Welcome to the NICU Consortium
January 25, 2017
Agenda

9:00 am  Welcome, Announcements
9:15 am  The Impact of Pregnancy Loss and Infant Death: Perspectives on Families and Providers
         Dr. Stacey Bromberg & Dr. Jen Harned Adams
10:30 am The Most Vulnerable Population: Recognizing, Healing, and Preventing Secondary Trauma in Professionals: Working with Premies, Medically Fragile Babies, and their Families
         Emily McNeil, LPC & Sarah McNemee, LCSW
11:35 to 12:30 pm  NICU Consortium Steering Committee – You may join us if you wish

Annual Wine & Chocolate Pairing!
Saturday, February 11th, 2017   6:30pm - 9:30pm
Admission:
$35 Individual  $65 Couple
All proceeds go to benefit Colorado Pregnancy & Newborn Loss Services
Online registration, venue directions & parking information at:
www.coloradopregnancyloss.org/Events

The Impact of Pregnancy Loss and Infant Death: Perspectives on Families and Providers
Stacey R. Bromberg, PhD and Jennifer Harned Adams, PhD
NICU Consortium: January 25, 2017

OBJECTIVES
¬ Understand unique facets of loss on families
¬ Gain insight into role of caregivers in grief experiences
¬ Gain sense of clinical competence in interacting with families experiencing loss
¬ Understand importance of self-care as part of best practice

“Three Rules of Work:
Out of clutter find simplicity; From discord find harmony;
In the middle of difficulty lies opportunity.”
- Albert Einstein
What is lost when a baby dies?

When a parent dies you lose your past,
But when a child dies, you lose your future.

- When does attachment begin?
- When do we start planning for the future?

The impact of attachment

When do we become a ......?

Is it Grief or is it Trauma?
Is it Sadness or is it Traumatic Grief?
(And does it really matter??)

We are a society that in general denies grief, avoids the emotion whenever possible, and expects those grieving to quickly “deal with it” and “get over the loss.” Listening to the stories of loss is difficult. It requires taking the time to slow down and “be” with the painful emotions. We are unsure of what to say, how to act, what to do. In our fast-paced, efficiency-focused society, people often do not recognize the benefit of telling or listening to the story.

Stories help make sense of the insensible...

- Kirsti A. Dyer
Even though their baby is still alive and may have a good outcome, NICU parents are still grieving:
- Loss of happy pregnancy
- Loss of pregnancy milestones
- Loss of hoped-for birth experience
- Loss of maternity leave
- And many more
- Most parents feel ashamed of or guilty for mourning these losses
- Parents may be shamed by friends, family members and HCPs for mourning these losses

How do the parents reference the pregnancy
- Listen to the parents, and use their language
- Words to avoid: “tissue”, “it”

Meaning making is critical to healing
- What does it mean, why did it happen?
- Continuity of care- how have your other appointments been part of your story?
- Providers are important characters in the story

Beginning a journey
- Becoming part of a family’s story
- Create space for mourning
- Begin conversations
- Making a moment last a lifetime
- Preparing for discharge

“The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.”

-Rachel Remen, Kitchen Table Wisdom

How Do You Grieve?
Your Perspective (think about your lens…)

- What do you see?
- What do you hear?
- What do you feel?
- What do you need?

Type of Work-Related Grief

- Primary trauma
- Secondary trauma
- Vicarious trauma
- Compassion fatigue
- Organizational compassion fatigue
- Burnout
- These can be counterbalanced by compassion satisfaction

Uniquely rewarding experience

- Opportunity to observe the common human experience in people of all different backgrounds
- Patients inspire their care providers with their ability to survive and move forward in life
- Changes in compassion and insight
- Develop in one's own spirituality
- Deeper appreciation for own life

Compassion Satisfaction
(rewards of working with bereaved parents)

- Physical
- Emotional
- Interpersonal
- Cognitive
- Workplace signs of distress

Signs of Occupational Stress

“In the event of decompression in the cabin, oxygen mask will automatically drop down. Make sure you put yours on first, before you try to assist others.”

-Preflight safety instructions
Storytelling is the most common strategy utilized in meaning making.

"Tell your story...from the beginning - the first experiences in your life that led you toward caregiving - to the present."

"When clinicians write about their challenges either in their work or in their everyday lives, it may prove useful to include a focus on the cognitive and emotional aspects of the challenges faced. Such writing... may help generally with both physical and mental health, and may also enhance the likelihood of experiencing vicarious post-traumatic growth."

