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Review

Family integrated care; A Florence Nightingale Foundation scholarship and international journey of discovery for improvement in neonatal care. A review of services☆

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ABSTRACT

Family Integrated Care (FICare) is a philosophy and model of care that supports parents in becoming active members of the team caring for their baby now living in the neonatal intensive care unit. As nurses with over 25 years' experience in neonatal care and an enthusiasm to always enhance care for infants and their families, the authors wished to see first-hand how this model of care works. After being awarded a travel scholarship by the Florence Nightingale Foundation with funding by The Sandra Charitable Trust to research and study implementation of the Family Integrated Care (FICare) model, FICare is currently being implemented in the NICU at Derriford Hospital, Plymouth Hospitals NHS Trust.

Introduction

Aim

The aim of this study was to initiate FICare in the NICU at Derriford Hospital, Plymouth Hospitals NHS Trust and throughout the Southwest Neonatal Operational Delivery Network (ODN) to improve outcomes for infants and families.

FICare is a program of care which facilitates involvement of parents of preterm infants as an integral part of their baby's care team, rather than being perceived as a visitor to their baby on the NICU.

FICare was developed in Toronto, Canada following the publication of a study related to parental involvement in the NICU by Professor Levin in Tallinn Estonia. Increased parental involvement evolved out of necessity due to low staffing levels, but the integration of parents into care practices demonstrated reduced length of hospital stay and improved weight gain (Levin, 1994). These results were further studied and substantiated in a more formalized programme of FICare which was developed by a team in Toronto, CA. The FICare programme is based around 4 pillars of FICare; staff education and support, parent education and support, psychosocial supports and environmental supports.

An initial trial and audit of FICare in hospitals in Toronto and the surrounding areas of Canada showed improved outcomes for infants including reduced length of hospital stay, increased breastfeeding rates and reduced hospital acquired infections, as well as improved maternal mental health (O'Brien et al., 2013). These research findings demonstrate that FICare improves neonatal care not only for the infant but also the entire family unit. Observations of FICare practices were planned at Tallinn, Estonia, Toronto, CA, and one of the first hospitals in the United Kingdom to offer this programme of care, St. James hospital in Leeds. Additionally, attendance at a three-day FICare conference in Toronto was scheduled.

Background

Both authors have worked in neonatal care for over 25 years and have continuously sought to improve care delivery to infants and families in the NICU at Derriford Hospital, Plymouth Hospitals NHS Trust (PHNT). The authors were instrumental in developing a neonatal outreach service, a bereavement support service, a neonatal transitional care service and a course for midwives to become skilled in the routine examination of the newborn infant (REN). Quality improvement initiatives to support 'family centred care' practices have been implemented. Transitional Care allows mums to stay with their baby (late preterm infant or growing preterm infant no longer requiring neonatal intensive care), whilst neonatal outreach care expedites discharge to home while supporting the transition from hospital to home. These

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services help facilitate parent and infant bonding/attachment by minimizing the potential separation that a NICU stay incurs. These strategies are in line with the Secretary of State, Jeremy Hunt's vision for maternity and neonatal services collaborating to improve standards of care for infants and mothers outlined in the Maternal and Neonatal Health Safety Collaborative.

(NHS Improvement Dec 2016)

In many neonatal intensive care units across the world, parents are not “allowed” or “permitted” to become fully integrated into their infant's care. Until recently, parents have been asked to leave the unit during ward rounds and handovers (nursing and medical). Parents have verbalized their feelings of frustration in that they must ask staff for “permission” to get their own baby out of the incubator for cuddles. By not “allowing” parents full access to their infant, it is difficult for parents to become fully engaged as parents while in the NICU. Never was this more apparent than with a recent case of parents whose preterm twins were in the hospital (NICU and then the Transitional Care Ward) for 6 weeks. During outreach home visits, it quickly became apparent that their family unit was falling apart. Both parents appeared to be struggling to bond with their babies. In speaking with the mum about her feelings, she stated that she “did not feel bonded with her babies after their time in the NICU”. Services from clinical psychology, perinatal mental health, family support worker, close liaison with the family health visitor, as well as the General Practitioner were all initiated. Concerns were raised that the hospital system had failed this family, and a goal was set to do something to prevent this from happening again to other families. Sadly, this will not be the only case of poor bonding/attachment or subsequent post-natal depression that is frequently seen in parents who have a baby in a neonatal unit.

In the highly technological environment of today's NICU, infants are physically, psychologically, and emotionally separated from their parents. Separation from an infant, the inability to parent while in a hospital, the appearance of an infant with multiple lines and tubes, and the infant's lack of responsiveness, impair parental infant attachment; decrease parental self-confidence and foster feelings of being a “surrogate parent” (Shah et al., 2011). These environmental elements in the NICU are factors that may adversely affect parent–infant attachment and parental involvement (Altimier, 2015; Mangelsdorf et al., 1996).

