Maternal Mental Health: Perinatal Loss Julia Ewanowski, LCSW MPH



OUTLINE

- Terms & Prevalence Impact on
- Termination
- Common Responses
- Miscarriage
- Loss of a twin/multiple
- Loss of control of one's body

- Impact on Relationship
- Other types of losses
- PMADS
- Five Stages of Grief
- Our Role
- Resources



PREGNANCY LOSS TERMS & PREVALENCE

- Miscarriage up to 20 weeks
- Intrauterine Fetal Demise (IUFD) 20 weeks and beyond that results in delivery (stillborn)
- Neonatal Loss- loss post delivery
 - More than 1 million fetuses in the US die each year before birth
 - Majority before 20 weeks gestation, prior to confirmation of pregnancy
 - 15% of recognized pregnancies will end in a intrauterine loss
 - 80% of losses occur within the first three months of pregnancy
 - 14% of losses occur in the 2nd trimester
 - 6% of losses occur in the 3rd trimester

"They didn't 'just have a miscarriage'- their baby died.

They didn't 'have a stillborn'- they had a baby that didn't survive.
They didn't 'just go through baby loss'- their child died.
Language changes

everything

Zoe Clark-Coates



LOSS THROUGH TERMINATION

- 3 out of 10 women in the US have a termination by the time they are 45 years old
- Regardless of reason, most women feel complex feelings of grief and/or relief
 - Guilt, shame and or **reluctance to share** this loss with others
- Sometimes making a decision under time constraints
 - State by state laws about gestations age limitations
- Physical/emotional pain to undergo the termination procedure
 - Medical abortion (generally up to 14 weeks)
 - Surgical abortion (14- 24 weeks)
- Late stage abortion clinics (26+ weeks)
 - Frequently used for maternal health risks and fetal anomaly diagnoses received post state regulation guidelines
- Stay aware of the political climate & language used



COMMON RESPONSES

- Difficulty internalizing the fact that death has occurred
- Bonding occurs well in advance of birth
- A violation of expectations "this wasn't supposed to happen"
- Envision of a lifetime with baby at moment of confirmation of pregnancy
- Self-esteem and stigma "miscarriage"
- Trust and control violation of one's own body "something is wrong with me" or "my body failed"
- Anticipated parenthood



MISCARRIAGE: COMMON RESPONSES

- Highly stigmatized, person may feel shame or silenced like they are not supposed to tell others
- Rainbow baby- increased anxiety in pregnancy following loss-
 - Coming to term: Uncovering the truth about miscarriage by Jon Cohen
- Cultural standard: wait to share pregnancy news until you are "out of the woods" after first trimester
 - Not a predictable timeframe-many losses occur later
 - Essentially translates: don't share your good news (pregnancy) in case it becomes bad news so that you won't have to share the bad news-furthers the silence and isolation of infant loss
 - Dr. Jessica Zucker, PhD #ihadamiscarriage
 - "...But if every woman who has lost a pregnancy to miscarriage or stillbirth told her story, we might at least feel less alone"



LOSS OF A TWIN OR MULTIPLE

- Rates of multiple births are increasing (reproductive technology)
- Early (1st trimester) losses or "vanishing twin"
- Loss due to medical intervention (selective reduction)
- Bed rest post twin loss
 - High-risk pregnancy: loss of a typical pregnancy
- Many conflicting emotions:
 - Sadness
 - Shock
 - Guilt
 - Relief
 - Bittersweet happiness for the surviving twin
 - Grief process is complicated *likely trauma response
- Loss of identity as a "mother of multiples"



LOSS OF CONTROLS OF ONE'S BODY

- Lose confidence on her own body, sense of safety completely violated
- Shocked to discover potential ambivalent feelings or even relief, about the loss which can often lead to guilt
- In effort to gain control over the situation, often look for ways to place blame (self-criticize)
- May not have shared the news of her pregnancy yet
 - Friends/family may minimize the loss ("You were only a few weeks pregnant" or "You can try again")
- Fear and anxiety in subsequent pregnancies
- Multiple miscarriage/infertility: complex feeling of loss of control of one's body
 - "My body is broken"
 - Feelings that you are not a "real woman"
 - Fear of inevitability that it will probably end in heartbreak
 - High rates of trauma*



