Family Integrated Care Models

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Neonatal Care: Where have we come from and where are we going?

1900s exhibitions
1950s – Doctors and nurses know best
1970s onwards – high tech environment
Consideration of the environment

Developmentally supportive care

The importance of infant contact for attachment (Klaus and Kennell)

Skin to skin/Kangaroo Mother Care

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Family

“There is no such thing as a baby only a baby and someone”

Winnicott 1947

“We’re not just nursing a baby we’re building a family”

Mother, father, grandparents and siblings

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Neonatology is highly specialised healthcare where the human and social aspects of care are particularly important and challenging.

For parents neonatal care can arouse deep emotions and anxiety. Parents can feel helpless at the cot side of a critically ill baby.

Educating and engaging parents with the care of their baby can reduce their anxiety, improve experience and bonding.

Babies who have strong bonding with their parents have better developmental outcomes (Reynolds et al 2013)
The POPPY Project: researched parent experience, facilities and environment in neonatal care (Redshaw et al, 2010)

Bliss baby charter: 
the rights of a premature or sick baby

The Baby charter standards highlight the importance of both clinical and family centred care working hand in hand.

Bliss Audit Tool/accreditation – benchmarking care

NHS England has produced clear national guidance to focus on the family-centred approach in neonatal intensive care; “involving families in the care of their own children and helping parents understand their baby’s needs” (NHS England, 2013)

BAPM has identified family engagement in neonatal care as one of their agreed focus in their strategic plan in the next 3-5 years (BAPM, 2014).
Neonatal Care journey

The Neonatal BFI Accreditation Standards

1. Building close and loving relationships
underlies our most loving, creative and moral behaviours and builds who we become later in life

2. Enabling babies to receive breastmilk and breastfeed when possible
Nutrition, protection and nurture

3. Parents as partners in care
Getting the first important relationship of anyone’s life more or less right is a necessity not a luxury this is society’s best chance to heal itself

Child Psychotherapy Trust 2003
Consequences of not providing optimal care

• Long term impact for the family and the baby

• **Cortisol** – stress – insecure early attachment - impact on brain development, poorer outcomes: link to aggression, depression, anxiety, lower immunity etc

• Impact on parents mental health

• Secure attachment and bonding - crucial to the ability to build secure relationships later in life: emotional resilience, higher IQ, fewer behavioural problems, more independent, co-operative, better self esteem

**Oxytocin** – generates sense of wellbeing, closeness, love and affection: essential for bonding and relationship building, baby brain development and growth
Neonatal care

Family

Baby

Nurse

Doctor

Therapist
The evidence goes back to 1979

Shortage of trained neonatal intensive care nurses in Tallinn, Estonia prompted Levin to implement a “Humane Neonatal Care" model

Parents provided nursing care for the infant (except for admin of IV fluid and medication)
Nurses provided teaching and guidance to parents.

Results: 30% improvement in weight gain, 30% reduction in infections, 20% reduction in NICU length of stay, 50% reduction in nurse utilisation and overall improved satisfaction among parents and staff

(Levin 1994)
Humane Neonatal Care Initiative


VIEWPOINT

Humane Neonatal Care Initiative

A. Levin

Talitza Children’s Hospital, Tallit, Erez, Israel

At the end of 1980s and the beginning of 1990s, the United Nations International Children’s Emergency Fund (UNICEF), the World Health Organization (WHO) and several other organizations initiated the Baby Friendly Hospital Initiative (BFHI) movement (1). It spread all over the world and now more and more hospitals are given the name of BFHI every month. What does the BFHI mean? Is it just another campaign or has it called forth life itself? I believe the latter to be true.
Humane Neonatal Care Initiative

1. The mother should be able to stay with her sick baby for 24 hours a day.

2. Every staff member should care for the mother and the infant and should be able to cope with psychological aspects.

3. The staff should promote breastfeeding to every mother and learn the techniques of expressing breast milk.

4. The psychological stress of the mothers should be decreased during the whole treatment period.

5. Unless medically indicated, newborns should not be given anything other than breast milk.

6. If the infant cannot suckle, breast milk should be given by tube and preferably by the mother.

7. The number of tests and examinations should be reduced to a minimum.

8. Mother-and-child skin-to-skin and air-to-air contact should be used as much as possible, and the use of technical equipment in childcare should be reduced.

