UNDERSTANDING AND ADDRESSING THE NEEDS OF WOMEN EXPERIENCING PERINATAL LOSS LEADING TO HOSPITAL PROTOCOL CHANGE

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Abstract

Perinatal loss is a relatively common occurrence and is defined as any loss, from conception through the first 28 days of life, including miscarriage, stillbirth, and neonatal death. In this dissertation, perinatal will refer to the death of an infant due to miscarriage or stillbirth. Researchers says that understanding how mothers perceive the care after perinatal loss can play a significant role in their care, treatment, and health. The purpose of this appreciative inquiry action research study was to examine what women need to feel supported, emotionally, physically and spiritually within a hospital setting and how these supports impact women experiencing perinatal loss. Through participation interviews from women who experienced the loss and questionnaires answered by nurses and social workers, an investigation of what women perceive to be beneficial in receiving care after perinatal loss. Interviews were used to collect information from a sample of nine women who experienced prenatal loss in a hospital setting, as well as five nurses or social workers who provided support to these individuals were asked to participate in an interview, but if unable to then a questionnaire will be email to them. The information collected in this study was useful to medical and mental health professionals to develop more effective interventions to assist staff to support the women experiencing the loss, while validating the loss and treating the women with respect.

Dedication

It was July 9th, 2008 when my life changed, never to be the same again. The doctor walked in the room and said, "I am sorry, but your baby has died." Those words will forever be in my mind and heart. I delivered my daughter, Anna Mae at 16 weeks on July 10th. Since this experience, I have always had a passion for helping bereaved parents and for making society understand the intense emotions that are involved with such a loss. This dissertation is dedicated to my daughter, who has been the shining light in this process.

Acknowledgments

Unbeknownst to me, the loss of my daughter Anna would lead me to pursue my doctorate. If it was not for her entering my life almost 8 years ago, I would not have had the passion to pursue this journey. It is due to her short, yet inspirational life that I am able to research how women can be supported while in a hospital after a perinatal loss. Not only has Anna impacted my life—I want her spirit to be carried on. In completing this dissertation, I hope to honor my daughter by helping others become educated on perinatal loss.

I first would like to thank God for giving me the strength to keep going when I wanted to throw in the towel, and answering my prayers along the way. Nothing is greater than the power of God. Throughout this journey, my family has been there for me every step of the way, whether watching my boys so that I could study, listening to me vent on how stressful this dissertation process has been, or just encouraging me along the way. It has been truly amazing to receive their support over the years of completing this journey. Both my son's Brody and Brackin have seen me stressed, sad, happy, and frustrated during this process. However, they always would pick up my spirits by telling me how much they love me. Brody and Brackin keep their sisters' spirit alive by talking about her, attending special events like the walk to remember, sweet pea sisters and brothers gathering, going to her grave, and sending notes in balloons to heaven. My sons have been such an inspiration to my journey. Special thanks to my husband, Michael, who read all my papers and stayed up late nights to help me study. He has been an amazing support system and continues to give me unconditional love through this experience.

I would also like to thank my mentor, Dr. Ruth Ahlman, for providing me with guidance throughout the many processes of this dissertation. She has dedicated numerous hours to reading and revising my dissertation. Without her guidance, I would not have been able to complete this process.

Lastly, I was able to have the amazing opportunity to meet wonderful women who have experienced perinatal loss. These resilient women were willing to provide me with such valuable information and displayed such strength in telling their story. I could not have asked for nicer and caring women to work with throughout this study. The healthcare professionals were also an important aspect to this study. I thank every person in the study: without them, it would not have been possible.

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CHAPTER 1. INTRODUCTION

Introduction

When pregnancy is interrupted by a miscarriage, stillbirth, or other types of fetal demise it can be devastating to the family going through such a traumatic event. According to March of Dimes Foundation (2014), as many as 10–15% of known pregnancies end in a loss (para. 1). When a loss occurs, it is pivotal that the family receive support from healthcare professionals as well as social workers within the hospital. According to the literature, the care, treatment, and support of women have improved greatly in the last 30-50 years (Johnson & Langford, 2010). However, it has only been since the late 1960s and early 1970s that pregnancy loss has been recognized as a grief-producing phenomenon (St. John, Cooke, & Goopy, 2006).

Kersting and Wagner (2012) stated that perinatal loss is a tragic event that can cause emotional and physical suffering. Perinatal loss can bring about several conditions of mental health, such as depression, complicated grief, posttraumatic stress disorder, and a myriad of emotions (Stratton & Lloyd, 2008; Ward, 2012). Hospitals have attempted to support women who have experienced perinatal loss by developing grief and loss support groups or other types of programs to promote a healthy grieving process. Unfortunately, the timing of such interventions and approaches is after the trauma. As such, interventions need to be developed so that women are able to feel supported during this time of loss (Leon, 2008).

The research methodology used for this study was appreciative inquiry action research, a qualitative approach. This study allowed bereaved women to communicate

openly their experiences about perinatal loss and how support within a hospital setting affected their experience. The women had the opportunity to participate in a semistructured, open-ended phone interview. Data collected was analyzed to gain insight on how interventions could be improved within the hospital setting. Information that is provided through the interviews, field notes, open-ended questionnaires to healthcare professionals currently working with women experiencing perinatal loss, and member checking was shared with hospital administration for use in future program planning. Healthcare professionals in this study included social workers and nurses.

While this dissertation focuses on women's perspective regarding perinatal loss, more research needs to continue to be done on fathers, perspectives, family support, cultural context of perinatal loss, and roles of support groups. In this chapter, a description of the problem is offered, as well as a discussion of the purpose of the study and the research design. Lastly, a discussion of grief, bereavement, and other definitions will be provided for clarity.

Background of the Problem

Prior to the 1960s, there was absence of awareness in both medical and psychological literature that perinatal loss generated considerable suffering, due to perinatal loss not being discussed among society (Moore, Parrish, & Black, 2011). Perinatal loss was considered a silent loss that was not discussed (Moore et al., 2011). It was not until the 1980s that literature directly discussed perinatal loss and raised awareness among healthcare professionals. Peppers and Knapp (1980, as cited in Leon, 2008) were among the first to make society aware of the grief and emotion that women feel after perinatal loss (Leon, 2008). It is important to note that birthed stillborn babies

50-70 years ago were not held or seen, and professional safeguarded parents from having any physical contact with their babies (Blood & Cacciatore, 2014). It was viewed that this separation was thought to prevent grief (Koopmans, Wilson, Cacciatore, & Flenady, 2013). Literature has continued to show a major gap in the ways perinatal loss is acknowledged within society and how hospitals support those who have experienced a perinatal loss (O'Leary & Warland, 2013), even after 35 years of literature. There was no understanding by society or healthcare professionals of a parent's need to process the loss (O'Leary & Warland, 2013).

Since that time, hospitals have made significant changes to policies and procedures to increase awareness among healthcare professionals. Research of perinatal loss is growing, but the bereavement experience for women continues to be underresearched (Gold, Boggs, Mugisha & Palladino 2015). More qualitative research needs to occur to help gain a better understanding of how women can be supported, both physically and emotionally. Hughes and Goodall (2013) reported that perinatal loss continues to receive little recognition and remains unacknowledged or underemphasized, despite knowing that the care provided by professionals during the time of loss has a lasting impact on families. This dissertation therefore investigates how to support women who experience a perinatal loss and what interventions would be beneficial to increase support within the hospital setting.

Statement of the Problem

Within a hospital setting, many women felt that the behaviors and attitudes of health professionals were not helpful and adequate care is not provided by hospital staff (Stratton & Lloyd, 2008). Women that experienced depression, anxiety, and self-blame

felt a lack of support (Stratton & Lloyd, 2008; Ward, 2012). Stratton and Lloyd (2008) found women perceived that statements like "you can have another baby" displayed negative attitudes from healthcare providers (p. 8). Women need to be shown compassion, validation, and understanding when experiencing a perinatal loss. Women need to be shown that their baby mattered and want to have opportunities to say goodbye (Garstang, Griffiths, & Sidebotham, 2014). Garstang, Griffiths, and Sidebotham (2014) found that women wanted professionals to understand that they wanted the following three items: "to say goodbye to their child, to understand why and how their child died, and to feel supported by professionals" (p, 272). Stratton and Lloyd (2008) noted that evidence-based guidelines for providing hospital-based interventions following a miscarriage were beneficial to women. Interventions provided by the healthcare professionals and social workers decreased feelings of loneliness and isolation (Stratton & Lloyd, 2008). In conducting this study women will have the opportunity to share what interventions helped both in early and late pregnancy losses. Therefore, understanding perinatal loss and how care is provided within the hospital will have a direct impact on the recovery process for women experienced the loss.

