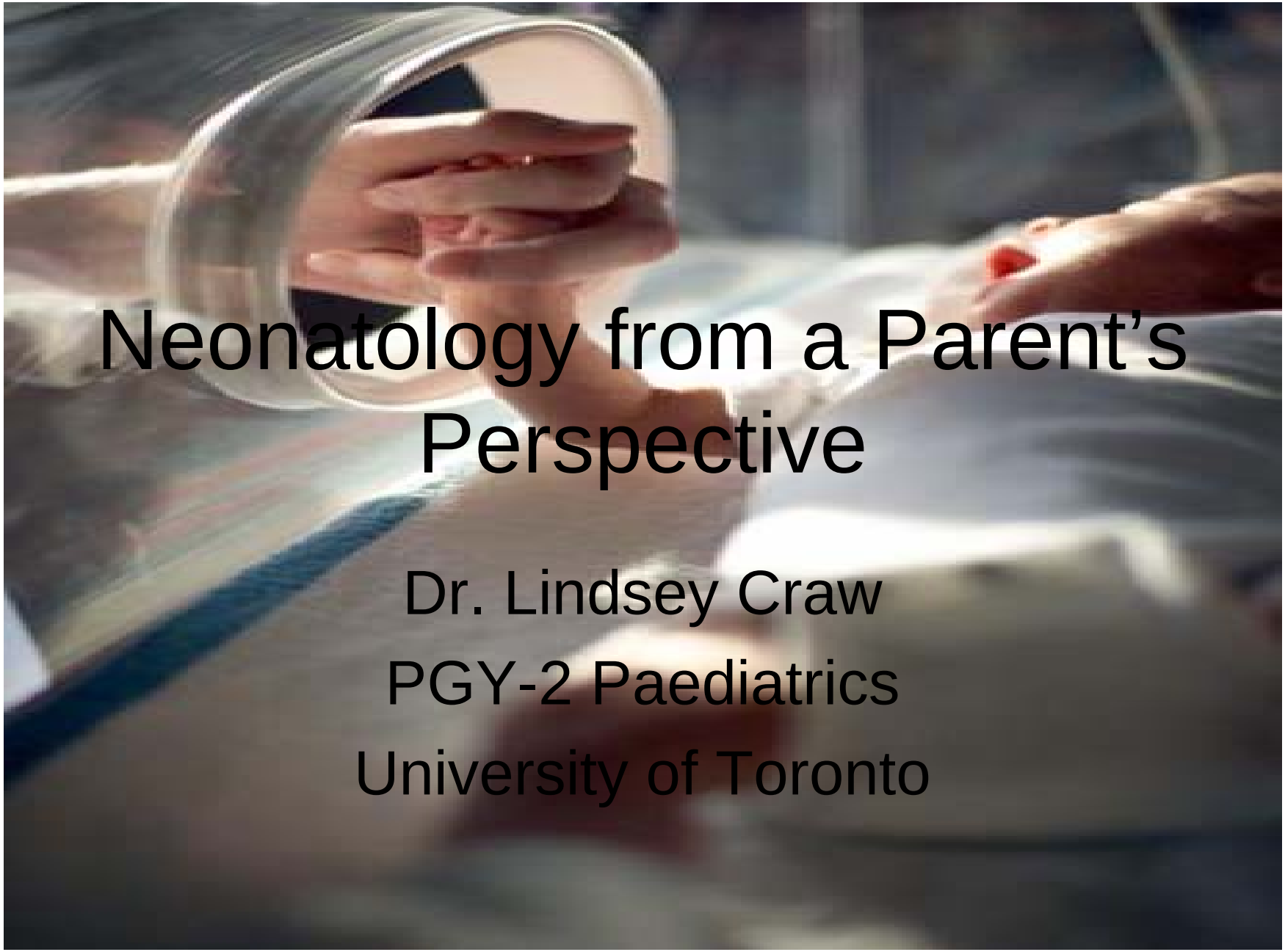

Neonatology from a Parent's Perspective

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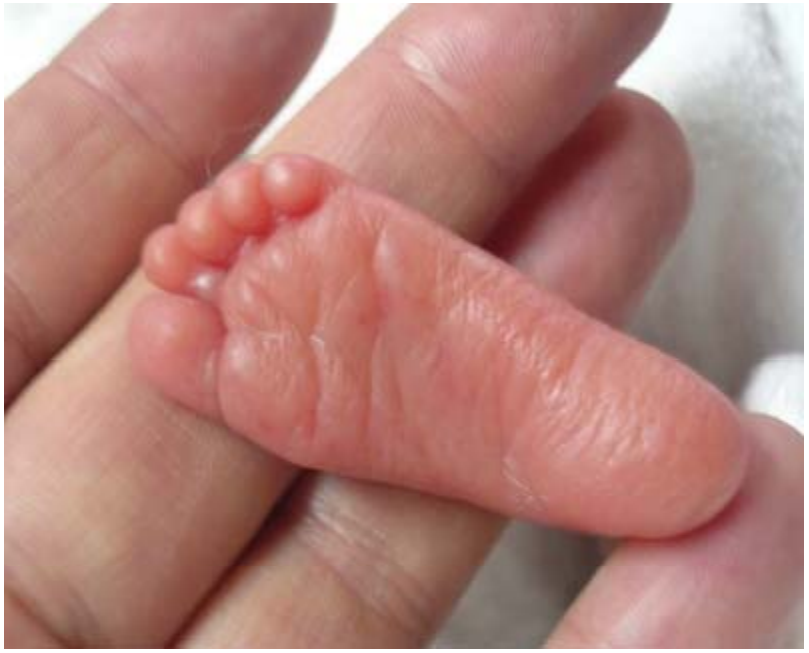
Objectives

1. To understand the parental perspective of having an infant in the NICU
2. To consider how the experience may be unique for fathers and adolescent parents
3. To appreciate the financial burden families face
4. To look at end-of-life decisions from a parent's perspective
5. Suggestions for improving the parental experience



A Change in Expectations

Your Expectation

Your Reality

Sources of Parental Stress

- Personal and family stressors
- Prenatal and perinatal experience
- Infant illness and appearance
- Concern about outcome
- Feelings of guilt
- Sadness over a lost dream
- Loss/alteration of parental role
- Not getting to “know” the baby
- Separation from their child
- Alienation/sense of not belonging/loneliness
- Being unprepared
- Ineffective communication with healthcare providers

The Maternal Perspective

Aagaard & Hall (2008)

- Metasynthesis of 14 qualitative studies
- Mothers' experiences of having a premature infant in the NICU
- 5 Themes emerged

Themes

1. **“From their baby to my baby”**
   - Feeling like a stranger or visitor to becoming an engaged mother and partner
   - Fearing attachment to the new baby
   - Developing a concept of “my baby” through seeing, touching, skin-to-skin and supplying breast milk

2. **“Striving to be a normal mother”**
   - Delayed development of maternal identity
   - Separation leads to feelings of guilt and abandonment
   - Participating in care and decision making contributes to the sense of being a “mother”

3. **“The neonatal environment: from foreground to background”**
