; 90% of the parental respondents were mothers; 60% were aged between 30 and 40 years; 9% were single mothers, for 34% this was their first child. The majority of infants at follow-up were preterm infants who were born at less than 29 weeks. The hospitalized infants of the parent respondents were preterm or with congenital malformations (20%), with an overall mean gestational age of 29 weeks.

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### Parental integration in the NICU and satisfaction with parental involvement

We divided the activities into medical and non-medical activities, as well as access to documentation and information

(see Appendix). The non-medical items included: changing diapers, giving bottle feeds, reading stories, singing to the baby, taking photographs in the incubator, receiving information about breast feeding, being there at rounds, etc. For each of these items over 97% (and usually 100%) of parents and all respondents agreed that parents were participating in these activities, and should be participating (Table 1). For more “medical” items, there was a general pattern of answers: physicians were generally in favour of more parental involvement, significantly more than other groups, including nurses. Nurses were generally divided and other providers had even more reservations. For example, 35% of parents reported being present during a resuscitation or thought parents should be there when they want to. In contrast, 80% of physicians thought parents should be there, 30% of nurses and 22% of other providers (Table 1).

Parents were generally satisfied with their degree of involvement with non-medical items (Table 1). The main frustration parents expressed regarding those activities was variation in practice from one nurse to another “(examples of parental quotes are given later in the article)”. For some items, parents were satisfied. For example, being present during intubation (48%), resuscitation (35%), vaccination (88%), presenting their baby at rounds (53%). Parents who reported they were present generally reported they thought parents should be present if they wanted to. When parents reported they were not present during intubations, they either did not think parents should be at resuscitations or that only parents who wanted to engage should be present. Many parents, in open-ended comments, described why they did not want to get involved in certain activities. On the other hand, 20% of parents reported wanting to participate in an activity they did not participate in. This dissatisfaction was aimed at some interventions and certain information: early access to information about the NICU (“how it works”), participating in discharge plans; where all clinicians also identified this as a weakness.

For some items, there was a relative consensus that parents did not wish to perform, such as checking the site of an IV infusion, which clinicians also generally did not think this should be delegated. Other items were more variable, such as adjusting oxygen concentrations (after instruction and with the consent of the care team) 30% of parents wished to adjust the oxygen, compared to 50% of physicians, and only 13% of nurses or other professionals.

## How can we optimize FiCare? Open-ended comments

### Parental perspectives about benefits and potential harms of FiCare

In their open-ended responses, when they reported benefits of FiCare, parents overwhelmingly thanked the team (especially the nurses) and invoked three main themes: 1) FiCare enabled them to be a family and feel like “real” parents; 2) Their desire to feel like and be “good parents”; and 3) The strength and empowerment associated with FiCare, in some cases even repairing past trauma, such as guilt they felt about

having delivered a sick baby. The following quotes illustrate these 3 themes:

*“I really enjoy doing these things, it made me feel like a real mother at first, and then at some point, like a good mother. I have failed my birth, but I can help her heal, be in charge sometimes and feel I can control some things.”* (Mother of a 25-week baby, in the NICU for 2 months).

*“I think of doctors and nurses as the specialists of everything that happens to my baby, the medical stuff. [...] I want to become a specialist of my baby, for all the non medical things, to be a parent.”* (Mother of a baby with a congenital anomaly, in the NICU for one month).

*“It helped me become a father for real.”* (Father of a 24-week baby, at 18-month follow-up).

*“I love the care we got. At first, I felt the nurses did all the things I should have done, the job my broken uterus should have done. That I wasn’t a mom. I was scared of the unit and even of my baby. [...] I started feeling stronger because of all these things I did. I thank all the nurses for their help and it is really nice to be able to suggest things to improve this for other parents.”* (Mother of 27 week baby at 18-month follow-up).

A third of parents reported guilt associated with being asked to perform tasks that they were unable/unwilling to do or felt pressure to be more present:

*“Every day, a nice nurse would ask me if I would come back in the evening. I had 2 other small children at home who reacted to my absence and an exhausted husband who cannot stop working. So I ended up every night either crying at home missing my baby, or crying in the NICU missing my other kids. Your family integrated care occurs at home too. I wish they understood [...] sometimes just asking us hurts.”* (Mother of baby born at 27 weeks, at 18-month follow-up).