IMPACT OF LOSS ON RELATIONSHIPS

- Relationships can be strengthened through sorrow
- However, 12% of couples separate after a perinatal loss
- Anger, guilt and attempts to place blame on one another
- Often the partners are not in sync with each other's grieving process
- Differences can cause relationship strain as couples attempts to reconcile their fetal loss



OTHER TYPES OF LOSS

- Financial Loss
- Role of "Mother"
- Loss of naivety of uncomplicated pregnancy
 - high risk pregnancies
 - pregnancy after loss
- "Limbo of loss"place of uncertainty
- Relationship conflicts

- Cultural context of loss/death
- Anniversaries
- Clothes/possessions
- Holidays
- Talking with your other children

"...for the bereaved, it's moving into a new calendar year which their loved ones will never live in"

Zoe Clark-Coates



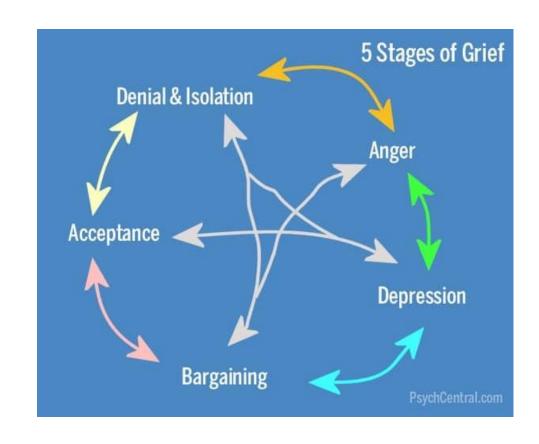
PREGNANCY LOSS AND PMADS

- Moms who experience perinatal loss are at increased risk for:
 - PTSD (panic, nightmares, persistent fears)
 - OCD (reoccurring behaviors to manage distressing thoughts, beliefs, images)
 - Anxiety symptoms (significant at 4 months)
 - Excessive guilt and feeling to blame self
 - Tearfulness and depressed mood
 - Anger, loss of faith
 - Detachment from self, others
 - Avoidance of peers/other pregnant women
 - High levels of anxiety in subsequent pregnancies (constant worry about possible loss, cannot "enjoy" pregnancy for fear of loss)
- 36% of male partners reported severe anxiety at 6 weeks post loss-don't forget the dads!!!



FIVE STAGES OF GRIEF

Denial and Isolation
Anger
Bargaining
Depression
Acceptance



Elizabeth Kubler-Ross



DENIAL

- Paralyzed or in shock or blanketed with numbness
- Not a literal denial
 - "I can't believe this happened"
 - "Did I just dream this? This must be a mistake"
 - "This can't be true"
- Protective instinct: helps us survive the loss, gives a moment away from the pain
- Our minds can't fully process the experience
- Denial lets in only what can be handled



ANGER

- Presents itself in many ways:
 - Self*
 - As a mom, likely to be angry that you couldn't protect your baby
 - Angry at your body
 - Medical staff; healthcare system
 - Towards loved one; family; friends
 - Bad things happen to babies
 - You are left behind without your baby
 - "Parents aren't supposed to outlive their children"
 - Existential anger towards God
- Not logical/valid
- Source of strength (anchor); Encourage to feel; pain underneath



BARGAINING

- Before loss:
 - "It I can just make it to ____ (viability, term, healthy baby),
 I'll never do... be a better person... give back..."
- After loss:
 - "What if I do this... can I wake up and realize this was a dream
- "If only" statements
 - "If only I didn't go for the run..."
 - Guilt is bargaining's companion
- "What if" statements
- Escape from pain
- Distraction from sad reality
- Never actually believe the "if only"

"Baby Loss:

A million what if's.

