

Perinatal Mental Health: Loss and Grief

Marianela Rodríguez-Reynaldo, PhD, PMH-C

May 17, 2022



Mountain Plains (HHS Region 8)

MHTTC

Mental Health Technology Transfer Center Network
Funded by Substance Abuse and Mental Health Services Administration

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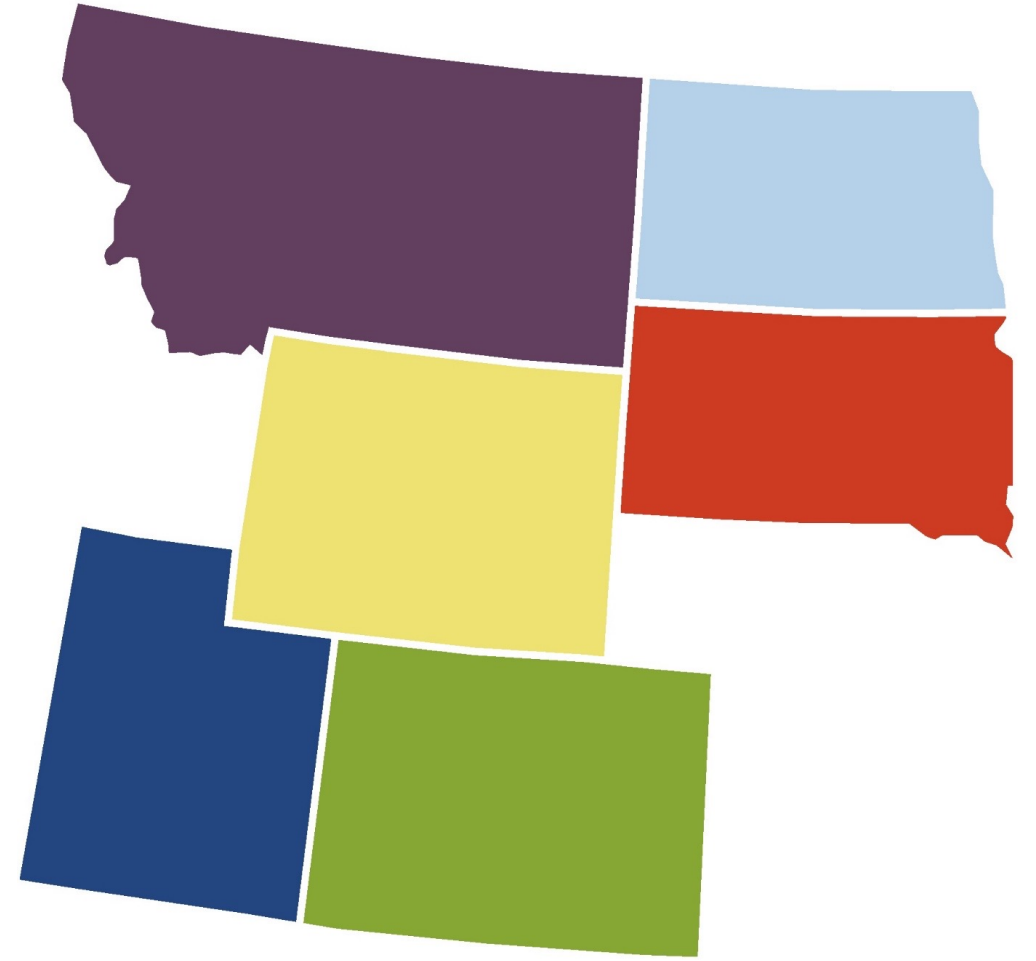
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The Mountain Plains Mental Health Technology Transfer Center

The Mountain Plains Mental Health Technology Transfer Center (Mountain Plains MHTTC) provides training and technical assistance to individuals who serve persons with mental health concerns throughout Region 8 (Colorado, Montana, North Dakota, South Dakota, Utah and Wyoming).

