Supporting Perinatal Loss Clients in the Community



LABBN
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Learning Objectives



After this lecture, participants will be able to:

- Understand what a family may be going through following the loss of a child
 - Including feelings, physical reactions, logistical things that the family may need to set up, etc.
- How to talk with families after the loss of their child
 - Including managing your own feelings and asking for help from a supervisor if needed
- What kind of support families may need following the loss of a child
- When and how to offer support
- Community resources that a Parent Coach could provide

My Story









What is Perinatal Loss?



Types of Perinatal Loss

- Miscarriage (< 20 weeks)
- Ectopic or molar pregnancies,
 Blighted ovum
- Termination for medical reasons
- Stillbirth (> 20 weeks)
- Neonatal death (1st 28 days)
- Infant death (1st year of life)



Tracking Perinatal Loss



- Increase of perinatal loss during Covid
- FY 20-21: 12 losses
- FY 21-22: 8 losses
- Family Strengthening Network
 Sentinel Event Protocol



Pregnancy & Loss History



Using intake form to assess pregnancy & loss history

- How many losses
- Type of loss(es)
- When losses occurred in the birth order (children before or after loss)

Grieving in Communities of Color



- Weathering
- Systemic Racism
- Implicit Bias



RTZ Website https://rtzhope.org/bipoc

http://www.laist.com/2018/06/28/americas black babies are paving for societys ills what will we do to fix it.php



https://rtzhope.org/bipoc

Loss in the LGBTQ+ Community



- Systemic discrimination
- Complex family-building journey
- Non-gestational parents

RTZ Website

Parents: https://rtzhope.org/lqbtq

Providers: https://rtzhope.org/providers



Ending a Wanted Pregnancy (TFMR)



- Societal stigma
- Making a decision
- Lack of services



RTZ Website for Parents - TFMR

Preparing Parents



What Parents Experience



- Shock/disbelief
- Anticipatory grief
- Fear and anxiety
- Making impossible decisions
- Second-guessing their decisions

Supporting Parents



- Empathy
- Ask how they'd like you to refer to the pregnancy
- Ask if they named the baby
- Give them time and space
- Don't assume

Reducing Regrets and Creating Healing Experiences in the Hospital



RTZ Hospital Guide



nere is not any one, perfect way to walk through this process, nor is there much anyone can do to prepare for such a hearthr

We want you to know you are not alone. Other parents i your situation have contributed to this guide, developed i give examples of actions you might consider at this time. We hope it will make the only moments with your chill beautiful peaceful, and without regret.

IF YOUR BABY HAS DIED IN-UTERO

OW DOWN—there is no rush (unless medically necessary),
a family member or close friend to make calls to notify others
your baby has passed away.

Request a room at the end of the maternity ward or on anothe

- Ask the nurses to describe what your baby will look like after he/she is born.
- ❖ You may also decide to use a bereavement doula in your area to

IF YOUR BABY WILL BE BORN ALIVE BUT IS NOT EXPECTED TO LIVE

In addition to the suggestions above, the following may pertain to you:

- What are the final wishes you have for your baby? Would you like to take your baby outside in the sunshine, moonlight, or garden?
- Ask the nurses to describe what you may see or hear during your baby's dying process.
- Request a private and peaceful space
- You may hold your baby as he/she passes

- AFTER YOUR BABY IS BORN, WE RECOMMEND:
- Having skin-to-skin contact with your baby
- Rocking, holding, kissing, and cuddling your baby
- ◆ Bathing your baby
- Putting a diaper and clothes on your baby
- Singing and reading a book to your baby
- Asking hospital staff for a lock of hair from your baby
- Making hand and foot prints
- Taking photographs of and with your baby. You will only have this one opportunity to capture these images which you will cherish for the rest of your life. For a volunteer bereavement photographer, we recommend www.nowilaymedowntosleep.org or a local contact through your hospital.
- Requesting a religious service or ceremony in the hospital (i.e. baptism) if applicable
- Asking your care provider for a comfort cot or ice packs so you can prolong your time with your precious child.

ou may also have the legal option to take your baby homer a home memorial/funeral should you desire it, even our ask for an autopsy. If you do this, keep ice package young and under the infant's body at home

RTZ website Hospital Guide

Making Memories



- Normalize the experience
- Reduce future regrets
- Give the family as much time as they want with their child
- Discuss photographs
- Creating memorial items and healing experiences
- Know that trauma is all relative



(Photo https://www.nowilaymedowntosleep.org/)

Involving Siblings



- Assure them they did nothing wrong.
- Answer questions in an age appropriate manner.
- Give grieving children choices whenever possible.
- Limited amount of tolerance for uncomfortable feelings.

RTZ website: Siblings and loss



(Photo https://www.nowilaymedowntosleep.org/)

What to Say and Not Say



What Not To Say



- Everything happens for a reason
- At least...
- Time heals all wounds
- It's going to be okay
- Let go, move on
- Have faith
- Be thankful...



