Perinatal Loss and Grief: Supporting Families

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Objectives

- The learner will be able to identify various types of perinatal loss.
- The learner will be able to describe the different stages of grief.
- The learner will be able to explain factors influencing the grief response of bereaved parents.
- The learner will be able to identify strategies to facilitate grieving and to support bereaved parents.
- The learner will be able to describe how men grieve differently than women.
- The learner will be able to identify community resources that provide support to bereaved parents.
What is Perinatal Loss?

- **MISCARRIAGE**: also known as spontaneous abortion

- **ECTOPIC PREGNANCY**: embryo implants in fallopian tubes or anywhere outside of the uterus. **EMERGENCY TREATMENT REQUIRED**

- **MOLAR PREGNANCY**: fetus dies, but placenta and/or chorionic villi continue to grow rapidly in cancer-like way

- **STILLBIRTH**: death of a fetus in utero after 20 weeks, before birth. Occurs in 1-2% of births
What is Perinatal Loss?

- **NEONATAL DEATH:** death before 28 days of life. 1% of births. May be due to prematurity, birth defects
- **ELECTIVE ABORTION:** voluntary termination of pregnancy, whether or not the fetus is viable
Losses related to Assisted Reproduction

- INFERTILITY
- PREIMPLANTATION MISCARRIAGE:
- PREIMPLANTATION TERMINATION
- MULTIFETAL PREGNANCY REDUCTION (MFR, also known as SELECTIVE REDUCTION)
Attitudes Towards Pregnancy Loss

- **Early 1900s**
  - Stillbirth, pregnancy loss & neonatal loss common
  - Grieving families received community support

- **Today:**
  - Less than 1% pregnancies result in the death of the infant
  - Decreased ability for families to cope
The Reproductive Story

- Begins in childhood
- Develops as the child grows and matures
- Fantasies and expectations of life as a parent
Factors Influencing the Reproductive Story

- Family Constellation
- Family Lore
- Cultural Influences
- Ethnic & Religious Background
- Peer Group Norms
- Impact of Medical Technology
- Media
Definitions

- **Grief:**
  - The emotional response to a loss
  - Shock, numbness, anger, guilt, sadness, anxiety

- **Mourning:**
  - The process, often culturally defined, that one goes through to deal with these emotions

- **Bereavement:**
  - The time period during which grief is being resolved
Models of Grief - Stage Theories

- Elizabeth Kubler-Ross (1969)
- Denial (this can’t be happening to me)
- Anger (why is this happening)
- Bargaining (if I promise to do better this will not happen)
- Despair or Resignation (loss of hope; there is no way to stop it)
- Acceptance (it has happened)
Stage Theories

- People do not necessarily move through the stages in order.
- People may not complete one stage before moving on to the next.
- People may experience all of the stages in a short time and then return to prior stages.
Conceptual Model of Parental Grief
Phase of Acute Distress

- Symptoms:
  - Shock
  - Numbness
  - Intense crying
  - Depression

- Tasks:
  - To accept the reality of the loss
  - Many decisions required (naming, autopsy, funeral arrangements)
  - Normal functioning impeded
Phase of Intense Grief

- Emotional Symptoms:
  - Loneliness, emptiness, yearning
  - Guilt
    - For not preventing loss of infant
    - Punishment for unrelated event, such as prior abortion
  - Anger, resentment, bitterness, irritability
  - Fear & Anxiety (especially about getting pregnant)
  - Disorganization
  - Difficulty concentrating and forgetfulness
  - Sadness and depression
Phase of Intense Grief

► Physical Symptoms

► Arms may ache to hold child or nurse the baby
► Wake to sound of baby crying
► Sleep difficulty, nightmares
► Heart palpitations, shortness of breath
Phase of Intense Grief

Tasks:
- Working through the pain
- Adjusting to life without the wished-for child

Other issues:
- Deciding what to do about nursery and baby clothes
- Family members often rush to take down nursery to spare the parents
- Parents need to be involved in the decision
Reorganization Phase

