

Abstract

Compassionate clinical practice guidelines for healthcare providers for respectful disposition after miscarriage are presented. When woven into the whole of a clinician's practice, these guidelines provide the framework for giving women and their families the care they want and deserve when experiencing miscarriage. Relying on theoretical concepts of personhood, place, and protection, care providers can assess the unique meaning a woman assigns to her early pregnancy loss and offer interventions that embrace the concept of respectful disposition. Respectful methods of disposition involve a continuum of care that shows respect for remains and relies on person-, family-, and culture-centered nursing care. Policies, practices, and perspectives that flow from respectful disposition have women and families at their core and flexibility to cocreate care. This involves courage and competence. Several states have enacted fetal disposition laws, but these mandates are of questionable benefit because the expertise of healthcare leaders, nurses, physicians, chaplains, and other stakeholders must be involved in this sensitive and important area of care. Compassionate care cannot be legislated. We offer a practical approach to respectful disposition, including how to handle and prepare remains and examples of burial and memorial services, which will give clinicians the ability to respond empathetically and respectfully to the heart-rending plea of a woman who asks, "Where is my baby?"

Key words: Burial; Fetal death; Miscarriage; Spontaneous abortion.

RESPECTFUL DISPOSITION

After MISCARRIAGE:

CLINICAL PRACTICE RECOMMENDATIONS

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Since the beginning of time, women have carried the promise of new life in their wombs. During pregnancy, they have faced the potential for childbearing loss through miscarriages, stillbirths, and the early death of their infant. Joy or sorrow, expectation or hopelessness, arms cradling a newborn or empty, and devoid of the warmth and gentle stirring of a tiny body; these are the realities of pregnancy.

The frequency of miscarriage is often shocking to those who are not familiar with the data. Rowlands and Lee (2010) indicated that one in four women of childbearing age miscarry, whereas the results of a national survey indicate that 750,000 to 1,000,000 miscarriages occur in the United States each year (Bardos, Hercz, Friedenthal, Missmer, & Williams, 2015). These numbers have not changed substantially over the last several decades (Lang & Nuevo-Chiquero, 2012). What has changed is the silence that once shrouded this experience. Since the early 1980s, Resolve Through Sharing® and National Share, among other organizations, have shed light on the impact of miscarriage on women and their families through the voices of parents and their professional care providers. Clinical practice standards, research, and evidence-based curricula led to a new understanding of the type of interprofessional care needed (Walter, Limbo, & Wilke, 1984–2012, 2017).

Initially referred to as the "one-to-one helping relationship" (Limbo & Wheeler, 1986–2003), the concept of relational care highlighted the importance of establishing and maintaining a relationship between patient and care provider. The relationship featured compassion and

accompanied the new understanding that a majority of women experiencing a miscarriage grieved the loss of their pregnancy. Those feelings of grief extended to a desire to have their pregnancy recognized, to perhaps name their unborn, to have mourning rituals, and to create an ongoing legacy of remembrance.

Respectful fetal disposition refers to both policies and perspectives that thoughtfully attend to the handling and disposition of remains from an early pregnancy loss and that rely on the patient's own meaning of her loss in the provision of care (Wojnar, Swanson, & Adolfsson, 2011). Respectful disposition, then, is a set of principles that includes procedures for safe and respectful handling of all products of conception, for providing accurate and sensitive information to the woman, for disposition options including private burial and hospital-based care, and for honoring her wishes and decisions.

The purpose of this article is to inform clinical practice with an understanding of the concept of respectful disposition and of the policies, perspectives, and guidelines that may follow. We discuss the *Principles of Respectful Disposition*; legislative actions, including a current list of state-enacted disposition laws; and clinical practice guidelines with descriptions of handling and preparing remains, examples of parental "final acts of caregiving," (Limbo & Lathrop, 2014, p. 10) and information about memorial services and remembrance rituals.

Most women who miscarry consider it as the loss of a baby, a wished-for child, a child of a certain age, or a pregnancy.



Background

Respectful disposition is not a steady state; rather, it is a continuum of care. Of utmost importance in respectful disposition is consideration of personhood, place, and protection. These perspectives inform policies and standard operating procedures that demonstrate respect for fetal remains. Respectful disposition, then, refers to actions taken by the institution that embrace the woman and the meaning she has given to her pregnancy loss. At this intersection of institution and patient, what is offered to the woman is accurate disposition information; person-, family-, and culture-centered nursing care (Lor, Crooks, & Tluczek, 2016) by compassionate caregivers; and the opportunity, if possible, to see, touch, name, and be witness to her baby.

