NATIONAL CURRICULUM IN REPRODUCTIVE PSYCHIATRY

Infertility and Perinatal Loss

Progressive Case Conference

Psychological Aspects of Perinatal Loss

Facilitator Guide

Contributors

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Structure of Session

Sessions are typically designed to last 90 minutes but can be modified for a longer or shorter session by presenting both or only one of the cases. Before the session, the trainees should read the articles in this module's pre-reading section. During the session, the cases will be distributed to trainees and read along by a resident volunteer. The group will then discuss the case and formulate the diagnosis and treatment approach based on facilitator-guided questions. This session can be run by a single facilitator who oversees the entire group.

Breakdown of Session:

1) Review overview (5 minutes)
2) Case Presentation Part 1a, including the reading of the case and discussion questions (30 minutes)
3) Case Presentation Part 1b (15 minutes)
4) Case Presentation Part 2a (30 minutes)
5) Case Presentation Part 2b (15 minutes)

Goals and Objectives

At the completion of this session, participants will be able to:

1) Define various kinds of perinatal loss (Case 1)
2) Define psychological reactions and psychiatric disorders associated with perinatal loss (Cases 1 and 2)
3) Learn how to differentiate bereavement vs. persistent complex bereavement disorder and other psychiatric disorders such as Depression, Anxiety, and PTSD (Case 2)
4) Learn about some of the appropriate treatments and interventions in the setting of perinatal loss (Cases 1 and 2)
5) Discuss interview techniques that are suggested when evaluating and treating women with perinatal loss (Case 1)

Resources Required

1) A faculty (or senior resident) facilitator
2) A whiteboard can be helpful for writing notes during large group discussions
3) Facilitator and student guides

Pre-assessment Learning

Before attending the classroom didactics on this module, please review some basic concepts regarding the psychological aspects of perinatal loss by reviewing the following resources:

- Self-study guide for perinatal loss
- Barnes D.L. (Ed.). (2014). *Women's Reproductive Mental Health Across the Lifespan.* Springer.
    a) The Reproductive Story: Dealing with Miscarriage, Stillbirth, or Other Perinatal Disease by Janet Jaffe
- Bhat, A., & Byatt, N. (2016). Infertility and perinatal loss: when the bough breaks. *Current psychiatry reports*, *18*(3), 31.
- *The Psychology of Reproductive Traumas: Infertility and Pregnancy Loss:* Diamond DJ, Diamond M. The psychology of reproductive traumas: Infertility and pregnancy loss. Fertility and Sterility. 2005;83(5):S14

Overview

It is thought that most individuals have a reproductive story or mental representation, which is a narrative by aspiring parents as they imagine what their child will be like and what they will be like as parents. This narrative includes the internalized images of parenthood, the dreams and hopes of parents for their children, and factors such as their background, history, culture, traumas, and experiences within their family of origin can affect it. This reproductive story might not be fully conscious for many women and men until they face infertility or perinatal loss. (Jaffe, 2017) Infertility, perinatal loss, or other medical traumas can disrupt and change these mental representations and reproductive stories in fundamental and often traumatic ways with lasting psychological effects on parents, their relationship, and possibly on how they relate to their children.

Perinatal grief following a reproductive loss can often be disenfranchised by close family, friends, or society. Both women and men receive a message that they should grieve a particular way and on a particular timeline. They are encouraged to get past their grief quickly or told they should not experience certain feelings. Reproductive loss, similar to other losses, affects women and men differently. For example, although it does not apply to all women and men, it is not uncommon for women to grieve intuitively and experience and express their grief soon after the loss. An intuitive grieving style can include strong, affective, and emotional reactions that are more feelings-oriented and expressive. Men tend to grieve instrumentally and often escalate in their experience and expression of grief later, sometimes up to years, after the loss. An

instrumental grieving style can be marked by a tendency to internalize their processing, is less emotional, more physical, and focused on being active and doing. (Doka & Martin, 2011)

This progressive case conference encourages learners to discuss and learn about the *psychosocial* aspects of perinatal loss and *refine diagnostic skills* when determining treatment options primarily for women who have experienced this loss.

Case Presentation Part 1a: Guided Case Presentation (Psychological aspects)
Facilitator: Ask one of the trainees to read the case out loud

Emma is a 35-year-old Black woman, G3P1, coming to see you for a preconception consultation for anxiety. She reports a 1-year history of increased anxiety, difficulty concentrating at work, and feelings of not being fully present when spending time with her three-year-old daughter. She reports being in a good marriage but admits feeling more distant and struggling with sexual intimacy sometimes. Recently, Emma's husband has expressed his desire to try for another baby. While Emma agrees with expanding their family, she admits feeling anxious and ambivalent about trying again. She is uncertain of why she feels anxious. During the intake, she reports also being anxious about taking psychotropic medication during pregnancy.

