



## Invisible Loss: A Delphi Approach to Develop A Term for Individuals Who Experienced Perinatal Loss

Rachel Diamond <sup>a</sup>, Jessica L. Chou<sup>b</sup>, and Susan Bonis<sup>c</sup>

<sup>a</sup>Department of Counseling and Family Therapy, Adler University, Chicago, IL, USA; <sup>b</sup>Department of Counseling and Family Therapy, Drexel University, Philadelphia, PA, USA; <sup>c</sup>College of Nursing, University of Wisconsin-Milwaukee, Chicago, IL, USA

### ABSTRACT

The purpose of this Delphi pilot study was to 1) identify potential benefits to people who experienced perinatal loss if a term were established; 2) develop a term for people who experienced a perinatal loss because, at present, no term exists; and, 3) identify areas of consensus and contention between perinatal loss professionals and parents when considering terminology. Fifty-five participants (perinatal loss professionals,  $n = 33$ ; perinatally bereaved parents,  $n = 22$ ) proposed, reviewed, and rated terms through three rounds of surveys until *bereaved parent* was selected. Top terms were equally preferred between parents and professionals and, in general, participants described benefits to term development. Findings provide the perinatal loss community a first step in considering terminology.

### KEYWORDS

Bereaved parent; Delphi methodology; disenfranchised grief; perinatal loss; pregnancy loss

## Perinatal loss

*“My loss is invisible, it’s as though (my baby) never existed.”* – Participant

Perinatal death is a profoundly traumatic event (Diamond & Roose, 2016; Kersting & Wagner, 2012; Koopmans et al., 2013), affecting an estimated one million individuals in the United States each year (MacDorman & Kirmeyer, 2009). Perinatal death is typically associated with feelings of loss, grief, emotional numbness, and sorrow (Capitulo, 2005; Diamond & Diamond, 2017; Hutti et al., 2017; Wagstaff & Teska, 2018). A common finding in the extant perinatal grief literature is that it is not objective facts (e.g., length of pregnancy) that best comprise the significance of a perinatal loss experience nor predict grief reactions; instead, it is an individual’s perception of the loss that influences their reaction (Hutti, 1992). In other words, the meaning a person attributes to the perinatal loss is a critical determinant for the psychological response (Hutti et al., 2017). While the loss may feel real and significant for the individual(s) experiencing it, family, friends, and members

**CONTACT** Rachel Diamond  [rdiamond@adler.edu](mailto:rdiamond@adler.edu)  Department of Couple & Family Therapy, Adler University, Chicago, IL 60602.

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of the healthcare community often dismiss perinatal death as commonplace and, therefore, inconsequential (Diamond & Diamond, 2016; Markin, 2017). Further, the loss is often abstract without societal or legal means of recognition. For example, there are few socially sanctioned mourning practices for perinatal losses and, with early fetal deaths or when there is not a live birth (depending on the state) there may not be a legally recognized birth or death date/certificate to signify the existence of this significant experience. These invalidating messages about the experience has led to understanding this type of loss through the lens of disenfranchised grief (Doka, 1989). To further layer invalidation to this experience is the notable absence of a conceptual term that identifies individuals who experience this type of loss. Feminist therapists have long been tied to the perinatal loss experience, with efforts toward offering supportive services being seen for over 50 years (Layne, 2006). Accordingly, the aims of this paper are tied to the advocacy and support seen from the feminist movement. The present pilot study was conducted to begin to conceptualize a term for individuals who have experienced perinatal loss using Delphi methodology (Helmer & Rescher, 1959; Polit & Beck, 2017) with perinatal loss professionals and parents with first-hand experience. Recommendations are included for further term development.

### **Perinatal loss definition & experience**

The concept of the perinatal period emerged in the late 1940s as researchers and clinicians became increasingly aware of the relatively large number of deaths occurring in the period before and after delivery (MacDorman & Gregory, 2015; World Health Organization, 2006). A review of literature revealed varying parameters for what constitutes a perinatal death. During gestation, the standard definition of perinatal death only captures fetal deaths at and after 20 weeks (MacDorman & Gregory, 2015; World Health Organization, 2006). While this temporal definition captures intermediate (20–27 weeks gestation); and late (28 weeks or more gestation) loss, it excludes intrauterine deaths of the fetus prior to 20 weeks gestation (e.g., miscarriages; MacDorman & Gregory, 2015). Estimates of early fetal loss range from 10–25% up to 75%, as many pregnancies end in the first trimester before a pregnancy is confirmed (Kersting & Wagner, 2012; March of Dimes, 2017). At the other end of the perinatal period, the standard definition for newborn (neonatal) deaths include deaths among live births during the first 28 completed days of life (World Health Organization, 2006).

For the purposes of the present project, we conceptualized the perinatal period as broadly as possible to include early fetal deaths because the psychosocial experience may not differ based on weeks of gestation and this gestational period is the time in which most fetal deaths occur (Hutti, 1992; Hutti et al., 2017; MacDorman & Gregory, 2015). Our conceptualization is aligned

with that of perinatal loss researchers (Hill et al., 2008; Kersting & Wagner, 2012) and can also be seen within national organizations for perinatal bereavement care, such as Resolve Through Sharing (RTS) Bereavement Services (Midland & Limbo, 2004) and Share Pregnancy & Infant Loss Support, Inc (Share Pregnancy & Infant Loss Support, 2015).

