Respectful Disposition in Early Pregnancy Loss

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Abstract

This article discusses an issue rarely seen in the professional literature: the tangible ways nurses can respect a woman's needs following miscarriage by ensuring the safe handling and disposition of fetal tissue or remains. Concepts of personhood, place, and protection are important for nurses to understand within the context of a woman's response to miscarriage. Hospitals or clinics that foster a culture of respectful fetal disposition should have a system in place to bury tissue or fetal remains in a designated area; in fact, several states have enacted laws that regulate what hospitals and clinics must do, or what women must be offered, after a miscarriage or ectopic pregnancy. Barriers may exist to creating a culture of respectful disposition, including staff attitudes, perceived time and financial constraints, lack of knowledge, and inefficient communication between departments. Nurses can begin implementing change in this regard through conducting a needs assessment using guiding questions contained in this article. In addition, through communication, education, and implementation of respectful disposition, nurses can promote safe processes that will honor women's preferences and wishes for care following a miscarriage.

Key words: Bereavement; Burial; Fetal death; Medical waste; Spontaneous abortion.

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Over the past 30 years, authors and researchers influenced by a heightened sensitivity to perinatal death have written about and studied the emotional experience of early pregnancy loss. Responses to a miscarriage or ectopic pregnancy can vary from profound grief to a sense of relief, from feeling devastated to unfazed (Hutti, 1992; Murphy & Merrell, 2009). For some, having a miscarriage is a simple life event, a logical outcome of a pregnancy that somehow wasn't meant to be. For others, a miscarriage is the loss of a wished-for child, imbued with dreams and hopes for parenthood (Brier, 2008).

No one can predict with certainty, including a woman herself, how she will respond emotionally, spiritually, physically, morally, or cognitively to a miscarriage or ectopic pregnancy (Murphy & Merrell, 2009). The meaning a woman places on the experience, along with her cultural or religious beliefs, will influence her decisions for care during the miscarriage (Kobler, Limbo, & Kavanaugh, 2007; Popovsky, 2007; Swanson, Chen, Graham, Wojnar, & Petras, 2009). Such meaning may also influence her preferences for care of the fetal remains after the miscarriage is complete.

With such different perspectives, it is important for hospitals, ambulatory clinics, or any setting where a miscarriage or ectopic pregnancy could be diagnosed, to thoughtfully consider processes for the handling and disposition of fetal remains. A paucity of research exists related to women's preferences for the care of fetal remains following miscarriage. Yet women's voices are being heard as they relate their miscarriage experiences, fueling the interest of healthcare providers, healthcare organizations, and legislators.

This article will enhance nurses' awareness and skill in providing care to women experiencing an early pregnancy loss. Content includes options for disposition, a hospital needs assessment survey, and a summary of existing state legislation and recommended practice guidelines for clinicians providing care to families.

Background

Approximately one in five known pregnancies ends in miscarriage (before 20 weeks gestation), with 80% occurring in the first trimester (DeCherney, Nathan, Goodwin, & Laufer, 2007). About 1.5% to 2% of pregnant women a year experience ectopic pregnancy, that is, implantation of the embryo outside the uterus (Chang et al., 2003). Limited current literature addresses national or international disposition practice following early pregnancy loss. Scotland's national guidelines advocate "sensitive disposal of human tissue," yet fewer than 50% of women who were surveyed in that country reported being involved with decisions about tissue disposition (Cameron & Penney, 2005). The Royal College of Nursing (United Kingdom) 2007 guidelines (RCN Gynaecology Nursing Forum Working Group) called for "sensitive disposal of all fetal remains," (p. 3) whether in a hospital, private clinic, or in primary care.

Gold (2007), in a systematic review of parent experiences with healthcare providers in the United States, noted that careless handling of babies who died is distressing to parents. Over 25 years ago, Resolve Through Sharing, an organization that provides perinatal bereavement education and parent support materials, included guidelines and a protocol on "Return of Surgical Pathology Specimen" to parents in its training manual (Limbo, Goettl, Smiley, & Wheeler, 1984). Despite this history of interest in care of fetal remains, careful handling of products of conception is not universally practiced, nor is it considered standard practice in hospitals, clinics, and laboratories.

