Bereavement support for families and professionals

Wednesday, February 20, 2019
2:00 PM – 3:00 PM ET
Housekeeping Notes

• **Webinar is being recorded and will be available within 2 weeks on our website:** [www.ncfrp.org](http://www.ncfrp.org)

• All attendees will be muted and in listen only mode

• Questions can be typed into the “Questions” pane
  – Due to the large number of attendees, we may not be able to get to all questions in the time allotted
  – All unanswered questions will be posted with answers on the NCFRP website

• Handouts are available in the “Handouts” pane
Guest Speakers

Sonsy Fermín, MSW, LCSW, CDR, USPHS
Acting Chief, Healthy Start East Branch, HRSA
About the National Center

• The National Center for Fatality Review and Prevention (NCFRP) is a resource and data center that supports child death review (CDR) and fetal and infant mortality review (FIMR) programs around the country.

• Supported with funding from the Maternal and Child Health Bureau at the Health Resources and Services Administration, the Center aligns with several MCHB priorities and performance and outcome measures such as:
  – Healthy pregnancy
  – Child and infant mortality
  – Injury prevention
  – Safe sleep
HRSA’s Overall Vision for NCFRP

• Through delivery of data, training, and technical support, NCFRP will assist state and community programs in:
  – Understanding how CDR and FIMR reviews can be used to address issues related to adverse maternal, infant, child, and adolescent outcomes
  – Improving the quality and effectiveness of CDR/FIMR processes
  – Increasing the availability and use of data to inform prevention efforts and for national dissemination

• Ultimate Goal:
  – Improving systems of care and outcomes for mothers, infants, children, and families
Acknowledgement

This webinar was made possible in part by Cooperative Agreement Numbers UG7MC28482 and UG7MC31831 from the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as part of an award totaling $1,099,997 annually with 0 percent financed with non-governmental sources. Its contents are solely the responsibility of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.
Webinar Goals

• Describe the types of infant and child loss encountered by fatality review teams
• Explore best practices for working with families – supporting families following a child or infant loss, communicating with the bereaved, expressions of grief, recognizing complicated grief reactions
• Processing our own feelings on grief and loss, vicarious trauma, gain resources for self-care
“Pregnancy is a time of great excitement and changes. There is so much to look forward to when anticipating a new life. For this reason the loss of a pregnancy is often one of the most heartbreaking experiences for the infant’s parents”

https://foreverfamilies.byu.edu
Types of pregnancy loss

• Ectopic Pregnancy: a pregnancy that is not in the uterus. The fertilized egg settles and grows in a location other than the inner lining of the uterus.

• Miscarriage: the spontaneous loss of a pregnancy from conception to 20 weeks gestation.

• Stillbirth: an infant born without signs of life, generally after 20 weeks of gestation.
Types of pregnancy loss

- Infant death: the death of any live born infant prior to his/her first birthday
  - Neonatal deaths - an infant death within the first 27 days of life
  - Post neonatal deaths – an infant death occurring from 28 – 364 days

“The most sensitive index we possess of social welfare”

Sir Arthur Newsholme, 1908
Types of child loss: Age 1-4, 2017

- Accidents/unintentional injuries
- Congenital malformations/chromosomal abnormalities
- Cancer
- Assault/homicide

National Vital Statistics System, National Center for Health Statistics, CDC
The National Center for Fatality Review and Prevention
Types of child loss: Age 5-9

- Unintentional injuries
- Cancer
- Congenital anomalies
- Homicide
Types of child loss: Age 10-14

- Unintentional injury
- Suicide
- Cancer
- Congenital anomalies
Types of loss: Age 15-24

- Unintentional injury
- Suicide
- Homicide
- Cancer

National Vital Statistics System, National Center for Health Statistics, CDC
The National Center for Fatality Review and Prevention
Guest Speakers

Rose Winchell, MSW, LSW
Bereavement Care Coordinator
Philadelphia Department of Public Health

Nichole Schwereman-Stangel,
MA, MS, LPC, CT
Bereavement Coordinator
CISM Coordinator
Children’s Hospital of WI
Best Practices:
Working with Bereaved Families
What is Grief?