- God has a plan
- Keep busy
- You are young, you can have more children
- At least you can get pregnant
- Be thankful you have other children
- Your baby would have been very sick if she/he lived

What's Helpful To Say



- We are here to support and guide you through this
- I am so sorry for your loss
- I care about you
- You didn't do anything wrong
- This isn't your fault
- Ask if they named the baby, and if so use the baby's name
- Ask if they took photos and if they would share; tell them their baby is beautiful
- Check on the partner too

Talking With Parents



- Acknowledge the loss
- When to follow-up?
- What if they don't respond or hang up?
- Ask: How are you feeling? What type of support are you getting? If appropriate, ask about the baby.
- Listen without judgement
- Multiple losses

MATERNAL HEALTHCARE BILL OF RIGHTS

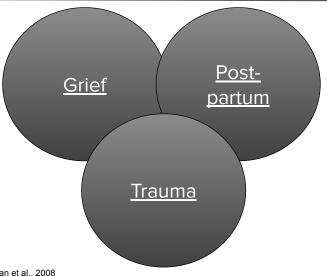
https://rtzhope.org/blog/2021/9/2/bipoc-maternal-healthcare-bill-of-rights

Perinatal Loss and Mental Health



Mental Health and Perinatal Loss





Gold et al., 2016; Rich, 2018; Surkan et al., 2008

Common Themes Among Bereaved Parents



- Isolation Feeling alone
- Bodies have failed them
- Self-blame
- Shame
- Guilt
- Anger towards health care providers
- Avoidance of health care providers associated with loss
- Changes in relationships with spouse, family, friends

Typical Trauma Symptoms



- Depressed mood, irritability, or anger
- Feelings of insecurity, guilt, and low self-worth
- Anxiety
- Flashbacks to the loss
- Inability to remember moments around the loss experience
- Inability to concentrate, recurring thoughts, being in a mental fog
- Sleep too much or too little

RTZ Website Navigating Trauma After Loss

Suicidal Thinking in Perinatal Loss



What is a problem? Patient is feeling hopeless, overwhelmed, and unable to function. Suicidal thoughts. Follow clinic procedure for suicidal clients.

Example of suicidal thoughts in perinatal loss

- I can't go on
- I did something wrong
- I want to be with my baby
- I can't live without my baby
- I deserve to die
- If I hadn't done _____ my baby would have lived, I should be punished
- No one is talking to me, they think I killed my baby, I can't do this anymore

Partners Grieve Too



- Delayed grief
- Signs of grief and trauma
- Postnatal Paternal Depression

RTZ Website Partners Grieve, Too

Navigating life after baby loss



What's helpful?



- Creating meaning
- Ongoing bonds with the deceased child
- Ritual
- Social Support (family and friends)
- Support groups (bereaved parents)
- Movement
- Nature

RTZ Website Finding Healing and Improving Wellbeing

Creating connections to baby



- Talking and/or writing to baby
- Photos of baby
- Sacred area
- Connect through nature
- Wear jewelry with baby's name, birthstone, etc.
- Participate in remembrance walks
- Donate or volunteer in baby's honor

RTZ Website Connecting With Your Child

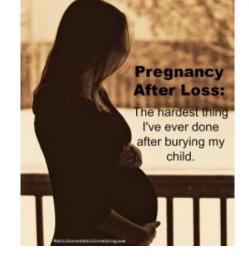
Pregnancy After Loss



Pregnancy After Loss (PAL)

Between 50-80% of women who have experienced a pregnancy loss will become pregnant again.

Having a subsequent healthy pregnancy does **NOT** resolve the mental health problems women experience after a miscarriage or stillbirth.



RTZ Website: Pregnancy After Loss

Pregnancy After Loss (PAL)



- Can be traumatic and complex
- Can experience a duality of emotions
- Can be difficult to form attachment



Responsive care



As providers, it's important that we:

- Be responsive to parent's individual needs and concerns
- Take time to discuss previous losses
- Ask them what would be most helpful
- Encourage them to reach out by phone to ask questions or go into office to receive reassurance

Cote-Arsenault & Morrison-Beedy, 2001

How to support



- Understand that the new baby does not replace the deceased baby
- Realize that this new baby will not "heal" the grieving parents
- Validate continued bonds with their deceased child
- Remember and honor the deceased child

Attachment to new baby



- Encourage the parent-(new) baby attachment
- Acknowledge that pregnancy after loss is difficult
- Validate their feelings
- Help them realize this is a different pregnancy, with a different baby, and a different outcome

Empower parents



- Continue to check in with them, as emotions change over time
- Help them gain a sense of agency/control
- Advocate for themselves with other medical providers/procedures
- Help to create a birth plan

Referring Out for Support



Referring Out for Support



All parents who experience loss need support.

