Wisconsin Association for Perinatal Care

WAPC

POSITION statement

CHILDBEARING LOSS AND GRIEF

Introduction and Purpose

The purpose of this statement is to provide guidance to caregivers who provide services to those who have experienced pain and suffering from a childbearing loss. The statement delineates quality perinatal bereavement care and services. The position statement addresses

1. strategies for helping families deal with perinatal loss.
2. desired outcomes for clients and family members.
3. unique considerations for specific types of loss.

The statement is intended for care providers. However, if families read this statement, they may find the ideas helpful in understanding their own loss, what they can expect from community caregivers, and how they can participate in their own healing. The statement is not written to advance a particular course of treatment, but rather to create an environment within which all members of the health care and support team can contribute to the well-being of women and their families.

Grief in the childbearing years may occur as a response to a recent or past childbearing event that produces a sense of loss. These events include, but are not limited to, adoption, infertility, loss of a baby during pregnancy or within the first year of life, maternal death, interruption of pregnancy for medical reasons, multifetal reduction, and abortion. Also included are unexpected birth outcomes, such as a traumatic labor and delivery; birth of a premature infant; or birth of an infant with special needs. Ideas for the position statement are derived from experience, the literature, and survey results. Caregivers who wrote the statement, some of whom have personally experienced a loss related to childbearing, are from numerous disciplines and settings.

The Magnitude of Childbearing Losses

Recent statistics indicate that the number of childbearing family losses in the United States each year is impressive.

- Approximately 15-20% of clinically diagnosed pregnancies end in miscarriage.[1]
- Approximately 30,000 babies are stillborn.[2]
- About 20,000 babies die as newborns (within the first month of life).[3]
- Over 8,000 children die as infants in the postneonatal period.[3]
- There are 800,000 elective abortions performed.[4]
- There are over 6 million women of childbearing age who have an impaired ability to have children.[5]
- 120,000 infants are placed for adoption.[6]
- There are nearly 60,000 babies born prematurely, weighing 1500 grams or less (approximately 3½ pounds), some of whom end up being children with special health care needs.[7]
- Nearly 400 women die from complications of pregnancy, childbirth, and the postpartum period.[8]

So what do these statistics mean? They mean that nearly every person reading this statement has been

affected by a childbearing loss in some way–through a family member or close friend, a work colleague, patients, or perhaps personally. Because these events happen day in and day out, care providers must be prepared to act in a helpful and responsive manner. Acting helpfully and responsively means acknowledging what happened, saying, "I'm sorry," avoiding clichés, and assessing the other's expectations about the experience (hopes, dreams, values, and meanings). It also means holding another in mind[9] (i.e., remembering) long after the loss occurs.

Providing support for families experiencing childbearing loss is a community activity. The roles of funeral directors, the clergy, physicians, social workers, parish nurses, public health nurses, and home visitors take on added importance as community resources become the primary source of support and guidance in the weeks and months after a loss.

Overview

Grief and loss during the childbearing years evoke highly emotional and personally meaningful issues for both providers and consumers of health care. Childbearing loss touches on issues of gender, class, sex, culture, ethnicity, fairness, economics, ethics, religion, family relationships, and parenting.[10] Childbearing loss

- challenges expectations of how life is supposed to be;
- creates a context for examining personal, cultural, and societal values; and
- provides an opportunity for reflection and growth.

Childbearing losses may affect women and their families for a lifetime. The effects of childbearing losses may occur well after the childbearing years have ended. They affect people across contexts: acute care, primary care, community, work, and home.

Sensitive, responsive bereavement care aids progression through grief and toward healing for all individuals affected by the loss. Acceptance of the reality of the loss helps individuals normalize the experience, and aids them in integrating the loss into current and future relationships.[11] Responsive bereavement care acknowledges and gives meaning to a person's experience and an individual's existence in a culturally conscious manner.[12] It is the groundwork for present and later provider/client relationships. The goals of responsive bereavement care are improved client health (mental, spiritual, emotional, social, and physical); cost effectiveness due to improved health; and satisfaction for family, provider, and community.

Goals

A good outcome after a childbearing loss would include

1. Describing oneself as feeling hopeful about the future.
2. Participating in meaningful relationships with others.
3. Being free of clinical depression.
4. Being able to parent in a sensitive, responsive way.
5. Expressing satisfaction with life and the future.
6. Being able to consider the possibility of another pregnancy without a high level of distress.
7. Feeling physically healthy.
8. Participating in meaningful life activities (family, religious community, social, hobbies).