In addition to unclear and varied temporal parameters of what constitutes a perinatal death, there also exists variations in terminology related to the individuals who experience perinatal loss. At present, there is no term to describe the identity of an individual who has experienced perinatal loss. This lack of an established term can be seen as recently as a 2017 special section on psychotherapy for pregnancy loss. Indeed, even within a special focus journal authored by experts in the field there is varying language used to refer to individuals who experienced perinatal loss (see Table 1). These variations are critical to note, as language facilitates communication and understanding for the people who experience the phenomenon and, consequentially, society at large.

Language is used to help organize thoughts, as well as to understand and find meaning in experience (Rosenblatt, 2016). The absence of a dedicated term creates barriers and challenges for the individual, as well as researchers and clinicians. Most losses, such as death of a spouse (i.e., widow/widower) or parents (i.e., orphan) are socially defined through specific terminology. Thus, the lack of a socially recognized term for an individual experiencing a significant event, such as perinatal loss, can further contribute to a sense of isolation and disenfranchisement. This lack of terminology coupled with societal reactions to this type of loss (e.g., minimization and avoidance), can

**Table 1.** Perinatal Loss Terms.

Perinatal Terms Used	Article Reference
<ul style="list-style-type: none"> <li>● Patients grieving the loss of a pregnancy</li> <li>● Women who experience a pregnancy loss</li> <li>● Patients who have suffered a pregnancy loss</li> <li>● Patients who have experienced a pregnancy loss</li> </ul>	Markin (2017). An introduction to the special section on psychotherapy for pregnancy loss: Review of issues, clinical applications, and future research direction. <i>Psychotherapy, 54</i> (4), 367–372.
<ul style="list-style-type: none"> <li>● Bereaved parents of babies who die during pregnancy or shortly after birth</li> <li>● Parents who have experienced a prenatal loss</li> <li>● Bereaved parents</li> </ul>	O’Leary and Henke (2017). Therapeutic educational support for families pregnant after loss (PAL): A continued bond/attachment perspective. <i>Psychotherapy, 54</i> (4), 386–393.
<ul style="list-style-type: none"> <li>● Clients experiencing pregnancy loss</li> <li>● Pregnancy loss clients</li> <li>● Bereaved parents</li> <li>● Postloss parenting</li> <li>● Couples who have had a loss</li> <li>● Reproductive loss patients</li> <li>● Patients who have suffered reproductive losses</li> <li>● Parents who have suffered reproductive loss</li> <li>● Women who have experienced pregnancy loss</li> </ul>	Jaffe (2017). Reproductive trauma: psychotherapy for pregnancy loss and infertility clients from a reproductive story perspective. <i>Psychotherapy, 54</i> (4), 380–385. Diamond and Diamond (2017). Parenthood after reproductive loss: How psychotherapy can help with postpartum adjustment and parent–infant attachment. <i>Psychotherapy, 54</i> (4), 373–379.
<ul style="list-style-type: none"> <li>● Clients (i.e., women and couples) dealing with pregnancy termination for fetal anomaly (PTFA)</li> <li>● PTFA clients</li> </ul>	Wenzel (2017). Cognitive behavioral therapy for pregnancy loss. <i>Psychotherapy, 54</i> (4), 400–405. Leon (2017). Empathic psychotherapy for pregnancy termination for fetal anomaly. <i>Psychotherapy, 54</i> (4), 394–399.

have detrimental effect on one's ability to process and cope. To address this language gap, we proposed the development of a pilot study as a first step toward conceptualizing such a term.

## **Feminist lens**

The feminist movement has been connected to infant loss, with the start of infant loss support groups over 50 years ago. As women's rights and voices became more prominent among society, so did support groups for women who experienced pregnancy loss (Layne, 2006). The present study was guided by a feminist lens in an effort to continue creating a platform of empowerment and voice for people who have experienced perinatal loss. Because language and the meaning behind can shape our experiences (Mize, 2003) and empower people; it is important to understand the potential benefits of identifying a preliminary term that may give language to people who have experienced perinatal loss.

## **Research aims**

The principal aims of the present study included:

- (1) Identify potential benefits to people who have experienced perinatal loss if a term were established.
- (2) Develop a term for people who have experienced a perinatal loss for further exploration because, at present, no such term exists.
- (3) Identify areas of consensus and contention between professionals and parents when considering terminology for persons who have experienced perinatal loss.

## **Study design and methods**

### ***Design***

The present study was designed as a pilot study to be an important, first step in the development of a term for persons of perinatal loss. Delphi survey methodology was used to directly access perspectives of professional experts in the field of perinatal loss, as well as individuals who had personal experience with perinatal loss. Delphi methodology was originally developed to resolve dilemmas related to selecting a plan of action based on a group consensus (Helmer & Rescher, 1959). In this case, Delphi was used to find agreement on a term for individuals who experienced perinatal loss. This goal is consistent with use of the method to resolve the dilemma of "defining a foundational concept" (Jorm, 2015, p. 889). Typically, statistical procedures are used to distill information gathered from a panel of experts about a broad research question; responses are thematically analyzed and

given back to participants for clarification and comment. Parents with first-hand expertise were also included on the panel creating a platform of empowerment and voice for people who have experienced a perinatal loss so as to not just rely on professionals to comprise the expert panel, as is typical of Delphi studies. Furthermore, unlike typical studies that employ Delphi methodology, the present study was not simply seeking consensus from the panel to find agreement (e.g., 75% median threshold consensus) across, for example, a list of statements (Diamond et al., 2014). Instead, our goal for using Delphi methodology was to find agreement on a single outcome – a term for individuals who have experienced a perinatal loss as the first step in conceptualizing a potential term for future use in practice settings. While we understood it was unlikely unanimous agreement could be achieved, our aim was to achieve majority agreement on a single term. To reduce the risk of significant attrition that could compromise results, we planned for the term to be selected by participants following three rounds.