*“There are many questions that made me uneasy. I do not want to feed my baby with a tube. I never have wanted to describe her at rounds. This is my third child and I want to be a good dad to all my children. For me, dads don’t do these things, even if you tell me they could or should. Those are temporary medical things. Being a dad for me means many things I answered, like speaking to her, singing her songs, changing the diaper, giving her baths, taking her in my arms, being interested in the next step and what is going on. I don’t want to be a nurse and a doctor, it is important to me to remain a dad. If she needs to come home with tubes, and had a handicap, then my answers would be different.”* (Father of a baby born at 24 weeks, in the NICU for 3 months).

### Parental frustration associated with nursing FiCare variability

Mainly for non-medical items, many parents expressed frustration at the nursing variation: being allowed to perform some items on some days then being prevented from doing so on other occasions. This sometimes had an impact on parental trust.

*“It is hard to know what your role is, as a parent. The same day I can be told she is too unstable for kangaroo, and after the nurse changes, that I would be good for her, why hasn’t it been done? Then you feel super down. Then you feel anger, like is one too stressed or another carefree? Then you just want to leave. Small things affect me right now.”* (Mother of baby born at 28 weeks, in the NICU for 5 weeks).

**Table 1 – Selected results from QI FiCare initiative.**

TASKS	Was routine in the NICU at the time of the study	Did you, as a parent: parental answers	Should parents who want be able to				Themes invoked in open-ended comments
			parents	MDs	nurses	Other clinicians	
Non-medical item such as bath, kangaroo care (average of all items)	YES	97%	100	100	99	97	Essential items identified by all. Satisfaction expressed by all. PARENTAL FRUSTRATION about variation in nursing practices especially for feeding and skin-to-skin.
Give tube feeds	Case by case	6	50	90	44	31	Nursing answers were heterogeneous: half were extremely positive while the other half expressed reservations. Themes invoked by all participants groups were to PERSONALIZE for each parent.
Give oral medication	Case by case	7	52	72	52	47	
Change oxygen levels	NO	4	33	38	15	12	The items least popular to implement by all groups: mostly negative comments in all groups.
Verify IV site	NO	3	12	35	16	10	
Be there during a resuscitation	Case by case	35	35	80	31	22	Heterogeneous answers by parents and all clinicians (except MDs). Themes invoked by all participants groups were to PERSONALIZE for each parents.
Be there during an intubation	Case by case	48	59	52	30	34	
Obtain information about my baby at any time	YES	98	100	100	97	87	Essential items identified by all. SATISFACTION expressed by all. Many recommendations to improve FiCare.
Obtain information about the NICU early	Yes but not optimal	33	99	100	97	98	Essential items identified by all. DISSATISFACTION expressed by all about these items. Many recommendations to improve these processes.
Participate in discharge planning	Yes but not optimal	20	86	92	97	95	

*“What I find hard is all the different opinions about how much and long I have to be there if I want to breastfeed, and then how often she goes on the breast, stays on the breast, how tired she seems to some nurses and then not others. I am so confused. The contradictions are really stressful and make me feel guilty.”* (Mother of a baby born at 29 weeks, in the NICU for 6 weeks).

#### **Wide variations in clinicians’ perspectives regarding FiCare: from unconditioned adherence to extreme reservations**

Among the clinicians, there was a great deal of variability in the responses. Physicians were the group most in favour of FiCare, all of them expressing a wish for more FiCare, but generally failing to acknowledge that nurses were those who were the ones in charge of the majority of FiCare tasks. About half the nurses were extremely positive about FiCare, only expressing reservations about how to train nurses, decrease the medicalization of parents and the complexity of applying FiCare concepts in a uniform fashion. Many recognized nursing variation of care as problematic: some nurses would sometimes be considered as “nice” by some parents when

not following the protocols in place in the unit, not wanting to be labelled as the “rigid” nurse. More than 50% of the nurses expressed comments illustrating their resistance to increasing FiCare, most of which were based around patient security, their role and responsibility as a nurse (“my patient, their baby”). Respiratory therapists, pharmacists, psychologists and all other clinicians in the NICU had similar reservations. There were a great number of good recommendations to improve FiCare by decreasing variations and personalizing FiCare to decrease negative impacts. The following quotes illustrate the variation of answers from one clinician to another.

