

# Family Integrated Care: A Transformative Model Supporting Parenting in Neonatal Intensive Care Units

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Dr Karel O'Brien



# FAMILY INTEGRATED CARE: A TRANSFORMATIVE MODEL SUPPORTING PARENTING IN NEONATAL INTENSIVE CARE UNITS

Staying in neonatal intensive care units is extremely difficult, not only for the babies requiring specialist care but also for their parents. **Dr Karel O'Brien** from the University of Toronto is part of a wider community of scientists who have devoted their careers to studying the benefits of family-centred models in neonatal units. This vital work is improving the physical and psychological outcomes for families involved in this critical but challenging and stressful process.

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## Admissions to Neonatal Intensive Care Units

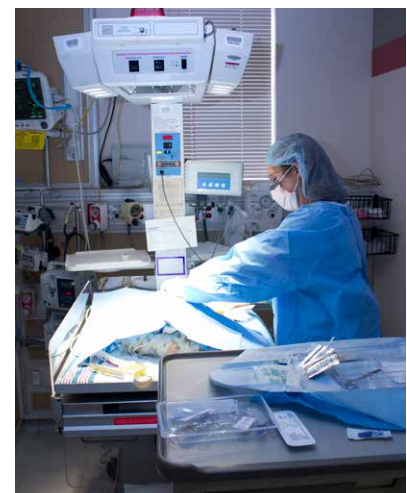
Babies who experience problems at birth and need special care are often admitted to neonatal intensive care units. This is especially common for children born prematurely. One in twelve live births in Canada are premature, meaning that the infant is born at less than 37 weeks gestation.

While a necessary intervention for the survival of premature infants, the neonatal intensive care unit is a complex and demanding environment. Premature infants are vulnerable to infection and poor nutrition, for example, and often undergo painful procedures. The neonatal intensive care unit often also creates a physical and emotional barrier between infants and their parents at a critical time for the development of parent-infant relationships.

## Implications of Premature Birth for Brain Development

If born prematurely, infants face higher chances of neurodevelopmental disorders. While many escape serious conditions such as cerebral palsy, more subtle impacts such as deficits in attention and behavioural regulation, and psychological difficulties such as depression and anxiety, are often found throughout childhood and adulthood.

One reason for this is the underdevelopment of various structures of the brain when infants are born prematurely. Gaining less weight and head growth are clearly linked with delays in the development of structures on the outer layer of the brain. The hippocampus, which is situated deep in the brain, and the prefrontal cortex, situated at the front of the brain (and our most evolved brain structure), both play a key role in memory, thinking and emotional regulation. These structures are particularly vulnerable to the release of cortisol – the body's stress



hormone. Infants who are exposed to high levels of cortisol are known to be at risk of developing behavioural and psychological difficulties. Unfortunately, infants in neonatal intensive care experience high levels of cortisol not least due to the need for potentially traumatic and painful interventions.

As such, the biological effects of premature birth are compounded by the stress and challenges of the neonatal care environment, creating a complex



and multifactorial risk scenario for the premature infant. Undoubtedly, the disruption and stress that can occur due to neonatal intensive care present a serious cause for concern.

### **Impact on Parental–infant Relationships**

A further critical factor is the impact of the neonatal intensive care unit on the development of the parent–infant relationship. It is well-established that parent–infant interactions play a key role in infant development and overall life trajectory.

Dr O'Brien saw the potential for increased parental interaction to help reduce the disruption and stress experienced by infants in neonatal intensive care. She explains, 'My clinical experience and research made it clear that parental engagement in care could decrease infections and improve growth. Meanwhile, other studies had shown that parental holding decreases infant pain during procedures.' Skin-to-skin contact between mother and baby, for example, promotes the release of oxytocin – known as the 'love hormone' in both and also reduces cortisol. Of particular importance to Dr O'Brien was the observation that parental interactions can help mitigate the negative impact of stress on the infant, and that developmentally responsive care from parents can help protect the developing brain.

### **A Transformative Model: Family Integrated Care**

Family Integrated Care (FICare) is a model of neonatal care that provides a structure which supports family-centred care. Involving parents as much as possible in their newborn's care can benefit both the baby's and parents' physical and mental well-being. In FICare, parents are provided with the necessary

support to adopt a more active role in their baby's care than has been typically possible, allowing them to be an active part of the wider neonatal intensive care unit care team instead of being passive observers.

