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Professional Support Desired by Men and Women Following a Perinatal Loss

THESIS

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by

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ABSTRACT OF THE THESIS

Professional Support Desired by Men and Women Following a Perinatal Loss

By

Holly Mueller

Master of Science in Genetic Counseling

University of California, Irvine, 2017

Professor Virginia Kimonis, MD, MRCP, Chair

This study was designed to determine what professional support is desired by men and women following perinatal loss. Perinatal loss is common and can have devastating emotional effects. Social and professional support can lead to improved healthcare outcomes, but is not always readily offered or accepted. The purpose of this study was to assess coping styles of individuals after perinatal loss, the type of professional support thought to be most beneficial, and how this support should be offered.

Individuals who have experienced perinatal loss (151 women and 15 men) responded to an online survey. Results showed that women were significantly more likely than men to receive multiple and varied types of support. Of those individuals that did not receive professional support, a majority cited that they either preferred to deal with the loss privately or that they received all needed support socially, however a significant portion (n = 13, 17%) were not aware that such support exists. In-person support groups and individual therapy were reported to be the most helpful forms of professional support following a perinatal loss and a majority of individuals prefer to be informed of services by a medical professional within thirty days following perinatal loss.

How individuals cope following perinatal loss is variable and there is no one form of support that will fulfill all needs. It is crucial to offer access to multiple options to help couples through this potentially devastating experience. Medical professionals, including genetic counselors, should supply information for professional support when appropriate.

I. INTRODUCTION

1.1 Overview of perinatal loss

Perinatal loss – whether a miscarriage, stillbirth, or neonatal death – is unfortunately a common experience for both men and women and can have devastating emotional effects on couples (Huffman, Schwartz & Swanson 2014). Both social and professional support can lead to improved healthcare outcomes for couples, but professional support is not always readily offered and/or accepted. The purpose of this study is to assess coping styles of men and women in the event of a perinatal loss, the type of professional support that is thought to be most beneficial dependent on coping style and gender, and when/how this support should be offered.

1.1.1 Considerations for this study

The terms "fathers", "mothers" and "parents" are used throughout the introduction to refer to individuals who have experienced a perinatal loss. This terminology was chosen because results of previous research has shown that this is how a majority of this population referred to themselves (O,Leary & Thorwick 2005).

1.1.2 Definition of perinatal loss

Perinatal loss includes intrauterine fetal death that is early (<20 completed weeks of gestation), intermediate (20-27 weeks gestation), and late (>28 weeks gestation) and also includes neonatal death through 28 days after birth. These events are fairly common with approximately one in four women experiencing pregnancy loss at some point in their lives (Hamama-Raz, Hemmendinger, & Buchbinder, 2010). Further, approximately 12% to 31% of all

conceptions end spontaneously in an early or late fetal death (Hutti 2004), and about 30,000 babies are stillborn in the United States each year (Cacciatore, DeFrain, Jones & Jones 2008).

1.2 Grief following perinatal loss

The widespread view in both medical and non-medical communities used to be that the trauma of the loss is not considered significant, however grief following perinatal loss has gained recognition (Conway & Russel 2000). It has historically been assumed that grief related to perinatal loss was minimal due to the lack of concrete experience with the pregnancy and could be solved by a healthy subsequent pregnancy (Conway & Russel 2000). As more research has focused on the effects of perinatal loss, society's view has gradually changed to acknowledge the gravity of the emotional effects associated with perinatal loss. Studies have shown that the intensity of grief following pregnancy loss can be significant and traumatic, last for months to years, and extend into subsequent pregnancies (Hutti 2004). According to a study done by Kersting and Wagner in 2012, grief related to perinatal loss declines over a period of two years and is associated with higher incidence of psychological morbidity including post-traumatic stress, depression, anxiety and sleeping disorders (Kersting & Wagner 2012). Further, during pregnancies following a perinatal loss, there is an association with increased parental anxiety. When these couples become pregnant again, they may continue mourning the loss of the previous pregnancy while simultaneously attempting to develop bonds of attachment with their new unborn infant (Armstrong & Hutti 1998).

Grief related to perinatal loss is somewhat unique compared with other forms of trauma-related grief for many reasons. First, this grief can be associated with a combination of feelings including guilt, self-blame, confusion of identity, and "child envy" (Kersting & Wagner 2012,

Hutti 2004) with "child envy" being defined as the feeling of being envious of other people's children. Especially in the absence of living children, a perinatal loss may affect a couple's status as "parents," because there are no tangible signs of parenthood to affirm their assumed roles (Cacciatore, DeFrain & Jones 2008). There is an unnaturalness of the loss, and the couple may feel that they have failed as protectors and future parents (Cacciatore 2008). For women, there can also be a sense of biological failure or loss of femininity, because child bearing is supposed to be a natural, feminine occurrence.

Parents who have experienced a perinatal loss have few or no direct life experiences with the infant and there is a lack of shared memories of the baby with individuals other than the parents, leading to minimization of the trauma by society (Kersting & Wagner 2012, Hutti 2004). There will not usually be any funeral or other ritual of mourning, and the loss will often not be recognized by the family and friends of the parents (Kersting & Wagner 2012) leading to ambiguity regarding this family member's presence or absence in the family (Cacciatore, DeFrain & Jones 2008). Many individuals outside of the experience assume that the associated grief can be resolved by a healthy future pregnancy, and may suggest getting pregnant again as a solution not recognizing that the unique and increased anxiety parents often experience during a subsequent pregnancy can be overwhelming in itself (Armstrong & Hutti 1998). The parents are dealing with the loss of an idea of what their family could have looked like rather than the loss of something tangible. This loss is associated with a multitude of secondary losses including the loss of hopes and dreams related to parenting, the loss of the experience of raising a child, and the loss of one's sense of safety in the world (Wing, Burge-Callaway, Clance & Armistead 2001).

The difficulties and uniqueness associated with coping with this loss can lead to the affected mother and father feeling isolated from their communities and often each other. Community support may be lacking for a variety of reasons, including that grief related to perinatal loss is not well understood by society and pregnancy loss is not often openly discussed (Conway & Russell 2000). Many men and women end up not disclosing the perinatal loss to anyone other than their partner due to their sense of the community's inability to understand their grief (Conway & Russell 2000). Friends and family may not recognize the full extent of the loss because although the baby may be physically absent, for many bereaved parents there is still a psychological presence that continues in ways that may not be apparent to other individuals (Cacciatore, DeFrain & Jones 2008). The experiences that the parents have had related to the pregnancy are extremely intimate and typically not recognized by individuals outside of the relationship. This can cause the grieving parents to cope alone, sometimes even separately from each other. There is a need for the family to recognize the loss, to adjust to their new roles however they choose to define them, and to overcome communication issues (Cacciatore, DeFrain, Jones & Jones 2008).

Although parental grief associated with perinatal loss is profound regardless of the number of years since the loss, the gestational age, or the cause of the loss (Avelin, Radestad, Saflund, Wredling & Erlandsson 2013), several factors can negatively or positively affect how a couple may cope with the experience. Social support from friends, family and religious communities has been consistently associated with less resulting grief (Kersting & Wagner 2012) and a supportive social environment is key in facilitating healing after a loss (Cacciatore, DeFrain & Jones 2008). Similarly, lack of support from a partner and poor marital relations have been associated with more intense grief (Huffman, Schwartz, & Swanson 2014, Cacciatore,

DeFrain & Jones 2008). One study found that the most important predictor of maternal anxiety and depression after stillbirth was the level of support from her partner and family (Cacciatore, DeFrain & Jones 2008). Another important factor is presence or absence of living children. Families without children who suffer a pregnancy loss have significantly higher levels of grief than families who already have children (Kersting & Wagner 2012). Contrary to what one might assume, several studies have evaluated the association between gestational age and level of distress after perinatal loss, and did not find an increase in psychological distress with later gestational age (Kersting & Wagner 2012). Therefore, parents who experience a perinatal loss at any stage of pregnancy may develop similar grief symptoms, indicating the importance of support spanning losses of all gestational ages.

1.2.1 Gender specific coping and grief responses following a perinatal loss

Bereaved mothers and fathers tend to have different grieving styles, assumed roles and emotional expressions of loss, which can lead to conflict over coping styles and other matters during an already emotionally charged time (Avelin, Radestad, Saflund, Wredling & Erlandsson 2013). The effects of perinatal loss on women have been studied extensively while the effects of perinatal loss on men are not as well-understood (Moore, Parrish & Black 2011). The effects of a pregnancy loss on fathers have been "largely overlooked in academic research", thus posing important questions for future research (McCreight 2004). A number of quantitative studies have compared grief responses of fathers and mothers after perinatal loss, although many of these studies have been limited by sample size of males. Although the results have been somewhat contradictory, overall the findings support the idea that fathers experience grief after perinatal loss, but these reactions are generally less intense than mothers' reactions (Kersting and Wagner

2012). A study by Goldbach, Dunn, Toedter, and Lasker (1991) found that both mothers and fathers experienced high levels of despair, active grief, and difficulty coping, yet the mothers experienced significantly higher measures during the first six to eight weeks following the baby's death. It is important to note, however, that a majority of the previous studies comparing men and women used measures based on women's reported experience, and therefore may not fully index the male experience (Huffman, Schwartz & Swanson 2014). A study by Puddifoot and Johnson in 1999 found that men scored similarly to women in overall grief, but men displayed less active grief, more despair, and more difficulty coping. Perinatal losses are more often seen as private, "minor" events in a woman's life (Conway & Russell 2000) rather than a traumatic event that influences both men and women. One theory that has been proposed by multiple studies predicts that while the emotions felt by men and women following a perinatal loss are comparable, the differences arise from the social, institutional and familial structuring of the male experiences (McCreight 2004). Men are thought to suppress their feelings of sadness, anger, and loss so as to not upset their partners (Hutti 2004). According to McCreight (2004), in accordance with previous research, men set aside their own grief and emotional needs in order to support their partner following a perinatal loss. In addition, coping mechanisms of men differ from those of women. There are definitive differences between maternal and paternal grieving styles, roles, and emotional expressions of loss directed towards others (Cacciatore, DeFrain, Jones & Jones 2008). For example, fathers typically react with anger while mothers experience more guilt. Mothers typically experience higher levels and more enduring depression, yearning, anxiety, guilt, shame and trauma symptomatology, and tend to have a greater need to talk about the loss (Cacciatore et al 2008). There are several possible explanations that may contribute to gender differences in grieving. The differences may be due to differences between mothers' and

fathers' attachment to the developing infant, differences by gender in reaction to stress, differences in gender-role socialization involving emotional expressiveness and willingness to acknowledge and report emotions, differences influenced by different methods of coping among men and women, and finally the differences of identity configurations and different social environments that women and men experience after the loss (Moore, Parrish & Black 2011). In addition, the way a father bonds with his unborn baby may be different, and may incorporate dreams about the future child rather than a newborn. A study by Martin and Doka in 2000 identified two expressions of grief: intuitive and instrumental. Intuitive is a more feminine style of grief communication that focuses on seeking social support, narration, and open expression, while instrumental is a more masculine style of grief communication that involves cognitive processes, refocusing of grief on tasks and activities, and is more often solitary, structured, and bounded (Zinner 2000). It should be mentioned that a more feminine style of grieving may be the primary mode of expression for some fathers, and a more masculine form of grieving for some mothers (Cacciatore, DeFrain & Jones 2008).

Coping styles of men and women also tend to be different following a trauma. In previous studies comparing the coping styles of men and women following a miscarriage, women reported that emotional support was used significantly more frequently than men, but no differences were found for the use of positive reframing, self-blame or venting (Kelly, Tyrka, Price & Carpenter 2008). They also predict that lower levels of positive reframing and higher levels of self-blame may be a risk factor for the development and experience of negative affect and may contribute to a higher prevalence of depression and anxiety (Kelly, Tyrka, Price & Carpenter 2008). Although these are the stereotypical representations of grief and coping mechanisms according to gender, every individual will have a unique response dependent on

their specific personality, past experience, and biology. Not all men or women will follow what are thought of as masculine or feminine grief patterns respectively, but the overall trends can be used to explain population patterns. It is thought that these differences in coping style may lead to misunderstandings and conflicts between bereaved mothers and fathers and contribute to further pain and isolation (Wing, Burge-Callaway, Clance & Armistead 2001).

It has been said that 'the person who is most often forgotten in a family bereaved by a miscarriage is the father' (Wilkinson, 1987, pg.30). Men have consistently reported that they frequently felt their loss had been devalued by the wider community (McCreight 2004), and the focus is mainly placed on the women. Traditionally, fathers' feelings related to a perinatal loss are rarely given much consideration because there is an assumption that a father's bond to an unborn child is less than a mother's bond (Conway & Russell 2000). Symptoms of grief in men were found to be similar to those of women, except that men report less crying and feel less need to discuss their loss. Men were found to internalize and deny their grief, or attempt to distract themselves. Men have reported feelings of helplessness in how to help their partner and the need to be strong and suppress their own feelings (McCreight 2004, Huffman, Schwartz & Swanson 2015). Men's grief may be overlooked as a consequence of social expectations of how a man should act, and as a result, they may lose focus on coping with their own grief (Moore et al 2011). Although men may not outwardly show grief, the pressures created by mourning are significant, especially if they do not have the opportunity to openly grieve (O'Leary & Thorwick 2005). Due to these pressures, men are more reluctant to seek support within a group setting and less likely to get emotional support outside of the marriage relationship (O'Leary & Thorwick 2005). These barriers are thought to make accepting and receiving help more difficult and leave fathers more at risk for developing chronic grief (O'Leary & Thorwick 2005), defined as

grieving that lasts for a prolonged period of time and is associated with feelings of hopelessness, loss of meaning or belief systems, and intense preoccupation and longing for a lost loved one or situation.

1.3 Professional support

Few studies exist that have examined and validated the types of support that are beneficial to couples after a perinatal loss (Moore, Parrish, & Black 2011). Support from family, friends and healthcare professionals is strongly associated with reduced distress and adaptation to problems following a perinatal loss (Wing, Burge-Callaway, Clance & Armistead 2001). Psychological services for bereaved parents following this experience are steadily increasing as perinatal losses are more openly talked about in society. Directly following the perinatal loss, there are early intervention practices that should be in place to guide parents through the grief process (Wing, Burge-Callaway, Clance & Armistead 2001). For example, after a stillbirth parents are encouraged to recognize the reality of their loss by holding or naming the baby and in certain circumstances by having a memorial or funeral service. For any loss, parents should be provided ongoing opportunities for discussions with medical professionals about the cause of death and the parents' feelings and concerns about the death. The family should be provided with multiple follow-up contacts, including some form of bereavement counseling for grieving family members. Medical professionals need to be aware of the psychological needs of newly bereaved parents and more research must be done on the helpfulness of early intervention services (Wing, Burge-Callaway, Clance & Armistead 2001), such as offering memorabilia related to the pregnancy, discussing professional support options, and meeting with a chaplain, if desired. Although these interventions are available, many couples still report significant

psychological morbidity several months after a perinatal loss. There is still a need for intervention research to determine the most appropriate type and timing of intervention (Conway & Russel 2000).

Support groups are a form of professional support in which persons with common experiences or concerns provide each other with encouragement, comfort and advice. Couples may find it helpful to converse with someone who understands what they are going through. It has been shown that women are more likely than men to need to validate their loss through sharing in discussions with others, although not all individuals will benefit from the support group environment (Moore, Parrish & Black 2011). It is unclear whether men and women seek out and benefit from the same support mechanisms. In one study, fathers clearly saw the value and the need for support but struggled with how this should be provided and many fathers perceived support groups as mostly "just for the mothers" (O'Leary & Thorwick 2005). While it is difficult to draw confident conclusions on the effectiveness of support groups for people seeking help with grief-related issues, support groups can serve as a rite of passage and cushioning following the loss (Cote-Arsenault & O'Leary). Some individuals may prefer other forms of professional support including, but not limited to, individual therapy, online forums, social media, online support groups, or religious support. Not all individuals will desire support, and some forms of support may be viewed as more helpful to some than others. Developing strategies to assess and support the emotional needs of fathers will guide more appropriate interventions (O'Leary & Thorwick 2011). By determining what support men and women would find helpful following a perinatal loss and when to offer this support, the appropriate resources can be offered to guide these couples through this potentially devastating experience.

1.4 Significance of this study

There is no definitive answer for how to cope with perinatal loss, but determining ways to identify who would benefit and from what type of support they would benefit from could help individuals through the difficult grieving process following a perinatal loss. The death of a baby, regardless of the stage in pregnancy, "affects everything from the definition of parenthood to parenting styles with living children, from the sense of self as sexual beings to the view of what it means to have a career" (Cacciatore, DeFrain, Jones & Jones 2008). The purpose of this study is to determine the coping styles of men and women, the type of support that would be most beneficial, and when and how this support should be offered following the event of a perinatal loss.

1.5 Statement of hypotheses

The tested hypotheses included but were not limited to that gender, stage of pregnancy, and coping styles would predict whether or not professional support was received, that men and individuals who experienced earlier perinatal losses would be less likely to have been aware that professional support was available, and that individuals who received professional support would have perceived it as being beneficial.

II. MATERIALS AND METHODS

This study was evaluated and classified as exempt research by the Institutional Review Board of the University of California, Irvine (HS# 2016-3232)(Appendix D).

2.1 Recruitment

Participants were recruited to take part in an anonymous web-based survey that was created on SurveyMonkey, a free, online survey development company. No researcher had any direct contact with the participants. Social media posts and email were used to solicit participation and enrollment was through online and in-person support groups, specialty clinics, and social media (Facebook). An electronic flier with information regarding the survey, contact information for the researchers, as well as the direct link to the survey was generated for distribution through NSGC's email lists. The social media post, email content, and electronic flier are available for review in Appendix C.

2.2 Participants

The participant population included individuals, 18 years or older, who have experienced a perinatal loss in their lifetime. This includes men and women who have experienced a miscarriage, stillbirth, or postnatal loss up to 28 days after birth. The survey was only available in English, and therefore the participants were required to read and understand English. All other population characteristics were accepted. There was no discrimination based on gender, race/ethnicity, age or education level.

2.2.1 Protection of participants' privacy

There was no collection of patient identifying information for this research. There was no direct contact between the researchers and the participants nor were there any known harms or discomfort associated with the study aside from potentially feeling upset while recalling events related to the perinatal loss. All research data was stored confidentially and securely on a password protected computer and through a password protected account on SurveyMonkey.com.

2.3 Informed consent

Informed unwritten consent was obtained via the use of an IRB-approved study information page that served as the initial page of the online survey. By clicking "Next", the survey participant gave informed consent as a research participant. The information page included the purpose of the study, general background on perinatal loss, eligibility requirements, and the research team's contact information. The participant had the opportunity to exit the survey at any time.