- Support groups
- Counseling/therapy
- Psychiatry
- Acupuncture
- Movement/Exercise/Yoga

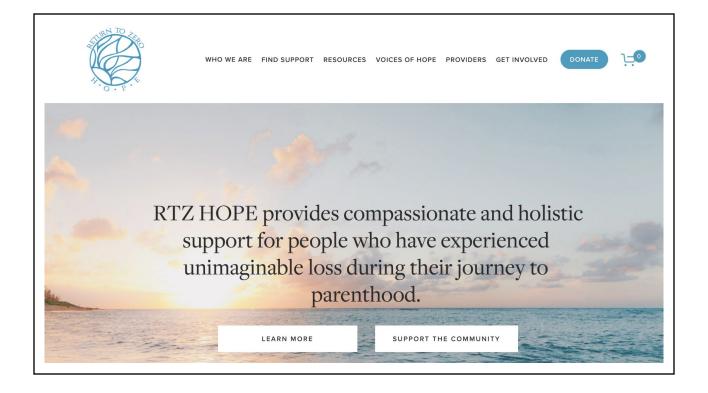
Support Directories



Pregnancy and Infant Loss Directory (Part of RTZ HOPE)

Maternal Mental Health NOW Provider Directory (Los Angeles specific)

RTZ HOPE Virtual Support Groups (cost for group, but people can ask for funding support)



Links to further resources

RTZ HOPE Virtual Support Groups

RTZ HOPE Perinatal Bereavement Brochures

RTZ HOPE Pregnancy and Infant Loss Directory

Return to Zero: HOPE Pregnancy After Loss

RTZ HOPE Providers page



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Questions



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Slides we removed....



Validate All Losses



No matter how long a woman is pregnant

Preparing for Procedures



- D&C/ D&E
- Caesarian
- Labor induction
- Stillbirth

Labor & Delivery



- Slow things down
- Create a safe space
- Modified birth plan
- Always use the term "baby"; if the parents have named their baby, use his/her name
- Take care of both parents



Parenting the Baby



- Naming the baby
- Having skin-to-skin contact
- Rocking, holding, kissing, and cuddling baby
- Bathing the baby
- Putting a diaper and clothes on baby
- Singing and reading to baby
- Ask parents if they would like to request a religious service or ceremony in the hospital (i.e. blessing, baptism)



(Photo http://narrative.ly/capturing-the-briefest-of-lives/)

Paternal Postnatal Depression



- What is this?
- Why is it under-diagnosed?
- **Symptoms**
- Untreated

Pregnancy After Loss (PAL)

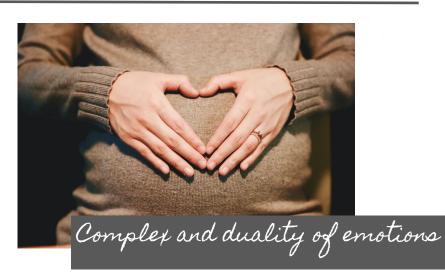




Can be a traumatic experience

Pregnancy After Loss (PAL)





Pregnancy After Loss (PAL)





Trauma of the Ultrasound





"It is the **subjective perception** of trauma that appears to be more important in the development of symptoms of PTSD." (O'Leary)

Mental Health in Pregnancy After Loss



Risk Factor for Mental Health Challenges



Experiencing perinatal loss and birth trauma puts a woman at higher risk of developing mental health complications in subsequent pregnancies

- After a stillbirth, significantly more depression in the 3rd trimester during subsequent pregnancies
- Higher anxiety if conception occurred within a year of stillbirth
- After a stillbirth, 21% of women reported PTSD symptoms in the 3rd trimester during subsequent pregnancies

Gaudet, Sejourne, Camborieux, Rogers, & Chabrol (2010); Gold, Leon Boggs & Sen (2016); Main & Hesse (1992); O'Leary (2004)

Navigating Pregnancy After Loss



Helping Parents Navigate PAL



Acknowledgement

Normalization

Empowerment

Helping Parents Navigate PAL



Honoring the deceased child

Attaching to the new baby

Creating connections to deceased baby



- •Talking and/or writing to baby
- Photos of baby
- Sacred area
- Connect through nature
- •Wear jewelry with baby's name, birthstone, etc.
- •Participate in remembrance walks
- •Donate or volunteer in baby's honor

Passing the gestational stage of loss



Going beyond the gestational stage of their prior loss in the current pregnancy, <u>may</u>:

- Reassure parents
- Have hope for the future (of having a live baby)
- Allow themselves to invest and bond with the child

Gaudet, Sejourne, Camborieux, Rogers, & Chabrol (2010)

Fathers, Partners, and Loss



Risk Factor for Mental Health Challenges



Experiencing perinatal loss and birth trauma puts a woman at higher risk of developing mental health complications in subsequent pregnancies

In addition, the existence of mental health problems:

- Is an added risk factor for poor fetal outcomes during a subsequent pregnancy
- Can negatively affect the attachment to the subsequent child

Gaudet, Sejourne, Camborieux, Rogers, & Chabrol (2010); Gold, Leon Boggs & Sen (2016); Main & Hesse (1992)

Stillbirth and subsequent pregnancy



- Significantly more depression in the 3rd trimester during subsequent pregnancies
- Higher anxiety if conception occurred within a year of stillbirth
- 21% of women reported PTSD symptoms in the 3rd trimester during subsequent pregnancies

O'Leary (2004)

Parenting after loss



- Anxiety
- Fear
- Guilt
- Grief