Reproductive History: She reports two previous perinatal losses. One was at eight weeks of pregnancy when she was 27 years old, and most recently, she had a loss at 21 weeks about a year ago. She had multiple episodes of bleeding throughout that pregnancy and was reassured by her OB team. When she was 21 weeks pregnant, she went to see OB for another episode of bleeding. Her exam and ultrasound were reassuring during the visit, so she was sent home. On her way back home, she had more cramps and bleeding. She presented to the ED, and on ultrasound, the baby had no heartbeat. The patient delivered via an uncomplicated vaginal delivery following labor with loss of the fetus.

Past Psychiatric History: Emma has had a history of generalized anxiety disorder, a history of panic disorder, resolved, and one episode of depression in the past year.

Social History: She lives with her husband of eight years and their 3-year-old daughter. She works as a manager at a local bank. She completed her MBA when she was 29 years old. She denies the use of tobacco, alcohol, and drugs.

Guided Case Questions/Discussion
Facilitator: Pause for discussion

1) What are the types of perinatal loss presented in this case? What additional types of perinatal loss are possible, and what are some examples?

Elicit the following:

a. **<u>Early pregnancy loss</u>** is defined as loss of pregnancy prior to 13 weeks' completed gestation. Also referred to as "miscarriage" or "spontaneous abortion."
    i. Examples of these include: ectopic pregnancy, molar pregnancy, and blighted ovum.
b. **<u>Fetal demise</u>** is defined as loss of pregnancy past 20 weeks' gestation. Some references will say 13 weeks' gestation is the beginning of fetal demise. Also referred to as "stillbirth."
    i. Examples of these include: growth problems of the fetus, genetic disorders, birth defects
c. **<u>Neonatal death</u>** is defined as the death of a neonate in the first 28 days of life.
    i. Common examples include: genetic and/or structural abnormalities (e.g. Trisomy 18).

2) What are the psychological responses or psychiatric conditions that are common following perinatal loss(es) such as Emma's?

Elicit the following:

<u>Psychological Responses:</u>

a. Loss of self-confidence
b. Guilt and shame
c. Increased relationship discord
d. Lower quality of life
e. Isolation and lack of communication about the loss with others
f. Body image concerns or preoccupations
g. Disturbances in the sense of self and representations of one's life
h. Anxiety
i. Anger
j. Sadness
k. No distress
l. Relief

<u>Psychiatric Conditions:</u>

a. Bereavement (Grief Reaction)
b. Persistent Complex Bereavement Disorder
c. Depressive disorders
d. Anxiety disorders
e. PTSD
f. OCD

3) What other interview questions would you ask to get more of her reproductive story?

Elicit the following:

a. What had you imagined your family would be like?
b. What did you imagine parenthood will be like for you? Did you have thoughts about what your children will be like?
c. What did you imagine your relationship with your child would be like?
d. How have these losses affected your sense of yourself, your life, and your intimate relationship with your partner?

4) What interview techniques would be essential when discussing her anxiety?

Elicit the following:

- Acknowledge the loss by saying: "I'm sorry for your losses."
- Validate the feelings of Emma and her husband and let them know they are not alone. This may need to be repeated throughout treatment.
- Begin to provide psychoeducation on reproductive stories and narratives of life
    - The aforementioned bullet points assist in developing rapport and creating a safe environment where patients feel heard and validated. This will enfranchise the grief many people painstakingly have carried in silence for so long.
- Inquire about the patient's understanding of the grief process. Assess to what extent they have pathologized their response to the loss.
    - Since reproductive loss is disenfranchised, it is often pathologized by the individuals and families experiencing the loss as well as by professionals caring for those experiencing the loss.
    - When clinically appropriate, grief needs to be validated and normalized. Provide psychoeducation that there is no right or wrong way to grieve, and no set timelines to grieve. This will give the patient permission and space to grieve without hindrance. Understanding grief and the space permitted to grieve can decrease one's risk of psychopathology.
- Ask for elaboration of feelings, including anxiety and sadness. Validate expected anxiety triggers such as birthdays, baby showers, holidays, seeing other parents with babies, special days such as Mother's and Father's Day, and health concerns with her 3-year-old daughter or husband.
- Ask: "Have you had any additional pregnancies?:" If yes, "Can you tell me what happened?"
- Ask: "Have you struggled with infertility?"
- Ask about dreams and aspirations for her family and herself as a mother

