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# *Using Theory to Inform and Guide* PERINATAL BEREAVEMENT CARE

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## **Abstract**

Providing nursing care to perinatally bereaved women and their families is difficult, emotionally demanding, and complicated. Here we demonstrate how, through understanding the theoretical underpinnings of Guided Participation and perinatal grief intensity, nurses can significantly expand their competence and confidence in their ability to provide highly individualized, supportive, relationship-based perinatal bereavement care. The way that parents respond to a perinatal loss may range from little response to highly intense, long-lasting grief. Grief after such losses may be intensified when the loss experience is highly incongruent with a parent's expectations, and the parent is unable to act to reduce this incongruence. The Hutti Perinatal Grief Intensity theoretical framework and the Perinatal Grief Intensity Scale may be used to help identify parents who are likely to experience highly intense grief and need for professional follow-up after perinatal loss. However, many parents who experience intense grief have little experience in coping with such feelings. Guided Participation is a middle-range theory of teaching and learning. It is used in the context of perinatal bereavement to help bereaved parents navigate the feelings and numerous grief-related issues that occur as a consequence of the loss, with the nurse serving as the expert guide. This combined theoretical approach to care assists nurses to assess grief intensity and to provide highly effective, relationship-driven care.

**Key words:** Communication; Grief; Learning; Teaching.

Providing care to women and their partners during and after a perinatal loss is one of the most challenging areas of nursing practice (Limbo & Kobler, 2010; 2016), especially for nurses with limited knowledge about the psychosocial effects of perinatal bereavement or effective ways to communicate with grieving families (Hutti et al., 2016). This is true for all nurses, regardless of the area in which they work (Hutti et al., 2016).

Perinatal losses can be highly traumatizing experiences for parents (Cacciatore, 2017) and nurses (Hutti et al., 2016). The care that nurses provide to intensely bereaved parents is difficult, emotionally demanding, and complicated (Limbo & Kobler, 2016). To better organize this complicated care, nurses began using perinatal bereavement checklists. *Resolve Through Sharing*, a bereavement education and support organization, developed checklists beginning in 1981 at the program's inception. Checklists serve as communication tools, letting other team members know what tasks have been completed for an individual patient. Particularly for inexperienced nurses, these checklists may become a "procedure" for perinatal bereavement care; a recipe for providing standardized nursing care to patients who are all assumed to be grieving. However, it is now well documented that the responses of parents to perinatal loss may vary dramatically, from little or no grief to highly intense, profound, and unbearable grief, especially during the first and second trimesters when the meaning of the loss for parents can fluctuate greatly (Huffman, Swanson, & Lynn, 2014; Limbo & Kobler, 2010; Hutti et al., 2017). It was not until 1986 that this variability in response was first identified in a yearlong quantitative study of 60 women followed after a miscarriage. Seventy-five percent of these women felt they had lost a pregnancy or baby. The other

25% considered the miscarriage a life event, but not one that created a feeling of grief (Limbo & Wheeler, 1986).

Perinatal bereavement is not a one-size-fits-all experience, and the care of women and their partners must be highly individualized to be perceived as supportive (Limbo & Kobler, 2010; 2016). We suggest there should be no standardized approach to providing perinatal loss care. We want to encourage nurses to use perinatal bereavement checklists to *organize* care, but there is currently no evidence that they should *direct* nursing care without first being individualized to the woman and her family. Therefore, checklists should include a reminder to healthcare providers to assess the meaning of the loss and provide care in keeping with the woman's goals and values associated with meaning.

To take practice out of the realm of care that is directed by a checklist and into a much higher, more authentic, and responsive level, nurses need theory to help guide care. Here we demonstrate how, through understanding the theoretical underpinnings of Guided Participation (Pridham, Scott, & Limbo, 2018) and perinatal grief intensity (Hutti et al., 2017), nurses can significantly expand their competence and confidence in their ability to provide highly individualized, supportive, relationship-based perinatal bereavement care (Limbo & Kobler, 2016). Then, using a case study approach, we will apply these theories to the care of a perinatally bereaved client.