We belong to the Technology Transfer Center (TTC) Network, a national network of training and technical assistance centers serving the needs of mental health, substance use and prevention providers. The work of the TTC Network is under a cooperative agreement by the Substance Abuse and Mental Health Service Administration (SAMHSA).



Land Acknowledgement Statement

Today, the University of North Dakota rests on the ancestral lands of the Pembina and Red Lake Bands of Ojibwe and the Dakota Oyate - presently existing as composite parts of the Red Lake, Turtle Mountain, White Earth Bands, and the Dakota Tribes of Minnesota and North Dakota. We acknowledge the people who resided here for generations and recognize that the spirit of the Ojibwe and Oyate people permeates this land. As a university community, we will continue to build upon our relations with the First Nations of the State of North Dakota - the Mandan, Hidatsa, and Arikara Nation, Sisseton-Wahpeton Oyate Nation, Spirit Lake Nation, Standing Rock Sioux Tribe, and Turtle Mountain Band of Chippewa Indians.



The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

STRENGTHS-BASED
AND HOPEFUL

INCLUSIVE AND
ACCEPTING OF
DIVERSE CULTURES,
GENDERS,
PERSPECTIVES,
AND EXPERIENCES

HEALING-CENTERED AND
TRAUMA-RESPONSIVE

INVITING TO INDIVIDUALS
PARTICIPATING IN THEIR
OWN JOURNEYS

PERSON-FIRST AND
FREE OF LABELS

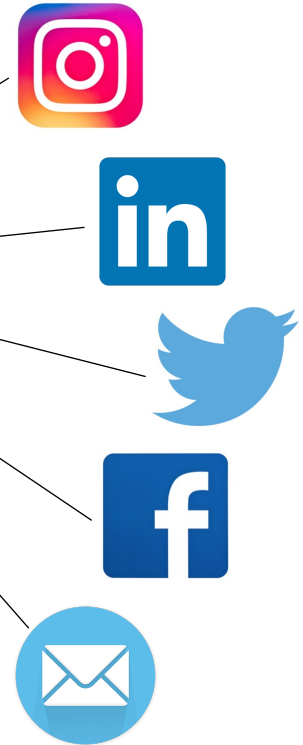
NON-JUDGMENTAL AND
AVOIDING ASSUMPTIONS

RESPECTFUL, CLEAR
AND UNDERSTANDABLE

CONSISTENT WITH
OUR ACTIONS,
POLICIES, AND PRODUCTS

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A hand is shown holding a pink and teal ribbon, which is a symbol for perinatal loss. The ribbon is looped around the fingers and extends across the bottom of the frame. The background is a dark, textured wooden surface. A teal rectangular box is overlaid on the right side of the image, containing the title and author information.

Perinatal Loss and Grief

Marianela Rodríguez-Reynaldo, PhD, PMH-C

1. Identify key concepts related to perinatal loss.
2. Consider the impact of grief and loss during the perinatal period.
3. Examine effective ways to support individuals who have experienced perinatal loss.

*Trigger warning

*Self-care.



Objectives

Take a moment...

- Do you customarily think of perinatal work as dealing with grief and loss?
- Do you integrate questions about perinatal loss in your clinical history/intake? What do you do with that information?
- Make a list of all the instances in which losses may occur, from the decision to get pregnant through birth.
- How many did you list?

General Definitions

- **Loss** a state of being without usually accompanied by grief.
- **Grief** is an emotional response to the loss of something or someone held dear; it is the internal response to loss.
- **Mourning** is the process, often culturally defined, that one goes through to deal with these emotions. It is a public or external response to the death of a loved one.
- **Bereavement** is the period of time during in which grief is being resolved.

IF YOU'RE PREGNANT DURING A PANDEMIC YOU MAY BE GRIEVING

@healthy.highriskpregnancy



Sudden changes
to your birth plan &
labor options that
you didn't choose



Cancelled
celebrations of
important
milestones



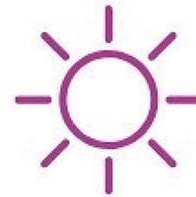
The expectation
of a peaceful
delivery without
fear



Being able
to nest in
peace



Being physically
surrounded by help
in the postpartum
period



Preparing to
welcome a
baby with joy
instead of fear



Waiting to
introduce baby in
person to
important loved
ones

Recognizing Our Own Feelings

- Who has/have experienced perinatal loss in your family?
- What was my first experience with death?
- How do I feel about death?
- Am I comfortable talking to others about death?
- Do I have any unresolved issues regarding a death/loss in my life?

