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**PERINATAL LOSS AND PARENTAL GRIEF:
THE CHALLENGE OF AMBIGUITY AND
DISENFRANCHISED GRIEF**

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ABSTRACT

Following perinatal loss, a type of ambiguous loss, bereaved couples struggle with and experience distress due to various forms of ambiguity. Moreover, the juxtaposition of their grief with society's minimization often disenfranchises them from traditional grieving processes. The purpose of this study was to explore sources of ambiguity and disenfranchised grief related to perinatal loss. Audio-taped interviews with 13 bereaved couples at 2, 6, and 13 months following the death of their fetus or infant were analyzed. Several categories of ambiguity and disenfranchised grief emerged, pertaining to: (a) the viability of the pregnancy; (b) the physical process of pregnancy loss; (c) making arrangements for the remains; and (d) sharing the news. This study uncovers

the many sources of ambiguity and disenfranchised grief that bereaved couples face in interactions with family, friends, society, and healthcare professionals. These insights may inform healthcare professionals in their attempts to ease distress related to perinatal loss.

BACKGROUND

Perinatal death, defined as the death of a baby, can include such losses as ectopic pregnancies, miscarriages, stillbirths, and neonatal deaths (Callister, 2006). Perinatal loss has well-documented detrimental effects on the health and well-being of the bereaved parents individually, and as a couple (Bennett, Litz, Lee, & Maguen, 2005; Lang, Goulet, & Amsel, 2004; Vance, Boyle, Najman, & Thearle, 2002). Yet many parents who suffer a perinatal loss feel disenfranchised in their grieving processes compared to those mourning more traditionally accepted deaths.

Compared to other types of mourning, like the loss of a parent or a sibling, the loss of a child is associated with a grief experience that is particularly severe, long-lasting, and complicated—with symptoms that fluctuate in intensity and duration (Rando, 1986; Zeanah, Danis, Hirshberg, & Dietz, 1995). Among healthcare professionals and society at large, however, perinatal loss is generally viewed as a less traumatic or prolonged experience than the death of an older child or an adult. Perinatal loss has been characterized as an ambiguous loss, stemming from the concurrent physical absence of and psychological presence of the fetus or infant (Boss, 2004a; Cacciatore, DeFrain, & Jones, 2008). This sense of ambiguity has the potential to be further compounded by the disenfranchisement of the parents' grief, resultant from the juxtaposition of personal feelings of extreme grief with society's dismissal of such a short-lived or even "unborn" life.

"Many people find it hard intuitively to understand why the grief for a child who has not lived long enough to define him—or herself should be so prolonged or intense" (Rubin & Malkinson, 2001, p. 231). Bereaved parents often find it hard to reconcile their intense feelings with society's lack of validation. According to Leon (2008):

The raw material feeding the grieving process is scarce or absent after perinatal loss. Grieving demands recollecting the sights, sounds, smells, and touch of the beloved—the favourite chair in which he would sit the sound of his laughter, and the image of his smile. When the unborn child dies, there is so little to grieve. . . . So much of perinatal loss involves grieving the loss of the future: relinquishing the wishes, hopes, and fantasies about one who could have been but never was (but briefly). (The Impact of Perinatal Loss section, ¶ 6)

Those thoughts and feelings can be associated with the disenfranchisement of the grief experience (Capitulo, 2005), and may intensify, interrupt, or confuse the healing process. The loss represents a physical absence, but also a psychological

presence, especially for the mother who carried the child in her womb prior to its death. Such an ambiguous loss can also impact the coping capacities of bereaved family members (Boss, 2004a). It can contribute to depression, relational conflict, and the erosion of relationships (Boss, 2006). The grief can strike both partners as a couple or separately, in a similar or different fashion. These experiences can alter how spouses feel about themselves, each other, and their other close relationships (Gilbert & Smart, 1992; Lang, Goulet, & Amsel, 2004; Najman, Vance, Boyle, Embleton, Foster, & Thearle, 1993; Olivier, 1999).