2.4 Survey

The questionnaire was created using SurveyMonkey.com and the direct link to the survey was http://www.surveymonkey.com/ProfessionalSupportDesiredbyMenandWomenFollowingaPerinatalLoss. The survey can be viewed in Appendix A. The survey consisted of 24 previously validated questions from the Brief COPE Inventory, 24 multiple choice questions, and 3 free response questions. The inventory COPE (Carver, Scheier, & Weintraub 1989) is a previously validated measure of coping strategies. It includes 14 subscales including mental disengagement, active coping, denial, substance use, and acceptance along with two broader subscales including

maladaptive and adaptive coping strategies. Due to the extensive length of this inventory, a shorter version called the Brief COPE was developed (Carver 1997) and was used in the current study to assess the coping strategies of men and women. The total time to complete the survey was about 10-15 minutes. The major themes addressed were 1) characteristics of individuals that received professional support, 2) barriers to professional support, 3) characteristics of the type of received professional support, and 4) what type of professional support would be preferred. The survey relied on skip logic technology in order to route the participants to specific questions based on their answers so as not to ask them questions that did not apply to them. Some of the questions were adapted from the previously validated Brief COPE Inventory and other questions were developed and edited by the research team. At the conclusion of the survey, participants were directed to a page that included information for resources related to perinatal loss. This page can be viewed in Appendix B.

2.4.1 Survey scoring

The 24-item Brief COPE survey was scored according to pre-validated measures distinguishing maladaptive and adaptive coping strategies. Questions 1, 3, 4, 6, 8, 10, 14 and 17 of the Brief COPE survey are associated with use of maladaptive coping strategies and questions 2, 5, 7, 9, 11, 12, 13, 15, 16, 18, 19, 20, 21, 22, 23 and 24 are associated with use of adaptive coping strategies. The medians of each group were calculated and individuals whose calculated score was at or below the median qualified as not using maladaptive/adaptive coping strategies respectively and individuals who scored above the median qualified as using maladaptive/adaptive coping strategies respectively. The calculated median for maladaptive coping strategies was 14 points and for adaptive coping strategies the median was 38 points.

A question asking what form of professional support respondents participated in following the perinatal loss gave the following options: books, in-person support groups, individual therapy, online forums, social media, and support from religion/spiritual beliefs. Participants could respond with one or multiple answers. For analysis, the answers were grouped in various different ways to assess overall trends. First, the responses in-person support group and individual therapy were grouped as in-person professional support and the responses books, social media, and online forums were grouped as other professional support. Second, the answers were grouped into whether the individual chose one professional support option, two professional support options, or three or more professional support options.

Perceived helpfulness of received professional support was scored on a 5 point scale: 1=strongly agree; 2=agree; 3=neutral, 4=disagree; 5=strongly disagree. The higher the individuals score the less helpful they perceived their received professional support to be. Participants' opinions on whether or not professional support would have been helpful following the perinatal loss retrospectively was also scored on the same 5 point scale: 1=strongly agree; 2=agree; 3=neutral; 4=disagree; 5=strongly disagree. The higher the score the less helpful that individual believed professional support would have been following the perinatal loss.

The following question was scored on a 4 point scale: "Please mark how likely the following statement is: If I were aware that professional support was available at the time of the perinatal loss, I would have participated". The scale is scored as follows: 1=very likely; 2=somewhat likely; 3=not very likely; 4=not at all likely. The higher the score, the more likely that individual would have been to receive professional support had they been aware of the option following a perinatal loss.

The survey included three free response questions that were each individually coded. All

responses are available in Appendix E, F, and H. Following a question asking what professional support was received following the most recent perinatal loss, the participants were asked "What about this support did you find to be helpful?". The lead researcher compared responses and answers were grouped into different themes including: not feeling alone, receiving advice on spousal support, talking about feelings, receiving support from others who understand, receiving religious support, gaining perspective, learning about resources, and normalizing feelings. Each response could have one or multiple themes. The second question asked "What about this support did you not find to be helpful?". Only three individuals responded to this question and therefore the answers were not grouped into themes and these results were not used to make any conclusions. Individuals were asked what professional support option would be the most helpful following a perinatal loss. Following this question, participants were asked to answer a free response question that asked "Why do you believe this option would be most helpful". The answers to this question were grouped into themes including: to seek answers for why it happened, to not feel alone, to hear and share experiences with others who understand, to receive knowledge from professionals, to grow in faith, to maintain privacy, for benefits of an online community (i.e. large numbers, anonymity). The answers to the free response questions were used in analysis as well asto provide context for other statistically significant comparisons. Quotes from responses to all three free-response questions were used as supporting evidence in the conclusion.

Question 23 asked what form of professional support would be most helpful following a perinatal loss with the options: in-person support group, individual therapy, online forums, social media, support from medical staff, support from religion/spiritual beliefs, none, and other (please specify). Any individual that chose other (please specify) were asked to elaborate in a free-

response format with all responses available in Appendix G. If the free response answer mentioned a specific support resource that was one of the given, the answer was counted for that category. For analysis, the answers were grouped in a post-hoc fashion to assess trends. Specifically, in-person support group and individual therapy remained separate while all other categories were combined.

2.5 Statistical analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) Version 23 (IBM Corp 2014) and the Statistical Analysis System (SAS) (SAS Institute Inc 2011). This is a descriptive study of professional support desired by men and women following a perinatal loss based on gender and coping strategy. Prior to analysis, several new variables were created. Brief COPE maladaptive and adaptive scores were created by summing the scores of the questions associated with maladaptive/adaptive coping strategies respectively. The median of each of these groups was calculated and participants were quantified as using maladaptive/adaptive coping strategies if their summed score was above the calculated median.

Chi-square analysis was used to test for association between nominal (categorical) variables. If expected counts were fewer than 5 after grouping, a Fisher's exact test was performed for contingency table analysis. 2-tailed tests were used for all analysis and p-values of less than 0.05 were considered statistically significant. Survey analysis of the Brief COPE raw scores was performed using independent samples T-tests to determine if there was a statistically significant difference in the mean value between two groups, using a significance level of $p<0.05$. No correction was made for multiple comparisons.

III. RESULTS

3.1 Sample characteristics and demographic information

A total of 166 study respondents took the survey. Of the 166 eligible respondents, 152 completed the entire survey. Females represented 91% of respondents and males 9%. Further, 94% of individuals were married while 6% were single. The majority of respondents, 91%, reported Caucasian ancestry, 2% African American, 1% Hispanic, 2% Asian etc. as noted in Table 1. Age groups were divided as follows: 12% were 21-29, 57% were 30-39, 24% were 40-49, 4% were 50-59, 4% were over the age of 60. The majority of individuals, 41%, reported recruitment to the study by Facebook or another social media site, 31% by a friend or family member, 12% by NSGC listserv, 10% by a member of a support group, and 7% by a medical professional.

Individuals were asked about how many perinatal losses they have experienced with the options being one perinatal loss (57%), two perinatal losses (25%), three perinatal losses (13%), and four or more perinatal losses (5%) (Figure 1). This data is also present in Table 2. Participants were also asked at what stage of pregnancy the perinatal loss occurred and how much time has passed since the most recent perinatal loss (Table 2). Participants were asked to report what stage of pregnancy the perinatal loss occurred: 64% of participants reported a first trimester loss, 21% reported a second trimester loss, 8% reported a third trimester loss, and 7% reported a loss after birth. Lastly, 11% of participants reported less than six months since the most recent perinatal loss, 9% reported less than one year, 32% reported one to three years, 49% reported more than 3 years.

TABLE 1: CHARACTERISTICS OF 166 ENROLLED RESPONDENTS	Total	
	N	%
Age (years)		
21 to 29	20	12
30 to 39	95	57
40 to 49	39	24
50 to 59	6	4
60 or older	6	4
Gender		
Female	151	91
Male	15	9
Level of education		
Less than high school degree	0	0
High school graduate or equivalent (e.g., GED)	5	3
Some college, no degree	14	8
Associate degree	13	8
Bachelor degree	60	36
Graduate/professional degree or equivalent	74	45
Relationship status		
Married	155	94
Widowed	0	0
Divorced	2	1
In a domestic partnership or civil union	2	1
Single, but cohabitating with a significant other	2	1
Single, never married	5	3
Ethnicity/race		
Caucasian	151	91
Black or African American	3	2
Hispanic	1	1
Asian	4	2
Native Hawaiian or Pacific Islander	0	0
Native Indian or Native Alaskan	0	0
Other	4	2
No answer	3	2
Religion		
No religion	53	32
Christianity	105	63
Jewish	5	3
Spiritual	2	1
Other	1	1
Recruitment source		
By a friend/family member	51	31
By a medical professional	11	7
By a member of a support group	16	10
By Facebook or another social media site	68	41
NSGC listserv	20	12

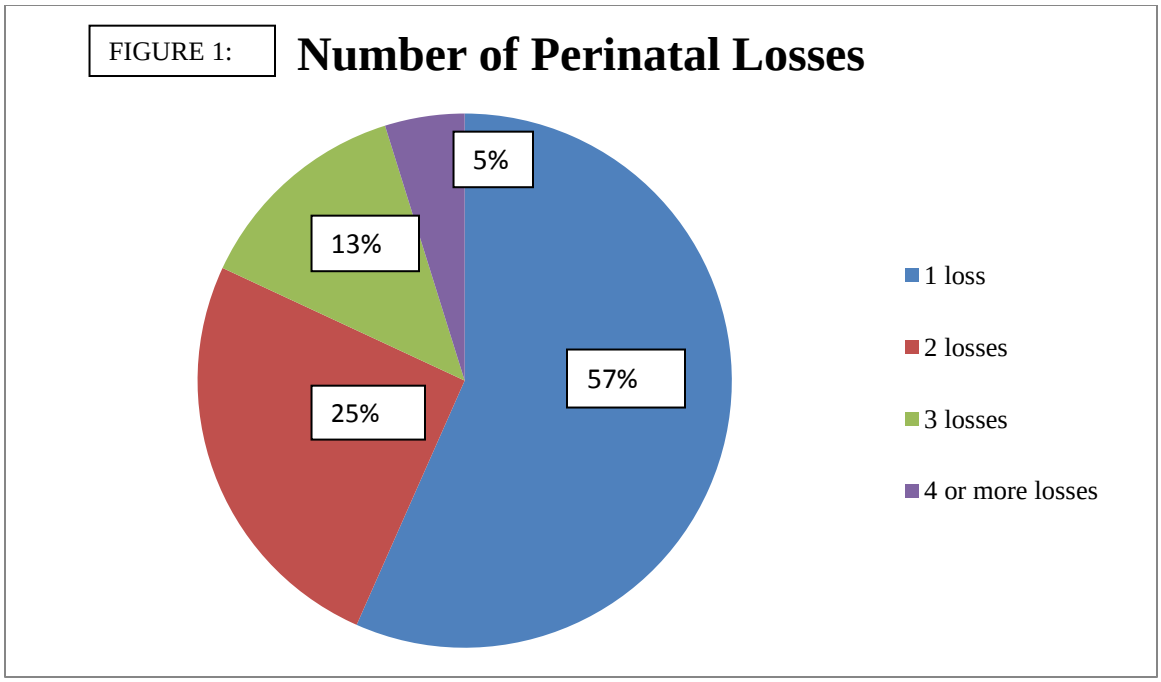

Figure 1 shows the 166 respondents' number of experienced perinatal losses.

TABLE 2: STAGE OF PREGNANCY AND TIME PASSED SINCE LOSS	Total	
	N	%
Number of perinatal losses		
One	94	57
Two	42	25
Three	22	13
Four or more	8	4
Stage of perinatal loss		
First trimester (0-12 weeks)	106	64
Second trimester (13-27 weeks)	35	21
Third trimester (28-40 weeks)	13	8
After birth	11	7
Time passed since perinatal loss		
Less than six months	18	11
Less than one year	14	9
One to three years	52	32
More than three years	81	49

Table 3A depicts the frequencies of maladaptive and adaptive coping strategies quantified from the 24 item Brief COPE survey. 48% of respondents' calculated sums were above the median for maladaptive coping strategies and 52% of respondents' calculated sums

were at or below the median. 46% of respondents' calculated sums were above the median for adaptive coping strategies and 54% of respondents' calculated sums were at or below the median.

Table 3B compares the use of maladaptive coping strategies with the use of adaptive coping strategies. The McNemar Test p-value was not significant (p= 0.826) indicating that the use of one coping strategy did not predict whether or not another coping strategy was used.

TABLE 3A: COPING STRATEGY		
	N	%
Maladaptive Coping Strategies		
Yes	74	48
No	79	52
Total	153	
Adaptive Coping Strategies		
Yes	71	46
No	82	54
Total	153	

TABLE 3B: MALADAPTIVE VERSUS ADAPTIVE COPING STRATEGY	Adaptive Coping Strategy		
	No	Yes	Total
Maladaptive coping strategy			
No	39	40	79
Yes	43	31	74

McNemar's test: p-value = 0.826.

3.2 Characteristics of individuals that received professional support

Individuals were asked if they received professional support following their most recent perinatal loss. It is important to note all answers are specific to the individual's most recent perinatal loss in the event that the participant has experienced more than one loss. A total of 78 respondents (51%) answered that they did not receive professional support following the perinatal loss, and 74 respondents (49%) answered that they did receive professional support.

Table 4 and Figure 2A show responses to the above question by gender and Table 5A and Figure 2B show the responses by stage of pregnancy of the perinatal loss. The Fisher's Exact Test for the cross-tabulation between gender and received support was not significant (p=1.00). The Fisher's Exact test of the cross-tabulation between stage of pregnancy and received support was significant (p=0.0098).

Table 5B and Figure 2C show the results of a cross-tabulation comparing the number of experienced perinatal losses to the number of individuals that received support. The chi-squared analysis of this comparison was not significant p= 0.232.

TABLE 4: GENDER VS WHETHER OR NOT SUPPORT WAS RECIEVED	Gender			
	M	(%)	F	%
Support received	7	47	67	49
Support not received	8	53	70	51
Total	15		152	

Fisher's Exact Test: p = 1.00

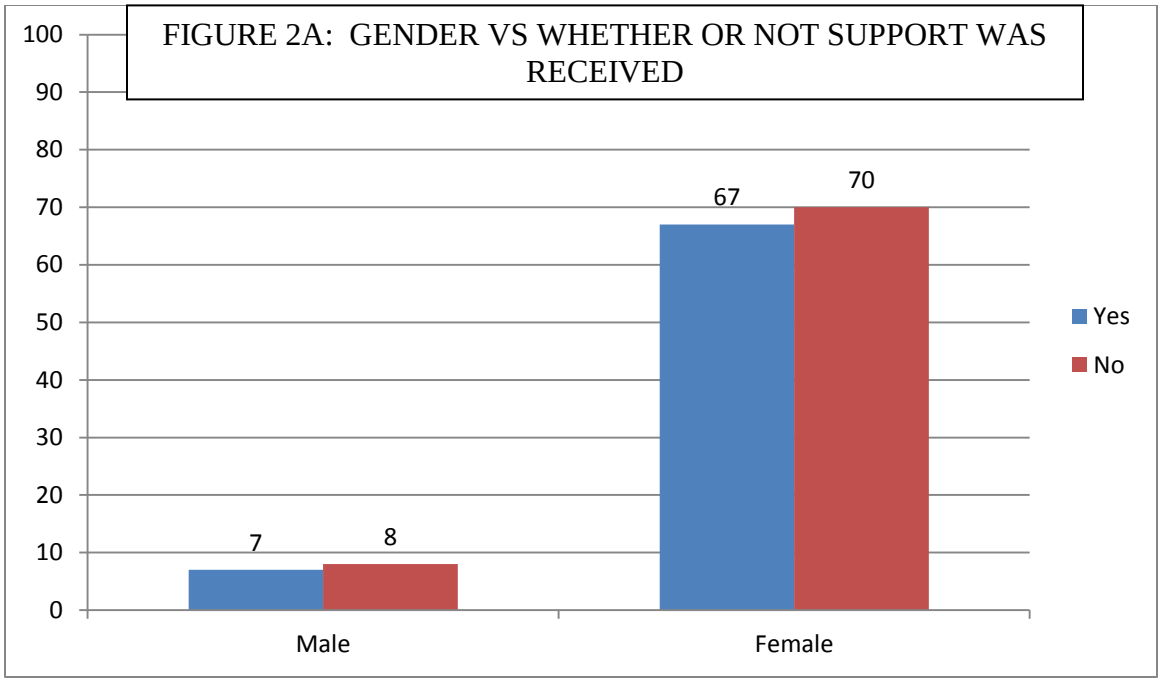

Figure 2A compares gender and whether or not professional support was received. 15 men and 137 women answered this question. The 2-sided Fisher's Exact Test p-value was 1.00 for this comparison.

TABLE 5A: STAGE OF PERINATAL LOSS VS WHETHER OR NOT SUPPORT WAS RECEIVED	Total	
	N	%
First trimester		
Yes	38	25
No	58	13
Second trimester		
Yes	20	21
No	14	8
Third trimester		
Yes	8	11
No	5	49
After birth		
Yes	8	11
No	1	49
Total	152	

Fisher's Exact Test: p = 0.0098.

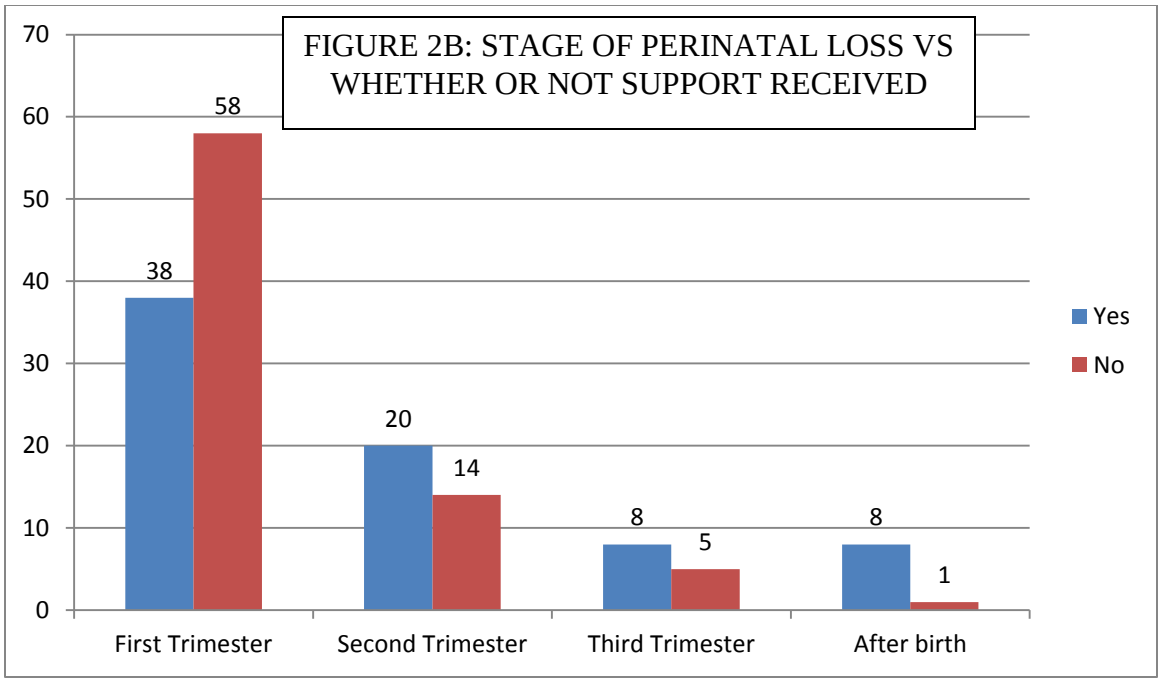

Figure 2B is a breakdown of how many participants received professional support following the perinatal loss distributed by gestational age of the perinatal loss. The p value was significant (p= 0.0098).