Theoretical Perspective: Personhood, Place, and Protection

In order to best advocate for honorable treatment of fetal remains, nurses should be aware of three important concepts as related to miscarriage: personhood, place, and protection. Each concept conveys unique aspects of a woman's understanding of her own early pregnancy loss experience, which in turn can guide clinical interventions. One mother who experienced a miscarriage at 17 weeks gestation stated:

> *"We lost Mathew on June 10, 1983. I woke one night to severe cramping and we rushed to the ER, where I was a staff nurse at the time. I remember feeling Mathew kicking as my husband sped through town. I was 17 weeks pregnant and had not felt movement for very long, but he was kicking me. [After he was born], they put him in a stainless steel pan and took him out of the room. I asked to see him and she brought him back...[I] appreciated the fact that we got to see him and touch him. He was beautiful, with little fingers that even had fingernails, hair, little tiny lips, and I thought he resembled our daughter! The next day we were given a chance to see Mathew again. This time he was wrapped in baby blankets and had a gown on!! I was so comforted; finally someone was treating him like a baby. We had him blessed by the Catholic chaplain. We were given the option of a funeral or to let the hospital "take care of things." I was so distraught at this point I couldn't think. My husband decided we should let the hospital take care of things. I know now it was his way of trying to protect me...a few weeks later...I decided I was going to get my baby and have him buried on top of my Mom's grave...I knew it would be the perfect place for our son.....Mom loved children. So I called the bereavement coordinator. I asked, 'Where is my baby?'" (name withheld, 2009).*

Personhood

Scholars, politicians, authors, philosophers, religious leaders, and others debate when life begins. In the story above, the mother was clearly viewing her experience as the loss of her son.

Research published in the mid-1980s (Limbo & Wheeler, 1986) in which approximately 75% of women with an early pregnancy loss felt they lost a baby drew

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attention to variation in meanings attributed to miscarriage. Côté-Arsenault and Dombeck (2001) identified the importance of personhood as related to perinatal loss. In their study, a quantitative measure of "personhood" was assessed by asking, "What did you feel you lost?" The data showed that women most often identified their loss as a pregnancy, baby, a baby with a name, or a child who would now be a certain age. Just as the mother above strongly conveyed, those perceiving the loss of a person, their baby, may greatly value the careful treatment of the baby's body, regardless of size, after death.

Place

One of our fundamental needs as humans is to have a place in this world. "Place" has both literal and symbolic meanings as noted in the seminal work of Pesso (1973), a theorist and psychotherapy clinician. When pregnancy brings about the birth of a living baby, parents may cradle the baby in their arms, providing a literal place of safety and love, while continuing to have expectations about this child's symbolic place in their future lives. With the death of the wished-for child, even very early in pregnancy, the parents do not have an external way to keep that place reserved. Respectful disposition can provide both a symbolic and literal place for what has been lost through miscarriage or ectopic pregnancy.

For Mathew's mother, learning the exact location of his body was very important, even in the years subsequent to his death. The hospital's practice at that time was to dispose of miscarriage remains under 20 weeks with general laboratory waste; thus, Mathew's body was buried in a landfill. Most parents would not envision a landfill as the final resting place for their baby. Rather, our society promotes respectful burial of our dead, with subsequent memorialization providing a tribute to the deceased's ongoing place in our hearts and in the world. Mathew's mother had expected to hear that her son had such a tangible burial place for his body.

Protection

Like the concept of place, protection is another basic need of humans, with both literal and symbolic meanings (Pesso, 1973). Typically, women see their bodies as offering "protection" to their developing baby. The uterus is a safe home, meant to nourish and safeguard their child until a full-term birth (Alhusen, 2008). Thus, a woman may make lifestyle changes that she believes help her unborn baby grow and develop. These changes could include eating nutritional foods; monitoring her physical activities; managing her stress; and refraining from cigarettes, alcohol, and other drugs. Symbolically the woman understands that her baby is fragile and defenseless, and relies on her for safe keeping and passage into the world. The diagnosis of an inevitable miscarriage challenges the woman's ability to protect (Layne, 2003). Respectful disposition can allow the healthcare providers to continue this notion of protection by caring for the remains after the miscarriage in a sensitive way.

