Effectiveness of Family Integrated Care in NICU’s
Objectives

* To provide a brief overview of Family Integrated Care (FICare)
  * The philosophy
  * The practical aspects

* To share knowledge of our Canadian experience to date
“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.”

- Dr. Adik Levin

describing “humane care”

Parents are part of the team and their presence and their care is critical to their child’s wellbeing.

Parents have a role in decision making.

Parents need to learn how to take care of their baby and how to work with the healthcare team.

Parents parenting in the NICU!
Family Integrated Care (Pillars)

- Parent education and support
- Staff education and support
- Environmental supports
- Psychosocial supports
Providing experiences that enhance parents' control and independence and support their role as caregivers in the NICU

- Parent curriculum delivered in small group education sessions
- Coaching by bedside nurses
- Parent skill checklist/parent chart
- Parents presenting on rounds

Parent education: teaching parents what they do not know
Staff education: teaching staff to support families

- Administrative/leadership and commitment
- Providing staff education, support and tools so that staff can support families as they grow to become part of the team
  - Nursing education workshop curriculum
  - Staff/parent communication tools (parent chart, white board, skills checklist)
  - Ongoing staff education
- Parents/families were invited to collaborate in professional education of interdisciplinary team members
Psychosocial supports

- Peer to peer support
- Veteran parent support
  - group support or one-on-one support
- Group social work and midwifery support
NICU environmental supports

* Unit policies to support infant holding and mothers being present at their baby’s bedside
* Unit practices to support parent engagement
* Environmental support for prolonged parent/family presence at the bedside
  * chairs, breast pumps, parent rest space, food preparation area, parent meeting area, parent education space
Formal structure

- Steering committee with representation from all disciplines including veteran parents and nurses
- Workgroups with a parent lead in each group
- Administrative support and make sure that the project is aligned with the values of your institution
Engaging staff

- Build alliances particularly with front line staff
- Work through myths and truths of FICare
- Keep everyone informed
- Get feedback re how processes might work/challenges
- “How will this affect my work?”
- Do site assessment re educational needs/support required
- Develop a collaborative & responsive plan
- Do what you can with what you have
Coaching of parents by nursing staff

- Humanizing care
- Demonstrating and facilitating attunement to the infant
- Building a trusting relationship with the family
- Coaching parents how to become attuned to their infant with each caring moment
• Knowledge-Beliefs-Culture

• Best quality of medical care requires engaging families

• The infants well-being is dependent on the parent engagement

• Integrating families is key to delivery of family centered care
FICare Pilot Project

- Pilot start date: March, 2011
- Expected length of study: 12 months
- Number of patients needed: 40 patients

Location
- 4 bed spaces reserved in Level II FICare area

Time Commitment for Parents
- Minimum 8 hours each day - during day

Inclusion Criteria:
• < 35 weeks gestation
• On low level respiratory support
• A primary caregiver parent, willing and able to commit to spending 8 hours per day with their baby between the hours of 0700 and 2000.
• Parental consent

Exclusion criteria:
• Palliative care
• Severe congenital anomaly.
• Critical illness (unlikely to survive)
• Parental request for early transfer
• Parental inability to participate.
Challenges for staff

• The changed role of nurses
  • From doer to supporter
  • Partnership rather than control
  • Educator+++
  • Champion/advocates

• Unit culture shift
Challenges for parents

Parents understanding their role
Mother’s health, childcare, distance
Sustaining attendance at parent education sessions
Sustaining veteran parent support
Parents ability to attend rounds
Pilot study: Who were the parents who participated?

- 42 mothers (4 sets of twins)
- 17 (40%) had other children at home
- 22 (55%) were Canadian born; 11 lived in Canada >10 years
- All had at least grade 10 high school education;
- 27 (71%) were employed outside the home
- Varied in age from 23-45 years (mean 33 years)
Pilot Study: Key Outcomes

- Babies in the family integrated care group
  - 9% improved weight gain over the controls
- There was less nosocomial infection
- There was less ROP
- There were fewer incident reports
- Higher breast feeding rates
  - 85% of the infants went home on >90% breast milk
  - Most of those were actually breast fed on discharge
- Parental stress scores decreased significantly over time

**Hypothesis:** Infants whose families complete the FICare program will have greater weight gain and better clinical and parental outcomes compared with infants provided with standard NICU care