Qualitative studies have been able to find a correlation between support from healthcare providers lower anxiety and depression with women experiencing a loss (Koopmans et al., 2013). Smart and Smith (2013) noted that women often do not have an understanding about treatment options after the loss. Literature has shown that there are few qualitative studies that explore the perception of women on the way they can be supported in a hospital setting (Hughes & Goodall, 2013). Literature suggests that the recovery of women is influenced by whether they feel that they are receiving satisfactory

care (Stratton & Lloyd, 2008). Women struggling with perinatal loss need to be supported within the hospital and given validation, support, and time to deal with the loss. Having healthcare professionals show a lack of empathy, little communication, and failure to acknowledge the loss as a major event no matter which stage the loss occurred has made women feel unsupported while experiencing a perinatal loss (MacConnell et al. 2012). The research goal of this study is to understand the perceived needs of women who experienced a perinatal loss and address the outcomes with hospital personnel.

Purpose of the Study

The overarching goal of this research is to understand and address the needs of women experiencing perinatal loss. Understanding how hospitals can support these women will potentially impact women's experiences. Smart and Smith (2013) argued that team approaches, like a transdisciplinary team, are effective and ensure that comprehensive care is provided to women suffering a loss. Providing women with support by a team rather than an individual will help make sure that all aspects of her recovery process are met. Smart and Smith (2013) also discussed other areas that caused issues for supporting these women: financial constraints within the hospital, inefficient communication between departments, and attitudes among nursing staff. In addition, the authors identified that no matter the type or size, hospitals struggled with delivering effective care to families who suffer a loss (Smart & Smith, 2013). Pastor-Montero et al. (2012) also argued hospitals struggle with delivering effective care, stating that few hospitals have put into place protocols or interventions for cases of perinatal loss. More exploration of the grieving process during and after a woman leaves the hospital needs to continue being researched.

As more research becomes available in perinatal loss, new approaches for developing better standards of care can be developed. Providing women with adequate information and support is needed to improve the grieving process. Hospital professionals should begin understanding the significance of trauma related to perinatal loss and how it may affect those experiencing it. Therefore, understanding and addressing the needs of women will also help hospital administration understand or review existing problems with their protocols.

Perinatal loss emotionally impacts not only on the parents who experienced the loss, but also the professionals involved in their care. The purpose of this study was to develop an understanding of what women need to feel supported. This will then give healthcare professionals the knowledge to increase support to women by providing multiple interventions, which will allow for professionals to deliver effective patient-focused care. Carlson (2012) acknowledged that nurses and other professionals may not provide opportunities for women to make memories, by denying women to hold their babies, take pictures, etc.… because of their own lack of knowledge on the subject. Having healthcare professionals understand that allowing women to be given opportunities to make memories will help the women with their grieving process, but also it provides patients to choose what interventions are important to their care. Jonas-Simpson, Pilkington, MacDonald, and McMahon (2013) supported this view by reporting that little attention is given to nurses during training in both school and work pertaining to handling perinatal loss. Nurses stated that it was difficult caring for bereaved women and expressed the need for further education and preparation (Jonas-Simpson, Pilkington, MacDonald, & McMahon, 2013). The lack of knowledge and education for nurses and

other professionals supporting perinatal loss has influenced patients and made them feel unhappy with the care they received (MacDonald & McMahon, 2013). This study provides suggestions on what women have perceived as being supportive interventions, which have helped with feels of validation of their loss. Encouraging the women to memorialize the loss and finding ways to give symbolic memories to the mother will promote validation of the baby (Leon, 2008).

Significance of the Study

An unexpected death of an infant, whether through early pregnancy loss, stillbirth or neonatal death it is often devastating and a traumatic event (Roose & Blanford, 2011). Grieving this loss needs to start at the hospital to help promote healing. Healthcare professionals may need to have more training and knowledge to support these women. Many women experience disenfranchised grief which can be defined as a loss that is not recognized openly (Moore et al., 2011; Rowlands & Lee, 2010). Likewise, society shows lack of support and acknowledgement of the loss (O'Leary & Warland, 2013). While most studies have focused on perinatal loss from the perspective of both parents, effects on subsequent pregnancies, and nurses' perspectives, few studies investigated the perception of care from the women's perspective through appreciative action research inquiry. The intent of this study is to investigate how hospitals can improve best practice protocol in order to support women who experience perinatal loss.

Understanding how to intervene and develop best practice protocols will improve the experiences of women suffering a perinatal loss. The impact of this study contributes to changes in hospital protocols and interventions throughout local and regional hospitals. Sutan et al. (2010) mentioned that healthcare professionals need to assess the significance

of parents' perception on perinatal loss before giving care or providing interventions. There is no universal response to perinatal loss, but instead a combination of resources, tools and interventions. This study provides healthcare professionals the platform to review current policies and protocols, and develop new policies and protocols to better support the women during this distressing time.

Research Design

The study employed an appreciative inquiry action research methodology, using a qualitative approach with semistructured phone interviewing to collect data and to capture the personal experiences of nine women who experienced perinatal loss. Interviews were offered to nurses and social workers. However, if they were unable to interview, a questionnaire with five open-ended questions was sent through email. Appreciative inquiry action research is particularly appropriate for this study because collaboration with the women through phone interviews was an effort to increase understanding of how they can be best supported by soliciting their first-hand knowledge and experience. Adams (2010) noted that semistructured interviews aim to explore in-depth experiences with a clear purpose and structure. This method assisted in mapping out the organizing ideas of what "being supported" means through the eyes of the participants. Adams (2010) suggested that using a semistructured interview can let the participants feel that they are truly being listened to for the first time.

The questionnaires that were provided to healthcare professionals included five open-ended questions used to solicit information on professionals' perception of care, support provided and trainings that have helped or hindered a women's experience. Nurses and social workers responded to a flyer that was located in the hospital so that

professionals can self-identify. The questionnaire took about 30-60 minutes to complete and was emailed back within two weeks of receiving the information.

Research Questions

The goal of this research study is to address the needs of women who experience perinatal loss in order to improve hospital protocols. The main research question is: What are the needs of women who experience perinatal loss, and are those needs being met within a hospital setting? The three research subquestions are:

1. What are the physical, emotional, spiritual, and social needs of women who have experienced a perinatal loss?
2. What do women find to be helpful in coping with perinatal loss when in a hospital setting?
3. What are examples of compassionate care as revealed by women who have experienced perinatal loss?

Assumptions and Limitations

A limitation to this study was that the participants who self-disclosed did not deliver in the same hospital. It is assumed that their experiences related to the loss and services of the hospital staff will differ. When recruiting for this study, women who were dissatisfied with their support may be the only ones wanting to participate, therefore possibly skewing results. Another limitation is that women may not be truthful or give a negative perception of what was actually offered. The intent of this study was to gather data on what women perceived as helpful/not helpful support offered by hospital healthcare professionals.

To deal with the limitations of the study so that they did not affect the outcome of the study, questions for the women not only addressed their dissatisfaction with support in the hospital setting, but also what was helpful. This allowed for a better perspective of what is working well and what needs improvement. Truthfulness and having a negative attitude were addressed when signing the informed consent form. Participants were asked to be as truthful as they can be and inform them that the information disclosed will be confidential. Having the participant understand their confidentiality may have encouraged the participant to tell the truth. Lastly, due to the size and variation of age, location, racial differences, expectations of care, socioeconomic status, and perceptions of the participant, information was not able to be generalizable to all women who have experienced a perinatal loss. However, the study did focus on how healthcare professionals can better support and address the needs of women experiencing perinatal loss.