*“Parents are already doing so many things. In my opinion, the difficulty is not what parents do, but the philosophy in the unit and the culture that recognizes the parents as the principal caregivers for their baby. For this, it is so important to be flexible and act in a case-by-case manner, in a collaboration with the parent.”* (neonatologist)

*“As a resident, it is hard to know what parents can and can’t do. I am mixed up. I do not have children and I am limited in what I can think about this. I am not sure parents all want to be there during*

interventions even if I am taught more and more to integrated them everywhere in pediatrics. Are we formatting them to be there? [...] I have found you always have to ask the nurse, no matter what.” (pediatric resident)

“We should aim for more presence and participation by parents. Breastfeeding once a day is not acceptable. It should be 4-8 times a day for moms who want to breastfeed. We should do everything possible for parents to be in charge of all the care items, the quickest possible.” (neonatology fellow)

“Yes for parents giving tube feeds, yes for medication, all the time. Parents should be able to do skin-to-skin anytime, with or without catheters. Parents should all present their children at rounds, not only those who want to, we can show them. We can be a team.” (neonatal nurse)

“We need to be there for parents at all time and accompany them in their road. We need to include them, but in a way that makes sense and is based on evidence and accepted by nurses. No to skin-to-skin anytime, with catheters, for example. We need to have uniform protocols so some do not look like compassionate nurses and others rigid ones.” (neonatal nurse)

“The culture has changed a lot during my career but needs to change more. Nurses’ role is to support and teach parents to care for their children. For parents to become the specialists of their children.” (neonatal nurse)

“Medical rounds should be done without families. We are integrating parents more and more and so many speak about their children, this is an ethical problem. Rounds are when we, professionals, give our opinion on medical care, where we may question some aspect of it. Parents do not need to hear all these stressful things. Sometimes, real things cannot be said, because we do not want to make them sad or hurt them more than they are.” (respiratory therapist)

“This is my patient, and it is their baby. It is not their responsibility to do these things. They should do the caring part parents do: change diaper, kangaroo = be parents.” (neonatal nurse, referring to tube feeds and parents changing oxygen levels)

“Parents do not have a nursing degree, they should not do these techniques. They don’t have a professional order they subscribe to if they do mistakes.” (neonatal nurse, referring to giving tube feeds, medication and adjusting oxygen)

“We are doing enough at the moment and it is great to be there for parents, but we should really not do more. I did not do a nursing degree for parents to do my job.” (neonatal nurse)

### **The importance of veteran resource parents and wish for increased involvement**

Involving resource parents was deemed as positive and to be continued, and often given as the best example of FiCare in the unit. Parents reported that communicating with other parents, either NICU parents or parents who had previously lived through an NICU experience (resource parents who work with the PAF team) was helpful.

“We get a lot of medical information but meeting other parents who have lived the same thing was the most helpful, to speak about parent stuff.” (Father of preterm infant hospitalized in the NICU for 3 months)

“It took me a long time to feel like a parent, like I could face the music. It did not happen all of a sudden and nurses and doctors need to know this. Do not force us to do things if we are not ready.

What helped me the most was communicating with other parents. Online support groups helped me connect with parents who had been there [...] to understand that some of my feelings were normal. Also, meeting resource parents on the unit was the most positive experience for me. Knowing that it was normal that I did not feel like me, like a perfect mom, or not really like a mom at the beginning.” (Mother of 20-month old, at follow-up)

### **Personalizing care**

One of the central themes invoked by parents and clinicians, was how to personalize FiCare: how to empower some parents while not burdening others or adding to their guilt. Guilt and decreasing guilt was a major topic raised by parents and by some nurses.

“We have failed our birth, delivery and breastfeeding. We cannot face more failures. You need to realize you can crush us with one small comment that was not meant to hurt us. I felt that THE good outcome for my baby was to feed directly from the breast, and this was what I would get right. But it would be better to celebrate what works than making plans for another possible failure, because it did not work. And it hurts. A nurse was so helpful in pointing out that my baby was 100% breastfed and had received only MY milk, that I was amazing. Do not confuse hospital goals and family goals.” (Mother of baby born at 23-weeks, in the NICU for 4 months)

We have framed the following quote as it is now used as an example of what to say when asking parents if they want to engage in a FiCare activity not all parents wish to engage in, such as presenting their baby at rounds, receiving a lot of information, being there for procedures, etc. We now used the “some parents... other parents” expression daily during clinical duties or teaching (clinical care and ethics) and thank this mother for her wise words.

