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# *Stillbirth: Patient-centered Psychosocial Care*

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**Abstract:** Evidence-based practice and patient-centered practice are not mutually exclusive clinical ideals. Instead, both styles hold tremendous potential for complementarity in healthcare and should be used to enhance clinical relationships in which caring is humble, mindful, and nuanced. The onus of the responsibility for many decisions about care after stillbirth falls on clinical staff. Yet, even in the dearth of literature exploring standards of care during stillbirth the results can be conflicting. Thus, research in both patient-centered and evidence-based approaches suggest that less emphasis should be placed on the standardization of care; rather, the focus should be on relational caregiving that underscores the uniqueness of each patient and their family, recognizes culture, and encourages affirmative, rather than traumatizing, provider reactions.

**Key words:** stillbirth, psychosocial care, patient-centered care, evidence-based practice, psychotherapy

*“Not long ago, a baby’s death was an unspeakable event in a hospital .... The baby was whisked away before parents could see or hold their baby .... The mother was given tranquilizer if she became too upset, if she lost [control].”*

*I. Leon*

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## *The Cost of Loss*

Bereavement, particularly when sudden and traumatic such as in the case of stillbirth, poses the risk of many negative long-term social, psychological, and biological outcomes. Some of those hazards include anxiety, dysthymia, suicidality, loneliness, anhedonism, substance abuse, inorganic pain, and attachment and relational problems as well as increased premature mortality.<sup>1–4</sup> Complicated, or prolonged grief, has been recognized by clinicians as a problem facing a percentage of those traumatically bereaved, however, only recently has a psychometric validation of diagnostic criteria been proposed for inclusion in the *Diagnostic and Statistical Manual of Mental Disorder-V*.<sup>2</sup>

Some women experiencing the stillbirth of a baby meet the risk criteria for complicated and traumatic grief resulting in significantly diminished functioning. Rando<sup>3</sup> suggests that certain circumstances increase the likelihood of complicated grief including: sudden death that is especially traumatic, violent, mutilating, or random; the death of a baby or child; the perception that the death was preventable; a markedly dependent relationship;

concurrent mental health problems; and a perceived lack of social support during and after the loss. Similarly, according to Worden,<sup>4</sup> complicated grief reactions include: (1) chronic grief that is excessive in duration, (2) delayed grief that has been inhibited by suppression, (3) exaggerated grief that is exacerbated by multiple factors such as marginalization, shame-induced stigma, or physiological trauma, and (4) masked grief that results in somatic symptoms or alexythmia. The highest risk to the individual is when all the 4 criteria overlap. That is, grief becomes protracted, the griever has no safe place to express grief, the loss was socially stigmatized or invisibilized, and eventually the emotions associated with the loss are expressed through somatic ailments or self-harming behaviors, such as social withdrawal, cutting, eating disorders, or engaging in risky behaviors. To date, no studies have measured the economic impact of stillbirth. Yet, considering the psychosocial risks to women and their families, inarguably, the aggregate cost to society is quite high.

### ***The Exigency for Patient-centered Care***

*“Somehow I feel I’ve failed as a woman. I just didn’t get it quite right. Most women come home with a baby after nine months of pregnancy. I came home with a tabletop full of drugs. And let me tell you, that Percocet is good stuff. Not a baby, but damn good stuff.”*

*Kara Jones, Flash of Life*

If birth, even when the outcome is a live baby, can result in posttraumatic stress and depression for many women,<sup>5,6</sup> stillbirth would significantly increase both the risk and the likelihood of poor psychological adjustment in the postpartum period. Rowe-Murray and Fisher<sup>7</sup> found 3 variables affecting postpartum depression

following a live birth: lack of support, pain, and suboptimal contact with the baby right after birth. Each of these is often manifested and exaggerated in the instance of stillbirth, thus, the exigency for social support, as with any child’s death. However, stillbirth also presents with some peculiarities.

