FAMILY SUPPORT IN THE NICU

HOW WE GOT HERE AND WHERE WE WANT TO GO

Annie Rodriguez RN
Teresa del Moral MD
Family Support: Why?

- The impact of Pediatric Critical Illness and Injury on Families: A systematic Review.

  How critical illnesses in childhood are a source of distress that impacts the entire family dynamics (Shudya, Pediatrics 2006)

- Prematurity can be considered one of these conditions with a major impact in the family
Family Support: Why?

- Parents experience preterm birth as highly stressful (Miles 1993, Shields-Poe 1997)
- Stress that can lead to symptoms of anxiety and depression (Shaw 2006)
- “It is also important for trainees to understand the short and long-term effects of neonatal illness in the family.”
  - Perinatal Medicine Fellowship Training in Long-Term Outcomes of Neonatal Intensive Care Unit Graduates (DeRegnier et al 2005)
Family Support: Why?

Neonatal health providers need to combine technological intensive care for preterm infants with a sensitive and individualized approach supporting parents in their role as primary advocates and long term caregivers (Lawton 2002)
Family Support: Why?

- Family centered care is based in the assumption that the family is a child’s primary source of strength and support. 
  

- Importance of parental involvement to facilitate parent-child interaction and to enhance long term developmental outcome. 
  
  (Brazy 2001)
American Academy of Pediatrics / Institute for

Family-Centered Care *(Policy Statement, Pediatrics 2003)*

- Family centered care is based in the assumption that the family is a child’s primary source of strength and support

Perinatal Medicine Fellowship Training in
Long-Term Outcomes of Neonatal Intensive Care Unit Graduates *(DeRegnier et al 2005)*

- It is also important for trainees to understand the short and long-term effects of neonatal illness in the family
A PARENT TO PARENT SUPPORT PROGRAM FOR MOTHERS OF VERY PRETERM INFANTS IN THE NICU: RANDOMIZED TRIAL

Lourdes Falcon, Roberto Echeverri, Teresa del Moral

Supported by a grant
Community of Pediatrics Training Initiative / Ann Dyson Foundation
Parental Stressor Scale: NICU

A self-report questionnaire to assess parents’ perception of stressors associated with the NICU experience (Miles 2003)

- appearance and behavior of the sick infant,
- alterations on the parental role
- sights and sounds of the physical environment
- relationship with the staff
- overall experience of having their infant in the NICU
Correlation baseline PSS and Infants CRIB score
## Parental Stress Score Baseline (first week)

<table>
<thead>
<tr>
<th>N= 46</th>
<th>Control</th>
<th>Intervention</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sights and sounds</td>
<td>2.0 ± 0.8</td>
<td>2.2 ± 0.7</td>
<td>NS</td>
</tr>
<tr>
<td>Infant’s appearance</td>
<td>2.7 ± 1.3</td>
<td>2.6 ± 0.9</td>
<td>NS</td>
</tr>
<tr>
<td>Alteration of parental role</td>
<td>3.2 ± 0.9 *</td>
<td>3.4 ± 0.9*</td>
<td>NS</td>
</tr>
<tr>
<td>Relationship with the staff</td>
<td>1.9 ± 1.1</td>
<td>1.8 ± 1.1</td>
<td>NS</td>
</tr>
<tr>
<td>Overall Experience</td>
<td>2.7 ± 1.7</td>
<td>2.8 ± 1.7</td>
<td>NS</td>
</tr>
</tbody>
</table>

