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# Perinatal bereavement: A principle-based concept analysis

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### Perinatal Bereavement: A Principle-based Concept Analysis

#### Abstract

#### Aim

This paper is a report of an analysis of the concept of perinatal bereavement.

# **Background**

The concept of perinatal bereavement emerged in the scientific literature during the 1970s. Perinatal bereavement is a practice based concept, although it is not well defined in the scientific literature and is often intermingled with the concepts of mourning and grief.

# Design

Concept Analysis.

#### **Data Sources**

Using the term 'perinatal bereavement' and limits of only English and human, Pub Med and CINAHL were searched to yield 278 available references dating from 1974 – 2011. Articles specific to the experience of perinatal bereavement were reviewed. The final data set was 143 articles.

#### **Review Methods**

The methods of principle-based concept analysis were used. Results reveal conceptual components (antecedents, attributes and outcomes) which are delineated to create a theoretical definition of perinatal bereavement.

#### **Results**

The concept is epistemologically immature, with few explicit definitions to describe the phenomenon. Inconsistency in conceptual meaning threatens the construct validity of measurement tools for perinatal bereavement and contributes to incongruent theoretical definitions. This has implications for both nursing science (how the concept is studied and theoretically integrated) and clinical practice (timing and delivery of support interventions).

# **Conclusions**

Perinatal bereavement is a multifaceted global phenomenon that follows perinatal loss. Lack of conceptual clarity and lack of a clearly articulated conceptual definition impede the synthesis and translation of research findings into practice. A theoretical definition of perinatal bereavement is

offered as a platform for researchers to advance the concept through research and theory development.

**Keywords:** Concept analysis, Principle-based concept analysis, Perinatal bereavement, Perinatal loss, Nursing

#### **INTRODUCTION**

Perinatal bereavement follows perinatal loss; thus it is a global, complex and multifaceted phenomenon that is of concern to nurse clinicians and nurse researchers around the world. Perinatal loss is commonly defined as loss of an infant through death via unintended or involuntary loss of pregnancy by miscarriage, early loss (less than 20 weeks), stillbirth (> 20 weeks gestation), or neonatal loss (newborn through 28 days of life) (Robinson *et al.* 1999, DiMarco *et al.* 2002).

In the United States, care of women experiencing perinatal loss fell to medical clinicians starting in the early 20th century as more women began to give birth in hospitals rather than at home (Limbo & Kohler 2010). Prior to the 1970s, the death of a baby, whether by miscarriage, stillbirth, or neonatal death, was not viewed by the medical community as a meaningful loss (DiMarco et al. 2001); thus there was little acknowledgement of the phenomenon of perinatal bereavement. Historically, three major factors contributed to the recognition of perinatal bereavement as a 'real' phenomenon: the emergence of attachment theory to understand maternal bonding during pregnancy (Rubin 1975, Peppers & Knapp 1980); changing social conditions which gave voice to the suffering of women experiencing perinatal loss (Toedter et al. 2001); and technological advances in neonatal care (Hughes & Riches, 2003), including regionalization of neonatal intensive care (Sahu, 1981). The seminal work of Kennell, Slyter and Klaus (1970) on the response to pregnancy loss produced the first documented empirical evidence that women experience a significant mourning response following the death of an infant. The surge of literature on the topics of perinatal bereavement during the decade of the 1980s is testimony to the change in attitude and attention that was given to the newly recognized phenomenon that follows perinatal loss, referred to both in the literature and in clinical practice as perinatal bereavement.

### **BACKGROUND**

Despite the use of the concept of perinatal bereavement in clinical practice and the measurement and exploration of the concept in research studies, few explicit definitions exist to clearly define the phenomenon of perinatal bereavement and thus distinguish it from other related terms such as grief and mourning. For a concept to be adequate for scientific use, the definition of the concept must be clear and precise so that it is consistently understood and used (Penrod & Hupcey 2005a). Thus, the lack of a clear conceptual definition of the concept of perinatal bereavement in scientific literature is problematic, limiting its praxis and raising questions related to the boundaries of the concept in relationship to other concepts.