9. Aggressive therapy should be reduced to a minimum.

10. The mother and infant should be considered as a closed psychosomatic system. Everyday ward rounds should focus not only on the infant but also on the needs of the mothers (include a gynaecologist and other specialists).

11. Healthy family members (father, grandparents or helpers) should be allowed to visit the mother and baby during a prolonged stay at the hospital.

It seems to me that units for sick newborn babies might have a wider name: the Humane Neonatal Care Initiative (14).

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A randomised trial of continuous skin-to-skin contact after preterm birth and the effects on salivary cortisol, parental stress, depression, and breastfeeding

Evalotte Mörelius a,b,*, Annika Örtenstrand c, Elvar Theodorsson d, Anneli Frostell e

a Department of Social and Welfare Studies, Division of Health, Activity and Care, Linköping University, Norrköping, Sweden
b Department of Pediatrics, County Council of Östergötland, Linköping, Sweden
c Department of Woman and Child Health, Division of Neonatology, Karolinska Institutet, Stockholm, Sweden
d Department of Clinical and Experimental Medicine, Division of Clinical Chemistry, Linköping University, Linköping, Sweden
e Department of Behavioural Sciences and Learning, Division of Psychology, Linköping University, Linköping, Sweden

“…almost continuous SSC has a buffering effect on infant stress reactivity during handling at one month corrected age … congruent with the theory that early physical contact has an impact on the infants brain systems that manage stress”
FNI: calming activities facilitated by Nurture Specialists;
- in the incubator – calming interactions between mother and infant via odour exchange, touch, vocal soothing and eye contact;
- during holding (skin to skin)
- family sessions to engage, help and support

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Depression and anxiety symptoms of mothers of preterm infants are decreased at 4 months corrected age with Family Nurture Intervention in the NICU

Martha G. Welch • Meeka S. Halperin • Judy Austin • Raymond I. Stark • Myron A. Hofer • Amie A. Hane • Michael M. Myers
Electroencephalographic activity of preterm infants is increased by Family Nurture Intervention: A randomized controlled trial in the NICU

Martha G. Welch a,b,c,d,x,1, Michael M. Myers a,b,d,1, Philip G. Grieve b,e, Joseph R. Isler b, William P. Fifer a,b,d, Rakesh Sahni b, Myron A. Hofer a,d, Judy Austin f, Robert J. Ludwig a, Raymond I. Stark b, the FNI Trial Group

FNI leads to increased frontal brain activity during sleep, predictive of better neurobehavioural outcomes

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“…an intervention that facilitates emotional interactions between mothers and infants in the NICU may be key to altering developmental trajectories of preterm infants”
Numerous studies and reports not new intuitive what parents would do if given a chance and support.
Family Integrated Care

The Pillars

PILLAR 1

Staff Education and Support

- Providing education and tools for staff to enable them to educate, mentor and support parents in caring for their infant in the NICU
- Allowing staff to feel comfortable with the model of care and embrace their role as key facilitators of FICare

PILLAR 2

Parent Education

- Providing parents with the knowledge, skills, and confidence required to care for their infants in the NICU setting
- Enabling parents to be part of the health care team by offering small group education and the opportunity to participate in medical rounds, while being supported by individual bedside learning

PILLAR 3

NICU Environment

- Ensuring that unit policies and procedures are supportive of the model
- Creating a physical and social environment that is conducive to the implementation of FICare

PILLAR 4

Psychosocial Support

- Providing adequate psychosocial support for families to enable their participation in FICare
- Creating and supporting opportunities for peer-to-peer support

Respect our patients and colleagues: quality care | Work together for the
Family integrated care

Studies from Shoo Lee’s team at Mt Sinai Hospital Neonatal Unit, Toronto, Canada has shown that establishing family integrated care within a neonatal intensive care in a multicultural western country is feasible (6-9)

Infants born ≤35 weeks’ gestations with a parent willing and able to spend ≥8 hours a day were included.

Veteran parents, medical, nursing and allied health professionals designed the parents’ training curriculum.

When infants were deemed medically stable, the parents were delivering care at least 8 hours a day.

Parents were included as equal members of the team.
Family integrated care

Improved clinical outcomes:

• decreased parental anxiety and depression
• increased parent-infant bonding
• higher breastfeeding rate
• improved infant health
• weight gain improved
• reduction in nosocomial infections
• Decreased total length of stay

Refs: O’Brien & Lee
Family integrated care

A n international clustered RCT of infants <33w admitted to tertiary NICUs 9 in Canada, 6 Australian and 1 New Zealand; to evaluate weight gain, clinical and parental outcome of FIC compared to standard NICU care. This study finished enrolment in September 2015, and published results expected soon.