- Discuss what feelings she believes are typical or to be expected versus abnormal for someone who would experience the same situation.
    - Provide a patient information sheet for what to expect after abortion, miscarriage, infertility, stillbirth, or neonatal death from a mental health standpoint
    - Provide the patient and family with web-based and local resources accessible 24/7 to promote healing
    - Providers may develop a list of web-based and local support resources for the patient, including individual counseling and support groups specific to perinatal loss

Case Presentation Part 1b: Guided Case Presentation, continued
Facilitator: Ask one of the trainees to read the case out loud

You acknowledge and validate the feelings Emma and her husband have experienced and ask them to elaborate more on these feelings and experiences. You inquire about Emma's reproductive story, any history of previous losses or reproductive traumas, her dreams and aspirations for her family and herself as a mother, and the feelings she is experiencing due to grief.

In a whispering voice, Emma reveals a history of abortion as a teenager that she has rarely discussed with anyone, and the feelings of self-blame, guilt and shame resurfaced after this recent perinatal loss. She further admits she has not shared this with her husband.

Guided Case Questions/Discussion
Facilitator: Pause for discussion

1) How do you understand the effects of the abortion she had as a teenager on her current grief?

Elicit the following:

- Process some of the negative messages she has told herself and perhaps what her specific culture/religion has reinforced.
- Elicit more about her social, cultural, and religious background and the ways they might affect her psychological reactions to these losses
    - Discuss how cultural humility and cultural competency pertaining to culture, ethnicity, gender, sexuality, and SES help understand their impact on the psychological reactions of individuals with such losses.

2) Could Emma and her partner have different grief processes and coping methods? How can that contribute to decreased sexual intimacy and the increased marital discord they are experiencing?

TRANSITION TO NEXT CASE

Case Presentation 2a: Guided Case Presentation (Diagnosis and Management)
Facilitator: Ask one of the trainees to read the case out loud

Elizabeth is a 33-year-old white woman, gravida 2 and parity 1, referred to you for depression following the loss of her infant daughter. She is currently one month postpartum. Her daughter was diagnosed with Trisomy 18 at 20 weeks' gestation and passed away three days after birth. She reports having difficulty with excessive crying, guilt, poor energy, and frequent thoughts of death and dying. She reports being fearful that she or one of her family members may also pass away. She also describes insomnia, poor appetite, and thoughts of wanting to be with her daughter in heaven. She states that these symptoms have gotten worse since her delivery. She is anxious and tearful on exam. She reports that she was more optimistic prior to delivery and feels that she should be more thankful for the time she spent with her daughter. She has joined a support group on social media regarding the loss of an infant. She is very hesitant to take medications, stating "I don't want to box my grief up and pretend it doesn't exist."

Past Psychiatric History: She has been seeing a therapist for one year since the sudden death of her father and describes this as supportive. She reports taking escitalopram (Lexapro) one time in the past after her father's death but reported significant GI side effects and did not continue.

Social History: She lives with her husband and 3-year-old son. She denies marital discord. She became a stay-at-home mother during her pregnancy. She did complete college. She has started a blog to help with her grief. She has supportive family and friends. She denies the use of tobacco, alcohol, and drugs.

Guided Case Questions/Discussion
Facilitator: Pause for discussion

1) What are the differences and similarities between Bereavement, Persistent Complex Bereavement Disorder, and Major Depressive Disorder?

Elicit the following:

- **<u>Bereavement ("Grief Reaction")</u>**
    - Predominant affect: feelings of emptiness and loss

- Dysphoria likely to decrease in intensity over days to weeks
- Occurs in waves
- May have positive emotions and humor
- Preoccupied with thoughts of the deceased/loss
- Self-esteem is generally preserved
- Suicidal ideation is focused on joining the deceased
- In the context of miscarriage: The grief that follows miscarriage often declines significantly by six months for both men and women, yet sometimes persists for up to 2 years

- **Persistent Complex Bereavement Disorder (formerly Complicated Grief Disorder)**
  - Duration (12+ months in adults) of symptoms
  - Affect can include: Intense feelings of sadness, anger, irritation, pain, detachment (from others), sorrow, hopelessness, emptiness, low self-esteem, bitterness, self-blame for the death, or longing for the presence of the deceased
  - Difficulty focusing on things other than the death of a loved one
  - Focusing intensely on reminders of the deceased *or* excessive avoidance of such reminders
  - Problems accepting the reality of the death/disbelief or emotional numbness
  - Confusion about the role in life without the deceased with difficulty pursuing other interests or planning for future
  - Increased risk-taking behaviors, such as increased alcohol or substance use
  - Suicidal thoughts or actions (desire to be with deceased)