Nurses and other healthcare professionals hold an advantaged position to help with mitigating these effects, yet studies suggest their impact in this regard can also be inadequate—and even hurtful. Their lack of knowledge about the physical, emotional, and social impact of perinatal loss on individuals and families, together with a sense of discomfort with bereavement and how to attend to the bereaved, frequently spills over into care provision (Lang, Edwards, & Benzies, 2005; Lang & MacLean, 2007; Udja & Bendiksen, 2000). Rather than helping, care providers can often intensify parental grief when they fail to recognize how their reactions, comments, and behaviors impact on the experiences of their vulnerable patients. Words and actions from staff at and around the critical time of loss are not forgotten. Just as comforting words of kindness and touches have the potential to have long-lasting healing effects, callousness and indifference (often unintentional) can severely compound an already difficult experience for the bereaved (Leon, 2008). It has been reported that, more often than not, bereaved parents receive inappropriate or insensitive care following a perinatal death, even though there are well accepted standards of care that exists in the theoretical and research literature, as well as among professionals in the field (Covington & Theut, 1993; Joanna Briggs Institute, 2006; Lang et al., 2005). Healthcare professionals are in an ideal position to address this problem, as they may be able to influence couples' perceptions of the situation.

Original Study

This descriptive study was part of a larger longitudinal study involving 110 bereaved couples who had experienced a fetal or an infant death (Lang et al., 2004). The aim of the larger study was to test Lang's (2004) *Supportive Bereavement Care Model*. This model, influenced by Boss' (2002) *Crisis Model of Family Stress* (CMFS), is composed of **An Event (A: perinatal loss)**, **Resources (B: internal—hardiness and external—marital and social support)**, and **Perceptions and Meaning Making (C: appraisal of the event)**, all together leading to **Outcome (X: health and well-being)**. A pivotal element of this model is the “**family as the focus of care,**” reflecting the importance of caring for the bereaved individually and together within the context of the family. The study revealed that bereaved parents' perceptions of their perinatal loss experience were

among the leading and consistent predictors of emotional health in coping with their situation. In addition to internal resources such as hardiness, satisfaction with marital and social supports was predictive of how bereaved parents appraised the situation and ultimately their health and well being, regardless of the age of the baby at death. This highlights the potential for providers to support bereaved parents and families in how they perceive and cope with the death of their baby (Lang et al., 2004).

The objective of this current study was to explore sources of ambiguity and disenfranchised grief related to perinatal loss.

METHOD

Bereaved couples who had lost their baby during pregnancy or within the first month post-birth in hospital, were recruited from seven Montreal university hospitals following scientific and ethical approval from each institution. Participants were 18 years of age or older, living with their spouse, and able to read and understand English. Couples were visited in their home at 2 months (T1), 6 months (T2), and 13 months (T3) post-loss by an experienced family systems-trained nurse clinician and researcher (the principal author). During each visit, couples participated in a conjoint, audio-taped, unstructured interview.

Given the exploratory purpose of the interview, couples were asked only one major question at T1: "Can you tell me a little about what happened?" At subsequent visits (T2 and T3), their reflections focused on their experiences and perceptions since the previous interview, as prompted by: "Can you tell me about what has been happening since the last time we met?" Efforts were made by the interviewer to limit her responses, in order to allow the parents' stories to flow until they reached their natural conclusions. In general, interviews lasted between 45 and 90 minutes.

For the purpose of this study, 13 complete sets of interviews with bereaved couples were analyzed. A total of 39 interviews were conducted across T1, T2, and T3. Purposeful selection was determined by:

1. clarity of audio-taping of interviews;
2. whether participants lost their baby during gestation or shortly after birth while still hospitalized; and
3. whether cases had narratives that explicitly related to ambiguity, ambiguous loss, and disenfranchised grief.

Data Analysis

Using a content analysis approach, interview data were coded using QSR/N6 qualitative analysis software (QSR, 2002). A nurse research assistant coded the verbatim transcripts and developed a preliminary coding framework based on the following definitions of ambiguity, ambiguous loss, and disenfranchised grief.

Ambiguity refers to myriad of situations or issues that bereaved couples encounter and endure that are unclear, indefinite, or uncertain to them or others surrounding the death of their baby. Ambiguous loss is defined by Boss (2006) as a loss in which an important component is missing, thwarting mourning customs and rituals, and preventing typical coping behaviors. As for disenfranchised grief, it is described according to Doka (1989) as the experience of loss or a state of bereavement that is “not openly acknowledged, publicly mourned or socially supported” (p. 4).