TABLE 5B: NUMBER OF EXPERIENCED PERINATAL LOSSES VS WHETHER OR NOT PROFESSIONAL SUPPORT WAS RECEIVED	Total	
	N	%
One loss		
Yes	36	43
No	48	57
Two losses		
Yes	24	58
No	17	41
Three losses		
Yes	9	45
No	11	55
Four or more losses		
Yes	5	71
No	2	29
Total	152	

Chi-squared: p = 0.232.

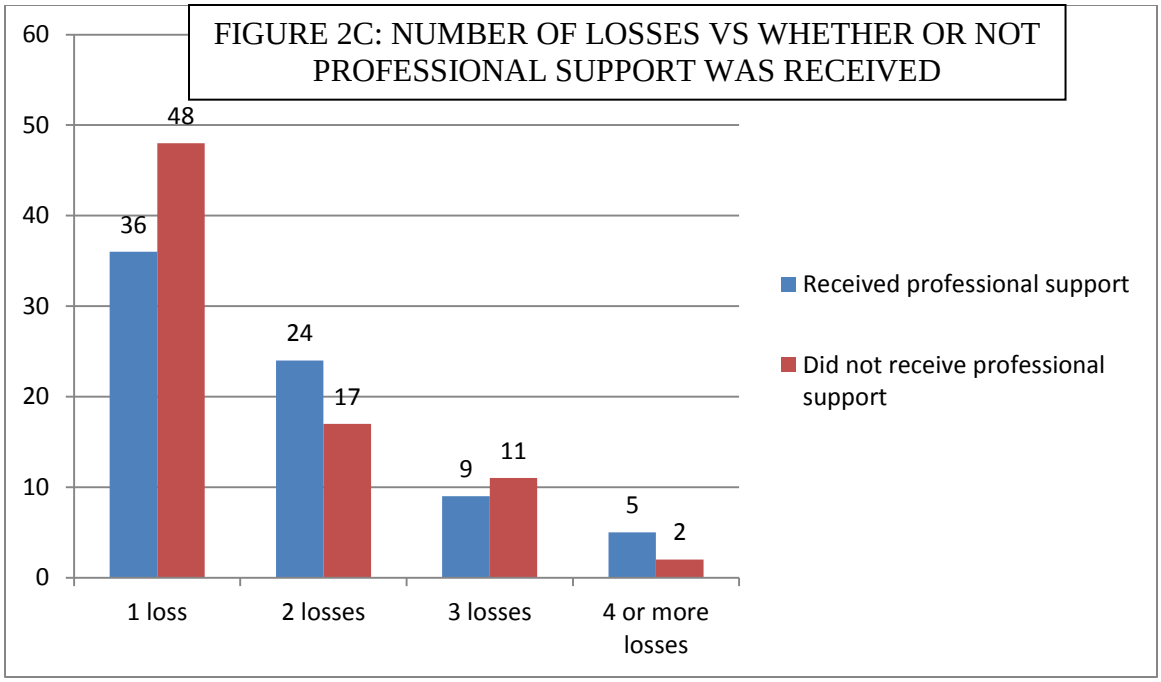

Figure 2C is a depiction of the comparison between the number of losses experienced by the participant versus whether or not professional support was received. 152 participants answered this question. The p-value was not significant (p= 0.248).

Figure 3A and 3B portray the raw data of the maladaptive and adaptive coping strategy scores from the Brief COPE. The mean of the maladaptive coping strategy scores was 37 and the mean of the adaptive coping strategies scores was 15. A lower score indicates use of a less maladaptive or adaptive coping strategy while a higher score indicates a more maladaptive or adaptive coping strategy respectively.

Table 6A is a cross-tabulation of coping strategy versus received support. Of individuals who were coded as having maladaptive coping strategies, 50% reported that they had received support following the perinatal loss and 50% did not. Of those individuals who qualified as having adaptive coping strategies, 60% reported receiving support and 39% reported that they did not. The Fisher's Exact Test was used to determine the statistical significance of the comparison of coping strategy with whether or not professional support was received. The p-value comparing maladaptive coping strategy with received professional support was not

significant at 0.871 and the p-value comparing adaptive coping strategy with received professional support was significant at 0.014.

Table 6B displays results of the independent samples t-test comparing coping strategy between the two groups based on whether or not professional support was received. For maladaptive coping score, there was no difference between the two groups (p= 0.925). For adaptive coping score there was a significant difference (p= 0.003).

Table 6C portrays the cross-tabulation of coping strategy and gender. 47% of males and 48% of males qualified as having maladaptive coping strategies and 20% of males and 49% of females qualified as having adaptive coping strategies. The Fisher's Exact Test p-value for the comparison of maladaptive coping strategies and gender was not significant at 1.00 and the p-value for the comparison between adaptive coping strategies and gender was significant at 0.053.

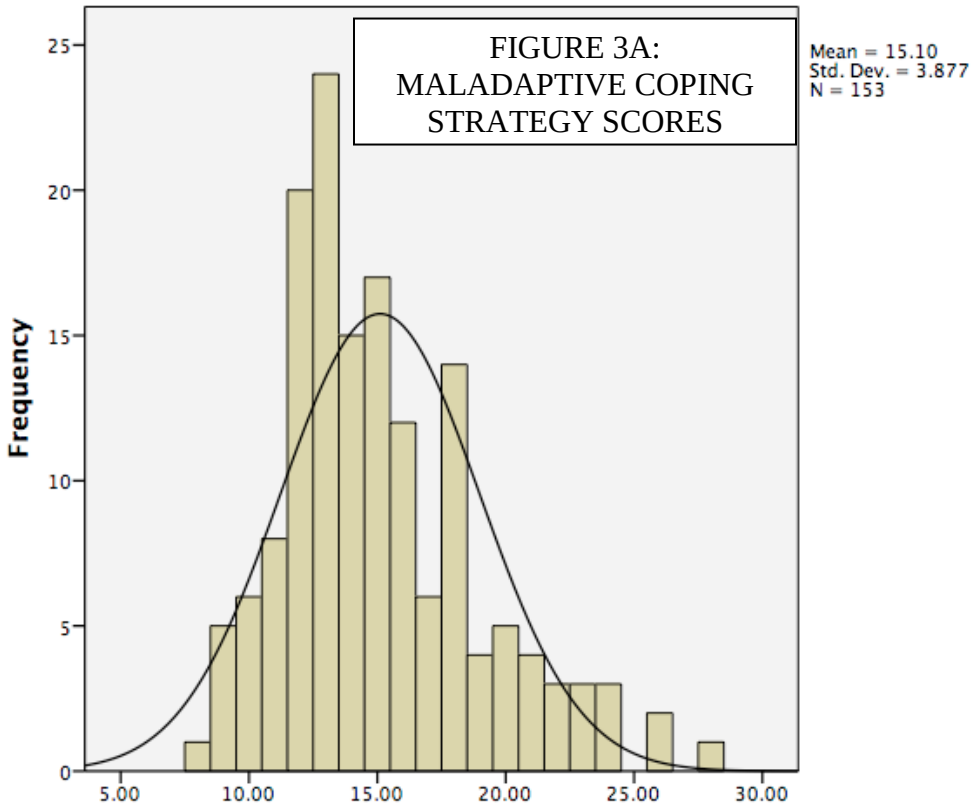

Figure 3A is a histogram of raw maladaptive scores pulled from the Brief COPE. The mean for maladaptive coping strategy scores was 15.

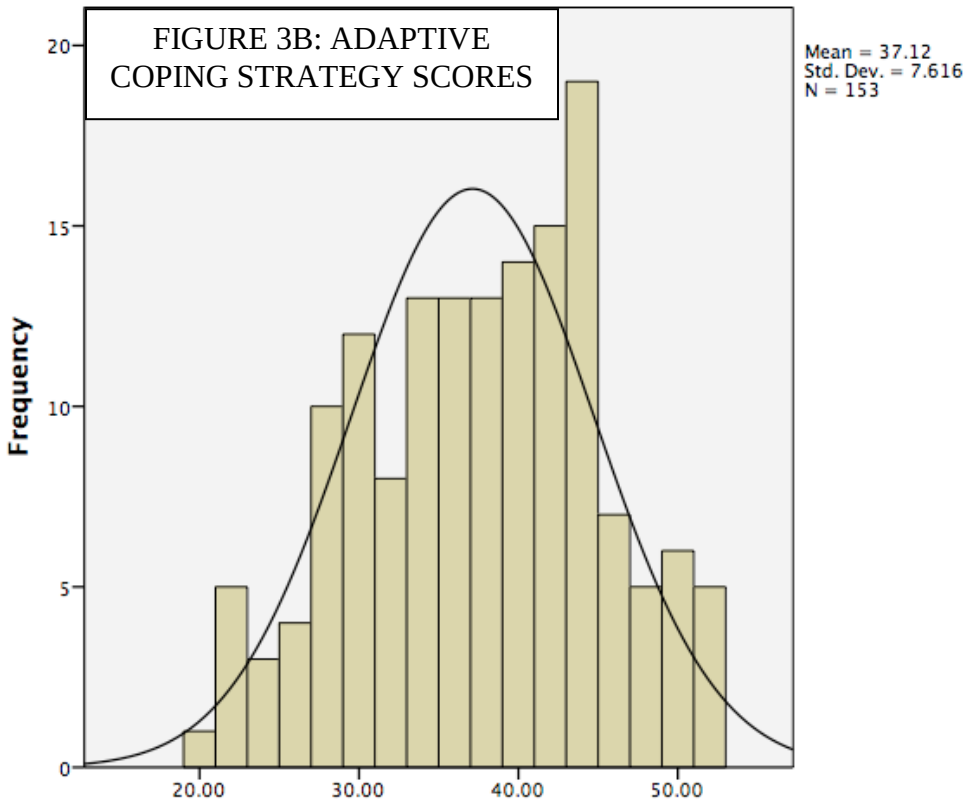

Figure 3B is a histogram of raw adaptive scores pulled from the Brief COPE. The mean for adaptive coping strategy scores was 37.

TABLE 6A: COPING STRATEGY VERSUS WHETHER OR NOT PROFESSIONAL SUPPORT RECEIVED	Received Support	
	No	Yes
Maladaptive coping strategy		
Not maladaptive	41	37
Maladaptive	37	37
Total	78	74
Adaptive coping strategy		
Not adaptive	50	32
Adaptive	28	42
Total	78	74

Fisher's Exact Test: p = 0.871, 0.014.

TABLE 6B: INDEPENDENT SAMPLES T-TEST OF COPING STRATEGY AND WHETHER OR NOT PROFESSIONAL SUPPORT WAS RECEIVED

	Whether or not professional support received						Mean Difference	95% CI for Mean Diff.		
	Yes			No						
	M	SD	n	M	SD	n			F(df)	*p*
Maladaptive Coping Strategy	15.2	3.3	74	15.1	4.3	78	.060	-1.2, 1.3	4.207 (150)	.925
Adaptive Coping Strategy	38.9	6.9	74	35.3	7.9	78	3.60	1.2, 6.0	2.272 (150)	**.003**

TABLE 6C: COPING STRATEGY VS GENDER	Gender			
	M	%	F	%
Maladaptive coping strategy				
Not maladaptive	8	53	71	51
Maladaptive	7	47	67	49
Total	15		138	
Adaptive coping strategy				
Not adaptive	12	80	70	51
Adaptive	3	20	67	49
Total	15		138	

Fisher's Exact Test: p = 1.00, 0.053.

3.3 Characteristics of received professional support

Table 7 is a breakdown of the answers to the question "What type of professional support did you receive? Check all that apply". The provided options were books, in-person support group, individual therapy, online forum, social media, support from my religion or spiritual beliefs, and other (please specify). 14% of males and 46% of females selected books, 57% of men and 43% of women selected in-person support groups, 57% of men and 49% selected individual therapy, 100% of males and 37% of females selected online forums, 0% of males and 34% of females selected social media, and 28% of males and 22% of females selected support from religion/spiritual beliefs. No males or females selected the other (please specify) option. A Fisher's Exact Test was used for the following comparisons. There was no significant difference

between males and females with whether they had used each given professional support option. The p-values were not significant at 0.131, 0.693, 1.00, 0.088, 0.091, and 0.661 respectively.

Table 8 and Figure 4A portray the answers from 7 males and 66 females to whether they received in-person support only (individual therapy or in-person support group), other professional support only (books, online forum, social media), or a combination of both. 6 males (86%) and 14 females (21%) selected in-person professional support only, 1 male (14%) and 18 females (27%) selected other professional support only, and 0 men (0%) and 34 women (52%) selected both. The Fisher's Exact Test p-value was significant (p= 0.00086).

Table 9 and Figure 4B portray results from 7 men and 67 women to how many forms of professional support were received. The majority of males (57%) reported receiving 2 forms of professional support while the majority of females (42%) reported receiving three or more. No males reported receiving three or more forms of support. The p-value of the Fisher's Exact Test was significant (p= 0.0279).

TABLE 7: GENDER VS TYPE OF RECEIVED PROFESSIONAL SUPPORT	N			
	No	Yes	%	p
Books				
Males	6	1	14	.131
Females	36	31	46	
In-person support group				
Males	3	4	57	.693
Females	38	29	43	
Individual therapy				
Males	3	4	57	1.00
Females	34	33	49	
Online forum				
Males	0	7	100	.088
Females	42	25	37	
Social media				
Males	7	0	0	.091
Females	44	23	34	
Support from religion/spiritual beliefs				
Males	5	2	28	.661
Females	51	15	22	

TABLE 8: TYPE OF RECEIVED PROFESSIONAL SUPPORT VS GENDER	Gender			
	M	%	F	%
In-person professional support only (in-person support groups, individual therapy)	6	86	14	21
Other professional support only (books, online forum, social media)	1	14	18	27
Both	0	0	34	52
Total	7		66	

Fisher's Exact Test: p= 0.00086.

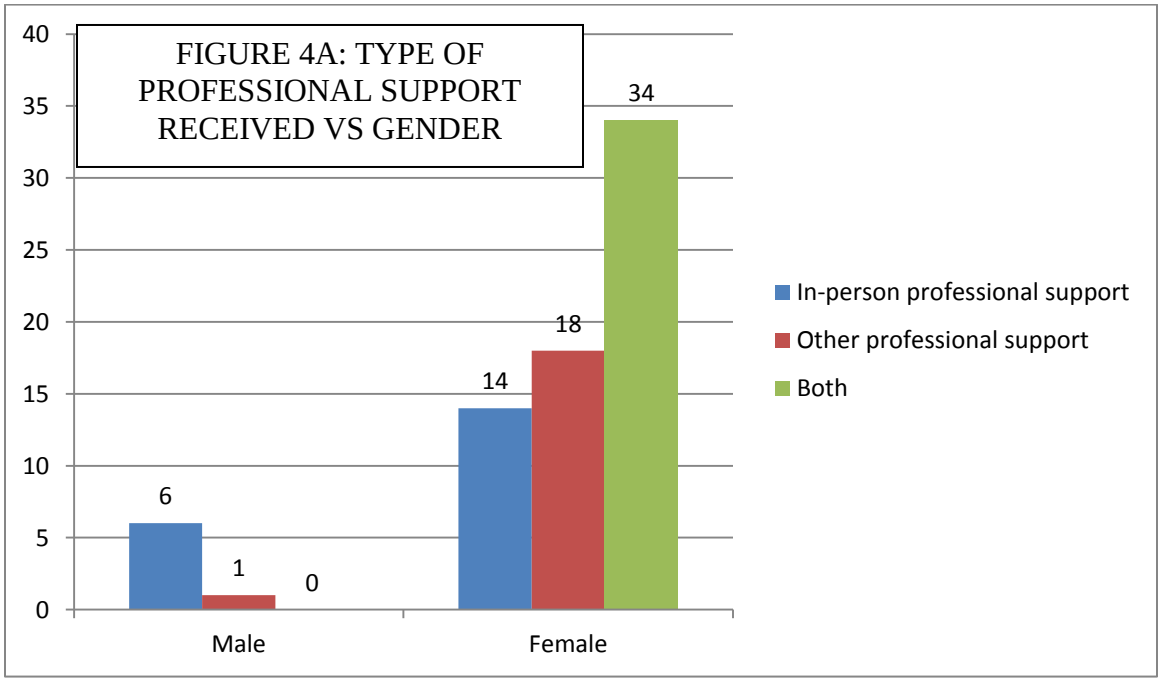

Figure 4A show results to a cross-tabulation between the percent of men and women that received professional support with whether they received in-person support only, other professional support only, or both. The p-value was significant (p= 0.00086).

TABLE 9: NUMBER OF SUPPORT TYPES RECEIVED VS GENDER	Gender			
	M	%	F	%
One type	3	43	25	37
Two types	4	57	14	21
Three or more types	0	0	28	42
Total	7		67	

Fisher's Exact Test: p= 0.0279.

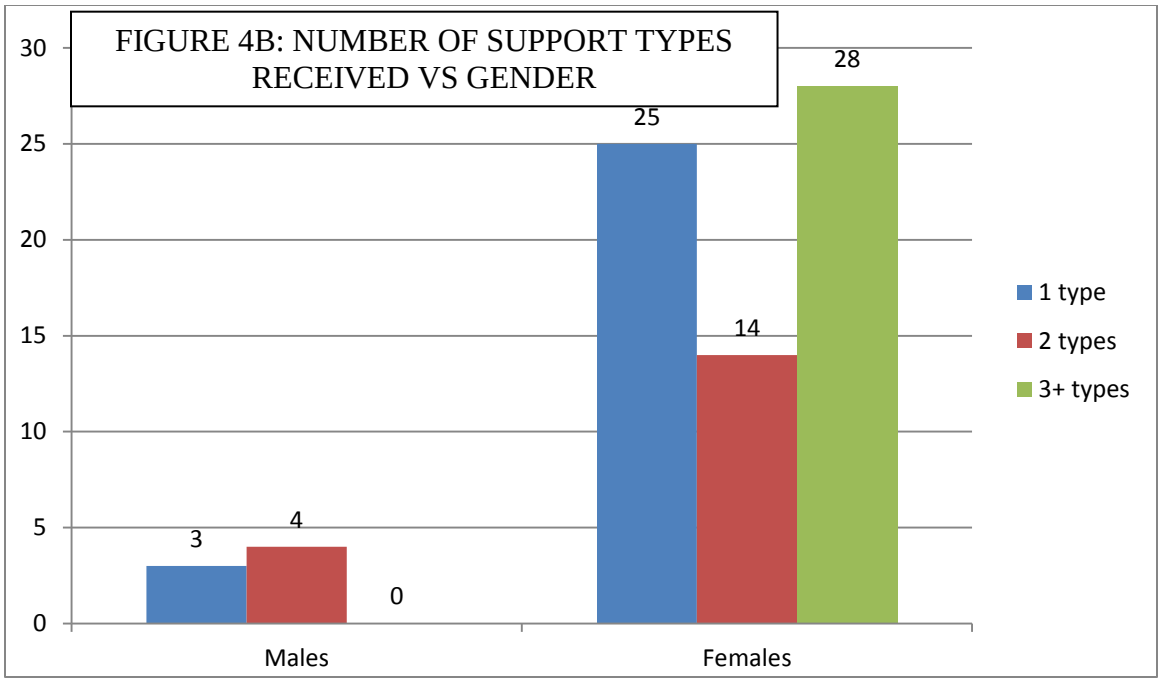

Figure 4B shows results from 7 men and 67 women to the cross-tabulation of gender versus the number of professional support types received. The p- value was significant (p= 0.0279).

