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## Editorial

## Family integrated care: Changing the NICU culture to improve whole-family health



The birth of a baby is a milestone event in every family's life. It is generally a joyous occasion where parents get to know their newest family member. However, when a baby arrives much too early, or complications arise, and a neonatal intensive care unit (NICU) stay is required, a momentous occasion becomes a stressful, anxiety-filled fight for survival and healthy outcomes. In these stressful moments families are separated by perceived medical necessity and it can take weeks or months before parents fully bond and care for their new infant. Parents are frequently treated as visitors in the NICU, only able to visit their infant during certain times of the day and all the basic caregiving roles (e.g. changing diapers, taking temperatures) are fulfilled by nurses. Parents frequently feel like outsiders, that they don't fully understand what is going on, and that they are not included in decisions regarding their infant's health. From these experiences, NICU parents have high levels of stress and anxiety and frequently have trouble connecting with their new infant.

### 1. Philosophy of FICare

Family Integrated care (FICare) is a program developed in Canada for tertiary NICUs that changes the care paradigm for infants in the NICU. FICare introduces the philosophy that the NICU should be caring for parents alongside their infants because newborns, no matter how early they are born or how sick they are, require their parents' care. We were inspired to develop FICare after reading and observing the work of Adik Levin (1994) in Estonia where the mother-baby unit at Tallinn Children's Hospital emphasized the importance of the social and emotional bond between parents and their infants for the wellbeing of the entire family. His research suggested that integrating mothers into the NICU and expecting them to provide all of their infant's care resulted in improved infant and parent outcomes. We developed FICare to translate the idea of integrating parents into their infant's care team to the Canadian NICU environment and health care system. With the implementation of FICare and the resulting change in the NICU culture we found that when parents were incorporated into their infant's care team they became empowered, which resulted in parents learning how to become an active participant in NICU activities, their infant's primary caregiver, and a decision-maker on their infant's health team. Together, these changes allowed infants and their parents to bond, enabled parents to be their infants' advocate, and gave families the tools to achieve the best health outcomes for their infant. This special issue focuses on the cultural translation and evaluation of FICare in the UK where it has been branded as Integrated Family Delivered Care (IFDC). To begin the discussion, Banerjee et al. outlines the core principles of FICare and

illustrates how the principles of family-centered care are the scaffolding for actualizing the program, but FICare expands on those principles to incorporate parents into the direct care of their infants.

FICare was developed by a multidisciplinary team that included veteran parents, nurses, and physicians who explored how best to support the integration of parents into the medical care team. This collaborative effort with veteran parents led to the multidimensional implementation approach, described as the four pillars of FICare, and ultimately the success of FICare itself. The four pillars of FICare are defined as staff education and support, parent education, NICU environment, and psychosocial support and are each an integral component of the FICare program, but communication and interaction with parents underlies all aspects of FICare. In this issue, Deierl et al. draw our focus to the parent experience in the NICU and how the implementation of FICare can help. Feedbacks such as these drove us to develop the parent education program, where we focus not only on small group education for parents, but also bedside skill teaching and parent participation on rounds. Furthermore, through family stories Aloysius et al. highlight how caregivers can only really support parents once they understand the parent experience. The implementation of FICare requires that staff hear parent stories as part of their orientation and continuing education in the NICU. We found that parent presentations to staff are the most effective method to convey the parent experience, though other tools such as videos and written stories may also be valuable. Understanding the parent experience is one component of the IFDC nurse education program highlighted by Aloysius et al. in the article "Integrated Family Delivered Care; Development of a Staff Education Programme." When nurses and other staff put the parent experience first it becomes clear that parents can be essential members of their infant's health care team when given the opportunity. Staff education and support is one of the four pillars of FICare which enables nurses to change their role from solely focusing on the infant to being the key parent educator, supporter and coach. Supporting families rather than just the infant is key to improving outcomes in the NICU. The curriculum as developed by for FICare was offered as a four-hour training module; however, during the implementation of the model across Canada and in the UK delivery of such a long training session proved difficult. Aloysius et al. describe a modification to the curriculum by the IFDC team which resulted in "bite sized" learning modules that are 30 minutes long and can be taught by trained staff of all grades. The "bite sized" learning modules are an inventive way to incorporate new concepts into the busy work day of a NICU nurse and may make it easier to provide the education to a greater number of staff in different levels of institutions.

With FICare, one challenge is to sustain and encourage ongoing collaboration between parents and health care staff for the infant's entire hospital stay. FICare challenges staff to have an explicit, shared goal with families: to train parents to be the best caregivers for their infants so that together we can make the infants' journey home the best it can be for both infants and parents. As part of FICare parent coaching happens both at the bedside and through small group parent education sessions. It is important for the FICare team to find ways to celebrate parents for acquiring new bedside skills and to reward staff for improving their skills as educators and coaches. A good example of an event that achieves both these goals is the kangaroo-a-thon discussed in "Celebrating a fortnight of skin-to-skin" by Platonos et al. A kangaroo-a-thon is an event that is frequently used in NICUs to increase the visibility of skin-to-skin care and motivate staff to support it. Such an event also creates an opportunity to provide staff with updated information about the benefits of and skill training for skin-to-skin. Kangaroo-a-thons are a wonderful way of building collaborative relationships between staff and families where both parties have an explicit shared goal.