The Canadian Neonatal Networks is in process of implementing family integrated care as standard of care.

Similar models are currently being trialled in China, Europe and US.
Our Journey

Breastmilk and breastfeeding

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Unlimited parent access - headphone QI project

Headphone project on the Neonatal Unit
Enabling Parents to stay with their Baby during Ward Rounds and Handovers

Parents involvement in care

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Current neonatal unit practice

- Multidisciplinary team ward rounds

Weekly MDT ward round – what are we thinking?

Dietitian – what is the current weight, are they growing? Do they need any supplements?

Psychologist – has the family got the support to be able to be with their baby regularly?

Discharge coordinator – has mum registered the birth, started to get things ready at home?

SLT – is the baby showing signs of wanting to suck and getting a chance to practice?

Lactation consultant – is mum expressing regularly and getting a good volume of milk?

Developmental care – does the baby have regular skin to skin cuddles and the opportunity to hear mum and dad’s voice?

Physio – are they getting some tummy time? How are they moving?

- Parents presenting

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Family Integrated Care

A model to bring together and formalise what we are doing, take it one step further and enable evaluation

http://familyintegratedcare.com
Unifying goal:

To support parents to become equal members of the neonatal team and participate in providing active care for their infant with the help of a competency-based training.

“We understand and believe that even the best medical care cannot replace your presence and the love you can provide to your baby”
Benchmarking and planning

Listening to families, parent engagement

- veteran parents focus groups
- Parent surveys

“Parents on the neonatal unit feel helpless and more like a spectator than a carer. We felt every health professional knew our son better than us, and bonding was difficult. This planned project really puts not only babies but babies and parents at the centre together. We would have liked to have more options and choices around his general care. “
Parents Focus group

“Having spent 14 weeks in hospital with Jessica I hope that I will have gained experience and insight that you can draw on. Jessica received outstanding care at both units but I knew it was time for her to go home when I started thinking that she would get better care at home, as she would be on a one-to-one with me 24/7.

No doubt these feelings would have started earlier if 'Family Delivered Care' had been available when I was on the unit.

It would have offset a lack of confidence, due to her being so tiny and having been cared for by professionals for so long, along with becoming somewhat institutionalised. “
Project strategy and plan

- Funding for 2 years from Imperial Charity:
  - Create training materials for parents
  - Develop a parent App, provide I pads
  - Paper parent binder, printed copies
  - Create training material for staff
  - 2 project co-ordinators
  - 1 psychology assistant

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Summary of project plan

Information about Integrated Family Delivered Care:

• Parents approached after delivery
• Parent Information Leaflet, introduction to the App and visit to the Low Dependency Unit
• Parents welcome to join the educational program/group activities at any time
• When infants are medically stable and transferred to the low dependency side of the units the parents can decide if they wish to participate (formally).
• Parents will be expected to stay 6-8 hours a day providing care to their babies.
Enrolment and training:

- Enrolled parents will receive more intensive training for a short period (around 2 weeks) from nursing and AHPs.
- Based on a prepared curriculum with 1:1 personal training, group exercises, competency assessments, and written and electronic material (website and App).
- Access to Ipads/printed version of training manual.
Summary of project plan

Providing on-going care:

• Parents who are trained will be the primary caregivers to their baby under supervision of the nurses for 6-8 hours every day.
• Involved equally in the team: presenting on WR, discussing plan
• They will help train newly enrolled parents
• Rolling programme of weekly parent education and support sessions.
Summary of project plan

After discharge:

Parents will have on-going support from

• neonatal outreach community team
• Next Steps Parent Group - MDT
• Veteran parents to participate in training sessions
**Parent App structure**

- No connection to patient data or any hospital system
- Parents can register with their name & email
- Data entry only by parents
- Handles multiples
- Functions:
  - Parents can document their journey
  - Diaries: personal, (milk)expressing, feeding, skin to skin, growth chart
  - Notes and Message functions
  - Developmental timeline and Glossary of terms
- Educational curriculum:
  - 15 chapters about neonatal care

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General Development

Your Baby born at this time weighs around 650 g and is about 34 cm long. Your Baby is extremely fragile at this point, and needs help from special procedures, medications and equipment. Your baby’s skin is not so transparent and fragile any more. It takes about 10 days for premature babies skin to completely mature after delivery.

