

# **Perinatal Loss: A Continuum of Loss**

Module IX

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## Perinatal Loss



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This module is intended to introduce you to the topic and issues surrounding pregnancy loss and its aftermath. Responses to perinatal loss vary widely, but for many families, the loss is unexpected and they do not know what to do, what to expect, or how to handle their grief. As we move through this module, we will discuss the various types of perinatal loss and the effects of the loss on the mother and family. It is important to note as we begin our discussion that experience of loss may be profound, regardless of the gestational age of the fetus. This module also includes insights and strategies for caregiving, teaching, and helping families cope and continue their lives.

**Note to Instructors:** As you present content in this module, please be prepared to discuss your facility policies and protocols related to managing perinatal loss.

## Objectives

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- Define types of *perinatal loss* and frequency of occurrence for each type
- Describe emotional responses to perinatal loss as they relate to fetal/neonatal gestational age, culture, and religion
- Articulate the significance of perinatal loss on the lives of families
- Describe unique aspects of perinatal loss, including the process of grief and mourning
- Provide rationale for care of mother, father, baby, and family members

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Before we begin, let's review the objectives for this module. On completion of this presentation, you will be able to:

- Define types of perinatal loss and frequency of occurrence for each type
- Describe emotional responses to perinatal loss related to fetal/neonatal gestational age, culture, and religion
- Articulate the significance of perinatal loss on the lives of families
- Describe unique aspects of perinatal loss, including the process of grief and mourning
- Provide rationale for care of mother, father, baby, and family members

**(Objectives continue on next slide)**

## Objectives (*cont'd.*)

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- Describe anticipatory guidance for self-care after hospital discharge
- Evaluate the need for counseling regarding the timing of subsequent pregnancy
- Recognize the potential effects of perinatal loss on subsequent children and parenting
- Articulate the importance of nursing care for women and families experiencing perinatal loss

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## *Perinatal Loss: Definition and Types*

*Perinatal loss: nonvoluntary end of pregnancy from conception through 28 days of life.*

TYPE OF LOSS	DESCRIPTION
Ectopic pregnancy	Implantation outside of uterus
Miscarriage	Loss occurring $\leq$ 20 weeks gestation ( <i>early-pregnancy loss</i> )
Stillbirth	Loss occurring $>$ 20 weeks gestation ( <i>late-pregnancy loss</i> )
Neonatal death	Loss occurring from birth through 28 days of life

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*Perinatal loss* is most often defined as the nonvoluntary end of pregnancy from conception, during pregnancy, and up to 28 days of the newborn's life. There are several types of loss. The definition of each type of loss may vary slightly from state to state, but the exact parameters are not critical. Specification of the *weeks of gestation* (postmenstrual age) and/or *fetal weight* should typically be stated (American Academy of Pediatrics [AAP] and American College of Obstetricians and Gynecologists [ACOG], 2002).

**Perinatal loss, which is also referred to as *pregnancy loss*, includes ectopic pregnancy, or tubal pregnancy; spontaneous abortion (*miscarriage*, in lay terms); late-pregnancy loss, or stillbirth; and, last, neonatal or newborn death (Woods & Woods, 1997).** A *neonatal death* is defined as the death of a live-born neonate up to the 28th day of life. The definition of *live birth* includes demonstrated signs of life such as breathing, a beating heart, pulsation of the umbilical cord, and movement of voluntary muscles. The beating neonatal heart is distinguished from transient cardiac contractions and breathing from transient respiratory effort or gasps (AAP & ACOG, 2002).

Neonatal death may be viewed in different ways by parents, depending on the circumstances, and may be managed differently by hospital staff from early- or late-pregnancy loss because of the additional clinical management and involvement of a neonatal team (Gemma & Arnold, 2002).

Other types of pregnancy loss that are not included on this slide include the following: elective termination or abortion, selective termination of multifetal gestation following fertility treatment, and pregnancy termination because of genetic or other fetal anomalies. These types of losses are distinguished from ectopic pregnancy, miscarriage, stillbirth, and neonatal death because of the element of choice, which often is a very difficult process for the woman and her partner. Responses to the various forms of elective termination of pregnancy are often very similar to spontaneous losses, but the element of decision making is different. However, much of what is covered in this module is applicable, regardless of the nature of the pregnancy loss (Kowalski, 2001).