In our story, the mother acknowledges that it was her husband's wish to protect her from pain that led them to follow the hospital's standard practice for disposition of their son's body. She implies that she would have been more cognizant of protecting Mathew if she had not been so distraught and unable to think clearly. Safe and secure handling of the tissue or fetal remains by the nursing staff extends the idea of protection and may be seen as comforting to women and their families.

Many healthcare providers today honor personhood, place, and protection through supportive interventions to women experiencing an early pregnancy loss. For example, "personhood" may be symbolized through offering a tangible memento such as an ultrasound picture or a baby ring (Capitulo, 2005). If parents have chosen a name for the baby, a nurse can acknowledge the baby's "place" in a family by calling the baby by name. "Protection" could be honored by supporting a woman's decision to miscarry naturally (needing to keep the baby protected inside the womb for as long as possible) by providing information and supplies. Although most institutions have developed standards of care for the interventions provided during perinatal loss, many have not fully developed processes to ensure careful handling of tissue or fetal remains.

Developing a Culture of Respect for Disposition: What Is Needed for Change?

Nurses should review their institution's current practice for disposition of fetal remains to determine whether personhood, place, and protection are being respected and honored. After a thorough assessment of current institution, local, and state disposition practice, nurses can move forward with implementing change where warranted.

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Questions to Assess Current Fetal Disposition Practice

1	What is the hospital's and/or clinic's mission or vision statement and how does respectful disposition coincide with these documents?
2	How many patients experience miscarriage or ectopic pregnancy in your institution every year? (Include data from emergency room, ambulatory or day surgery, labor and delivery, high-risk antepartum, outpatient offices, urgent care, inpatient gynecology, infertility, medical or surgical units).
3	What is the hospital's current practice for disposition of tissue or fetal remains from an early pregnancy loss?
4	Are women currently informed that they have a choice for disposition of their fetal tissue or remains? Is this an institutional standard offered to everyone?
5	Is laboratory examination of tissue after a miscarriage or ectopic pregnancy routine? If your hospital or clinic uses an outside laboratory, what is the laboratory's policy for handling of tissue or fetal remains after an early pregnancy loss?
6	Do handling or disposition procedures change if there is no tissue left after the laboratory examination?
7	What are the cultural and religious practices or traditions of patients and families routinely cared for at your institution? Do any of these identified groups have specific end-of-life preferences or requirements for their fetal tissue or remains?
8	What are the current local ordinances or state laws regarding care of fetal remains less than 20 weeks gestation?
9	Does state law require women to *sign a consent form* for fetal disposition (Table 1)?
10	Do you provide a hospital-organized burial on a regular basis for fetal remains from pregnancies less than 20 weeks?

Assessment of Current Practice

To fully capture the institution's current fetal disposition process, nurses should first determine all areas of the hospital or clinic where women experiencing an early pregnancy loss could be cared for, then gather facts on how the flow of care occurs in each setting. Box 1 includes questions to guide assessment of practice. The nurse should create a detailed report of the institution's current disposition process, including responsible departments, disciplines, and personnel involved with the handling of the fetal tissue or remains.

Legislation

After determining current practice within their institution, nurses need to become informed about state legislation and local ordinances regarding disposition of fetal remains. In most areas of the United States, pregnancies ending before 20 weeks completed gestation do not require reporting of the fetal death, and a death certificate is not automatically generated. Therefore, parents experiencing an early pregnancy loss are not legally bound to make any disposition choice. At this time, only Colorado, Florida, Illinois, Missouri, and Ohio specify disposition options for fetal tissue or remains under 20 weeks completed gestation (Table 1).