   - Frightening, busy, crowded, noisy environment of the NICU
   - With increased comfort, focus shifts to the baby and the NICU is in the background

4. **“From silent vigilance to advocacy”**
   - Caregiving develops from passive to active (touching and holding -> feeding and diapering)
   - To reclaim the role of “mother”, they learn as much as possible about their infant’s condition and treatment and become the “expert” on their child

5. **“Mother-nurse relationship: from answering questions to chatting to sharing knowledge”**
   - Initially seeking to acquire knowledge through asking questions
   - The mother-nurse relationship is strengthened through “chatting”
   - With an increased sense of maternal competence, she becomes the expert on her baby

Maternal Perspective

- **Wigert *et al.* (2006)**
  - Qualitative study interview study of 10 mothers
  - Asked: “Please describe your experience when your child was cared for in a NICU”
  - 3 themes emerged

Themes

1. **“Feeling of interaction”**
   - The need for communication, information and trust to understand the situation
   - When continuous information was provided, confidence in caregivers developed
   - Feeling understood and treated as an individual was part of this confidence

2. **“Feeling of belonging or not belonging”**
   - Did not belong on the post-partum floor or in the NICU
   - There was no bed or place for mothers in the NICU –> feeling unwelcome
   - Impossible to be alone with their child

3. **“Maternal feelings”**
   - Powerlessness
   - Insufficiency in not being able to care for their child by themselves
   - Feeling of not being the “mother”
   - Feeling that the child belonged to the caregivers

