Enhancing Parent Support

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On behalf of NICU babies
and their parents
Alta Bates Summit Medical Center
Disclosures

No conflict of interest

Honorarium
Objectives

At the end of this presentation the participant will be able to describe:

Stressors NICU parents and babies experience.

Our unique program enhancing support for parents and babies.

Program impact from a parent perspective.
Enhance

verb

Intensify, increase, or further improve the quality, value, or extent of.
Alta Bates Summit Medical Center
Newborn Intensive Care Unit
7122 births

1200 admissions to the NICU

115 babies less than 1500 grams

Babies born less than 28 weeks may stay 4 months or more...
Multiple Trauma

Beginning with the early delivery. Second trauma is seeing their baby experience traumatic medical procedures, life threatening events and also witnessing other babies. Third trauma often given serial bad news.

Shaw, Psychosomatics 2006
Parental Stressors

Sights and sounds:
- monitors, equipment, alarms

Infant behavior:
- tubes, color, size,
- movements,
- labored breathing
Stressors

Parental role alteration:
- being separated
- fear of touching
- feeling helpless

Staff behaviors and communication:
- explaining too fast
- not enough information
- conflicting information

Carter, J et al. Personality and Mental Health 2007
Parental Stress

One mother described sleeping with her shoes on always expecting a call.
The supermarket scanner made her think it was her baby’s monitors alarming.

Jaxon spent 6/12 in the NICU

New York Times August 2009
“For parents in NICU, trauma may last”
Parents of 23 week twins

“From the moment of their birth and continuing until after discharge we felt like we were continuously triaging and just hanging on.”

New York Times August 2009
“For parents in NICU, trauma may last”
Will my baby live?

Will my baby be disabled?
“You’ll hear the magical thinking that interrupts the thoughts of parents – the kinds of thinking that we try to use to guide our decisions and create meaning out of a senseless ordeal that our children are forced to endure.”

Father of 25 week twins describing the story he heard on the radio.

“Radiolab Kelly Benham & Tom French Parents of 23 6/7 week baby girl. Tampa Bay Times Reporter”
What have we done to support parents and babies?

In 2002 Compassionate Beginnings™ was introduced in the NICU.
Purpose

To teach parents ways to communicate with their baby through touch

- Skin to skin - kangaroo
- Resting hands – containment
- Heart to heart

Goal – to promote bonding & attachment.
Benefits for baby

Appropriate stimulation for brain development and a sense of being loved.
Benefits for Parents

Parents understand their vitally important role in the care and development of their baby.
Discharge & beyond

Limited studies focusing on parent experiences transitioning to home

- Critical time
  - Feelings of fear, anxiety, low self esteem, failure and inability to cope
  - Limited social support

Rowe & Jones, Journal of Neonatal Nursing 2010
What happens after discharge?

- Home visits?
- High Risk Infant Follow – Up clinic?
- Appointments?
- Re-hospitalizations?
- Back to work?
Post Traumatic Stress Disorder

- Depression
- Anxiety
- Insomnia
- Numbness
- Anger
- Aggression
- Hyper vigilance
PTSD

Parents’ immediate and long term experiences can impact child’s health and their own adaptation

Shaw et al  Psychosomatics 2006
Enhancing Parent Support

Our program goals:

- Enhance & expand support for NICU families after discharge
- Integrate existing early intervention programs
- Build upon existing relationships with NICU specialists
- Provide early intervention services for babies not eligible for Regional services
Existing resources - Relationship based

- Infant massage therapist
- Physical therapist
- Lactation consultant
- Early intervention therapists
- High Risk Infant follow up
- Infant mental health specialist
Post Discharge Classes & Services

- Infant massage
- Developmental play groups
- Interim therapeutic services
  - OT/PT/speech/developmental specialist
- Infant mental health
Massage
Playgroups
Encouraging parents

- Brochures in the NICU
- Free parking
- Bus/bart tickets
- Snacks
- Spanish speaking providers
- Translators available
- Entire program offered at no cost to parents
Outcomes

- Strengthening parenting skills & confidence
- Providing supportive network
- Evolving developmental needs
- Positive family feedback
- Waiting list for massage classes
- Repeat families in all classes
- Providing specialty interventions that the babies would not otherwise be able to access!
For each question, think back to BEFORE you participated in the infant massage class and rate yourself. Also, rate yourself NOW, that you are participating in the infant massage class.

<table>
<thead>
<tr>
<th></th>
<th>BEFORE YOU PARTICIPATED IN THE INFANT MASSAGE CLASS</th>
<th>NOW THAT YOU HAVE PARTICIPATED IN THE INFANT MASSAGE CLASS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel comfortable caring for my baby</td>
<td>[0 1 2 3 4 5]</td>
<td>[0 1 2 3 4 5]</td>
</tr>
<tr>
<td>I can tell when my baby is getting too much stimulation</td>
<td>[0 1 2 3 4 5]</td>
<td>[0 1 2 3 4 5]</td>
</tr>
<tr>
<td>I know what to do to support my baby when he or she is stressed</td>
<td>[0 1 2 3 4 5]</td>
<td>[0 1 2 3 4 5]</td>
</tr>
<tr>
<td>I know how to communicate or interact with my baby.</td>
<td>[0 1 2 3 4 5]</td>
<td>[0 1 2 3 4 5]</td>
</tr>
<tr>
<td>I feel very connected to my baby.</td>
<td>[0 1 2 3 4 5]</td>
<td>[0 1 2 3 4 5]</td>
</tr>
<tr>
<td>I feel I am able to share my love and support with my baby</td>
<td>[0 1 2 3 4 5]</td>
<td>[0 1 2 3 4 5]</td>
</tr>
<tr>
<td>I feel capable of handling whatever comes my way in caring for my baby.</td>
<td>[0 1 2 3 4 5]</td>
<td>[0 1 2 3 4 5]</td>
</tr>
</tbody>
</table>
Success?
Other programs

Creating Opportunities for Parent Empowerment
COPE
Educational – behavioral program for parents of preemies
Designed to inform, educate and help parents cope

Cope for Hope programs
Study

Examined effects of providing COPE program on maternal anxiety and depression 2 months after discharge.

Mothers reported decreased stress, depression & anxiety at 2 months corrected age.

Parent Support

NICU Family Support Program

- Volunteers who provide parent to parent support
- Provide educational materials for parents.

www.marchofdimes.com/.../the-nicu-family-support-program.aspx

Hand to Hold

- National volunteer parent peer support network and resource navigation

www.Handtohold.org
Developmental Interventions

Cochrane review of early developmental interventions demonstrated interventions post discharge had similar effects on cognitive and motor development compared with interventions started in the NICU.

Spittle et al BMC Pediatrics 2009
We believe that the goal of the NICU is to bring the baby back within the family’s embrace by developing and nurturing the family’s rightful role as primary caregiver.
We can support the family from the very beginning by strengthening their relationship with their baby in the NICU

We can continue to foster this relationship after discharge
When early parent – infant attachments are healthy and secure, the benefits literally last a lifetime.
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Foundation for Healthy Family Living. www.healthyfamily.org
Funding

2002  - $69,000  (SCDD)

2004  - $50,000  (ABSMC Foundation)

2005  - $150,000  (2 year grant ECC)

2010  - $89,000  (18 month grant ECC)

2011  - $119,960  (2 year grant ECC)