Family Centered Neonatal Couplet Care: Scientific Context & Implementation in Practice

"The Karolinska Way"

Neonatal Couplet Care Conference
Manchester, NH, USA April 28, 2011

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Karolinska University Hospital
Stockholm, Sweden
Neonatal Family Centred Couplet Care

Continuous improvement & research for neonatology of the future

Changing the future for infants in intensive care
The ultimate objective of neonatology
Can developmental care help us to get there?
Figure 2. Serial MR Imaging of Brain Growth in a Normal Female Preterm Infant
Impact of rearing conditions during the neonatal period on adult brain function
Prematurity associated with medical conditions in adulthood:

**Hypertension**
- Edstedt Bonamy et al, Pediatric Research 2005
- Johansson et al, Circulation 2005

**Sympatoadrenal hyperactivity**
- Johansson et al, J Internal Medicine 2007

**Smaller vascular bed (capillary density)**
- Edstedt Bonamy et al, J Internal Medicine 2007

**Smaller aorta**
- Edstedt Bonamy et al, Pediatric Research 2005
- Edstedt Bonamy et al, Acta Paediatrica 2008 (1)
- Edstedt Bonamy et al, Acta Paediatrica 2008 (2)

**Smaller kidneys (normal GFR)**
- Rakow et al, Pediatric Nephrology 2008

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![Graph showing adjusted OR for diastolic and systolic blood pressure across gestational weeks.](image)
C-Section Affects the Genome

Titus Schlinzig, Mikael Norman et al.
Synactive Model of Developmental Care

Systems perspective

H. Als
Survival – live-born infants (n = 707) acc. to gestational age at birth JAMA 2009
Temporary parental benefit when the child is ill

60 + 60 days/ parent and year, can be extended if there is a life-threatening condition (~< 32+0 wks)

General parental benefit:
What is the scientific support, the level of evidence?
The Stockholm Neonatal Family Centered Care Study: effects on length of stay and infant morbidity

A Örtenstrand, B Westrup, E Berggren Broström, I Sarman, S Åkerström, T Brune, L Lindberg, U Waldenström

Karolinska Institute, Stockholm Sweden

Intervention:

True (?) family centered care
– parents could stay 24 / 7 from admission to discharge

- parents had a separate room in the unit from the first day.
- The infants moved from the “acute” room into the family rooms as soon as they reached a stable state.
Infants randomized into the study

Randomized infants
\[ n = 366 \]

- Allocated to family care: 183
  - with congenital disease: 2
    - Analyzed by Intention-to-treat: 183
      - Without congenital disease: 181
  - without congenital disease: 181

- Allocated to standard care: 183
  - with congenital disease: 5
    - Analyzed by Intention-to-treat: 182
      - Without congenital disease: 177
  - without congenital disease: 182

(1 infant death)
### Included infants

<table>
<thead>
<tr>
<th>Gestational age at birth</th>
<th>Family care n = 183</th>
<th>Standard care n = 182</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 – 29, n (%)</td>
<td>28 (15.3)</td>
<td>31 (17.0)</td>
</tr>
<tr>
<td>30 – 34, n (%)</td>
<td>102 (55.7)</td>
<td>103 (56.6)</td>
</tr>
<tr>
<td>35 – 36, n (%)</td>
<td>53 (29.0)</td>
<td>48 (26.4)</td>
</tr>
<tr>
<td>Pair of twins</td>
<td>21</td>
<td>24</td>
</tr>
</tbody>
</table>
## Length of stay in hospital

Adjusted for: gestational age at birth\textsuperscript{A}, non-Swedish-speaking background\textsuperscript{A,B}, setting\textsuperscript{A,B}

<table>
<thead>
<tr>
<th></th>
<th>Family care</th>
<th>Standard care</th>
<th>difference days</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 183</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All infants \textsuperscript{A}, mean</td>
<td>27.4</td>
<td>32.8</td>
<td>-5.3 (p = .05)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>By gestational age \textsuperscript{B}</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24 – 29 w, mean</td>
<td>56.6</td>
<td>66.7</td>
<td>-10.1 (p = .02)</td>
</tr>
<tr>
<td>30 – 34 w, mean</td>
<td>19.2</td>
<td>23.6</td>
<td>-4.4 (p = .16)</td>
</tr>
<tr>
<td>35 – 36 w, mean</td>
<td>6.4</td>
<td>7.9</td>
<td>-1.4 (p = .39)</td>
</tr>
</tbody>
</table>
Length of stay in *intensive care* (level II and level III)