Theoretical Perspective: Personhood, Place, and Protection

Limbo, Kobler, and Levang (2010) asserted that respectful fetal disposition is informed by three important concepts: *personhood*, *place*, and *protection*. These theoretical concepts are the basis for how women come to understand their loss and create meaning from the experience (Limbo et al., 2010). Personhood refers to the woman's own designation of what was lost to the miscarriage. Some perceive that loss as loss of a baby, of a wished-for child, or of a pregnancy; but others feel no sense of loss (Brier, 2008; Côté-Arsenault & Dombeck, 2001; Limbo & Wheeler, 1986–2003). No matter the patient's perspective at the time of the miscarriage, compassionate and respectful treatment is the course of action with the remains handled with care.

Place and protection are considered basic needs and have both literal and symbolic meaning (Pesso, 1973). In the literal sense, a baby is cocooned in its mother's womb. Symbolically, the mother has a place in her heart and mind that also contain the baby. In the aftermath of miscarriage, both literal and symbolic place may be realized by respectful disposition that incorporates a casket, a container, and/or burial.

While in the womb, the mother's understanding of protection was realized as she used her own body to guard her baby from harm. After birth, the mother understands her symbolic role in ensuring that the vulnerable baby is kept safe. Yet miscarriage has severed the mother's ability to provide protection, and she must now look to others to fulfill this work (Layne, 2003; Limbo & Lathrop, 2014). Healthcare institutions and care providers that engage in respectful disposition can bring about the dignified and sacred protection the baby deserves. Respectful disposition may also include the woman and her family working with a funeral director or, if allowed by local ordinances, selecting a private plan for burial without a professional guide.

Principles of Respectful Fetal Disposition

Healthcare facilities care for human tissue in numerous ways. Here we are concerned with care of only one type

Respectful disposition is a continuum of care that includes procedures for the safe and respectful handling of all fetal remains, accurate and sensitive patient information, disposition options, and that relies on person-, family-, and culture-centered nursing care.

of tissue or remains: that which is part of the ending of a pregnancy through miscarriage. Thus, we refer exclusively to remains after an unexpected and/or sudden loss of a pregnancy at fewer than 20 weeks. The diagnoses vary, but the remaining tissue is similar. For example, a woman may be diagnosed with an inevitable miscarriage, a spontaneous miscarriage, ectopic pregnancy, or molar pregnancy. It is critical to remember that it is not the specific pregnancy loss diagnosis that guides respectful disposition, but rather the *meaning of the loss* to the woman. That meaning is derived individually and may be based on one's own worldview, life circumstances, cultural features, values, faith, and beliefs.

Respectful Methods of Disposition

There are practical, legal, moral, and socially acceptable processes for disposition of human remains after death (postmortem). These processes guide decision making and allow families a context for feeling reassured that they have carried out their rights and responsibilities to the deceased. Still, the task of considering and determining the final arrangements can be fraught with emotion and discomfort for surviving family members. This is particularly true after miscarriage. Lacking consideration of such a life event, women may feel painfully uninformed and ill-prepared.

Burial. We support burial as the most respectful method of disposition and recommend, if feasible, that it be the default practice endorsed by healthcare organizations. Burial shows an intent to give dignity to the loss by thoughtfully and carefully engaging in a process, creating an identifiable place for disposition, treating the remains in a humane manner, and providing for the rituals of mourning and commemoration as customary in our society. We understand burial may not be practical, or even possible, for hospitals and clinics with a high number of miscarriages. However, women and their families may choose to engage the services of a funeral director or, if allowed by local ordinances, select and bury the remains at a place of their choosing.

Cremation. If the patient and/or healthcare facility wish to rely on heat for tissue disposition, we advise cremation. The process of cremation involves heating the cadaver, in this case the products of conception, in the cremation chamber, or *retort*, of a crematory facility (Cremation Questions, 2004).

The remains after miscarriage are very fragile. There are no hardened elements, such as bone. Instead, remains contain fluid, blood, and tissue (placental and fetal), and cremation results in the disappearance of any solids. Thus, care providers should let parents know that they will not receive “ashes” or other elements of cremains. Even a baby who dies at full term has a small amount of remains after cremation.

