Family Support and Family-Centered Care in the NICU: Origins, Advances, Impact

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Objectives

• Understand the definition, purpose and philosophical underpinnings of Family-Center Care (FCC) in the neonatal intensive care unit (NICU);
• Explore current barriers and facilitators to delivery of FCC in the NICU;
• Identify where evidence exists that FCC practices improve family support, health care and outcomes;
• Recognize steps we can all take to increase and enhance FCC.
1870-1930: The Age of “Sideshows”

- The role of the incubator
- Initial results of hospital care
- Sideshows emerge
  - Continued emphasis on technology
  - Little parental involvement
1930-1965: Age of Exclusion

- Continued decline in home births
- Rise in artificial nutrition
- Concern about infection and sterility
- Increasing technology
- Increasing understanding of neonatal pathologies
- Strict hospital rules and policies = nurse as gatekeeper

1965-1980: Age of Awareness

- Recognition of attachment disorders
- Recognition of infant’s communication skills
- Birth of “environmental” neonatology and the role of the family
- Infant Stimulation: good or bad, too much or too little
1980-2009: Age of Enlightenment

- Recognizing the impact of FCC on baby outcome
- The birth of developmental care and the role of the family
- Understanding the role of the physical environment
- Joining forces
- Rapid development and promotion of:
  - Philosophy, concepts, and principles of FCC
  - Importance of family role
  - Best practices and potentially best practices
  - Evidence for specific components of FCC

Philosophy

Family Centered Care is...
An approach to medical care rooted in the belief that optimal health outcomes are achieved when patients’ family members play an active role in providing emotional, social, and developmental support.

AAP Committee on Hospital Care and Institute for Family-Centered Care, “Policy Statement on Family Centered Care and the Pediatrician’s Role” (2003)

1. Open and honest communication between parents and professionals
2. Parents need same facts and interpretation of facts as the professionals
3. In situations involving high mortality and morbidity risk, parents have the right to make decisions regarding aggressive treatment
4. Antepartum parents should be given information about adverse outcome risk and given right to state treatment preferences in advance.

Parents and professionals must work together to:
5. ...alleviate baby’s pain.
6. ...ensure appropriate NICU environment.
7. ...ensure safety and efficacy of treatments.
8. ...create programs and policies to promote parenting skills and maximum involvement.
9. ...promote meaningful long-term follow-up.

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Principles of FCC-Child & Family

1. Respecting each child and his or her family
2. Honoring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family’s experience and perception of care
3. Recognizing and building on the strengths of each child and family, even in difficult and challenging situations
4. Supporting and facilitating choice for the child and family about approaches to care and support
5. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family
6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
7. Providing and/or ensuring formal and informal support (e.g., family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood
8. Collaborating with families at all levels of health care, in the care of the individual child and in professional education, policy making, and program development
9. Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health
Core Concepts

- People are treated with **respect and dignity**.
- Health care providers communicate and share complete and unbiased **information** with patients and families in ways that are affirming and useful.
- Individuals and families build on their strengths through **participation** in experiences that enhance control and independence.
- **Collaboration** among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.

Institute for Family-Centered Care

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Delivery of FCC in the NICU

- NICU Staff
- Design/Physical Environment
- Other Parents
  - Parent Volunteers
  - Parent Support Groups
- Technology-based
  - Online
  - Videoconferencing
  - Computer stations
Components of FCC in the NICU

- Breastfeeding support
- Unlimited parent presence
- Kangaroo care
- Palliative care support
- Parent participants in care and decision-making
- Support of specific populations
- Transport support
- Sibling support
- Parent education seminars
- Bereavement support
- NICU staff support
- Family support activities (scrapbooking)
- Transition to home
- Information/materials
- Parents on rounds
An approach to medical care rooted in the belief that optimal health outcomes are achieved when patients’ family members play an active role in providing emotional, social and developmental support.