Definition of Terms

Bereavement. When individuals are going through the process of suffering a loss and beginning to recover from said loss (Kowaleski, 1997).

Fetal death. Death that occurs prior to the delivery or extraction from the mother. After the fetus is extracted it does not show evidence of life, no heartbeat, not breathing, or movement of muscles (Kowaleski, 1997).

Grief. An emotional state that occurs after a loss which incorporates a wide range of feelings. Longitudinal studies have stated that in a normal grieving process the grief declines over a 2-year time period after the loss occurs (Kersting & Wagner, 2012).

Miscarriage. A spontaneous abortion that is an unplanned end to a pregnancy before the fetus can survive outside of the perinatal environment (Kersting & Wagner, 2012).

Perinatal loss. "A late term pregnancy loss typically occurring at 20 weeks or more, stillbirth, or infant death within the first month of life" (Kersting & Wagner, 2012).

Stillbirth. "The expulsion or extraction from its mother of a product of conception after 16 weeks gestation which shows no evidence of life after such expulsion or extraction" (Pennsylvania Department of Health & Vital Statistics Law, 2012).

Expected Findings

This study was able to find support for the evidence that developing interventions such as, allowing women time alone with their infant or providing an opportunity to begin the grieving process within the hospital will allow for more positive experiences when dealing with perinatal loss (Kersting & Wagner, 2012). The most important intervention that any professional can give when dealing with women experiencing a perinatal loss is validation of the loss (Moore et al., 2011). Moore, Parrish, and Black (2011) noted that if a healthcare provider denies validation to the women it may actually cause more grief and lead to distress.

Studies have revealed that parents value mementos such as plaster cast footprints, locks of hair, infant clothing worn in the hospital, and photographs of their baby (Kavanaugh & Moro, 2006; Kelley & Trinidad, 2012; Williams, Munson, Zupancic, & Kirpalani, 2008). These mementos may be collected by hospital staff like social workers, nurses, bereavement counselors, and chaplains as part of bereavement caregiving to help the parents remember their child (Kavanaugh & Moro, 2006; Kelley & Trinidad, 2012;

Williams et al., 2008). However, hospital interventions may depend on the timing of the perinatal loss within that pregnancy period (Moore et al., 2011). While providing grief support, opportunities to express needs and spending time with the baby may increase feelings of support (Moore et al., 2011).

Organization of the Remainder of the Study

This chapter contains an overview of the overarching problem of this appreciate inquiry action research study, which is to understand the needs of women experiencing perinatal loss. The objective of this study is to gather data from women who have experienced perinatal loss and solicit their suggestions for immediate interventions timed as close to the loss as possible. Chapter 2 provides a review of literature, including the theoretical orientation for the study. Also included in Chapter 2 is a synthesis of the research findings and a critique of the previous research done in the area of perinatal loss. Chapter 3 discusses the research design and target population and participant selection, as well as the study procedures, instruments, and methods of data collection and analysis. Lastly, ethical considerations is discussed. Within Chapter 4, the data analysis of the collected information is reviewed and the results are presented. Chapter 5 summarizes the results and discusses the findings from the study, the limitations, and recommendations for future research and interventions.

CHAPTER 2. LITERATURE REVIEW

Introduction to the Literature Review

The death of a baby is so devastating it can cause parents anxiety and the inability to think reasonably (Geller, Psaros, & Kornfield, 2010; Harris, 2010). Having healthcare professionals understand perinatal loss and how care is provided within the hospital may have a direct impact on the grieving process of women who experience such a loss. It has been shown in literature that within the healthcare system there lacks a standard of care that addresses treatment of and the emotional impact that countless women experience following a perinatal loss (Geller et al. 2010). Johnson and Langford (2010) noted that there has been remarkable improvement in the treatment, support, and care of women who suffer a perinatal loss at greater than 20 weeks gestation; however standardized practice for the treatment of women who experience loss at an earlier stage still continues to be underdeveloped in the healthcare system.

As stated, within a hospital setting, many women feel that healthcare professionals' behaviors and attitudes are not helpful, and hospital staff do not provide them with adequate care (Evans, 2012; Geller et al., 2010; Stratton & Lloyd, 2008). This may be due to a lack of empathy from nurses who say things like, "it was for the best" or "try again." Additionally, Gergett and Gillen (2014) and Friedrichs and Lawrence (2014) further supported the finding that women identify the use of insensitive language as an unsatisfactory aspect of care influencing families' recoveries. This theme continues to be consistent throughout much of the nursing literature on caring for women experiencing a perinatal loss.

Communication needs to continue throughout all phases of perinatal loss, admission, delivery, and aftercare to be effective (Friedrichs & Lawrence, 2014). When communicating with parents, it takes a clinician as well as healthcare professionals, like nurses, doctors, chaplins, bereavement counselors and social workers to have the knowledge of what information should be given and when to give it so that the women have an understanding of the process during the loss (Friedrichs & Lawrence, 2014). MacConnell, Aston, Randel and Zwaagstra (2012) noted that it can be difficult and a bit overwhelming for healthcare professionals to have conversations with bereaved parents, especially if they have little knowledge about perinatal loss. Currently, there seems to be a lack of skills, strategies, and resources for professionals on coping with perinatal loss (Pastor-Montero et al., 2012), which may lead to a communication breakdown.

Nonetheless, literature has shown that over the last 30 years there is an increased acknowledgment of the distress women who suffer a perinatal loss experience caused by unsatisfactory aspects of professional care (Geller et al., 2010). Johnson and Langford (2010) reported that 30 years of literature resulted in an overwhelming agreement that providing intervention immediately after perinatal loss will reduce the emotional distress of that loss when it occurs in any period of that pregnancy. Therefore, the literature shows that the relationship between healthcare professionals and women drive the success in emotional recovery.

Technology, Social Norms, and Perinatal Loss

In Western medicine, the perception of society is that "everything can be fixed" has grown due to technological advancements (Leon, 2008). This has created a false belief in women that perinatal loss does not occur frequently. Kennell, Slyter, and Klaus

(1970) were the first to document grief responses among parents after perinatal loss. However, one area has remained relatively underexplored within perinatal loss: society's response to perinatal loss (Harris, 2010). Social and cultural expectations on how individuals should respond to a loss and how they actually respond differ and may inhibit women's expression and feelings of shame (Harris, 2010).

Within Western society, there are unspoken social rules to which society should abide (Harris, 2010). Some of these social norms for bereavement are seen in such policies such as employees only getting three days off work to grieve a loss depending on the relationship to the decease (Harris, 2010). Harris (2010) claimed that society has an opinion on what is considered "acceptable" bereavement. Most women begin to grieve and do not get the recognition from society, because society does not see perinatal loss as a valid loss (Harris, 2010). *Disenfranchised grief* is described by Harris (2010) as that which is not a recognized loss, and not seen as an acceptable social norm of bereavement. Overall, Western society has their own views and attitudes toward death and bereavement (Harris, 2010). Perinatal loss continues to be a loss that is not recognized by most of society as a valid loss.

Typical resources to treat grief are counseling, support groups, and text-based information. Due to recent technological advances, Internet-based support is increasing and there is a strong need for quantitative and qualitative research to be conducted in this area. Technology can be examined in several ways when exploring perinatal loss. First, technology can be utilized as a means of support. Dominick et al. (2009) researched the efficacy of psychoeducational Internet self-help tools to educate and support bereaved individuals. Dominick et al. (2009) examined how to make sense of grief, Internet

interventions by assessing sites utilizing five categories: (a) my grieving style, (b) who am I? (c) how am I doing? (d) typical reaction to grief, and (e) individual factors affecting grief. Each area was reviewed to make sure interventions help bereaved individuals to gain knowledge and self-sufficiency, and their satisfaction with the support interventions. The findings of the study offered practical interventions that have a positive impact on individuals. These were accessing email based cognitive behavioral Internet interventions, on line grief support tools and groups, and coping skills (Dominick et al., 2009). Having an Internet self-help tool for not only the parents but also the professionals would be beneficial to help communicate what tools and resources positively impact recovery from perinatal loss.