Brain and Sensory development

Your Baby’s brain is growing dramatically and the majority of their energy will be used for this purpose. Your Baby’s primitive memory is developing now; this means that they can now learn to recognise your voice as distinct from others. Although the eyes can open now, light is still disturbing for them, so they tend to keep their eyes closed. He/she may be able to sense your movement, listen to your voice and the
Babies born earlier than 28 weeks are known as extremely premature. Extremely premature babies may require high level of intensive care. Almost all of the babies born this early still have immature lungs but they rarely require prolonged mechanical ventilation, but may need CPAP. Your Baby may have an immature immune system and be vulnerable to infections and other complications.

What you can do

Spend as much time as you can with your Baby, and learn to do cares around him/her. Avoid stroking movements and rather use a still, warm hand for calming. You can learn how to settle your Baby to sleep in a comfortable position. Touching and holding your baby helps you to build a loving relationship with them and helps their brain to develop and grow. Sing or read to your baby and watch him/her while sleeping.

Continue to focus on regular expressing. Breast milk is the best for your Baby and you can use milk for mouth cares. Once your Baby is medically stable, you should have long skin-to-skin sessions, which have several beneficial effects for you and your Baby. Give your baby a dummy to suck during tube feeds so they associate sucking with having a full tummy.

Come on the ward rounds and tell us about your Baby. Learn how to perform good hand hygiene and cleanliness.
1. Introduction to the Integrated family delivered neonatal care programme
2. Life in the Neonatal Unit
3. Routine Cares
4. Monitoring vital signs – nursing
5. Working together as a team
6. Medical conditions/interventions and progress of the sick or preterm infant
7. Ventilation – nursing
8. Fluids and nutrition – nursing
9. Making milk for your baby
10. Nutrition and Growth
11. Medication and Drug Chart
12. Developmental care: how to support your Baby’s development
13. Coping in the NICU
14. The Journey to suck feeding
15. Discharge planning and post discharge support

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### Learning

- Websites, electronic materials:
  - FIC programme, Mount Sinai Hospital, To [www.familyintegratedcare.com](http://www.familyintegratedcare.com)
  - Bliss: [www.bliss.org.uk](http://www.bliss.org.uk)
  - Best Beginnings, Small Wonders DVD: [www.bestbeginnings.org.uk/smallwond](http://www.bestbeginnings.org.uk/smallwond)
  - National Childbirth Trust: [www.nct.org.uk](http://www.nct.org.uk)
  - Infant Journal: [www.infantgrapevine.co.uk](http://www.infantgrapevine.co.uk)
  - Early Babies: [www.earlybabies.com](http://www.earlybabies.com)
  - Miracle babies Foundation: [www.miraclebabies.org.au](http://www.miraclebabies.org.au)

### Glossary

- Apnoea monitor
- Apnoea
- Aspirate
- Breast pump
- Blood gas
- BMF
- Birth weight
- Bradycardia (Brady)

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Testing: Parent user group feedback

“It is a lovely way to record the moments and memories especially when there is nothing you can take inside the ward other than your phone. I tried keeping a written journal but gave that up very soon as I had to wait till I get to the parents' room before I could do this and these obviously could not be attached to photos. I think the app will let parents capture their truest emotions in real time and the value of this in the later years when their babies can look back and see their journey is priceless, what a life story work that will be! “
Parent competencies

- Orientation
- Infection control
- Team work - documentation and communication
- Basic care skills
- Expressing milk
- Medication and drug chart
- Developmental care
- Feeding journey
- Discharge planning

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Outcomes and evaluation

We will investigate if this new care model

- improves parent experience
- reduces parent anxiety, stress levels and depressive symptoms:
- increases confidence in parenting skills
- increases parent infant bonding.
- Improves parental attachment

(HADS) (13) and MORS-SF (My baby questionnaire) refs 10,11

• Evaluate the education program: whether it meets the parents’ needs and if the delivery/training process was effective
• Evaluate staff training and feedback
Family Delivered care

Parents as partners in care

• Letting the parents in to be parents
• Listening (hearing and acting) on their experiences and views
• 100% involvement as a member of the team

There are no “difficult” parents, just scared parents trying to seek control
Parental Involvement in Neonatal Pain Management: An Empirical and Conceptual Update

Linda S Franck, RN, PhD, FRCPCH, FAAN\textsuperscript{1}, Kate Oulton, BN(Hons), MA\textsuperscript{2}, & Elizabeth Bruce, RGN, RSCN, BSc(Hons), MSc\textsuperscript{3}

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Parental involvement in neonatal pain management

![Diagram showing involvement levels from Uninvolved Parent to Involved Parent.]