Principle-based concept analysis provides a powerful way to theoretically define a concept and to determine the state of the science regarding a concept (Penrod & Hupcey 2005b). It is important to establish 'the best estimate of probable truth' (Hupcey & Penrod 2005, p. 205) surrounding the concept of perinatal bereavement to understand the current use and meaning of the concept and to determine the best methods for advancing the concept. Moreover, well-defined concepts contribute to theory development, which in turn informs practice and research. Therefore, the purpose of this paper is to present the findings from a principle-based concept analysis of perinatal bereavement to introduce a theoretical definition of perinatal bereavement that will be useful for nurse researchers and clinicians.

The methods of principle-based concept analysis as explicated by Penrod and Hupcey (2005b) were used to analyze the concept of perinatal bereavement. Four principles (epistemological, pragmatic, linguistic and logical) were applied to a data set culled from the scientific literature. Conclusions summarized from the results of the analysis of each principle were critically examined. Analysis of the data revealed implicit meaning and conceptual components of the concept that are frequently attributed to the concept but not comprehensively presented in a scientific definition. A theoretical definition of perinatal bereavement was developed by integrating the conceptual components and what is known about perinatal bereavement as revealed in the scientific literature through the lens of the four principles. Since the purpose of this concept analysis is to describe the state of the science of perinatal bereavement to present a theoretical definition as a product, only scientific literature was reviewed in keeping with the tenets of principle-based concept analysis (Hupcey & Penrod 2005).

#### **Data Sources**

Using the search term 'perinatal bereavement' and limits of only humans and English, a search was performed in Pub Med and CINAHL. No time restrictions were applied to the search so that the origin of the concept's appearance in the literature could be determined and important evolutionary progressions of the concept could be ascertained (Penrod & Hupcey 2005b). The initial search yielded 278 available references dating from 1974 to 2011. The titles and abstracts of each article were reviewed and duplicates were removed. Articles that were not specifically related to the experience of perinatal bereavement were eliminated. Two additional references were retrieved as secondary references when these key sources were noted as citations across several articles. The final data set included 143 references (see Supplemental Information).

#### **RESULTS**

### **Epistemological principle**

For a concept to be considered 'epistemologically mature' (Penrod & Hupcey 2005b, p. 405), it must be well defined and well differentiated from other concepts in the literature. None of the papers reviewed for this concept analysis included an explicit definition of perinatal bereavement, although all of the data implicitly suggest that perinatal bereavement follows loss of a pregnancy or loss of an infant through death. Distinguishing perinatal bereavement from

other related concepts of mourning and grief was an important first step in evaluating the epistemological principle. In other words, is perinatal bereavement a distinct phenomenon and if so, how does it relate to and stand apart from the other concepts of mourning and grief? Definitions of grief and mourning are presented to distinguish the concepts as uniquely different from, yet related to perinatal bereavement.

Grief is a symptom of bereavement (Flenady & Wilson 2008), but not the only response to bereavement (Kastenbaum 2007). Grief is the emotional reaction that follows the loss of a valued other (Brier 2008); or a normal response (Bruhn & Bruhn 1984) characterized by intense and deep sorrow that may be manifested in psychological, physical, behavioral, or social ways (Bartellas & Van Aerde 2003).

Mourning has been cited as an expression of bereavement (Ryan *et al.* 1991) that is time limited (Brost & Kenney 1992) and dynamic, differing from person to person and over time (LaRoche *et al.* 1982). Mourning is described as the manifestation of culturally patterned behaviors during bereavement (Kastenbaum, 2007) that incorporate the experience of the loss into the outward expression as life is lived (Ferrell & Coyle 2006).

