

THE LIVED AND EDUCATIONAL EXPERIENCE OF MOTHERS HAVING AN INFANT WITH NEONATAL JAUNDICE (NJ)

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BACKGROUND AND SIGNIFICANCE

- NJ occurs in 80% of preterm infants (<37 weeks) and 60-70% of term infants (>38 weeks) (Wennberg, Ahlfors, Bhutani, Johnson, & Shapiro, 2006).
- Mothers are now responsible for the outpatient recognition and treatment of NJ.
- Knowledge of the target audience (mothers) is essential to develop effective educational programs (Bastable, 2008).

PURPOSE

1. Describe the lived and educational experience of mothers having an infant with NJ.
2. Document the content, source, timing, of infant care advice received by mothers having an infant with NJ.
3. Explore the impact of infant care advice on the mother's
 - a. perceptions of her mothering role,
 - b. perceptions of her infant, and
 - c. infant feeding decisions.

STUDY DESIGN, METHODS, & PARTICIPANTS

- Phenomenology (Streubert, 1991).
- The infant care advice was compared with the American Academy of Pediatrics (AAP) Clinical Practice Guideline for the Management of Hyperbilirubinemia in the Newborn Infant 35 or More Weeks of Gestation (2004).
- Six (6) mothers with infants treated for NJ were interviewed, data was transcribed verbatim, and then analyzed.



IMPLICATIONS FOR PRACTICE:

Based on the findings of this study:

- Current educational practice needs to be reevaluated which reflect the mother's readiness to learn.
- Health care professionals must keep current with latest clinical practice guidelines in order to disseminate clear, and accurate infant care advice.
- Further research is needed focusing on mothers having an infant with NJ.

FINDINGS #1:

Eight major themes emerged from the data relating to the mother's lived experience.

1. physical and emotional exhaustion
2. feeling robbed
3. distressed by infant's physical appearance;
4. loss of control;
5. maternal vigilance;
6. feeling discounted but not for long;
7. family impact
8. supportive environment

Three themes emerged from the mother's educational experience pertaining to the content, source, and timing of infant care advice.

1. Everyone has a different opinion, therefore, no one really knows for sure;
2. Feeling at fault and defensive; and
3. Knowing now "what I would do differently if I had another baby."

FINDINGS #2

Participants reported

- First learning about NJ verbally from their doctor
- Searching the internet
- No recall of receiving verbal or written information:
 - During prenatal childbirth classes or
 - At hospital discharge

The infant care advice received as given by pediatricians, family practice physicians, registered nurses, lab technicians, family, and friends as treatment for NJ:

- Consistent with AAP Guidelines (2004):
 - Breastfeed 8-12 times in a 24 hour period
 - Follow up visit within the first few days of discharge.
- Contrary to AAP Guidelines (2004).
 - "Put the baby in the sunlight"
 - "Just let him sleep"
 - "Stop breastfeeding and switch to formula"
 - "Rectally stimulate the baby to eliminate the NJ"

FINDINGS #3

Mothers Described

- **Feeling responsible, distress, criticized, and defensive** when asked about their infant's neonatal history of NJ by HCP especially if the treatment had been delivered by a competing hospital system.
- **Confusion and uncertainty** of who to believe, whom to listen to, or which advice to follow when exposed to multiple HCP advocating inconsistent and conflicting infant care advice.
- Their infants as "**good**" babies, **very calm, sleepy, easy going, docile, and babies** that just loved to sleep for long periods.
- **Distress relating to their baby's heel**, which was often described as raw from multiple heel sticks.
- **Concern for the baby's eyes** due to the phototherapy treatment.
- **Breastfeeding as challenging** due to the need to frequently rub and stimulate her drowsy sleepy infant.
- **No alteration in long term infant feeding plans**, despite being advised to supplement with formula, sterile water, glucose water, and Pedialyte by family, friends, and health care professionals (HCP).