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White Paper

Introduction

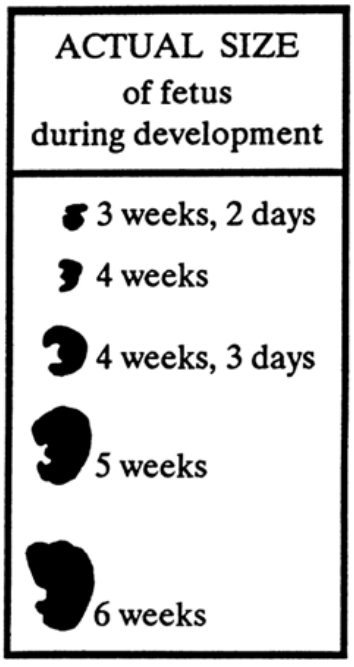
It's never too early in a woman's pregnancy to provide just what she and her family need when they suspect a miscarriage. To do so, a healthcare professional's most important responsibility is to assess the meaning of the miscarriage. This is followed by intervention strategies for medical safety and effectiveness that offer support, create an environment of caring, and provide hope regarding what will happen next.

Here are some key concepts that this white paper highlights:

1. It's never too early refers to the timing of supportive measures when a woman experiences the threatened or certain involuntary ending of a pregnancy before 20 weeks' gestation.
2. It's never too early to assess what the miscarriage means to the woman. A thorough, sensitive assessment holds the key to providing the right care at the right time.
3. It's never too early to honor the choices and directives of the woman and her family through communication and co-creating care.

Defining Miscarriage

A miscarriage is the involuntary, unexpected ending of a pregnancy before 20 weeks' gestation (MacDorman & Gregory, 2015). Miscarriages occur at any point along this timeline, with approximately 80% of miscarriages occurring during the first trimester (within 12 6/7 weeks' gestation) (Cunningham et al., 2014). Miscarriage occurs approximately 750,000 times annually in the United States (MacDorman & Gregory, 2015).



A miscarriage is unpredictable; a woman can miscarry anywhere at any time. Women miscarry at home, at work, in cars, at a restaurants, and at worship services. Bleeding may be light, heavy, or sporadic, and it may be accompanied by slight to intense cramping. The bleeding may start and stop in the beginning or come full on. Some women will go to an urgent care clinic, a hospital emergency department (ED), or a provider's clinic for assistance. Others will attempt to manage the inevitable bleeding, cramping, and pain on their own no matter where they happen to be. No interventions have been proven to prevent miscarriage.

There are three treatment options available for miscarriage: surgical, medical, and expectant management. Most women choosing surgery do so to avoid the uncertainty of waiting for the miscarriage to happen naturally and do not wish to insert misoprostol tablets (medical management) into their vagina to cause uterine contractions. Women who watch and wait (expectant management) may wish to avoid interfering with the natural process of miscarriage. Given time, all nonviable gestations usually end spontaneously without medical intervention.

Understanding the Emotional Responses

The loss of a pregnancy at any gestational stage can lead to a variety of emotions. Women and their partners are likely to be cast into an unfamiliar and distressing place yet will have decisions to make and plans to carry out.

About 75% of women experiencing a miscarriage view the ending of the pregnancy as the loss of a baby while 25% view the loss as a part of life (Limbo & Wheeler, 1986). It is critical to understand the meaning of the miscarriage to each individual woman in order to understand and possibly predict her emotional response (Wojnar, Swanson, & Adolfsson, 2011). Some women characterize the loss as a baby, a wished for future, a pregnancy, an aspect of motherhood, and a specific child with an imagined future (Brier, 2008; Côté-Arsenault & Dombeck, 2001; Limbo & Wheeler, 1986; Swanson, 1999). Those who experience grief may feel angry, sad, tearful, guilty, worried, or afraid (Brier, 1999). Other women may feel unburdened by the loss or freed from making difficult decisions. As noted in Levang, Limbo, and Ziegler (in press), the meaning of a pregnancy loss is unique and derived from one's own world view, life circumstances, cultural features, values, faith, and beliefs.

A miscarriage can be an emotional emergency without being a medical emergency. The feelings or thoughts of a woman experiencing a miscarriage may be heightened and lead them to present in the emergency department. For information on caring for a woman experiencing miscarriage in the emergency department, see Appendix A.

Determining the Meaning of This Loss Experience to the Patient

Meaning-making is a term that refers to the process of making sense of life events and experiences, relationships, and the self (Wojnar, Swanson, & Adolfsson, 2011). People engage in meaning-making throughout life and, especially, when they come face-to-face with life-changing circumstances. For women and their families, the possibility of a miscarriage gives rise to the question of what meaning was assigned to this pregnancy. For care providers, understanding is critical to providing patient-centered care. The ability to provide sensitive and appropriate medical care comes from learning and understanding the unique meaning that the patient has created and embraced.