The subthemes that emerged through an inductive coding process further shaped the structure of the coding framework. This framework formed the basis for the identification and exploration of similarities and differences, both among and between couples, with regard to ambiguity, ambiguous loss, and disenfranchised grief. Members of the research team also independently coded each set of interviews using the proposed framework. The team then met with the research assistant to compare coding and to revise the analytic framework. Minor alterations (i.e., addition or subtraction of a few sub-codes) were made to the original analytic framework in order to reconcile different interpretations of data. In general, the team reached consensus on the coding system and structure.

RESULTS

Characteristics of Participants

Couples were between 28 and 44 years of age ($M = 34$, $Mdn = 33$) and had been married or living together between 1 to 11 years. More than half (54%) of the participants had completed a university education. Thirteen percent of participants were English-Canadian while the remainder were self-described as “other” Canadian (e.g., French, Greek, Italian, Lebanese, Chinese). This culturally diverse portrait is reflective of the cultural mosaic in Montreal, Canada, where the study was conducted, and contrasts with the profile of participants in a number of other bereavement studies. Of the 13 deaths, nine occurred at less than 20 weeks gestation, two were stillborn after 20 weeks, one passed away hours after an early delivery at 6 months gestation, and another passed away at 3 weeks of age while still in hospital. Median gestation time was 12 weeks, while the average was 17 weeks. Three couples had experienced a previous perinatal loss and nine couples had other children at the time of the first interview. None of the pregnancies were terminated voluntarily.

Sources of Ambiguity

Ambiguity emerged in different forms and circumstances to contribute to the suffering of bereaved couples. This variety included ambiguity: (a) about the viability of the pregnancy, (b) about the physical process of losing the pregnancy, (c) around arrangements for the remains, and (d) in sharing the news of the loss.

The Viability of the Pregnancy

Ambiguity about the viability of the pregnancy was present in varying degrees of intensity among couples. For example, couples who had experienced a previous loss often expressed feelings of fear and uncertainty about the potential for yet another loss. In the words of one father, “You always worry . . . until the baby comes out and you actually see the baby . . . until the doctor tells you everything is fine . . . you always worry a little bit.” (Neonatal loss, 26 weeks gestation).

In some cases, parents suspected that something was “not right” with their pregnancy. Bleeding, pain, reduced or lack of fetal movement, and other unusual signs or symptoms triggered concern and worry. Different and sometimes conflicting results of diagnostic tests often added to their feelings of uncertainty. One woman reported that positive blood tests and her doctor’s reassurances provided her with hope for a few days, until an ultrasound revealed no heartbeat.

In many cases, participants described the time period around the diagnosis of a non-viable pregnancy as a protracted, complex, blurred, and frustrating process. For example, one couple described how the wife was sent for blood tests because of vaginal bleeding and was told that if the doctor’s office did not telephone, it meant that everything was alright. However, the office was closed for a week, and because the couple had not heard any news, they assumed that all was well. Several days later, worrisome symptoms developed. An internal exam indicated that everything was “fine,” and an ultrasound was scheduled for a few days later. Nevertheless, the following day they returned to the hospital because of heavy bleeding resulting in fetal death. This mother said:

The one thing I never found out—and I wish I find the time to pursue it—is how far along was I pregnant? And what caused it? . . . [The doctor] wasn’t able to give me any of the answers I was hoping for. (Fetal death, first trimester).

The findings underscore the feelings of ambiguous loss when news that a fetus is no longer viable is delivered days or even weeks after the actual death. As one father explained, “To me, the hardest part was the roller-coaster ride because nothing could be done. . . . The uncertainty. . . . Even the doctors could never give us a 100% that the baby was gone. That was probably the worst part.” (Fetal death, 9 weeks gestation).

The Physical Process of Pregnancy Loss

In cases where fetal death had been confirmed, and the couple was awaiting the passage of the fetus, it was unclear how long they would have to wait and what to do when the fetus passed. Some couples were instructed to go home and wait until the delivery occurred naturally. “How will I know that I have lost it? What will it look like? What should I do with it when it’s born?” were some

of the questions the parents struggled with. One mother said, “They told me that in the worst case scenario it could take up to 2 or 3 days and that seemed . . . horrendous. . . . To prolong the grief and the suffering was just. . . . Thank God it went as quick as it did.” (Fetal death, 32 weeks gestation).