Incineration. Although both cremation and incineration use intense heat to reduce bodies to basic chemical compounds, cremains are handled differently. Incineration is a treatment process for waste. As such, fetal remains would be considered pathological or anatomical waste and may be commingled with other anatomy wastes, such as tissue, organs, body parts, and fluids (Cornell University, 2011). It is this distinction between a process aimed at treating medical waste versus a process meant for humans that makes cremation more respectful for fetal remains. Incinerated waste is deposited in a sanitary landfill, whereas cremated remains are buried, scattered, or entombed.

Informed Consent

Informed consent is one of the cornerstones of medical treatment today and a compelling aspect of respectful disposition. It refers to healthcare institutions providing adequate information to gain voluntary agreement or refusal from a competent patient as to treatment (Appelbaum, 2007). Informed consent has both legal and ethical meaning because it involves one's right to make decisions over her body; what Dickens and Cook (2004) refer to as “self-determination.”

Informed consent after miscarriage includes offering the woman the opportunity to learn about the available disposition options, processes, and procedures employed by the institution. These can be explained orally and/or provided in writing with the intent that a continued dialogue with the patient is optimal. As noted by Dickens and Cook (2004), informed consent “. . . is not an event or signed form, but an on-going process or quality in the [healthcare provider]-patient relationship” (p. 313).

Fetal Disposition Legislation

Lack of uniformity in how hospitals, clinics, and other healthcare institutions recognize miscarriage, address informed consent, and handle fetal remains has prompted states to enact fetal disposition laws. Eighteen states have such legislation (see Supplemental Digital Content, <http://links.lww.com/MCN/A43>). The first state-enacted disposition legislation was written in 1994 in Maine. Its provisions called for shared responsibility between the facility and parents. If parents wanted disposition outside the hospital, they were required to initiate that request. Maine did not make parental notification a feature of its provisions and, thus, informed consent was not contemplated within the legal standard.

Informed consent was first mandated in state legislation in Illinois in 2001. The law stated that a mother was to be notified of her right to determine disposition and given 24 hours to provide a written response.



Respectful disposition of fetal remains must begin at the level of the healthcare institution rather than with state-enacted laws.

Illinois' legislation appears to have been ground breaking. Soon Florida (2003) and Nebraska (2003) also required informed consent. In later years, Alabama (2006), Kansas (2008), Minnesota (2008), Ohio (2008), West Virginia (2008), and Indiana (2014) adopted similar regulations.

In states that did not embrace the concept of informed consent, regulations still provide some measure of control over disposition. Alaska, for example, allows parents an option for a fetal death certificate. Colorado requires that a woman or her designee make a timely request for remains. In Georgia, parent(s) must give authorization for disposition if the fetal remains leave the facility. Oregon's legislation stipulates that "upon request" a parent or parents' authorized representative can seek a disposition permit.

The 18 states with disposition legislation fall into two distinct groups: *Informed Consent States* and *Limited Protection States*. The nine Informed Consent states are Alabama, Florida, Illinois, Indiana, Kansas, Minnesota, Nebraska, Ohio and West Virginia, and the nine Limited Protection states are Alaska, Colorado, Georgia, Maine, Michigan, Missouri, Oregon, South Dakota, and Texas. Limited Protection States place few demands on the facility to assist with final disposition; instead, they put more responsibility on the patient (e.g., requiring her to request the remains). Although their regulations vary, the states in both groups have provided critical recognition of miscarriage and have attempted to influence standards of care.

Clinical Practice Guidelines for Respectful Fetal Disposition

Ideally, respectful fetal disposition is tailored to the individual healthcare setting owing to the many varia-

tions in institutions, the factors that guide their core mission, and state law.

Informing the Woman Experiencing Early Pregnancy Loss

Patients are compassionately introduced to the fetal disposition program via an informational packet. Excessive direction in its content is mediated by way of philosophical neutrality, that is, by careful consideration of the varied worldviews, cultures, religions, experiences, and customs of patients. The packet explains the fetal disposition options and clarifies the institution's standard practice for all pregnancies that end before 20 weeks gestation. Patients are assured that personal arrangements can be made and that the hospital or clinic will aid in this process. The packet includes contact information for the bereavement coordinator or other care specialists and their availability to explain and discuss disposition options in greater detail if desired.