“Just asking: «do you want to be here during the intubation?» makes me think that I need to be there. That this is what good parents do. And I want to be a good parent, or show them I am a good parent, and I also want to feel like a good parent. What kind of parent wants to leave their child when asked if they want to stay? If there is no good answer, they should say something like: « some parents want to be there during the intubation, it makes them feel in control, for these parents, imagining is worse than seeing. For other parents, it is different, seeing an intubation on their child is too stressful and it does not help them or their family. What kind of parent are you?» (Mother of baby born at 25-weeks, in the NICU for 3 months)

### **Prioritizing the implementation of FiCare interventions**

Following this study, the interdisciplinary PAF team selected high priority interventions based on family needs and desires as well as the openness of the healthcare team (Table 2). We have not implemented items that were not popular neither for parents nor for clinicians, such as universal tube feeding by parents, checking IV site and changing oxygen levels.

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## **DISCUSSION**

Having a baby in intensive care is a stress for parents, many of whom experience lasting effects of that stress. Symptoms

**Table 2 – FiCare priorities identified during the QI initiative with the aim of increasing benefits to parents while decreasing harms to families while taking the providers' voice in consideration.**

FiCare priorities	QI Actions
Assisting parents early to adapt to their new roles in the NICU as team members	-Welcome package optimized by Resource parents and PAF team: reviewed written materials* and video -Weekly prenatal support groups for prospective parents (of children who will be admitted to the NICU)
Improve integration of parents in discharge planning	Development of the discharge nurse role: co-ordination of all phases of discharge with parents, on-line and in person weekly teaching sessions to parents, ongoing support.
Decreasing FiCare nursing variation by developing guidelines and protocols	Protocols/guidelines to decrease nursing variation and work with families as a team: what is enough "stability" to enable skin-to-skin care, when parents can start giving PO medication, which parents receive training to tube-feed their children, feeding evaluation and score for transition from tube to breast/bottle feed, feeding protocol for feeding on demand, interdisciplinary nutrition rounds including parents.
Particular attention to personalize care where parents described potential harm.	Creation of "support clinicians" who are mentors on the unit and assist others in FiCare. Support conferences 6 times a year with emphasis on FiCare and communication with parents.
Enhancing interaction with veteran resource parents	Optimization of weekly parents support-groups/ information seminars, which include veteran resource parents. Two prenatal sessions: "Being a parent in Neonatology" and "breastfeeding my sick baby" and 7 postnatal sessions: "Being a parent in the NICU"; "Transition from intensive to intermediate care"; "My baby's lungs and breathing"; "Nutrition in the NICU"; "How can I organize my parental leave and my family?"; "Getting ready for the discharge." The sessions are evaluated by the parents to ensure that they continue to satisfy their needs.

\*[https://www.chusj.org/getmedia/8d373e06-b655-4c0d-85c8-d2fd38fadcea/F-2814\\_guide-de-vie\\_Neonatologie.pdf.aspx?ext=.pdf](https://www.chusj.org/getmedia/8d373e06-b655-4c0d-85c8-d2fd38fadcea/F-2814_guide-de-vie_Neonatologie.pdf.aspx?ext=.pdf)

\*\*<https://vimeo.com/449839052/d88643480b>

of post-traumatic stress disorder are frequent,<sup>19,20</sup> which has long term impacts on the family<sup>21</sup> and the child.<sup>22</sup> Recognizing the importance of these factors was the basis of the push toward FiCare, which has thankfully become almost universal in many units. However, many families continue to find adaptation to the NICU difficult and are uncertain about their role. FiCare is a worthwhile goal and is beneficial to many families. But each family, each unit and each country are different. Our survey showed that, despite being in a unit that was committed to FiCare, for many medical interventions, a substantial proportion of parents wished to participate and were not allowed to do so. On the other hand, for many interventions there were also substantial numbers of parents that did not participate and did not want to.