### **Participants**

Purposeful and snowball sampling were used to recruit participants which resulted in 55 participants for the panel: professionals ( $n = 33$ ) and parents ( $n = 22$ ). All participants were over 18, English-speaking, and within the United States. Delphi studies have demonstrated stability with panels of around 20 or more (Jorm, 2015); however, because the research team understood the possibility of attrition given the higher than typical number of rounds, a larger panel was sought. In Round 2, 42 participants responded: 28 professionals and 14 parents. In Round 3, 31 participants responded: 21 professionals and 10 parents.

Qualifications for professional experts included clinical expertise, such as certification in perinatal loss care (CPLC); professional contributions, such as related publications; and/or years and focus of experience in perinatal loss. Parent experts were identified and recruited from perinatal loss organizations in the Midwest and New England that the PI had a previous affiliation. The clinical directors of these programs managed the recruitment of parent participants so that the research team was not in direct contact until after parents expressed interest. Parents were actively involved in the perinatal loss organization (e.g., served as peer support parents) and were identified by the organization to have the following qualities: developed insight into the grieving process, resolved their grief to be able to participate in a meaningful way, and were able to provide helpful information from their own experience.

### **Data collection**

Online responses to survey questions were collected through three rounds conducted over 6 months. Upon participants electronically indicating they

had reviewed informed consent, they were directed to the Round 1 survey that gathered participant demographic information and asked open-ended questions about perinatal loss terminology. In the Round 2 survey, participants were provided each unique term generated in Round 1 and asked to rate each term. Participants utilized a visual analog scale in which they could rate each response from 0 (lowest) – 100 (highest). A comment box was additionally provided to allow for modifications and/or rationale for ratings. In the Round 3 survey, participants were presented with the five terms receiving the highest overall ratings from Round 2. In this round, participants were asked to rank order the terms from 1 (most preferred) – 5 (least preferred).

### ***Data analysis***

As is typical in Delphi research, the analysis of data in the present study required both qualitative (Round 1) and quantitative (Round 2 and 3) approaches (Skulmoski et al., 2007). Thematic analysis was used to identify codes, themes, and categories. The first-round survey responses were read and reread independently by each researcher to find meaning and develop understanding in the words participants used. Words and phrases were highlighted and reference notes were made. A table was constructed to organize the highlighted terms and phrases into categories based on emerging themes. Themes and categories were compared among the researcher team and tied to the data.

Rounds 2 and 3 involved a quantitative approach in order to determine a majority agreement on terminology and to highlight similarities and differences between participant groups (i.e., parent and professional participants). Statistical summaries of mean (M) and standard deviations (SD) of Round 2 responses were analyzed between groups and by total responses. Between-group and total responses from Round 3 were also generated into statistical summaries of percentages. Using the statistical summaries from Round 2 and 3, comparative analysis was used to assess for consensus and contention between participant groups using t-tests, chi-square test of goodness-of-fit and Freeman-Halton extension of Fisher's exact test.

## **Results**

### ***Descriptive data***

Professional participants (n = 33) included individuals with relevant professional knowledge and experience (Baker, Lovell & Harris, 2006) in perinatal loss (See Table 2). The professional experts were multidisciplinary with the majority (57.6%) identifying as nursing professionals with varying levels of education and responsibilities coordinating perinatal loss bereavement