- None
  - Views infant comfort as nurse or doctor role only
- Be Informed
- Be Present
- Provide comfort
- Be Advocate
  - Primary responsibility in partnership with clinical care team

Figure 1. Parental roles in infant pain management.
Figure 2. Model of parent involvement in infant pain management with illustrative opportunities, barriers and trajectories. Holes = opportunities for parental involvement; Shaded surfaces = barriers to parental involvement; Arrows = examples of trajectories of parental involvement.
The journey: close and loving relationships

- Attunement
- Attachment
- Ownership
- Confidence

fear to touch
- observing and watching
- initiating physical contact
- participating in caregiving
- confidence in caregiving
Attachment and bonding

• Essential to the positive parenting relationship

• The parent is the single constant in the child’s life – long after we are memories

• Parents are the “experts” in their babies characteristics and needs

• Key features: PROXIMITY, RECIPROCITY, RESPONSIBILITY
Building a Happy Baby:

Babies have a strong need to be close to their parents as it helps them feel secure and loved. When they feel secure they release the hormone oxytocin which helps their brains grow and helps them be happy babies and more confident children and adults. Holding, smiling and talking to your baby releases oxytocin in you too which makes them calm and happy.

MYTH:

Babies become spoilt and demanding if they are given too much attention

REALITY:

When babies needs for love and comfort are met they will be calmer and grow up to be more confident

“Parents presence is a medicine”
Piglet: "how do you spell love?"
Pooh: "you don't spell it, you feel it."
Shifting the nursing relationship
Therapeutic nurse-parent relationship

• Helping healing relationship
• Based on mutual trust and respect
• Delivery of sensitive individualised care
• Responding to the family’s physical emotional and spiritual needs
• Enables parents to be equal partners in achieving the families overall wellbeing

“Wish I could take you home with me”
“Mummies in blue”

“Thankyou for the support and education.
We’re ready to take our baby home”

CO-DEPENDENCE
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INDEPENDENCE
Implementing the “Theory of caring”
Jean Watson

“Being with”
• Accompany them on their journey in the NNU
• “be present” make yourself emotionally available
• Quality time is more important that quantity

“Knowing”
• Exploring, asking and listening, what is their personal reality?
• What does it mean to have a baby on the NICU
• Avoiding assumptions
Implementing the “Theory of caring”

“Doing for”
• Nurturing the parent infant relationship
• Facilitating meaningful interactions
• Teachable moments and anticipatory guidance

“Enabling”
• Reconnecting the parent and infant
• Validating the parent infant relationship – your son/daughter
• Help parents think through/makes sense of things
Implementing the “Theory of caring”

“maintaining belief”

• Believing in the capacity of the parents to rise above their present circumstances
• Believing in yourself colleagues ability to work/act in the best interest of your patient
• Maintaining a hopeful /positive attitude
• “going the distance”
Our Journey

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My Memories about Today's Skin-to-Skin:

Day 37: Today was the first time I held you, son. You instantly took all the pain I had away. I love you.

You are the strongest son I know. I am so proud of you.

Such a wonderful experience.

2/5/17

Seeing my husband have his first skin-to
son with his toddler son was an incredible moment.

First Cuddles
20-year Follow-up of Kangaroo Mother Care Versus Traditional Care

Nathalie Charpak, Rejean Tessier, Juan G. Ruiz, Jose Tiberio Hernandez, Felipe Uriza, Julieta Villegas, Line Nadeau, Catherine Mercier, Francoise Maheu, Jorge Marin, Darwin Cortes, Juan Miguel Gallego, Dario Maldonado

1993-96: short and mid term benefits on survival, neurodevelopment, breastfeeding, quality of mother infant bonding

2012-2014 62% of participants of original RCT were enrolled – results for 264 weighing <1800g analysed

Effects on IQ and home environment still present 20 years later; KMC parents more protective and nurturing; reduced school absenteeism, hyperactivity, aggressiveness and socio deviant conduct of young adults

Changes on neuroimaging
Thank you to all our families

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