- **Major Depressive Episode:**
  - Persistent depressed mood and inability to anticipate happiness or pleasure
  - Not tied to specific thoughts or preoccupations
  - Notably not limited to the loss experienced
  - Self-critical or pessimistic thoughts
  - Feelings of worthlessness and self-loathing
  - Suicidal ideation is focused on ending one's own life

Similarities among bereavement, persistent complex bereavement disorder, and MDD:

- Feelings of guilt
- Intense sadness
- Rumination

- Insomnia
- Poor Appetite
- Weight loss

Differences among bereavement, persistent complex bereavement disorder, and MDD:

Grief/Bereavement is often experienced differently from clinical depression:

- Feeling as if one is still pregnant
- Dreaming that one is still pregnant and/or about the baby
- Wanting to hold the baby
- Planning things for the baby
- Finding it challenging to think about anything else
- Imagining what the baby would look like
- Emphasize especially the severity difference between bereavement and persistent complex bereavement disorder and the different themes of suicidal ideation in persistent complex bereavement disorder and MDD

Clinically there is not always a clear and easy distinction among these diagnoses, and many patients might experience a variety of symptoms. The full differential is broad.

2) What diagnosis do you think Elizabeth has?

Elicit the following:

- Bereavement ("Grief reaction")
- Persistent Complex Bereavement Disorder (formerly Complicated Grief Disorder)
- Major Depressive Disorder
- Anxiety Disorder
- Post-traumatic stress disorder

Reinforce the diversity of diagnoses given, that all of these could be correct, and that there are limits to the DSM in these situations. It is also possible to have more than one diagnosis, complicated by the evolving nature of these symptoms and diagnosis/diagnoses for many women.

3) What treatment options could be presented at this initial appointment?

Elicit the following:

- Emphasize the importance of family support
- Emphasize the importance of marital therapy
- Emphasize the importance of cultural/religious/spiritual/community support

- Discuss memorial options, including memorial services, memory boxes, memorabilia (i.e., Poppy's Plates)
- Individual Psychotherapy
- Couples and/or family therapy
- Emphasize the importance of collaboration and possible discovery of new information/referral for partner
- Medication management
- Safety assessment
- Support groups (in-person and virtual networks)

Case Presentation Part 2b: Guided Case Presentation, continued
Facilitator: Ask one of the trainees to read the case out loud

Elizabeth left her first appointment and decided that she did not think medications were the right choice for her but continued to see you and her therapist. Over the next few sessions with you, she continued to endorse depressive symptoms most days over the past several weeks, including feeling depressed, anhedonia, feelings of guilt, perseverations on death and dying, poor appetite, isolating herself at home, poor concentration, and weight loss. Furthermore, she endorsed having difficulty spending time with her 3-year-old and difficulty being present with him.

Facilitator: Pause for discussion

1) Would you change your initial diagnosis of this patient? If so, why?

Elicit the following:

- Major Depressive Episode
    - She now meets the criteria for MDE, including 1) feelings of depression, 2) anhedonia, 3) feelings of guilt, 4) poor appetite, 5) poor concentration, 6) Increased thoughts (rumination) of death and dying.
    - Symptoms have been going on for more than two weeks
    - Interfering with function (i.e., child care)
- A more severe form of bereavement or Persistent Complex Bereavement Disorder (if she meets the criteria for 12 months) could still be left on differential

2) What treatment recommendations would you give at this point?

Elicit the following:

- Antidepressant (Selective Serotonin Reuptake Inhibitor)
- Individual Psychotherapy (CBT, Interpersonal Psychotherapy)

- Group psychotherapy or support group
- Mindfulness practices (yoga, meditation)
- Couples and/or family therapy
    - Others in extended family may be affected by the loss and/or may want to learn how to be supportive

Case Presentation Part 2c: Guided Case Presentation, continued

Elizabeth elected to start escitalopram and engage in cognitive behavioral therapy after this appointment. She had moderate improvement over the next several months. At a follow-up medication management appointment at ten months postpartum, she informs you that she is eight weeks pregnant with her third pregnancy. She reports increased anxiety since finding out that she was pregnant and having conflicting feelings of happiness and guilt. She also reports that her husband has been more distant since they found out about this pregnancy, which has put a strain on their marriage.

Facilitator: Pause for discussion

1) What are some difficulties women experience in their subsequent pregnancies after having perinatal losses? What are the difficulties that their partners can experience?