**Table 2.** Participant Demographics.

Demographics	Parent Expert		Professional Expert	
	n=22	%	n=33	%
Gender				
Male	2	9.1%	1	3.0%
Female	20	90.9%	32	97.0%
Identified Race*				
Non-Hispanic White or Euro-American	18	81.8%	33	100%
Black, Afro-Caribbean, or African American	1	4.5%	0	0.0%
Latino or Hispanic American	2	9.1%	0	0.0%
East Asian or Asian American	0	0.0%	0	0.0%
South Asian or Asian American	0	0.0%	0	0.0%
South Asian or Indian American	1	4.5%	0	0.0%
Middle Eastern or Arab American	0	0.0%	0	0.0%
Native American or Alaskan Native	0	0.0%	0	0.0%
Other	1	4.5%	0	0.0%
Current Location				
Northeast United States	6	27.3%	4	12.1%
Northwest United States	0	0.0%	1	3.0%
Southeast United States	5	22.7%	7	21.2%
Southwest United States	2	9.1%	1	3.0%
Midwest United States	9	40.9%	11	33.3%
Mid-Atlantic United States	0	0.0%	9	27.3%
Highest Educational Degree				
Certificate	1	4.5%	0	0.0%
Some College	1	4.5%	0	0.0%
Associates	2	9.1%	1	3.0%
Bachelor's	6	27.3%	12	36.4%
M. Ed	3	13.6%	0	0.0%
MSN	3	13.6%	5	15.2%
MSW	2	9.1%	2	6.1%
MBA	1	4.5%	0	0.0%
MS	2	9.1%	1	3.0%
MDiv	0	0.0%	2	6.1%
PhD	0	0.0%	9	27.3%
DNP	0	0.0%	1	3.0%
Other	1	4.5%	0	0.0%
Primary Profession				
Researcher/Scholar			4	12.1%
Nurse			19	57.6%
Therapist/Clinician			7	21.2%
Professor			2	6.1%
Minister/Chaplain			1	3.0%
Years working in Perinatal Loss Community				
2-5 Years			6	18.2%
5-10 Years			6	18.2%
10-15 Years			5	15.2%
15-20 Years			3	9.1%
20+ Years			13	39.4%
% of week working in Perinatal Loss Community				
0-10%			4	12.1%
10-20%			9	27.3%
20-40%			7	21.2%
40-60%			3	9.1%
60-80%			4	12.1%
80-100%			6	18.2%
Perinatal Loss				
Yes	22	100%	17	51.5%
No	0	0.0%	14	42.4%
Missing Data	0		2	6.1%
Perinatal Loss Experience*				
Ectopic	1	4.5%	0	0.0%
Single Miscarriage	11	50.0%	10	30.3%
Multiple Miscarriages	5	22.7%	4	12.1%
Stillbirth	8	36.4%	3	9.1%
Newborn Death	7	31.8%	1	3.0%

\* percentages can exceed 100, as more than one answer is possible

programs. Years of experience and percentage of time working in the perinatal loss community varied: the majority (63.6%) had 10 or more years of experience and; notably, all professionals who reported spending 0–10% of their work week in the perinatal loss community had 5 or more years of experience. While professional experts differed from the parent experts in that they were not required to have first-hand experience with perinatal loss, 17 (51.5%) reported having experienced some type of perinatal loss.

Parent experts (n = 22) reported a range of perinatal losses, with the majority (57%) reporting more than one loss experience (See Table 2). Participants had a variety of ways in which they had participated in the perinatal loss community, with the most common being volunteer work (n = 15; 68.2%).

## **Delphi results**

### **Round 1**

Participants were asked to respond to two open-ended questions. The first question asked: *How would people who have experienced a perinatal loss benefit from the establishment of a common term?* The overarching theme that emerged was a perceived benefit to the establishment of a term. All 14 (100%) of the parent participants and 25 (89%) of professional participants responded that people who experienced perinatal loss would benefit from establishment of a common term. Three subthemes were identified: 1) community and connection, 2) validation of loss and 3) identification.

### **Community and connection**

Responses from 6 (37.5%) parents and 5 (25.0%) professionals indicated an established term could benefit the perinatal loss community by promoting a sense of community and connection. This was exemplified in the words of this parent, “*sense of belonging, sense of unity, being part of a group and not alone as we often feel alone.*” A response by a professional participant supported this notion of community and support, “[...] *a common term would start to give a language to an experience that typically is not spoken of which helps alleviate isolation and shame.*”

### **Validation of loss**

Responses from 6 (37.5%) parents and 6 (30.0%) professionals indicated an established term could validate and legitimize the loss. This was exemplified in the words of one parent who responded, “*We would finally have a word in our culture that may honor this deep loss*” and another who responded, “*it helps validate that the loss was a real loss of human life.*” Similarly, a professional responded, “*it would acknowledge the loss in a way that is currently ignored. Most commonly I hear ‘Am I still a mother/father?’*”

### Identification

Responses from 6 (37.5%) community and 10 (50.0%) professional participants indicated an established term could create an ability to have a means of identification that can benefit the ecological system affected by the loss: the individual, the microsystem directly interacting with the bereaved, and larger systems. The notion of identification could directly benefit individuals who experienced perinatal loss by establishing a focus on the grief process. As one professional explained, *“it would help with their identity and the processing of their grief.”* Additionally, the establishment of a term was also seen as having benefits in the microsystem in which the bereaved individual interacts. Specifically, responses focused on improved communication of the loss with others. As one parent described, *“people wonder what to call those of us that lost a baby. We are still parents. Perhaps it would be easier on others if there was a word for it.”* This notion of support was reiterated by a professional, *“it has been my experience that people who suffer the loss of a baby struggle with the term parent. They know they are a parent, but sometimes feel that others do not see them as a ‘parent’ because their baby is no longer here.”* Finally, identification could affect larger systems through enhancement of funding, research, and medical opportunities by shifting the belief system and understanding of the experience for perinatally bereaved individuals. One parent noted, *“[establishment of a term] identifies us as a group – that can be studied/funded or simply acknowledged.”* A professional identified the following benefits within the medical system, *“if there was a common term that could be used in a patient’s chart, then the patient may not have to explain over and over again the circumstances around the death which could create less trauma for the parent.”*

In addition to the themes discussed above, it is notable that four professional participants expressed varying opinions related to development of a term. One conveyed a need for different terms for different types of losses, *“I don’t know if there is one single term that will fit for everyone.”* Three others questioned the need for any term to be established, *“I can’t see how a name would unite them more than their experience of their loss already does.”*

The second question in Round 1 asked: *What terms have you heard used for people who have experienced perinatal loss?* The terms were analyzed and categorized into two groups reflective of: 1) identity as a person and 2) identify as experience (see [Table 3](#) for complete list of responses).