## Hutti Perinatal Grief Intensity Theoretical Framework

Theory provides organization of knowledge about perinatal bereavement; a way to explain how nursing practice works in relation to bereavement care and predicts

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how nursing practice may influence patient outcomes after a perinatal loss (McEwen, 2014). Understanding theories related to perinatal bereavement enables nurses to provide individualized, responsive, relationship-based care that can then be organized with a procedure checklist.

The Huttu Perinatal Grief Intensity theoretical framework (Hutti, 1992) was developed to help healthcare professionals identify men and women at risk for highly intense grief after perinatal loss. The framework serves as the basis for the Perinatal Grief Intensity Scale. The scale was developed with statements made by both perinatally bereaved men and women (Hutti, dePacheco, & Smith, 1998), but it has only been tested with women (Hutti et al., 2017; Huttu et al., 2018). For that reason, our statements in this article are limited to women who have experienced perinatal loss. The Perinatal Grief Intensity Scale is a 14-item clinical instrument designed to identify current grief intensity and predict women with greatest risk for future intense grief, severe depression, and/or anxiety, and need for follow-up after perinatal loss (Hutti et al., 2017; Huttu et al., 2018).

Our research has consistently validated three factors as significantly influencing grief intensity after perinatal loss: the woman's perceptions of the *Reality* of the pregnancy and baby within; the *Congruence* between the actual loss experience and the perceived ideal regarding how the loss experience should unfold; and the woman's ability to *Confront Others* that is, to make decisions or act in ways to increase this congruence (Hutti, 1992).

### Reality

Perceptions about the Reality of the pregnancy and baby within usually change over time. In early pregnancy, women may recognize the presence of pregnancy, but they may not "feel pregnant" (Hutti et al., 1998). As the pregnancy progresses, women begin to feel pregnant and perceptions of a nonspecific baby begin to form (Hutti et al., 1998). Women become attached to the pregnancy and the idea of a baby, but not to a specific child. With time, the woman begins to think of herself as a mother and her baby as having specific personality traits and, often, a name (Hutti et al., 1998). Awareness of the fetus as a specific person is the basis for the woman's developing prenatal attachment to her unborn child (O'Leary & Warland, 2013). In his classic research on attachment and loss, Bowlby (1988) contends if attachment is present and a loss occurs, grief will follow.

Depending on where women are in this prenatal attachment continuum at the time of their loss, their response to the loss will vary. If neither the pregnancy nor baby is real to the woman at the time of the loss, that is, if she has not begun to attach and a loss occurs, she will generally not view herself as a mother, will perceive the loss as *something that just happens*, and little or no grief is expected. If the pregnancy is real but the baby is not real, that is, if the woman is attached to the pregnancy and the idea of a baby, there will be grief over the loss,

but it is likely to be relatively short-lived. If both the pregnancy and baby are real to the mother, that is, if the mother has become attached to the baby within, she will perceive the loss as the death of her son or daughter. These mothers will generally experience acute and long-lasting grief (Hutti, 1992; Huttu et al., 1998).

It is critical for nurses to understand how a woman perceives the pregnancy and baby within at the time of the loss before they intervene. Certainly, as the pregnancy progresses, the likelihood of a woman perceiving her unborn child as a son or daughter increases, but nurses should not assume that a woman with an early loss will not perceive her unborn baby as a son or daughter just because the loss occurred at an early gestational age. Likewise, not every woman with a later loss will perceive the baby as a son or daughter (Hutti et al., 2017). The Reality factor determines how a woman perceives her loss and whether a woman will respond to it with or without grief; however, the Congruence and Confront Others factors can modify this initial response, making it easier or harder for women to bear.

### Congruence

Congruence refers to the relationship between the (a) actual loss experience and (b) how the woman perceives the loss should proceed, assuming that she must go through it (Hutti et al., 2017). Whether a woman feels supported during her loss depends on the congruence between the way her family, friends, and healthcare professionals interact with her and the way in which the woman perceives her relational needs from them. If the woman perceives the loss as a son or daughter, and her friends, family, and healthcare professionals validate her right to grieve and the bereavement-related decisions she makes, the woman is likely to feel supported. If the woman perceives the loss as a life event and is not grieving, and her friends, family, and healthcare professionals focus their concern on the woman's comfort, she is likely to feel supported. However, if there is incongruence, such as a woman who perceives the loss as *something that just happens*; but is presented by her nurse with a memory box and a teddy bear to help her remember *the baby*, she is likely to feel upset, misunderstood, and her emotions invalidated (Hutti et al., 2017). Incongruence can be reduced if individuals are able to Confront Others, although this ability is uncommon during a perinatal loss (Hutti et al., 2017).