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Who is YOUR circle?

REGULATION MODEL

Development

Other

Self

Break
Announcements and Updates

NICU Consortium Fellows — Please join us as a NICU Consortium Fellow — Only $25.00/year. Information on the Special Kids, Special Care Website
Benefits include:
- Certificate of Professional Development Education for 2 hours when you attend one of the NICU Consortium Meeting/Webinars and complete the program’s evaluation survey
- Recognition in the NICU Consortium newsletter, unless you prefer not to be acknowledged publicly
- "Fellows" registration fees on other Special Kids, Special Care educational offerings such as:
  - Interdisciplinary Institute — held bi-annually
  - NICU Consortium Programs — Feeding and Teaching Scale
  - Annual workshops

NICU Consortium Champions — represent small businesses, non-profit organizations, individuals, and community and state organizations that care about families who have had a baby in the Neonatal Intensive Care Unit (NICU). We want to recognize your partnership in our continuing efforts to support families through the NICU Consortium Educational Meetings/Webinars, the NICU Consortium newsletter, and on the NICU Consortium webpage. For more information check out the Special Kids, Special Care website.

Special Kids, Special Care Website: www.specialkids-specialcare.org
The Most Vulnerable Population: Recognizing, Healing, and Preventing Secondary Trauma in Professionals Working with Preemies, Medically Fragile Babies and their Families

Emily McNeil, LPC, BC-DMT & Sarah McNamee, LCSW, MBA
NICU Consortium Educational Meeting
Colorado Department of Public Health and Environment
January 25, 2017

Who We Are
Emily McNeil, LPC, BC-DMT & Sarah McNamee, LCSW, MBA

Presentation Goals
• To provide a general understanding of the impact of trauma on premature and medically fragile infants and their families.
• To increase understanding of the impact of burnout, compassion fatigue, and secondary trauma on professionals working with the most vulnerable population.
• To strengthen strategies for greater mental health, well-being, and resilience while maintaining a career working with infants and families exposed to trauma.

The Most Vulnerable Population: Babies
Preemies, Medically Fragile Babies, and their Families
• Age
• Medical and developmental challenges (possibly life-limiting)
• Involvement in services implies increased risk in other areas (i.e., relationships, socio-economic)
• Early exposure to trauma

The Most Vulnerable Population: Professionals
The Helpers who Work with Premie and Medically Fragile Babies and Families
• Nervous systems in close contact “wire up” with each other
• Parallel process
• Giving inherently “empties our cups”
• The systems in which we work can also contribute to helper vulnerability

What is Trauma?
• “Emotional response to a terrible event” (APA)
• “Extreme stress that overwhelm a person’s ability to cope” (Giller)
• “Psychologically distressing event outside the range of usual human experience; often involves intense fear, terror, and helplessness” (Perry)
• “Traumatic events overwhelm ordinary systems of care that give people a sense of control, connection, and meaning” (Herman)
Types of Trauma

- Medical
- Transgenerational
- Epigenetic
- Little “t”/Developmental
- Single Event
- Chronic
- Neglect
- Relational/Attachment
- Pre-Natal

Trauma Specific to the NICU Population

Caring for the Caregiver

“The single most important factor in success or failure of trauma work is the attention paid to the experience and needs of the helpers” (Saakvitne, Pearlman, Tabor, & Terr, 1999).

Compassion/Empathy Fatigue

Empathy - feeling the feelings of others
Fatigue - tired/exhausted/weary

Symptoms:
- Irritation
- “Off-color” jokes/atypical
- Bad day

Burnout

Burnout is “the response to the chronic emotional strain of dealing extensively with other human beings, particularly when they are troubled or having problems” (Maslach, *Burnout: The Cost of Caring*).
- It's not about if you become burned-out; it's about when.
- Many in helping professions, helpers feel burnout after about 6 years.
- Can happen over and over again throughout one's career.

Secondary Trauma

Secondary traumatic stress is “the natural consequent behaviors resulting from knowledge about a traumatizing event experienced by a significant other. It is the stress resulting from wanting to help a traumatized or suffering person” (Figley, 1995).
How Secondary Trauma Affects The Body

Adapted from Levine, Porges, and Ogden, in Wheatley-Crosbie, 2006.