3.4 Perceived helpfulness of received support

Table 10 is a breakdown of the participant responses to "Please mark how strongly you agree or disagree with the following statement: I found this support to be helpful", "What about this support did you find to be helpful?" and "What about this support did you not find to be helpful?" The first question was on a 5-point scale from strongly agree to strongly disagree. The second two questions were free response format. Individuals who responded strongly agree, agree, or neutral to the first question were lead to the question asking what was helpful about the support they received. Themes applied to the responses to this question included: not feeling alone, spousal support advice, talking about feelings, receiving support from others who understand, receiving religious support, gaining perspective, learning about resources, and normalizing feelings. Individuals who responded disagree or strongly disagree to the first

question were directed to the question asking what was not helpful. 3 individuals responded to this question and all answers are written in Table 10.

TABLE 10: PERCEIVED HELPFULNESS OF RECEIVED PROFESSIONAL SUPPORT	Total	
	N	%
Support was helpful:		
Strongly Agree	35	47
Agree	25	34
Neutral	11	15
Disagree	2	3
Strongly disagree	1	1
Total	74	
What was helpful about the professional support you received?		
I didn't feel alone	21	32
Advice on how to support spouse	2	1
Talking about feelings	30	46
Support from others who understand	42	65
Religious support	3	5
Perspective	5	8
Resources	3	2
Total	106	
What was not helpful about the professional support you received?		
"Hearing the horror stories from other people made me anxious. It made perinatal loss feel more common and made me question whether I would be able to have any children in the future"	1	33
"I went to one in-person group session with my wife. It was a bad experience. I listened to other people tell very sad stories, and saw that some of them had been very broken. It was depressing and I didn't find it personally helpful at all. My wife had better success with other support groups"	1	33
"The counselor I saw did not seem to understand or know how to support my feelings of loss, hopelessness, and helplessness."	1	33
Total	3	

Each participant response to the second two questions could include one or multiple options.

Participants responded to the statement "Please mark how strongly you agree or disagree with the following statement: I found this support to be helpful" with the possible answers of strongly agree, agree, neutral, disagree, and strongly disagree. Table 11 and Figure 5 show answers from the 67 female respondents and 7 male respondents who reported that they had received professional support following the perinatal loss. 33 females (49%) and 2 males (29%) responded strongly agree, 22 females (33%) and 3 males (43%) responded agree, 10 females

(15%) and 1 male (14%) responded neutral, 1 female (2%) and 1 male (14%) responded disagree, and 1 female (2%) and 0 males (0%) responded strongly disagree. The Fisher's Exact Test p-value was not significant (p= 0.3259). For analysis, the strongly agree and agree responses were combined and the disagree and strongly disagree responses were combined.

Table 12 shows results to the cross-tabulation between stage of pregnancy and perceived helpfulness. Regardless of stage of pregnancy loss, the majority of individuals strongly agreed or agreed that received professional support was helpful. 81% of individuals with a first trimester loss, 55% of individuals with a second trimester, loss, 75% of individuals with a third trimester loss, and 87% of individuals with a loss after birth marked either strongly agree or agree. This Fisher's Exact Test p-value was not significant (p= 0.1520).

TABLE 11: PERCEIVED HELPFULNESS OF RECEIVED PROFESSIONAL SUPPORT VS GENDER	M	%	F	%
Strongly Agree	2	29	33	49
Agree	3	43	22	33
Neutral	1	14	10	15
Disagree	1	14	1	2
Strongly Disagree	0	0	1	2
Totals	7		67	

Fisher's Exact Test: p = 0.3259.

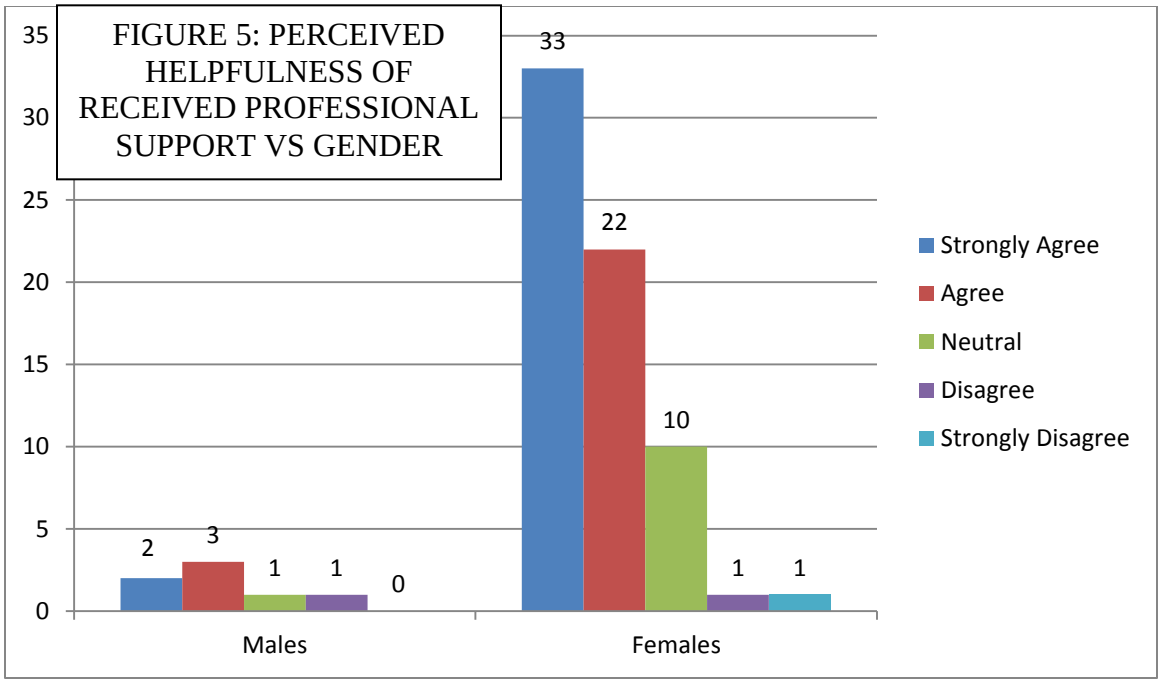

Figure 5 show the breakdown of the perceived helpfulness of received professional support of the 67 women and 7 men who reported receiving professional support following the perinatal loss. The p-value was 0.3259.

TABLE 12: STAGE OF PERINATAL LOSS VS PERCEIVED HELPFULNESS	N	%
First Trimester (0-12 weeks)		
Strongly Agree	18	47
Agree	13	34
Neutral	7	18
Disagree	0	0
Strongly Disagree	0	0
Total	38	
Second Trimester (13-27 weeks)		
Strongly Agree	6	30
Agree	10	50
Neutral	3	15
Disagree	0	0
Strongly Disagree	1	5
Total	20	
Third Trimester (28-40 weeks)		
Strongly Agree	4	50
Agree	2	25
Neutral	0	0
Disagree	2	25
Strongly Disagree	0	0
Total	8	
After birth		
Strongly Agree	7	87
Agree	0	0
Neutral	1	13
Disagree	0	0
Strongly Disagree	0	0
Total	8	

Fisher's Exact Test: p = 0.1520.

Table 13A is a cross tabulation between the type of professional support that was received and perceived helpfulness. 70% of individuals that received in-person professional support (in-person support group or individual therapy), 89% of individuals that received other professional support (social media, online forum, or books), and 82% of individuals that received both forms agreed that professional support was helpful following the perinatal loss. A Fisher's Exact Test was performed for and the p-value was not significant (p= 0.3648). Table 13B is a cross tabulation between the number of forms of received professional support with perceived helpfulness. 79% of individuals that received one form of support, 84% of individuals that

received 2 forms of support, and 82% of individuals that received three forms of support agreed that the received support was helpful. The Fisher's Exact Test showed no significant difference between the number of received support types and perceived helpfulness (p= 0.9322).

TABLE 13A: TYPE OF RECEIVED SUPPORT TYPE VS PERCEIVED HELPFULNESS	N	%
In-person professional support only		
Strongly Agree	10	50
Agree	4	20
Neutral	3	15
Disagree	2	10
Strongly Disagree	1	5
Other professional support		
Strongly Agree	9	47
Agree	8	42
Neutral	2	11
Disagree	0	0
Strongly Disagree	0	0
Both		
Strongly Agree	15	44
Agree	13	38
Neutral	6	18
Disagree	0	0
Strongly Disagree	0	0
Total	73	

Fisher's Exact Test: p= 0.3648.

TABLE 13B: NUMBER OF RECEIVED SUPPORT TYPES VS PERCEIVED HELPFULNESS	N	%
One form of professional support		
Strongly Agree	12	43
Agree	10	36
Neutral	4	14
Disagree	1	4
Strongly Disagree	1	4
Two forms of professional support		
Strongly Agree	10	56
Agree	5	28
Neutral	2	11
Disagree	1	6
Strongly Disagree	0	0
Three or more forms of professional support		
Strongly Agree	13	46
Agree	10	36
Neutral	5	18
Disagree	0	0
Strongly Disagree	0	0
Total	74	

Fisher's Exact Test: p= 0.9322.

3.5 Reasons why support was not received

The 78 participants who responded that they did not receive professional support following the perinatal loss were asked to choose the reason that most closely fit why they did not receive professional support. The options could choose one of the following options: I didn't think it would be helpful, obstacles (i.e. time, distance) prevented me from receiving support, I was not aware professional support was available, I preferred to deal with the loss privately, I received all needed support from friends, and none of these reasons. A majority of participants selected either that they preferred to deal with the loss privately or that they received all needed support from friends. Results are displayed in Table 14.

Results from the 78 individuals who responded to the statement "Choose the reason that most closely fits with why you did not receive professional support" were separated by stage of pregnancy in Table 15 and Figure 6A. The majority of individuals who experienced a first

trimester loss cited that they preferred to deal with the loss privately or that they received all needed support from friends. About 20% of these respondents reported that they were not aware professional support was available. The majority of individuals who experienced a second trimester loss responded that they preferred to deal with the loss privately or none of these reasons. 60% of individuals who experienced a third trimester loss answered that they did not think professional support would be helpful and 40% said that they preferred to deal with the loss privately. The one individual that responded to this question who experienced a loss after birth stated that they received all necessary support from friends or family. The Fisher's Exact Test p-value for this comparison was .0049 indicating that the stage of pregnancy was significantly associated with the reason why professional support was not received.

Table 16 and Figure 6B show results of 78 respondents to the cross-tabulation of gender and the reason why professional support was not received. The majority of females (50%) responded that they received all needed support from friends while the majority of males (40%) responded that they preferred to deal with the loss privately. The p-value of the Fisher's Exact Test comparing gender with the reason why professional support was not received was not significant (p= 0.6902).

TABLE 14: REASON PROFESSIONAL SUPPORT WAS NOT RECEIVED	N	%
I didn't think it would be helpful	4	5
Obstacles (ie. Time, distance) prevented me from receiving support.	4	5
I was not aware professional support was available.	13	17
I preferred to deal with the loss privately.	30	39
I received all needed support from friends.	20	26
None of these reasons.	7	9
Total	78	

TABLE 15: STAGE OF PERINATAL LOSS VS REASON WHY SUPPORT WAS NOT RECEIVED	N	%
First trimester		
I didn't think it would be helpful	1	2
Obstacles (ie. Time, distance) prevented me from receiving support	3	5
I was not aware professional support was available	12	21
I preferred to deal with the loss privately	22	38
I received all needed support from friends	17	29
None of these reasons	3	5
Total	58	
Second trimester		
I didn't think it would be helpful	0	0
Obstacles (ie. Time, distance) prevented me from receiving support	1	7
I was not aware professional support was available	1	7
I preferred to deal with the loss privately	6	43
I received all needed support from friends	2	14
None of these reasons	4	29
Total	14	
Third trimester		
I didn't think it would be helpful	3	60
Obstacles (ie. Time, distance) prevented me from receiving support	0	0
I was not aware professional support was available	0	0
I preferred to deal with the loss privately	2	40
I received all needed support from friends	0	0
None of these reasons	0	0
Total	5	
After birth		
I didn't think it would be helpful	0	0
Obstacles (ie. Time, distance) prevented me from receiving support	0	0
I was not aware professional support was available	0	0
I preferred to deal with the loss privately	0	0
I received all needed support from friends	1	100
None of these reasons	0	0
Total	1	

Fisher's Exact Test: p= 0.0049.

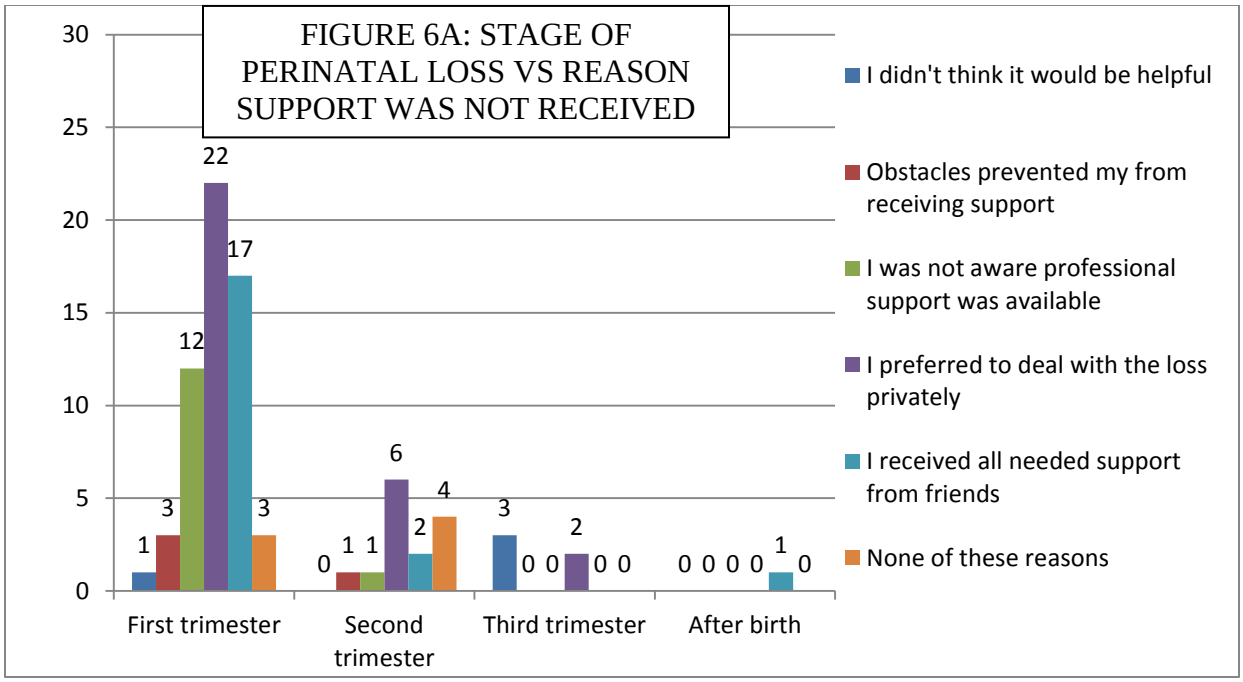

Figure 6A shows results from 78 participants comparing the reason why professional support was not received with the stage of pregnancy of the perinatal loss. The p-value was significant (p= 0.0049)

TABLE 16: GENDER VS REASON WHY SUPPORT WAS NOT RECEIVED	M	%	F	%
Reason why support was not received				
I didn't think it would be helpful	0	0	4	6
Obstacles (ie. Time, distance) prevented me from receiving support	0	0	4	6
I was not aware professional support was available	1	13	12	17
I preferred to deal with the loss privately	2	25	28	40
I received all needed support from friends	4	50	16	23
None of these reasons	1	13	6	9
Totals	8	101	70	100

Fisher's Exact Test: p= 0.6902.

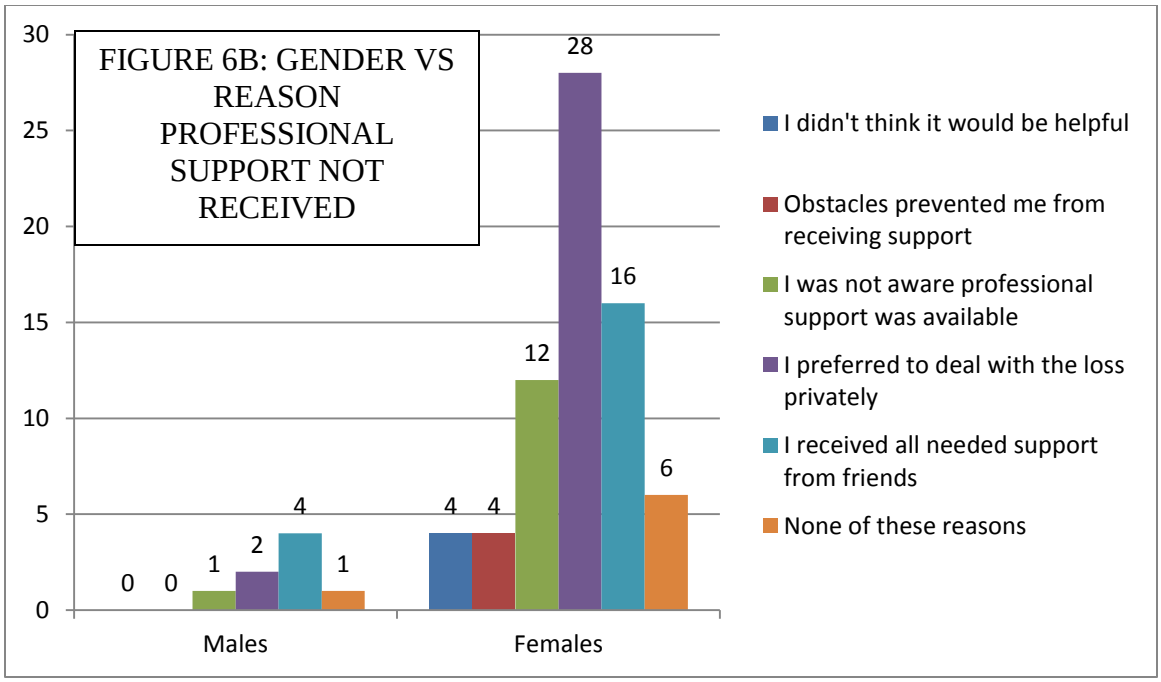

Figure 6B shows results to the cross-tabulation of gender and the reason why professional support was not received. 78 respondents answered this question. The p-value was not significant (p= 0.6902).