The concept of perinatal bereavement was not clearly and explicitly defined in this data set, however when discussing perinatal bereavement some authors defined the more general term of bereavement as following loss by death of a close loved one or significant other (Lemmer 1991, Bartellas & Van Aerde 2003; Reed 2003). The specification that bereavement follows loss through death is an important distinction to note. Thus, perinatal bereavement as it is implicitly defined in the literature does not follow other maternal types of loss, such as giving up an infant for adoption, the birth of a less than normal infant, a less than hoped for birth experience, or infertility.

How perinatal bereavement is defined is an important consideration for nurses who plan and deliver perinatal bereavement support. Because no explicit definitions were found in this data set, we must rely on implied meaning embedded throughout the literature to form the definition of perinatal bereavement. The one consistent meaning that was implied in these data is that perinatal bereavement is the period that follows loss of a pregnancy or loss of an infant through death. The absence of an existing theoretical definition is particularly concerning in light of the scientific studies reporting outcomes of the measurement of perinatal bereavement. This insight is particularly salient to the discussion of the next principle of principle-based concept analysis, the pragmatic principle.

#### Pragmatic principle

The pragmatic principle asks: 'Is the concept of perinatal bereavement applicable and useful within the scope of scientific inquiry and to what degree has it been operationalized?' (Penrod & Hupcey 2005b). For a concept to be pragmatically mature, the manifestations of the concept should be recognizable to members in a discipline where the phenomenon is encountered (Penrod & Hupcey 2005b). The concept of perinatal bereavement is a practice-based concept that traverses the disciplines of nursing, medicine and psychology. The utility of the concept of perinatal bereavement appears high as evidenced by the use of the concept in multiple contexts

of perinatal loss in this data set that spans several decades. Nevertheless, attempts to measure the phenomenon of perinatal bereavement have pre-empted the establishment of an explicit definition of perinatal bereavement. Once more we assert that clarity of conceptual labels is important and concepts must be both well-defined and well operationalized to be distinguished in a discipline and pragmatically useful for practice and research. Thus, while the concept of perinatal bereavement is used extensively in both practice and research, the lack of a scientific definition and thus explicit boundaries to delineate the phenomenon, remains problematic.

Perinatal bereavement has been operationalized in measurement tools as mourning and grief. For instance, Kennell *et al.* (1970) operationalized perinatal bereavement by assessing the 'mourning score' of each participant on a scale of 0–24. Since then, researchers from various disciplines have devised multiple tools purported to measure perinatal bereavement and have in some cases even used the words 'perinatal bereavement' in the name of the tool. Examples of these measurement tools are reported here to illustrate that while the concept of perinatal bereavement has utility and applicability, it is not consistently operationalized as reflected by the measurement tools. Likewise, we learn something of the temporal context of perinatal bereavement as the measurement tools are applied to a variety of types of perinatal loss: miscarriage, stillbirth and neonatal loss.

In many of the tools used to measure perinatal bereavement in this data set, grief is the primary variable that is examined. For instance, Hutti *et al.* (1998) presented the Perinatal Grief Intensity Scale to measure and predict intensity of grief after early pregnancy loss. The Perinatal Bereavement Grief Scale (PBGS) was developed to investigate the reactions to perinatal bereavement after miscarriage by measuring grief, yearning and preoccupation with the loss (Ritsher & Neugebauer 2002). The Perinatal Bereavement Scale (PBS) was designed to measure the bereavement of parents who have experienced a perinatal loss through miscarriage, stillbirth, or neonatal death (Theut *et al.* 1989). Notably, the scale was initially intended to measure perinatal bereavement in couples after the birth of a subsequent child to evaluate unresolved grief from a prior perinatal loss. According to Theut *et al.* (1989), the scale can differentiate between parents who are bereaved from an early perinatal loss and a late perinatal loss. The authors assert that the tool measures perinatal bereavement and they refer to the results as 'grief scores' thereby implicitly implying that grief is a central response in perinatal bereavement.