One such idiosyncratic difference is a psychological phenomenon known as ambiguous loss, based on the work of Pauline Boss.<sup>8,9</sup> Ambiguous loss may arouse profoundly debilitating grief responses, occurring in situations where there is physical absence and psychological presence. Her theory can be readily applied to stillbirth: though the child is physically absent after death, psychological presence and pining often continue for months or years, manifesting in many ways. The lack of tangible evidence of the baby’s existence may undermine the legitimacy of a mother’s emotions, provoking role distress. Adding to the complex nuances of stillbirth is its societal demarcation from other types of child death. Stillbirth is often regarded by academics, clinicians, and the general population as a “pregnancy loss” rather than the death of a baby. These merging influences make some women feel marginalized and may actuate ambiguous grief.<sup>10</sup> Ambiguity is manifested through protracted denial, indistinguishable boundaries, relentless information seeking, and emotional outbursts. In particular, clinicians have the opportunity to circumvent and attenuate some of the effects of boundary ambiguity, perhaps by helping women actualize their losses through patient-centered caring.

As early as the 1970s, researchers discovered links between compassionate provider reactions and grief responses.<sup>1,8–15</sup> Mothers who experienced stillbirth reported very high levels of anxiety, and this state could be reliably predicted by psychosocial conditions, including a perceived lack of support from others.<sup>13,16,17</sup> The immediate care a woman receives during

stillbirth has a significant affect on her emotional status up to 3 years after the baby's death.<sup>17</sup> Rather than using strict guidelines, preset protocol, checklists, and platitudes when interacting with grieving mothers, caregivers should, instead, focus on the relationship itself as an axiom of person-centered care.

### ***Clinical Recommendations for Care in the Era of Evidence-based Practice***

*"I like to blame the caseworker, as if it is her fault I did not hold my son. But, at that moment in time I refused to hold him. What I did not know, until I saw the photos the nurse took, was that death was a full 6 lbs 4 oz with perfect hands and feet, full lips full head of dark curly hair ... I did not know that holding my son would have been the same as when Romeo held Juliet's lifeless body to him, embracing a flash of life."*

*Kara Jones, Flash of Life*

Evidence-based practice and patient-centered practice are not mutually exclusive ideals toward which a clinician should strive. Instead, both styles hold tremendous potential for complementarity in healthcare and should be used to enhance patient-centered care that is humble, mindful, and nuanced.<sup>14,15,17,18</sup>

There are many experiential aspects related to stillbirths, and all child deaths for that matter, of which clinicians need to be aware.<sup>19</sup> Women—and their families—need to decide whether or not they wish to see, hold, and photograph the dead baby. They will need to choose which, if any, mementos they want to keep, such as hand and foot prints and molds, blankets, or a lock of hair. They will need to decide whether or not to have an autopsy, and if so, where that autopsy will occur. They will need to choose the form of final disposition, burial or cremation, and choose an appropriate mortuary—or home fun-

eral—for the baby. They will need to fill out legal documents. In some states, this is a Certificate of Fetal Death. In others, they may have the option of choosing a Certificate of Birth resulting in Stillbirth. They will need guidance around surviving children, deciding whether or not to include them in the hospital event or the successive memorial service. They will need to be educated about the experience of traumatic loss, efficacious of interventions, such as support groups or psychotherapy, and future family planning. Often, the onus of many of these responsibilities falls on clinical staff. Yet, even in the dearth of literature on standards of care following stillbirth, the empirical outcomes can be conflicting.

For example, amidst the evidence in stillbirth research, there exists significant discrepancy in outcomes over specific recommendations in the standardization of care. Most of the dispute in the evidence revolves around seeing and holding the dead baby. Some studies suggest that such rituals increase the risk of long-term psychological harm to women and their subsequent children<sup>20</sup> whereas other studies show the opposite effect.<sup>15,17,20</sup> In a longitudinal study of Dutch parents whose children died at various ages ranging from stillbirth to 29 years of age, parents who had an opportunity to say farewell had lower grief scores than those who did not across the age groups. In addition, those who chose home funerals, that is, they cared for their child's body during the postmortem period in their home, also reported lower grief scores 2 years following the loss. The researchers suggest that this process assists parents in confronting and realizing their loss.<sup>21</sup> Boss agrees that seeing the baby's body helps a mother to begin the process of relinquishment while revising attachment. Not having seen the remains, she contends, interferes with that process and incites ambiguous grief.<sup>9</sup>

What do clinicians do when empirical evidence is seemingly contradictory?

Researchers in patient-centered approaches suggest that less emphasis should be placed on the standardization of care; rather, the focus should be on relational caregiving that underscores the uniqueness of each patient and their family, recognizes culture, and encourages affirmative, rather than traumatizing, provider reactions. It is a model based on authentic, mutual relationships.