### Identity as a person

Language from both parents and professionals included terms related to being a parent (e.g., mother and father) either on its own or coupled with descriptors tied to the loss (e.g., bereaved, grieving, without a child, etc.). Additionally, there were unique terms provided that described the person having had this specific loss. One such example is vilomah, a word borrowed from Sanskrit meaning

**Table 3.** Commonly used Terms for Perinatal Loss at Present.

<b>Identity as a Person</b>
<ul style="list-style-type: none"> <li>● Angel mother, father, parents<sup>1,2</sup></li> <li>● Baby loss mother, father, parents<sup>1</sup></li> <li>● Bereaved mother, father, parents<sup>1,2</sup></li> <li>● Empty arms<sup>2</sup></li> <li>● Grieving mother, father, parents<sup>1,2</sup></li> <li>● Loss mother, father, parent<sup>1,2</sup></li> <li>● Mother, father, parents<sup>2</sup></li> <li>● Mother, father, parents without a child<sup>2</sup>; Childless mother, father, parents<sup>1,2</sup></li> <li>● Naphro<sup>2*</sup></li> <li>● Perinatally bereaved parents<sup>2</sup></li> <li>● Perinatal loss parents<sup>2</sup></li> <li>● Psychological parent<sup>2</sup></li> <li>● Reavan<sup>2*</sup></li> <li>● Still mother, father, parent<sup>1</sup>; Still a mom, dad, parent<sup>1</sup></li> <li>● Unemployed parent<sup>2</sup></li> <li>● Vilomah<sup>2*</sup></li> </ul>
<b>Identity as Experience</b>
[Description of experience]
<ul style="list-style-type: none"> <li>● Barren; infertile; sterile<sup>1</sup></li> <li>● (History of) stillbirth<sup>2</sup></li> <li>● Lost their baby<sup>2</sup></li> <li>● Maternal fetal demise<sup>2</sup>; reproductive demise<sup>2</sup></li> <li>● Miscarriage<sup>1,2</sup></li> <li>● Multiple losses<sup>2</sup></li> </ul>
Mother, Father, Parents [description of experience]
<ul style="list-style-type: none"> <li>● ... of babies born too soon<sup>2</sup></li> <li>● ... of a stillborn baby<sup>2</sup></li> <li>● ... of a baby who died as a newborn<sup>2</sup></li> <li>● ... with difficulty having a baby<sup>1</sup></li> <li>● ... with multiple losses<sup>2</sup></li> <li>● ... who have experienced the death of an unborn or newly born infant<sup>2</sup></li> <li>● ... who had a pregnancy loss<sup>2</sup></li> <li>● ... who lost a child/baby<sup>2</sup></li> </ul>
No terms
<ul style="list-style-type: none"> <li>● <i>Never heard a term, just her baby died, or she lost a baby</i><sup>1</sup></li> <li>● <i>I haven't heard any terms unfortunately other than she/they just lost their baby</i><sup>1</sup></li> <li>● <i>I have never heard a term. They are always referred to as 'she has had a miscarriage, she has had a stillbirth, or her baby died shortly after birth'</i><sup>2</sup></li> <li>● <i>In general, I have not heard terms used for persons who have experienced a perinatal loss</i><sup>2</sup></li> </ul>

1 Information provided by parent participant(s)

2 Information provided by professional participant(s)

\*Naphro: Meaning provided for term by participant: 'orphan' spelled backward

\*Reavan: Participant provided no meaning for term

\*Vilomah: Meaning provided for term by participant: means 'empty' in Sanskrit, same language we adapted widow (also empty) from

“against a natural order” – as in children should not precede their parents in death (Holloway, 2006). The terms presented here support the need for the development of a term specific to the individual and their experience with perinatal loss.

### **Identity as experience**

In contrast, both parents and professionals provided descriptions of one's experience of perinatal loss that highlighted the lack of a unique term. As one example, one parent explicitly made note that descriptions are provided

with “*nothing specific to the person*” and another parent reported that they “*never heard a term.*” The terms categorized in this group described the experience alone, not the person. That is, they were not linked to the identity of the person or, at best, made little reference to the actual person.

The final questions asked in Round 1 included: *If a common term was established for people who experienced a perinatal loss, what term would you recommend?* Twenty-three unique terms were generated. The terms and their corresponding rationale were compiled (see [Table 4](#)).

### **Round 2**

The 23 terms generated in Round 1 were provided back to participants to review and rate. The statistical summaries of participants’ scores can be found in [Table 5](#). T-tests revealed statistically significant differences ( $p = .05$ ) between parents and professionals for the term *perinatal loss mom/dad/parent* and the term *parent*, with ratings for the parent group being higher for both. Results demonstrate no statistical difference on ratings between parents and professionals for all other terms (See [Table 5](#)).

Using the combined group ratings, the top five rated terms from Round 2 included: 1) *bereaved mother/father/parents*, 2) *perinatal loss mother/father/parents*, 3) *perinatally bereaved parent*, 4) *pregnancy loss*, and 5) *referred to as the baby’s mom/dad* (e.g., *Sara’s mom*). Additionally, participants included the following responses that were not anticipated in the original design: a) the need for different terms for different types of losses and b) no need for the establishment of a term. Therefore, relevant questions were added to Round 3.