**Methods:** cRCT in infants born ≤33 weeks gestation admitted to 19 Canadian, 6 Australian and 1 New Zealand tertiary-level NICU

**April 1 2013-August 2015**

**Note:** Parental consent required for both arms

Inclusion:
- ≤ 33 weeks gestation
- Low level or no respiratory support
- Parent commitment to spend 6 hours per day between 7am and 8pm to enable attendance at rounds, 5 days per week
- Expected to stay 3 weeks in the program

Exclusion:
- Palliative care
- Major life threatening anomaly
- Critical illness unlikely to survive
- High level respiratory support
- Scheduled for early transfer
- Parent inability to participate e.g. health, social or language issues
Randomized (Sites) n=26: (19 CAN, 7 AUS/NZ)

Sites Randomized to FICare (n=14)
- 10 CAN and 4 AUS/NZ

Discontinued FICare (n=1)
- Poor site enrollment

FICare: 3012

Excluded (n=2117)
- Did not meet inclusion criteria (n=1223)
- Declined to participate (n=894)

FICare (n=895)

Discontinued FICare (n=155)
- Transfer/discharge/noncompliant n=115
- Death n=6
- Withdrawal n=34

Control: 2015

Excluded (n=1124)
- Did not meet inclusion criteria (n=969)
- Declined to participate (n=155)

Control (n=891)

Discontinued FICare (n=259)
- Transfer/discharge/noncompliant n=256
- Death n=1
- Withdrawal n=2

FICare*
- Analyzed n=895
- Excluded n=0

Control*
- Analyzed n=891
- Excluded n=0

*All patients enrolled in FICare were analyzed, even if FICare was discontinued
## Baseline Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Control</th>
<th>FICare</th>
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<tbody>
<tr>
<td></td>
<td>(N = 891)</td>
<td>(N = 895)</td>
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<tr>
<td>Sex, % (n/N)</td>
<td>53·8 (479/890)</td>
<td>55·7 (497/893)</td>
</tr>
<tr>
<td>Birth weight (g), mean (SD)</td>
<td>1264 (419)</td>
<td>1219 (413)</td>
</tr>
<tr>
<td>Weight at enrolment, mean (SD)</td>
<td>1442 (474)</td>
<td>1407 (382)</td>
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<tr>
<td>Gestational age group, % (n/N)</td>
<td></td>
<td></td>
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<tr>
<td>22 - 28 weeks’</td>
<td>42·3 (377/891)</td>
<td>49·7 (445/895)</td>
</tr>
<tr>
<td>29 - 33 weeks’</td>
<td>57·7 (514/891)</td>
<td>50·3 (450/895)</td>
</tr>
<tr>
<td>Age at enrolment (days), median (IQR)</td>
<td>12 (6 - 23)</td>
<td>15 (8 - 28)</td>
</tr>
<tr>
<td>Corrected gestational age at enrolment (weeks), median (IQR)</td>
<td>32 (30 - 33)</td>
<td>32 (30 - 33)</td>
</tr>
<tr>
<td>CPAP at enrolment, % (n/N)</td>
<td>50·4 (433/859)</td>
<td>49·9 (398/797)</td>
</tr>
<tr>
<td>TPN at enrolment, % (n/N)</td>
<td>44·2 (380/859)</td>
<td>38·8 (309/797)</td>
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<tr>
<td></td>
<td>Control</td>
<td>FICare</td>
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<tr>
<td>Maternal age (sd)</td>
<td>31.4 (5.5)</td>
<td>31.3 (5.5)</td>
</tr>
<tr>
<td>Employed outside home (%)</td>
<td>73%</td>
<td>77%</td>
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<tr>
<td>Married or cohabiting</td>
<td>91%</td>
<td>91%</td>
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<tr>
<td>&gt; 15 years education</td>
<td>64%</td>
<td>67%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>67%</td>
<td>74%</td>
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cRCT: Key Outcomes

- Babies in FICare
  - Gained weight faster than the controls
  - Were more likely to be completely breast fed (> 6 feeds) and fed at the breast
- Parental stress and anxiety scores were significantly lower in parents who enrolled in FICare than controls at day 21
- No significant differences in the secondary outcomes of mortality and morbidity
Lessons Learned

* Do with what you have
* Always say “Yes and....
* Project enabled by nurse and parent involvement and successful because of it
* Building resilience in families can have effects far beyond the NICU