- Search for meaning
- Why me?
- What do I do with the rest of my life?
- Reduction of distress
- Reentering normal life activities with more enthusiasm
- Ability to make future plans, including decision about another pregnancy
Reorganization Phase

- Tasks:
  - Improve functioning at home and work
  - Return of self-esteem and confidence
  - Put the loss in perspective
Duration of Grief

- Typically intense; tends to decline after first year of bereavement
- There may be “swells of grief” that are “triggers” that remind parents of the loss
- Feelings of sadness triggered around significant days and events
  - Due date, date of conception, birth date, anniversary of the death
  - Holidays, child-focused celebrations (Halloween)
Duration of Grief

- Disorientation occurs at 5-6 months, peaks before the first anniversary
  - Feelings of disorientation, depressed, guilt
  - Now aware of reality of the death and the emptiness it has brought
- Diminishes after a cycle of “firsts” without the child
  (Mother’s Day, Father’s Day, birthday, anniversary of death, Christmas)
Duration of Grief

- After 18 months
  - Sense of release, pattern of stable eating and drinking habits
- Second year:
  - Family begins to understand
  - Reconcile loss into daily life
Developmental Tasks of Pregnancy

- Pregnancy is validated (first 3 months)
  - Loss represents something wrong with the mother’s body

- Fetal embodiment (4-6 months)
  - A sense that “somebody” is really there
  - Loss may lead the woman to question her ability as a mother
Developmental Tasks of Pregnancy

- **Fetal Distinction** (begins at 6 months)
  - Mother views baby as individual distinct from herself
  - Loss brings pain of severed emotional ties

- **Binding-in** (begins at 8-9 months)
  - Mother prepares to give up baby to the birth process
  - Mother anticipates physical emptiness, new responsibilities
  - Loss brings devastating emptiness and pain
Unique aspects of Perinatal Grief

- Customs exist for stillbirth or neonatal loss
- No established rituals for miscarriage or infertility
- Losses are less tangible, less recognized by society
- No actual body to grieve over
- “Disenfranchised grief” - not publicly recognized or acknowledged
- Few people aware of loss; minimal support available
Pregnancy Termination Due to Genetic Birth Defect

- Psychological sequelae are less common when termination occurs in first trimester and is wanted for genetic or social reasons.

- Psychological sequelae most often occur in women when:
  - they have difficulty arriving at the decision.
  - they have the abortion late in pregnancy.
  - the pregnancy is desired.
  - she feels coerced by her partner or others.
Decision to Terminate

- Abortion is controversial
- Prevents parents from sharing decision with other family and friends
- Couples worry that this may be their only chance for a child
- May conflict with cultural or religious doctrine
- May grieve as intensely as those who have spontaneous pregnancy loss
- Leads to feelings such as guilt, despair, sadness, depression, anger
Multi-fetal Pregnancy Reduction

- Risks of Multiple Pregnancy increased with Assisted Reproductive Technology
- Risks greater with 3+ fetuses
- **Mother:**
  - Loss of entire pregnancy
  - Premature delivery
  - Pre-eclampsia
  - Gestational diabetes
  - Post-partum hemorrhage
- **Babies:**
  - Prematurity
  - Low birth weight
  - Handicaps
Multi-fetal Pregnancy Reduction

- Decision is painful and ironic
- High level of ambivalence
- Distressing and stressful experience
- Pre-pregnancy psycho-education & counseling essential
Special Considerations in MFR, Medical Termination

- Element of choice
- Perception of loss
- Sense of isolation
Loss of One Baby in a Multiple Birth

- Parents are required to parent and grieve at the same time
- Help parents acknowledge the birth of all babies
- Help parents to anticipate insensitivity to loss by other people

- Issues to address:
  - Coping without “extra special” family
  - Telling surviving child about twin
  - Deal with that child’s possible survivor guilt
  - Decide how to celebrate birthdays, death days or special holidays
Factors Affecting Intensity & Length of Grief

- NOT necessarily determined by duration of pregnancy
- More important is the psychological attachment to developing fetus
- Could have significant grief after failed IVF
- Type of perinatal loss not a factor
- Was pregnancy desired or not; readiness or wish to take on responsibility of becoming a parent
- Extent and intensity of attachment
- Ultrasound and other technology, allows earlier attachment
Factors Affecting Intensity & Length of Grief