Inadequate professional care inhibits the realization of these goals.

Strategies for helping families deal with perinatal loss[13,14,15]

Acknowledge the loss or the potential for loss. Learn what is on the other's mind about the experience.

"I'm wondering how you're doing with all of this."

"How have things been for you since you started your treatments?"

"Some women feel sad that they won't experience what they consider to be a normal pregnancy. How is it for you?"

"I'm so sorry."

"I've been thinking about you a lot."

Take advantage of opportunities to **create some type of positive memory** of the experience.

Provide information based on the client's or family member's interests.

Make connections between a prior experience and the current one; between present and a future provider; between resolution of a previous problem and possible future problems.

Establish a dialogue. Help others break what may be an overwhelming feeling of loss into smaller pieces.

"What are you most concerned about now?"

"What could I help with at the present time?"

Let someone know that they are **being held in mind**.[9] Being held in mind is a powerful intervention. Knowing they are thought about in their absence helps people maintain connections and remain hopeful about relationships and the future. Parents often acknowledge a condolence card or letter from a care provider as one of their most meaningful mementoes.[16]

Responding to Differences

Competent care (i.e., sensitive, responsive, and respectful care), and thereby, culturally competent care,[17] requires a genuine interest in the other's well-being, a kind and gentle approach in interactions with them, and a willingness to ask when there is uncertainty.

Separating culturally competent care from competent care is an artificial division. A competent caregiver avoids assumptions about what another might be feeling, what is important, or what something means. Here are some guidelines for competent bereavement care:[18,19]

- Approach all clients with respect and genuine interest in their experience.
- Ask, "What would be important to you right now?"
- Understand that simply being aware of a group's cultural practices is an inadequate response to an individual who may or may not have adopted those practices.
- Understand that differences within groups (e.g., within the Latino community) may be just as powerful and common as differences between groups (e.g., between Latinos and Euro-Americans) in how someone responds to loss.
- Take personal grief, hesitation, or frustration–stemming from the provider's own cultural perspective–elsewhere. Talk to a colleague, friend, or clergy.
- Whether a woman has a same-sex or opposite-sex partner, acknowledge the relationship.
- Acknowledge elders who are present by introducing yourself and being attentive to their needs (e.g., the need for a chair). Have them explain what is important for ritual.

Suggestions for Writing a Condolence Note

Dear _____,

Acknowledge the loss: *I am sorry that things did not work out as you had hoped. [I am sorry that your baby _____died.]*

Let them know that you hold them in mind: *I am thinking about you and your family.*

Highlight a memory: *I remember_____.*

Close with a wish or hope: *I hope that your special memories bring you comfort. [I hope that the days will look brighter soon].*

Signed_____

- Say, "I'm sorry." Learn those words in the languages of your usual clients.
- Shake hands when you are introduced (or introduce yourself). Use "Mr." and "Mrs." until asked to do otherwise.
- If you are wondering about something, ask.
- Do not assume that stoicism or lack of emotion indicates the absence of grief. If you are not sure, say, "People respond in different ways to this experience. I'm interested in knowing how things are for you."[20,21]
- Couples frequently grieve differently. Encourage them to seek help outside the relationship as well.[22]

"Culture" implies more than differences in race, ethnicity, or socioeconomic status. Each family is a unique culture. Differences among families in the usual and customary cultural expectations, intentions, and feelings are often centered in these key areas:

- Family hierarchies (Who leads? Who follows? Are the rules rigid or flexible?)
- Family closeness (Do family members show emotional closeness or distance?)
- Differences in outward expression of grief (Have men and women been socialized differently?)
- How decisions are made (By consensus? Through one person's authority?)
- Respect for the role of elders in decision making (Are elders present? Do family members look to them?)
- Spiritual/religious needs or practices (Do family members adhere strongly, weakly, or not at all to religious or spiritual principles and guidelines?)
- Personality types (Same? Different? How do they fit together?)