The negative effects of Internet support groups remain to be seen, since this is a fairly new phenomenon. There are pros and cons to Internet-based support groups. Strengths include that the bereaved individual gains knowledge within their home. However, an individual may not get the validation they need to process grief. When dealing with perinatal loss telling the story and receiving immediate verbal and nonverbal feedback is extremely helpful with the grieving process. When healthcare professionals offer strategies for dealing with perinatal loss they need to be open with the pros and cons on Internet support groups. Making sure that women have the best tools to cope with the loss is just as important as the actual care they are receiving from healthcare professionals.

The second way technology affects perinatal loss concerns the attachment between a mother and her unborn baby, which is formed from hearing the heartbeat earlier, ultrasounds, and the fetal monitoring performed in a doctor's office or in the

home (Young, 2013). These technologies together or individually help to integrate the unborn child into the family at a very young gestational age (Young, 2013). This may lead to more intense feelings when a pregnancy does not end with a living child. Technology is available worldwide and this globalization has a complex influence on perinatal health, which has directly impacted how medical care is provided.

Healthcare Professionals and Perinatal Loss

Throughout the literature, it has been stated that healthcare professionals may be affected by perinatal loss, which makes it more difficult to provide best practices (Jonas-Simpson et al., 2013). Rondinelli, Long, Seelinger, Crawford, and Valdez (2015) showed that healthcare professionals need more education on perinatal loss, and a team approach may help improve the comfort level of professionals so they can focus on providing patient-focused care to women. However, Roehers, Masterson, Alles, Witt, and Rutt (2008) found nurses are generally comfortable, but lack knowledge on how to provide quality care to bereaved women. Roehers et al. (2008) found participants did not know what the best resources were for the woman, or their own emotional responses made the situation uncomfortable. More than half of the participants felt that more education would be helpful, which was the same theme that emerged from the Rondinelli et al. (2015) study. Evans (2012) further stated that experienced and skilled nursing care for women who have experienced perinatal loss is a crucial part of the woman's long-term emotional recovery. Unfortunately, patients still report their nursing care is less than optimal (Nelson, 2015; Rowlands & Lee, 2010).

Women's negative experience with healthcare professionals is a longstanding problem (Geller et al., 2010; Gergett & Gillen, 2014). Prior to 1980s, a common practice

for healthcare professionals were to discourage parents from seeing or having contact with their deceased baby (Blood & Cacciature, 2014). To decrease bereaved parents' shock or grief, healthcare professionals suggested to forget the experience or to try again (Leon, 2008; Moore et al., 2011). Healthcare professionals were not always able to provide support when they themselves were not given the proper tools and knowledge about perinatal loss and its emotional impact on the parents (Olson, 2013). Zavotsky, Mahoney, Keeler, and Eisenstein (2013) evidenced this in their study on why emergency departments (ED) may not be providing comprehensive bereavement care. Findings showed ED staff do not have the tools to assist with emotional support during perinatal loss (Zavotsky, Mahoney, Keeler, Eisenstein, 2013).

Throughout the literature, validation is an extremely important aspect of support (Gergett & Gillen, 2014). Validation of a perinatal loss is shown by having others show compassion and gave confirmation that they loss their child. Validation needs to come from healthcare professionals as well as the community. Professionals need to promote healing and validation within their interventions as well as give meaning to the death of the baby, empowering women to take ownership of their experience (Gergett & Gillen, 2014). Healthcare professionals have used Swanson's theory of caring, which helps provide empathy and understanding to women. Using Swanson's theory of caring as a framework to help provide woman-centered holistic care (Gergett & Gillen, 2014), as well as effective physical and psychological care has been used my medical professionals. By implementing new practices, resources, and education for professionals, professionals will be able to offer women ways to grieve the loss through healthy outlets starting within the hospital.

Emerging Interventions in Perinatal Loss

Hospital interventions combined with community-based interventions can address the numerous factors that create and intensify problems in individual and family functioning after experiencing a perinatal loss (Rowlands & Lee, 2010). Rowlands and Lee (2010) noted that there is evidence that medical care within the hospital setting is lacking in appropriate interventions. Their study explored social and healthcare contexts regarding the impacts of healthcare professionals and hospital protocols on women's journey through miscarriage. This study was conducted by using semi-structured interviews that focused on factors that helped or hindered women's ability to cope with their miscarriage. The findings of this study revealed two main themes: how others responded to the miscarriage and focusing on the self and the women's personal journey through perinatal loss (Rowlands & Lee, 2010). Women in the study were angry at medical practitioners due to insensitive comments that made their miscarriage seem insignificant Rowlands & Lee, 2010).

Professional interventions with bereaved families have changed significantly over the past several decades (Blood & Cacciatore, 2014). Permitting families' time to grieve with their baby and to be photographed with the baby are newer interventions within the hospital setting (Blood and Cacciatore, 2014). Other qualitative research showed that women who named, touched or held, and said goodbye to their baby felt more of a healing experience during the loss (Rowlands & Lee, 2010).

Theoretical Orientation for the Study

Several theories are relevant to research on perinatal loss. Swanson's theory of caring (Hutti et al., 2016), posttraumatic growth (Tedeschi & Calhoun, 1996, 2008), the diffusion of innovation theory (Kaminski, 2011), and other theoretical bereavement responses are used when providing treatment to women experiencing perinatal loss.

Posttraumatic Growth

Posttraumatic growth is an emerging concept in bereavement theory that emphasizes positive personal transformations in the aftermath of loss (Tedeschi & Calhoun, 2008). Black and Wright (2012) defined posttraumatic growth as making positive psychological change, which can be a result of confronting experiences that have been challenging. Tedeschi and Calhoun (1996) described bereavement from a systematic approach to explain the change that occurs among individuals and groups after crisis along with the ensuing inevitable struggle. This model shows that psychological growth can only occur from the struggle within such crisis, as with the loss of a loved one (Tedeschi & Calhoun, 1996, 2008). Losses that are sudden or unexpected, such as perinatal deaths, may be more likely to lead to contemplation about the causes, reasons, purpose, and existential meaning of loss (Tedeschi & Calhoun, 2008). These contemplations can in turn act as catalysts for existential or spiritual growth (Tedeschi & Calhoun, 2008). Many challenges occur with the bereaved due to emotional distress. These struggles are managed by engaging in intense cognitive thinking, processing beliefs, goals, and life narratives (Bray, 2013). At this point, deep thinking occurs, which allows cognitive changes that involve rebuilding a meaningful view of the self (Bray, 2013).

In situations where posttraumatic growth has occurred, individuals are more likely to be able to deal with their distress, develop new personal narratives, and acquire wisdom and new understanding (Bray, 2013). Through these struggles, the bereaved individual begins to adopt new beliefs and values, view themselves and the world differently, and have an increased appreciation of life (Bray, 2013). Posttraumatic growth is not about the moment of distress, but about the journey to healing. When a woman experiences perinatal loss and is able to be supported from external and internal resources, the woman may begin to adjust their mindset and begin to grow from the traumatic event.

Women who develop coping skills may be searching for spiritual guidance. In their later work, Tedeschi and Calhoun (2008) placed less emphasis on religion and more on addressing existential questions by demonstrating that grieving individuals can experience considerable posttraumatic growth outcomes in the domain of spirituality regardless of spiritual or religious beliefs (Calhoun, Tedeschi, Cann, & Hanks, 2010). Struggles with existential questions, change, and meaning-making provide a valuable perspective of human development in Tedeschi and Calhoun's (1995, 2008) model and its assessment of a bereaved individual both pre-trauma and [after] trauma (Bray, 2013). The overall theoretical framework focuses on making individuals stronger from the trauma they have faced. Having healthcare professionals encourage women to get involved in support groups, following up with aftercare, and providing validation within the hospital will set them up for positive change in regards to a healthy grieving process.