- Have there been other perinatal or other losses
- Difficulty and length of time to conceive
- Amount of outside intervention needed for conception
- Are there any other living children
- Previous childbirth experiences
- Nature of Parents’ relationship
- Woman’s Age; time in her life
- Meaning of the pregnancy
- Physical health
- Religiosity
- Likelihood of a subsequent successful pregnancy
Using the Reproductive Story

- Patients Recognize What Has Been Lost
- Communication with Their Partner Improves
- Patients Feel Less Isolated
- Grieving is Facilitated
- A New Ending Can Be Written
What has been lost?

- Experience of Pregnancy and Childbirth
- Loss of Feeling Healthy & Normal
- Loss of Control
- Self-blame & Shame
- Are We Parents or Not?
- Loss of One’s Sense of Self
What has been lost?

- Loss of a Sense of Belonging
- Loss of Closeness with One’s Partner
- Loss of Sexual Intimacy and Privacy
- Loss of Financial Freedom
- Loss of Trust in the World
Unique Aspects of Perinatal Grief

- Grief is Prospective
  - Mourning re: hopes, wishes, fantasies of the future
  - Baby known only to parents and possibly other immediate family

- Narcissistic
  - Intense guilt, shame, envy, rage, self-blame
  - Not usually experienced with other losses.
Unique Aspects of Perinatal Grief

- Grieving is difficult
  - Little opportunity for anticipatory grieving
  - Absence of visible and publicly acknowledged “object” to mourn
  - Few socially acceptable avenues for mourning
  - Lack of social support
Couples May Grieve Differently

- Differences in cognitive style
- Emotional issues specific to one member of couple
- Partners may “take turns”
- One person may feel as if “not grieving right”
- Gender differences in grief
Women and Grief

- Strong need for emotional catharsis
- Cry, need to talk and express feelings
- Exhausted
- Overwhelmed
- Want to isolate
- Feel anxious and depressed
- Some women may hesitate to make decisions
- Culture may dictate that men make decisions
Men and grief

- Often not acknowledged as grieving
- Stoic partner
- Self-blame, loss of identity
- Distressed by mother’s grief
- Feels helpless to help his partner
- Cultural expectation to be strong & protect partner
Men and Grief

- Take charge of planning and decision making
- Deal with reactions through thought, not feelings
- Avoid emotional displays
- Use cognitive, problem-solving strategies to cope
- Appear to function well; likely masking devastation
Cultural Factors in Bereavement

- Differences in pressure on women to produce children
- Woman often gets blamed for childlessness
- Acceptable to ask about customs and be educated by client
- Do not make assumptions about client’s belief system based solely on race and ethnicity.
Cultural Factors in Bereavement

- Many cultures do not support use of Reproductive Technology
- Pressure to reproduce vs. prohibitions against ART
- Desire to have children may override religious bans
- Guilt and anxiety
- Pregnancy termination may conflict with cultural or religious doctrine
Intimacy & Communication in couples

- Many things inhibit desire for closeness
- Focus on communication re: desire for intimacy
- Re-establish intimacy by holding each other, talking, etc.
- Remind them that they cannot be everything to each other
- May need to rely on friends, family or other sources of support
Supporting Grieving Parents

- Validate the loss
- List and label the losses that have been experienced:
  - Imagined or real baby
  - Loss of identity
  - Loss of fitting in with peers
  - Loss of adult developmental tasks
  - Loss of reproductive story
Supporting Grieving Parents

► Create rituals
► Help a couple feel like they are doing something
  ► Funeral or memorial service
  ► Plant tree
  ► Light candles
  ► Set off balloons
  ► Write to child
► Create Memories
Educate about grief

- Differences in coping
- No right or wrong way to grieve
- No time line
- No “should”
- Give permission to take the time needed to process the loss
Nursing Care

- Couples say that compassionate treatment by medical staff is most helpful thing
- Greatest complaint: lack of sensitivity, responsiveness, communication, and concern by medical caregiver
Assessment

