Family Participatory Care in India: Partnering with families to care for small and sick new-borns

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Year 2007

State of Newborn care

SETTING
• 16 bedded
• referral neonatal intensive care unit of north India
• Severe HR constraints

Incessant Alarms !!
Wet Babies!

Common scene outside the neonatal unit.....
Parent Attendants lined waiting............ !!

IV swellings!
Misplaced Tubes/probes!!
“Can we start ‘engaging ’ the waiting parent attendants as nursing aides for their own babies?”

WHAT DID WE SEE?

FRINGE BENEFITS!!!
- Parents
- Babies
- Nurses
Gaps: Conventional care

- Less Attention to
  - Sick babies’ development
  - Psychosocial needs of family

- Parental involvement in care/decision making is limited.

- Universal human workforce shortages: compromised QoC.

- Lack of continuum of care at home.
Family Centric Care: A Paradigm Shift

An approach, an attitude, a mindset, a concept that aims to develop and nurture family's role in partnership with health care team in care of a patient.

- NET outcome: improved health outcomes
- likely to be cornerstone of continuum of care
Family-Centered Care to Complement Care of Sick Newborns: A Randomized Controlled Trial

From Departments of Pediatrics and ^Microbiology, PGIMER and Dr. RML Hospital; ^Biostatistics, AIIMS; and
*Management Studies, IIT; New Delhi, India.

<table>
<thead>
<tr>
<th>Outcome variables</th>
<th>Control group (n=147)</th>
<th>Intervention group (n=148)</th>
<th>Mean difference (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Culture positive nosocomial infection rate</td>
<td>7.17</td>
<td>6.43</td>
<td>0.74 (-4.21, 5.6)</td>
<td>0.76</td>
</tr>
<tr>
<td>Culture negative nosocomial infection rate</td>
<td>9.86</td>
<td>10.56</td>
<td>-0.70 (-6.65, 2)</td>
<td>0.82</td>
</tr>
<tr>
<td>Duration of stay, median (IQR)</td>
<td>11 (7.18)</td>
<td>11.5 (7.17.5)</td>
<td>(0.042, 0.134)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Mortality, No. (%)</td>
<td>13 (8.8)</td>
<td>10 (6.8)</td>
<td>(0.59, 0.74)</td>
<td>0.5</td>
</tr>
<tr>
<td>Breastfeeding rate, No. (%)</td>
<td>98 (66.7)</td>
<td>119 (80.4)</td>
<td></td>
<td>0.007</td>
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</tbody>
</table>

No ↑ in Infection
↓Hospital stay
↑ Breast feeding
Audio-Visual Training Tool: 4 Modules

1- Entry Protocol

2- Developmentally Supportive Care
2- Developmentally Supportive Care contd...(Feeding)

3- Kangaroo Mother Care
4- Preparation for Discharge and care at Home
Institutionalising Family Centred Care: The Process

1. Induction at Admission & Identification of Primary Care Provider
2. Daily Trainings Scheduled
3. Demonstrations and Practice
4. Supervised Learning
5. Peer To Peer Learning
6. Independent Doing
7. Discharge Counseling
8. Continuum of Care at home
Aim: Getting *mother to participate in care of* their babies through acquired competencies

Lessons Learnt

- **Mothers:** Easy buy in!

- **Providers:** Challenges!!
  - Accepting P-A as a co-partner in care!
  - Diminished authority?
  - Watch Dog Effect!!
  - Tend to task shift!!
  - Expected to deliver a standard of care!!

Implementation: ‘HOW’

- Engaging in care
- Capacity building (trainings)
- Sensitisation
- A link for continuum for care after discharge
Measures & Attributes of Implementation
(June’16-July’17)

1. Measure of Implementation
   - Workspace readiness (Infrastructure-Facilities)
   - Parent/Attendant preparedness (Practices)
   - Staff preparedness (Attitudes)

2. Feasibility
   - 61% Males
   - 37% Fathers
   - 20% Grandparents
   - 41% > 50 years old
   - 25% Illiterate

3. Acceptability
   **Qualitative study (2016)**
   - Primary gains: (Empowerment, Skills, Continuum of Care)
   - Improved patient-staff relation

4. Measure of Quality of Care
   Participatopn of Mothers in Care in processes of care
   - Nesting,
   - Positioning,
   - Cleaning,
   - Skin to Skin Care
Country Scale up (2014- till date)......
To conclude, Family Centred Care ....

• A humane way to care.

• Creates an opportunity for lifelong bonding.

• Family’s right to a respectful care: (Need to protect, support & promote.)

• Operational feasibility & acceptability in Indian health care setting seem to be promising.

**Family Centred Newborn Care holds the key for developing social accountability of health that may help achieve Sustainable Development Goals.**
Acknowledgement

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• Our unit staff /doctors and RML Hospital