### Confront Others

Confronting others gives the woman the opportunity to ask friends and family to stop well meaning but hurtful behaviors and to ask them, instead, to match her own responses. If a woman is unable to Confront Others about behaviors she finds unacceptable and unsupportive, she is likely to experience feelings of increased anger and victimization. For example, even if a mother clearly perceives her baby as a son or daughter, as do most mothers experiencing a neonatal death, their grief can be made

more intense by insensitive care or interactions with others. When a mother's interactions with health-care professionals and significant others about the baby's final days of life are incongruent with her wishes, and the mother feels powerless to do anything about it, mothers will often feel intense anger at themselves and those they perceive as unsupportive. The presence of intense anger, combined with acute grief, may compound the mother's "ability to mourn, and increase her despair and overall grief intensity" (Hutti et al., 2017, p. 129).

The Hutti Perinatal Grief Intensity theoretical framework (1992) predicts the most intense grief responses will occur (a) in individuals for whom the baby is perceived as real (High Reality); (b) when the actual loss experience is perceived as occurring in a way that others do not understand or find unacceptable (Low Congruence); and (c) in individuals who perceive themselves as unable to do anything about it (Low Confront Others).

## Guided Participation

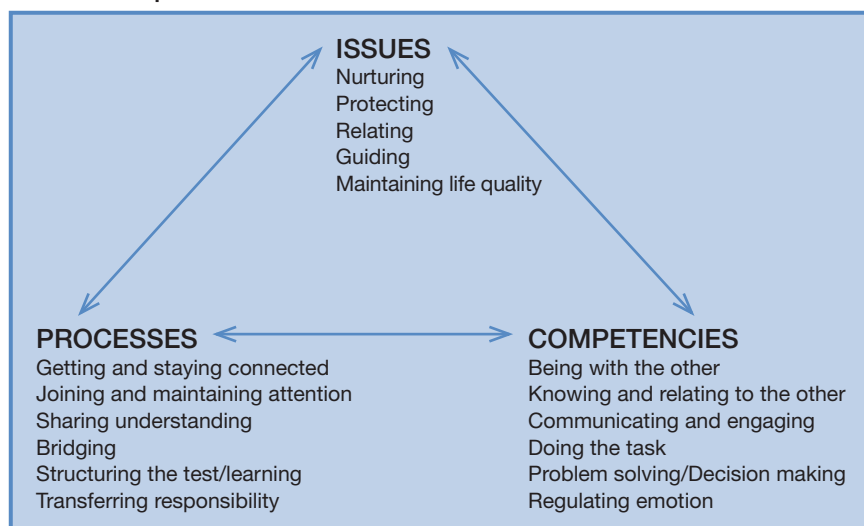
Guided Participation research conducted by Pridham and colleagues over a period of decades (Pridham, 1998; Pridham et al., 2018) uniquely highlights teaching and learning as reciprocal processes. We consider Guided Participation a good fit for communicating with patients and their families about grief intensity. It enables nurses to assess grief intensity in the early hours post loss and intervene beyond what is possible using the Hutti et al. (2017) framework alone. The major components include *issues*, *processes*, and *competencies* (Figure 1).

### Issues

Issues, as used in guided participation, refer to problems that need to be solved. An issue may be identified by guide or learner, or by both. Healthcare professionals orient guided participation toward specific bereavement-associated categories of issues related to nurturing, protecting, relating, guiding, and maintaining life. The subsequent goal relates to helping bereaved clients develop increased competency in addressing these issues, and improved, maintained, or promoted health (Pridham et al., 2018). The following loss-related examples illustrate how an issue may be identified.