The provision of skin-to-skin care is an area where parents can quickly become involved in their infants care. However, as discussed in this issue by Lim et al., what appears as a simple task can be very complicated in the NICU environment. After qualitatively analyzing semi-structured interviews with seven neonatal nurses, Lim et al. affirms that there are many barriers to initiating skin-to-skin in extremely low birth weight infants. Awareness of the perceived barriers to skin-to-skin will allow us to identify solutions for incorporating skin-to-skin into the care of extremely low birth weight infants. Fundamentally, we need to find ways of doing what is best for our patients, particularly from a patient's point of view.

## 2. Harnessing technology

The creation of FICare comes at a time when technological innovations are rampant and our relationship with technology is changing dramatically. Families are now accessing health care information in a completely different way than they would have a few years ago. For this reason, engaging families by using technology is an important way to provide timely, quality information and guidance to families. To that end, the Imperial College IFDC team developed a mobile application that provides parents with relevant, accurate information and enables them to track their infant's care. In the manuscript "Innovations: Supporting Family Integrated Care," Banerjee et al. describe how the parent application technology can enhance the family integrated care experience by enabling parents to control how and when they access information regarding their infant's care.

Similarly, the NICU environment, another one of the four pillars of FICare, may also be facilitated by technological innovations. As discussed by Banerjee et al., using fingerprint entry to facilitate parents' access to the NICU is the strongest way to tell parents that they are not a visitor, but essential to their infants' care. This type of entry system eliminates both physical and often custodial barriers to parent NICU access. Comfortable chairs, bedside breast pumps, food preparation areas and rest space are all necessary to support FICare. Banerjee et al. also describes the use of sound blocking headphones to facilitate parents remaining at their infant's bedside during ward rounds in units that are concerned about privacy issues. Other innovative tools like vCreate can be used to improve parent-nurse two-way communication and perhaps even participation on rounds when parents cannot be present. Incorporating technology into FICare and other care-by-parent platforms can only make them stronger and more relevant to parents' daily lives, both in the

NICU and post-discharge.

## 3. Harnessing community

A large part of FICare's success is because of the early engagement of parents into the design, implementation, and assessment of FICare. From the beginning, veteran NICU parents were active participants in the design of the research, education, and support aspects of the FICare program. Continued involvement of parents is essential to achieving a family-centered NICU culture. Even today, veteran parents continue to play a large role in the expansion of FICare across Canada. FICare provides families psychosocial support, the last pillar of FICare, through peer-to-peer support and group social work support. By creating a FICare NICU community, we both create opportunities for NICU parents to support each other during their hospital stay and continue to engage experienced FICare parents as facilitators of peer-to-peer support post-discharge, either in small group work or as parent buddies.

The success of FICare is illustrated in the communities that it has built. The implementation of the FICare model is now being advocated and supported by family charities and networks. The article in this issue entitled "Putting families at the heart of their baby's care" by Kelly et al. highlights the efforts of Bliss, a UK charity advocating for the best neonatal care, to standardise family centered care in the UK and to advocate for the adoption of FICare. Bliss has done a fantastic job developing a charter that includes seven core principles of family-centered care which units can use to audit their practice with the goal of improving neonatal care. Bliss has become a strong advocate for families by creating a family integrated care working group of multidisciplinary health professionals and parents, organizing workshops, and helping units explore the implementation of FICare throughout the UK. Similarly, Miracle Babies in Australia and the Canadian Preterm Baby Foundation in Canada have also taken up the banner to support FICare implementation.

FICare serves as a model for how to improve patient outcomes by truly engaging families in care provision. The success of the model challenges us to identify other areas where we can achieve improved care for infants/young children by providing families with education and support, which will lead to improved child and family outcomes. We can envision a future where parents continue to be an integrated part of their infant's care team post discharge. We believe that parents can deliver early interventions for their child at home, with community help, rather than medical professionals alone. Providing peer-to-peer support, community events directed at parents of preterm babies, online resources, mental health check-ins and continuing parent education gives parents the tools they need to support their child's specific needs long-term.

Interestingly, implementing FICare enabled some NICUs to reach out to the local community through media reports, social media and parent stories and develop new community links that they had not explored before. For example, some NICUs harnessed private philanthropy to support parents with meals when they were in the NICU or to share resources that were also used for families with a diagnosis of cancer. In the future, we may find other opportunities to collaborate with community groups like libraries, bookstores, or toy stores that could provide families with resources to assist them post discharge.

As this special issue shows, the model of FICare is adaptable to many different social contexts. We are fortunate at this moment to be able to look beyond the survival of preterm infants to the quality of long-term social, emotional, and neurodevelopmental outcomes of survivors and their families. We have found that, unlike other interventions studied in randomised controlled trials, FICare cannot be undone. Once parents and staff realise the benefits

of the powerful bond created between families and infants, they all continue to work together to graduate, not just babies, but successful families out of the NICU.

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