Adjusted for: gestational age at birth\(^A\), non-Swedish-speaking background\(^A,B\), setting\(^A,B\)

<table>
<thead>
<tr>
<th></th>
<th>Family care (n = 183)</th>
<th>Standard care (n = 182)</th>
<th>difference days</th>
</tr>
</thead>
<tbody>
<tr>
<td>All infants (^A), mean</td>
<td>13.3</td>
<td>18.0</td>
<td>-4.7 d ((p = .02))</td>
</tr>
<tr>
<td>By gestational age (^B)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24 – 29 w, mean</td>
<td>32.4</td>
<td>43.1</td>
<td>-10.6 d ((p = .04))</td>
</tr>
<tr>
<td>30 – 34 w, mean</td>
<td>6.0</td>
<td>8.5</td>
<td>-2.5 d ((p = .02))</td>
</tr>
<tr>
<td>35 – 36 w, mean</td>
<td>1.5</td>
<td>2.5</td>
<td>-1.0 d ((p = .24))</td>
</tr>
</tbody>
</table>
## Infant morbidity

Adjusted for: gestational age at birth, non-Swedish-speaking background, setting

<table>
<thead>
<tr>
<th>Condition</th>
<th>Family care n = 183</th>
<th>Standard care n = 182</th>
<th>OR (95% CI)&lt;sup&gt;A&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verified Sepsis, %</td>
<td>7.1</td>
<td>9.8</td>
<td>0.68 (0.3-1.6)</td>
</tr>
<tr>
<td>Verified NEC, %</td>
<td>2.7</td>
<td>3.3</td>
<td>0.83 (0.2-2.8)</td>
</tr>
<tr>
<td>Diagnosed. PDA, %</td>
<td>15.3</td>
<td>16.9</td>
<td>0.90 (0.4-1.9)</td>
</tr>
<tr>
<td>IVH grade II-III, %</td>
<td>3.3</td>
<td>3.8</td>
<td>0.95 (0.3-3.2)</td>
</tr>
<tr>
<td>ROP stage II-V, %</td>
<td>2.7</td>
<td>6.6</td>
<td>0.34 (0.1-1.1)</td>
</tr>
<tr>
<td>BPD moderate-severe, %</td>
<td>1.6</td>
<td>6.0</td>
<td>0.18 (0.04-0.8)</td>
</tr>
</tbody>
</table>
# Ventilatory assistance and supplemental oxygen

Adjusted for: gestational age at birth, non-Swedish-speaking background, setting

<table>
<thead>
<tr>
<th>All infants</th>
<th>Family care n = 183</th>
<th>Standard care n = 182</th>
<th>difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory support n (%)</td>
<td>90 (49)</td>
<td>109 (60)</td>
<td>OR: 0.65 (0.4-1.0)</td>
</tr>
<tr>
<td>Mechanical ventilation days, mean</td>
<td>0.6</td>
<td>1.3</td>
<td>-0.7</td>
</tr>
<tr>
<td>CPAP, days, mean</td>
<td>6.5</td>
<td>8.7</td>
<td>-2.2</td>
</tr>
<tr>
<td>Supplimental oxygen days, mean</td>
<td>11.0</td>
<td>12.2</td>
<td>-1.3</td>
</tr>
</tbody>
</table>
Family care might operate through the common pathways of pain and stress

Parents in Family care may have a greater opportunity to co-regulate the caregiving with the needs of the infant

→ time the care-giving

→ Parental presence/skin-to-skin may contribute to better sleep organization
Conclusion

Family care in a level-II NICU, where parents could stay 24 hours per day from admission to discharge may reduce …

- length of stay for preterm infants
- bronchopulmonary dysplasia
Recent trials on post-discharge interventions which focus primarily on sensitive and responsive parent-infant interactions, infant development and self-regulation of infant primary functions as autonomic stability, motor and state organization and attention/interactive capacities – to organize the infant behavior in order to gain control over its own body and world around him.