**Nurturing and Relating.** A baby in the neonatal intensive care unit is nearing the end of life and separated by distance from his single mother and other family members. The nurse and mother both view her inability to nurture her baby as a highly significant issue. Together

**FIGURE 1.** Guided Participation Issues, Processes, and Competencies



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er they determine that the baby's nurse will connect baby and mother through smart phone technology once a day. This helps the mother continue to build competence of being with her baby through his ability to hear her voice. His mother notes *He always quiets when I talk to him.*

**Protecting.** After a miscarriage at 10 weeks' gestation, a mother says to the emergency department nurse, *I'm my baby's mother. Mothers protect their children and I couldn't even keep my baby safe during pregnancy.* A guided approach to this mother's identification of the issue of protecting typically begins with understanding the mother's thoughts, beliefs, feelings, and values in more detail. The nurse may use the process of joining and maintaining attention by *wondering* with the mother (a way of guiding), *I wonder if you could tell me more about your responsibility for protecting.* This approach helps expand the issue and give the nurse and mother a clearer understanding of her beliefs about herself. This can lead to conclusions that do not include self-blame.

**Maintaining Life Quality.** The mother of a much-loved and hoped-for baby may experience intense pain and suffering when learning of her baby's impending or actual death. Mothers may describe their feelings by using terms such as *hopeless*, *alone*, and looking for brighter days that *never seem to come*. These feelings are especially true for several months after the loss (though this time frame may vary greatly), which Bowlby (1988) identifies as *searching and yearning*. The issue of maintaining life quality moves to the forefront. The parents' acknowledgment of what is happening and may happen in the future serves to create a foundation for their journey. To assist parents on this journey, the nurse guide needs education about what the parent may expect so that knowledge can be shared with mourners to enhance their life quality

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*We introduced Guided Participation to demonstrate how the Perinatal Grief Intensity Scale can be adapted using relational and communication competencies into gentle questions that can be used immediately after a loss to assess meaning.*

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during this time of overwhelming sadness and hopelessness. Guides both need and provide education about grief in a reciprocal relationship that benefits both guide and learner. After learning about grief, parents may feel a strong sense of relief that what they have come to believe to be their own “weird experiences” are shared by many who struggle with such pain.

#### **Processes**

Guided Participation is implemented through one or more of the following nonhierarchical processes: (1) getting and staying connected, (2) joining and maintaining attention, (3) sharing understanding, (4) bridging, (5) structuring the task/learning, and (6) transferring responsibility. The guide engages the learner by using one or more of these six processes (Pridham et al., 2018).

#### **Competence**

Guided Participation theory emphasizes the importance of six areas of competence for guide and learner: (1) being with, (2) knowing and relating to the other, (3) communicating, (4) doing the task, (5) problem solving, and (6) regulating emotion. The guide and learner develop or enhance competencies through their relationship as they work together on an issue, which can be identified by either.

## **Application of Grief Intensity and Guided Participation**

### **Exemplar Case**

*Janae Edge, age 22, is 16 weeks pregnant with her first child. She began having cramps and bleeding this morning. Janae is single and has no contact with her baby's father. After being “worked in,” Janae was told by her doctor that a miscarriage was inevitable. Janae called her mother, who took her to the hospital. Within 45 minutes of arriving in the ED, she delivered a 100-gram, 11.6-cm. female fetus. Janae is now crying. Her mother is standing by her bed holding Janae's hand, looking scared and helpless. Her ED nurse knows how to manage Janae's physical pain and hemodynamic issues, but she is unsure of what to say. Janae's nurse has no idea what the meaning of this loss is for Janae.*

Understanding *meaning*, that is, how a woman perceives the loss, is the key to providing high-quality peri-

natal bereavement care (Huffman et al., 2014). Guided participation can be used to assess the meaning of pregnancy loss by exploring how the guide and learner discuss the meaning of the pregnancy. The Reality subscale statements from the Perinatal Grief Intensity Scale may be used by nurses to explore how women perceive their loss. The Reality subscale statements include:

1. The pregnancy did not seem real to me.
2. I did not think of the baby as a person.
3. I did not think of the baby as having a specific personality yet.
4. I felt I had lost my son or daughter, not just my pregnancy.
5. Both my pregnancy and baby seem real to me.
6. It seemed more like the loss of a pregnancy than the loss of a baby.

Ideas from these questions can be used by hospital-based nurses as part of the guided participation process to explore the meaning of Janae's miscarriage with her. Guided Participation is structured with three questions:

**What is the issue?** The issue is to understand what the ending of the pregnancy means to Janae, ultimately to learn more about her response to the loss and its intensity. The issue may be identified by either the guide or learner.