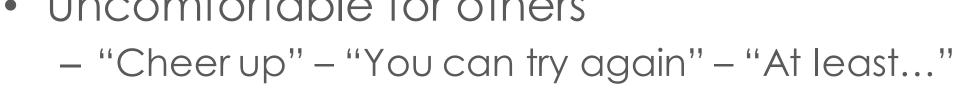
A billion if only's. A trillion I wishes"

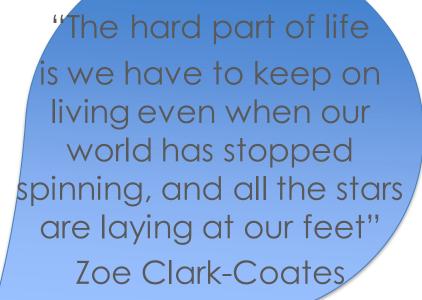
Zoe Clark-Coates



DEPRESSION

- Empty feelings
- Not a sign of mental illness
 - Appropriate response to loss
 - Clinical depression can be Assessed by trained provider
 - Antidepressants can still be helpful
- Withdrawal from life
 - Protective dampening of nervous system
 - Adapt to something overwhelming
- Uncomfortable for others





ACCEPTANCE

- Accepting the reality of the loss and is permanent
 - Not being "okay" with what happened
 - Likely will not ever be "okay"
- Learn to live with the loss
- Remembering, recollecting and reorganizing
- Reintegration
 - Live with the loved one we lost
 - More good days than bad
 - May feel guilty
- Process, not end point

"As long as the sun continues to shine and the stars light up the darkest of skies, I will miss you"

Zoe Clark-Coates

WHAT IS OUR ROLE AS HEALTH PROFESSIONALS?

- Safety first
 - Medical
 - Emotional
 - EPDS
 - Crisis assessment
 - If you're concerned (or EPDS is 10 or more, call SW)
 - Trauma- needs treatment
 - Medication
 - Therapy
 - Support groups
 - Other resources

- Considerations:
 - OB history, multiple losses/infertility
 - Complicated loss
 - Supports
 - family, friends, finances)
 - Internal resources
 - Our own stuff!
 - biases, judgements, perinatal histories, some research to support partnering and sharing of our loss- do so carefully!



WHAT CAN YOU DO TO HELP?

- Show up nonjudgmentally and use words VERY carefully: a silent, non-intrusive and supportive presence is best
- Remember that grief has physical reactions as well as emotional reactions
 - Poor appetite, disturbed sleep patterns, restlessness, low energy, other pains
- Encourage person to talk about their pain and stress- this helps the normal process of grieving to occur
- Reassure the grieving person that their feelings and reactions are normal and necessary for healing

AVOID:

- everything happens for a reason
- you can have other children
- time heals all wounds
- god has a plan
- your baby wouldn't want you to be sad
- god needed another angel
- at least...
- you're so strong
- Focus on expressing your compassion and support rather than asking questions
- Try not to speculate or make assumptions- patients pick up on those!
- Ask for and use the baby's name
- Check in with dads too



PREGNANCY LOSS RESOURCES

- Center for loss in Multiple Births <u>www.climb-support.org</u>
- Helping twins who have lost their twin https://www.twinlesstwins.org
- Grief support for child death https://www.compassionatefriends.org/
- Grief info & support for children https://good-grief.org
- Healing Mama Trauma:
 https://healingmamatrauma.com/resources/postpartum-healing/
- Mommies enduring neonatal death: <u>Https://www.mend.org/resources/</u>
- Quietly united in loss together:
 https://www.facebook.com/groups/473138636104746/
- Good Mourning Bears: https://www.facebook.com/groups/555678861488078/
- Pregnancy and infant loss: http://www.shareparentsofutah.org/p/blog-page-28.html
- First Candle SIDS Alliance SIDS and stillbirths -education and resources, online support group: https://firstcandle.org
- Grieve out Loud Pregnancy & infant loss online support, resources, education: www.grieveoutloud.org
- Share Parents of Utah pregnancy, stillbirth, and infant loss support groups, resources, training: <u>www.sharparentsofutah.org</u>
- Healing your Empty Arms –Coaching & Counseling for grief of baby or child: https://healing-your-empty-arms.teachable.com