Family-Centered Care in the NICU

- What Do We Know?
  - Need for FCC
  - Implementation Models
  - Overall Impact of FCC in the NICU
  - Measuring Specific Components of FCC

- Are we Using What We Know?

- What More Do We Need to Know?
The Needs of NICU families


Implementation

Implementation models, best practices, and systems change

- AAP: Role of the Pediatrician
- Institute for Family-Centered Care
- March of Dimes NICU Family Support
- Family-Centered Care Map
- Vermont Oxford Network, NIC-Q
Components of FCC in the NICU

- Kangaroo Care (skin-to-skin holding)
- Supporting mothers in providing breast milk
- Supportive information
- Empowering activities
- Parenting Preterm Infants
- Parent participation in infant caregiving
- Parent education/readiness for discharge
- Parent-to-Parent support
- Designated, dedicated staff person
- NICU Design/physical environment

Impact of a family-centered care initiative on NICU care, staff and families. *Journal of Perinatology, 2007*

The effect of skin-to-skin contact (kangaroo care) shortly after birth on the neurobehavioral responses of the term newborn: A randomized, controlled trial. *Pediatrics, 2004*

Challenging the Precepts of Family Centered-Care: Testing a Philosophy. *Pediatric Nursing, 2000*

Reducing preterm infants’ length of stay and improving parents’ mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) Neonatal Intensive Care Unit Program: A randomized, controlled trial. *Pediatrics, 2006*

Evaluation and development of potentially better practices for improving family-centered care in neonatal intensive care units. *Pediatrics, 2003*

The Stockholm Neonatal Family Centered Care Study: Effects on Length of Stay and Infant Morbidity. *Pediatrics 2010*
March of Dimes: Champion for All Babies

March of Dimes helps moms have full-term pregnancies and healthy babies. *And if something goes wrong, we offer information and comfort to families.* We research the problems that threaten our babies and work on preventing them.

NICU Family Support® Core Program Goals

- Providing information and comfort to families during the NICU hospitalization of their newborn, during the transition home, and in the event of a newborn death
- Contributing to NICU staff professional development
- Promoting the philosophy of family-centered care in NICUs
March of Dimes NICU Family Support “changed our NICU culture”
--- Hospital Administrator Interview

81% of staff said that NICU Family Support resulted in more informed NICU parents

79% of staff said the program resulted in less stress on parents

75% of staff said that NICU Family Support resulted in increased confidence of parents at discharge
Changes after Implementation of NICU Family Support

- Open and honest communication between parents and staff
- Involvement of parents in decision-making
- Sharing information and the meaning of information with parents
- A partnership between professionals and parents in the provision of care
- The development of policies and programs to promote parenting skills and family involvement
Putting Evidence into Practice

Percent of NICU staff who consider kangaroo care highly effective in reducing parent stress: 73%

Percent of NICU staff who consider kangaroo care highly effective in providing comfort to parents: 80%

Percent of NICU staff who stated that kangaroo care was routinely performed in their units: 86%

Putting Evidence into Practice?

- Kangaroo Care (skin-to-skin holding)
- Supporting mothers in providing breast milk
- Supportive information
- Parent participation in infant care-giving
- Parent education/readiness for discharge
- Parent-to-Parent support
- Designated, dedicated staff person
Building the Body of Evidence

- Some components of FCC in the NICU have minimal to no research
- Population-specific research is minimal
- Information and outcomes about inequities is lacking
- Outcomes needing additional study:
  - Maternal health outcomes (especially subsequent preterm birth)
  - Family stability and security
  - Infant health outcomes (including rehospitalization)
  - Longer-term child health outcomes
- Site specific research
- Examination of financial and other resource implications
- Additional research needed even in well-studied areas

Actions You Can Take

- Examine...your own approach to FCC and its components
- Practice...what is demonstrated to work
- Innovate...by developing new practices to be evaluated
- Collaborate...through sharing and learning with other NICUs
- Build...the body of research and evidence for FCC in the NICU
References


References (continued)


References (continued)