### **Round 3**

Round 3 involved two parts. Participants were asked to rate the top five generated terms into order of preference, then were asked to respond to two questions: 1) *Do you feel there should be different terms for different types of loss?* 2) *Do you think the establishment of a term is needed to describe a person/s who experienced perinatal loss?*

#### **Top five rating**

*Bereaved parent* was the highest ranked term, put in the top position by 14 (45.2%) of the 31 participants: 5 parents (50.0%) and 9 professionals (42.9%) (See [Table 6](#) for descriptive statistics). Using the descriptive summaries from Round 3, a chi-square test of goodness-of-fit was performed. Greater than 20% of the expected counts were less than 5 and not all individual expected counts were 1 or greater (Yates et al., 1999). Therefore, categories were collapsed to compare participants who chose *bereaved parent* as the top-rated term as compared to choosing another term. *Bereaved parent* was equally preferred between parents and professionals,  $X(1) = .140$ ,  $p = .103$ .



Table 4. Term Development.

Terms	Parents		Professionals	
	Reason(s) Provided	Reason(s) Provided	Reason(s) Provided	Reason(s) Provided
Bereaved mother/ father/parents*	<ul style="list-style-type: none"> <li>It's inclusive and doesn't designate the person with their particular experience</li> <li>I saw it online and I feel like it suits the situation</li> </ul>	<ul style="list-style-type: none"> <li>Their parenthood is real, as is their grief</li> <li>It's clear and concise</li> <li>It defines the relationship and the emotion</li> </ul>		
Perinatal loss mother/ father/parents Perinatally bereaved parent	<ul style="list-style-type: none"> <li>Fits most accurately- 'loss or bereaved parents' include those who lose an older child which seems in many ways like a different kind of loss</li> </ul>	<ul style="list-style-type: none"> <li>It defines the context, the relationship, and the timing. To reiterate a statement from the previous response, the relationship aspect (parent) depends on the meaning the experience has for the one going through it (e.g., numerous research findings indicate that "miscarriage" can mean "loss," "death of a child," or other)</li> </ul>		
Pregnancy Loss	<ul style="list-style-type: none"> <li>To me <i>Pregnancy Loss</i> seems more meaningful than <i>Miscarriage</i>. <i>Miscarriage</i> is so widely used, that I find anymore it doesn't carry the weight of the loss as <i>Pregnancy Loss</i> could potentially</li> </ul>	<ul style="list-style-type: none"> <li>In my experience parents are most comforted if they are referred to as their baby's mom/dad</li> </ul>		
Referred to as their baby's mom/dad (e.g., Sara's mom) * [Different terms for different losses]	<ul style="list-style-type: none"> <li>There should be different terms for different types of perinatal loss so the parent does not have to further explain their situation (one term for a miscarriage, one term for still birth, one term for a neonatal death)- each of these terms may be related</li> <li>Means 'empty' in Sanskrit, same language we adapted widow (also empty) from</li> </ul>			
Vilomah Parents Grieving mom/dad/ parent			<ul style="list-style-type: none"> <li>Makes sense</li> <li>I am unsure about a common term. I find psychotherapy patients grieving the loss of a pregnancy/baby prefer different terms. For example, some prefer to be called a parent and some do not. I supposed the term "grieving parent" is the best one I can think of but doesn't seem to really capture the experience of being a parent without a baby and again some patients do not want to be called a parent.</li> <li>For a start term includes parent and a child has died – but does not include death during a pregnancy or perinatal loss</li> </ul>	
Loss mom/dad/parent	<ul style="list-style-type: none"> <li>Inclusive of gender; <i>Parenthood</i> is respected when so much of society minimizes that component of our loss</li> </ul>			
Forever mom/dad/ family	<ul style="list-style-type: none"> <li>That is what we are – we are forever grieving and loving our children. Nothing and no one – not a different child or time – will change it. We will forever miss them and love them. I also like that this doesn't have a religious connotation or put other "beliefs" on others as in something to do with angels.</li> </ul>			

(Continued)