**What process might the guide use to begin a discussion?** If the guide (nurse) and Janae have had a few minutes to get to know each other (process of getting and staying connected), this conversation would likely begin with a reflective statement, such as *I wonder what this miscarriage has been like for you*. Using the term *wonder* can usher in thoughts and feelings that have not been previously considered. Assessing meaning in this gentle way leaves open all possibilities from *This just wasn't meant to be. I hope I can get pregnant again* to a sobbing mother who says *My baby depended on me and now look what happened*.

In our case, Janae's eyes filled with tears and she said *I can't believe it hurts so much. I've only known I was pregnant for a few weeks*. Janae's tears and the words “*hurt so much*” provide a window into Janae's grief intensity. This approach also presents the opportunity to use some of the ideas from the Reality subscale of the Perinatal Grief Intensity Scale to further confirm the assessment with a question such as: *At 16 weeks, it is possible for women to view their miscarriage in different*

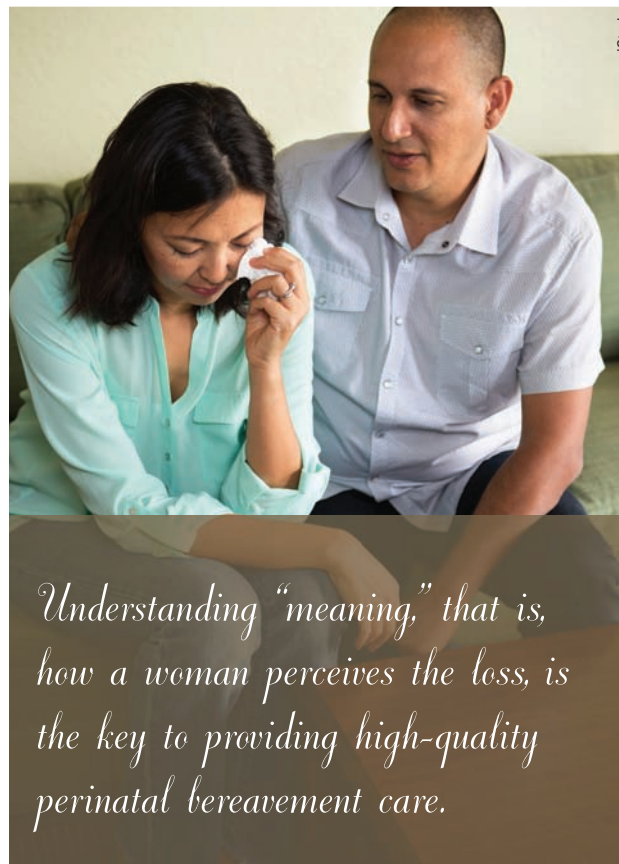
ways, and all are normal. Some women see miscarriage as something that just happens. Others see it as the loss of a pregnancy. Others view it as the loss of a person that they think of as a son or a daughter. I wonder how this miscarriage feels for you? We recommend using the Reality subscale as a guide for questions such as these, rather than as an instrument to be completed during the loss. The Reality subscale represents only one third of the Perinatal Grief Intensity Scale. The scale does not become accurate for identifying grief intensity and predicting outcomes until after 2 weeks post loss (Hutti et al., 2017; Hutti et al., 2018).

**What area of competence might be critical at this juncture?** Guided Participation requires the use of multiple areas of competence, which may be possible even with great time constraints. For example, the nurse's initial assessment may result in seeing heavy bleeding, which needs immediate attention (doing the task). At the same time, the nurse may take the woman's hand (being with), provide information about what she is seeing (doing the task, relating), and begin to think ahead to ways of stopping or slowing the bleeding (problem-solving). All the areas of competence assume the nurse already understands the meaning this loss has for the woman.

**Being with.** Being with involves offering emotional support to help Janae feel less alone. If the nurse believes this skill is most important in the moment, he or she may sit down (if not already seated), place tissue within reach (avoid *handing* the tissue to Janae as it may actually deter emotional expression), and simply sit in silence; using compassionate silence, as described by Back, Bauer-Wu, Rushton, and Halifax (2009). *Being with* requires concentration and practice as a nursing skill. Filling the silent space with words when someone else is expressing emotion is both tempting and common. Sitting in silence allows the other to be aware of having someone nearby but not feeling forced to speak.