SHARE Pregnancy & Infant Loss: www.nationalshare.org

PREGNANCY LOSS RESOURCES

Books:

- Not Broken by Lora Shahine
- Saying Goodbye by Zoe Clark-Coates
- Empty Cradle, Broken Heart: Surviving the Death of Your Baby Paperback by Deborah L. Davis
- Pregnancy After a Loss: A Guide to Pregnancy After a Miscarriage, Stillbirth, or Infant Death Paperback by Carol Cirulli Lanham
- Unspeakable Losses: Healing From Miscarriage, Abortion, And Other Pregnancy Loss Paperback by Kim Kluger-Bell
- A Silent Sorrow: Pregnancy Loss Guidance and Support for You and Your Family (Revised and Updated 2nd Edition) Paperback by Ingrid Kohn
- Healing Your Grieving Heart After Miscarriage: 100 Practical Ideas for Parents and Families by Alan D. Wolfelt
- Empty Arms: Hope and Support for Those Who Have Suffered a Miscarriage, Stillbirth, or Tubal Pregnancy by Pam Vredevelt
- Couples Communication After a Baby Dies: Differing Perspectives by Sherokee Ilse and Time Nelson
- Coming to Term: Uncovering the Truth About Miscarriage by Jon Cohen

Websites:

http://www.postpartum.net/

https://postpartumprogress.com/

https://www.psiutah.org/emotional-health/resources-info/



TERMINATION RESOURCES

Books

- A Time to Decide, A Time to Heal by Molly Minnick, Kathleen Delp and Mary Ciotti
- Our Heartbreaking Choices by Christie Brooks
- Precious Lives Painful Choices: A Prenatal Decision-Make Guide by Sherokee Ilse
- Empty Cradle, Broken Heart by Deborah Davis
- Our Heartbreaking Choices: forty-six Women Share Their Stories of Interrupting a Much-Wanted Pregnancy by Christie Brooks

Websites:

- Endingwantedpregnancy.com
- Aheartbreakingchoice.com



VIDEO FOR PARTNERING THROUGH GRIEF

 https://www.facebook.com/buzzfeedfyi/ videos/312037746243989/



DID YOU KNOW...

- The #1 complication of childbirth is Postpartum Depression (PPD)
- The largest group of Americans with depression are women in childbearing years
- It's not always love at first sight when **mom** & baby meet. Don't worry, It will come. #RealMotherhood Shame
- 1 in 7 women experience PPD
- Maternal depression is the most

under-diagnosed obstetric complication in America



BABY BLUES

Affects: 80% of mothers
Symptoms are transient
and can last up to two
weeks postpartum

- Mood swings/hypomanic
- Anxiety
- Sadness/tearful
- Irritability
- Crying
- Feeling overwhelmed

- Reduced concentration
- Appetite problems
- Trouble sleeping/ exhausted

*With support, rest, and good nutrition, baby blues resolve naturally



POSTPARTUM DEPRESSION

Affects: 20% of mothers

Symptoms can begin immediately and **up to a year** postpartum

- Feelings of anger or irritability
- Lack of interest in the baby
- Appetite and sleep disturbance
- Crying and sadness
- Feelings of guilt, shame

- or hopelessness
- Loss of interest, joy or pleasure in things you used to enjoy
- Possible thoughts of harming the baby or yourself

*Symptoms, especially untreated, can last for many months if not longer



POSTPARTUM ANXIETY

Affects: 6- 10% of mothers

Symptoms can begin immediately and **up to a year** postpartum

- Constant worry
- Feeling that something bad is going to happen
- Racing thoughts
- Disturbances of sleep and appetite
- Inability to sit still
- Physical symptoms like

dizziness, hot flashes, and nausea

*Symptoms, especially untreated, can last for many months if not longer



POSTPARTUM OCD

Affects: 5- 11% of mothers
Symptoms can begin

immediately and up to a year postpartum

- Scary thoughts about baby
- typically horrified by these thoughts
- Extreme anxiety about the thoughts/images
 - Ego-Dystonic
 - Unlikely to harm baby