A wife who loses a husband
is called a widow.

A husband who loses a wife
is called a widower.

A child who loses his
parents is called an orphan.

*There is no word for a parent
who loses a child.*

That's how awful the loss is.

#rompeelsilencio

por un diario respetado

ADRIÁN NACIÓ SIN VIDA.
SU HERMANO NO LE REEMPLAZA.
HEMOS TENIDO 2 HIJOS, UN
HIJO NO SE SUSTITUYE.



#rompeelsilencio

por un diario respetado

VERA ESTUVO AQUÍ DENTRO 38 SEMANAS
NO ME DIGAS QUE NO ES MI HIJA.
NO ME PIDAS QUE LA OLVIDE.



Why the silence?

- Unborn baby is not perceived as a “**social being**”.
- **Physical** = we cure it, we forget, we hide.
- Lack of conceptual clarity in the literature impede research



The death of any child is tragic.

BUT

But the disparity in urgency, funding and action to prevent stillbirth is obvious.

› \$17 million in federal funds allocated annually for SIDS research.

› \$26.8 million allocated for pediatric cancer research by the American Cancer Society alone.

› \$298 million allocated for prematurity research

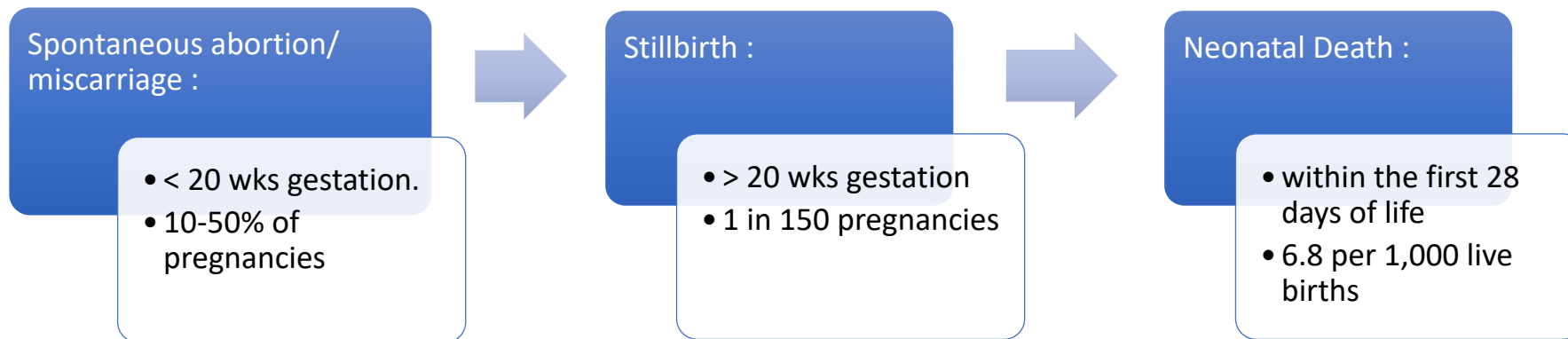
› **Less than \$3 million in federal funds allocated annually for stillbirth research.**


Star Legacy Foundation
www.starlegacyfoundation.org

Source: National VRI Statistics Reports
Vol. 61, No. 6, October 10, 2012

Definitions and terminology

- Perinatal loss is most often defined as the involuntary end of pregnancy from conception, during pregnancy, and up to 28 days of the newborn's life (AAP & ACOG, 2002).