The most frequently used tool in this data set is the Perinatal Grief Scale (PGS) which considers variables thought to be predictive of grief, such as physical health of the mother, gestational age at the time of the loss and quality of the marital relationship (Toedter *et al.* 1988). The authors assert that perinatal grief can be acute, (normal), delayed, or chronic (pathologic). In this data set, a total of 27 research reports used the PGS to measure perinatal grief during bereavement following a pregnancy loss. The PGS has been frequently used in concert with other tools to produce correlations of grief after perinatal loss with variables such as depression (Zeanah *et al.* 1993, Swanson *et al.* 2002, Burgoine *et al.* 2005), marital satisfaction (Lin & Lasker 1996), impact of other life events (Johnson & Puddifoot 1996, Hunfeld *et al.* 1997a, Kroth *et al.* 2004; Serrano & Lima 2006) and social support (Lin & Lasker 1996, Kroth *et al.* 2004). These findings suggest that perinatal bereavement is a complex phenomenon and while its chief manifestation is grief, it is influenced by multiple variables that may not be captured in a single measurement tool nor conceptualized as only the experience of grief.

Some researchers have adopted adult bereavement measurement tools and applied these measures to the experience of perinatal bereavement (Lindberg 1992, DiMarco *et al.* 2001), while others have measured perinatal bereavement by assessing psychiatric symptoms such as depression and anxiety (Forrest *et al.* 1982, Vance *et al.* 1995). However, the general bereavement measurement tools do not capture the nuances unique to perinatal loss that the other tools address.

To summarize the findings of the analysis of the pragmatic principle, the concept of perinatal bereavement has been operationalized in the context of perinatal loss through early pregnancy loss (Hutti et al. 1998), miscarriage (Theut et al. 1989, Ritsher & Neugebauer 2002), stillbirth and neonatal death (Theut et al. 1989, Franche 2001), elective termination for fetal anomalies (Burgoine et al. 2005) and subsequent pregnancy after perinatal loss (Côté-Arsenault & Mahlangu 1999, Côté-Arsenault & Donato 2007). The existing tools used to evaluate perinatal bereavement primarily measure grief, although there is some variation in the constructs that are measured and the contexts where they are applied. The multiple variables that are often measured in concert with the grief measures give evidence of the complex nature of perinatal bereavement. Thus, it is probable that no single tool captures the totality of the experience. It is important to note here that the epistemological immaturity of the concept markedly influences the pragmatic principle. The implied meaning discovered in the epistemological analysis of perinatal bereavement holds true through the analysis of the pragmatic principle in that perinatal bereavement has been measured after loss through death of an infant or loss of a pregnancy. Yet, because the concept of perinatal bereavement has not been consistently defined in the literature, manifestations of the concept have not been cohesively synthesized, therefore restricting the pragmatic utility of the concept.

# Linguistic principle

The linguistic principle was applied to ascertain the consistency in use and meaning, as well as the fit of a concept in the context of use (Penrod & Hupcey 2005b). Analysis of the linguistic principle revealed that perinatal bereavement is consistently used in the literature to refer to the experience that begins immediately following a perinatal loss; however the lack of a precise definition (epistemological immaturity) limits the depth of meaning across contexts. Research endeavors to study and compare the experience of perinatal bereavement have been fraught with difficulties related to the contextual variable of time, such as gestation at the time of the loss and duration of bereavement (Toedter et al. 2001, Flenady & Wilson 2008). The data were clear that the term perinatal bereavement is used in reference to the time that begins after the unintended or unexpected loss of a pregnancy or death of an infant, or after a planned termination for fetal anomalies. The concept of perinatal bereavement has been applied to both early loss by miscarriage and later losses to stillbirth or neonatal death (Barr & Cacciatore 2007, McCreight 2008). Zeanah et al. (1993) studied the grief responses in women who electively terminated pregnancies for fetal anomalies and concluded that their grief was as intense as those with spontaneous losses. The experience of perinatal bereavement has been studied at various intervals, such as one year after miscarriage (Swanson et al. 2007), four months after miscarriage (Adolfsson et al. 2006) and even years after the death of an infant (Hunfeld et al. 1997b; Schaap et al. 1997; Swanson et al. 2002).