Signs Of Secondary Trauma

- Increased sensitivity to violence
- Bouts of grief and despair
- Numbing responses
- Feeling of loss of the "ideal child/ideal client"
- Distancing from family, friends, children, coworkers, missing work
- Cynicism and sadness
- Increased instances of illness
- Guilt
- Feeling overwhelmed
- Overeating, drinking, working, spending or watching TV/video games
- Feelings of hopelessness
- Irritability, angry outbursts, mood changes
- Blaming client
- Jumpiness, increased heart rate, increased or decreased sensitivity to sensory input
- Poor sleep

Ways to Improve Symptoms of Secondary Trauma

- Eat healthy foods
- Get enough sleep
- Relaxation techniques
- Spend time with supportive people
- Create "containers" around the trauma
- Find a "defusing/venting" partner
- Education about trauma & secondary trauma
- Radical self-care!
- Intentional and loving breaks from clients
- Humor
- Self-care regimens – walking, munching, playing time with animals
- Bathroom breaks!
- RELATIONSHIPS
- Professional boundaries

More Ways to Improve Symptoms of Secondary Trauma

- Go to counseling
- Alert others to signs
- Vacation rules
- How you schedule your day
- Work with others
- Move your body
- Nurture a strong ethical or spiritual world view
- Find balance
- Say “no”
- Transitional activities
- Mindfulness
- Go panoramic
- Stay present
- Reflective supervision/consultation

Vicarious Resilience

- Caregivers can also have a positive nervous system response to their clients’ resilience and, therefore, increase their own resiliency in the face of stress.
- The babies and families are:
  - Inspiring
  - Brave
  - Role models
  - Survivors

Belly Breathing

One way to practice:
- Hands on belly
- Slow breath in through nose – belly rises
- Hold/breathe
- Exhale slowly through mouth – belly falls
- Take a moment
- Repeat 5-10 breathes
Thank you to our Grantors, Sponsors, and In-kind Contributors

Newborn Hope for their support of the “Safe Sleep Going Home” Program

HCP – Colorado Department of Public Health and Environment, Program for Children with Special Health Care Needs for their continued support of the NICU Consortium Educational Meetings/Webinar

Tri-county for their support implementing the Consortium and the NICU Outreach and Transition Partnership

Mother’s Milk Bank, La Leche League, Mt. Plains, and Colorado Breastfeeding Coalition for their support of the First Premie Rock – Celebration of Strength and Joy

(Recognizing Prematurity Awareness Month)

Providing conference call access, presentation AV equipment and space for our meetings

NICU Executive Committee

Chair/Secretary
- Carolyn Kwerneland
  Tri-county Health Department – HCP Coordinator

Co-Chair
- Lori McLean, RN, BSN
  Boulder County Health Department – HCP Coordinator

Treasurer
- Sarah McNamee, LCSW, MBA
  McNamee & Associates, LLC

NICU Representatives
- Kathy Farnum, RN, BSN, CCM
  Case Manager NICU North
  Children’s Hospital Colorado

- Kendra Perkey, MS, RD, CNSC
  NICU Dietitian/Supervisor
  Rocky Mountain Hospital for Children

Community Representative/SKSC BoD Liaison
- Renee Charifsee-Smith, MA, CCC-SLP
  University of Colorado Denver, JPA Partners, ENRICH

- Sophia Yager, RN, BSN
  Nursing Supervisor
  Jefferson County Public Health, Special Kids, Special Care

Parent Representative
- Amber Menzies
  Moms of Olive and Rayn
  Denver, Colorado

MCH Nursing Consultant
- Barbara Deloian, PHD, RN, CPNP, IBCLC
  Special Kids, Special Care

Thank you!

NICU Consortium Meeting

Next Meeting
April 26, 2017
9 am to 11:30 am

If you would like to present a topic or hear a topic that would be of interest, please let us know.

www.specialkids-specialcare.org
specialkids@sk-sc.org

Special Kids, Special Care
Sign Up

❖ For info about either of these program send Barbara an e-mail at: specialcare@sk-sc.org
❖ NICU Outreach: Safe Sleep Going Home Program: Wearable Sleep Sac Blanket Requests
❖ Family Support Grant - Applications for newborn cribs, respite care, lactation consultation, or other health support services needed by families
❖ To receive announcement about future NICU Consortium Meetings, the newsletter, or other information, please sign up on the website
❖ Website: www.specialkids-specialcare.org