In a population-based study of 636 postpartum women, of whom 314 had a stillbirth and 322 had a live birth, Rådestad et al<sup>17</sup> found that the process of birth was physically and psychologically more painful when the baby was stillborn. The hospital stay was also briefer, and mothers were less satisfied with the care they received. Thus, an expedited hospital discharge may replace the provision of emotional support from medical staff.<sup>17</sup> Other mothers have expressed feeling ignored during the postpartum period. Fear, misinformation, and the lack of training may contribute to avoidant staff responses. There have been many contributing factors to the misinformation and inadequate care following stillbirths, including concern over litigation, personal fear, and anxiety around death, a political environment that has failed to accept stillbirth—even when late and unexplained—as the death of a child, and a historically paternalistic system that wrests control from women over their birth experiences. Patients whose providers were perceived to be insensitive to their emotional state during traumatic births claimed they felt vulnerable and helpless as a direct result of their interactions.<sup>17,22</sup> Ineffective communication that incited feelings of disrespect, indignity, and paternalism increased the likelihood of dissatisfaction, negative psychological outcomes for women, and litigation.<sup>17,19,22–24</sup> These disaffirming and traumatizing provider reactions to loss compromise relational trust and exacerbate fragilities during stillbirth.

Conversely, person-centered care wherein the relationship is the apogee “alleviates vulnerability in all of its forms”<sup>23,24</sup> and may help to buffer the negative effects of traumatic events like stillbirth. Interdisciplinary bereavement teams addressing perinatal death at hospitals ameliorate somatic distress and relieve hostility in grieving mothers. The benefits of these interactions are particularly discernible in cases in which women reported low social support from family and friends.

Although clinicians are often faced with a constellation of familial and individual needs, bereaved mothers may be unable to coordinate services, navigate an overwhelming hospital system, or ask the right questions without guidance and support. Thus, clinicians should strive toward a baseline knowledge about the epidemiology of stillbirth, relevant psychological theories for traumatic bereavement and interventions; expertise in verbal and nonverbal communication during a crisis (including a supportive and noncoercive style); commitment to both evidence and patient-based care that is culturally competent; mastering the ability to coordinate appropriate services within the community; and making time to advocate, when necessary, for systemic change.

The 3-function doctor-patient model can be used as an evidence-based, relational guide for clinicians working with the bereaved.<sup>25</sup> This trilogy emphasizes (1) gathering data to understand the patient, (2) developing rapport and responding to the emotions of patients, and (3) psychoeducation. Under this model, communication provides an exchange of useful information, promotes action and interaction, allows the patient to access feelings about an experience, and provides an opportunity for caregivers to express caring by addressing the 3 fields of understanding: cognitive, emotional, and psychomotor.

First, gathering data to understand the patient requires that caregivers take time to become familiar with the sociocultural intricacies of each patient. It prompts the acquisition of information, such as religious beliefs, previous history of loss, and structure of the family system, that will be important in building trust and mutual understanding. This process of relational knowing may also serve to enhance joint decision-making processes. For example, the religious views of woman who has experienced stillbirth may inform her attitude toward an autopsy or final disposition. The second principle, developing rapport—or a relationship—with the grieving mother and then responding to her emotions is imperative. Ritualization may be especially important for women after the death of a baby. However, a mother who is too fearful to hold her stillborn baby may make irreversible decisions because she is emotionally overwhelmed, or she may be feeling pressured by others not to see the baby. This may lead to later regret, particularly if she was offered a brief opportunity to hold the baby but she denied.<sup>15</sup> Although rituals are a profoundly intimate decision, through a caring relationship with the clinician, a woman can make decisions based on her authentic desires rather than based on fear. Through this relationship, the caregiver is able to respond empathically and patiently to a mother's authentic needs. Finally, psychoeducation that is conveyed with warmth and honesty about what to expect during and after the birth, offering ritual options such as holding the baby, photographs, or mementos, may give them a sense of informed control. Effective communication during psychoeducation hinges on 9 very important principles: (1) never interrupt the speaker, and allow for a pause between main thoughts; (2) avoid jumping to conclusions; (3) pay attention and engage easily; (4) listen for feelings, beliefs, and ideas; (5) avoid impulsive reactions or solutions; (6) pay

attention to the patient; (7) maintain respectful nonverbal communication; (8) accept the emotional sentiment of the other person; and (9) listen attentively. This model, overall, sets the stage for a caring environment in which important, potentially irreversible, decisions can be made without coercion or regret. Clinicians should also avoid paternalistic responses because it is inconsistent with woman-centered principles for care. They should, instead, build rich relationships that empower women to make their own healthcare choices after stillbirth, and facilitate rather than denigrate their maternal, feminine responses to loss.