Thus there is agreement in the existing literature about when perinatal bereavement begins, but there are varying reports about the duration of perinatal bereavement. For instance, according to some researchers, perinatal bereavement has no certain end point (Theut *et al.* 1990), lasting months to years and even extending into future pregnancies (Hutti, 2005). Others assert that perinatal bereavement lasts a lifetime (Capitulo, 2005). The duration of perinatal bereavement has been limited to one year by Kowalski (1991), while Badenhorst and Hughes (2007) suggest that grief is prolonged if there is no improvement after six months. The experience of perinatal bereavement in the context of subsequent pregnancies has been explored with findings to suggest that future pregnancies stimulate anxiety and grief related to former perinatal loss (Barr 2006; Côté-Arsenault & Donato 2007). Hence there is no consistent time limit offered in the literature to suggest a definite end point or expected resolution of perinatal bereavement.

The literature suggests that cultural norms also influence duration and manifestations of perinatal bereavement. For example, in India, a later loss is more distressing than an early loss and mothers are discouraged from attaching to the baby since the death is considered a misfortune (Mehta & Verma 1990). In the Muslim culture, the bereavement period is prescribed and lasts three days followed by 40 days of mourning (Hebert 1998). The cultural context of the perinatal bereavement experience has also been studied in African Americans (Kavanaugh & Hershberger 2005), in Thai women (Prommanart *et al.* 2004) in Dutch women (Janssen *et al.* 1997) and in German parents (Lorenzen & Holzgreve 1995). While the manifestations of perinatal bereavement vary across culture and time, the concept's lowest level of applied meaning in each of these contexts is consistent in that it refers to a time that follows perinatal death.

# Logical principle

Lastly, the data were examined to evaluate how the concept holds its boundaries through theoretical integration with other related concepts (Penrod & Hupcey 2005b). These data reveal that the conceptual boundaries are inconsistent for perinatal bereavement, grief and mourning. This conclusion is supported with the reported findings of a concept analysis of grief by Cowles and Rodgers (2000) who found that the words bereavement, grief and mourning are often used interchangeably. Untangling related concepts is essential to develop theory for practice. Without clear boundaries, concepts cannot be accurately defined and measured, therefore possibly inhibiting the development of appropriate interventions.

Analysis of these data did not reveal theory specific to perinatal bereavement, although examples of general grief theory were used to support the study of perinatal bereavement. For instance, Adolfsson and Larsson (2010) used a general grief taxonomy as proposed by Bonanno and Kaltman to study perinatal bereavement as a process in Swedish women who had experienced miscarriage. Likewise, Bartellas and Van Aerde (2003) conceptualized bereavement as a process of grieving applying Rando's theory of grief as phases.

# **Conceptual Components**

Informed by the findings from each precept of the principle-based concept analysis, the conceptual components of perinatal bereavement can be organized to include antecedents, attributes and outcomes. The characteristics of perinatal bereavement were determined through

an analysis of implicit meanings of the concept of perinatal bereavement as revealed in the analysis of the four principles in this data set. These conceptual insights contribute to the final product of the principle-based concept analysis: a theoretical definition.

#### Antecedents

The primary antecedent to perinatal bereavement is the unintended or unexpected loss of an infant through death from miscarriage, stillbirth, or neonatal death (Barr & Cacciatore 2007), or loss of an infant by elective termination for fetal anomalies (Van Putte 1988; Zeanah *et al.* 1993). Perinatal bereavement is experienced uniquely by parents (Chan *et al.* 2008). One important antecedent surrounding the perinatal loss that is consistently noted in the literature is the dream of the expectation of parenthood, new life and future hopes. (Hutti 2005, Callister 2006, O'Leary & Thorwick 2006). These are disrupted when the loss occurs.