Monitoring mental health after a childbearing loss

Research has shown that a clinical depression is evident in approximately

- 20% of women six months after a miscarriage and stillbirth,[23,24]
- 10 to 15% of all postpartum women,[25] and
- 3 times more mothers of full term than pre-term infants.[26]

Depressive symptoms may be twice as likely in women with infertillity than those without it.[27] There are a number of simple screening tools available to find out who has a high level of depressive symptoms. In addition to depression, recent research indicates that clinicians should also monitor women who experienced miscarriage, stillbirth, a traumatic delivery, and other losses for symptoms of post-traumatic stress disorder (PTSD) and other types of anxiety.[23,28]

Persistent yearning for what was lost may complicate grief. With persistent yearning, mourners experience intrusive thoughts and spend a great deal of time and energy obsessing. They may also cling to objects or symbols that represent what they yearn for. New research on mothers of stillborns indicates that those who think and talk about what the baby is experiencing as if the baby were still alive (e.g., cold, loneliness) are more vulnerable to complicated bereavement that can affect the relationship with a subsequent child.[29] Clinical depression, PTSD, anxiety, and persistent yearning are symptoms that require an evaluation by a qualified mental health professional.[30,31] Treatment may involve psychotherapy, medication, behavior changes (diet, exercise, etc.) in combination or alone. Any of these mental health challenges cause unnecessary sadness and suffering for the mourner. Professional providers can help by recognizing the symptoms and referring if necessary.

A summary of types of childbearing losses

The ideas presented in the "interventions" column on the following pages are suggestions based on what many families find helpful. It is essential that caregivers tailor the intervention for each family. Tailoring implies that the provider understands a family's expectations and intentions related to their loss. Recent research underscores the significance of caregivers offering options in a straightforward, noncoercive manner.[29] It is important to have both written and verbal information provided to parents on taking photos of babies after death. Families who experience a childbearing loss often ask, "Why did this happen?" or "Why did this happen to me?" Genetic counselors and spiritual advisors may assist families in their search.[32]

Type of Loss	Unique Features	Interventions
Early pregnancy loss, no visible baby[33,34]	May not experience a sense of loss. Distinguish between loss of a pregnancy versus loss of a baby. No visuals for identification or validation of pregnancy.	If a sense of loss, offer to create symbols to represent what was lost. Provide ultrasound photo. If a woman has experienced multiple early pregnancy losses, genetic counseling might be useful.
Early pregnancy loss, visible baby[32,33,35]	May not expect to see a visible baby. Baby may look "perfect" and hard for parents to understand why the pregnancy ended.	Provide options to see and hold, pictures, foot- and handprints using plaster molds, ritual of blessing, and naming. Provide final disposition options. If a woman has experienced multiple early pregnancy losses, genetic counseling might be useful.
Ectopic pregnancy[36,37]	Intense abdominal pain, may not know she's pregnant. May be found early with ultrasound because of infertility. May be viewed as a surgical procedure at the time and later as a lost opportunity to be a parent. May affect future childbearing.	Acknowledge/validate the pregnancy loss. Offer memento such as a baby ring or a blessing, if desired. Refer for questions about future childbearing.
Loss of one or more babies in a multiple pregnancy[38]	Experience joy and grief at the same time, confusing–"I don't know how to feel"; grief is usually stronger than joy.	Validate feelings. Provide for memory making (e.g., photos, footprints, and rituals) with deceased and live infant(s) together and apart; bury deceased infants together when possible.
Placing a baby for adoption[6,39]	Often a struggle between one's own desires and what is believed to be best for the infant.	Discuss times of bittersweet grief such as birth of another baby, baby's birthday, holidays. Encourage mementoes.
Being adopted (closed)[6,40]	May dread being asked about family history or medical history.	Discuss times of bittersweet grief, such as the first sexual experience, birth of first child.
Infertility[41]	This is a "baby in mind" with intangible losses: control, self-esteem, pregnancy/childbearing experience, generational continuity, parenting experience, societal expectations, relationships, and "normalcy" in life routines.	Listen carefully for expectations associated with the identified intangible losses. Help reconstruct expectations (e.g., by defining an end point to fertility treatment). Give honest information about outcomes.

