

NICU Referrals and More.... The Emotional Rollercoaster of the NICU Family Experience



Trudy J. Esch, M.S., R.N.
Perinatal Nurse Consultant
Michigan Department of Community Health

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Objectives

1. State 3 challenges that a family may face when their baby is in the NICU
2. Describe 3 roles of the MIHP provider in assisting the family as they transition to their home with a NICU graduate
3. Recognize the social determinants of health impact on the NICU family

The NICU Experience

- “It’s a jungle out there! No matter how long you are in the NICU, it’s a marathon, not a sprint – pace your self, because it is an emotional rollercoaster.” (Family Advisory, n.d.)
- Non-normative transition to parenthood



The NICU Experience, cont.

- Babies are admitted to the NICU for a variety of reasons – some of the major ones listed:
 - Prematurity/lowbirth weight - multiples
 - Medical problems/Birth defects
 - Neonatal sepsis
 - Seizures or serious neurologic dysfunction
 - Significant birth injury
- Babies may be in the NICU for a short time (hours/days) or for an extended time (weeks/months)
- Some babies never make it out of the NICU
 - the first month of life is the highest percent of infant deaths;
 - the leading cause of infant death is prematurity/low birth weight followed by birth defects

THINK – PAIR – SHARE

Think of a family with a baby in the NICU.

- How does the family **FEEL**?
- What are the family **CONCERNS**?
- How do **SOCIAL DETERMINANTS** impact their experience?



Landing in the NICU

- Most families do not choose to have their baby in the neonatal intensive care unit (NICU)
- Their lives are suddenly turned upside down as they go from being excited to welcome their child into the world to suddenly spending their days worrying in the unfamiliar and intimidating environment of the NICU
- **SHARE:** How does the family **FEEL?**



How does the family FEEL?

- THIS WAS NOT THE PLAN that they had for their baby!
 - Grief for what should have been
 - Loss of the perfect delivery
 - Grief over the loss of the “perfect” baby
 - Adjustment of expectations/hope for child in the face of uncertainties
 - The anticipated homecoming is not what was expected



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- If the baby came very early the family may not be prepared for the baby yet
 - No Baby Shower
 - No Baby space designated
 - No diapers or other supplies
- **SHARE:** What are the family **CONCERNS?**



What are the family CONCERNS?

Traumatic & Overwhelming A Rollercoaster Ride



- The “perfect” baby the family dreamed about is suddenly in a unit full of machines, tubes and other equipment
- Families are faced with medical terms they may not understand
- Their baby has to go through tests, procedures and possibly surgery
- This tiny human is attached to IV’s and wires – maybe a ventilator
- The baby may be located on a separate floor of the hospital they gave birth in – or another city
- It can be weeks, even months before some parents can bring home their new baby