The following tips can help determine the meaning the patient has given this pregnancy:

- Listen to the patient's description of the pregnancy.
    - Does the patient use the term "baby"?
    - Has the patient given her pregnancy a name?
- How does the patient respond to the following:
    - "I wonder how you are doing with all of this."
    - "What do you feel that you are losing (have lost)?"
- Does the patient refer to herself as "mother"?

Helping the Patient Be Sure

As noted by Limbo, Glasser, and Sundaram (2014), "being sure" is central to a woman's ability to navigate through a miscarriage. She needs to be sure that her pregnancy has ended and be sure that she has chosen the treatment option that is right for her. Women in one longitudinal study described that if

they chose a treatment option that ended the pregnancy (surgery or medical), they needed to be sure the pregnancy was not viable (Limbo, Glasser, & Sundaram, 2014). Ultrsonography provides a high level of certainty, confirming the health of the pregnancy for most women (Limbo, Glasser, & Sundaram, 2014). Comparing the two ultrasound images below, the dark circle in Image 1 is evidence of an empty uterus, called a blighted ovum. Although the woman is pregnant, the embryo did not form. Image 2 shows a 7-week size fetus with four limbs, a body, and a head tucked onto the side of the uterus.

Image 1

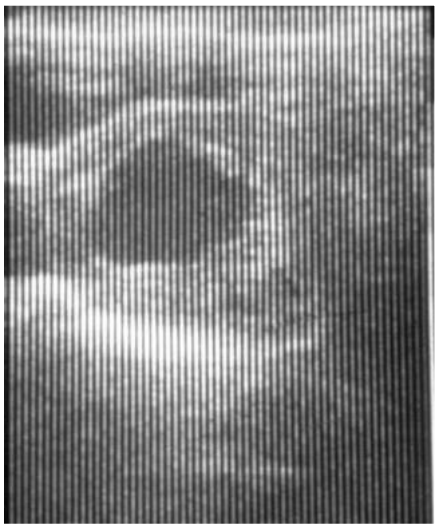
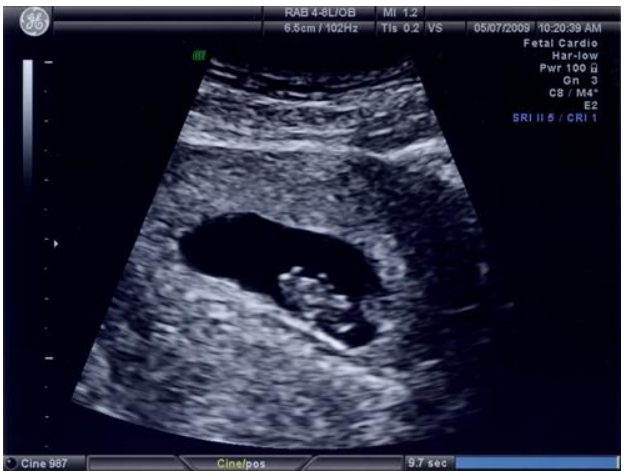


Image 2



Communicating With the Patient

A care provider's interactions with the patient are likely to occur at a time when the patient may display heightened emotions along with atypical physical responses. Her fear, anxiety, and/or worry may impede her ability to talk coherently, to listen attentively, or to adequately process what is happening around her. This is understandable and normal. If possible, care providers should find a private space to interact with someone showing signs and symptoms of miscarriage. An empty room at the far end of the hall that is rarely used, or perhaps intended for other uses (e.g., a care conference), would be satisfying.

While there may be little time for the healthcare provider to prepare in advance, it can be helpful for the provider to take a minute or two to collect his or her thoughts and formulate a plan before stepping into the room. The provider should recognize that compassion and empathy play key roles in the woman's response, whether or not she is experiencing a sense of loss (Weng et al., 2013; Back & Arnold, 2014). The PRAM framework, explained in *Meaningful Moments: Ritual and Reflection When a Baby Dies* (Limbo & Kobler, 2013) is intended as a critical reminder to **P**ause, **R**eflect, **A**cknowledge, and be **M**indful as one prepares for a first interaction with a patient at a time that is likely distressing for both patient and care provider. A mindful approach such as PRAM helps care providers ready themselves for what may be an emotionally-laden and spiritually challenging communication (e.g., hearing a question such as "Why did this happen to me?").

