Disclosures

• I have no disclosures to make

Objectives

1. Learn about family-centered care in the NICU
2. Understand the importance of FCC
3. Steps to implement FCC
4. Looking forward “family-integrated care”
Hospitalization of Children

• Prior to the 1970s most hospitalized children were separated from their family/parents
• During the 1970s and 80s the importance of families role in the pediatric patient was recognized
• Slower to implement family involvement in the NICU
  ▪ Common for NICUs to still have “visiting hours”
  ▪ Closed multidisciplinary rounds
  ▪ Parents treated as visitors

What is Family-Centered Care

• Family-Centered Care is an approach to planning, delivering, and evaluation of health care that is grounded in mutually beneficial partnerships among families and health care providers.
  ▪ Family plays a vital role in ensuring the health and well-being of the patient
  ▪ Family needs to be seen as partners in making health care decisions
Why Family-Centered Care

- Multiple studies have indicated that parents
  - Feel disconnected with their baby
  - Unable to contribute meaningfully to their care
  - Doubtful of their ability to care for the baby once they are discharged
  - Feel like visitors in the NICU
  - Undermined (by staff) in their role as parents
  - Inconsequential in their infants well being

Principles of Family-Centered Care

- Respect and dignity
- Information sharing
- Core Concepts of FCC
- Participation
- Collaboration

Institute for Patient- and Family-Centered Care

Principles of FCC in the NICU

- **Respect** – each child and his or her family
- **Diversity** – honoring diversity
- **Strengths** – recognize and build on individual basis
- **Choice** – supporting and facilitating family choice
- **Flexibility** – policies and practices
- **Sharing** – honest and unbiased information
- **Support** – providing ongoing support
- **Collaborating** – all levels of healthcare
- **Empowering** – make informed choices

AAP policy statement

Guideline for Practice (NANN)

- **Family-centered care** is provided to the infant’s family
- The **role of the family** in the life of the hospitalized infant is irreplaceable and has an impact on lifelong physiological and psychological events.
- The family (as defined by the infant’s parents or guardians) has **unrestricted 24-hour access** to the infant and is provided the opportunity to parent and participate in care.
Respect and Dignity

• Health care providers
  ◦ Listen and honor family decisions and choices
  ◦ Listen and acknowledge family values, beliefs, and cultural background
  ◦ Incorporate families into the plan of care

Information Sharing

• Health care providers must communicate and share complete, unbiased information with families in ways that are affirming and useful
• Information needs to be timely, complete, and accurate to allow families to effectively participate in care and decision making

Families are more informed than ever before
Participation

- Families must be encouraged and supported in **participating in care and decision making** at the level they choose.

Collaboration

- **Families and providers collaborate** to create:
  - Policy and program development
  - Implementation and assessment of programs
  - Designing of health care facility
  - Professional education
  - Delivery of care

Steps to Creating a Family-Centered Care NICU

1. Assemble a team
2. Complete assessment inventory
3. Reflect on findings
4. Develop an action plan
5. Repeat assessment process
Team

- Team needs a **leader** who has some authority
  - Manager/director
- Team should be **multidisciplinary**
  - All staff should be represented
  - **Days** and **nights**
- Include a **family** if possible

Review and Reflect

- Take time to **review the findings** of the assessment.
  - Identify areas of strengths & weakness
  - Identify areas where leadership and staff agree and differ
  - Build on common ground
Develop Action Plan

- Plan should include
  - Both **short and long term goals**
  - **Establishment of a formal committee** to
    - Oversee and coordinate the change process
    - Encourage collaboration
    - Ensure that changes are directed at improving quality and safety

Repeat Assessment

- Assessment should be **repeated every 18 months to two years**
  - Review changes
  - Look at improving or adding to FCC practices

Areas of Focus

**Staff training**
- Parent education
- Parental participation in decision making
- Parent presence and participation in care-giving
- Family presence in the NICU
Staff Training & Education

- Study in Journal of Clinical Nursing found that nurses agreed that there are benefits to FCC in the NICU but that staff need “support, guidance, and education”
- Start in orientation if possible
- Find unit champions (super users)
- Formal education
- Have a plan to deal with staff who resist change

Parent Education

- Have a plan to let parents visit the NICU if anticipating a NICU baby
  » Birth advisor, trained nurses, LC, MD
- Honest information
- Use common language
- Ask parents about their background and experience and use that information to guide your education

Parental Participation in Decision Making

- Collaboration between medical staff and parents on how best to manage care
- Best if starts before birth
- Attendance at medical rounds
- Attendance at change of shift report
- Family meetings not just for bad outcomes
- Primary nursing
Infant Care

- **Parents involved** in everyday care (not just temperature and diapers)
- Unlimited **access to infant**
- **Presence** during difficult procedures
- Extended **skin-to-skin time**
- **Feedings** both bottle and breast

Family Presence in the NICU

- **Expand visiting hours** for extended family
  - Pre-screen young siblings
  - Coloring books/activity books for young children
- **NICU lounge**
  - A place for families to eat, make a call or rest
- **Support groups**

Bedside Report and Multidisciplinary Rounds

- **Explain the purpose** of rounds and report
- Develop practices that **respect privacy and confidentiality**
- **Structure the format and setting**
- **Clarify time**
- Model **open communication**
- **Education**
One NICU’s Journey to FCC

- 31 bed level IIIB NICU
- Open unit (no private rooms)
- Instituted multidisciplinary rounds with family presence approximately five years ago
- In January 2012 unit open 24/7
  - Parents are encouraged to remain at bedside and listen to change of shift report
  - Nursing staff would do bedside safety checks for alarm settings, fluids, lines, etc...

Barriers to Implementation Indentified by Bedside Nurses

We identified three common themes surrounding perceived barriers to implementing bedside shift report
1. HIPAA
2. Time
3. Sensitive data

HIPAA

- Intention of HIPAA was not to impede or interfere with communication between healthcare professionals and patients or their family
- Information that is overheard during normal hospital communication is NOT a HIPAA violation
  - Have risk management come and talk with staff to help clarify HIPAA
Time

- Nurses were concerned that families and patients would ask too many questions and this would increase the time spent during shift change
  - Discuss the purpose of shift change report prior to report, including the importance of not interrupting the nurses
  - Families should be updated prior to change of shift
  - Change of shift is NOT a time to discuss test results or new medication/treatments with the patient
  - Allow parents to op-out or to indicate they don’t want medical issues discussed with family members present

Discussing Sensitive Data

- Test results or labs that need to be addressed by the physician
- Sensitive issues such as drug abuse, family dynamics, etc...
  - Have a code work or phrase to indicate a need to discuss something outside the presence of the family/patient

The future
Family-Integrated Care

Jennifer Tano holds her son Thomas in the neonatal intensive care unit of Mount Sinai Hospital in Toronto on Wednesday, Sept. 11, 2013. Thomas was born premature at 27 weeks gestation. (THE CANADIAN PRESS/Galit Rodan)

Read more: http://www.ctvnews.ca/health/health-headlines/nicu-program-that-gives-parents-charge-of-baby-s-care-cuts-stress-1.1466866#ixzz2gDGwOV7e
How do you cook a frog?

Questions
References


References


Additional Resources

• Institute for Patient-and Family-Centered Care, 6917 Arlington Road, Suite 309, Bethesda, MD 20814. 301-652-0281. www.ipfcc.org

• National Patient Safety Foundation, 268 Summer Street · 6th Floor, Boston, MA 02210 Phone: (617) 391-9900. http://www.npsf.org/