In recent years, additional states have enacted fetal disposition laws in an effort to promote careful handling of fetal remains within hospitals, clinics, and birthing centers. Table 1 summarizes the current legislation implemented in affected states. Each legislative effort was driven by parents' own experiences of miscarriage in which they were not informed that they could choose the method and place of disposition. Those currently working to pass fetal disposition laws are focused on two essential goals: (a) that all women experiencing a miscarriage are informed they have a choice, and (b) that all healthcare settings develop consistent standards of care for fetal remains.

Similar fetal disposition legislation has been introduced or is under consideration in several other states. Awareness of pending legislative efforts affords healthcare providers the opportunity to support, recommend changes, or propose limitations—essential because, once enacted, such laws affect clinical practice. With or without legislative mandates, a *culture* of respectful disposition among professional disciplines is necessary to provide family-centered care tailored to the individual needs and circumstances of those who experience early pregnancy loss.

Anticipation of Potential Barriers to Respectful Disposition

Nurses will likely identify potential barriers to process changes within their institution. Healthcare providers may have strong personal beliefs against the need for fetal disposition after a miscarriage. Some may believe that providing disposition options will be an intrusion into the woman's life, creating grief where none exists. Others may view care of fetal tissue as unnecessary, morbid, or interfering with the process of moving on from loss. If such barriers exist, nurses who are interested in this topic can explain to colleagues the importance of assessing the meaning each woman holds for her perinatal loss and the subsequent need for honoring personhood, place, and protection.

Additional barriers may exist when multiple departments or disciplines have to work together to implement changes in hospital disposition practices. Territorial issues or lack of cooperation between units may hinder communication in the care of these families. Perceived

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Table 1: State-Enacted Disposition Legislation

State	Year Enacted	Legislative Reference	Legislative Specifics	Specified Disposition Options
Colorado	2001	Revised Statues Part 4, Article 15 of Title 25	Woman must make timely request for remains	Entombment, burial, cremation
Florida	2003	Sec. 383.33625 Stephanie Saboor Grieving Parents Rights Act	Notification of Disposition of Fetal Demise. Election in writing within 24 hours of notice	Hospital disposition to follow procedures for other human tissue. Parent must choose licensed funeral director
Illinois	2001	Public Act 92-0348	Disposition Notification Form. Election in writing within 24 hours of notice	Burial or cremation Common burial of fetal tissue
Kansas	2008	Disposition of Fetal Remains Act BH 2342	Written policy for disposition options. Parental notification	Not specified.
Minnesota	2008	HF 3222, sec. 4, 145.1622	Policy for informing woman of disposition options	Not specified.
Missouri	2008	Disposition of Fetal Remains Act Chapter 194 Sec. 194-375 to 194-384	Oral and written notification within 24 hours of miscarriage. Counseling made available internally or referral outside	Cremation, burial, incineration in approved medical waste incinerator, separate from other medical waste
Nebraska	2003	LB 95 71-20, 121	Written policy for disposition. Election within 14 days of miscarriage	Not specified.
Ohio	2008	517-071 Grieving Parents Act	Oral or written notice of disposition policy. Notice of right to Fetal Death Certificate	Single grave with family member, cremation, separate group burial
South Dakota	1998	34-25-32.3 & 34-25-32.6	Discuss or disclose method of disposition	Not specified.

lack of time may also be a barrier; staff may be concerned that accompanying a parent to the laboratory, arranging a blessing for the baby in the recovery room, or reviewing disposition options may affect the ability to meet other patient care needs. Nurses may have to push beyond these barriers to best accommodate the family's needs and care preferences.

Nurses should be familiar with the cultures, religions, and preferences of the patient populations they serve because such factors can significantly influence proper disposition care. Being mindful of how cultures and religions define care for a body after death will assist nurses to incorporate such care in the revised disposition processes for their institution.

Some hospitals have overcome the financial barrier to providing group burial by persuading local cemeteries to provide burial plots at no or little cost. Nurses are advised to work with hospital administrative leaders to evaluate costs and identify possible sources of funding for group burial. Sources may include auxiliaries and foundations.