The Norwegian / Tromsö RCT (Kaaresen et al Early Hum Dev 2008 & Pediatrics 2010)
- Modified Mother Infant Transaction Program
  - 1&2 years: reduced parental stress
  - 5 years: +½ SD in cognition

The Amsterdam IBAIP RCT (Koldewijn K, J of Pediatr)
- Infant Behavior Assessment Intervention Program (Rodd Hedlund)
  - 2 years: improved motor (PDI) and for the infants with “double risk” (low maternal education and BPD or abnormal cranial ultrasound also improved mental development (MDI)).
Results at corrected age of 3 years

Nordhov SM, Rønning JA, Dahl LB, Ulvund SE, Tunby J, Kaaresen PI.

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
<th>Crude Difference, Mean (95% CI)</th>
<th>Adjusted Difference, Mean (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=67</td>
<td>N=67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MDI mean (SD)</td>
<td>97.9 (11.1)</td>
<td>92.3 (15.6)</td>
<td>5.7 (0.9 - 10.5) .02</td>
<td>4.5 (-0.3 – 9.3) .06</td>
</tr>
<tr>
<td>≥100 n (%)</td>
<td>30 (44)</td>
<td>23 (34)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>85-99 n (%)</td>
<td>30 (44)</td>
<td>27 (40)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>84-70 n (%)</td>
<td>6 (9)</td>
<td>12 (18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;70 n (%)</td>
<td>1 (1.5)</td>
<td>5 (4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PDI mean (SD)</td>
<td>93.7 (13.6)</td>
<td>92.8 (14.5)</td>
<td>1.2 (-3.8 to 6.5) .6</td>
<td></td>
</tr>
<tr>
<td>≥100 n (%)</td>
<td>23 (35)</td>
<td>23 (35)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>85-99 n (%)</td>
<td>34 (51)</td>
<td>31 (47)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>84-70 n (%)</td>
<td>6 (9)</td>
<td>7 (11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;70 n (%)</td>
<td>3 (5)</td>
<td>5 (7)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Results at corrected age of 5 years

**Nordhov SM, Rønning JA, Dahl LB, Ulvund SE, Tunby J, Kaaresen PI.**


<table>
<thead>
<tr>
<th></th>
<th>Intervention (N = 66)</th>
<th>Control (N = 65)</th>
<th>Crude Difference, Mean (95% CI)</th>
<th>Adjusted Difference, Mean (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Full scale IQ (SD)</strong></td>
<td>102.3 (13.5)</td>
<td>95.6 (19.2)</td>
<td>7.2 (1.3 to 13.0)</td>
<td>6.4 (0.6 to 12.2)</td>
</tr>
<tr>
<td>&lt; 70, n (%)</td>
<td>1 (2)</td>
<td>6 (9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70 – 84, n (%)</td>
<td>2 (3)</td>
<td>11 (17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>85 – 99, n (%)</td>
<td>29 (44)</td>
<td>17 (26)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 100, n (%)</td>
<td>34 (52)</td>
<td>31 (48)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Verbal IQ (SD)</strong></td>
<td>102.4 (14.0)</td>
<td>96.3 (18.1)</td>
<td>6.2 (0.4 to 11.9)</td>
<td>5.5 (-0.3 to 11.3)</td>
</tr>
<tr>
<td><strong>Performance IQ (SD)</strong></td>
<td>101.3 (15.8)</td>
<td>95.3 (18.4)</td>
<td>6.9 (0.8 to 13.0)</td>
<td>6.3 (0.2 to 12.3)</td>
</tr>
</tbody>
</table>
Behaviour and mortality at 5 years

Subtests of the NEPSY test battery: activity and distractibility
Acta Paediatrica 2004;93:1-10