Using the theoretical framework of Tedeschi and Calhoun (2008) post-traumatic growth model an individual can have psychological growth, spiritual and healthier

grieving outcome (Bray, 2013). Post-traumatic growth occurs when a bereaved individual acquires a new understanding and adopts new beliefs and values due to the struggles they faced while being challenged emotionally (Bray, 2013), spiritually, and mentally with the loss. When a loss occurs it can significantly change their relationship with their religion and spirituality (as cited in Bray, 2013). Post-traumatic growth will allow a bereaved woman to make cognitive changes and learn how to manage their distress, but at the same time allowing themselves to transform their thoughts (Bray, 2013). Integrating the post-traumatic growth model to those who have had perinatal losses will give them the ability to cope and function as well as normalize their feelings.

Diffusion of Innovation Theory

Another important issue with perinatal loss is how new clinical practices and procedures are implemented in hospitals. Healthcare systems as well as other organizations may struggle with implementation of new innovative ideas even if backed by research (Kaminski, 2011). French sociologist Gabriel Tarde was known to be the first researcher to explore the diffusion theory (as cited in Kaminski, 2011). However, Rogers (2003) introduced adopter categories of innovation, which are innovators, early adopters, early majority, late majority, and laggards that popularized the diffusion of innovation theory (Kaminski, 2011).

Addressing perinatal loss involves the transformation of healthcare professionals and services. However, with new innovation there needs to be early adopters who serve as leaders who become the catalyst to launch the initial point in the innovation adoption process (Kaminski, 2011). Implementing new practices, procedures or policies requires change in thinking and acceptance from early adopters. New innovations also require

continuous quality improvement, which can provides hospitals with strategies to influence perceptions, attitudes, and professionals to support new ways in dealing with perinatal loss. Quality improvement is an approach in analyzing the current methods and making improvements to current practices so they are efficient (U. S. Department of Health and Human Services Health Resources and Services Administration, 2011). Having this support will enable women to receive the best care that they deserve as well as facilitate goal-driven and purposeful actions from healthcare professionals.

Healthcare professionals applying diffusion of innovation theory furthers their understanding of implementing new interventions that offer women the support that they need while in the hospital setting. However, adopting new innovations in healthcare is not as easy. Diffusion of innovation theory explains that implementing evidence-based practice is not only driven by the patient welfare but also by interest of the healthcare system (Murray, 2009). Murray (2009) noted that for adoption to occur, the innovation must address an issue that clinicians or other professionals perceive as a problem. As such, an intervention to provide support for women experiencing perinatal loss may not be adopted if professionals do not identify the lack of support as a problem. Healthcare systems need to be willing to become innovators and adopt new procedures or approaches even if others do not perceive it as a problem if it is supported in the research.

Clinical Interventions

This contemporary issue of perinatal loss is very important to social workers who work in the hospital setting and who provide emotional counseling to grieving families. Blood and Cacciatore (2014) noted that women value when healthcare professionals show compassion, empathy, and use honest communication to show that their loss is

significant. Healthcare professionals need to ensure that they respect the individuality of the bereaved person and offer appropriate person-centered care and support (Blood & Cacciatore, 2014). MacConnell, Aston, Randel, and Zwaagstra (2012) discussed that the healthcare system needs to have interventions that involve healthcare professionals and center around decreasing unnecessary medical protocols and restructuring practices to be sensitive to family attachment to the infant. Therefore, social workers, nurses, physicians, and other healthcare professionals need to provide comforting words, validation, and understanding to those who have experienced a perinatal loss.

Carlson (2012) argued that it can be stressful and perhaps challenging for nurses (or social workers) to provide memory-making opportunities for women if they are unsure of how to discuss options with parents. It appears that professionals try to treat parents with respect and understand the importance of keepsakes, but are uncomfortable approaching women to ask their thoughts on photographs and other mementos (Carlson, 2012). Having healthcare professionals offer this is important and training hospital workers on how to better communicate with parents is essential to the healing process.

Reactions to perinatal loss vary among genders, races and cultures. For example, it has been found that women are more likely to become depressed, and men are more likely to become overinvolved in tasks (Swan & Scott, 2009). Each person who experiences grief and traumatic loss will handle it in a different manner. Some individuals will be able to cope without therapy, while some will need intensive therapy to address depression, increased anxiety, or posttraumatic stress disorder. However, the various factors (individual, familial, economic, medical, and cultural) that affect the psychological response to pregnancy loss are not well understood by nurses, possibly

limiting the effectiveness of interventions that aim to reduce psychological distress (Shreffler, Greil, & McQuillan, 2011). Therefore, interventions need to be tailored to a woman's specific needs (Sutan & Miskam, 2012).

Synthesis of the Research Findings

Over the last several years, research on perinatal loss has shown the impact when women do not receive adequate support within the hospital setting (Blood & Cacciatore, 2014). A number of emerging themes are common to the literature explaining why women are dissatisfied with hospital support. Below outlines some of the themes that have emerged over the last 10–15 years of research.

Blood and Cacciatore (2014) stated that over 20 years ago, healthcare providers defended against parents holding or seeing their baby to eliminate feelings of sorrow and despair, giving tranquilizers to dull the shock of the loss, advising parents to forget the experience, and suggesting another pregnancy. Healthcare professionals are not always able to provide support when they themselves are not given the proper tools and knowledge about perinatal loss and its emotional impact on the parents (Blood & Cacciatore, 2014). This theme has continued over the years. Rowlands and Lee (2010) reported in her findings that women indicated that they were not provided sufficient support from medical professionals.

Additionally, Soto (2011) explored a hospital-based intervention for adolescents with perinatal loss. No matter the population, when women experience perinatal loss, interventions may need to focus on bringing meaning and resources cope with the loss. Regardless of age, social workers and healthcare providers' role is to support and offer interventions (Soto, 2011). An important aspect of providing interventions to those who

experience perinatal loss is to understand the women's struggles (Soto, 2011). Validation is important for women experiencing perinatal loss, as women find it difficult to cope with those who do not acknowledge or understand the significance of their loss (Rowlands & Lee, 2010).

St. John, Cooke and Goopy (2006) exploratory qualitative study investigates three women's experiences of perinatal loss within the healthcare system. Information was gathered by using mini-biographies and in-depth interviews that were conducted with women to record their experiences and stories; these were then analyzed. During the review of data, patterns among the three women evolved, including a lack of support within the healthcare system to help them deal with grief. The study's findings showed each of the women faced self-blame, anger, isolation, and guilt due to their loss. They discussed a disregard by society and direct care professionals for pregnancy loss. It was pointed out that there is a need for research on how society deals with perinatal loss. While each woman lost her baby at different stages, all had a negative experience (St. John et al., 2006).

Limbo and Kobler (2010) completed a literature review concentrated on the relationship between nurses and women experiencing loss. Limbo and Kobler (2010) expressed that nurses can provide a source of hope and healing for the grieving mother. Communication between the healthcare professionals and the women will build trust in the relationship. Zavotsky et al. (2013) agreed that providing communication and emotional support is important, however most healthcare professionals do not have the tools or education to provide emotional support.

Pastor-Montero et al. (2012) conducted a participatory action research study to promote changes to improve care provided to parents who experienced perinatal loss. They found that most hospitals do not have protocols in place for perinatal loss (Pastor-Montero et al., 2012). Not having protocols may lead to women feeling inadequately supported. The study also states that healthcare professionals lack the knowledge and ability to support these women (Pastor-Montero et al., 2012). Improving professional practice will support the grieving process and ensure comprehensive care within the hospital.

A review of literature was completed by Olson (2013) to investigate healing through loss. The review found an emerging theme that healthcare professionals are failing to meet the needs of women and women are reporting dissatisfaction with their overall care (Olson, 2013). The primary reason for the dissatisfaction was negative attitudes from the healthcare professionals. Other reasons were lack of emotional support, too much medical jargon, and poor communication (Olson, 2013). As such, more training may be needed for healthcare professionals to support women and meet their needs, both emotionally and physically.

A review of literature by Rowlands and Lee (2010) indicated that there is a need for society to acknowledge that perinatal loss is a difficult and traumatic event and more action research and qualitative studies need to examine how perinatal loss affects women's feelings of support and their emotional responses. Throughout literature, there were discussions of the standard of care in the past and present (Cacciatore & Bushfield, 2009). This was insightful to see how far we have come in the last 40-50 years, in assisting with perinatal loss.