If the hospital sponsors a memorial service, those details can be included in the informational packet. We encourage that such events be held at least annually and provide for intact, group burial in a casket without cremation. The observance should be made available to all women, from those who underwent very early loss, to those who experienced ectopic pregnancy, molar pregnancy, or other instances in which remains are very small. We suggest that burial be at a location that signifies respect and sacredness, and will be viewed as private, comforting, and caring to the patient and her family. Cemeteries and memorial gardens are two such environments.

Caring for the Remains

Most hospitals and clinics send all products of conception fewer than 20 weeks' gestation to the histology laboratory for ordered testing and description of the remains for the medical record. Many then retain the remains in a special area until released to the patient, buried with other miscarried remains, or otherwise handled as surgical specimens. It is our position that the first two alternatives are more respectful options. Clinical staff may wish to follow these steps in caring for remains from a surgical dilation and curettage: (a) set the small plastic basket from the suction canister onto cotton gauze to allow as much liquid and/or moisture to drain as possible, (b) sprinkle baby powder on the tissue to absorb any last moisture and create a pleasant scent, (c) place a layer or two of dry cotton gauze around the basket, (d) wrap a 12" × 12" square of baby blanket tightly around it and secure with fabric tape, and (e) place patient identification on each bundle.

Adapt the same process for patients who miscarry during their stay or bring remains in from home. Fetal remains of later gestational age can be rinsed or bathed and dressed, if the size allows. Extra care can be extended

by wrapping in a shroud or baby blanket. A small corner of the blanket can be removed as a keepsake for the patient.

Bundles can be set next to one another in a common casket with careful attention to ample spacing. This process of cocasketing can be described to the patient in comforting ways to ease any concerns, for example, “The space is shared with other babies.”

Private Burial

Final disposition may include the woman choosing private burial or use of a funeral director. If remains were preserved with formalin, laboratory personnel can rinse formalin from the remains, place them in 100% alcohol for at least 15 minutes to restore the original skin color, and prepare the baby for presentation to the parents. Remains then can be bundled and identified in the same manner described above. The bundle can be set in a small box, placed in a fabric bag, and given to the patient (Figure 1).

Final Acts

Families often want to be personally involved. By welcoming and engaging the family in cocreation, the memorial service and burial can become more enriching and healing for all involved (Brin, 2004; Limbo & Kobler, 2013). Involvement encourages what Limbo and Lathrop (2014) described as “final acts of caregiving.” The healthcare provider and mother or parents can together create a special way of saying goodbye. Here are three examples that, among other things, represent our multicultural society and show what can be accomplished:

- A family of a very early loss made a small wooden burial box using wood from their house. They wanted to ensure that “the baby’s house would be the same as our house.” Each side of the box, nearly the size of a recipe card box, contained writing. The box lid was fitted with a hasp and lock. The parents placed their wedding photo and swatches from their own baby blankets inside. After the baby was tucked inside and the lock secured, the two keys for the lock were threaded onto chain necklaces and worn thereafter by the parents.
- A father needed the remains to be buried facing east toward Mecca. Staff laid the lid of the casket on the ground in the normal orientation for burial. East was found by using a compass and noting the direction on the lid. The remains were then delicately placed in the casket facing in the correct direction.
- Having once lived in Japan, a couple turned to the grieving tradition of Jizo after her miscarriage. As is customary, the mother crocheted a red hat and sweater for the small Jizo statue and settled it in their garden. The Jizo brought both concreteness and process to their pain (Elson, 2017).

Creating a Memorial Service

In our society, remembrance observances acknowledge the loss, support the process of mourning, encourage the work of grieving, and instill a sense of hope. Observances rely on rituals, that is, on symbolic experiences as a form of com-

munication. As Rabbi Brin (2004, p. 123) so eloquently stated, “The powerful energy of ritual helps parents heal from pregnancy loss by acknowledging the traumatic event, drawing to them the healing presence of their friends and family, and providing the comfort of tradition.”