**Table 4. (Continued).**

Terms	Parents Reason(s) Provided	Professionals Reason(s) Provided
Baby loss*		<ul style="list-style-type: none"> <li>• People often refer to the fetus they are carrying as the baby this or the baby that (kicking, rolling, resting), so there is some common consensus that there is a baby inside. It is also more specific than pregnancy making it more real and human. Miscarriage and stillbirth describe a time limited event that is now in the past and while some of the trauma of that event may still be relevant to process what is more relevant is to be able to talk about what was lost and miscarriage and stillbirth do not really speak to this piece</li> <li>• I can only, ever, remember hearing parents who have suffered the loss of a baby saying they were Parents of an Angel. I have seen it time and time again in this community.</li> </ul>
Parent/Parents of an Angel		
Something with the root word "hope" Angel mom/dad/ parents Courageous mother*	<ul style="list-style-type: none"> <li>• We always have hope</li> <li>• Because your babies are angels in Heaven now. Inclusive to both parents, heard it time and again in the community</li> </ul>	
Babyless parents		<ul style="list-style-type: none"> <li>• Women who suffer stillbirth or neonatal death come home after birth with no baby. They are continuously asked about their pregnancy or congratulated, only having to tell the story over and over. Those who weren't visibly pregnant yet suffer in silence--no one asks them about their baby. Instead, these mothers congratulate other mothers and listen to other people's birth stories and no one ever knows how much they hurt. Then there are those women who choose to carry a baby with a life-limiting diagnosis. In my opinion, they are the most courageous. They go about those months of pregnancy just hoping to meet their little one alive. All the while, people ask them about the baby and what the nursery looks like, etc.</li> <li>• It offers validation that a baby did exist and turned human beings into parents, whether their baby lived to be met or died before that time. Babyless clearly defines there is no baby to hold in their arms and to raise.</li> <li>• Because they are forever lost and always loved</li> </ul>
Forever loved lost Something that means "torn meeting" Psychological parent*	<ul style="list-style-type: none"> <li>• The divine meeting of a new life with their parent or parents was torn or ripped apart by the death of the new life</li> </ul>	<ul style="list-style-type: none"> <li>• Developmentally we make a psychological leap when attempting to become a parent. With a perinatal loss, the shift in identity has occurred even though there is no baby to bring home. We become psychological parents before becoming physical parents.</li> </ul>
Fathered or Mothered No term needed*	<ul style="list-style-type: none"> <li>• No reason</li> </ul>	

\* Term generated by individual(s) who included professional expert(s) who reported personal perinatal loss

**Table 5.** Results of Descriptive Statistics and T-Tests for Rating of Terms by Groups.

Terms	Group						95% CI for Mean Difference	t	df
	Parents			Professionals					
	M	SD	n	M	SD	n			
Bereaved mother/ father/ parent	65.08	28.92	13	69.12	29.06	26	-24.01, 15.93	-.41	37
Perinatal loss mother/ father/ parents	66.50	28.48	12	45.50	25.58	24	1.92, 40.08	2.24*	34
Perinatally bereaved parent	43.08	34.99	13	45.67	31.44	36	-26.51, 18.40	-.37	34
Pregnancy Loss	48.82	37.66	12	45.05	36.77	21	-24.00, 30.74	.25	31
Referred to as their baby's mom/ dad (e.g., Sara's mom)	47.64	36.27	11	36.91	32.80	22	-14.85, 36.30	.86	31
[Different terms for different losses]	34.20	35.80	10	38.56	32.30	18	-31.56, 22.85	-.33	26
Vilomah	34.08	31.08	12	40.47	34.98	19	-31.70, 18.92	-.52	29
Parents	57.30	35.26	10	28.55	29.85	20	3.61, 53.89	2.34*	28
Grieving mom/ dad/ parent	42.91	34.85	11	35.55	32.74	20	-18.35, 33.06	.59	29
Loss mom/ dad/ parent	47.73	40.77	11	32.74	30.04	23	-10.22, 40.20	1.21	32
Forever mom /dad/ family	42.82	33.17	11	36.00	33.87	24	-18.12, 31.75	.556	33
Baby loss	27.00	26.29	11	30.67	31.02	21	-26.11, 18.78	-.33	30
Parent/ Parents of an Angel	25.00	29.67	11	32.16	29.34	19	-30.02, 15.70	-.64	28
Something with the root word "hope"	26.36	30.76	11	18.79	19.34	19	-11.08, 26.24	.83	28
Angel mom/ dad/ parents	28.45	36.76	11	21.43	22.49	21	-13.98, 28.03	.68	30
Courageous mother	25.00	28.64	11	18.11	23.21	18	-13.02, 26.80	.71	27
Babyless parents	17.25	18.39	8	29.21	31.84	19	-32.24, 8.31	-1.22	22.12
Forever loved lost	23.22	36.16	9	26.76	34.94	21	-32.34, 25.26	-.25	28
Something that means "torn meeting"	26.00	32.03	9	15.42	21.99	19	-15.22, 36.38	1.03	26
Psychological parent	14.27	23.35	11	12.06	15.68	17	-12.90, 17.32	.30	26
Orphaned parent	18.63	20.77	8	20.11	25.07	19	-22.26, 19.30	-.15	25
Fathered or Mothered	16.11	32.92	9	5.56	5.93	18	-14.80, 35.92	.96	8.26
No term needed	8	15.74	6	26.62	34.77	13	-43.07, 5.84	-1.61	16.99

\* p &lt; .05.

**Table 6.** Descriptive Statistics for Preferred Term by Participant Group.

Participant Group	Term				
	Bereaved Parent	Perinatal Loss Parent	Perinatally Bereaved Parent	Pregnancy Loss	Referred to as Baby's Parent
Parent	5 (50.0%)	4 (40.0%)	1 (10.0%)	0 (0%)	0 (0%)
Professional	9 (42.9%)	2 (9.5%)	7 (33.3%)	3 (14.3%)	0 (0%)
Total	14 (45.2%)	6 (19.4%)	8 (25.8%)	3 (9.7%)	0 (0%)

Numbers indicate the number of participants who identified the respective term as their top rank. Numbers in parentheses indicate column percentages.

