

## Family Perspectives on Developmentally Supportive & Family Centered Care and Transitions to Home

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## Financial Disclosures

- Debra Paul, OTR/L
- None that are relevant to this content



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## Objectives

1. Describe the stressors parents experience in the NICU and with the discharge to home.
2. Identify supports for families to facilitate smooth transition from NICU to home.
3. Describe supportive interventions to strengthen the parenting role.



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### Getting ready to go home

- Meeting elements of discharge criteria
  - Preterm infant's ability to successfully oral feed is one of final challenges infant must meet.
- As discharge to home gets near, parents question their ability to care for their infant without support of NICU staff and technology.
  - Transitioning from highly supportive environment to an isolated home environment.



Jefferies, 2014

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### Going home



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### Transition

- Period of vulnerability associated with changes in health status, role, realities and expectations.
  - Studies have shown overexposure to stress can leave body in weakened state which may impair learning, memory, and ability to act and have negative impact on cognition.



Raines, 2013

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### Addressing stress

- Descriptive survey study examined occurrence and areas of stress experienced by mothers as they prepared for discharge from NICU to home.
  - All mothers in the survey experienced stress leading up to their infants' discharge with most significant stress related to their ability to assume parent role.



Raines, 2013

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### Leaving the NICU

- Where did my resources go? In the NICU there were specialists available to intervene.
- Reality sets in and relief turns to apprehension
  - Uncertainty and trepidation
  - A sense of being overwhelmed
  - Fear
    - What I do if...?
    - Am I prepared for...?
    - Not sure what to expect...?



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### Parents assume primary responsibility for feeding once home

- Families are often ill prepared to manage feeding difficulties.
- Critical when parents are in the NICU that they are provided multiple opportunities to practice feeding and engage in other caregiving interactions with their baby.

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### Preparing parents for possible challenges



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### Feeding the preterm infant following discharge

- Study by Reyna, et al, (2006) examined mothers' perceptions of their experiences with feeding in early weeks following discharge.
  - Themes that emerged included:
    - interpreting infant behaviors, managing the feeding process, and realizing knowledge gaps



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### Findings

- Mothers in the study struggled initially until feeding behaviors became more predictable.
- Focus on anticipatory guidance in NICU critical including communication on expected changes in feeding habits over first 2 to 3 weeks infant at home.



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### Promoting a successful transition

- Discharge teaching
  - Discussion of scenarios to help with decision making
  - Understanding feeding process
  - Setting up home environment to support infant's adjustment to demands of feeding once home
- First week at home
  - Weight check(s)
  - Evaluation of feeding and infant's feeding abilities



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### Laying the foundation for positive outcomes

- Early identification of infants with special needs helps to provide appropriate medical, psychosocial, financial, and preventative services.
- System for early identification and referral to community services relies on the healthcare provider and/or family.
  - Essential in prevention of many health and developmental consequences.

Browne & Deloian, 2007

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### How do we ensure smooth transition home?

- Components of successful transition
  - Communication between healthcare providers & family
  - Home visits
  - Infant assessment/parenting skills
  - Education (variety of formats)
  - Support groups



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## A new journey begins...

Bringing home a medically complicated infant has a significant impact on a family's home life.



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## Post-discharge from the NICU

- Impact of NICU stay
  - Shortened NICU stays can result in infants going home with unresolved medical problems.
  - Earlier discharge of children with special health care needs leads to families needing closer and more frequent follow up. (Purdy, et al, 2015)
- Challenges parents are faced with include:
  - transitioning to a pediatrician
  - daily management
  - impact on family and friends
  - re-hospitalization
  - financial concerns (Maroney, 1995)