It has been well documented in recent years that mothers who have had an infant in the neonatal unit are more likely to suffer from postnatal depression. One study reported rates of up to 22% compared with 15% in mothers of healthy newborn infants (Hawes, et, al., 2016). Post-traumatic stress disorder is also more prevalent in parents that have an infant discharged from the NICU. Post-traumatic stress disorder (PTSD) rates of 25% post-NICU have been demonstrated as opposed to 9% in mothers of healthy infants (Kim, et, al., 2015).

In July 2016, after attending the international neonatal ReASoN conference and hearing Professor Shoo Lee speak about the FICare model, the authors were impressed by this concept and results of the FICare trial. The authors were determined that FICare was a practice that should be offered to families on the neonatal unit at Plymouth Hospital's NHS Trust (PHNT). It was believed that the FICare model would benefit families on neonatal units in Plymouth and within the Southwest ODN, thus it was determined that the best methodology to start the FICare journey would be to visit hospital units with effective FICare programmes in order to observe care practices and speak to both staff and families involved in this type of care.

Travels

A travel scholarship was applied for through the Florence Nightingale Foundation for our team to observe and study the practice first-hand. The concept of FiCare originated at the Children's Hospital in Tallinn, Estonia. Estonia was formally part of the USSR which had poor staff wages, resulting in a shortage of available neonatal nurses to care for infants. Parents were therefore encouraged to come and stay on the neonatal unit with their babies in order to provide adequate care for them, day and night, while nurses educating them on how to provide this care. Although FICare started out of necessity, the resulting outcomes from this practice were positive and infant wellbeing improved.

Two days were spent in the Tallinn Children's Hospital, observing care on the neonatal wing which is for infants requiring low level high-dependency care and special care. Additionally, time was spent in the NICU/PICU where infants requiring intensive care or higher level high-dependency care are initially admitted and cared for. Medical Director, Dr. Liis Toome, and Lead Nurse, Marleen Magi, and their entire team were very welcoming and both staff and families spent time sharing their FiCare experiences. In Tallin children's Hospital's NICU, all mothers are asked and expected to ‘room in’ with their baby on the neonatal wing from admission to discharge home while providing most of the care for their baby. The unit is set up with single rooms plus four-bedded and cot rooms, not dissimilar from the Transitional Care Ward in PHNT. Parents stated that they were pleased to be able to stay with their baby and were proud of the care they provided to their babies. They were also pleased with the ability to discuss their baby's issues, needs, and care plans with the medical, nursing and allied health staff. However, one mother did say that she could meet all of her babys' care needs at home, and it was only the fact that one of her twins was still below 2 kg that prevented them from leaving the hospital.

The Separation and Closeness Experiences in the Neonatal Environment (SCENE) research study, in which Tallinn Children's Hospital was a part of, showed a mean of 21.51 h/day that mothers spent on the unit (results ranged from 3.41 to 22.43 h/day parents spent on the unit with their baby (Raiskilla et al., 2017). Time was also spent with a volunteer peer support worker on the unit who four years prior, had 25-week gestation twins (born 15 weeks too early) on the unit. After her experience in the hospital with her twins, she was keen to come back and support other parents. Her twins were first on the NICU/PICU; which did not subscribe to the level of parental involvement offered on the neonatal wing. In the NICU/PICU, parents were not allowed to touch their babies or hold them. She explained that the NICU/PICU can be very difficult for parents, due to the lack of involvement, and welcomed the transition to the neonatal wing, where parents are welcomed, and expected to stay and care for their babies on a full-time basis. As a volunteer peer support worker, she is working with the NICU/PICU manager to change the current practice, allowing for increased parental involvement on the unit.

After two days in the old town of Tallinn, it was on to a very different city with large modern skyscrapers, Toronto Canada, for the FICare conference. The FICare conference had delegates and speakers from around the world, including China, where they have recently introduced FICare into selected units as part of a trial. The conference not only provided a good factual basis for FICare with lectures and interactive workshops, but also provided an opportunity to network and share ideas with nurses and physicians from neonatal units in across the globe. Perhaps the most impressive and informative sessions were those delivered by parents, those who have experienced the FICare programme first-hand and were now volunteering in neonatal units as ‘veteran parents’. The Veteran parent role provides parent education and support and are key to the effective implementation of a FICare programme. Professor Shoo Lee organized an observational day in each NICU at Mount Sinai and Sunnybrooks hospitals, both large neonatal units. Mount Sinai is linked to Sick Kids Hospital across the road and admits infants requiring surgery, whilst the majority of Sunnybrook's population includes extreme preterm infants. Both units are designed so that each infant is nursed in a cubicle with space for a parent to sleep if they choose. Ward rounds on each unit were attended to experience interdisciplinary rounds with parents presenting their infant. Opportunities to speak with medical, nursing and allied health staff that devised the FICare programme were provided. Much was learned from this team about the involvement of veteran parents in their support of new parents.