- Miscarriage
- Intrauterine Fetal Demise (IUFD)

Perinatal Loss (Kowalski, 1987)

- Infertility/ fertility challenges
- Ectopic pregnancy
- Abortion (elective, therapeutic or spontaneous)
- Elective reduction
- Fetal death, death of a multiple
- Neonatal death
- Sudden infant death syndrome (SIDS)
- Adoption

Frequency in United States

- More than 1 million pregnancy losses annually
- 1 in 160 births (24,000 babies a year) are stillborn
- 25% of all conceptions end in loss
- 24.5 % (28 weeks until birth)
- 33.8% are neonatal deaths (> 28 days)
- 16.1 % occur from 28 days to 1 year of age.

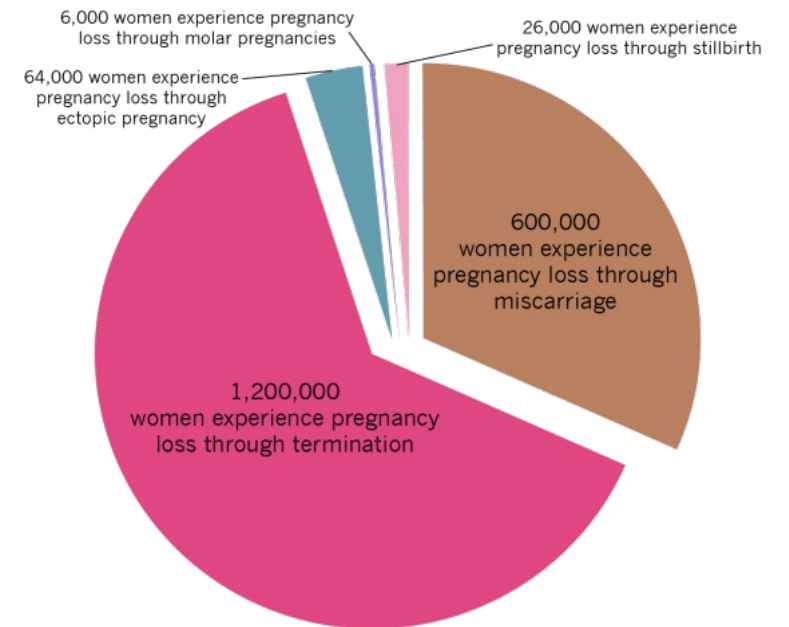
1 in 4 is not just a statistic. It's *me*.



Speak out about pregnancy loss.

Etiology and risks

- 76% of cases worldwide are unexplained
- Half of the world's stillbirths linked to intrapartum complications
- Fetal growth restriction
- Placental abnormalities
- Diabetes increases risk of stillbirth x 5
- Race (non-Hispanic black women)
- Obesity
- Age





Unique aspects of perinatal grief

Paradoxes

- Death can happen before birth.
- Go through pregnancy and end up without a baby.
- The body behaves as if there was a baby to nurture.
- The ability to conceive and give birth to a healthy child.
- Parents outliving their children.



Todd Hochberg

Other aspects to consider that impact the grieving process

- No established rituals
- Minimal support available
- Few socially acceptable avenues for mourning
- Little opportunity for anticipatory grief
- High technology
- No actual body to grieve
- Prospective vs retrospective grief