* *P < 0.05*
## Parental Stress Score Post-intervention

<table>
<thead>
<tr>
<th></th>
<th>N= 46</th>
<th>Control Mean ± SD</th>
<th>Intervention Mean ± SD</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sights and sounds</td>
<td></td>
<td>2.3 ± 0.7</td>
<td>2.7 ± 0.9</td>
<td>NS</td>
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<tr>
<td>Infant’s appearance</td>
<td></td>
<td>2.7 ± 1.0</td>
<td>3.0 ± 1.0</td>
<td>NS</td>
</tr>
<tr>
<td>Alteration of parental role</td>
<td></td>
<td>3.1 ± 0.9</td>
<td>2.9 ± 0.9</td>
<td>NS</td>
</tr>
<tr>
<td>Relationship with the staff</td>
<td></td>
<td>2.3 ± 1.0</td>
<td>2.4 ± 1.1</td>
<td>NS</td>
</tr>
<tr>
<td>Overall Experience</td>
<td></td>
<td>3.5 ± 1.4</td>
<td>2.4 ± 1.6</td>
<td>&lt;0.05</td>
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</table>
FAMILY SUPPORT: HOW?

CAUSES OF STRESS

NEEDS OF THE FAMILY

INTERVENTIONS
A self report scale of 45 statements rating the importance of family needs while their infants are admitted to the NICU including

Support
Information
Comfort
Assurance
Proximity
NFNI Baseline Scores (First week)

<table>
<thead>
<tr>
<th></th>
<th>Non Hispanic (n=17)</th>
<th>Hispanic (n=31)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assurance</td>
<td>1.6 ± 1.0</td>
<td>3.1 ± 1.2</td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>Comfort</td>
<td>1.9 ± 0.6</td>
<td>2.8 ± 0.9</td>
<td>p &lt; 0.01</td>
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<tr>
<td>Proximity</td>
<td>1.6 ± 1.1</td>
<td>3.1 ± 1.1</td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>Support</td>
<td>2.0 ± 0.7</td>
<td>2.8 ± 0.9</td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>Information</td>
<td>1.6 ± 0.9</td>
<td>3.1 ± 1.2</td>
<td>p &lt; 0.01</td>
</tr>
</tbody>
</table>
Decrease Causes of Stress

Disruption of the parental role
IMPLEMENTATION OF MOTHER KANGAROO CARE PROGRAM

- Development of a protocol
- Implementation
  Hospital Policy
  Education of personnel
  Education of families
Needs of the families

- Support
- Information
- Confort
- Assurance
- Proximity
EMOTIONAL SUPPORT
NICU PARENT SUPPORT NETWORK: FIRST STEP TOWARDS THE FAMILY CENTERED CARE

• Approximately 50 “buddies”
• After the study was finished 100 more families have been matched with support buddies
FAMILIES AS ADVISORS: A STEP TOWARDS THE FAMILY CENTERED CARE

The objective of this project is to build a collaborative partnership between parents and professionals necessary to enhance our NICU capacity to provide family-centered services.
PADRES Y PADRINOS CONSEJEROS
UN PROGRAMA DE APOYO PADRE A PADRE
CONOCIENDO LAS NECESIDADES DE LAS FAMILIAS EN LA UNIDAD DE
CUIDADOS INTENSIVOS
MANUAL DE ENTRENAMIENTO PARA PADRINOS

George Washington University
NICU Family Support

“The March of Dimes/University of Miami “NICU Family Support Project” provides support services to families and extended families of a newborn infant admitted to the Neonatal Intensive Care Unit (NICU) at Holtz Children’s Hospital.
SOCIAL SUPPORT:
Group activities
Expressive Arts

Physicians and nurses are discovering that art, music, dance and poetry can all have profound healing effects on their patients. Art brings to the human spirit a sense of freedom and joy. Replacing fear with hope and darkness with light is the essence of modern body-mind-spirit medicine.”

Source: "Creative Healing," by Michael Samuels, M.D. & Mary Rockwood lane, R.N., M.S.N., Ph.D.
Mosaic-tiled Columns

Family participants, physicians, nurses and social workers created all the individual tile pieces under the direction of the expressive arts facilitators. They had been instructed to reflect on the NICU journey in terms of images, symbols, metaphors and color representations.

A large conference room in the hospital became a creative arts work area. Over a two-day period, over 30 people participated in creating clay tiles by rolling clay, stamping symbols, cutting out designs and brushing on glazes. After having to turn hospital staff away at the end of the second day, the artists carefully placed all the clay pieces in their prepared pizza boxes and headed back to their studio.