Parents noted a lack of available resources and supportive social norms to guide them in how to proceed. A father said:

They don’t really tell you how to deal with it or what options there are. So the only thing that [the physician] offered was: ‘Well, go home. Maybe in a couple of days or so the baby will pass. What you do is you put it in a plastic bag. . . .’ (Fetal death, 15 weeks gestation).

In many cases, parents felt that the staff did not take the time to explain or help them anticipate what to expect in terms of how and where they would deliver their deceased baby.

Another mother expressed her concerns over unanswered questions. She commented on how she felt her physician’s schedule did not allow for them to discuss her third miscarriage and the extreme pain that she had experienced during the dilation and curettage procedure:

And until today I don’t know if that was normal [the extreme pain] for me to have gone through that. I guess I didn’t freeze. It’s the only thing I can think of. No one answered my questions. Was it normal for me to have experienced all that? (Fetal death, 10 weeks gestation).

Making Arrangements for the Remains

Many of the couples were unsure how to handle the remains of the fetus or infant. Some couples struggled with the dilemma of whether they, as parents, should take responsibility, or if they should allow the hospital to manage “the task.” Some parents were sensitive to the fact that the remains were sometimes treated more like biomedical waste than a baby who had died. One mother reported being told that they could find only “debris” in her uterus. This kind of terminology was perceived by parents as dehumanizing the baby.

With perinatal loss there are no clear or customary mourning rituals. Parents were seldom encouraged to make funeral arrangements or to engage in other commemorative activities. This made them feel deprived of the right to mourn, which increased their distress and suffering. One mother said:

When you lose a parent or someone in the family, the mourning period is sitting Shiva, and the burial and everything. That’s supposed to help you. . . . You get to talk about the person. You get to feel. . . . You get to cry, to get the support from the community. When you lose a baby, and especially early on . . . nobody knows about it. (Fetal death, 10 weeks gestation).

Sharing the News of the Loss

This was especially complicated for couples when the loss occurred before the mother began to show physical evidence of being pregnant. Uncertainty about who to tell, how much to tell, and under what circumstances was common. Of primary concern for several couples was whether or not, and how to tell their children about the death of their sibling. They were often apprehensive about how the knowledge and experience of such a death would affect their young children. As one mother said, “How is my son going to react? . . . , I mean, he’s two and a half. To what extent does he understand what was coming home? I don’t know.” (Fetal death, 32 weeks gestation).

Many couples found it difficult to define the loss and find meaning in the experience. Couples asked questions such as “What did we lose? Was it a baby or a ‘specimen’? Was it a boy or a girl?” In addition, their identity as parents also came into play: “Are we parents or not?” “Do you see us as bereaved parents or as patients undergoing a medical procedure?”

The narratives from the couples in this study reveal that various sources of ambiguity and uncertainty are woven into the fabric of perinatal loss. From worrying about the viability of the pregnancy, to the physical aspects surrounding death of the fetus or infant, through the arrangements and sharing the news with family and the community, ambiguity contributes an additional layer of stress and suffering to the bereaved surrounding this ambiguous loss.

DISENFRANCHISED GRIEF

In this study, aspects of disenfranchised grief were clustered into the following experiential and relational categories: (a) within the marital relationship, (b) when communicating with health professionals, and (c) when interacting with extended family and community.

Within the Marital Relationship

Within couples, spouses had different expectations about how to react, how to behave and what was an appropriate length of time to grieve. The findings indicated that women needed to talk about the loss for a longer time than men. Couples reported that these divergent expectations created marital tension and limited the amount of support they could offer each other. As one father expressed:

We know that there is a difference but it’s just that it is not that she can’t talk about it. She talked about it for a while and then enough is enough. Now maybe other men would have let it go a lot longer than I did. But for me, it is just you have to get on with life. (Fetal death, 10 weeks gestation).