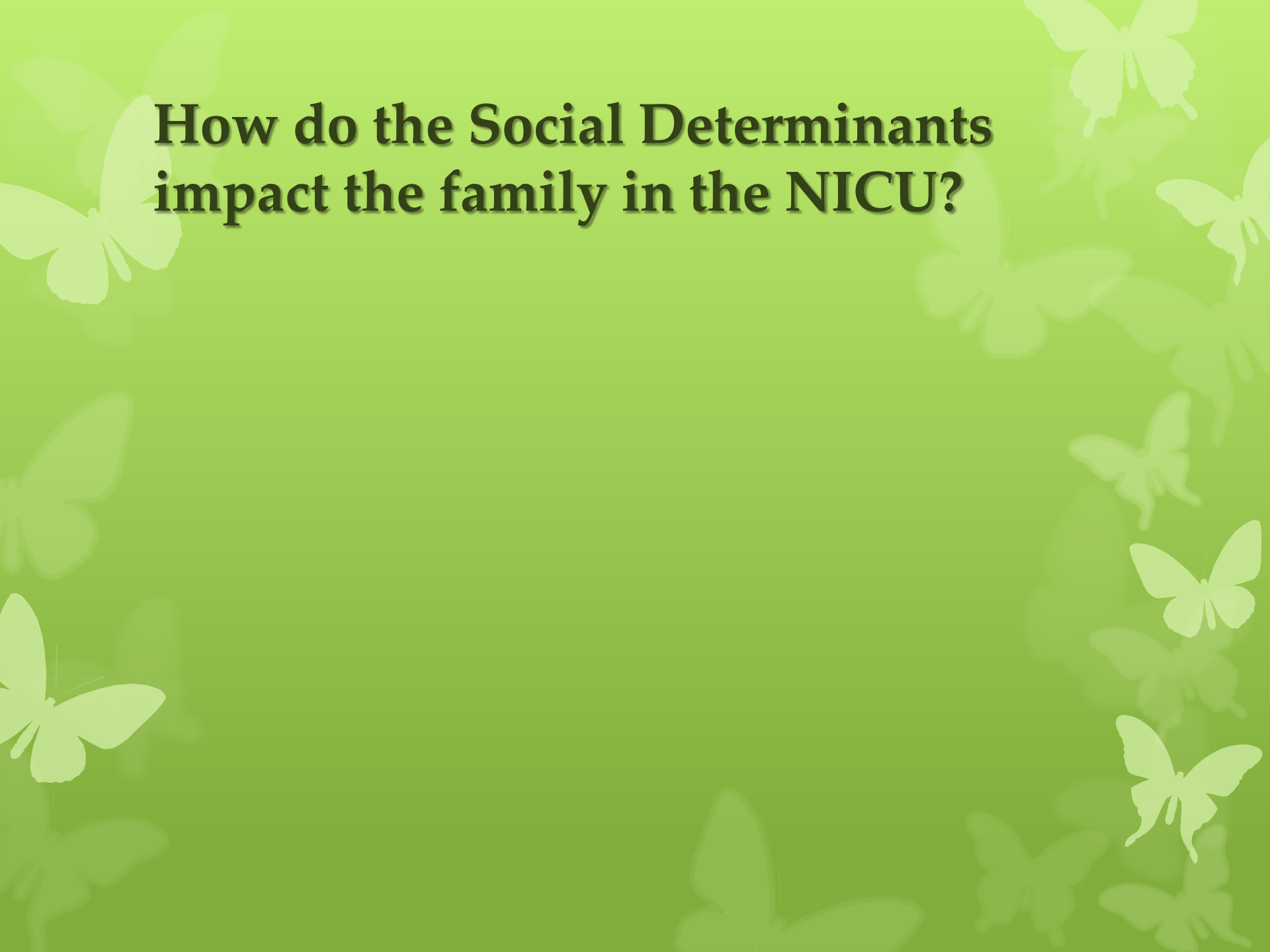
NICU becomes a second home

- Getting to the NICU can be a challenge
- Work, school and life schedules get interrupted
- Managing meals, and a place to sleep
- Being mindful of other siblings at home
- Some families live very far from the NICU that is “home” to their baby
- And life goes on...the bills have to be paid, the pets tended to, the lawn needs mowing...and so on



SHARE: How do SOCIAL DETERMINANTS impact their experience?

How do the Social Determinants impact the family in the NICU?



Mother's Role

- Momma has already faced leaving the hospital (being discharged) without her baby
- Momma is also recovering from birth herself
- Someone ELSE (i.e. the nurse) is the primary caregiver – even though helping with the baby's care or kangaroo care is encouraged



- Each mother may have her own comfort level or lack of comfort caring for her baby
- Mother's CAN pump their milk to give to their baby if the baby cannot go to the breast

Father's Role

- Father's traditionally are the “providers” in the family.
 - Returning to work while their baby is still in the NICU can be difficult
 - Unexpected expenses related to the NICU admission can be worrisome
- Father's have a dual role of caring for his partner who is recovering from birth and
- Father's also want to be involved in the care of their baby



Parenting Role

Obeidat, Bond & McCallister (2009) report:

- The admission of the infant to the NICU was a time mothers experienced shock and a sense of crisis
- the inability to perform “normal” parenting role is a source of distress
- the inability of parents to protect the infant from pain, helplessness, loss of control, fear and uncertainty are other sources of distress
- Factors contributing to parental satisfaction in the NICU include
 - Assurance
 - Caring communication
 - Appropriate pain management
 - Parental participation and proximity
 - Emotional, physical & spiritual support



Sibling's Role

- There is a lot of literature on the care of the sick child and how a well sibling may be overshadowed by the sick child
- The well sibling may not understand why mommy and daddy are not home as often as they used to be
- The well sibling may be left in the care of other relatives or friends – and even though their caregiver is beloved – it is not the same as mommy or daddy