The next steps entailed firing the clay pieces and procuring other tile to be broken and used as the background for the handmade tiles. A 10' x 7' table was built and the fired clay pieces were laid out on top of a mesh backing. The symbols and images related to despair were positioned at the bottom of the column and those representing personal transformation at the top. Once the design was complete, the tiles were glued to the mesh. It was then brought to the hospital site, in several pieces, to be installed.
Meu nome é Marli Oliveira Hernandez, sou a mãe de Isabella Hernandez, uma linda menina nascida aos 5 meses e meio (23 semanas), pesando 585 gramas e de 29 cms, no Jackson Memorial Hospital – Miami – aos 10 de novembro de 2000.

No dia do parto eram muitos meus temores, todo o tempo que estive na sala de emergências pensava que a vida de meu bebê poderia estar em risco e sua saúde e qualidade de vida sendo afetada.

**Informação Biográfica:**
**Pais:** Roberto Hernandez e Marli Oliveira Hernandez  
**Dia de Nascimento de Isabella:** 10 de novembro de 2000 as 23 semanas.  
Isabella nasceu pesando 585 gramas e 29 cms, esteve no Hospital por três meses. Roberto e Marli vivem em Miami e não tem outros filhos.
HEALING SESSIONS

[Description of the image: A group of people are engaged in various activities at a table covered with art supplies. A young girl is holding a small box and smiling, standing next to an adult woman.]
HEALING SESSIONS
INFORMATION
Culturally Sensitive Education for Parents in the NICU

- Welcome
- Identification
- Hand washing
- Visitation policies
- Confidentiality
- NICU team
- Equipment
- Interaction with the baby
- Importance of follow up
Chè Paran ak Zanmi

Felisitasyon pou pitit ou ki fenk fèt! Menm sa te lkontan w ap tan tibebe w fèt, ou kapab santi ou chaje nan bay l tout li swen espesyal tibebe w bezven. Konnen ke ou pap passe esperyans sa a pou kont ou, e nou la pou gide w ak ba w sipò nan tan difisil sa a. Se “Neonatal Intensive Care Unit” (NICU) (Sol Swen Entansif Neyonatal -SSEN) ki ap pran swen tibebe w, paske li ou te fèt bonè (paske li te prematre) oubyen paske li te fèt malad. Ou kapab santi ou pè epi ou pa konprann tout sa ki ap passe. Santiman sa yo nòmal e plizyè paran nan memm situasyon an konn santi memm jen.

Anplwaye nan Sant Holtz “NICU” toujou disponib pou ede w pandan sejou w nan lòpital la. Nou rekonèt ou se moun ki pi epòtan nan vi tibebe w koulè ya e toujou. Nou ta remmen travay asann avèk ou pou maksimizè potansyèl tibebe w ak ogmante konfisyans ou gen nan tèt ou pou ranpli tout bezven li yo.

Lè ou vin jwenn avèk pitit ou

Tan ou passe avèk pitit ou, trèzenpòtan pou ede tibebe w refè. Ou se moun ki pi epòtan nan ekip moun ki ap bay tibebe w swen sante e nou ankouraje pou w vin pran swen li tout lè li pasib. Ou byenvin la a tout lè pandan lajounen ou tanwit. Nan jou ou pa kapab vin vizite, nou ankouraje w pou rele “NICU” a pou reserwa nouvèl sou progrè pitit ou.

Identifikasyon
Le w nanre nan sa “NICU” a (SSEN) joun non sekret, oubyen joun non enfimèt yo apò mande pou idantify w kon paran tibebe a. Le sa a ou kapab trite brezol ki gen non tibebe w oubyen gen eviden jwenn fèt.

Supported by
AAP CATCH grant
THANK YOU

• NICU Staff
• Families
• Lourdes Falcon
• Paula Lalinde