- Desire to keep baby safe
 - Hypervigilance, "checking"
- Avoidance of the thoughts or feared situations
 - Fear of being left alone with baby

*Symptoms, especially untreated, can last for many months if not longer



POSTPARTUM PTSD

Affects: 9% of mothers

Symptoms can begin immediately and up to a year postpartum

- Re-experiencing
 (flashback, bad dreams,
 frightening thoughts) with
- Avoidance
- Heightened arousal
 - Birth Trauma
 - Medical complications
 - Harm to mother or baby
 - Past pregnancy loss
 - Unplanned C-Section

- Feeling of powerlessness;
 poor communication with providers
- Past sexual abuse
- NICU baby
- May not present immediately but once baby is discharged

*Symptoms, especially untreated, can last for many months if not longer

POSTPARTUM BIPOLAR DISORDER

Affects: 22% of mothers

Symptoms can begin immediately and **up to a year** postpartum

- Periods of severe depression
- Periods when mood much better than normal (mania)
- Rapid speech
- Little need for sleep
- Racing thoughts, trouble concentrating

- Anxiety
- Irritability
- Continuous high energy
- Overconfidence
- 100x more likely to have Postpartum Psychosisneed careful monitoring during pregnancy

*Mania Signs and symptoms are more severe and require immediate treatment



POSTPARTUM PSYCHOSIS

Affects: 1-2% of mothers
Sudden onset, symptoms
usually begin in the first 2
weeks postpartum

- Delusions: strange beliefs
- Hallucinations: seeing or hearing things that aren't there
- Feeling very irritated
- Hyperactivity
- Decreased need for or inability to sleep

- Paranoia and suspiciousness
- Rapid mood swings
- Difficulty communicating at times

*Signs and symptoms are more severe and require immediate treatment



RISK FACTORS

History of Mood or Anxiety Disorders

- Personal or family history of depression, anxiety, bipolar, disordered eating, OCD
- History of Trauma
- Symptoms present during pregnancy; pregnancy complications

Significant Mood Reactions to Hormonal Changes

 Puberty, PMS, Hormonal Birth Control, Pregnancy Loss, History of Infertility

Concurrent Stressors

- Sleep disruptions
- Poor Nutrition
- NICU babies
- Diabetes
- Thyroid imbalance

Psychosocial Factors

- Inadequate social or family support, marital stress, domestic violence
- Financial stress, poverty
- Loss of insurance (Medicaid)
- Cultural or racial minority



ASK





THE EPDS SCREENING TOOL

The Edinburgh Prenatal/Postnatal Depression Screening

- The EPDS was developed to help assist health professionals in detecting mothers suffering from Perinatal Mood Disorders/PPD
- 10 Item, Self-Screen Tool
- Pre & Postnatal Use, Copyright-free
- Available in 23 languages
- Available in Epic flowsheets



EPDS- RECOMMENDATIONS

• Timing:

- First prenatal visit
- 1x in second trimester
- 1x in third trimester
- 6-week postpartum visit
- 6 & 12 mo by OB/PCP
- 3, 9, &12 mo pediatric
 visits

Positive Screen:

- Score > 10
- Anything but"never" to question10
- Fathers cutoff: 5/6
- Anxiety questions:3, 4 and 5

Do not make assumptions, ask every woman, ask more than once, provide resources



POSITIVE SCREEN

- Stay calm.
 - 1. Notify Provider
 - 2. Document in Epic
 - 3. Consult, Social Work
 - 4. Provide Referral
- Practice Active Listening
- Withhold Judgment
- Reflect

- Clarify
- Summarize
- Actively suicidal, homicidal, or experiencing psychosis: go to nearest ED!

Key phrase: "You are not alone, it's not your fault, it will get better."