Within the hospital there are social workers, chaplains, and other counselors to meet with parents. Cacciatore and Bushfield (2009) discussed hoe improving standards of care in the hospital setting can improve the mental wellbeing of women after experiencing perinatal loss. Changing standard practice requires future research. Since perinatal loss is becoming a less taboo topic, more research is being conducted in different areas including the effects of perinatal loss and subsequent pregnancies, and mental health (Roose & Blandford, 2011). Research continues to show that women rarely have an emotionally supportive experience when suffering a perinatal loss (Smart & Smith, 2013). Smart and Smith (2013) noted that women did not have an understanding of treatment options after the loss.

Recommendations from the Literature

Although perinatal loss is becoming more acknowledged within the hospital setting, it continues to be underresearched. As professionals continue to move forward with researching this topic there may be a need to develop new approaches in screening for complicated grief (Kersting & Wagner, 2012), how hospital professionals support individuals who have experienced perinatal loss (Rowlands & Lee, 2010) and providing these individual with adequate information and care. Hospital professionals need to begin to understand the significance of trauma related to perinatal loss and how it can affect the individual.

As practitioners, there should be an increase in knowledge of how pregnancy loss is different in each culture, race, and gender to begin to decide if that particular individual is grieving normally or if they are having complicated grief. Complicated grief is typically an intense painful emotion that is prolonged and often is triggered by a

traumatic event (Wetherell, 2012). Symptoms need to be looked at and information needs to be provided to parents who have lost a baby so that they can get the help they need so as not to develop complicated grief (Kersting & Wagner, 2012).

Also, healthcare systems should become more aware of their ability to help families who have suffered a loss and begin to provide healing at the hospital. A hospital-based intervention combined with community-based intervention (Rowlands & Lee, 2010) may need to be developed in healthcare systems so that all angles of the individuals are looked at, including physical health, mental health, and the ability to access support within their communities.

Furthermore, interventions on how to help with those who have experienced a perinatal loss are in need of in-depth research. Researchers need to look at the types of emotions that are linked to a perinatal loss and decide what interventions can provide the best outcomes at both macro and micro levels (Cacciatore & Bushfield, 2009). Bereaved women will continue to mourn the loss of their babies and some will need validation, support, and time to heal (Leon, 2008). Professionals can begin to promote healing and validation within their interventions, as well as ascribe meaning to the death of their baby (Stratton & Lloyd, 2008). However, it is still unclear as to why society and healthcare professionals frequently avoid women who have experienced perinatal loss, and how to help bereaved women decrease the feelings of abandonment, helplessness and frustration toward society's perspective.

There continues to be a need for additional support for bereaved women and education for healthcare professionals to learn how to support individuals as they cope during the grieving process (Hutti et al., 2016). Additional research in this area would

allow for practitioners to better understand how to assist with family members' ability to cope with the loss and provide interventions to the bereaved women; and hopefully educate all professionals involved in caring for those who have had a perinatal loss.

Policy Issues Related to Perinatal Loss

Society's opinion of women's grief after a loss can be influenced largely by policies, however the value of that loss can be misconstrued leading to improper definitions of what perinatal loss is and more importantly what it means to the women who suffer it (Cacciatore & Bushfield, 2009). Legitimization for bereaved parents through policy changes is long overdue, and this change needs to be supported by social workers and policymakers. Several states have made policy changes due to the grassroots efforts of mothers who have experienced such a loss (Cacciatore and Bushfield, 2009). For example, birth certificates are now given to deceased babies. Previously, those who have delivered a baby were presented with a death certificate, but not always a birth certificate (Division of Vital Records, 2013). The Division of Vital Records (2013) implemented a Certificate of Fetal Death in 1950. A Certificate of Fetal Death is filed after delivery of a stillborn fetus when the gestational period is over 16 weeks and shows no evidence of life. This particular legislation became effective on February 13, 2012 in Pennsylvania (Division of Vital Records, 2013). While legislation has made some positive movement, until accurate scientific data solidify enough political impression of the timing at which an unborn is considered human there will continue to be inaction among legislators (Cacciatore & Bushfield, 2008). A shift in the macro culture is needed to address perinatal loss (Cacciatore & Bushfield, 2009). Furthermore,

a debate continues in regards to social policy considerations in prenatal loss within social work.

Summary

As professionals continue to move forward with researching perinatal loss, there may be a need to develop new approaches to supporting women, and understand better perianal loss and mental health among those of different races, genders, and cultures. Practitioners and healthcare providers, must have the knowledge of how pregnancy loss is different in each culture, race, and gender to begin to decide if a particular individual is grieving normally. Patient symptoms may need to be evaluated more in-depth and information needs to be provided to women who have lost a baby so that they can get the help they need. Healthcare systems should begin to increase their awareness of their ability to help families who have suffered a loss and begin to provide healing at the hospital. A multidisciplinary team may be developed in healthcare systems so that individuals are addressed holistically.

CHAPTER 3. METHODOLOGY

Purpose of the Study

This appreciative inquiry action research study gathered data from women who have experienced perinatal loss and solicited their suggestions for immediate interventions timed as close to the loss as possible. Healthcare professionals were also recruited to participate in this research study to gain insight on current interventions. The findings of this study aim to assist in improving the support provided to the women within a hospital setting, by gathering information on their experiences regarding their treatment after the loss.

Research Design

Appreciative inquiry will provided the framework for undertaking this action research (Stowell, 2013). Appreciative inquiry, as in all action research, has a goal of change. In this case, the change is hospital protocols addressing perinatal loss. Appreciative inquiry assumes that the action research process helps participants develop new capacities and is empowering (Stowell, 2013). Action research seeks change across individual groups and behaviors to develop solutions in collaboration with participants that is sensitive to their needs and desires (Stowell, 2013). As such, action research relies on a qualitative approach.

Creswell (2014) explains qualitative research as an approach that explores and helps us to understand a problem through the lens of social or human perspective. This approach allowed information to be gathered from those who have experienced such loss. Using semi-structured phone interviews enabled me to identify concerns or problems

with how care is currently given, and this information will hopefully lead to social change.

To begin the process, data were gathered by using semistructured phone interviews and literature reviews (Cachia & Millward, 2011). Using phone interviews allowed for the participant to discuss their experience with perinatal loss openly without feeling uncomfortable. Moore et al. (2011) noted that allowing for authentic dialogue will help promote a more natural conversation and will engage the participant in a comfortable, ethical, and productive manner. When dealing with perinatal loss, most women have not been able to tell their stories and experiences due to the fact that those around them do not understand and are not able to support them in a way that is helpful (Moore et al., 2011). When conducting the semistructured phone interviews, the participants began to develop a trusting relationship and were able to reveal information about their individual experiences in the hospital setting.

Healthcare professionals were recruited to answer an open-ended questionnaire. The flyer was posted in social media pages and put up at local hospitals so that healthcare professionals could self-identify. Every participant signed an informed consent form prior to answering any questions. The informed consent was emailed to the participant and returned with an electronic signature. Once the information was received, the questionnaire was sent to the healthcare professional and the interviews were scheduled.

Target Population and Participant Selection

There were two target populations: (a) women who have experienced a perinatal loss (recruited through related Facebook support groups), and (b) nurses and social workers (recruited through social media and flyers in hospitals). A flyer was posted to

explain the research study. Purposeful sampling was used to obtain a small, manageable sample size (n = 10), since the potential sample size could have been larger than this study can accommodate (Nastasi, n.d.). While purposeful sampling has some caveats like bias, it was the best technique for the present study. Nastasi (n.d.) reported qualitative studies should have large enough samples for concepts, themes, and redundancy to occur. For interviewing key informants, a rule of thumb is approximately five to 30 people (Nastasi, n.d.).

There have been several studies that have been conducted that support the sample size that was used in this study. Bennett, Ehrenreich-May, Litz, Boisseau, and Barlow (2012) evaluated cognitive behavioral interventions for perinatal loss and used five women who suffered a perinatal loss to conduct their study. With this small sample size the study was able to yield significant clinical information. Fenstermacher (2014) used eight adolescent females to conduct her study. Within this study the same size was relatively small; however it was an adequate representation of perinatal research.