Elicit the following:

<u>Women in subsequent pregnancies:</u>

a. These mothers have to grieve the loss of one baby while bonding to another baby.
b. There can be increased anxiety (5-fold increase vs. women with prior live births), depression (2-fold increase vs. women with prior live births), and PTSD in the subsequent pregnancy, precipitated by:
    i. Changes in fetal movement
    ii. Ultrasounds
    iii. Milestones in the pregnancy
    iv. Anniversary of the stillbirth
    v. Feelings of attachment to the fetus
c. Parents might have challenges bonding with the new baby
d. Mothers can experience an increase in anxiety postpartum with the next delivery. Anxiety can manifest as rejecting help from others in the baby's care, disrupting sleep due to monitoring the baby, being overly concerned about the baby's behavior (i.e., somatization), or being more irritable.

e. There can be a delay in the grief process for parents or the delivery of a new baby can cause an increase in grief

Partners

a. Fathers can experience bereavement of their stillbirths, suggesting a significant antenatal attachment
b. Consider the differences between intuitive and instrumental grievers (described earlier).

For both parents:

a. There is a potential for Replacement Child Syndrome (where the subsequent child is believed to serve the function of replacing the deceased one as a way of parents avoiding grief), and it would be beneficial if mothers can keep these babies in mind as two separate babies. (Markin 2018)

References and further readings:

1. American College of Obstetricians and Gynecologists (2022): https://www.acog.org/womens-health
2. Barnes D.L. (Ed.). (2014). *Women's Reproductive Mental Health Across the Lifespan.* Springer.
    a. The Reproductive Story: Dealing with Miscarriage, Stillbirth, or Other Perinatal Disease by Janet Jaffe
3. Bhat, A., & Byatt, N. (2016). *Infertility and perinatal loss: when the bough breaks*. Current psychiatry reports, 18(3), 31.
4. Doka, Kenneth J and Martin, Terry L. Grieving Styles: Gender and Grief [online].Grief Matters: The Australian Journal of Grief and Bereavement, Vol. 14, No. 2, Winter 2011: 42-45. Availability: <https://search.informit.com.au/documentSummary;dn=339916590087229;res=IELHEA>ISSN: 1440-6888. [cited 30 Mar 19].
5. Fredenburg, M. (2008). *Changed: Making sense of your own or a loved ones abortion experience*. San Diego, CA: Perspectives.
6. Hutner, L. A., Catapano, L. A., Nagle-Yang, S. M., Williams, K. E., & Osborne, L. M. (2022). *Textbook of women's Reproductive Mental Health*. American Psychiatric Association Publishing. Chapter on Infertility and Perinatal Loss.
7. Kersting, A., & Wagner, B. (2012). *Complicated grief after perinatal loss.* Dialogues in clinical neuroscience, 14(2), 187.
8. Life Perspectives: http://www.abortionchangesyou.com/
9. Life Perspectives: https://www.miscarriagehurts.com/
10. Markin, R. D. (2018). *"Ghosts" in the womb: A mentalizing approach to understanding and treating prenatal attachment disturbances during pregnancies after loss.* Psychotherapy, 55(3), 275.
11. Jaffe, J. (2017). Reproductive trauma: Psychotherapy for pregnancy loss and infertility clients from a reproductive story perspective. *Psychotherapy,54*(4), 380-385. doi:10.1037/pst0000125
12. Jaffe, J., & Diamond, M. O. (2011). *Reproductive trauma: Psychotherapy with infertility and pregnancy loss clients*. American Psychological Association.
13. Stroebe, M., Schut, H., Boerner, K. (2017). *Cautioning Health-Care Professionals. Bereaved Persons Are Misguided Through the Stages of Grief.* Omega (Westport). 74(4): 455–473.
14. Kluger-Bell, Kim. *Unspeakable Losses: Healing from Miscarriages, Abortions, and Other Pregnancy Loss.* Harper, 2000
15. Muglu J, Rather H, Arroyo-Manzano D, et al: Risks of stillbirth and neonatal death with advancing gestation at term: A systematic review and meta-analysis of cohort studies of 15 million pregnancies. PLoSMed 16(7):e1002838, 2019

16. Obst KL, Due C, Oxlad M, Middleton P: Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model. BMC Pregnancy Childbirth 20:11, 2020
17. Van P, Meleis AI: Coping with grief after involuntary pregnancy loss: Perspectives of African American women. J Obstet Gynecol Neonatal Nurs 32(1):28–39, 2003
18. Worden, J. Williams. *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practioner.* Springer Publishing Company, 2009.

Resources:

1. Postpartum Support International: https://www.postpartum.net/get-help/psi-online-support-meetings/
2. Return to Zero: H.O.P.E. http://rtzhope.org/