For the couples themselves, misunderstandings and divergent perceptions about the meaning of the loss and about the “right way” to grieve also sometimes created emotional distance or dissonance between them. One father acknowledged his frustration when he said, “I mean at one point, I even became impatient. I said, you know, ‘Get on with the program!’” (Fetal death, 9 weeks gestation).

Communicating with Health Professionals

Health care professionals were often perceived by couples as minimizing the loss by treating it as a medical event while not recognizing it as the loss of their baby. Couples felt the providers’ attitudes reflected that this type of loss was less important or significant than other types of loss. One mother was told by her doctor that she could take 1 week off work, after receiving the news that her 14-week pregnancy was non-viable, and delivery of the deceased fetus would likely occur within the week. In contrast, after a live birth she would have been given 4 weeks off work. When she asked the doctor what would happen if her dead fetus was not delivered within the week, she was told she should go back to work anyway.

Health professionals were sometimes perceived as depersonalizing the couple and their baby. Parents experienced insensitive and even irreverent behaviors and comments from professionals in relation to medical procedures and to the “disposal” of the remains. One mother described the disenfranchisement she felt when she asked a nurse about what had happened to her baby’s body. “Why do you want to have a funeral?” the nurse asked, adding that it was too late to request funeral arrangements. “In my mind she was saying: we threw your baby out and it’s over now, you can’t get it back,” the mother said. When she asked if her baby had been male or female, the nurse said she would have to wait for the autopsy report (Fetal death, 19 weeks gestation).

While mothers were usually the main focus of medical attention, fathers reporting feeling ignored and unacknowledged as a legitimately grieving parent. One mother reported, “People can see how it affects the woman. Right away, there’s a physical way and everybody can appreciate the emotional way and . . . the father seems to not . . . not get as much attention in the whole process.” (Fetal death, 15 weeks gestation).

The language used by health professionals (e.g., words such as “spontaneous abortion,” “miscarriage,” or “fetal tissue”) added to couples’ sense of disenfranchisement and contributed to the perception that their loss was insignificant to others. As one mother explained:

I got affected . . . when she said: “You had an abortion.” . . . I kind of looked at her like: “What?” And she says: “It’s just a term.” And I got mad. That’s the only time I got mad. I said: “Change your ‘terms’ cause it’s not an abortion. . . . It’s not an abortion to me.” (Neonatal death, 26 weeks gestation).

Interacting with Extended Family and Community

In general, the extended family and community were perceived by parents as lacking understanding of perinatal loss and not recognizing it as being as significant or painful as other deaths. One mother, who experienced a neonatal loss and had since given birth to a healthy child, recalled how she considered the infant she lost to have been her first born, but that others did not agree:

I went to a salon maybe two weeks ago, and . . . somebody asks me: "Is this your first baby?" . . . No! I'm not scared to say that she died and why she died. For me, I like talking about it. . . . Even though she was there for . . . four hours. And that lady . . . she said: "No! She wasn't alive!" You shouldn't say that to people. (Neonatal death, 26 weeks gestation).

Lack of acknowledgment by friends and family of important dates, such as the baby's birthday, the anniversary of death or pregnancy loss, or the expected due date was also difficult for bereaved couples. Such dates were honored by the couple privately, in keeping with the perceived social norms that undermine the expression of grief surrounding perinatal loss. This alleged lack of support further contributed to couples' feelings of isolation and disenfranchisement. One mother described how her husband was the only other person who remembered the significant date: "Nobody said anything at all. It was just really hard as the day went on. . . . It's not like it happened 20 years ago. It happened a year ago . . ." (Fetal death, 19 weeks gestation). Another mother described how the baby's birthday was more difficult than the date of death: "I spent that day, like, reliving everything. . . . But the death didn't . . . I didn't really do anything on that day because that wasn't really the important day for us." (Neonatal loss, 3 weeks post delivery while in hospital).

DISCUSSION

In this study, couples were not primed or asked specific questions in references to the concepts of ambiguity, ambiguous loss, or disenfranchised grief, yet these notions were plainly evident in the narratives of these bereaved couples. The uncovered suffering experienced by these bereaved couples sheds light on contributing factors. Perinatal loss is a unique type of ambiguous loss. Often parents have already picked out names, bought furniture and outfits, and even planned activities that they would be doing with their baby long before that baby is visible to the rest of the world. This experience is compounded by the strong physical and emotional reactions experienced by the parents while others' minimized or negated the loss.