Table 17 displays answers to questions that asked the participant to retrospectively assess whether or not they agree that support would have been helpful and whether or not they would have participated had they known professional support was available. The 64 respondents who did not receive professional support answered the first question and the 13 respondents that reported they were unaware professional support was available answered the second question. 42.2% of participants strongly agreed or agreed, 39.1% were neutral, and 18.8% disagreed or strongly disagreed agreed that professional support would have been helpful. 76.9% of respondents stated that it was very or somewhat likely and 23.1% stated that it was not very likely that they would have participated had they known professional support was an option. Table 18 displays the above results by gender. A Fisher's Exact Test was used for analysis of both response sets. When respondents were asked if in retrospect, they believe support would have been helpful, a majority of both males and females were either neutral or agreed. This

comparison was not significant (p = 0.7406). Figure 6C displays the answers to these results. Of the individuals that responded to whether or not they would have participated had they been aware professional support was available, the majority of women responded somewhat likely and the one male respondent responded somewhat likely. This comparison was not significant (p= 0.308).

TABLE 17: RETROSPECTIVE OPINIONS	Total	
	N	%
In retrospect, support would have been helpful		
Strongly Agree	7	11
Agree	20	31
Neutral	25	39
Disagree	9	14
Strongly disagree	3	5
Total	64	
I would've participated if I were aware professional support was available		
Very likely	1	8
Somewhat likely	9	69
Not very likely	3	23
Not at all likely	0	0
Total	13	

TABLE 18: RETROSPECTIVE OPINIONS VS GENDER				
	Male	%	Female	%
In retrospect, professional support would have been helpful				
Strongly Agree	0	0	7	12
Agree	3	43	17	30
Neutral	4	57	21	37
Disagree	0	0	9	16
Strongly disagree	0	0	3	5
Total	7		57	
I would've participated if I were aware professional support was available				
Very likely	0	0	1	8
Somewhat likely	1	100	8	67
Not very likely	0	0	3	25
Not at all likely	0	0	0	0
Total	1		12	

Fisher's Exact Test: p = 0.7406, 0.308.

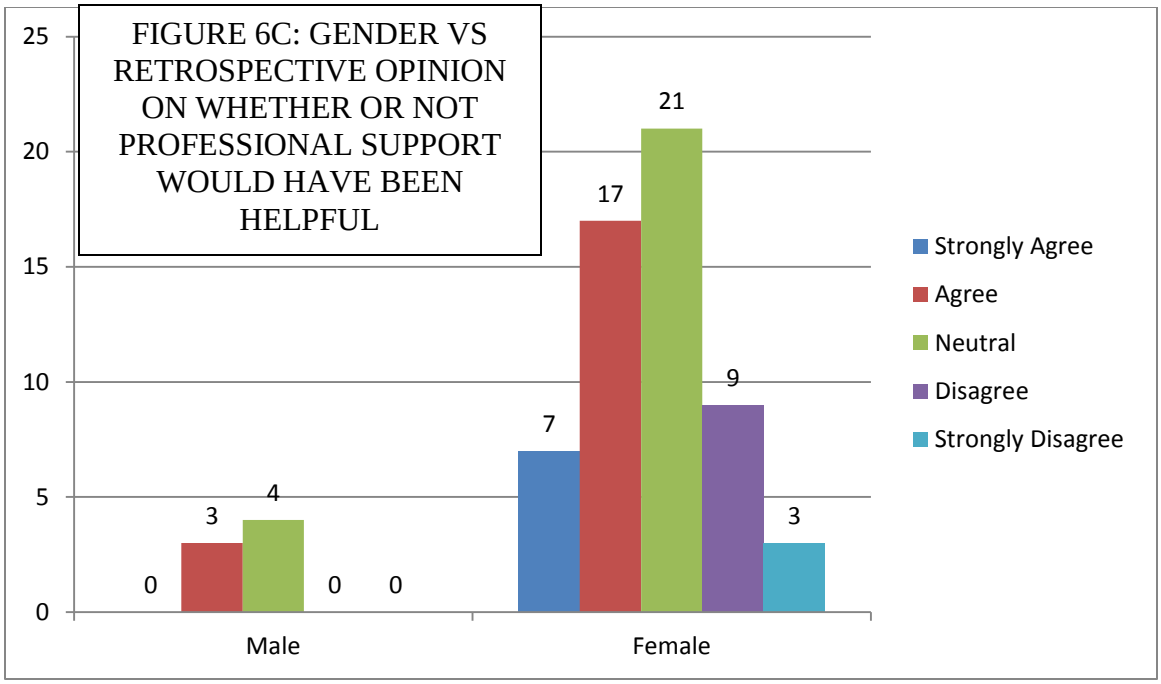

Figure 6C show the comparison between gender and whether or not they believe professional support would have been helpful following the perinatal loss. 7 males and 57 women responded to this question. The p-value was not significant (p= 0.7406).

3.6 Preferred professional support

Table 19A portrays the answers to the question "What form of professional support do you believe would be most helpful following the event of a perinatal loss?". Participants were required to select one answer from the following choices: in person support group, individual therapy, online forum, social media, support from medical staff (ie. Doctors, nurses, genetic counselors), support from religion/spiritual beliefs, none of these, and other (please specify). The table presents the answers by gender. A majority of men and women preferred in-person forms of professional support with 57.1% of males and 29.8% of females preferring individual therapy and 28.6% of men and 34.7% of females preferring in-person support groups. The Fisher's Exact Test p-value was not significant (p= .5547). Table 19B displays the same data as Table 19A in a collapsed form for post-hoc analysis. The collapsed groups were in-person support group, individual therapy and other (online forum, social media, support from medical staff, support

from religion/spiritual beliefs, none of these, and other (please specify)). The Fisher's Exact Test comparison between gender and whether in-person support groups, individual therapy, or other forms of professional support would be preferred was not significant (p= 0.1025).

Table 20A portrays answers to the same question separated by the stage at which the pregnancy was lost. This data was collapsed and analyzed post-hoc with the results displayed in Table 20B. The collapsed groups were in-person support group, individual therapy, and other (online forum, social media, support from medical staff, support from religion/spiritual beliefs, none of these, and other (please specify). Only one participant who experienced a loss in the third trimester or after birth selected options other than in-person support group or individual therapy while 44 individuals who experienced a loss in the first or second trimester selected the other option. The Fisher's Exact Test comparing these three groups with stage of pregnancy was significant (p= 0.035).

Table 21 shows results to the free response question "Why do you think this option would be most helpful?". Common themes were coded from the answers and included: to seek answers for why it happened, to not feel alone, to hear and share experiences with others who understand, to receive knowledge from professionals, to grow in faith, to maintain privacy, and for benefits of an online community (ie, large amount of people, anonymity). Each response could have one or multiple themes. 37% of responses contained the theme "to hear and share experiences with others who understand", 25% of responses contained the theme "to not feel alone".

TABLE 19A: PREFERRED PROFESSIONAL SUPPORT VS GENDER				
	Male	%	Female	%
In-person support group	4	29	42	35
Individual therapy	8	57	36	30
Online Forum	0	0	10	8
Social media	0	0	5	4
Support from medical staff (i.e. doctors, nurses, genetic counselors)	1	7	14	12
Support from religion/spiritual beliefs	0	0	5	4
None of these options	1	7	3	3
Other	0	0	6	5
Total	14		121	

Fisher's Exact Test: p = 0.5547.

TABLE 19B: IN PERSON OR OTHER PROFESSIONAL SUPPORT PREFERENCE VS GENDER				
	Male	%	Female	%
In-person support group	4	29	42	35
Individual therapy	8	57	36	30
Other	2	14	43	36
Total	14		121	

Fisher's Exact Test: p= 0.1025.

TABLE 20A: PREFERRED PROFESSIONAL SUPPORT VS STAGE OF PREGNANCY	N	%
In-person support group		
First trimester	23	19
Second trimester	13	11
Third trimester	6	5
After birth	4	3
Individual therapy		
First trimester	27	22
Second trimester	7	6
Third trimester	6	5
After birth	4	3
Online forum		
First trimester	8	7
Second trimester	2	2
Third trimester	0	0
After birth	0	0
Social media		
First trimester	2	2
Second trimester	2	2
Third trimester	0	0
After birth	1	1
Support from medical staff (ie. Doctors, nurses, genetic counselors)		
First trimester	12	10
Second trimester	3	2
Third trimester	0	0
After birth	0	0
Support from religion/spiritual beliefs		
First trimester	4	3
Second trimester	1	1
Third trimester	0	0
After birth	0	0
None of these options		
First trimester	3	2
Second trimester	1	1
Third trimester	0	0
After birth	0	0
Other		
First trimester	3	2
Second trimester	3	2
Third trimester	0	0
After birth	0	0
Total	135	

Some participants selected multiple options.

TABLE 20B: PREFERRED PROFESSIONAL SUPPORT TYPE VS STAGE OF PREGNANCY	N	%
In-person support group		
First trimester	23	19
Second trimester	13	11
Third trimester	6	5
After birth	4	3
Individual therapy		
First trimester	27	22
Second trimester	7	6
Third trimester	6	5
After birth	4	3
Other		
First trimester	32	23
Second trimester	12	9
Third trimester	0	0
After birth	1	1
Total	135	

Fisher's Exact Test: p= 0.035. Some participants selected multiple options and therefore the total is more than 100%.

TABLE 21: WHY THIS WOULD BE THE MOST BENEFICIAL OPTION	Total	
	N	%
Why do you believe this option would be most helpful?		
To seek answers for why it happened	4	5
To not feel alone	20	25
To hear and share experiences with others who understand	30	37
To receive knowledge from professionals	8	10
To grow in faith	2	3
To maintain privacy	12	15
For benefits of an online community (i.e. large numbers, anonymity)	5	6
Total	81	101

Each response could have one or more associated themes and therefore the N value and percentages may not add up to the expected numbers.

Table 22 shows a breakdown of participants' preferred characteristics of professional support including the preferred gender to be involved and what they would like to benefit from professional support. The given options for the first question were: "same sex only", "co-ed", and "a mix of both same sex and co-ed groups". 32.6% of participants answered same sex only, 6.7% answered co-ed, and 60.7% answered a mix of same sex and co-ed groups. The options for the second question were: "to hear experiences of other individuals who have had a similar

experience", "to obtain correct information about perinatal loss (ie. causes, risk of recurrence)", "to receive suggestions on how to support my partner", and "to receive validation of feelings". 37.0% of participants answered "to hear experiences of other individuals who have had a similar experience", 15.6% of participants answered "to obtain correct information about perinatal loss (ie. Causes, risk of recurrence)", 8.9% of participants answered "to receive suggestions on how to support my partner" and 38.5% of participants answered "to receive validation of feelings".

Table 23 and Figure 7A depict the answers to the question asking about the anticipated benefit from professional support by gender. The majority of females would like to hear experiences from other individuals who have had a similar experience or to receive validation of feelings while the majority of men would like to receive suggestions on how to support their partner. The Fisher's Exact Test comparing gender with anticipated benefit from professional support was significant ($p = <0.0001$).

Table 24 and Figure 7B display results of the cross-tabulation between gender and what gender they would like to have involved in professional support with the options being same-sex only, co-ed only, and both same-sex and co-ed. A majority of males (86%) and majority of females (58%) chose a mix of both same-sex and co-ed groups. The Fisher's Exact Test p-value was not significant ($p = 0.0654$).

TABLE 22: CHARACTERISTICS OF PREFERRED PROFESSIONAL SUPPORT	Total	
	N	%
Which gender would you like to be involved?		
Same sex only	44	32
Co-ed	9	7
A mix of both same sex and co-ed groups	82	61
Total	135	101
What do you want to receive from professional support?		
To hear experiences of other individuals who have had a similar experience	50	37
To obtain correct info regarding perinatal loss (ie. Causes, risk of recurrence)	21	16
To receive suggestions on how to support my partner	12	9
To receive validation of feelings	52	38
Total	135	

TABLE 23: ANTICIPATED BENEFIT FROM PROFESSIONAL SUPPORT VERSUS GENDER				
	Male	%	Female	%
Anticipated benefit from professional support				
To hear experiences of other individuals	3	21	47	39
To obtain correct information regarding perinatal loss	1	7	20	17
To receive suggestions on how to support my partner	8	57	4	3
To receive validation of feelings	2	14	50	41
Total	14	99	121	100

Fisher's Exact Test: p = <0.0001.

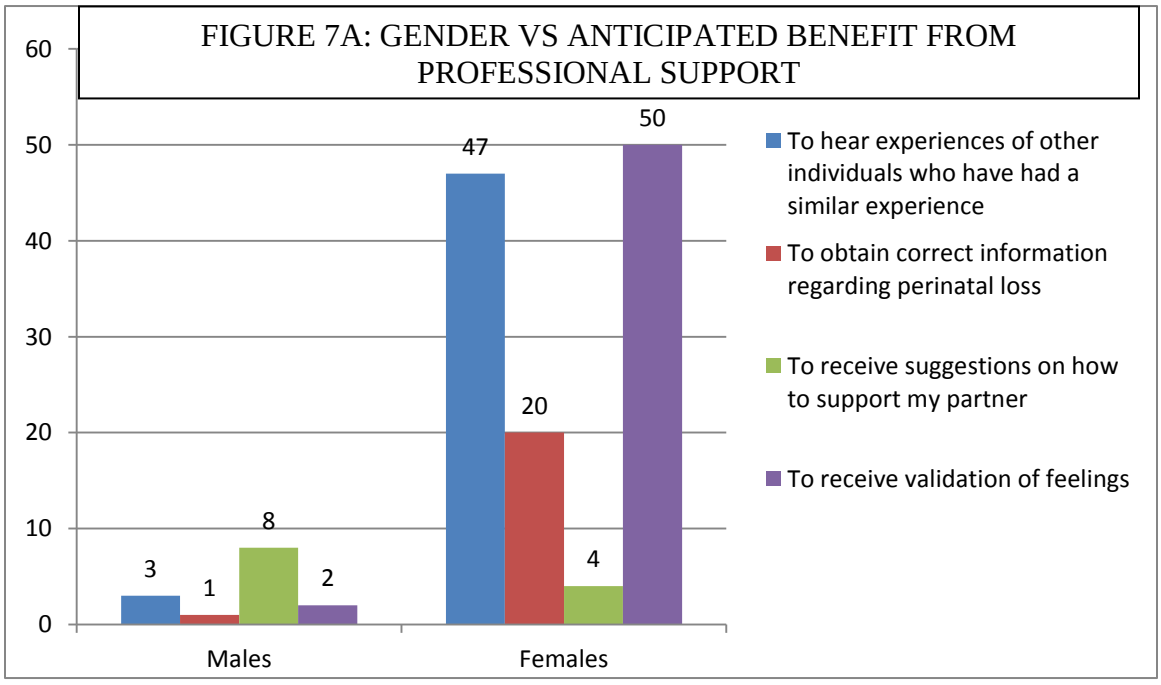

Figure7A show results from 121 females and 14 males to the question asking what they would like to receive from professional support. The p-value was <0.0001.

TABLE 24: GENDER PARTICIPATION VS GENDER				
	Male	%	Female	%
Same sex only	1	7	43	36
Co-ed only	1	7	8	7
Mix of both same sex and co-ed	12	86	70	58
Total	14	100	121	101

Fisher's Exact Test: p= 0.0654.

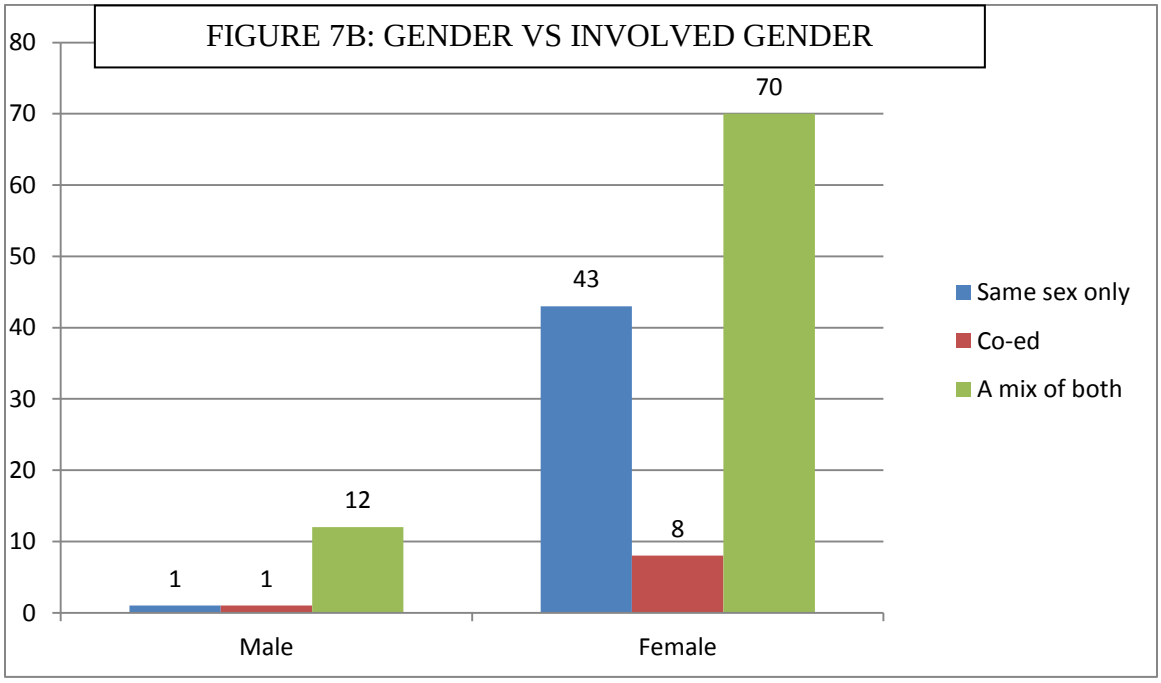

Figure 7B shows results from 14 men and 121 women to the question "What gender would you prefer to be involved?" characterized by gender. The p-value was not significant (p= 0.0654).

3.7 How and when individuals would like to be informed of professional support options

Table 25 shows results from 136 respondents to the questions asking how and when individuals would like to be informed of professional support options. 74% of individuals stated that they would prefer to be informed by their medical provider and 86% of individuals would like to be informed 0 to 30 days after the perinatal loss.

TABLE 25: HOW AND WHEN INDIVIDUALS WOULD LIKE TO BE INFORMED OF PROFESSIONAL SUPPORT OPTIONS	Total	
	N	%
How would you like to be informed?		
Through social media	17	13
From your medical provider	99	74
Through fliers posted in medical offices	3	2
Friends/Family	15	11
All of the above	2	2
Total	136	102
When would you like to be informed?		
0-30 days after the perinatal loss	116	86
1-3 months after the perinatal loss	16	12
3 or more months after the perinatal loss	3	2
Total	135	100

Respondents could select multiple answers for the first question so percentages may not add up to 100.