Parental Perspective

- **Cleveland (2008)**
  - Systematic review of 60 studies
  - To answer the following:
    - A) What are the needs of parents who have infants in the NICU?
    - B) What behaviours support parents with an infant in the NICU?
  - 6 needs and 4 behaviours were identified

Needs

1. **“A need for accurate information and inclusion in the infant’s care and decision making”**
   - Parental distress was associated with receiving inaccurate and/or incomplete information
   - Contradictory information lead to confusion, decreased trust in the healthcare team and increased parental anxiety

2. **“A need to be vigilant and watch over and protect the infant”**
   - Wanted to oversee the infant’s care but as trust increased this watchfulness relaxed

3. **“A need for contact with the infant”**

4. **“A need to be positively perceived by the nursery staff”**
   - Feared being labelled as “difficult” and felt the need to conform to the “good mother” role

5. **“A need for individualized care”**

6. **“A need for a therapeutic relationship with the nursing staff”**
   - Mothers saw nurses as “gatekeepers” between themselves and their infants
   - Parents identified nurses as their primary source of information

Behaviours

1. **“Emotional support”**
   - Nursing support
   - Support from other parents

2. **“Parent empowerment”**

3. **“A welcoming environment with supportive unit policies”**

4. **“Parent education with an opportunity to practice new skills through guided participation”**
   - COPE (Creating Opportunities for Parent Empowerment) intervention by Melnyk *et al.* (2006)
   - 4 sessions educating parents about the appearance and behaviour of preterm infants and specific activities to practice at the bedside
   - Results: More positive parent-infant interaction and parenting beliefs, less maternal stress, anxiety and depressive symptoms and 3.8 day shorter NICU stay

What About Fathers?

Johnson (2008)

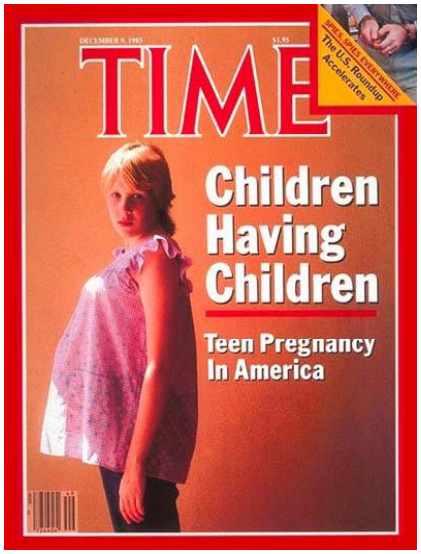
- Most studies have looked at the experience of mothers
- Mothers need a sense of responsibility and control in caring for their infant
- Fathers need confidence in the health care team
- Loss of control was a major obstacle for some fathers
- Fathers have a sense of responsibility to return to work (coping mechanism)

•Without support and encouraging participation, fathers can become distanced from the family

•Fathers should be involved in hands-on care

•Ward (2001): Fathers ranked assurance and information needs as less important than mothers but there were no differences in terms of comfort and proximity needs

What About Teen Mothers?



Boss *et al.* (2009)

- 42 teen (<21 y.o.) mothers interviewed
- Assessed understanding of the diagnoses, treatment and illness severity and who they spoke to from the medical team
- Results: 60% showed poor knowledge of either their infant's illness severity, treatment or diagnosis
- Greatest misunderstandings involved estimates of illness severity
- 46% of neonates were in "critical condition" but only 17% of mothers thought their infant was "very sick"
- Adolescents who reported speaking with a physician were less likely to accurately assess the severity of their infant's illness (48 vs. 82% p=0.03)
- Maternal age and educational level were NOT associated with improved knowledge of illness severity
- Teens reported reluctance to ask health care providers to clarify technical language

Financial Considerations

Argus *et al*. (2009)

- Prospective case series of 59 families with babies in the NICU for at least 2 weeks in Melbourne Australia
- Results:
  - Considerable financial burden on families who have a baby in the NICU.
  - Costs are ~ 25% of the family's average gross weekly income
  - Greatest costs are attributable to food and transportation
  - 39% of families experienced a loss of income secondary to pre-term delivery of their infant

What About End-of-Life Decisions?