Infant deaths occurring after 28 days are not included here because, frequently, a healthy baby was taken home and became part of the family, prior to his or her unexpected death. These deaths differ in many ways and, therefore, fall outside of the perinatal loss umbrella.

## Causes and Frequency of Perinatal Loss

- Cause of many early-pregnancy losses are unknown
- Fetal anatomic abnormalities or uterine scarring can interfere with implantation, fetal growth and development
- Perinatal loss occurs in more than 1 million women/year in the U.S.
- Early losses: up to 25% of all conceptions
- Late losses: approximately 2%-4% of pregnancies
- Rates of pregnancy loss have not been significantly reduced in the U.S., except for a drop in the stillbirth rate

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**The causes of many pregnancy losses are never known.** For example, many early-pregnancy losses are due to **genetic issues** that are rarely diagnosed. **Anatomical abnormalities of the mother or fetus** can also interfere with implantation, fetal growth, and development. **Pregnancy loss is very common**, occurring in more than an estimated 1 million women each year in the United States. Early losses, most commonly manifested during the first trimester, are estimated to occur in up to 25% of all conceptions. Late losses (i.e., after 20 weeks) occur in approximately 2%-4% of all pregnancies, in the form of stillbirths, preterm births, or neonatal deaths (Gemma & Arnold, 2002; Martin, Kochanek, Strobino, Guyer & MacDorman, 2005).

There are some cases where treatments have been developed, such as the use of progesterone to maintain pregnancy until placental hormones take over, or where maternal autoimmune or clotting disorders have been discovered in previous pregnancies and treatment with heparin or other drugs has reduced subsequent losses. **Overall, however, the number of perinatal losses remains relatively stable and the rate of preterm birth (a frequent cause of neonatal death) continues to be alarmingly high. Although the stillbirth rate has decreased 10.7% in the last decade, the rate for African Americans remains twice that of Whites and other ethnic minorities** (Gemma & Arnold, 2002; Martin et al., 2005). The reasons for this disparity are likely multifactorial but not well understood.

## Emotional Responses to Perinatal Loss

- Often very intense emotions
- Men and women grieve differently, but they both grieve
- Grieving may last a few weeks, several months, or more than a year



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**The emotional response to perinatal loss varies individually but is commonly very intense.**

When acceptance and excitement about the pregnancy exist, the loss is most likely seen as the loss of a baby, not just a pregnancy (Côté-Arsenault & Dombeck, 2001). **Men and women grieve differently**, which can sometimes cause conflict between partners. Women tend to grieve more openly than men, but men report a deep sense of loss and a period of mourning. Women tend to grieve longer than men; they also have physical changes to deal with after the loss. **Grieving may last a few weeks, for several months, or, often, longer than a year.** Some feel that grieving never ends but changes in intensity and focus over time (Gemma & Arnold, 2002; O'Leary & Thorwick, 2006).

After several weeks, the focus of a couple's life should begin to move from their grief as all encompassing to the incorporation of their loss into their daily lives with periodic eruptions of sadness. Even when couples feel that they are doing pretty well, they will likely be surprised by the intensity of their response to anniversary dates of their due date, birth date, delivery date, or other milestones.

## Responses to Grieving Parents

### 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?
- This isn't what you expected...

### Hurtful

- It was not meant to be
- It was for the best
- You are young; you can have another baby
- Over time you will forget your baby
- When is the last time you felt your baby move?

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**Some responses to grieving mothers and their partners are helpful and others are hurtful. Let's take a moment to review comments on this slide that are helpful, and those that can be hurtful.**

Well-meaning individuals sometimes say thoughtless, hurtful things; therefore, nurses should practice saying the helpful comments. Communicate your sadness and concern without trying to make things better. Often you just need to provide your presence; being there conveys care more than you know.

**Seemingly innocent phrases such as, "When is the last time you felt your baby move?"**, which is frequently asked when a woman comes in with reduced fetal movement, could have a profound negative effect on a mother. If she doesn't remember when she last felt movement, this question may leave a mother whose baby died in utero with a tremendous sense of guilt because she may feel that was not paying attention enough to know (Côté-Arsenault, 2003a; Kowalski, 2001; O'Leary, 2005). Instead of asking specific questions, it might be better to ask broad, open-ended questions such as, "Tell me what has been going on." A more useful history is likely to emerge if you listen to the woman recall past events and the possibility of painful, pointed questions is avoided.