Narrative intervention is both evidence-based and patient-centered and has proven helpful in reducing adverse psychological outcomes for women. Women who received as little as 30 minutes of supportive counseling experienced a significant reduction in anxious and depressive symptoms during the postpartum period.<sup>26</sup> One postvention program that included telephone counseling commencing 72 hours after birth and lasted for 3 months revealed markedly decreased posttraumatic stress symptoms in women.<sup>27</sup> Another randomized, controlled study showed that even those suffering from complicated grief benefit from narrative psychotherapy. Interventions included retelling the story, exposure therapy, and confrontation over the course of about 6 months.<sup>28</sup> The process by which a clinician listens and is fully present with a patient is an expression of caring. Swanson<sup>29</sup> researched caring as a nurturing way of relating to and valuing the other. The expression of caring for another manifests as

- Knowing: Striving to understand an event as it has meaning in the life of the other by avoiding assumptions, centering on the other, assessing, seeking cues, and engaging;
- Being with: Becoming emotionally present to the other by being there, conveying availability, and not burdening;

- Doing for: Helping by action through comfort, anticipation, competence, protection, and preserving dignity;
- Enabling: Facilitating the other's experience through unfamiliar events by informing and explaining, supporting and allowing, generating options, validation, and feedback; and
- Maintaining belief: Faith in the other's ability to handle a difficult event and find meaning by holding the other in esteem, hope, realistic optimism, and stability.<sup>29</sup>

Boss suggests that a worthwhile therapeutic goal is to help patients normalize their experiences when grief is ambiguous and complicated. She suggests normalizing guilt and other negative emotions by allowing a place for the story to be told and retold until there are more associated positive attributions.<sup>8</sup> She discourages pathologizing responses and encourages listening. Another important intervention includes modalities in the creative arts to help patients manage and express distress associated with traumatic loss. And her approach supports holding a psychological space for the stillborn child within the family, as a reconstruction and reassessment occurs after the loss. Boss extends the responsibility of caring to the broader community.<sup>8</sup> Caring requires attendance and attendance takes time. Indeed, these types of person-centered interventions require clinical, and administrative, commitment to person-centered caring. Nevertheless, best practice should include enacting and enforcing techniques that "prevent the genesis of psychological trauma" and advocating patient rights which may require systemic changes in current administrative policies and procedures,<sup>22</sup> including time delegation and staffing issues.

Other policy changes may affect mental health clinicians in hospital settings. Elio Frattaroli,<sup>30</sup> posits that current standards of psychiatric care may result in the objectification of patients wherein relationships are devoid of humanity and

connectedness. For example, he is critical of clinicians who habitually supplant clinical time in psychotherapy with psychopharmacology, suggesting that it is "a subtle but powerful dehumanizing force that undermines the life of the spirit and subverts the fundamental human quest for a more genuine transformation ...."<sup>30</sup>

By focusing on emotions such as anxiety, guilt, and shame, clinicians can be more accepting, less alienated from themselves and the patient. It is through the "feeling," not "thinking," where the discovery of self and other can occur. Frattaroli warns against what Freud termed *furor sanandi*, the rage to cure. Instead, he suggests that clinicians treat with compassion, and to respect the patient's symptoms or emotional state as a cue toward the path to wellness. Parental bereavement is most often not a disease to cure. Rather, it is a normal response to an aberrant and tragic outcome. The key for clinicians is meeting the patient in their grief and providing an opportunity for healing to occur within the framework of compassionate interventions.

### ***Communicating Caring***

*"Grief remains of the few things that have the power to silence us."*

*Anna Quindlen*

Much of a patient's feeling of being cared for hinges on effective communication. Humanistic communication is a quintessential characteristic of high-context, patient-centered care. Minority groups and women tend to be high-context communicators. This means they place less meaning on the actual words being spoken, and more emphasis on the nonverbal communication and context. This style of communication is more feeling-centered and intuitive. Conversely, low-context communicators rely heavily on the precise spoken word. This results in reduced empathy and perceptivity,

particularly during crises. In high-context communication, the cultural filters decipher implied meanings arising from the physical milieu, nonverbal communication, relationship interaction, or shared understanding of symbols. In low-context communication, the filters direct attention toward the literal meanings and interpretation of words and less to the subtle cues of nonverbal communication or the context surrounding the words.<sup>31,32</sup>