Brinchmann *et al.* (2002)

- Interviewed 35 parents about their participation in end-of-life decisions

- Summary:
  - Wanted to be part of the decision making but not to make the final decision
  - They felt they lacked the necessary medical knowledge and experience
  - Doctors carry the responsibility of making the final decision
  - Should be well-informed, listened to and if possible, told at a time when they are ready to receive the information
  - Wanted to be considered as individuals
  - Parents have to live with the consequences of the decision
  - Main concern was how doctors communicated with them and how the information was presented

What is Important to Parents

- Continuity of care
- Individualized care
- Consistent and effective communication
- Relationships with healthcare providers
- Parental involvement

- In a study by Reid *et al.* (2007):
  - 36% of parents could not identify a staff person whom they felt they could talk to
  - 25% felt they could not ask too many questions
  - 29% identified a lack of privacy which stopped them from having discussions with the staff

An Intervention to Increase Parent-Provider Communication

Weiss *et al.* (2009)

- Serial cohort study to determine if a targeted intervention improved the satisfaction of parents with provider communication
- Intervention: (1) Education module for medical providers, (2) Contact card for parents with medical providers names, job descriptions and contact information, (3) Poster of faces, names and titles of medical providers on display at the entrance
- **Results:**
  - Overall satisfaction increased after the intervention ($p<0.01$)
  - Families reported more communication with medical providers at the time of admission to the NICU ($p=0.01$)
  - 65% of families pre-intervention wanted more frequent communication compared to 36% of families post-intervention ($p=0.01$)
  - More parents reported that providers were available when they wanted to talk ($p<0.01$)
  - More parents felt that providers understood their concerns about their baby ($p<0.01$)

Family Centered Care

“Acknowledging the central role that the family plays in a child’s life and incorporating practices, policies and programs that support the family”

9 Principles:

1. Recognizing the family as a constant in the child’s life
2. Facilitating parent-professional collaboration
3. Honouring racial, ethnic, cultural and socioeconomic diversity
4. Sharing complete and unbiased information on a continuous basis
5. Responding to the child and family developmental needs as part of healthcare practices
6. Encouraging and facilitating family to family support and networks
7. Adopting policies and practices that provide families with emotional and financial support
8. Designing healthcare that is flexible, culturally competent, and responsive to families
9. Recognizing family strengths and individuality and respecting different methods of coping

Suggestions to Improve the Parental Experience

- One-on-one orientation to the NICU upon admission of their infant
- Minimize separation between mother and baby
- Give consistent information and include parents in decision making
- Help the mother feel that the baby is “hers”
- Guided participation to allow the mother to care for her baby whenever possible to promote bonding
- Accommodate parent’s emotional needs
- Staff should be knowledgeable, caring and approachable
- Seek opportunities to create meaningful moments
- Chatting with parents

THE END!

References

- Aagaard, H. & Hall, E.O.C. (2008). Mothers' experiences of having a preterm infant in the neonatal care unit: a meta-synthesis. *Journal of Pediatric Nursing.* 23(3): e26-36.
- Argus, B.M., Dawson, J.A., Wong, C., Morley, C.J. & Davis, P.G. (2009). Financial costs for parents with a baby in the neonatal nursery. *Journal of Paediatrics and Child Health.* 45: 514-517.
- Boss, R.D., Donohue, P.K. & Arnold, R.M. (2009). Adolescent mothers in the NICU: how much do they understand? *Journal of Perinatology*. 1-5.
- Brinchmann, B.S., Forde, R. & Nortvedt, P. (2002). What matters to the parents? A qualitative study of parents' experiences with life-and-death decisions concerning their premature infants. *Nursing Ethics*. 9(4): 388-404.
- Cleveland, L.M. (2008). Parenting in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic and Neonatal Nursing*. 37: 666-691.
- Johnson, A.N. (2008). Engaging fathers in the NICU: taking down the barriers to the baby. *Journal of Perinatal and Neonatal Nursing*. 22(4): 302-306.
- Reis, M.D., Scott, S.D. & Rempel, G.R. (2009). Including parents in the evaluation of clinical microsystems in the neonatal intensive care unit. *Advances in Neonatal Care*. 9(4): 174-179.
- Ward, K. (2001). Perceived needs of parents of critically ill infants in a neonatal intensive care unit (NICU). *Pediatric Nursing*. 27(3): 281-286.
- Weiss, S., Goldlust, E. & Vaucher, Y.E. (2009). Improving parent satisfaction: an intervention to increase neonatal parent-provider communication. *Journal of Perinatology.* 1-6.
- Wigert, H., Johansson, R., Berg, M. & Hellstrom, A.L. (2006). Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scandinavian Journal of Caring Sciences.* 20: 35-41.