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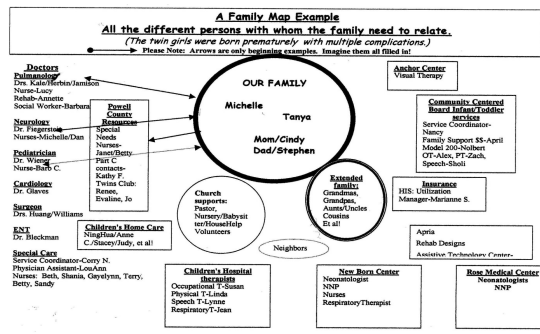
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## Navigating Complex Care Systems



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### Needs of parents of multiples underestimated

- Parents may juggle care of critically ill babies and healthy babies simultaneously.
- Parents of multiples require additional advice and information.
  - This help is often delayed or inadequate.




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### A Parent's Story

"Our biggest challenge was feeding her, and unfortunately I was the only person who could consistently get her to take the bottle. The pressure and responsibility I felt over her feedings literally made me sick with worry that she would wither away into nothing. Most days we would spend anywhere from 6 to 9 hours engaged in some type of feeding battle. Of course, I rarely won the fight. I was physically exhausted and emotionally drained pretty much all of the time. Finally after four straight months of her losing weight, my husband and I made the heartbreaking decision to have g-tube surgically placed...thankfully, it was probably the best decision we have ever made."



Mother of a child with feeding issues

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### NICU experiences: Lessons learned and advice to clinicians

- Parents experience both negative and positive impacts after the NICU experience.
  - The information we share and how it is delivered matters.
- Help parents prioritize their energy, e.g. recognizing what they can and cannot control.
- Life will not always be like this...the roller coaster will become a train with a known destination.

Janvier, et al, 2016

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“Understanding the parent-infant needs is essential to support healthy parent-infant relationships during the early years of the infant’s life both within the NICU and post discharge”.



Purdy et al. 2015

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### Partnering with parents

- Remember, every family has a story.
  - When a problem arises, or when families have questions, they need to be listened to and to be believed.
  - Guide and follow the family in their journey.
- Put families in contact with the right people and the right resources



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### Making it work

- Follow the parent’s lead and support parental expertise.
  - suspend judgment
  - parents need to believe they are the expert of their child
- Promote active involvement of **all** family members.
  - Recognize impact of having an infant with special health care needs on family dynamics



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### Making it work

- Sharing of information and how it is presented can help to build a trusting relationship.
  - Your words matter!
- Don't be offended if you offer support and families don't take it...they may have other priorities.
  - Check in with families at a later time...they may be in a place where the information is accepted and can move forward.



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### Making it work

- Engage in observation & offer descriptive affirmation.
  - Share positive thoughts
- Provide developmental interpretations in a meaningful way.
  - Ask questions: "Does this make sense?"



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### Making it work

- Be aware of the dilemmas, disappointments and devastation parents may experience.
  - Sometimes the outcomes are not what we wanted or expected.
    - As healthcare providers, we can help create meaningful moments.
- Don't underestimate the power of just "being there" for the families.



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### Making it work

- Anticipate needs of bereaved parents of multiples-follow up especially important
  - Minimize family distress
- Family may need help working out logistics with hospitalized infants and infants who have gone home



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### Parent perspective

- What I might need:
  - follow up when my baby goes home, especially if there are early signs of feeding problems, or problems with state organization and regulation;
  - create a place where I feel safe describing my experiences, thoughts and feelings-ask me how we are doing and what has been going on;
  - give me time to review the information and then follow up with me to see if I have questions;
  - when you have seen progress, remind me of this;
  - help me to see my baby's progress; and
  - be a coach and champion for me!



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“By preparing parents in the NICU for possible difficulties after discharge and identifying prospective sources of support, professionals can give parents an advantage in coping the first year.”



Maroney, 1995

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A parting thought..

*"We can be there for parents at tough moments or avoid them. Be there".*



Janvier, et al, 2016

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Thank you!

*When we take the time to try and walk in the parents footsteps we can be instrumental in bringing perspective and joy to a challenging experience.*



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References available upon request



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