The findings of this study help improve our understanding of how the many textures of ambiguity, ambiguous loss, and disenfranchised grief contribute to bereaved couples' suffering and influence their mourning experience surrounding perinatal death. Ambiguity and disenfranchised grief stem from a variety

of sources in the possibly unintentional, yet constraining, beliefs of family, friends, society in general, and specifically of healthcare professionals. These beliefs seem to amplify couples' negative experience and appraisal of the situation, as well as fuel their perceptions of poor health care provider support. Ambiguity, ambiguous loss and the sense of feeling disenfranchised not only impede bereaved parents' psychological wellbeing and efforts to cope and move forward, but also significantly compromises marital, family, and other relationships.

It is interesting to note how the experiences and expression of suffering differ between spouses. We can hypothesize the following circular communication pattern (Tomm, 1980): the more the wife shows her grief, the more the husband tends to withhold showing his grief, to suffer internally or silently in order to protect or comfort his wife. The more he withholds and suffers internally or silently, the more isolated and misunderstood the wife may feel which increases her suffering. These patterns may also occur between the bereaved mother or couple and the health care professionals because of similar misunderstandings and misinterpretations (Gilbert & Smart, 1992; Gottlieb, Lang, & Amsel, 1996; Joanna Briggs Institute, 2006; Lang et al., 2004; Lang, Goulet, & Amsel, 1996). No one is to blame, and all contribute in their own way to maintaining the pattern.

Clinical Implications

These narratives reveal the depth of misunderstanding among some care providers about the range and nature of parental feelings surrounding the death of their baby. Healthcare professionals need to be sensitive to and aware of their contribution to bereaved parents' distress surrounding perinatal loss. These vulnerable parents are often hyper sensitive to every look, touch, comment, or reaction by health care providers. Regardless of whether such interactions are perceived by the parents as being supportive or hurtful, they are filed in their memory forever (Joanna Briggs Institute, 2006) and will color their bereavement experience and the how they cope with the death of their baby. There is great potential for significantly easing the burden of these experiences through direct interactions with bereaved couples by conveying empathy, just in time information, and anticipatory guidance regarding what to expect physically, emotionally and socially (Lang, Duhamel, Fleischer, Sword, Aston, & Gilbert, in press). Furthermore, health care professionals can also support bereaved couples in their interactions with each other, their family, and the wider community.

Increasingly, hospitals are developing policies, protocols and specific checklists of procedures to follow when dealing with perinatal loss (Bennett et al., 2005; Lang et al., 2004, 2005). However, the rigid application of prescribed protocols, without a sensitive and empathic approach by healthcare professionals,

may lead to a false sense of security about the quality of care provided to bereaved parents (Covington & Theut, 1993).

A lack of perceived support affects the entire bereavement experience and may jeopardize the health of individuals who are unable to draw on their resources (Lang et al., 2004). It is important to pay attention to systemic processes on multiple levels—individual, family, and community—because it is often a person's familiar connections that provide comfort in distressing situations, such as surrounding a perinatal loss (Boss, 2004b). Evidence suggests that healthcare professionals may enable individuals to muster effective strategies to manage and to redefine an event in a more positive light (Frasure-Smith, Lesperance, Gravel, Masson, Juneau, Talajic, et al., 2000; Joanna Briggs Institute, 2006; Lang, Goulet, Aita, Giguere, Lamarre, & Perreault, 2001; Stroebe & Schut, 2001). By influencing behavior and fostering successful adaptation to life crises, caregivers can encourage and help to promote personal growth within grieving parents (Schaefer & Moos, 1998).

CONCLUSION

Bereaved parents experience ambiguity from a myriad of sources and a sense of disenfranchisement following an ambiguous loss such as the death of a fetus or infant. Such experiences not only impede bereavement and adaptation, but may also jeopardize marital and other relationships, including those with existing or future children. Healthcare professionals must first and foremost avoid increasing parents' anguish with words, actions and reactions during this life-transforming event while being more sensitive and attentive to their perceptions and potential needs.

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