#### **Attributes**

Overwhelmingly, these data reveal that the main attribute of perinatal bereavement is grief. Grief in the perinatal bereavement experience is complex, individualized and often accompanied by a wide variety of concurrent expressions such as sadness, irritability, depression, yearning, anger and crying (Badenhorst & Hughes 2007). The perinatal bereavement experience is modified or influenced by multiple factors that influence grief intensity, duration of bereavement and the ability to ascribe meaning to the experience. These factors are situational, internal, or external in nature (Figure 1).

#### Antecedents

- · Hopes and dreams of parenthood
- Sudden or unexpected loss of an infant through miscarriage, stillbirth, neonatal death or by elective termination for fetal anomalies
- Experienced by the parents

#### Attributes:

# Complex Emotional Response Manifested Mainly as Grief

### **External Modifiers:**

Culture Faith/Tradition Bereavement support

#### Situational Modifiers:

# Living children
Parenting a surviving twin
Recurrent perinatal loss
Future pregnancies
Stressful life events

#### Internal Modifiers:

Attachment Gender Personality

#### Outcomes:

- Interpretive experience with no prescribed ending point
- Renegotiating sense of self, redefining hopes and dreams of parenthood
- Ascribing meaning to the experience

Figure 1

#### Conceptual Components of Perinatal Bereavement

Situational modifiers of perinatal bereavement:

- Number of living children (Janssen et al. 1997)
- Parenting a surviving twin (Van der Zalm, 1995, Swanson *et al.* 2002)
- Recurrent perinatal loss (Serrano & Lima 2006)
- Subsequent pregnancies (Côté-Arsenault & Mahlangu 1999)
- Stressful life events (Kavanaugh & Hershberger 2005)

# Internal modifiers of perinatal bereavement:

- Attachment The presence of attachment increases the intensity of the grieving process during perinatal bereavement (Hutti 2005). Kowalski (1991) strongly asserts 'without attachment or bonding, there can be no sense of loss or bereavement; the two are irrevocably intertwined' (p. 369).
- Gender Men and women grieve differently following perinatal loss (Conway & Russell 2000, Armstrong 2001, DiMarco *et al.* 2001, Franche 2001, O'Leary & Thorwick 2006).

• Personality - Personality traits can modify, or influence grief during perinatal bereavement when there is a predisposition to shame, guilt (Barr 2004), or jealousy and envy (Barr & Cacciatore 2007).

# External modifiers of perinatal bereavement:

- Culture The perception of the perinatal loss is informed by culture, faith and tradition (Mehta & Verma 1990, Chichester 2005, Callister 2006), which in turn, influences the response during perinatal bereavement.
- Bereavement support Creating mementos, encouraging the parents to view and hold the baby, naming the baby and holding a funeral or memorial have been shown to positively help with grief intensity and duration of perinatal bereavement (Forrest *et al.* 1982, Lorenzen & Holzgreve 1995).

#### **Outcomes**

Perinatal bereavement has no prescribed ending point. It is an interpretive experience, often varying with the ebb and flow of life events (Uren & Wastell 2002). Perinatal bereavement is not an event, but rather it has been described as a journey (Williams *et al.* 2008). Families may struggle with the additional consequences of loss in terms of finding a sense of self, renegotiating parental hopes and dreams (Hutti 2005) and maintaining the marital dyad through the complexities of perinatal loss (Lang *et al.* 2004). Some families, particularly those who choose elective termination for fetal anomalies, may struggle with feelings of guilt (Robinson *et al.* 1999). Yet while perinatal bereavement is experienced differently in different people, there are common characteristics such as the presence of a grief response. One significant outcome of perinatal bereavement is the ability of parents to ascribe meaning to the experience (Kirk 1984).

#### **Theoretical Definition**

A theoretical definition is presented based on what is known about perinatal bereavement from a synthesis and integration of the findings of the principle-based concept analysis, including implied meanings and conceptual insights (antecedents, attributes and outcomes). This definition represents the best estimate of probable truth as revealed by the scientific literature and it is the final product of principle-based concept analysis (Hupcey & Penrod 2005).