Using statements that guide the woman—rather than question her—can be more effective in helping her reflect on her feelings (e.g., "I wonder what the physician has told you," or "How has it been since

you learned about the miscarriage?"). When the healthcare professional provides the patient with information both orally and in writing, instructions and directions are less likely to be lost or misinterpreted. Repeating information and soliciting acknowledgement can also ensure that the patient is tracking and absorbing details (Limbo, Glasser, & Sundaram, 2014; Pridham, Limbo, Schroeder, Thoyre, & Van Riper, 1998). See Appendix B for more information on communicating with the patient.

Co-Creating With the Patient and Family

Support, guidance, and interventions provided by the healthcare provider are best when they fit within the framework of patient-, family-, and culture-centered care (Lor, Crooks, & Tluczek, 2016). Relying on compassion and skill, care providers must work collaboratively to assure that the experience is what would be most meaningful to the patient. The key to co-creating care is jointly authoring and implementing a defined plan with objectives to achieve a satisfactory resolution.

Limbo and Kobler (2013) use the term "co-creating ritual" to describe how families and their healthcare providers find ways to add ritual to the experience, especially when the couple identifies the miscarriage as a loss. Co-creation requires careful listening on the part of the care provider. An example of co-creating care could begin with a couple expressing interest in a baby ring. In this case, a ritual can be created by asking, "Would you like the chaplain to meet with both of you and bless two rings in memory of your baby?" The rings would also offer a keepsake for the couple to take home.

With co-creation, the care provider and patient share responsibility for expectations, intentions, interventions, and decisions. Limbo and Kobler (2013, p. 7) noted, "Through co-creation, caregivers can acknowledge family members' ability to ascertain what is most important in the moments ahead. Instead of feeling the responsibility of being in charge, the caregiver may watch to see how interactions with the family unfold or say something simple such as, 'What is important to you right now?'" At the same time, jointly creating care allows the patient to engage in what Limbo and Lathrop (2014) called "final acts of caregiving." This refers to the opportunity to "mother" by engaging in actions that express love for the child and legitimize the woman's sense of motherhood.

Co-creating has the added benefit of reassuring care providers that they have honored the choices and directives of the patient and, thereby, empowered them rather than perpetuated the feelings of powerlessness that are part of a pregnancy loss. This outcome allows the care provider to build confidence in their skills, while helping the patient feel listened to and understood.

To co-create the care provider should

- rely on open-ended questions;
- engage the patient and family in defining what they need and desire;
- facilitate the generation of ideas, answers, thoughts, and intentions from the patient and her family;
- respect and include the input of the patient and her family;

- seek the participation of the patient and her family;
- eliminate and manage time pressures; and
- stay "in the moment" with the patient and her family.

Offering Memorial Services

Respectful disposition of remains following miscarriage includes the concepts of personhood, place, and protection (Limbo, Kobler, & Levang, 2010). A woman who attributes personhood to her miscarriage and considers it the loss of a baby will want to protect that baby and provide it with a respectful resting place. A way of honoring the loss through burial is by keeping tissue or remains separated and identified and designating a place for burying them (e.g., placement in a casket with other remains, burial in a designated burial space). Burial also serves as a way of protecting the remains, avoiding placement in a landfill or incineration with other body parts (both of which are common practices of hospital laboratories).

Memorial observances hosted by healthcare institutions can play an important role in helping patients and their families construct meaning from their loss. This critical task is sometimes overwhelming as there are often few answers to the many "whys" that the bereaved may pose in the wake of their miscarriage. The work of Victor Frankl (1959) provided a model for understanding how participation in burial rites can lead to positive meaning making. Frankl posited three strategies for meaning fulfillment: a) with deeds or creative work, b) through experiences or engaging with others, and c) by facing an irreversible fate. The many facets of a memorial service offer ample chance to engage in one or more of these strategies.

A memorial service offers the opportunity to incorporate ritual in the ceremony. Rituals, like a blessing or naming, provide formal recognition and assure patients and their families of the legitimacy of their feelings. Kobler, Limbo, and Kavanaugh (2007, p. 291) noted that, "Rituals provide an opportunity for adding new meaning or reconstructing a prior meaning to profound life events."

Burial and memorial service

Appendix A: Perinatal Nurses Advocating for Bereavement Care for Women who Miscarry in the Emergency Department

Joyce Merrigan, DNP, MS, RNC-OB, CPLC, wrote the following blog on care of families with miscarriage in the emergency department. Dr. Merrigan recently completed her Doctor of Nursing Practice degree. Her project consisted of designing a 4-hour training program for ED nurses on caring for women experiencing miscarriage and their families.

PERINATAL NURSES ADVOCATING FOR BEREAVEMENT CARE FOR WOMEN WHO MISCARRY IN THE EMERGENCY DEPARTMENT

by, Joyce Merrigan, RN

"If we don't do it……it will never be done."