This points out to us the importance of personalizing our approaches, that making it positive for a parent to participate in some interventions should not mean that it becomes mandatory and a "QI goal" for all parents. We should always reflect when implementing a training program for parents where the aim is for "all parents" to participate. Because not all parents participated in this QI initiative (75% response rate for parents who met recruitment criteria), it is likely that harms of FiCare (or less FiCare) were underreported and that many ethical issues were not reported. Indeed, many parents who were present in the unit, could participate in the QI initiative (answer a written questionnaire or be assisted to do so), reported feeling guilty for not engaging more. The quotes chosen were from parents who were able, at the time, to express their feelings in a constructive fashion and reflect on

their experience. We can only hypothesize that those who were less present in the unit, or felt they did not want to be there, would have similar -if not worse- feelings. It is important to not only create an integrated team with the parents who are frequently present during the time of morning rounds, but to also reach out to parents who are less engaged; what prevents them from engaging and what we can do to help them. Future studies should aim at obtaining the voice of those parents to improve the care for their families.

The guilt associated with a sick baby was a main theme invoked in parental answers. We can help by reminding families there is nothing they could have done to prevent what happened to their baby (when it is the case, in the majority of admissions). We can help parents navigate the NICU early, by informing them in different ways (website, video, written materials, parent sessions) and placing them in contact with resource (veteran) parents. And, most importantly, we need to be flexible and adapt to parents. This can be done in many ways, one of which is using the "some parents... other parents" approach when guiding and supporting them.

Countries are also all different: parental leave is of one year in our province, as in many Nordic countries. Parents here are not worried about reimbursement for NICU care. Some countries have much more limited provision that varies, for example, in the USA from state to state. Some families choose to start their family leave when the child is discharged, meaning they have less opportunity to be present during hospitalization. Perhaps in countries or areas with sub-optimal parental leave, clinicians fighting for more parental leave

would have a much larger impact than QI initiatives to have parents present at rounds. This has to be factored into the reality of families. FiCare is ethically complex: what a “typical parent” does or how parents define their roles will depend on their reality and that of the unit, which may “format them”, as a participant in our study pointed out. We realize that in units where the vast majority of parents move their families and sleep besides their baby and learn to adjust oxygen levels, answers in local QI initiatives will likely to be different to ours. This is why ethically, there cannot be only one definition of an optimal “FiCare package.”

In summary, FiCare is beneficial to families, but has inherent ethical issues and can harm some parents if not applied in ways that are sensitive to the reality of each NICU, and the reality of each family. QI initiatives can help optimize care. Changes should be pursued incrementally in order to be successful,<sup>14</sup> with implementation priorities identified by parents in order for FiCare to not be perceived as “family-imposed care.”