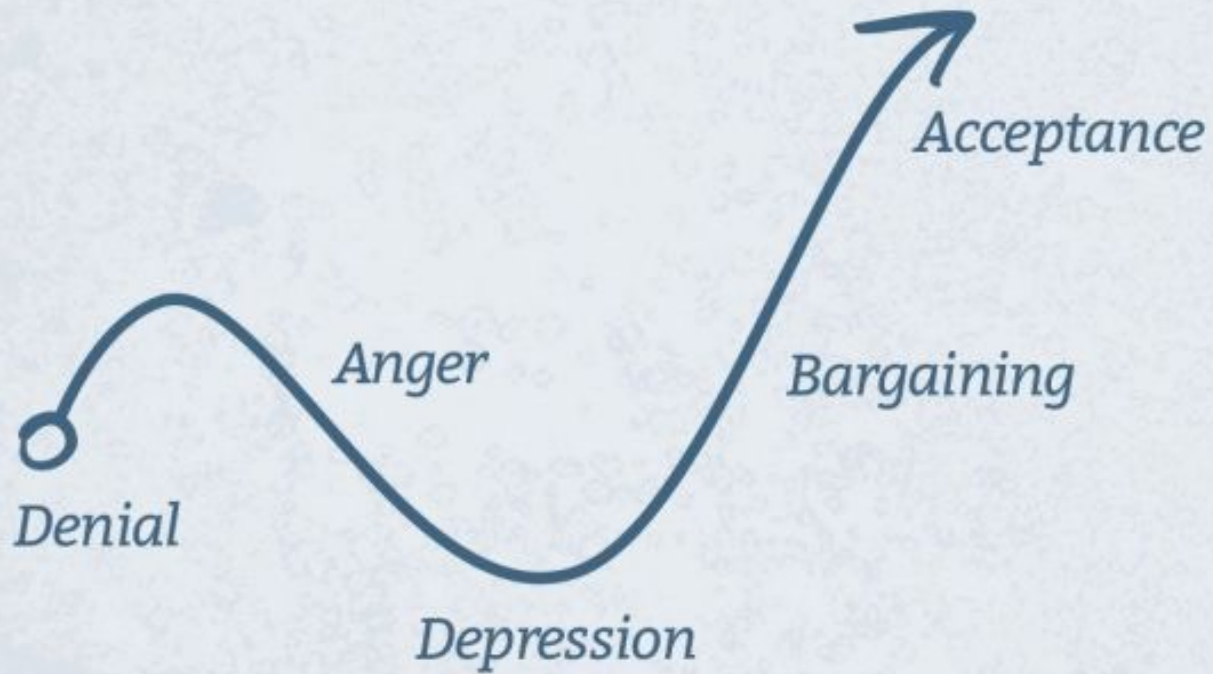
Major life transition

- Re-define our role as an adult.
- Abandon or adjust to the parental role.
- Reproductive story.
- Introjections- keeping a sense of the child and emotional bond.



Stages of Grief

The roadmap you expected:



The road you got:

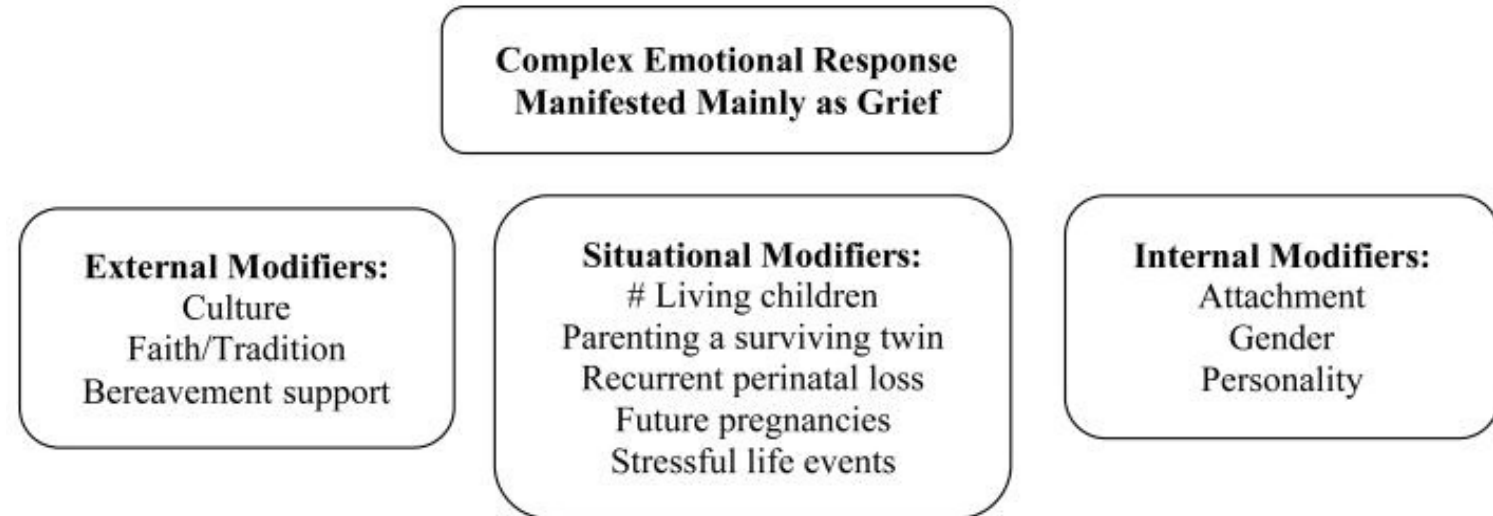


Perinatal Bereavement (Fenstermacher & Hupcey, 2013)

Antecedents

- Hopes and dreams of parenthood
- Sudden or unexpected loss of an infant through miscarriage, stillbirth, neonatal death or by elective termination for fetal anomalies
- Experienced by the parents

Attributes:



Outcomes:

- Interpretive experience with no prescribed ending point
- Renegotiating sense of self, redefining hopes and dreams of parenthood
- Ascribing meaning to the experience



Perinatal grief: a family's journey

Mother/pregnant person's grief

- Mothers whose experience the sudden death of a child tend to have more **intense grief** reactions than those mothers whose children die as a result of a chronic condition.
- **Mortality rates** are higher in mothers who have experienced the death of a child.
- **Isolation** from peers and from the world
- Cause **inner conflicts** and the need to re-organize self-esteem
- Grief impacted by physiological changes in her body and hormone levels
- **“Phantom”** fetal movements
- Her arms may literally ache for the baby

Father/partner's grief: Forgotten bereaved

- Differences in gender roles
- Underestimated in research and practice
- May not be validated to the same degree as the mother's grief
- May be perceived as mere witness
- Tends to peak around 30 months after the death of a baby.



Partner's grief

- General trust in life and the natural order was suddenly and severely tested.
- May experience physical pain.
- Need to protect partner and grieve in their “own way”.
- May return to usual routine more quickly.
- Sexual intimacy may be perceived as a reminder of the loss.

Non-binary people's experience

- 2020 international qualitative study
- Identified 10 themes including: feelings of devastation, minimization of loss; fears; lack of inclusion from hospital settings; lack of understanding from family; importance of friends
- Recommendations for clinical practice:
 - Focus on emotions attached to pregnancy
 - Need for targeted support for trans men and non-binary individuals
 - Training for hospital staff on the provision of trans-affirming medical care

Grandparents

- Grieve the death of their grandchild
- Hurt because their children are hurting
- Question their own existence, survivor's guilt
- May be asked to help with decision-making
- May try to take over, unsure how to help
- May have history of own perinatal loss that was unsupported



Siblings

- May minimize their own grief in order to avoid “upsetting” their parents
- May delay their own grief
- Behavioral changes
- May fear their own death
- Grieving parents may be emotionally unavailable
- Usually do not have a social support system to help them cope
- Survivors guilt





Pregnancy after loss

PAL

50-60% are pregnant within one year after the loss

- High risk pregnancy?
- Fear, anxiety vs. hope, optimism
- ANXIETY is the hallmark of PAL
- Substitute baby syndrome
- Impact on parenting



Common themes

- Fears: sexuality
- When does the joy come?
- Reliving memories of the previous pregnancy
- Fear of failure. Fear of forgetting the lost baby.
- Biological clock...
- When is the best time to conceive again? How do I know am ready?
- When the desire of having another baby outweighs the fear of the possibility of another loss...

Milestones

- Parents may need help addressing milestones:
- Gestational age of past losses, previous due dates, and anniversaries
- Ultrasonography, fetal heart rate monitoring, quickening, viability, and prenatal tests
- Setting up the nursery for the new baby

Pregnancy After Loss:

The hardest thing I've ever done after burying my child.



Support

What can be done in hospitals?