Ways to communicate caring nonverbally include: being fully present with the patient; using silence when appropriate; and, maintaining close, but nonintrusive proxemics, respectful eye contact (when culturally appropriate), open posturing (hands behind the back or at sides rather than crossed in the front), caring facial gestures and gentle tone of voice, and an unrushed demeanor. For example, an emphasis on certain words, tone of voice, and the speed of articulation all affect the receiver's perception of the message of caring. Slightly quieter speech, slowed speech, and an emphasis on caring words convey empathy.<sup>14,31,32</sup>

In oculosics, the use of eye contact when communicating, clinicians should pay attention to cultural cues. Most often, direct eye contact communicates caring and attention toward the other, and it helps the receiver unconsciously accept the truthfulness and sincerity of the sender. Western culture, in particular, values direct eye contact. However, some heritage-consistent Native American tribal members or Asians will avoid sustained eye contact. This nuance in communication styles calls for a sensitive, intuitive, and flexible response wherein the clinician adapts to the other person's communication style.<sup>31,32</sup> Effective nonverbal communication is important in conveying meaning that is congruent with the desired message: Verbal and nonverbal messages need to be congruent, as most of the meaning extracted by the receiver is done

so through the nonverbal message. In sum, eye contact when culturally appropriate, a moderated tone and pace of speech, the judicious use of touch (the top of the hand, closest shoulder, or on the back between the shoulders), and strategically applied silence will often convey a supportive, caring presence.

### ***The Call for Systemic Change***

Death education targeted toward clinical staff can be helpful in significantly increasing confidence making them more comfortable when dealing with bereaved parents. Some degree of grief sensitivity training should be extended to all staff including patient intake staff, pastoral staff, interns and residents, and even non-clinical staff. Yet, administrators do not always provide necessary training even for clinical staff. Chan et al, found that nurses' comfortable attitudes toward bereavement were directly correlated with their knowledge of the death of a baby. Nurses wanted more formalized training that emphasizes death studies, "improved communication skills, and greater support from hospital policy and team members relative to bereavement care."<sup>33</sup>

Hospital administrators may want to consider the implementation of a woman-centered education program focusing on relationships: one that is family inclusive and that supports, educates, and provides debriefing for partners and family members on how to help the grieving mother in the months subsequent to the baby's death. Hagenow recommends that the focus should be on the woman, rather than the hospital system. Recognizing the administrative barriers to person-centered care, such as managed care, economics, and compromised organizational structure, she calls on managers to change "traditional measures of corporate wealth" in which "financial assets derived from productivity and profits are broadened

to include community responsibility, social accountability, and personal fulfillment of employees.”<sup>24</sup> Another policy change might be to implement a postvention program with the grieving mother and her family. A cost-effective way to do this would be through formalized partnerships with well-established, nonprofit organizations that serve families who have experienced stillbirth.

### ***In Sum***

The death of a child is a complex and traumatic experience for women and their families, traversing culture, socioeconomic status, religion, and ethnicity. In particular, bereaved mothers, often overwhelmed by the traumatic nature of stillbirth, take their cues about how to interact with their dead baby from caregivers.<sup>13–15,17</sup> For this reason, clinicians should use an evidence-based approach that is patient-centered, careful not to impose their own values and beliefs. Rather, clinicians should take the time necessary to establish an intimate relationship with the patient, gently guiding the decisions that will be the least damaging and reap the most beneficial long-term choices for her and her family.

These choices, and their ramifications, may last a lifetime and are often not redressable. In the words of Adrienne Rich, “whatever is unnamed, undepicted in images, whatever is omitted from biography, censored in collections of letters, whatever is misnamed as something else, made difficult-to-come-by, whatever is buried in the memory by the collapse of meaning under an inadequate or lying language—this will become, not merely unspoken, but unspeakable.” In addition, for the grieving mother who is having the “unspeakable” experience, the sense of aloneness absent a caring milieu contributes to her invisibility, ushering her into the shadows, and exacerbating her loneliness and angst.

However, patient-centered care that humble, mindful, and nuanced builds authentic, meaningful, and healing human relation-

ships after stillbirth and may mitigate long-term negative psychological outcomes for mothers and their families. This type of relational caring moves beyond the acquiescence of “first, do no harm” prompting the imperative to “then do good.”

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