The image will be forever ingrained in my memory: the remains of a miscarriage scooped up by a gloved hand in the emergency department, tossed into a plastic specimen container and left on a counter. No condolences were offered to the woman who had experienced this loss. This memory haunts me to this day but also drives me to advocate for change.

"If we don't do it……it will never be done."

In the United States, 1 in 4 pregnancies ends in miscarriage. It is likely that you know of someone, or have personally experienced a loss. . The gestational age at the time of pregnancy loss appears to determine not only the setting for care, the emergency department (ED) or labor and delivery (L&D), but also the standard of care when it comes to addressing bereavement. This difference demonstrates that miscarriage continues to be treated as a physical complaint and is not acknowledged as the loss of life with emotional dimensions.

Labor and delivery units across the country have incorporated evidence-based practice standards, educated the bedside nurses, and rewritten policy and procedures to apply the principles of perinatal bereavement care into the standard of care for women experiencing loss after 20 weeks gestation. We have done a terrific job responding to the unique emotional, spiritual and cultural needs of this population. However, there is another unique group of women who may be slipping through the cracks; women who miscarry before 20 weeks gestation and receive emergency care in our EDs.

"If we don't do it……it will never be done."

Historically nursing care of women experiencing a miscarriage in the ED concentrated on the medical interventions to correct hemodynamics and nursing care to promote physical recovery. The plan of care was devoid of bereavement support and the communication and activities to validate the miscarriage as the loss of life. Bereavement care acknowledges miscarriage as the

loss of life and demonstrates that the products of conception need to be handled with respect and dignity. Bereavement care considers the spiritual, emotional and cultural expression of the pain that accompanies the loss of a baby. The depth of this pain does not correlate with the duration of the pregnancy. It cannot be assumed that because it was an eight-week pregnancy, the woman will not mourn the loss. This stated we cannot conclude that all women who miscarry will cry or require perinatal bereavement support. However, nurses must explore the personal meaning of the pregnancy loss being mindful of offering choices and accommodating individual requests.

The emergency department is fast-paced, has high nurse: patient ratios and often the standard operating procedure for the woman whose chief complaint is vaginal bleeding and not far enough along to send to L&D, is hemodynamic stabilization and discharge home. Perinatal nurses are sometimes asked to tend to the emotional needs of a distressed woman in the ED. Although perinatal nurses may happily accommodate the request, they may also be reluctant to leave the L&D unit and disrupt patient care there**.** ED and perinatal nurses working together in this regard could be viewed as collaborative but this approach can lead to fragmented care when women who are miscarrying are in need of continuity.

There are barriers to implementing perinatal bereavement care as the standard for women who miscarry in the ED. Besides time and culture, the most significant barrier is the inexperience with and knowledge of perinatal bereavement care communication skills and activities (Burkey, 2014; Chan, Chan, & Day, 2003; Evans, 2012; Rowlands & Lee, 2010; Zavotsky, Mahoney, Keller, & Eisenstein, 2013). Emergency nurses acknowledge they should provide specialized emotional care and support after a miscarriage but believe they lack the communication skills and knowledge to provide the best care (Chan et al., 2003). Fearful of saying something wrong, some ED nurses choose to remain silent, however, saying nothing may be as harmful as saying the wrong thing (Chan et al., 2003; Merrigan, 2016).

"If we don't do it……it will never be done."

The good news is there is a solid correlation between the comfort and ease in the delivery of perinatal bereavement support and formal education in the principles and methodologies! The ED nurse could be best prepared to meet the individual emotional, spiritual and cultural needs of these families if they had the opportunity to participate in a formal perinatal bereavement care education program (Evans, 2012). And who is better suited to lead this education but perinatal nurses. After all, if we don't do it, will it ever be done?

Joyce is a NCC certified OB RN and bereavement care coordinator. She presented perinatal bereavement care in the labor and delivery and most recently emergency room setting throughout the State of NJ. NJ MCH Consortia Perinatal Bereavement Committee and Fetal Infant Mortality Review Committee. Member of Organization of Nurse Leaders, NJ, ANA, NJNA, AWHONN, Hospice & Palliative Nurses Association (HPNA), Pregnancy Loss & Infant Death Alliance (PLIDA) and National Perinatal Association (NPA). She is currently pursuing her certification in perinatal loss (CPLC) through the Hospice & Palliative Credentialing Center (HPCC) and is also a fulltime DNP student focusing her doctoral project on the principles and methodologies of perinatal bereavement care for ED nurses with specific application to miscarriage.

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Appendix B: Caregiving Theory and Guided Participation in Bereavement Care Infographic

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