- Systematic review of quasi-experimental studies and randomized controlled clinical studies found:
- Interventions performed prior to perinatal death show that support the process and outcome with the use of conscious awareness of thoughts and feelings help with coping and reduce anxiety in women.
- The information that parents receive about what they are going to experience is important.
- Parents must be prepared and informed about the process.
- Trauma informed care; sensibility; awareness; holistic approach to care.

Honoring the baby

“Grieving is not a process of forgetting, but rather of remembering”

- Obtaining mementos from hospital (e.g., blanket, footprints, hair...)
- Rituals
- Cultural and spiritual diversity
- Photographs:
 - Validate the parent’s feelings at the time of death up to the present
 - Provide an affirmation of parenthood
 - Provide a tangible record of their time with their baby
 - Allow parents to connect with the many feelings and memories that may have been otherwise lost

Return to Home: Anticipatory Guidance

- What to say/how to tell others:
 - Supply parents with a few phrases (e.g., “Our baby has died,” or “We aren’t pregnant anymore”).
 - Suggest they plan what/how they might tell others.
 - Suggest sending mail to notify others.
- How to deal with the reactions of others
- Offer follow-up

Interventions after the loss...

That have been shown to improve depression, sleep, and the grieving process:

- Psychoeducation
- Psychotherapy
- Physical activity
- Group sessions
- Educating women, spouses, and extended family about PD and grief

Counseling and Psychotherapy

- Research is limited
- Couples therapy
- Internet-based CBT
- Support groups
- Individualized Psychotherapy
- Mindfulness



Goals of treatment

- **Validate loss**
- **Facilitate mourning process**
 - Creating a safe relationship in which to grieve
- **Catharsis**
 - Connection and understanding
 - Containment
 - Clarification of experience
- **Facilitate acceptance**
 - Reduce isolation
- **Normalize loss**
 - Telling others, the story
 - Development of new attachments

Clinical errors...

- Minimizing or avoiding painful affects related to the miscarriage
- Assuming grief is resolved upon a subsequent healthy pregnancy
- Neglecting early unresolved losses that are reawakened by the loss of the pregnancy

vs. Assuming...

- Miscarriage is often a traumatic loss in a woman's life
- Approach the traumatic event of the loss within a safe affect regulating relationship with the therapist.

Responses to Parental Grieving

HELPFUL

- I am so sorry.
- Some parents find that _____ is helpful. Would you like to try that?
- Your baby is beautiful.
- Do you see any family resemblance?
- What a shock this must be for you.

HURTFUL

- It was not meant to be.
- It was for the best. Your lucky you never took him home.
- You are young. You can have another baby.
- Over time, you will forget your baby.
- When was the last time you felt your baby move?

Support virtual groups | www.postpartum.net

- Black Moms in Loss Support Group
- Early Pregnancy Loss Support for Moms
- Fertility Challenges
- Pregnancy after Loss
- Pregnancy and Infant Loss for Moms
- Pregnancy and Infant Loss Support for Parents
- Termination for Medical Reasons
- Post-Abortion Support

It takes a village...

- International Stillbirth Alliance
- First candle
- missfoundation.org
- Miscarriage Matters
- March of Dimes
- Share.org
- RTZ.org
- Start your local support group



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Q and A



Let's connect!



Mrodriguez.inter@gmail.com



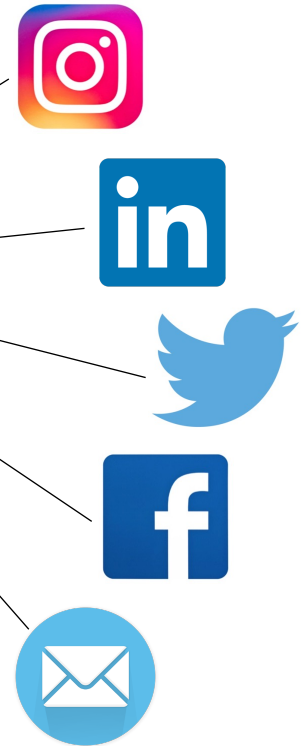
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