IV. DISCUSSION

Perinatal loss affects 25% of couples and can have devastating emotional consequences (Hamama-Raz, Hemmendinger & Buchbinder 2010 and Huffman, Schwartz & Swanson 2014). Social and professional support can lead to improved healthcare outcomes, but not all individuals have access to or accept professional support services. Grief related to perinatal loss is unique, and having professional support available that is geared towards helping couples through this trying time is important. Historically, emotional support, while limited, has been primarily focused on women (Moore, Parrish & Black 2011). The effects of perinatal loss on women have been studied extensively while the effects on men are not as well understood. The few studies that have been conducted suggest that while fathers' reactions may be less intense than mothers', fathers also experience intense grief after perinatal loss (Kersting & Wagner 2012). The purpose of this study was to assess coping styles of men and women after perinatal loss, the type of professional support that is thought to be most beneficial dependent on coping style and gender, and when and how these resources should be offered. The explored hypotheses included that gender, stage of pregnancy, and coping style would predict whether or not professional support was received. Specifically we anticipated that men and individuals who experienced earlier perinatal losses would be less likely to have been aware that professional support was available, and that individuals that received professional support would have perceived it as being beneficial.

Overall, some hypotheses were supported by the data and others were not. The stage of the perinatal loss was significantly associated with whether or not professional support was received, while gender was not. Coping style was also associated with whether or not

professional support was received with respect to use of adaptive coping strategies, but the use of maladaptive coping strategies was not. Men and women were equally as likely to cite not being aware of professional support options as a reason for why professional support was not received, going against the hypothesis that men would be less likely to have been aware that professional support options were available. Instead, a majority of both men and women cited preferring to deal with the loss on their own or receiving needed support from friends and family. The final hypothesis predicting that individuals who received professional support would have found it to be helpful was supported.

4.1 Characteristics of individuals that received professional support

Of the 166 respondents, half of the individuals reported receiving professional support following the perinatal loss and half did not. Neither gender nor number of losses was associated with whether or not individuals received support (Table 4, Table 5B). However, the stage of pregnancy at which the perinatal loss occurred was significantly associated with whether or not individuals received support (Table 5A). The later in pregnancy the perinatal loss occurred, the more likely the individual was to receive professional support. This pattern could be attributed to multiple factors. One factor could be that individuals who have losses earlier in pregnancy are less likely to be aware professional support is available, as detailed later. These individuals may not have had the opportunity to hear from their medical professionals about professional support options due to the fact that the individual did not utilize medical resources regarding their pregnancy because of the early stage, or potentially because from the medical professionals' point of view, early loss may not be thought of as traumatic as later losses. Another reason that individuals who experienced an earlier loss are less likely to receive professional support may be

because they prefer to deal with the loss privately, especially since the surrounding community may not have been aware of the pregnancy.

Individuals who use adaptive coping strategies were significantly more likely to receive support than individuals who do not use adaptive coping strategies while there was no significant association between the use of maladaptive coping strategies with whether or not individuals received support (Table 6A). Males were less likely than women to report the use of adaptive coping strategies following the perinatal loss while there was no significant difference between genders with the use of maladaptive coping strategies. Adaptive coping helps an individual to deal effectively with stressful events and minimizes distress associated with the event while maladaptive coping can result in unnecessary distress for the individual and others (Carver, Scheier, Weintraub, & Jagdish 1989). All individuals use maladaptive and adaptive coping strategies, even within one period of stress (Thompson, Mata, Jaeggi, Buschkuehl, Jonides, & Gotlib 2011), however individuals differ in how much each coping strategy is used. Referencing the above definition of adaptive coping, it makes sense that individuals who utilize adaptive coping strategies would be more likely to access professional support resources, as these resources are intended to minimize distress associated with the event. These results indicate that the use of adaptive coping strategies and gender may predict whether or not professional support is received.

4.2 Characteristics of received professional support

Males and females appear to differ in the forms of professional support that they received. In order to investigate this comparison, we grouped the participant responses regarding professional support options into the following three categories: in person professional support

(in-person support group and individual therapy), other professional support (books, online forum, social media) and both in person professional support and other professional support. The data demonstrates that there is a significant difference between men and women in the type of support received, and the number of different forms of support received (Table 8). While 86% of males received in-person professional support only (in-person support group or individual therapy), 14% received other professional support only (books, social media, or online forum) and none of the 7 men that responded reported receiving both in-person professional support and other professional support. In contrast, more than 50% of women reported receiving both in-person professional support and other professional support.

There was also a significant difference ($p = .0279$) in the number of support types received by men in comparison to women; men were much less likely than women to receive more than two types of professional support following a perinatal loss (Table 9). While none of the 7 men received three or more types of professional support, 28 women (42%) received three or more types of professional support, indicating that women were more likely than men to seek support from multiple avenues.

4.3 Perceived helpfulness of received professional support

Of those individuals who received support, more than 80% thought that professional support was helpful and fewer than 5% thought that it was not helpful (Table 10). Most often, individuals felt that professional support was helpful for the following reasons: they received support from others who understood, they could talk about their feelings, and they didn't feel alone in what they were going through. One of the male respondents who received professional support from an in-person support group stated "Hearing and listening to other parents who

understood what we were going through and who listened to us share our stories helped us to cope with the loss of our newborn. This support allowed us to safely process our loss with people who understood". Individuals who did not feel that professional support was helpful mostly cited that it was difficult for them to hear other couples' sad stories. It is important for medical professionals to be aware that all forms of professional support may not be the most beneficial environment for every individual. Asking patients what would be important for them to receive from professional support and whether or not it would be helpful to hear experiences of others in a similar situation may be a way to guide individuals towards the support that would be most beneficial for them. Overall, these results indicate that the professional support that is received by individuals is perceived to be beneficial and should continue being offered. Access should be available to professional support resources that offer an environment in which individuals can receive support from others who understand, if they desire this option, and can openly talk about their feelings. Also, it is important to offer multiple forms of professional support to generate the highest likelihood that received professional support will be beneficial.

Stage of pregnancy was not correlated with perceived helpfulness of professional support with the majority of individuals reporting that professional support was helpful regardless of stage of pregnancy (Table 12). As stated earlier, individuals who experienced a perinatal loss earlier in pregnancy were significantly less likely to have been aware that professional support was available. However, these results indicate that professional support is helpful for individuals who have experienced a perinatal loss at any gestational age and calls for professional support to be offered to individuals who have experienced a perinatal loss regardless of gestational age.

There was no difference in perceived helpfulness between those who received in-person professional support only (in-person support group or individual therapy), other professional

support only (books, online forum or social media) or both in-person professional support and other professional support. Therefore, perceived helpfulness is not dependent on whether the professional support is in person or not.

4.4 Reasons professional support was not received

A majority of the individuals chose the following reasons for not receiving professional support: I preferred to deal with the loss privately, I received all needed support from friends, and I was not aware professional support was available (Table 14). The first two reasons are reflective of individuals who *chose* to deal with the loss without receiving professional support while the third reason is reflective of a need for more resources. Over 20% of individuals reported that they either were not aware of professional support services or that there were obstacles (time or distance) that prevented them from receiving support. This shows a need for more avenues through which professional support can be offered to individuals who have experienced a perinatal loss. Respondents who experienced a first trimester loss were more likely to cite that they were not aware professional support was available than individuals who experienced a perinatal loss later in pregnancy (Table 15). This may be because individuals who experienced a perinatal loss earlier in pregnancy are less likely to have had an opportunity for contact with medical professionals regarding their pregnancy. The individuals that *chose* not to receive professional support rather than not being aware that it was available may not have announced the pregnancy to their friends or family and prefer to deal with the loss in a private manner. Interestingly, the stage of pregnancy during which the perinatal loss occurred was significantly associated with the reason for why professional support was not received. Individuals in the first trimester were more likely than other respondents to report that they

received all needed support from friends, however the majority of individuals from all groups aside from the one respondent with a loss after birth reported preferring to deal with the loss privately. Also notable, three of the five (60%) of individuals with a third trimester loss said they did not think that professional support would have been helpful, while only one of 58 (2%) individuals with a first trimester loss and no individuals with a second trimester loss or loss after birth cited this reason. An individual with a loss in the third trimester may not relate to individuals with a first or second trimester loss or to individuals who experienced a loss after birth. There are several professional support options specific to miscarriage and losses after birth, but fewer for those who experience perinatal loss in the third trimester. This result may be reflective of a need for stage of loss specific professional support options. However, this observation must be treated with caution given that among those individual who did not receive professional support, there were only 5 individuals in the third trimester category and only one individual in the after birth category. More responses would be needed to make meaningful comparisons. In combination, this data suggests that some individuals choose to deal with grief related to perinatal loss privately or with friends rather than from professional support resources. For those individuals that would benefit from professional support, it is crucial to generate avenues through which they can be made aware of professional support options.

Individuals who did not receive support were asked whether or not, retrospectively, they agreed or disagreed that professional support would have been helpful following the perinatal loss. Respondents were fairly equally distributed among the groups, referenced in Table 17. Individuals who reported that they were not aware that professional support was available were asked how likely it would have been that they would receive professional support had they been aware that it was available. 77% of individuals answered that it is likely they would have

received support and 23% answered that it is unlikely. When these answers were segregated by gender, the majority of males were neutral on whether or not professional support would have been helpful following the perinatal loss and the majority of females reported that they believe professional support would have been helpful. This is an important reminder that every individual is different and should cope with the loss in whatever way is helpful to them; all individuals should be offered multiple resources and professional support options.

4.5 Characteristics of preferred professional support

There was no significant association between gender and the type of professional support that respondents preferred (Table 19A). It is interesting to observe that the majority of men chose individual therapy while the responses of women were fairly evenly distributed between individual therapy, in-person support groups, and other types of support. A larger sample would be needed in order to determine if there is a true difference, however, both genders preferred individual therapy and in-person support groups more than the other option (86% of men and 65% of women).

Participants were asked the free-response question asking why the chosen professional support would be the most beneficial option (Table 21). There were 5 themes among these responses: to seek answers for why it happened, to not feel alone, to hear and share experiences with others who understand, to receive knowledge from professionals, to grow in faith, to maintain privacy, and for benefits of an online community. Most participant answers included the themes to hear or share experiences with others who understand (n=30, 37%) or to not feel alone (n=20, 25%). Regardless of the type of received support, most individuals used professional support as an outlet to connect with other individuals who had gone through a

similar experience. Some respondents cited a need for one-on-one support from a counselor while others appreciated having a community of individuals that understand. While connection and community were clearly important, privacy and anonymity were also factors in determining the preferences of participants. The theme of receiving support from others who understand is highlighted in the following free response: "You feel so so alone in this... connecting, face to face with other people is so important." Another respondent stated in a portion of the free response why she feels that a support group would be helpful: "…I had a hard time adjusting to what I began to think was my new identity, as someone who wouldn't have children despite thinking for most of my life that my body would be well-equipped to do so-- big breasts, big hips. Body image confusion was a huge factor in my depression about it. This seems like the kind of thing a support group would be helpful for." Many participants mentioned that every individual is different and no one option will fit every individual's needs.

Participants were asked to select from four choices (to receive validation of feelings, to hear from others who have shared a similar experience, to receive suggestions on how to support their partner and to receive validation of feelings) the statement that best describes what they would like to receive from professional support (Table 22). A majority of participants reported that they would find it most beneficial to receive validation of feelings and to hear from others who have shared a similar experience. Interestingly, when the answers were compared between genders, men were significantly more likely to cite that they would like to receive suggestions on how to support their partner, while few women chose this option (Table 23, $p = <.0001$). This indicates that support groups geared towards supporting men should address this need and offer constructive advice on how they can support their partner.

When participants were asked what gender they would like to be involved with when receiving professional support, a majority reported that they prefer a mix of both same sex and co-ed groups. Both genders were least likely to select the co-ed only option, and more men than women would prefer same sex only option (Table 24, p= .0654). Although not significant, these results indicate that both men and women would appreciate the opportunity to have support (either by an individual or within a group) with others of the same sex – and this appears to be particularly important for men. When medical professionals are informing individuals of professional support, it should be made apparent that there are options that include only individuals of the same sex and options that they can attend with their partner.

A majority of individuals would like to be informed about professional support options by their medical provider 0 to 30 days after the perinatal loss rather than through social media, from friends or family, or through fliers (Table 25). This finding fits with results from previous research that individuals who have experienced a perinatal loss may feel very alone and are dealing with grief at a time when others around them may not recognize that they need support. Within this context, it makes sense that some individuals may retrospectively realize that they may not find the support resources they desire if they depend only on their personal network to find support.

4.6 Considerations

While most participants reported positive interactions with medical professionals, quite a few respondents cited that they experienced a lack of empathy from the medical professionals they interacted with during and shortly following the perinatal loss. One participant stated "After I had my miscarriage and the doctor confirmed it they just sent me home. That was it. No answers,

no offer of support. It was lonely and scary." Another respondent stated "…it is often the medical professions who are dismissive of it and don't validate your emotions." It is crucial that medical professionals who interact with mothers and fathers who have experienced a perinatal loss express empathy and offer support resources. These medical professionals should be educated on what interactions are most beneficial to these individuals and should offer tangible information about professional support resources.

Because perinatal losses can be due to genetic reasons, any individual who has experienced two or more perinatal losses or a loss late in pregnancy should be referred to a genetic counselor. Genetic counselors can assume multiple roles within the context of a session with an individual who has experienced one or more perinatal losses. First, genetic counselors have a responsibility to assess the patient's history and offer testing to determine the etiology of previous perinatal losses, if indicated. Finding an etiology for perinatal loss may supply comfort to some patients and also can present the opportunity to prevent future perinatal losses. Secondly, the genetic counselor should address the psychological component of perinatal loss and discuss whether or not the patient has received professional support. When appropriate, professional support resources should be discussed and offered.

4.7 Limitations of the study

This study may have been limited by selection bias in several ways due to the survey's language and mode of distribution. The survey was available only in English, which limited the number of individuals that could participate in the survey due to a potential language barrier. The survey was also distributed electronically barring individuals with a lack of access to, or familiarity with, the Internet. Additionally, the majority of participants were recruited through

social media sites and the National Society of Genetic Counselors listserv, which may have contributed to our ascertainment of mostly female, more highly educated individuals. The study population was 91% female, limiting our ability to compare across genders. Investigators of future studies should be encouraged to try to recruit more males given our significant limitation. It is possible that there may be cultural differences in how people seek out and experience professional support following a loss. Professionals should use caution in making assumptions based on this data due to the limited diversity among the participants.

The survey was also distributed through support groups and may have led to an ascertainment of individuals that are more likely to seek professional support than would be seen in the general population. The individuals that were recruited through this method were already receiving professional support, potentially resulting in the ascertainment of individuals that are more likely to use adaptive coping strategies and more likely to believe professional support is available. This may suggest that, if the recruited sample were representative of the general population, there may have been fewer individuals who have experienced a perinatal loss who would have reported receiving support.

Half of the respondents reported that more than three years had passed since their most recent perinatal loss. Therefore, although respondents were asked to reflect on how they coped and what they would have found helpful at the time of the perinatal loss, their answers may not accurately depict how the individual coped and what they would have found helpful at that time. This ascertainment may have also caused a cohort affect if there are generational differences in how men and women interact within a relationship, which could affect the responses of both men and women. Future studies may consider limiting the population to individuals who have experienced a more recent perinatal loss.

After asking about what types of professional support were received, there was one question asking participants to report how much they agreed with the statement that the received professional support was helpful. However, the structure of the questions made it impossible to discern which professional support the participant was referring to, or if they were grouping the various professional support types into one group.

Themes were extracted from the three free response questions by the lead researcher. Optimally, this process would be completed by two individuals separately and conclusions would be compared and adjusted until a consensus is met. Investigators of future studies should complete a more thorough analysis of free response questions.

4.8 Future studies

While results of this study show that professional support is beneficial and is important to offer to any individual who has experienced a perinatal loss, this study was not focused on what specific activities are found to be helpful or unhelpful within the context of perinatal support. Also, it would be helpful to know how often individuals would like to receive professional support services and for how many months or years following the perinatal loss.

Another potentially interesting study lies in an analysis of whether or not perception of the cause or recurrence risk of perinatal loss is associated with whether or not professional support is received or thought to be helpful.

Few previous studies have focused on parental anxiety and needed support during subsequent pregnancies. This study focused on the most recent perinatal loss, but it would be worthwhile to investigate what professional support would be optimal for couples who are pregnant following a perinatal loss. Genetic counselors and some medical professionals see

many patients who have experienced at least one perinatal loss. Particularly in the event that an individual has experienced a recent perinatal loss and is pregnant again or considering getting pregnant, the professional and social support that the patient has received should be explored and additional options should be offered, when indicated.

One potentially important aspect that was not investigated in this study was that respondents were not asked to specify whether the perinatal loss was idiopathic or was known to be due to a fetal abnormality or maternal condition. It may be that the etiology of a perinatal loss impacts whether or not professional support resources are sought out, what type of professional support would be helpful, and whether or not that support is perceived to be helpful. This would be important for medical professionals to consider in the offering of professional support resources.

4.9 Conclusion

This study was designed to determine what professional support, if any, is desired by men and women following perinatal loss. Perinatal loss is common and can have devastating emotional effects. Both social and professional support can lead to improved healthcare outcomes for couples, but professional support is not always readily offered and/or accepted. The purpose of this study was to assess coping styles of men and women after perinatal loss, the type of professional support that is thought to be most beneficial dependent on coping style and gender, and when/how this support should be offered.

Results show that women were significantly more likely than men to receive multiple and varied types of support. Of those individuals that did not receive professional support, a majority cited that they either preferred to deal with the loss privately or that they received all needed

support socially, however a significant portion of participants were not aware that such support exists. This indicates a need for implementation of more routes through which individual can be informed of professional support options. In-person support groups and individual therapy would be the most helpful forms of professional support for most individuals following a perinatal loss, however other forms of support were also found to be helpful. It is important for professionals to be aware of the wide range of possible support options that are available to patients. Individuals should be informed of professional support services by a medical professional within zero to thirty days following perinatal loss.

While the primary focus of this study was intended to be a comparison of men and women, the small sample number of men limited the ability to make significant conclusions related to gender. Of interest, however, the study revealed that there are significant differences based on whether the loss occurred in the first trimester, second trimester, third trimester or after birth.

How individuals grieve and cope following a perinatal loss is variable and there is no one form of professional support that will fulfill the needs of all individuals. It is crucial to offer access to multiple forms of professional support to help couples through this potentially devastating experience. Medical professionals, including genetic counselors, should supply information on resources for perinatal loss groups when appropriate.

REFERENCES

Armstrong, D. & Hutti, M. (1998). Pregnancy after perinatal loss: The relationship between anxiety and prenatal attachment. *JOGNN*, 27(2), doi: 10.1111/j.1552-6909.1998.tb02609.x.

Avelin, P., Radestad, I., Saflumd, K., Wredling, R., Erlandsson, K. (2013). Parental grief and relationships after the loss of a stillborn baby. *Midwifery,* 29(6), doi: 10.1016/j.midw.2012.06.007.

Cacciatore, J., DeFrain, J., Jones, K.L.C. & Jones, H. (2008). Stillbirth and the Couple: A Gender-Based Exploration. *Journal of Family Social Work*, 11(4), doi: 10.1080/10522150802451667.

Cacciatore, J., DeFrain, J. & Jones, K.L.C. (2008). When a Baby Dies: Ambiguity and Stillbirth. *Marriage and Family Review*, 44(4), doi: 10.1080/01494920802454017.