Parents receive education as well as physical and psychological support to allow them to provide as much as possible of their infant's neonatal care. Nurses are recognised as the facilitator for the parents, providing the more technical aspects of care for the infant while coaching the parents in daily activities such as dressing, feeding, holding, bathing and talking to their baby. Finally, emphasis is placed on shared decision-making processes through the development of partnerships between patients, families and healthcare providers.

### **Initial but Promising Results**

The first study to test the practicality and safety of the FICare model took place at Mount Sinai Hospital in Toronto between 2011 and 2012. Parents spent several hours a day at the neonatal intensive care unit, and during this time, they received support tools and education sessions delivered by experienced nurses and other staff such as dieticians.

Involving parents as key members of the infant's healthcare team and helping parents take on the role of primary caregiver as soon as practically possible brought many benefits. These initial results confirmed that FICare parents became less stressed and more confident and competent in caring for their newborns. Better outcomes were also found for newborns, including increased weight gain and fewer adverse events and nosocomial (healthcare-associated) infections were





observed. Babies also spent less time in the neonatal unit and the number of re-admissions decreased.

This promising pilot work led Dr O'Brien and her team to conduct a randomised controlled trial (RCT) – an approach known as the 'gold standard' in research methodology – in Canada and Australia/New Zealand. This rigorous, international study confirmed the benefits of FICare for parents in reducing stress and anxiety, and for infants, better growth while in hospital. Furthermore, it was shown that the model of FICare could be effectively utilised across different settings, with the same positive outcomes.

#### **Benefits for Infants Aged 18 Months and Their Families**

Dr O'Brien and her colleagues then sought to explore the longer-term benefits of FICare. In this follow-up study, a large subset of parents and infants who had participated in the international RCT completed further assessments when the infants were aged 18 months.

The Infant Toddler Social Emotional Assessment was used to evaluate infant social, emotional and behavioural problems. The researchers also measured infant growth, parent-child interactions, and parental distress.

The results were incredibly encouraging. Not only did the infants who had received FICare demonstrate more positive behaviours and performance on the Infant Toddler Social Emotional Assessment, but their interactions with parents were also improved. This longer-term evidence allowed Dr O'Brien to justifiably conclude that 'Interventions supporting parents may decrease their stress and modulate the parent-infant relationship such that childhood outcomes are improved'.



In further studies, Dr O'Brien and her team examined the impact of FICare on babies born at less than 29 weeks gestation. Here, FICare infants had better scores on several scales including their motor skills and body mass index. Taken together, these results converge in supporting the integration of parents into the care of their infants.

#### **Critical Next Steps**

Dr O'Brien is committed to developing this programme of work to improve the care of preterm infants in neonatal intensive care units and beyond. She is now keen to find out whether the benefits associated with FICare will be sustained even into school age. In following up with the FICare participants, Dr O'Brien and her team want to understand the effect that FICare has on children's brain and behavioural development in the longer term, as well as on the complex dynamics between parents and infants. They are interested not only in what the final long-term consequences might be but also how exactly FICare modulates them. As such, future work will aim to unpick the underlying mechanisms of the observed benefits using innovative and rigorous research designs.

Despite recent advances in family-centred care, Dr O'Brien points out that there is still room for improvement. For example, current family-centred care includes multiple methods that vary from one unit to another. Improving the structure and unifying the methods of family-centred care could increase the effectiveness of such interventions.

Dr O'Brien's work highlights the importance of family-centred care methods in neonatal units. Empowering parents to take more initiative in care at neonatal units will undoubtedly have positive impacts on the mental and physical health of babies as well as the family as a whole. Given the lasting burden of preterm birth for children and their families, this inspiring programme of work is shedding valuable light on transformative ways to improve neonatal intensive care.



# Meet the researcher

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Dr Karel O'Brien obtained her Bachelor of Medicine, Bachelor of Surgery and Bachelor in the Art of Obstetrics at the National University of Ireland in 1983. She then completed her Master of Science in Clinical Epidemiology at the University of Toronto. Throughout her career, she has specialised in paediatric and neonatal care in clinical and academic settings, and since 2021, has been a Professor in the Department of Paediatrics, part of the Faculty of Medicine at the University of Toronto. She has been a Staff Neonatologist at Mount Sinai Hospital since 1992. Dr O'Brien has published extensively in her field and her work has received significant and prestigious funding. She has been featured regularly in the media highlighting the importance of family-centred care. Her work is changing how neonatal care is delivered by better supporting the development of positive parent-infant relationships to improve the short and long-term outcomes of infants and their families worldwide.

## CONTACT

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## FUNDING

Canadian Institutes of Health Research  
Ministry of Health of Ontario  
MSH-UHN AMO

## FURTHER READING

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