Perinatal bereavement is the experience of parents that begins immediately following the loss of an infant through death by miscarriage, stillbirth, neonatal loss, or elective termination for fetal anomalies. It is characterized by a complex emotional response, most commonly manifested as grief in both the mother and father, but often expressed differently between males and females, both in intensity and duration. The grief response of perinatal bereavement is influenced by situational, internal and external factors. Mourning occurs during perinatal bereavement as an expression of loss and is influenced by culture, religion and tradition. There is no prescribed timeframe for perinatal bereavement, although bereavement support interventions such as creating mementos, naming the baby, holding the baby and having a funeral service may decrease the intensity and duration of the grief response during perinatal bereavement.

#### DISCUSSION

The theoretical definition of perinatal bereavement reveals what is known about the phenomenon and serves as a launching point for concept advancement (Hupcey & Penrod 2005). The concept of perinatal bereavement is epistemologically immature, with few explicit definitions that are adequate to describe the complexity of the phenomenon. This inconsistency in conceptual meaning threatens the construct validity of tools designed to measure the phenomenon of perinatal bereavement and contributes to a potential for incongruent theoretical definitions.

An important next step is to place the findings of this concept analysis into the theoretical context of extant bereavement theory. No theories specific to perinatal bereavement were uncovered during this literature review. However, Swanson's Middle Range Theory of Caring, now widely applied to the care of parents who have experienced perinatal bereavement, is an example of nursing theory that was developed from qualitative research studies that explored the experience of perinatal loss in the context of miscarriage (Swanson 1991). Swanson (1991) identified five caring processes that help to frame intervention: Knowing, Being with, Doing for, Enabling and Maintaining belief. Maternal attachment theory as conceptualized by Rubin (1975) and Attachment Theory as explicated by Bowlby (1969) are classic works which have also been used to inform our conceptual understanding of perinatal loss.

Classic bereavement theories centered on the resolution of grief and detachment from the deceased loved one (Davies 2004). Bereavement theory has evolved to reflect a changing paradigm away from the view that a person must break all ties with the deceased to resolve bereavement. Bereavement is considered to be an intersubjective process that is unique to each person and includes maintaining connectedness to the lost person (Florczak 2008). The former thinking about grief as 'work' or as distinct phases and stages leading to resolution has shifted such that grief is thought to be more dynamic and potentially meaningful (Lindstrom 2002). Bereavement researchers are now viewing grief that follows loss as a catalyst for personal change leading to a re-framing of self (Paletti 2008). The findings of this concept analysis are congruent with the more recent bereavement theories that posit that individuals can maintain a healthy connection to the deceased and in fact even find the bereavement experience transformational. This perspective is critically important for nurses who are planning bereavement support interventions.

#### **IMPLICATIONS**

According to Penrod and Hupcey (2005a), concept advancement is an iterative process used to refine a concept to add new knowledge and understanding, thereby moving the state of the science forward. A well-done concept analysis provides a starting point for concept advancement through the design of focused research questions aimed at filling the gaps in our knowledge. Results of this concept analysis have pragmatic implications for both scientific inquiry and clinical practice. The inconsistency in conceptual meaning of perinatal bereavement threatens the

construct validity of tools designed to measure the phenomenon and contributes to a potential for incongruent theoretical definitions. To be scientifically useful and theoretically integrated, concepts must be precisely defined and clearly understood. Simply put, how we define perinatal bereavement impacts how the phenomenon is studied and ultimately how bereavement support interventions are planned and in what context such interventions are delivered and evaluated. Moreover, as Wright (2011) asserts, inconsistent conceptual labels and variability in operational definitions may hamper the efforts of healthcare providers who are searching the literature to learn more about perinatal bereavement.