Respectful Disposition Processes and Practices

In its simplest form, respectful disposition involves both consent of the woman and subsequent action by the institution. Ideally, disposition is sponsored, organized, and carried out by the institution, with all fetal remains placed in individual containers and buried together in a common casket at a recognized gravesite, avoiding landfills or incineration. A group memorial service may be held in conjunction with the burial.

Having a process in place for careful handling of fetal remains means women are informed that they may also choose private disposition—whether it be home burial, placement within an existing grave, or use of funeral services for burial or cremation. When possible, parents should be offered the option to see, touch, and acknowledge their baby. Finally, caring for remains respectfully maintains all of the supportive interventions described earlier to honor personhood, place, and protection by both the hospital and the family.

Implementing Change to Promote a Culture of Respect

After assessing their institution's current practice, reviewing state legislation, and identifying potential barriers, nurses are in a position to create new processes that promote a culture of respect for disposition needs after a miscarriage. Nurses will need to work collaboratively with management to establish communication links among leadership and clinical staff in all departments involved in the handling of pregnancy tissue or fetal remains.

As clinicians in each department voice their thoughts and concerns, nurses can listen carefully to ascertain

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At this time, only Colorado, Florida, Illinois, Missouri, and Ohio specify disposition options for fetal tissue or remains under 20 weeks completed gestation.

possible processes that can be enhanced or implemented to honor personhood, place, and protection for tissue and fetal remains. Nurses should not underestimate the individual gifts or resources other disciplines can bring to the process because a culture of respect promotes excellence in patient care that can be shared by all staff. The individually decorated caskets in Figure 1 are the work of two laboratory employees who prepare the remains for burial each year. One wrote this about her experience: *"I do take pride in this [hospital burial] every year and am glad I made a difference in what they [the caskets] used to look like. It brings more meaning to the family."*

Once departmental processes for respectful hospital disposition are determined, key persons should be identified to communicate and educate family members on disposition choices. Individual communication with patients and their family members may be enhanced through the offering of written information about miscarriage and available disposition options. Special care should be taken for those women who have not yet miscarried but face the possibility of the miscarriage happening at home or elsewhere. Since some women may not choose surgical intervention but wait for the miscarriage to occur naturally, nurses should discuss possible options for care of the tissue or fetal remains, as well as available hospital disposition choices.

Figure 1: Burial service.

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Once process changes are identified, nurses should work to educate all involved staff members. In-service training sessions or training modules may be developed to ensure that all staff understand and incorporate a culture of respect for fetal remains into their practice. Training should include the concepts of personhood, place, and protection. Staff can be instructed to carefully listen for the word "baby" or "my baby" to help ascertain the meaning a woman or family may have for the early pregnancy loss.

Finally, once the honorable treatment of remains has been initiated, nurses can continue to dialogue with their colleagues to identify areas for further improvement. Collaboratively with other clinicians in related departments, nurses can reflect on how implementation of respectful disposition processes will affect clinical practice and patient satisfaction.

Conclusion

Nurses stand in the unique position of both caring for women experiencing an early pregnancy loss and advocating to create processes that ensure respectful disposition of fetal tissue and remains. Through assessing current disposition practice, reviewing local disposition ordinances and state legislation, and collaborating among all involved clinicians, nurses can subsequently implement change that honors the meaning of the pregnancy loss for the woman and her family. Perhaps Mathew's mother captured this best in her reflections, written recently to someone who cared for her during her miscarriage 27 years ago:

> *"I do know that you have helped resolve my grief for the loss of my son by coming up with the idea to bury babies with proper respect and dignity. So many times I have thought of how you helped me. Whenever I drive by a landfill, and there are several in Michigan, I get a warm feeling that there are no babies buried there, as the Resolve Through Sharing program has made an impact all across our country and internationally as well. It is now standard practice (here) to bury babies in a common area in cemeteries and they are even identified by name!! How wonderfully comforting."* ✥

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Pregnancy Loss and Infant Death Alliance:
http://plida.org

Bereavement and Advance Care Planning Services:
http://bereavementservices.org

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