- It represents a **form of separation distress** following the disruption of a significant attachment through death
  
  (Bowlby)

- **Grief** is the response to loss that contains thoughts, behaviors, emotions and physiological changes

  (Columbia School of Social Work)
The Difference Between Grief Mourning and Bereavement

- **Grief**: Our internal experiences (thoughts and feeling) to the loss.

- **Mourning**: The outward expression of our grief. It is a person’s shared social response to loss.

- **Bereavement**: The act of being torn apart (what is happening now). Phrases heard like: There is an emptiness, a hole in my heart.

— Kimberlee Bow, MA, LPC, R-DMT, CT
Now I Lay Me Down to Sleep Community Outreach
Stages of Grief (Kubler-Ross)

- Denial
- Anger
- Bargaining
- Depression
- Acceptance
Communicating with Bereaved Families

- **What do families need?**
  - Reassurance that what they are experiencing is normal
  - Allow them opportunities to teach us about their own experiences of what grief is
Communicating with the Bereaved

https://www.thecomicstrips.com/subject/The-Grief-Comic-Strips.php
Things to Consider When Working with Bereaved Families

- Creating a “safe space” for the individual or family to embrace their feelings of loss
- **Active** listening and engagement
- Use **reflective** listening
- Be aware of **body language** and **tone**
- Ask **permission** before doing things
- Be **clear** and **concise** in your **speech**
- Maintain **awareness/cultural sensitivity**
- **Honor** the story
Common Expressions of Grief: Loss of a Child

- **Shock**: After the death and loss of a child families may initially feel numb.

- **Denial**: Disbelief in the death, expectations of son or daughter walking through the door, or hearing a cry on the baby monitor.

- **Replay**: Playing questions over in your mind of “what if’s” as you play out scenarios in which your child could have been saved.

- **Yearning**: Many parents report praying obsessively to have even five more minutes with their child so they can tell them how much they love them.

- **Confusion**: Memories may become clouded. Parents may at times even question their sanity, though these feelings are normal.
Common Expressions of Grief: Loss of a Child

- **Guilt:** Guilt appears to be one of the most common responses to dealing with the death of a child.

- **Powerlessness:** In addition to feelings of guilt, parents often have a sense of powerlessness.

- **Anger:** Anger and frustration are also feelings reported by most parents and are common to grief in general.

- **Loss of hope:** The parent is grieving for the child, but also for the loss of their hopes, dreams and expectations for that child. Time may not provide relief from this aspect of grief.

Recognizing Complicated Grief Reactions

- Most sudden and unexpected traumatic deaths result in complicated grief.
- Individuals are incapacitated by grief and focus on the loss to the exclusion of other interests and concerns.
- Associated with **dysfunctional behaviors**:
  - Avoidance of the loss
  - Daydreaming about being with the deceased
  - **Anguished** search for meaning
  - Narrative fixation a “**frozen**” story of loss
Recognizing Complicated Grief Reactions

Other symptoms include:

- Loss of support/\textit{disting}acing
- \textbf{Impaired} functioning
- Frequent \textit{preoccupation} with the deceased
- \textbf{Intense} feelings of \textit{emptiness} or \textit{loneliness}
- \textbf{Recurrent thoughts} that life is meaningless or unfair without the deceased
- A frequent \textit{urge to join the deceased} in death
Complicated Grief of Prolonged Grief Disorder

- **Persistent Complex Bereavement Disorder (DSM V)**
  - Individuals with persistent complex bereavement disorder, or complex or prolonged grief disorder, are incapacitated by grief and focused on the loss to the exclusion of other interests and concerns.
  - Physical symptoms include:
    - Cardiac Disorders
    - Immunological Dysfunction
    - Essential Hypertension
    - Suicidal Ideation and Attempts
    - Functional Impairment
Supporting Families Following a Child or Infant Loss