### Different terms

In this round participants were directly asked: *Do you feel there should be different terms for different types of loss?* Participant responses were mixed: 9 (29.0%) agreed there should be different terms for different types of loss. As one participant reported, *“yes, it shows respect and honor to the specific relationship.”* Alternatively, 14 (45.2%) responded no, as the following response demonstrates: *“no, because the grief process is not defined by the type of loss, but rather how that loss affects that person.”* Additionally, 8 (25.8%) responses were categorized as unsure, as indicated with the following: *“not sure – I can see both sides – if there were different terms it could better describe the loss, but it may also make it seem that certain losses are less painful than others.”* No difference was noted in distribution of responses between

parents and professionals ( $p = .70$ , Freeman-Halton extension of Fisher's exact test; Freeman & Halton, 1951).

### **No term**

Participants were also directly asked: *Do you think the establishment of a term is needed to describe a person/s who experienced perinatal loss?* Responses were less divided: 19 (65.5%) agreed that establishment of a term is needed. One individual commented, *"we are a community of people without a set name. It's awkward enough to have to describe who we are. A term makes it more socially acceptable . . . It eases the listener into a painful answer . . . It also bonds those of us together who have a shared experience."* Alternatively, 5 (17.2%) participants reported in the negative: *"No, why complicate things."* Lastly, 5 (17.2%) responded in an unsure or ambivalent way, *"there are many terms describing persons who have lost pregnancies and infants now. Do I think that we need a specific term, not necessarily but it might be meaningful to some."* No difference was noted in the distribution of responses between parents and professionals ( $p = .19$ , Freeman-Halton extension of Fisher's exact test; Freeman & Halton, 1951).

### **Discussion**

The meaning a person attributes to a loss plays a critical determinant for his or her psychological response (Hutti et al., 2017). And, language plays an important role in this process (Rosenblatt, 2016). This pilot study utilized Delphi methodology with a panel of parent and professional experts as a first step in understanding and addressing the profound absence of a term in our society for parents who have experienced the death of a child, specifically during the perinatal period. This has been seen both through variant use of language by professionals (e.g., terminology in scholarly writing; Table 1) as well as within the results of the present study (e.g., participants' reports of a perceived absence of unique term(s) for individuals who experienced perinatal loss; Table 3).

The pilot study demonstrated feasibility and a need for continued efforts toward term development. Responses in the present study suggested a perceived benefit for a shared, common term being developed to connect to the identity of bereaved parents from a perinatal loss. This affirmative stance supports the framework of disenfranchised grief for perinatal loss (Doka, 1989). Round 1 themes suggest that an established term could validate and legitimize the loss in a way that is not presently done. Validation could occur both on a personal level for the parent as well as increase society's means of being able to appropriately acknowledge the legitimacy of the loss. Following three rounds the term *bereaved parent* was selected.

While this study has demonstrated potential benefits of a common term, these benefits must also be weighed with the lack of majority agreement. That is, the term *bereaved parent* was selected with 45.2% of participants ranking it as their first choice. This should be understood adjacent to the responses of participants responding in favor of ‘different terms for different losses’ and those questioning if any term should be established. Therefore, the fact that majority agreement could not be reached may in fact be representative of the experience of grieving perinatal loss and is important in understanding assessment needs in the follow-up study.

### **Limitations and future research**

The decision to conduct a pilot study prior to embarking on the main research project can be difficult, but we recognized it as a necessary first step in uncovering unforeseen difficulties in the assessment and development of a term for perinatal loss (Hassan et al., 2006). Given the project’s time commitment (i.e., three rounds conducted over 6 months), there was a higher than typical attrition rate. And, because demographic variables were not collected at each round it is unknown who remained in the survey across time. Participants were not required to complete the previous round(s) to answer a survey; thus, we are unable to assess selective participant characteristics vulnerable to attrition. The next study will make efforts to minimize the number of rounds to collect data and record demographic information throughout to be able to have a deeper understanding of the participant pool over time.

An additional limitation of the present study was the small and homogenous nature of the sample. A more heterogeneous sample in terms of gestational stages/types of loss, gender, race, ethnicity, and religion will allow for a deeper clinical understanding of beliefs and values as it relates to terminology. Additionally, recruitment of parents not involved in the perinatal loss community will further aid in the understanding of fit of a term with parents of varied experiences. Lastly, a larger sample in which meaningful within-groups comparisons can be made will better allow us to understand what or who accounts for variability in perspectives which may be clinically meaningful.

### **Conclusion**

Following a perinatal loss, providers must explore the unique meanings each person attributes to the experience and how this impacts his or her thoughts, feelings, and behaviors (Markin, 2017). To this end, while we recognize the strengths in the methodology employed in this pilot study to gather the perspective from parent and professional experts in perinatal loss we must also balance this with recommendations in perinatal bereavement care to make a careful assessment of each person’s perceptions of the loss. As such,

we recognize the need to continue to assess the benefit of term development for perinatal loss and work toward appropriate term development. That is, while our methodological aim was to achieve majority agreement, the term *bereaved parent* was selected with only 45.2% of participants ranking it as their first choice. We understand the publication of this pilot study, while beneficial, is unlikely to produce many practical benefits; thus, we see this study as a first step in term development. The next study will be used to assess the fit and benefit of having this term developed for diverse individuals who experienced perinatal loss. The evaluation will also focus on within-group differences as it relates to important demographic characteristics (gender, ethnicity, and race, and individuals who experience perinatal loss at various gestational stages) to see how fit may differ between groups.

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## ORCID

Rachel Diamond  <http://orcid.org/0000-0003-2560-6052>

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