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### REFERENCES

- Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD. Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Semin Perinatol.* 2011;35(1):20-8. <https://doi.org/10.1053/j.semperi.2010.10.004>.
- Sabnis A, Fojo S, Nayak SS, Lopez E, Tarn DM, Zeltzer L. Reducing parental trauma and stress in neonatal intensive care: systematic review and meta-analysis of hospital interventions. *J Perinatol.* 2019. <https://doi.org/10.1038/s41372-018-0310-9>.
- Ortenstrand A, Westrup B, Brostrom EB, et al. The Stockholm Neonatal Family Centered Care Study: Effects on Length of Stay and Infant Morbidity. *Pediatrics.* 2010;125(2). <https://doi.org/10.1542/peds.2009-1511>: February 1, 2010e278-285.
- O'Brien K, Robson K, Bracht M, et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. *Lancet Child Adolesc Health.* 2018;2(4):245-254. [https://doi.org/10.1016/S2352-4642\(18\)30039-7](https://doi.org/10.1016/S2352-4642(18)30039-7).
- Galarza-Winton ME, Dicky T, O'Leary L, Lee SK, O'Brien K. Implementing family-integrated care in the NICU: educating nurses. *Adv Neonatal Care.* 2013;13(5):335-340. <https://doi.org/10.1097/ANC.0b013e3182a14cde>.
- He SW, Xiong YE, Zhu LH, et al. Impact of family integrated care on infants' clinical outcomes in two children's hospitals in China: a pre-post intervention study. *Ital J Pediatr.* 2018;44(1):65. <https://doi.org/10.1186/s13052-018-0506-9>.
- van Veenendaal NR, van der Schoor SRD, Heideman WH, et al. Family integrated care in single family rooms for preterm infants and late-onset sepsis: a retrospective study and medication analysis. *Pediatr Res.* 2020. <https://doi.org/10.1038/s41390-020-0875-9>.
- O'Brien K, Bracht M, Macdonell K, et al. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy Childbirth.* 2013;13(Suppl 1):S12.
- Segers E, Ockhuijsen H, Baarendse P, van Eerden I, van den Hoogen A. The impact of family centred care interventions in a neonatal or paediatric intensive care unit on parents' satisfaction and length of stay: A systematic review. *Intensive Crit Care Nurs.* 2019;50:63-70. <https://doi.org/10.1016/j.iccn.2018.08.008>.
- Gale C. Family Integrated Care for very preterm infants: evidence for a practice that seems self-evident? *The Lancet Child & Adolescent Health.* 2018;2(4):230-231. [https://doi.org/10.1016/S2352-4642\(18\)30038-5](https://doi.org/10.1016/S2352-4642(18)30038-5): 2018/04/01/.
- Backes CH, Soderstrom F, Agren J, et al. Outcomes following a comprehensive versus a selective approach for infants born at 22 weeks of gestation. *J Perinatol.* 2019;39(1):39-47. <https://doi.org/10.1038/s41372-018-0248-y>.
- Watkins PL, Dagle JM, Bell EF, Colaizy TT. Outcomes at 18 to 22 Months of Corrected Age for Infants Born at 22 to 25 Weeks of Gestation in a Center Practicing Active Management. *J Pediatr.* 2020;217:52-58. <https://doi.org/10.1016/j.jpeds.2019.08.028>.
- Janvier A. I'm Only Punching. *Arch Pediatr Adolesc Med.* 2007;161(9). <https://doi.org/10.1001/archpedi.161.9.827>.
- Patel N, Ballantyne A, Bowker G, Weightman J, Weightman S. Helping Us Grow G. Family Integrated Care: changing the culture in the neonatal unit. *Arch Dis Child.* 2018;103(5):415-419. <https://doi.org/10.1136/archdischild-2017-313282>.
- Moynihan KM, Jansen MA, Liaw SN, Alexander PMA, Truog RD. An Ethical Claim for Providing Medical Recommendations in Pediatric Intensive Care. *Pediatr Crit Care Med.* 2018;19(8):e433-e437. <https://doi.org/10.1097/PCC.0000000000001591>.
- Janvier A, Farlow B, Barrington KJ, Bourque CJ, Brazg T, Wilfond B. Building trust and improving communication with

- parents of children with Trisomy 13 and 18: a mixed-methods study. *Palliat Med.* 2019;269216319860662. <https://doi.org/10.1177/0269216319860662>.
17. O'Brien K, Bracht M, Robson K, et al. Evaluation of the Family Integrated Care model of neonatal intensive care: a cluster randomized controlled trial in Canada and Australia. *BMC Pediatr.* 2015;15:210. <https://doi.org/10.1186/s12887-015-0527-0>.
  18. Dahan S, Bourque CJ, Reichherzer M, et al. Beyond a Seat at the Table: The Added Value of Family Stakeholders to Improve Care, Research, and Education in Neonatology. *J Pediatr.* 2019;207:123–129. <https://doi.org/10.1016/j.jpeds.2018.11.051>.
  19. Ahlund S, Clarke P, Hill J, Thalange NK. Post-traumatic stress symptoms in mothers of very low birth weight infants 2–3 years post-partum. *Arch Womens Ment Health.* 2009;12(4):261–264. <https://doi.org/10.1007/s00737-009-0067-4>.
  20. Vinall J, Noel M, Disher T, Caddell K, Campbell-Yeo M. Memories of Infant Pain in the Neonatal Intensive Care Unit Influence Posttraumatic Stress Symptoms in Mothers of Infants Born Preterm. *Clin J Pain.* 2018;34(10):936–943. <https://doi.org/10.1097/AJP.0000000000000620>.
  21. Greene MM, Schoeny M, Rossman B, Patra K, Meier PP, Patel AL. Infant, Maternal, and Neighborhood Predictors of Maternal Psychological Distress at Birth and Over Very Low Birth Weight Infants' First Year of Life. *J Dev Behav Pediatr.* 2019;40(8):613–621. <https://doi.org/10.1097/dbp.0000000000000704>.
  22. Greene MM, Rossman B, Meier P, Patra K. Elevated maternal anxiety in the NICU predicts worse fine motor outcome in VLBW infants. *Early Hum Dev.* 2018;116:33–39. <https://doi.org/10.1016/j.earlhumdev.2017.10.008>.