The basic elements of a Memorial Service are Introduction and Welcome, one or more Readings, a Blessing or Tribute, Music or Song, a Reflection or Message, a Ritual of Remembrance, and Closing Blessing or Thank You. See Table 1 for suggested rituals. Memorial services can be hospital-based, conducted privately by the patient and her family, or even incorporated into bedside care. The essential focus is to respond to what families request, to what they say is meaningful to them, and to what best represents hope.

Conclusion

Miscarriage is considered traumatic due to its far-ranging impact on a woman’s life, including the loss of her “reproductive story” (Jaffe & Diamond, 2010). The shock and incomprehension that may arise when a pregnancy ends early leads many women to inherently trust and accept that hospital disposition of their fetal remains will be respectful and appropriate. Yet as the silence of miscarriage has been replaced with advanced medical information, a plethora of resources, and instantaneous methods of communication, women are more willing to declare what is respectful disposition and what is not.

Some states have written disposition legislation, but the question remains: Are there advantages to state-mandated disposition policies, or would it be better for the healthcare profession to engage the patient in defining and deciding what respectful disposition options are acceptable to her and her family?

Protocols for disposition of miscarriage remains already exist in healthcare institutions, even if that disposition is as medical waste. What respectful disposition offers is the knowledge that patients consented for their care by being

Figure 1. Burial Containers for Fetal Remains Bundle



Memories Unlimited
Dimensions: White box: 4.5 inches wide, 5 inches high;
Purple box: 9 inches long, 5 inches wide and 3 inches high

The meaning of the loss to the woman guides respectful disposition rather the specific diagnosis of pregnancy loss. That meaning is derived individually and may be based on one's own worldview, life circumstances, cultural features, values, faith, and beliefs.

invited into the process of decision making with options that honored the meaning they alone assigned to their early pregnancy loss. This is the essence of respectful disposition: empowering patients to construct their own healing narrative within a caring environment that thoughtfully and professionally guides and assists them.

Our inquiry into respectful fetal disposition has been driven by the sorrowful plea of those women who ask: "Where is my baby?" It is imperative that healthcare institutions take this question seriously and be able, at any time, to provide the precise answer. That can be done with respectful disposition policies and accompanying clinical practice that healthcare leaders develop and enact based on what they see as their responsibility to learn and grow through education, research, and clinical experience. The *Principles of Respectful Disposition* provide a pathway that acknowledges caregivers are dedicated experts who tend to the fragile and grieving women and their families experiencing early pregnancy loss.

Clinical Implications

Healthcare organizations and stand-alone laboratories need policies or standard operating procedures that include care of remains after all types of pregnancy loss. Respectful disposition after miscarriage includes, but is not limited to, the following skills, actions, or processes:

- All remains after the ending of any pregnancy should be treated respectfully.
- Provide staff education on how to communicate with pregnant women and family members about the

meaning of the ending of their pregnancy and what they wish to include in final acts of caregiving (which would include respectful disposition).

- Inform women that the miscarriage can happen when she is using the toilet. Give her a collection vessel (i.e., "toilet hat") or suggest she use a large bowl when she uses the toilet. Give her several pairs of latex rubber gloves.
- Have supplies on hand for creating a "bundle" (described previously) for remains.
- Provide the woman with reading material about miscarriage, signs and symptoms of impending miscarriage, and self-care after a miscarriage.
- Determine a burial site or place for cremation internment and give the woman information on when and where the burial or cremation internment will take place.

The keys to any patient encounter include (a) compassionate and empathic care based on (b) establishing and maintaining a relationship and (c) using language that is consistent with the woman's perception of the ending of her pregnancy. ❖

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Table 1. Rituals of Remembrance

Name	Theme	Materials	Instructions & Purpose
Mourning circle	Loving	Flowers, ribbons, or branches	Together, participants place flowers/ribbons/branches in a circle around the casket(s) to symbolize eternal love.
Bread upon the water	Cleansing and healing	Large bowl of water or stream/river/lake Loaf of bread	Participants shed their fears and sadness by tearing off a piece of bread and casting it into the water.
Companions in grief	Compassion	None	Form two lines and take turns sharing words or gestures of comfort to the participant walking through the line.
Love tokens	Remembering	2" Hearts cut from felt Safety pins Fabric marker	Using words, symbols, drawings, participants decorate a heart and pin it over their own heart.
River of connectedness	Unity	1" x 20" length of ribbon per participant	The leader ties the end of their ribbon to that of the next participant and so on until all are connected as one.

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