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Type of Loss	Unique Features	Interventions
Stillbirth[13,38,42,43]	The mother looks pregnant and is carrying a baby who is dead; baby's appearance is affected the longer the time between death and birth.	Acknowledge that the mother and her support people are doing an effective job in labor; acknowledge the birth, not just the death; no cry of a new baby is a moment of intense sadness and reality; offer the option to bathe, dress, name. Provide final disposition options. Consider genetic counseling.
Newborn death[44,45]	Parents want life support in most cases but willing to discontinue with adequate information–they do not want their baby to suffer.	Support decision to withdraw life support and prepare parents for what the death process looks like; provide skin-to-skin care, holding at last moments of life. Provide final disposition options.
Infant death[46]	Guilt, questioning "what if," "if only." When a baby dies in a home, parents or other caregivers are usually investigated. Parents may feel shock and anger. Baby is often "known" by many relatives and friends.	Create memories for those closest to the infant (siblings, grandparents). Offer multiple options regarding funeral and burial (e.g., placing drawings, pictures, toys in the casket, holding the infant for visitation).
Medical termination[47,48,49]	Guilt, have control of the decision making, fear of "doing the wrong thing."	Offer mementos, rituals as appropriate for beliefs. Encourage support group with others experiencing this type of decision making or loss. Consider genetic counseling.
Elective abortion[50]	Secretive. May be uncertainty throughout. Must be acknowledged repeatedly for medical history, "How many times have you been pregnant?"	Acknowledge grief, if present. Ask about access to pre- and post-abortion counseling. Refer if necessary. Ritual may be needed years later. Generally positive emotional outcomes.
Multifetal reduction[51,52]	Is usually secretive. Often no choice because of safety and health of the mother and limited number of babies that can survive. Guilt over wanting these babies, yet choosing to reduce the numbers.	Encourage expression of feelings/loss. Provide memories of babies reduced, if desired.

Type of Loss	Unique Features	Interventions
Unexpected birth outcomes[53,54,55,56]	The mother and perhaps father experience loss if their labor and delivery did not go as they had expected (e.g., difficult delivery, premature delivery, unexpected cesarean, unexpected anesthesia).	Understand that grief and joy can co-exist; do not attempt to remove their sense of loss by saying, "But you have a wonderful baby."
Birth of a special needs child[57]	Face difficult decisions regarding future pregnancy. Adapting to on-going parenting challenges.	Genetic counseling. Connect with community resources. Stress importance of creating mementoes.
Maternal death	Absence of parent to the new baby and other children; loss of partner; need for staff support if death occurred in a hospital.	Encourage family time with the mother; take her handprints with her baby's. Include both sets of handprints in the same photo.

Caregiver Response

Caregivers are reminded that this can be a traumatic experience for everyone involved. It is important for caregivers to identify resources available to them to process what has happened. There are several references related to caregivers caring for themselves at the end of the statement. Act proactively in terms of stress management and reduction.[58,59]

Conclusion

The emotional component of events related to childbearing carries with it the potential for great joy and great sorrow. How a caregiver responds to a woman or her family or friends when they experience a childbearing loss makes a difference at the time and in the months and years to come. A heartfelt expression of sorrow is the most powerful intervention a caregiver can provide. In addition, parents need and want information so they can make choices. Long after an event is passed and memories of the details have faded, people remember who said, "I'm sorry," or showed a genuine caring presence.

Resources

To learn more about childbearing loss and grief, visit the WAPC website at www.perinatalweb.org. Click "Bereavement/Loss Work Group" to find links to bereavement resources.

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Acknowledgments

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Bereavement/Loss Work Group Contributors to the Position Statement

Bonnie Gensch, RN, chair, Gundersen Lutheran Medical Center, La Crosse

Anita Braden, Episcopal Diocese of Wisconsin, Milwaukee, bereaved parent

Angela Brunhart, BS, MSW, SOS Milwaukee, adoptee

Patricia Grunwald, RN, MS, Meriter Hospital, Madison

Anne Harvieux, CICSW, BCD, Infant Death Center of Wisconsin, Milwaukee

Gary Hein, MDiv, St. Marys Hospital Medical Center, Madison

Michelle Helin, RN, Upland Hills Health, Dodgeville

Tammy Koenecke, RN, Reedsburg Area Medical Center, Reedsburg

Patricia Mehring, RNC, MSN, OGNP, Medical College of Wisconsin, Milwaukee

Betty Minton, RNC, St. Joseph's Hospital, Marshfield

Peggy Modaff, MS, CGC, University of Wisconsin-Madison

Kyle Mounts, MD, Newborn Care Physicians of Southeast Wisconsin, Milwaukee

Peter Narum, MDiv, MS-MFT, Bethel Lutheran Church, Madison, bereaved parent

Ted Peck, MD, Gundersen Lutheran Medical Center, La Crosse

Terry Schwartz, Funeral Director, Schwartz Funeral Home, Lancaster

Julie Simani, MS, RN, Madison, parent

Cheryl Weber, RN, BSN, Children's Hospital of Wisconsin, Milwaukee

WAPC Staff: Rana Limbo, PhD, RN, CS

WAPC Statewide Office
McConnell Hall
1010 Mound Street
Madison, Wisconsin 53715
Telephone 608/267-6060
Fax 608/267-6089
Email at wapc@perinatalweb.org
Website at www.perinatalweb.org

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