**Knowing and relating to the other.** Knowing and relating are central to developing a relationship. When Janae is having ultrasound imaging of her uterus, the nurse may get to know her preference and relate to her by asking *Would you like to watch while the ultrasound is done or do you prefer that I turn the screen away from you?* Encouraging Janae to choose her preference also increases the Congruence of her loss experience.

**Communicating with others.** If a nurse knows that Janae perceives this miscarried baby as a son or daughter but hears her mother saying things like *At least it happened early before you got to know it* without a response from Janae, the nurse can help Janae better manage these important relationships. In private, the nurse may ask Janae how she would prefer for her family to respond. Then, the nurse could ask permission to bring the family into the room and help Janae talk with them about how she perceives this loss and the things they could say that would help her feel supported. By providing this information to the family, the nurse is role-modeling and encouraging positive communication as a way for Janae to



*Understanding “meaning,” that is, how a woman perceives the loss, is the key to providing high-quality perinatal bereavement care.*

Confront Others and increasing the likelihood of greater Congruence.

**Doing the task.** In this scenario with nurse and patient, doing the task most often is understood as physical nursing care; taking and interpreting regular vital signs, assuring comfort by placing clean pads under her, and offering pain medication.

**Problem solving with others during the process of mourning.** The issues of nurturing, protecting, relating, guiding, and maintaining quality of life commonly arise within the context of loss (Pridham et al., 2018). A guide can help Janae to problem-solve ways to most effectively deal with these issues, thereby promoting greater Congruence between the actual experience and her preferred experience.

**Regulation and management of emotions, expectations, and intentions related to mourning.** This area of competence may be addressed by helping Janae express her emotions so that she may ask others for the help she needs. Further, the guide (nurse) can help Janae set realistic expectations and intentions for herself and others within the context of the loss.

## Conclusion

Using the Perinatal Grief Intensity Scale, the Hutti Perinatal Grief Intensity theoretical framework (Hutti et al., 2017), and Guided Participation (Pridham et al.,

## Clinical Implications

<ul style="list-style-type: none"> <li>Care must be highly individualized to be perceived as supportive by women and their partners.</li> </ul>
<ul style="list-style-type: none"> <li>Nurses must explore and understand the meaning the loss has for the woman and her family <i>before</i> intervening.</li> </ul>
<ul style="list-style-type: none"> <li>The Reality subscale questions from the Perinatal Grief Intensity Scale relate to meaning the loss may have for bereaved parents and may be used as a way to explore meaning during hospitalization for a perinatal loss.</li> </ul>
<ul style="list-style-type: none"> <li>The Perinatal Grief Intensity Scale (Hutti et al., 1998) is designed to be used during a follow-up visit with a healthcare professional, rather than during an initial hospitalization.</li> </ul>
<ul style="list-style-type: none"> <li>Using Guided Participation, nurses are capable of assessing grief intensity. After some initial moments to become introduced, a good way to begin a conversation with a patient unknown to you is to begin with a reflective statement, such as, "I wonder what this (miscarriage, stillbirth, newborn death) has been like for you." Using the term <i>wonder</i> can usher in thoughts and feelings that have not been previously considered.</li> </ul>
<ul style="list-style-type: none"> <li>Guided Participation assists nurses and the women and families in their care to examine the <i>issues, processes, and areas of competence</i> associated with coping with grief after perinatal loss.</li> </ul>

2018), we illustrated how caring for a woman who had just experienced a miscarriage might be approached. Although the Reality subscale of the Perinatal Grief Intensity Scale should not be administered until after about 2 weeks post loss, hospital-based nurses could use some ideas associated with the questions to explore the meaning the loss may have for Janae their patients. We introduced Guided Participation, a teaching and learning theory, to demonstrate how questions from the Perinatal Grief Intensity Scale can be adapted into gentle questions that can be used immediately after a loss to assess meaning. Doing so helps create a situation in which the woman feels cared for and, equally important, understood. At the same time, both Guided Participation and the Hutti Perinatal Grief Intensity theoretical framework provide the nurse with tools and direction that increase nurse comfort and competency while serving to establish and maintain a relationship with a vulnerable patient at what may be an exceptionally difficult time in her life. ❖

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The authors declare no conflicts of interest.

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