**Odds Ratio** for surviving …
(95% CI)

<table>
<thead>
<tr>
<th>Behaviour at five year follow-up</th>
<th>NIDCAP care</th>
<th>Conventional care</th>
</tr>
</thead>
<tbody>
<tr>
<td>normal</td>
<td>n=2</td>
<td>n=4</td>
</tr>
<tr>
<td>minor behavioural deficits</td>
<td>n=1</td>
<td>n=5</td>
</tr>
<tr>
<td>significant behavioural deficits</td>
<td>n=3</td>
<td>n=7</td>
</tr>
<tr>
<td>deceased</td>
<td>n=1</td>
<td>n=3</td>
</tr>
</tbody>
</table>

**NIDCAP / Control**

<table>
<thead>
<tr>
<th>with normal behavior</th>
<th>19.9 (1.1 – &gt;100)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>P-value</strong></td>
<td>0.04</td>
</tr>
</tbody>
</table>

Exact logistic regression correcting for gender, gest age, relative birth-weight, education of parents
Disability and mortality at 5 years

Acta Paediatrica 2004;93:1-10

Odds Ratio for surviving ... (95% CI)

**without disability**

14.7 (0.8 – >100)

P-value 0.08

Exact logistic regression correcting for gender, gest age, relative birth-weight, education of parents
Family centered
developmentally supportive
couplet care
at Karolinska

NIDCAP
is the foundation and standard of practice
NIDCAP

Newborn Individualized Developmental Care and Assessment Program
Family centered couplet care

- Minimize separation
- Support the parent’s confidence
- Facilitate bonding and attachment
Delivery and maternity at Karolinska-Danderyd

- Approx 10,000+ deliveries / year
  - 230 twins, 3 triplets
  - 400 born prematurely – 4.7%
- Planned C-sections: 16 beds for 26 c-sections/week
  - LOS: two days
  - week-ends closed
- Maternity and prenatal care: 24 beds
- Patient Hotel; 24 beds
  - Uncomplicated delivery admitted after 2-6 hours after delivery
  - Midwifes on each shift
Level II +

- Infants ≥ 27 gestational weeks
- INSURE (Intubation, Surfactant, Extubation), CPAP, chest tubes, catheters etc
- 24 beds for infants
- 8 beds for mothers in need of medical care – Couplet Care
- 12-14 infants in the Home Care Program
870 admissions – 8.5%
- 7.1% in the neonatal unit
- 1.4% in the maternity wards
  jaundice, hypoglycemia, Down’s Syndrome …
- 54 referred to Level III (6% of admitted, 5.3‰ of all born)
  - 12 for mechanical ventilation (1.3% / 1.2‰ of all born)
  - 6 for cooling (0.7% / 0.6‰ of all born)
- Perinatal mortality: 2.2‰
  stillbirths and deceased during first week
- Neonatal mortality: 0.3‰ (national 1.6‰)
  Live-born infants deceased during the first 28 days
Opportunities

- Minimized separation mother/father – infant
- Early skin-to-skin care
- Early parental involvement
- Early bonding
- Parents feel confident caring for their child → parents as primary care givers
- Parent’s presence enables more prompt responses / tuning in on the signals of the infant
- Positive effect on breastfeeding
Opportunities

- Parents feel secure/confident at discharge from hospital
- Early discharge → nurse visits in the home / home care
- A stimulating workplace: challenging and inspiring → staff satisfaction → staff continuity
Challenges

- A new way of working!
- ”Swapped” roles → parents as primary care givers
- The role of coaching instead of being the ”doer” → relationship based care
- Being flexible, willing to question routines
- Confidence in the monitoring system
- More time-consuming care??
- Integrity of the family
Challenges

- Extra need of planning one’s work
- Team communication
- How sick mothers can we care for?
Neonatal Family Centred Couplet Care

Continuous improvement & research for neonatology of the future

Changing the future for infants in intensive care

Opening symposium, Karolinska-Danderyd, 18 November 2009

http://web22.abiliteam.com/ability/show/khcichp/abbott_20101118/speed.asp
Opening symposium, Karolinska-Danderyd, 18 November 2009

In English at
http://web22.abiliteam.com/ability/show/khcichp/abbott_20101118/speed.asp

- Enter your name at “namn”
- Enter your e-mail
- Click “Visa” which means play.
  [it is not your credit card number!]
- Choose any presentation and enjoy it!