Carver, C.S., Scheier, M.F. & Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56 (2), doi: 10.1037/0022-3514.56.2.267.

Cote-Arsenault, D., O'Leary, J. Understanding the Experience of Pregnancy Subsequent to a Perinatal Loss. In Write, P., Limbo, R., Black, P. (Eds.) Perinatal and Pediatric Bereavement (pp.159-181), New York, NY: Springer Publishers.

Conway, K., Russell, G. (2000). Couples' grief and experience of support in the aftermath of miscarriage. *British Journal of Medical Psychology*, 73(4), doi: 10.1348/000711200160714.

Goldbach, K., Dunn, D., Toedter, L. & Lasker, J. (1991). The effects of gestational age and gender on grief after pregnancy loss. *American Journal of Orthopsychiatry*, 61(3), doi: 10.1080/10522150802451667.

Hill, P.D., DeBackere, K., & Kavanaugh, K.L. (2010). The parental experience of pregnancy after perinatal loss. *J Obstet Gynecol Neonatal Nurs*, 37(5), doi: 10.1111/j.1552-6909.2008.00275.x.

Huffman, C.S., Schwartz, T.A., Swanson, K.M. (2015). Couples and Miscarriage: The Influence of Gender and Reproductive Factors on the Impact of Miscarriage. *ELSEVIER*, 25 (5), doi: 10.1016/j.whi.2015.04.005.

Hutti, M.H. (2004). Social and Professional Support Needs of Families After Perinatal Loss. *JOGNN*, 34(5), doi: 10.1177/0884217505279998.

IBM Corp. Released 2014. IBM SPSS Statistics for Mac, Version 23.0. Armonk, NY: IBM Corp.

Kelly, M.M., Tyrka, A.R., Price, L.H., Carpenter, L.L. (2008). Sex Differences in the Use of Coping Strategies: Predictors of Anxiety and Depressive Symptoms. *Depress Anxiety*, 25(10), doi: 10.1002/da.20341.

Kersting, A., Wagner, B. (2012). Complicated grief after perinatal loss. Dialogues in clinical neuroscience, 14(2), PMCID: PMC3384447.

Martin, T.L., & Doka, K.J. (2000). *Men don't cry, women do: Transcending gender stereotypes of grief.* Philadelphia, PA.: Brunner/Mazel

McCreight, B.S. (2004). A grief ignored: narratives of pregnancy loss from a male perspective. *Sociology of Health and Illness*, 26(3). Doi: 10.1111/j.1467-9566.2004.00393.x.

Moore, T., Parrish, H. & Black, B.P. (2011). Interconception Care for Couples After Perinatal Loss: A Comprehensive Review of the Literature. *J. Perinat Neonat Nurs*, 25 (1), doi: 10.1097/JPN.0b013e3182071a08.

O'Leary, J. & Thorwick, C. (2005). Fathers' Perspectives During Pregnancy, Postperinatal Loss. *JOGNN*, 35 (1), doi: 10.1111/j.1552-6909.2006.00017.x.

SAS Institute Inc. 2011. Base SAS® 9.3 Procedures Guide. Cary, NC: SAS Institute Inc.

Thompson, R.J., Mata, J., Jaeggi, S.M., Buschkuehl, M., Jonides, J. & Gotlib, I.H. (2010). Maladaptive Coping, Adaptive Coping, and Depressive Symptoms: Variations across Age and Depressive State. *Behav Res Ther*, 48 (6), doi: 10.1016/j.brat.2010.01.007.

Zinner, E. (2000). Being a man about it: The marginalization of men and grief. *Illness, Crisis & Loss*, 8 (2), doi: 10.1177/105413730000800206.

APPENDIX A: Thesis Survey

Welcome to My Survey

You are invited to take part in a research survey about professional support desired by men and women following a perinatal loss (miscarriage, stillbirth or postnatal loss). Your participation will require approximately 10-15 minutes and is completed online at your computer. Please be aware of the risk of potentially feeling upset while recalling events related to the perinatal loss. Through this survey we hope to gain insight from individuals who have experienced a perinatal loss, as well as to learn what resources would be most beneficial following the loss. Taking part in this study is completely voluntary. If you choose to be in the study you can withdraw at any time. Your responses will be kept strictly confidential in a password protected computer. Any report of this research that is made available to the public will not include your name or any other individual information by which you could be identified. If you have questions or want a copy or summary of this study's results, you can contact the researcher at the email address listed here: hmueller@uci.edu. If you have any questions about whether you have been treated in an illegal or unethical way, contact the UC Irvine Institutional Research Board at IRB@research.uci.edu.

Clicking the "Next" button below indicates that you are 18 years of age or older, and indicates your consent to participate in this survey.

Introduction

Perinatal loss – miscarriage, stillbirth or neonatal death – is unfortunately a common experience for both men and women. Perinatal losses can have devastating emotional effects on couples. Both social and professional support can lead to improved healthcare outcomes for couples. I propose to survey men and women electronically to assess coping mechanisms and desired support following a perinatal loss. The purpose of this study is to determine the coping styles of men and women in the event of a perinatal loss, the type of professional support that would be most beneficial, and when/how this support should be offered. I hope to identify potential similarities and differences between men and women and determine what professional support services would be helpful following the event of a perinatal loss. This information may help inform future intervention strategies.

Demographic information

* 1. How were you made aware of this survey?

- By a friend/family member
- By a medical professional
- By a member of a support group
- By Facebook or another social media site
- Other (please specify):

* 2. Has your partner taken, or will your partner take, this survey?

- No
- Yes

* 3. What is your age?

- 17 or younger
- 18-20
- 21-29
- 30-39
- 40-49
- 50-59
- 60 or older

* 4. Are you female or male?

- Female
- Male

* 5. Which of the following best describes your current relationship status?

- Divorced
- In a domestic partnership or civil union
- Married
- Separated
- Single, but cohabiting with a significant other
- Single, never married
- Widowed

* 6. Ethnic origin (or Race). Please specify your ethnicity:

- American Indian or Alaskan native
- Asian
- Black or African-American
- Caucasian
- Hispanic
- Native Hawaiian or other Pacific Islander
- Prefer not to answer
- Other race (please specify):

* 7. What is your religion

- No religion
- Buddhism
- Christianity (including Church of England, Catholic, Protestant and all other Christian denominations)
- Hinduism
- Islam
- Jewish
- Other (please specify)

* 8. What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree
- High school degree or equivalent (GED)
- Some college but no degree
- Associate degree
- Bachelor degree
- Graduate or other professional degree

* 9. Do you have any living children?

- Yes
- No

* 10. How many total miscarriages or perinatal losses have you experienced with your current and/or previous partners?

- 0
- 1
- 2
- 3
- 4+

* 11. At what stage in pregnancy did your most recent miscarriage or perinatal loss occur?

- First trimester (0-12 weeks)
- Second trimester (13-27 weeks)
- Third trimester (28-40 weeks)
- After birth

12. At the time of the perinatal loss, what was your relationship status?

- Divorced
- In a domestic partnership or civil union
- Married
- Separated
- Single, but cohabiting with a significant other
- Single, never married
- Widowed

* 13. How much time has passed since your most recent perinatal loss?

- Less than 6 months
- Less than one year
- One to three years
- More than three years

The Brief COPE

* 14. The items on this page deal with ways you coped in the 3 months following the most recent perinatal loss. Each item says something about methods of coping. We want to know how much or how frequently you were doing what the item says following the perinatal loss—not whether it seemed to help or not, but how much or how frequently you were doing it. Try to rate each item separately in your mind from others. Use these response choices: (1) I didn't do this at all (2) I did this a little bit (3) I did this a medium amount (4) I did this a lot.

	1. I didn't do this at all	2. I did this a little bit	3. I did this a medium amount	4. I did this a lot
I turned to work or other activities to take my mind off things.	○	○	○	○
I concentrated my efforts on doing something about the situation I was in..	○	○	○	○
I said to myself "this isn't real".	○	○	○	○
I used alcohol or other drugs to make myself feel better.	○	○	○	○
I got emotional support from others.	○	○	○	○
I gave up trying to deal with it.	○	○	○	○
I took action to try to make the situation better.	○	○	○	○
I refused to believe that it happened.	○	○	○	○
I said things to let my unpleasant feelings escape.	○	○	○	○
I used alcohol or other drugs to help me get through it.	○	○	○	○
I tried to see it in a different light, to make it seem more positive.	○	○	○	○
I tried to come up with a strategy about what to do.	○	○	○	○

	1. I didn't do this at all	2. I did this a little bit	3. I did this a medium amount	4. I did this a lot
I got comfort and understanding from someone.				
I gave up the attempt to cope.				
I looked for something good in what was happening.				
I made jokes about it.				
I did something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping.				
I accepted reality of the fact that is had happened.				
I expressed my negative feelings.				
I tried to find comfort in my religion or spiritual beliefs.				
I learned to live with it.				
I thought hard about what steps to take.				
I prayed or meditated.				
I made fun of the situation.				

* 15. Following the pregnancy loss, did you participate in any type of professional support (ie. In-person support group, individual therapy, online forums, social media, books, or support from my religion/spiritual beliefs)?

- Yes
- No

* 16. What type of professional support did you receive? Check all that apply:

- [ ] Books
- [ ] In-person support group
- [ ] Individual therapy
- [ ] Online forum
- [ ] Social media
- [ ] Support from my religion/spiritual beliefs
- [ ] Other (please specify)

* 17. Please mark how strongly you agree or disagree with the following statement: I found this support to be helpful.

Strongly agree | Agree | Neutral | Disagree | Strongly disagree

* 18. Choose the reason that most closely fits why you did not receive professional support:

- I didn't think it would be helpful
- Obstacles(ie. time, distance) prevented me from receiving support
- I was not aware professional support was available
- I preferred to deal with the miscarriage privately
- I received all needed support from friends and/or family
- None of these reasons

* 19. Please mark how strongly you agree or disagree with the following statement: I believe, in retrospect, that professional support would have been helpful following the perinatal loss.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

20. What about this support did you find to be helpful?

21. What about this support did you not find to be helpful?

* 22. Please mark how likely the following statement is: If I were aware that professional support was available at the time of the perinatal loss, I would've participated.

- Very likely
- Somewhat likely
- Not very likely
- Not at all likely

* 23. What form of professional support do you believe would be most helpful following the event of a miscarriage?

- In-person support group
- Individual therapy
- Online forums
- Social media
- Support from medical staff (ie. doctors, nurses, genetic counselors)
- Support from religion/spiritual beliefs
- None
- Other (please specify)

24. Why do you believe this option would be most helpful?

* 25. Choose the one option that fits best. What would you find most beneficial to receive from professional support?

- To hear experiences of other individuals who have had a similar experience
- To obtain correct information regarding miscarriage (ie. causes, risk of recurrence)
- To receive suggestions on how to support your partner
- To receive validation of feelings

* 26. What gender would you prefer to be involved within the professional support?

- Same sex only
- Co-ed
- A mix of both same sex and co-ed groups

* 27. How would you prefer to be informed of the available services for support following a perinatal loss?

- Through social media (Facebook, etc)
- From your medical provider
- Through fliers posted in medical offices
- Religious figures
- Friends/family
- Other (please specify)

* 28. At what point following the perinatal loss would you prefer to be informed of the available services?

- 0-30 days after the miscarriage
- 1-3 months after the miscarriage
- 3+ months after the miscarriage
- Never

APPENDIX B: END OF SURVEY COUNSELING RESOURCE INFORMATION SHEET

Thank you

UNIVERSITY OF CALIFORNIA, IRVINE
COUNSELING RESOURCE SHEET

We appreciate your time and efforts as a participant in our study. We hope that you found your experience as a participant enjoyable and interesting. However, we acknowledge that some of the questions we asked are of a sensitive nature. Thus, we understand that you may have experienced some psychological discomfort during the study. Please contact the lead researcher, Holly Mueller, at hmueller@uci.edu if you have any other questions or concerns. Also, below is a list of resources that are available at low or no cost to help you deal with your feelings/concerns. We hope that you will take advantage of these resources if necessary.

UCI COUNSELING CENTER
Available for: UCI Students, Faculty, and Staff
Location: Student Services I, Room 203
Hours: 8am to 5pm, Monday through Friday
Phone: (949) 824-6457
Website: http://www.counseling.uci.edu/

HEALING HEARTS/FOREVER FOOTPRINTS
Available for: All Study Participants
Location: Saddleback Hospital and Other Hospitals
Phone: (714) 509-0065
Email: info@foreverfootprints.org
Website: www.foreverfootprints.org

AMETHYST NETWORK
Available for: All Study Participants
Location: Multiple Locations
Website: www.theamethystnetwork.org

EMPTY ARMS
Available for: All Study Participants
Phone: (949) 609-8370
Email: elaineq@saddleback.com
Website: https://saddleback.com/care/supportgroup/empty-arms-support-group/lake-forest

COMPASSIONATE FRIENDS
Available for: All Study Participants
Location: Multiple Locations
Phone: (630) 990-0010
Website: www.compassionatefriends.org

APPENDIX C: Request for Survey Distribution Blurbs

Facebook Status blurb:

Hello,
As a genetic counseling graduate student at the University of California, Irvine I am conducting a graduate research study on professional support desired by men and women following a perinatal loss. I created the attached survey in order to inform future intervention strategies for couples who have experienced a miscarriage, stillbirth or neonatal loss. If you have experienced a perinatal loss, please consider taking this 10 minute survey and passing it along to your partner. Feel free to share with other men or women who have experienced a perinatal loss.
Thank you!
(Insert link here)

Informational Content of Email to Leaders of Support Groups:

About the survey:
Perinatal loss – miscarriage, stillbirth or neonatal death – is unfortunately a common experience for both men and women. Perinatal losses can have devastating emotional effects on couples and it has been shown that both social and professional support can lead to improved healthcare outcomes for couples. The purpose of this study is to determine the coping styles of men and women following the event of a perinatal loss, the type of professional support that would be most beneficial, if any, and when/how this support should be offered. I hope to identify potential similarities and differences between men and women and determine what professional support services would be helpful following the event of a perinatal loss. This information may help inform future intervention strategies.

Link: https://www.surveymonkey.com/r/professionalsupportdesiredbymenandwomenfollowingperinatalloss

The survey should take no longer than 10-15 minutes. The first page includes an informed consent information sheet and the second page includes a general overview of the purpose of the study. The survey is attached here in PDF form for your review.

Content of NSGC Email Blast:

Dear NSGC member,

My name is Holly Mueller and I am a genetic counseling student at the University of California, Irvine. I am doing a research study on professional support desired by men and women following a perinatal loss (miscarriage, stillbirth, or postnatal loss). The goal of the project is to determine what professional support, if any, is desired by men and women following a perinatal loss and the best time to offer that support with the hope of shaping future intervention strategies. The study is intended for any man or woman that has experienced a perinatal loss in the past. If you, or any man or woman you know has experienced a perinatal

loss, please consider taking and/or sharing this survey. Further, please consider forwarding this to your partner as it is necessary for me to receive responses from both men and women to make meaningful conclusions.

Your participation will require approximately 10 minutes and is completed online at your computer. Please be aware of the risk of potentially feeling upset while recalling events related to the perinatal loss. Taking part in this study is completely voluntary and if you choose to be in the study you can withdraw at any time. Your responses will be kept strictly confidential in a password protected computer. Any report of this research that is made available to the public will not include your name or any other individual information by which you could be identified. The study was approved by the University of California, Irvine Institutional Review Board. If you have questions or want a copy or summary of this study's results, you can contact the researcher at the email address listed here: hmueller@uci.edu.

To access the survey please follow this link: https://www.surveymonkey.com/r/NSGCsupportdesiredbymenandwomenfollowingperinatalloss
THE LINK IN THE INITIAL EMAIL WAS INCORRECT. PLEASE REFER TO THIS LINK TO ACCESS THE APPROPRIATE SURVEY

Thank you for your time,

Holly Mueller
UCI Genetic Counseling Student
hmueller@uci.edu

The message above is a paid advertisement and the National Society of Genetic Counselors does not represent or endorse the accuracy of the information or the products or services described.

APPENDIX D: IRB Confirmation of Exempt Research Registration

CONFIRMATION OF EXEMPT RESEARCH REGISTRATION

January 05, 2017

HOLLY ANN-MARIE MUELLER
GENETICS AND GENOMIC MEDICINE
RE: HS# 2016-3232 *Professional support desired by men and women following a perinatal loss*

The human subjects research project referenced above has been registered with the UC Irvine Institutional Review Board (UCI IRB) as Exempt from Federal regulations in accordance with 45 CFR 46.101. This exemption is limited to the described activities in the registered UCI IRB Protocol Narrative and extends to the performance of such activities at the sites identified in your UCI IRB Protocol Application. Informed consent from subjects must be obtained unless otherwise indicated below. UCI IRB conditions for the conduct of this research are included on the attached sheet.

Information provided to prospective subjects to obtain their informed consent should, at a minimum, consists of the following information: the subject is being asked to participate in research, what his/her participation will involve, all foreseeable risks and benefits, the extent to which privacy and confidentiality will be protected, that participation in research is voluntary and the subject may refuse to participate or withdraw at any time without prejudice.

Questions concerning registration of this study may be directed to the UC Irvine Office of Research, 141 Innovation Drive, Suite 250, Irvine CA 92697-7600; 949-824-0665 (biomedical committee) or 949-824-6662 (social-behavioral committee).

Level of Review: Exempt Review, Category 2

Beverley W. Alberola, CIP
Alt. Member, Institutional Review Board
Registration valid from 01/05/2017 through 01/04/2022
UCI (FWA) 00004071, Approved: January 31, 2003

Determinations as Conditions of Exemption:

Informed Consent Requirements:

1. Signed Informed Consent Not Required
    a. Study Information Sheet Required

APPROVAL CONDITIONS FOR ALL UCI HUMAN RESEARCH PROTOCOLS

UCI RESEARCH POLICIES:

All individuals engaged in human-subjects research are responsible for compliance with all applicable UCI Research Policies. The Lead Researcher (and Faculty Sponsor, if applicable) of the study is ultimately responsible for assuring all study team members adhere to applicable policies for the conduct of human-subjects research.

LEAD RESEARCHER RECORD KEEPING RESPONSIBILITIES:

Lead Researchers are responsible for the retention of protocol–related records. The following web pages should be reviewed for more information about the Lead Researcher's recordkeeping

responsibilities for the preparation and maintenance of research files: Lead Researcher Recordkeeping Responsibilities and Preparation and Maintenance of a Research Audit File.

PROTOCOL EXPIRATION: The UCI IRB expiration date is provided on the exempt registration letter. All exempt protocols are registered for a maximum period of five years. If the study will continue beyond five years, a new Application for IRB review is required. No annual continuing renewals are required.

MODIFICATIONS & AMENDMENTS: Per federal regulations, once a human research study has received IRB approval, any subsequent changes to the study must be reviewed and approved by the IRB prior to implementation except when necessary to avoid an immediate, apparent hazard to a subject. Accordingly, no changes are permissible (unless to avoid an immediate, apparent hazard to a subject) to the approved protocol or the approved, stamped consent form without the prior review and approval of the UCI IRB. All changes (e.g., a change in procedure, number of subjects, personnel, study locations, new recruitment materials, study instruments, etc.) must be prospectively reviewed and approved by the IRB before they are implemented.