In recent years, ultrasound technology and genetic testing have enhanced the prenatal diagnosis of lethal fetal anomalies and thus sparked an increase in research about the bereavement experience for this population and the notion of perinatal palliative care. Thus, as our knowledge about perinatal palliative care grows, will the definition of perinatal bereavement need to expand to include anticipation of loss, thus beginning 'before' a death actually occurs? Moreover, does the loss experienced by couples with infertility fall under the same conceptual umbrella as 'perinatal bereavement'? The complexity of assisted reproduction raises the question of whether or not couples who choose to create, transfer, donate, or adopt embryos experience bereavement. Should the label of perinatal bereavement be applied to couples who experience failed in-vitro fertilization attempts? Practice implications abound: Who should receive perinatal bereavement support and when should support begin? For how long? How does the type of support vary across the spectrum of age, gender, past experience, ethnicity and culture? What are the outcomes of perinatal bereavement support and importantly, how can nurses foster positive outcomes after perinatal loss?

#### CONCLUSION

Perinatal bereavement is a complex, multifaceted phenomenon that impacts lives around the world. Nonetheless, it is only in the past four decades that healthcare professionals have acknowledged the impact of perinatal bereavement to parents who experience the loss of a baby. Nurses have described the work of caring for a couple who are experiencing perinatal loss and bereavement as uncomfortable, challenging and overwhelming (Roehrs *et al.* 2008). Researchers have demonstrated that after a baby dies, parents deal with a multitude of emotions that span an unpredictable amount of time; yet follow-up support for perinatal bereavement often remains inadequate (Williams *et al.* 2009).

While scientists have made huge strides to illuminate the experience of perinatal bereavement, much remains to be learned. For example, are there other experiences of pregnancy-related loss for which perinatal bereavement may be the right conceptual label? What impact will the advent of pediatric palliative care have on the timing and duration of the perinatal bereavement experience?

Much is still unknown about the perinatal bereavement experience with regard to various racial, ethnic and culturally diverse groups, as much of the empirical research has been done with White, married couples. Whitaker *et al.* (2010) call for more research on perinatal bereavement

in the Latino community to describe the experience and determine appropriate support interventions. We agree with Wright (2011) that more research is needed to build empirically derived theory specific to the experience of perinatal bereavement to inform further research and practice, ultimately resulting in improved care for bereaved mothers. Likewise, we assert that more qualitative research is needed to discover and describe the variations in the experience of perinatal bereavement across age groups, races and cultures so that the concept of perinatal bereavement can be advanced and appropriate bereavement support can be offered.

#### **SUMMARY STATEMENT**

# What is already known about this topic

- Perinatal bereavement is a global, complex and multifaceted phenomenon that follows perinatal loss.
- The concept of perinatal bereavement has been widely used in international clinical practice and research for the past four decades.
- In spite of the multiple tools available to measure perinatal bereavement, the concept is not well defined in the scientific literature and is most often operationalized as grief.

# What this paper adds

- The conceptual boundaries of perinatal bereavement are historically blurred with the concepts of grief and mourning and more recently, the contextual factors of other types of loss such as infertility.
- Perinatal bereavement is not the appropriate conceptual label for other related types of loss, such as placing an infant for adoption, the birth of a less than normal infant, or a disappointing birth experience.
- This concept analysis reveals that perinatal bereavement remains a unique interpretive experience with its own complex manifestations that are influenced by situational, internal and external factors.

#### **Implications for practice**

- How we define perinatal bereavement impacts how the phenomenon is studied and how bereavement support interventions are planned and evaluated.
- The inconsistency in conceptual meaning of perinatal bereavement threatens the construct validity of tools designed to measure the phenomenon and contributes to a potential for incongruent theoretical definitions.
- Nurse researchers should explore perinatal bereavement across cultures, ethnicities, past experiences and age groups so that the concept can be advanced and theory specific to the unique phenomenon of perinatal bereavement can be derived.

# **Supplementary Material**

# **Supp Material**

Click here to view. (34K, docx)

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- 1. substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- 2. drafting the article or revising it critically for important intellectual content. \*http://www.icmje.org/ethical\_lauthor.html

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# **Supplemental Information**

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