Other challenges families face

- More than 50% of mothers in the state are single parents who may or may not have a support system
- Some parents will need to return to work/school while their baby is still in the NICU – this can be very challenging
- Having a baby in the NICU is a stressful situation which can make mothers more prone to postpartum depression and anxiety
- Having a baby in the NICU is expensive
 - Transportation to/from hospital
 - Having a place to stay if the NICU is a distance from home
 - Finding inexpensive meals

Family Centered Care in NICU

Research – Importance of individualized, family supportive developmentally supportive care in the NICU to enhance developmental and family outcomes

- NICUs utilize a family centered approach to care

- Treat families with dignity respect
- Share information
- Encourage family collaboration
- Facilitation family participation in care

- Berns, Boyle, Popper and Gooding (2007) report

- 78% of parents were as involved in the NICU as they wanted to be; yet 22% said they would have liked more involvement
- Satisfaction with involvement varied by gestational age. Parents with babies < 32 weeks were satisfied with their involvement (84%); while parents with babies 33-34 weeks had a 74% satisfaction rate



Among parents who were less involved in the NICU than they desired (Berns, etal, 2007), the top activies they wanted to be more involved with included:



- Holding their baby
- Knowing what tests were being done and why
- Bathing
- Nursing at the breast
- Changing diapers
- Kangaroo care
- Administering medications
- Holding the nasogastric tube during feeding
- Providing breastmilk

Transition to Home



- 37% of parents surveyed (Berns, et al, 2007) received preparation for the transition home throughout their infant's stay in the NICU; parents want more information and interaction opportunities
- NICU graduate parents need to be prepared for and to expect chaos when going home (advice from other NICU parents – parent handbook)
- Parents are not the primary care giver in the hospital – once they are at home, they WILL be the primary caregiver.
 - This is EXCITING news for parents.
 - This is FRIGHTENING news to parents.

More from the Literature

Research – Assisting primary caregiver (typically the parent) to understand the behavioral communication of their young infant

- Preterm birth, birth defects/disabling conditions and prolonged hospitalization are family stressors and risk factors for subsequent family dysfunction and child abuse (AAP, 2008)
- Meta-analysis of 14 studies – Home Visiting for preterm infants promotes improved parent-infant interaction and infant development (Goyal, Teeters & Ammerman, 2013)

Research – Identifies and defines regulatory disorganization as a risk factor for later developmental organization and cognitive function

- Regulatory disorganization – adaptive skills on **feeding, crying and sleeping**; children with any of these 3 may go on to have more cognitive and socio-emotional delays; family in a lot more stress (Brown, Feldman, Goldstein, 2012)

Research - Mental Health Needs of Parents who care for fragile infant. NICU is stressful. Maternal anxiety & depression impact dyadic interaction with baby.

- Parents may experience acute stress disorder when baby in NICU and may develop post traumatic stress disorder (Brown, Feldman, Goldstein, 2012)
- Unresolved grief related to a preterm birth is associated with the development of insecure infant-mother attachment (Shah, Clements, Poehlmann, 2011) (N=74)
 - Distortions of child's condition
 - Unrealistic expectations re child's prognosis
 - Continued search for reasons why child born prematurely
 - Remain "stuck in the past"
 - Emotional tone of reliving birth experience may be angry or overwhelmed
 - Post term age 9 months, nearly ½ mothers expressed unresolved grief regarding infant's preterm birth
 - Resolution of grief has a protective effect on the development of secure infant attachment



In order to assist NICU Moms

Look at your own reactions 1st

- Forming meaningful relationships with babies and families and witnessing their difficulties can be challenging
 - Acknowledge your feelings of sorrow
 - Face your own past losses / unresolved grief from your past
- Meet your own emotional needs & physical/health needs (nutrition, exercise, humor, tears)
- Caring for yourself 1st allows you to be free to support and encourage the NICU Mom



Wipe the slate clean



Each mom/family is different

Find a healthy balance in your relationships with parents

- Get close to families
- Set limits and boundaries
- Don't take on their problems
- Balance between involvement and detachment