The deep bonding between a parent and a child blends with all of our expectations and assumptions about life to compound the pain of losing a child

(Sue Holtkamp, Ph.D)

- Encourage good support and boundaries
- Continue to help parents navigate the new relationship with the bereaved child and other surviving children
- Encourage parents to share in the moments of thoughts and feelings to their partner and other children only when they feel ready to do so


Supporting Parents Following a Child of Infant Loss

• How the death of a child affects a marriage
  □ Each partner becomes deeply involved in his or her own grief and is often dissatisfied with the quality or depth of their spouse’s grief.

  □ When coupled with the anger, frustration, guilt and blame that often surround a child’s death, parental bereavement can be a time of extreme volatility in a marriage.

  □ A bereaved couple may find it difficult to give comfort to each other when both are feeling an equal amount of grief.
Supporting Siblings Following a Child of Infant Loss

- **How surviving children are affected**
  - Children grieve in spurts
  - Children may take longer to understand the meaning of death and its impact
  - Children do not show the same emotions of grief as adults do
  - Many times children seem to be coping very well with a death, but then exhibit behavioral changes a few months later
  - A critical factor in how much or to what extent children are affected by loss is the support these children receive from their community: parents, siblings, extended family and friends.
Supporting Children Through Loss: What parents Can Do

- **Talk** to children about death in simple but matter-of-fact terms.

- Use truthful words like “**dead, dying, died**” and “**buried, cremated.**”

- Keep your answers brief but clear.

- **Show your emotions** — being authentic and honest provides a meaningful model for your child.

- Show **patience, reassurance** and **calm support** as often as you can.
Questions/Comments?
Fatality Review & Prevention: Your Passion, Your Pain

Nichole Schwerman, MA, MS, LPC, CT
Bereavement Coordinator/CISM Coordinator
Children’s Hospital of Wisconsin
Objectives

- Define differences between vicarious trauma, secondary traumatic stress and burnout
- Recognize the impact on the individual due to work
- Identify tools to build resiliency and practice self-care
Definitions

Vicarious Trauma (VT)

- Refers to changes in the inner experience of the professional resulting from empathic engagement with a traumatized client (NCTSN)

- Specifically impacts the professional’s
  - Identity
  - Worldview
  - Psychological needs
  - Belief system
  - Memory system
Definitions

Secondary Traumatic Stress (STS)
- The ‘natural consequent behaviors and emotions resulting from knowing about a traumatizing event experienced by a significant other—the stress resulting from helping or wanting to help a traumatized or suffering person’ or ‘the cost of caring for others in emotional pain’ (Figley)
- Symptoms nearly identical to PTSD
- Interchangeable with Compassion Fatigue

Burnout
- Results from the stresses associated with the interaction between staff and their work environment
Recognize work related stressors

- Direct contact
  - Working traumatized adults and children
  - Interviewing, assessing, and supporting immediate family members, as well as extended family members
  - Dysfunctional family dynamics/mental health issues
  - Lack of community resources/ability to support family
  - Having multiple responsibilities added to an already heavy work load

- Indirect contact
  - Reading case files, medical records, court records, and school records
  - Pre-investigative conferences
  - Seeing news coverage on case
What does this look like on the professional?

- **Avoidance:**
  - Of certain clients or questions
  - Being late, missing meetings or calling in

- **Feeling numb or detached from clients:**
  - Impact on client advocacy

- **Irritability:**
  - Difficulty concentrating, focusing, remembering things

- **Hyper vigilance:**
  - Feeling on edge
  - Intense focus or worry about safety or welfare of clients
  - Easily startled or upset

- **Feeling hopeless about the work:**
  - Loss of purpose
  - Dread going to work
What does this look like on the professional?