The target population was women 18 years of age or older who had delivered a perinatal loss between 6 to 32 months postpartum. The timeframe of 6 to 32 months post perinatal loss was chosen in light of Gausia et al. (2011) research on the psychological and social consequences among mothers suffering from perinatal loss. They recruited women 6 weeks to 6 months postpartum. Sutan et al. (2010) further interviewed mothers between 6 weeks to 12 months after the loss. The methodology also follows the Jonas-Simpson et al. (2013) study of nurses' experiences of grieving where there is a perinatal death. They recruited through information flyers and had six nurses volunteer for the

study. Using six nurses gave them valuable information and themes were able to emerge from the sample size.

Procedures

Approval for this study has been obtained by Capella University Institutional Review Board. Ethical review ensures research complies with federal regulations and ethical practices for human protections prior to approval (Capella University, 2016). Nine women who experienced a perinatal loss were recruited from local support groups. Once the woman self-disclosed that they were interested in the study, an interview was scheduled and the informed consent form was sent. If the woman chose to participate, then she signed the informed consent form either with an e-signature or "wet" signature prior to participating in the study. The women were asked to do one private telephone interview lasting 30–60 minutes. Women were encouraged to give feedback on their own experience as well as insight on how they felt supported by nurses and other healthcare professionals within a hospital setting.

Five nurses and/or social workers who work with women who experienced a perinatal loss were recruited through social media and flyers. If a healthcare professional chose to participate, they were contacted about the study. While corresponding with the healthcare professional, the informed consent was emailed prior to collecting any data. The healthcare professionals were asked to complete five open-ended questions through an interview or a questionnaire that was sent through email, which took approximately 30 minutes.

Action Research Protocol: Stringer's Model of Look, Think, Act

Look: Gathering information. Women who experienced a perianal loss were interviewed first through semistructured phone interviews. To recruit potential participants, an initial letter was posted on two support groups' Facebook pages: Sweet Pea Project and Share of Lancaster. This recruitment technique allowed for the potential participants to self-identify. Once the potential participant self-identified, the study and the inclusion criteria was discussed with them. If the criteria was met, they were sent an informed consent form via email or to their home address, depending on their preference. At this initial discussion, a phone interview was scheduled and the consent form was discussed. The informed consent form was reviewed again, once the signed copy was received. This allowed the participant to ask questions and to be sure that they wanted to participate in the study. Prior to the phone interview, the informed consent had to be returned with a signature before information was collected for the study.

Phone interviews were conducted on nine women who experienced a perinatal loss. Perinatal loss is defined by Kersting and Wagner (2012) as a late term pregnancy loss typically occurring at 20 weeks or more, stillbirth, or infant death within the first month of life. For this research study, perinatal loss is defined as the time of conception until 40 weeks gestation. As mentioned above, semi-structured phone interviews were used to collect data. The data collection instrument for this proposed study was open-ended interview questions. These questions were structured to elicit participants' experiences and suggestions for change. Field testing by four professionals occurred prior to the study beginning. Each professional was asked to analyze if the sample interview questions were appropriate to ask women who have experienced a perinatal

loss, were sequenced well and clear, and if additional questions should be added to help with the research.

Nurses and social workers were recruited to answer the open-ended questionnaire. Flyers were posted on social media and at local hospitals so that nurses and social workers could self-identify. Each self-identified nurse and social worker needed to sign an informed consent form prior to answering any questions. The informed consent was emailed to the participant and returned with an electronic signature. Once the information was received, either an interview was scheduled or a questionnaire was sent to the participant. If they chose to have the questionnaire sent to them, they had three weeks to complete the questionnaire once emailed to them.

Think: Analyzing the data. Coding and analyzing the data occurred throughout the study to identify themes. Information was collected by using field notes, open-ended questionnaires to healthcare professionals, member check, semistructured phone interviews, and verbatim transcripts of the recorded interviews. To code the information, the software program NVivo 11 was used to ensure accuracy. Upon first reading, key words/phrases was used to create categories and branches. These were assigned labels. As data under each category increased, the themes emerged.

Act: Planning, implementing and evaluating. Once the data had been analyzed, the results were presented to the bereavement services coordinator at a local hospital. A list of recommendations was also posted to the two websites from which participants were recruited for viewers to take the findings to their local hospitals.

Inclusion and Exclusion Criteria

Inclusion Criteria. To participate in the study, interviewees had to be women who have experienced perinatal loss within 6 to 32 months prior to the study's start date. Perinatal loss is defined for this study as the death of a fetus after conception until 40 weeks gestation. The loss is a naturally occurring loss (no therapeutic intervention). Participants were 18 years of age or older. Any education level, socioeconomic status, race/ethnicity, or religion could participate in the study. Participants were English speaking and capable of giving informed consent. Participants were willing to undergo an interview.

Questionnaire participants were nurses and social workers currently working with perinatal loss in a hospital setting. Participants were English speaking and capable of giving informed consent. Participants were willing to participate in answering five open-ended questions through an email questionnaire or interview.

Exclusion Criteria. Exclusion criteria for the women in this research study were as follows: under 18 years old; currently pregnant; loss occurred more than 33 months ago or less than 5 months ago; loss occurred from medical interruption and ectopic pregnancy; has had a neonatal loss; had a current diagnosis of acute psychotic disorder, acute posttraumatic stress disorder, depression, or bipolar disorder; or had a loss somewhere other than in a hospital setting. Healthcare professionals were excluded if they were not currently working in a hospital setting or did not work with perinatal loss.

Instruments

Three data sources for triangulation were used: audiotaped, semi structured phone interviews with member check; field notes; and open-ended questionnaires. Using these

three data sources improved the validity of the study. Using member checking established validity for the phone interviews because the participants were able to review and correct the data, ensuring that information was interpreted correctly, and allowing for follow-up questions if data were not clear. Interviews were used to gain the women's perspectives on how hospitals can best support women experiencing perinatal loss. Field notes were also kept to gather details like how the women reacted to the questions. Using member check established validity for the phone interviews because the participants were able to review and or correct errors. Lastly, an open-ended questionnaire for healthcare professionals was used to gather information from the professionals' perspective on the needs of women who experienced perinatal loss in a hospital setting.

The data collection instruments were field tested prior to being used in the study. The field testers were professionals who have expertise with the proposed population and research topic. Letters were sent asking for three professionals to analyze the interview questions, asking them to comment on:

- Whether the sample interview questions were appropriate to ask women who have experienced a perinatal loss;
- Whether the questions were sequenced well;
- Whether the questions were clear; and
- Whether additional questions should be added to help with the research.

Data Analysis

The questionnaires and interview transcripts were coded to identify themes. NVivo 11 software was used to ensure appropriate analysis. Upon first reading, key words/phrases were used to create categories and branches for each research question (see Table 1). These were assigned labels. As data under each category increased, the themes emerged. Answers from each data subset were analyzed individually.

Table 1

Data Collection Tool

Overarching Questions:	Data Subset:	Questions
Overarching Question 1: What are physical, emotional, spiritual and social needs of women who just experienced a perinatal loss?	Individual Semi-Structured Phone Interview, Field Notes, open-ended questionnaires from healthcare professionals, Member Check.	Q#9: Example: WB3; SSPI H10; MC
	Theme:	Q#11: Q#14:
Overarching Question 2: What do women find to be helpful in coping with perinatal loss when in the hospital setting?	Data Subset:	Questions
	Individual Semi-Structured Phone Interview, Field Notes, open-ended questionnaires from healthcare professionals Member Check.	
	Theme:	Q#7: Q#8 Q#10 Q#13
Overarching Question 3: What are examples of compassionate care as revealed by women who have experienced perinatal loss?	Data Subset:	Questions
	Individual Semi-Structured Phone Interview, Field Notes, open-ended questionnaires from healthcare professionals Member Check.	
	Theme:	Q#5 Q#6

Note. Code SSPI: Individual Semi-Structured Phone Interview; Code FN: Field Notes; Code OEQHP: Open-ended questionnaires from healthcare professionals; Code MC: Member

Checking. Participants will be coded 1-10 and the first letter will coincide with the place of delivery, which will be identified by the participant during the interview. Example WB3, or H10, then where the information came from (which data Subset will also be identified). WB3; SSPI. Healthcare Professionals will be coded as 1 for social worker or 2 for nurse; followed by one of these letters A, B, C, D, E, F, G; example 1A, 1B, 2C, etc.