This is their baby and their journey

**Have realistic expectations
for your work with families**



Common Elements for Home Care Plan

Hospital discharge for high risk neonate

1. Identification and preparation of the in-home caregivers
2. Formulation of a plan for nutritional care and administration of any required medications
3. Development of a list of required equipment and supplies and accessible sources
4. Identification and mobilization of the PCP, qualified home-care personnel and community support services
5. Assessment of the adequacy of the physical facilities within the home – a home environmental assessment
6. Development of an emergency care and transport plan
7. Assessment of available financial resources

(AAP, 2008)

**How do these elements fit with CARE
COORDINATION and the MIHP provider role?**

MIHP Provider Role – NICU families

If you are working with a mother who has a postpartum visit available.....

1. If the family is worried about caring for their baby once they get home, encourage the family to ask to room in with the baby in the NICU for 24 hours
 - Reminder: new parents often feel anxious and unsure.
 - Remember that parenting a NICU grad is different and challenging. It's natural to feel like a beginner, even as an experienced parent, as the parent learns how to meet baby's unique needs.
2. Encourage the family to ask for and accept help from family members and friends who would like to assist with household chores, providing meals, running errands, caring for older children or caring for pets

MIHP Provider Role – NICU families

3. Encourage the parents to have a “date night” before baby comes home
4. If they haven’t already, encourage the family to collect photos, footprints and other keepsakes from the NICU time
5. Anticipatory Guidance
 - Selection of pediatrician?
 - Car seat available and ready for baby to take the car seat challenge?
 - If the family plans on using childcare, begin to look at options for in-home versus out-of-home care while the baby is still in the hospital
 - Has mom taken care of her OB/GYN follow up appointment?
6. Be sure that the mother is taking care of herself. Mom needs to be well rested and ready to care for the baby when he or she comes home.

MIHP Provider Role – NICU families

Once the NICU graduate is home.....

1. Care coordination to provide ongoing multidisciplinary support of the family
2. If possible, identify at least 2 responsible caregivers
3. Remember families did not plan for their NICU admission. During the home visit assess the family home/environment
 - Baby space preparation
 - Baby supplies
4. Encourage the family to eat and serve simple, healthy meals such as cereal, soups, salads and sandwiches.

MIHP Provider Role – NICU families

5. Encourage parents to talk about their NICU experience
6. Support and facilitate the parental role. Find opportunity to praise mothers and fathers for things they do with their baby (must be worthy of praise) – parental empowerment – Boost her confidence, sense of control and feelings of connection to her infant and social support
7. Referral to individual or family therapy if
 - She thinks it may help her feel better
 - Her ability to cope with the situation is not improving and she feels stuck
 - She continues to find no joy in other parts of her life
 - She has trouble with her relationship with her partner or others close to her
 - She feels a parent support group isn't "quite enough"
 - She continues to feel detached from her baby
 - She has trouble getting out of bed or starting her day
 - She feels unable to cope or manage her other responsibilities
 - She thinks about harming herself or others

Resources

- Feeding Matters – Conquering pediatric feeding struggles to nourish healthy futures (Parents & families, Medical Community) <https://www.feedingmatters.org/>
- Fussy Baby Network – “If you’re struggling to care for a baby who is fussy, crying excessively, or has difficulties with sleeping or feeding, contact warm line for telephone support nationwide. <http://www.erikson.edu/fussybaby/>
- BABIES model (neurodevelopmental organization necessary during first few months)
 - B = Body Function (Biophysiologic Organization)
 - A = Arousal & Sleep
 - B = Body Movement
 - I = Interaction with Others
 - E = Eating
 - S = Self-soothing



GOAL:
NICU GRADUATES grow into healthy
& happy babies who survive and thrive



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Contact Information

Trudy Esch, MS, RN

Perinatal Nurse Consultant

Michigan Department of
Community Health

Washington Square Building – 3rd
Floor

109 West Michigan Ave

P.O. Box 30195, Lansing, MI
48909

517-241-3593

EschT@michigan.gov

Dawn Shanafelt, RN, BSN, BS

Perinatal Nurse Consultant

Michigan Department of
Community Health

Washington Square Building – 4rd
Floor

109 West Michigan Ave

P.O. Box 30195, Lansing, MI
48909

517-373-4411

ShanafeltD@michigan.gov