RESOURCES

- Utah maternal mental health collaborative- (PSI Utah)
 - https://www.psiutah.org/
 - Patient Handoutshttps://www.psiutah.org/professionals/patient-handouts/
 - List of specifically trained providers
 - List of Local support groups
 - Screening tools- EPDS
- Postpartum Support International (PSI) (800) 944-4PPD (944-4773) www.postpartum.net PSI volunteers are trained moms who've dealt with anxiety or depression. Support, resources, and information are free and confidential. Messages are returned within 24 hours.
- The Emily Effect: https://theemilyeffect.org/



RESOURCES

- Utah Department of Health Maternal and Infant Health
 Program- Community Resources Guide:
 https://mihp.utah.gov/wp content/uploads/MIHP English Community Resources.pdf
- Crisis Nursery-Family Support Center 801-955-9110: <u>www.familysupportcenter.org/</u>
- Mother to Baby- Information about medications during pregnancy and breastfeeding: www.mothertobaby.Utah.gov
- UNI Crisis Line: May be used to access crisis support via phone or the mobile crisis outreach team (MCOT) 801-587-3000



RESOURCES

Understanding Postpartum Depression

You've just had a baby. You expected to be excited and happy. But instead you find yourself crying for no reason. You may have trouble coping with your daily tasks. You feel sad, tired, and hopeless most of the time. You may even feel ashamed or guilty. But what you're going through is not your fault and you can feel better. Talk to your healthcare provider. He or she can help.

What is depression?

Depression is a mood disorder that affects the way you think and feel. The most common symptom is a feeling of deep sadness. You may also after childbirth. You may also be tired from caring for your baby and feel as if you just can't cope with life. Other symptoms include:

- Gaining or losing a lot of weight
- Sleeping too much or too little
- Feeling tired all the time
- Feeling restless
- Crying a lot
- Having too little or too much appetite.
- Withdrawing from friends and family
- Having headaches, aches and pains, or stomach problems that won't go away.
- Fears of harming your baby
- Lack of interest in your baby
- Feeling worthless or quilty
- No longer finding pleasure in things you used to
- Having trouble thinking clearly or making decisions
- Thinking about death or suicide

Depression after childbirth

You may be weepy and tired right after giving birth. These feelings are normal. They're sometimes called the "baby blues." These blues

go away after 1 to 2 weeks. However, postpartum (meaning "after birth") depression lasts much longer and is more severe than the "baby blues." It can make you feel sad and hopeless. You may also fear that your baby will be harmed and worry about being a bad mother.

What causes postpartum depression?

The exact cause of postpartum depression is unknown. Changes in brain chemistry or structure are believed to play a big role in depression. It may be due to changes in your hormones during and adjusting to being a mother. All these factors may make you feel depressed. In some cases, your genes may also play a role.

Depression can be treated

There are many ways to treat postpartum depression. Talking to your healthcare provider is the first step toward feeling better.

When to call your healthcare provider

- Call your healthcare provider if you:
- Cry for no clear reason
- Have trouble sleeping, eating, and making choices
- Questions whether you can handle caring for a baby
- Have intense feelings of sadness, anxiety, or despair that prevent you from being able to do your daily tasks

Resources

- National Institute of Mental Health866-615-6464www.nimh.nih.gov
- National Alliance on Mental Illness800-950-6264www.nami.org
- Mental Health America 800-969-6642 www.nmha.org
- National Suicide Hotline800-784-2433 (800-SUICIDE)



EMOTIONAL WELLNESS DURING PERINATAL PERIOD

Think...SUNSHINE!!

- 1. **Sleep**: 4-5 hours
- 2. Understanding: Therapy
- 3. Nutrition: Prenatal Vitamin and Jinega-33
- 4. Support: Local support group; Help Me Grow
- 5. Humor: good indicator of mood/wellbeing
- 6. Information: provide EPDS for self-assessment
- 7. Nurture: encourage wellness
- 8. Exercise: 20 minutes of gentle walking



Thanks ©