APPROVED VERSIONS OF CONSENT DOCUMENTS, INCLUDING STUDY INFORMATION SHEETS: Unless a waiver of informed consent is granted by the IRB, the consent documents (consent form; study information sheet) with the UCI IRB approval stamp must be used for consenting all human subjects enrolled in this study. Only the current approved version of the consent documents may be used to consent subjects. Approved consent documents are not to be used beyond the expiration date provided on the IRB approval letter. Current consent documents are available on the IRB Document Depot.

UNANTICIPATED PROBLEMS REPORTING: In accordance with Federal regulations and HRP policies, only internal (where UCI serves as the IRB of record), Unanticipated Problems must be reported to the UCI IRB. Unanticipated Problems should also be reported to the UCI IRB when UCI is relying on an external IRB, and the incident occurred at UCI or the incident occurred at an offsite location on a study conducted by a UCI LR. Unanticipated Problems must be submitted to the IRB via the Unanticipated Problems (UP) Report within 5 business days upon the Lead Researcher's (LR) knowledge of the event. For additional information visit the updated HPR webpage on Unanticipated Problems.

CHANGES IN FINANCIAL INTEREST: Any changes in the financial relationship between the study sponsor and any of the investigators on the study and/or any new potential conflicts of interest must be reported immediately to the UCI Conflict of Interest Oversight Committee (COIOC). If these changes affect the conduct of the study or result in a change in the text of the currently-approved informed consent document, these changes must also be reported to the UCI IRB via a modification request. Research subject to COIOC oversight is not eligible for Extended IRB Approval.

CLOSING REPORT:

A closing report should be filed with the UCI IRB when the research concludes. Visit the HRP webpage Closing a Protocol for complete details.

APPENDIX E: Full List of Free-Responses for Survey Question 19 Asking What About The Received Professional Support was Helpful

That I wasn't alone in my feelings, emotions, etc. The emotional support that other women whom also experienced miscarriages gave me was very beneficial to me. They truly understood me.
Therapy helped my spouse understand where I was at and what I was feeling. The online community helped me vent and understood me.
Discussing with individuals in the similar circumstances who understood.
It was an outlet to express my feelings and talk about what had happen.
Just talking to someone who wasn't a family member or friend.
I found other women who had been through the same thing and they had suggestions for things that had worked to improve their future pregnancies
They were experiencing and recovering from the same loss I was at the same time I was.
The friendships I made
It allowed me to talk about it with people who knew what it was like and wouldn't tell me that it was better than having a baby with problems.
People actually talking about it and not minimizing what had happened.
One on one therapy - was able to talk about how it made me feel and go through the stages of loss
Spiritual perspective and faith in God's plan
The people in my support group had unfortunately all experienced losses as well, but it was very beneficial to hear their stories and to understand that my feelings were not unusual and actually normal.
Talking to others who had been through the same thing.
Connecting with other women who had gone through the same thing.
talking
I read abook about a woman who suffered from several miscarriges and how she moved on, and I found the book to be encouraging.
perspective
open forum to be able to talk about my thoughts, process what happened, try to cope with my thoughts going forward
Knowing others went through it
I tended to keep a lot pent up until I got to therapy and then would just start crying and would say things out loud I didn't want to say anywhere else
Being able to talk about the loss, knowing you're not the only one who endured this type of loss, and remembering there are others with worse situations.
I longed for a sense of belonging. The miscarriages made me feel like I didn't fit in with friends who were parents or single people not trying for pregnancy. I felt very alone and the support groups helped me have a sense of community and to feel understood in a way others (not experiencing infertility) could not.
Talking to people who truly understand what I was going through. Not having to put on a brave face. Getting time and support to cry and process. Giving my partner a break from being my main support person. Not having to deal with strange pity reactions from others.
Connection, empathy, educations, resources, hope.
My husband and I found a grief counselor for 3 months of individual weekly sessions. I was already seeing a therapist in another capacity, but he recommended that we seek separate couples counseling specifically for this grief. I found the experience to be very helpful in working through my grief in a way that strengthened my marriage. I like private counseling versus group therapy because of the added privacy. I feel more comfortable

really expressing myself. And I feel that being there with my husband was especially helpful as it was a tragedy we both experienced together.
Helpful to be around people who understood.
Internet strangers have a huge range of experience, and within these groups I was able to learn how others dealt with miscarriage and apply that to my own life.
Just being able to talk, reason, understand, and vet through the pain of him passing away.
Believing in God and that my child was in my future even though she wasn't in my present life gave me hope. Having people praying for me helped as well.
The therapist I saw had also had miscarriages and it was helpful to talk to someone who understood how I was feeling and what I had gone through
Hearing that I was not alone and other people had been through what I was going through.
It was helpful to be around other people who had gone through my situation. Especially with the circumstances surrounding our loss (termination for medical reasons). It felt like no one I knew "in real life" had ever experienced this, but I actually found several on a loss forum that had.
Talk with my friends who have gone thru this. A lot of time to cry it out with suport from hubby and friends. One on one time with my pastor and took communion.
-Talking about it -having that allotted hour to process my feelings/grief, not having to worry how my words would impact my therapist or feel like I had to support them in anyway while talking about it felt like a relief --it was reassuring to hear that my feelings/thoughts/actions were completely normal -helping me to let go of some of the guilt for wanting to be pregnant again so quickly
Someone to Express my sorrow and frustration without judgement
Could talk about it and my feelings. Learn that it was common but others were reluctant to share about similar experiences.
I found it wshelpful to be in a group with peers that had similar experiences to ours. It helped to hear other stories and know we weren't alone. I also found individual therapy helpful too.
Knowing others had been in our situation and got through it
In the first three months, our Share support group was the most helpful because it meant so much to be in a room of other parents who had been through something similar. It helped to not only know that we were not alone, but that there wasn't anything wrong with us. We had a REALLY hard time finding an individual therapist that was a good fit for us who could understand that losing our daughter at 40.5 weeks, after her due date and shortly before birth, was a traumatic loss. We went through 3 other therapists before finding our amazing therapist that we see now as a couple for grief. She has helped us process so much. The physical aspect of the loss was also just devastating- my body could not understand that I didn't have a baby to feed and I was engorged and icing for 3 full weeks- having other Moms at our support group understand what that is like really helped me to feel less awful. The empathy and the community and feeling like we had a place where we could just "be" was a comfort. We still go every month to our support group. We also found as many books as we could right away and spent most of our days taking turns reading them out loud to one another. My biggest support was, and still is, my husband and partner, Jonathan. People understanding, listening and not trying to fix the unfix-able helped us learn to bear the unbearable,
Talking to others dealing with the same type of loss.
It was nice to know that others were dealing with the same thing and could relate the same thing I was feeling. However, it was also strange because some people in the group were still dealing with the loss, hard, 3+ years later. I could not allow myself to be that person.
Just that I'm not the only, which can feel like that most of the time. And that the feelings I was having was not just me, other felt the same way
Finding others who were going through the same thing
I knew that I was not alone. I had people to talk with who actually understood what I was experiencing.
Others who experienced what I had experienced. Also, the books gave me something to do and helped me

understand how I was feeling.
I've found professional counseling individually and as a couple to be helpful. I was involved in both types of counseling prior to this loss due to a personal history of depression and anxiety. I found talking about the loss with my therapists has helped me work through it and my feelings about it. I find it helpful to have professionals outside of my family and friends to help me process things.
Reading other women's stories about their experiences helped me know what to expect and to normalize the experience.
I was speaking with an objective third party who was t my partner or family and could look at the situation from the outside in. She gave good advice and offered me a space where I was listened to and was allowed to be sad.
perspective
Knowing wasn't alone. People knew and understood were I was coming from.
My religious beliefs helped me to be more accepting and be thankful that I had multiple live births before this miscarriage. Reading helped me realize that statistically I was so fortunate to have had multiple healthy births before I ever miscarried.
I was able to read of others that experienced miscarriage and relieve burden of failure, fault, and negative feelings.
Connection, release of emotion, a safe place.
It helped me to process things, to know that I was not alone, to validate my experiences and feeling as normal, to know that someone else cared and would talk about it with me.
Being with others who understood and didn't judge me. It also helped to hear their stories to give me different perspectives on loss.
Being able to vent and cry and not feel judged
Finding people in similar situations
Knowing I wasn't the only one suffering that immense loss and heartache and that there were others who could truly relate
A little
Not feeling alone. And the crazy things you feel, others who have lost, also feel. The in person support group has created a couple new friendships.
Being around and connected with others who have been through similar experiences.
Knowing I wasn't alone and my feelings were normal was a tremendous help.
Talking to others who understood without having to be face to face
Hearing other's experiences, sharing our story
Most of the support my wife and I received was through and grief and loss support group for parents whom lost a baby during pregnancy or shortly after birth. Hearing and listening to other parents who understood what we were going through and who listened to us share our stories helped us to cope with the lose of our newborn. This support allowed us to safely process our loss with people who understood.

APPENDIX F: Full List of Free-Responses for Survey Question 21 Asking What Was Not Helpful About the Received Support.

Hearing the horror stories from other people made me anxious. It made perinatal loss feel more common and made me question whether I would be able to have any children in the future.
I checked two different kinds of support at Q. 16 so I wasn't sure how to answer Q. 17. If it's not too late to change this survey to ask that question separately for each type of support selected, that might give you more meaningful results. I went to one in-person group session with my wife. It was a bad experience. I listened to other people tell very sad stories, and saw that some of them had been very broken. It was depressing and I didn't find it personally helpful at all. My wife had better success with other support groups. I also did 3 CBT sessions. That was OK. It didn't change my perspective on things but it felt good to tell the story through chronologically, and talk about it in confidence with somebody who isn't part of my family or social network.
The counselor I saw did not seem to understand or know how to support my feelings of loss, hopelessness, and helplessness.

APPENDIX G: Full List of Responses for Question 23 for participants that chose "Other (please specify)"

i wanted to select all of the above forms of support
whichever mechanism that works for the individual, perhaps a combination may best suit them.
Support from friends and family (like you would after any other loss)
I don't think one forum is what everyone needs. Each person and loss is different so it depends on what the individual deems helpful.
I can only speak to the experience of Stillbirth- In person support groups.
Personally I found individual therapy worked well for me. But I think the best choice depends on the individual and his/her circumstances. For example some people may prefer to take part in a support group or find it easier to use online support mechanisms.
I think it is such a personal thing, there isn't one thing that is most helpful for everyone.
Everyone is different
From several of the above. Hard to choose one.
support from friends
Not sureIt helps to have real life conversations about your experiences. A safe place to discuss openly with other people whom truly understand your pain.

APPENDIX H: Full List of Free-Responses for Survey Question 24 About Why This Professional Support Would be Preferred

It helps to have real life conversations about your experiences. A safe place to discuss openly with other people whom truly understand your pain.
When something shitty like this happens. People want to know why. What happened? Can we prevent this from happening again? They look to professionals to fix what they feel is broken.
You get to hear from the experience of others and realize you're not alone.
Other people who've been through what I've been through.
People are often more expressive when interacting online.
Low risk high reward
Professional emotional help would have been very beneficial
I think I needed to hear answers specific to MY experience and MY situation. I had medical questions and could only get emotional answers (from family/friends) .
For me, my faith was greatly strengthened in the months following my miscarriage
I'm a scientist and I needed to make sense and of what happened in a logical, non-emotional way to help me cope. Especially in the beginning.
Privacy
After I had my miscarriage and the doctor confirmed it. They just sent me home. That was it. No answers, no offer of support. It was lonely and scary.
Professionals are too clinical, can not relate. Support group has been where you are and can empathize.
Eternal perspective
In hindsight, dealing with infertility, and miscarriage was a little much probably for my family and friends to understand and help me cope with because they had not experienced it themselves.
I think this would be most helpful because it is often the medical professions who are dismissive of it and don't validate your emotions.
Simply because with an online forum, you will have the largest "audience" and the most people who have been in a similar situation. For me, I became obsessed with finding a reason why I had my two losses and was able to speak with the most people in an online setting about gained so much knowledge for their experiences.
It helps you to not feel alone.
They can give advice tailored to a woman's individual case
Seeing firsthand who has been affected. Friendships and bonds could also grow because of it.
The anonymity of an online forum makes it feel safe to let all your feelings out.
I've used individual therapy in the past in tough situations and found it helped.
Could be focused on my specific concerns, it is private, and because I have found individual therapy helpful in the past for other issues.
best individual fit for me
It would allow you to reach out when you needed support without having to attend a group. It would also help ou to feel supported.
comfort and familiarity
impossible to answer this for everyone, this is just for me. i say this because it was most helpful to me, but i know it wouldn't be for everyone. i didn't have an outlet otherwise so this was the best option for myself.
It's nice to have a safe place to say anything.
I think talking to others who have experienced the same would be reassuring and productive
It helps to share your pain with others who can understand the loss.
Discussing pain with someone who is practiced at providing a safe, constructive environment helps process the pain.

Meeting and sharing with people that can relate in a meaningful way to your loss, hear their coping mechanisms, maybe help one of them.
It helps to feel like one of many who are having the same negative experience and to learn from others how to cope.
I'm a private person so individual therapy would have helped me most. I had TERRIBLE support from my medical staff and they treated this miscarriage/ DNC in the worst way possible.
I found the in-person support group, individual therapy and online forums (specifically a blog I posted to and others that I read) to be incredibly supportive. The in-person group was the most rewarding for me as it helped me feel validated and less isolated with my grief and frustration.
Everyone's situation is different and individual therapy is the most well designed to help with that.
For me, one-on-one talking with a caring, empathic, informed person is the most helpful. For someone else, a spiritual approach would work better. I would never share something this painful and personal on social media.
You feel so so alone in this... connecting, face to face with other people is so important.
In a private therapy setting, people are more comfortable opening up about really painful experiences and their feelings about those things.
My situation was private and would have appreciated the discrete help
I'm not sure what option is most helpful
Everyone deals differently about a miscarriage.
I trust their input. I can find other people's stories online relatively easy. They don't help. Just make me more sad.
Knowing how frequently miscarriage happened would have made me feel less isolated
To know that you're not alone
I found the group therapy made me more upset. I "took on" other people's pain, especially those who were further along in their pregnancy (ie. still birth).
It is always better to talk with people who can understand your feelings and situation in a very specific way.
It's available anytime, and the group is mostly peers with similar experiences. That allows me to access support anytime I'm feeling down or have a specific question.
Keeps anonymity of situation and allows you to grieve privately while still reviewing support and advice.
To try and help me understand why it happened, what could be done to prevent it happening again.
In the beginning it is very personal. Especially when you have to make the decision to end life support. Groups for me where better once I was more functional.
People feel like they did it to themselves or are scared and individual therapy they know it's just them and the councler no one else there to judge them.
My husband handled it differently. I almost left him after because he wasn't there for me during his own sadness. I never put himself in my shoes.
Anonomous and on your own time.
I truly came to believe that grieving is a skill that needs to be learned with the help of a professional, just like anything else that's new.
Ability to somewhat "protect" yourself without having to be so "exposed" in an in-person setting. Really though, some people may not thrive in that same situation.
I think social awareness and education of how common it is. I was in awe at the number of friends who had one and dont talk about it.
It was a private matter that I would have felt more comfortable dealing with one-on-one.
ability to talk to others/meet others who have recently been through same thing - not same as talking to someone never meet online
I have found it very helpful to connect with other people who have experienced a miscarriage as well. It has been comforting to know that we are not alone, and that there are people who understand what we are going through. So I think a support group would be very helpful to have more of these opportunities. However, therapy is

helping me greatly, to have that one on one support that is catered to my needs and where I am at. I don't have to worry about supporting anyone else in my therapy session, for that one hour.
See above- I accessed in person support, individual therapy, caring doctors, pregnancy forums
It was imperative to meet and talk with others who had been through something similar. The community, the empathy and the bond helped us to get through all of the other days because we actually knew other people that had a similar horrific and devastating thing happen to them and their baby. Knowing we weren't alone was a lifeline.
With miscarriages, every person deals with it differently and has a unique experience.
personalize to how each person deals with grief
After that happens you want answers, too often the answers aren't there. All you are left with are emotions. In group support is the best way, the most human way, to express emotion by empathizing and understanding "you" aren't alone.
I sure, but it does help to know you are not alone with what you are going through and other have the same feelings and you are not crazy
It's more private and people are willing to open up more
You are still processing what has happened. You may not want to talk about it in person immediately following the loss, but you also want to know you're not alone.
The loss experience was stigmatizing in my own mind. And it strained communication with some of my friends, who didn't know what to say. I had a hard time adjusting to what I began to think was my new identity, as someone who wouldn't have children despite thinking for most of my life that my body would be well-equipped to do so-- big breasts, big hips. Body image confusion was a huge factor in my depression about it. This seems like the kind of thing a support group would be helpful for.
I run a support group and I see the good that the parents do for each other in times of need. Many of them use professional therapy as well, but the bond they form with other parents can really only be done through in person support groups.
I think my history of individual therapy allowed me to believe that continued individual therapy would help me through this difficult time. I think that even if I hadn't had a prior history of working with therapists, I would have still chosen individual therapy as my starting point following this loss. I'm a fairly private person and did not want to take part in a support group, either in person or online. I wanted to focus on handling my own emotions rather than worrying about what others would think or feel.
Personally, I prefer an individual approach with more of a dialogue.
No one around me understood
It would have allowed me to hear how others have dealt with and to feel less alone.
It's helpful because it needs to be talked about.
One can learn some of the stages of loss and grief and some of the physical symptoms that can occur, and can learn coping strategies without being exposed to the sadness of others. Maybe some people feel comfort in knowing that they are not alone in their journey, but I was not in that mind set. I wanted to hear how other people were coping and what was helpful to them, but I did not want to hear the tragic stories of others' losses.
everyone experiences loss in their own unique way
See answer to Q. 18.
Same as before
Each pregnancy and each person has unique stories/needs.
Everyone adjusts to perinatal loss differently
Connects where my needs are most met.
It's helpful to be around other parents who lost a child, who are grieving and processing things, knowing it is a safe space to talk about anything freely
Hearing from others on how to move forward (coping skills).

These people have been in the same situation
It's still such a taboo topic and misunderstood. Being with others who get it is comforting.
I did this with my first miscarriage.
Not feeling so alone
Knowing that I'm not alone is comforting.
I'm not a group person
Being able to acknowledge the loss of life with others going through the same situation helps
It helps you understand that it only hasn't happened to you
The personal touch is helpful.
To talk with people who went through the same thing. The only reason I didn't join the Share was I'm a neonatologist and I didn't want the possibility of former patients' parent in the group not feeling comfortable with me there as they were going through the different stages of grief, etc. I didn't want to limit their healing process.
I found it helpful to hear how others coped and to truly feel that I wasn't alone.
Able to talk thru feelings
It forces you to get out
In the immediate time of loss, they were all I had
Being around other people, hearing their stories, sharing our story, getting support
Talking to other people who "get it" is important. Others are able to normalize your feelings and reactions. Talking to people who have been there was helpful to us.