The Perinatal Grief Scale
<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Disagree or Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I feel depressed</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>I find it hard to get along with people</td>
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<tr>
<td>3</td>
<td>I feel empty inside</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4</td>
<td>I can't keep up with my normal activities</td>
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<tr>
<td>5</td>
<td>I feel a need to talk about the baby</td>
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<tr>
<td>6</td>
<td>I am grieving for the baby</td>
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<td></td>
<td></td>
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<tr>
<td>7</td>
<td>I am frightened</td>
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<tr>
<td>8</td>
<td>I have considered suicide since the loss</td>
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<tr>
<td>9</td>
<td>I take medicine for my nerves</td>
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<tr>
<td>10</td>
<td>I very much miss the baby</td>
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<tr>
<td>11</td>
<td>I feel I have adjusted well to the loss</td>
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<tr>
<td>12</td>
<td>It is painful to recall memories of the loss</td>
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<tr>
<td>13</td>
<td>I get upset when I think about the baby</td>
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<td></td>
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<tr>
<td>14</td>
<td>I cry when I think about him/her</td>
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<tr>
<td>15</td>
<td>I feel guilty when I think about the baby</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I feel physically ill when I think about the baby</td>
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</tbody>
</table>
Assessment Questions

- Nature of parental attachment to pregnancy or infant
- Related losses
- Ask open ended questions: “tell me about your labor and birth with Mia”
- Circumstances surrounding the loss
- Level of preparation; was there some warning or was the loss unexpected
Assessment Questions

- Understanding of cause of loss or death
- Special situations; i.e., infertility, ART, previous losses
- Immediate response of mother and father to the loss
- Social support network of parents
Plan of Care

- Care must be individualized for each parent and family
- Do not try to influence parents or make presumptions that limit their choices
- Consider cultural and spiritual beliefs
- Assist with options re: induction/delivery
Help Family to Actualize the Loss

- Be sure that the parents have been honestly told about the situation
- Use the words “dead” or “died” rather than “lost” or “gone”
- Listen to the parents’ stories
- Tell parents the sex of the baby
- Allow them to name the baby; use the name (if consistent with religious or cultural beliefs)
Help Family to Actualize the Loss

- Parents may find it helpful to see the baby
- Do not make them feel that they “should” see the baby
- Ask “some parents have found it helpful to see their baby. Would you like time to consider this?”
- Give them time to think about seeing the baby
Viewing the Baby

- Prepare the baby with lotion, diaper, blanket, etc.
- Treat the baby as one would treat a live baby.
- If there is an anomaly, point out normal features of the baby.
- Give parent the opportunity to bathe and dress the baby.
- Mark the door with a special card.
- Allow parent sufficient time with their baby; watch for cues that they have had enough time.
Help with decision making

- These decisions provide memories for a lifetime
  - Autopsy
  - Organ donation
  - Spiritual rituals, such as baptism
  - Disposition of body
Help Bereaved to Acknowledge/Express Feelings

- Encourage them to tell their stories; say “tell me about what happened?”
- Listen with care
- Ask the father for his own views
- Avoid the impulse to attempt to reduce pain
- Be comfortable with own feelings of grief and loss
Help Bereaved to Acknowledge/Express Feelings

- Allow parents to talk about questions surrounding loss, their sense of guilt
- Do not attempt to answer questions for which there is no clear answer
- Factual information (i.e. about frequency of miscarriage) can be helpful
- Acknowledge feelings ("you sound angry")
Normalize the grief process; Facilitate positive coping

- Reassure parents that their grief responses are normal
- Prepare them for the length of grief
- Educate about the grief process (physical, social, emotional responses)
- Help parents understand that each may respond and grieve differently
- Provide follow-up
  - Call
  - Referral to support group
  - Provide list of websites
Meet physical needs of bereaved mother

- Allow mother to decide if she wants to remain on maternity unit or be transferred
- Ensure that mother receives medication to manage physical symptoms
  - Milk coming in
  - Afterpains
- Post-partum care instructions
- Prepare to maintain open communication in couple
- Prepare for issues in sexual intimacy
Assist with family support