At Home

- Intrusive, negative thoughts and images related to clients and their stories
- Fatigue and physical complaints
- Strained relationships
- Irritability
  - Physical reactions to trauma reactions
  - Numbing, withdrawing
  - Substance Abuse
- Question religious beliefs
  - Change in worldview
  - Questioning purpose, meaning of life
- Anxiety, concern for safety, depression
How do professionals protect themselves?

- Become emotionally self aware—seek counseling
- Enhance your professional life
  - Seek supervision and mentorship
  - Continue professional development and training
  - Diversify your professional roles
  - Have good boundaries/know your limits
- Create a strong support system
- Build personal resiliency
Resiliency

- The ability to “bounce back” from difficult experiences
- The ability to use a variety of tools and resources to maximize one’s ability to recognize, respond and recover from stress
Subjective Units of Distress (SUDs)

Scale 0-100

- Baseline (10)
- Warning (60)
- Danger Zone (80)
Mindfulness

- Is living in the present moment—not living in the past or the future
- It is choosing what we want to pay attention to and for how long we want to pay attention to it
- Non-Judgmental
- Learning to be in control of your mind, instead of letting your mind control you
- Acceptance—it is what it is
Mindfulness

- Allows you to be fully present with your clients
- Allows you to “hold your space” when you are confronted with trauma
- Recognize what is happening inside of you; thoughts, emotions and physical sensations
- Allows you to respond rather than react
The power of self care

Building your Resiliency Toolbox

- Distraction
- Inspiration
- Relaxation
- Music
- Videos
- Fitness
- Things I like to do
- Other
The power of self care

Building your Resiliency Toolbox: Distraction

- Sudoku puzzles
- Photo puzzles
- Word searches
- Solitaire
- Netflix
- TV
- Painting
- Read
The power of self care

Building your Resiliency Toolbox: Inspiration

- Quotes
- Mantras
- Ted Talks
- Spiritual readings
- Other
The power of self care

Building your Resiliency Toolbox: Relaxation

- Guided Meditation
- Mindfulness
- Yoga
- Progressive Muscle Relaxation
- Breathing
- Journal
- Massage
- Other
The power of self care

Building your Resiliency Toolbox: Music, Videos

- Specific playlists
- Funny videos, etc.
- Podcasts
- Other
The power of self care

Building your Resiliency Toolbox: Fitness

- YouTube fitness videos
- Apps, ex: 7 min workouts
- Personal trainer
- Workout buddy
- Join a team
- Other
The power of self care

Building your Resiliency Toolbox: Things I like to do

- Dinner/drinks with friends
- Go to a concert/play
- Dance
- Garden
- Cooking class
- Other
The power of self care

Make a distinct break between work and home

- Before pulling out of the parking lot, stop and listen to music or call someone
- Take any identifiers off as a ritual
- Play your favorite music or enjoy the silence during the drive
- Listen to a book on tape
- Walk or bike to work
- Have a “I’ve arrived at home” ritual
The power of self care: At work

Personal
- Take a walk
- Wash your hands mindfully
- Talk to a trusted co-worker
- Take the yellow staircase
- Yoga Stretches
- Other

Team
- Create/Use a Critical Incident Stress Management (CISM) team
- Clinical Supervision
- Use ritual—individual or group
- Other
References


Questions

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  – Recording of webinar and copy of slides will be posted within 2 weeks on the NCFRP website: www.ncfrp.org
NCFRP is on Social Media: NationalCFRP
What’s Next?

Our next webinar:

NEXT WEBINAR
March 27, 2019
1:00 p.m. – 2:00 p.m. ET

New Resources from the National Center for Fatality Review and Prevention

To Register:
https://attendee.gotowebinar.com/register/7325918829213475596

The National Center for Fatality Review and Prevention
THANK YOU!

Additional questions can be directed to: info@ncfrp.org