- Help parents decide extent to which they want family involved
- If they wish, include children, grandparents, friends and family in rituals
- Provide education about how grief affects a family
- Help parents identify ways to let others know what they need
Create memories for parents to take home

- Encourage them to name the child (if consistent with cultural norms)
- Collect tangible mementos (ask parents if they want these items)
  - Articles that were used to care for the baby
  - Card with height, weight and head circumference
  - Footprints and handprints
  - Comb, ID bands, hat, blanket, etc
  - Photographs (all features of baby)
- Prepare Memory Box for mementos
- Encourage them to plan a funeral or memorial service
Be Sensitive to Cultural Issues

- Can influence issues such as seeing the child, naming the child, taking pictures
- Autopsies may not be allowed
- Cremation may be forbidden
- Baptism
Discharge care

- Provide sensitive care at discharge and after
- Do not discharge at a time when mothers with live babies are discharged
- Give them something to carry (a flower)
- Follow up phone calls
  - 1 month to six weeks later
  - At expected due date
- Grief conference
Grandparents

- Struggle with grief from two sources:
  - Loss of hoped for grandchild
  - Witnessing intense grief of their own child
- May be called upon to help with decision-making
- May try to take over
- Survival guilt; this death is out of normal order
Siblings

- Consider developmental level
- Feel included in the event
- Assure that they have someone to talk to
- Fear of abandonment when someone is sick
- Use words that are truthful, basic and consistent
  “dead, died”
- Parents can share feelings with children when parents cry
- Children are frightened, sharing feelings brings a sense of security
Siblings

- Have trusted friend stay with children during critical moments
  - At hospital
  - At services
- Stress that the child did not do or think anything to cause the death
- Reassure the child that it is uncommon for a baby to die; usually people do not die unless they are very old
Young Children/Preschoolers

- Respond to the response of parents
- Clinging, altered eating and sleeping
- Acting out behaviors; parents have little patience
- Repeating same answer to questions allows them to comprehend over time
Older Children/School Age

- More complete understanding of the loss
- Frightened by the event
  - May be angry
    - At baby for being sick
    - For taking time and energy from parents
- Acknowledge that feelings are normal
- Provide opportunities for self-expression (journal, art, letter to baby)
Teenagers

- May understand the loss fully
- Include in rituals to the extent that parent and child are comfortable
- Focus on finding safe place to work out feelings
- Provide opportunity to be with the dying baby or involved in process
Bereavement: DSM IV

- Focus of Clinical Attention is reaction to the death of a loved one
- Client may present with symptoms of Major Depressive Disorder
- Depressive Disorder diagnosed after 2 months
DSM-5: Proposed Criteria for Persistent Complex Bereavement Disorder

- A: Individual experienced loss of someone close
- B: Symptoms experienced more days than not
  - Yearning/longing
  - Intense sorrow and emotional pain
  - Preoccupation with the deceased
  - Preoccupation with the circumstances of the death
- Since the death, six of the following symptoms are experienced on more days than not and to a clinically significant degree, and have persisted for at least 12 months after the death in the case of adults, 6 months in children
  - Reactive distress to the death
  - Social/Identity Disruption
Pathological Grief

- Psychiatric symptomatology
- Intense grieving beyond the first year
- Absence of grief
- 20-30% psychiatric morbidity following perinatal loss
Risk Factors for Pathological Grief

- History of poor psychological functioning
- History of reproductive loss
- Infertility, prior pregnancy losses, elective abortions
- Medical history associated with the loss
  - Lupus, hypertension, cervical cancer, gestational diabetes, Group B strep
- Medical interventions to achieve or maintain pregnancy
- Treatment to achieve pregnancy, high-risk pregnancy, extended bed rest,
Risk Factors for Pathological Grief

- Age
- Older women facing biological clock
- Younger women lacking social support and resources
- Marital instability
- Social isolation
- Recent crises or losses
- Not every loss experienced the same way
Community Resources

- Support Groups
- Websites
- Books