Ethical Considerations

There are significant ethical considerations in research on perinatal loss due to the sensitive subject matter. Once participants were chosen, disclosure and consent was reviewed. Building trust is essential when wanting participants to disclose sensitive and personal information about the baby they lost and the emotional rollercoaster that they have been on since the loss occurred. When collecting data on those who have lost a baby, it was kept in mind that they would most likely have high levels of anxiety. If information shared was disconcerting, such as mentioning of self-harm or harm of others, a violation of confidentiality would occur.

Ethical considerations were given to women to ensure that they understood the benefits and risks associated with participation. Women and healthcare professionals were not be pressured to participate within the study. Permission was obtained to carry out the research by the women and healthcare professionals that self-identified. Women and healthcare professionals were informed of the study's intention and provided with informed consent.

This research had moderate risk for women involved within the study. Psychological harms were moderate; however, there could potentially have been discomfort, stress, or anxiety experienced during the interviews due to the discussion of losing a child. Prior to the interviews, handouts were provided to participants with support groups and online support programs to support the women's needs. Concluding

the research, these support programs were reviewed. Women were informed that mention of harm to self or others would result in a violation of confidentiality and termination of the interview.

Research participants were given sufficient information to minimize risk so they could make a decision about participating in the research. Research participants also were forewarned that questions would be of a sensitive nature, and steps would be taken to protect confidential information. Participants were informed of how their identifiable personal information was protected (Arwood & Panicker, 2013).

To decrease emotional distress due to the sensitive nature of perinatal loss, a series of debriefing questions was asked after the interview. This method of debriefing has been effective in perinatal loss studies (Kavanaugh & Hershberger, 2005). Fenstermacher (2014) expressed that one way to help avoid psychological harm to a vulnerable population is to assure them that they can choose to stop the interview at any time as well as skip questions that make them feel uncomfortable. Also, using strategies like offering appropriate support, arranging for referrals, and debriefing with participants minimizes distress (Hutti et al., 2016). To safeguard against coercion, healthcare professionals were ensured that there was no consequence for not participating. There were no professional connections to any hospital maternal fetal department. Confidentiality was ensured and allowed women or professionals to remove themselves from the study at any time without consequences.

Data collected (e.g., field notes, interviews, questionnaires, member check, notes, and voice recorders) were kept in a locked file cabinet in a locked office. The phone interviews were transcribed verbatim into a Word document that was kept in a password-

protected file to ensure confidentiality. All participants involved in the study had their names removed from the field notes, transcripts, findings, and final dissertation to protect confidentiality. A digital voice recorder was used for the interviews to ensure accuracy of each woman's interview. Storage of the digital voice recordings was saved in the Flash Memory Miniature Card. Once the audio was transcribed and saved on a PC, it was locked in a confidential file cabinet and the flash memory card will be destroyed after seven years to ensure confidentiality. The information on the PC was password protected. All consented and enrolled participants were assigned a unique participant identification number in order to maintain participant confidentiality. The interviews were conducted in a private office to ensure confidentially. Prior to beginning the interview, the participants were asked if this was a good time to talk, since they would be discussing sensitive information about loss. This helped to ensure confidentiality since the environment in which the participant was in, was not able to be seen.

Conclusion

The purpose of this study was to provide hospital administration with suggestions on procedures and protocols to help provide support to women experiencing a perinatal loss, ultimately providing a healthy grieving process. Having a standardized best practice tool will assist healthcare professionals to use the same guidelines or principals in supporting bereaved women. By conducting this study, women were able to share what experience they had and what was beneficial for them. Using an appreciative inquiry action research methodology will help guide healthcare professionals to provide quality and comprehensive care to grieving women.

CHAPTER 4. DATA COLLECTION AND ANALYSIS

Introduction: The Study and the Researcher

The purpose of this qualitative action research was to analyze the needs of women experiencing a perinatal loss and to suggest necessary changes to protocol in hospital settings. In the previous chapters, the current problem, research design, limitations, reviewed the literature, and the theoretical foundations for the study were discussed. This chapter contains an explanation of the data analysis and a discussion of the identified emerging themes. Here, the role of the researcher and the methodology used throughout the study will also be discussed.

As a woman who has experienced a perinatal loss, I have very strong feelings on this topic. At my 16 week routine prenatal check-up, the midwife was having trouble locating a heartbeat. Due to this concern, I was sent to get an ultrasound to make sure that everything was okay. When the ultrasound technician left, a doctor came in and broke the news that my baby had died. I gave birth to Anna Mae, a baby girl on July 10, 2008.

Since that moment, I have gone through a complicated journey of grief, sadness, and guilt. The death of Anna has inspired me to honor her life by supporting other women who have experienced this tragic event. This research, my doctorate of social work, represents a part of my journey. With this study, I hope to bring about positive change to hospitals and change the mindset and stigma of perinatal loss to hospital professionals.

Description of the Participants

There were two target populations for this research study: (a) women who experienced a perinatal loss, and (b) nurses and social workers. All the participants reside in the United States. The study included one woman from Texas, two women from New York, another from New Jersey, and five from Pennsylvania. As for the nurses and social workers, they worked in New Jersey and Pennsylvania hospitals. This study was conducted by reaching out to local and national support groups. Prior to posting the recruitment flyers and posting on Facebook and websites, the support groups that were asked to participate in this research study gave written approval to solicit participants. Individuals then self-identified to participate in the research study.

Qualitative data were collected by using semi-structured phone interviews as well as open-ended questionnaires for nurses and social workers. This allowed for a better perspective of the individuals' experience of perinatal loss (Kolb, 2012). Triangulation was used to validate data from multiple types and sources, interviews with member checking, questionnaires and field notes to ultimately understand the themes that emerged from the data sources (Creswell, 2014).

Nine semi-structured phone interviews were conducted with women who experienced a perinatal loss between May 1, 2013, and December 30, 2015, which included perinatal loss throughout the 40 weeks gestation, excluding ectopic pregnancies. One nurse and one social worker requested phone interviews to answer the questions while three other nurses answered questions via email. Nurses and social workers were asked the same five open ended questions. Purposeful sampling was used in accessing participants for the research.

The women who participated in this research study reported that they did not need additional therapy when asked the debriefing questions at the end of the interview. The overarching research question of this study was to consider the needs of women who experience perinatal loss and whether those needs are being met within a hospital setting.

Women Participants

Nine women participated in semi-structured phone interviews. Each interview was recorded and transcribed. The transcribed interviews were sent to the participants to make corrections or add additional information. Three participants added more information and made some changes which were included in the analysis progress, while six participants approved the transcription without making changes. Demographic information collected from the women participants showed that the average age of loss was 32.7 years old. Five out of the nine participants (55%) experienced two or more losses.

Table 2
Participants' Demographics

Women Participants	Age at Loss	Gestation age at loss (weeks)	Number of Losses
1	32	27	2
2	37	35	1
3	29	7/6	2
4	30/31	13/20	2
5	32	25	1
6	34	22/22	2
7	33	8/8/21	3
8	34	34	1
9	35	21	1

Nurses and Social Worker Participants

Four nurses were given open-ended questionnaires to complete while one asked to be interviewed. Each participant completed a consent form prior to answering the questionnaires or being interviewed. Three nurses completed questionnaires while one wanted interviewed, as well as one social worker participated in the study by being interviewed.

During the recruitment process, it became apparent that the hospitals involved in this study rely on the chaplains, not social workers, to provide bereavement support. It seemed social workers did not interact with the bereaved women, except at one of the hospitals. Lack of social workers working with this population made it difficult to find participants for the study. Several of the hospitals that were contacted confirmed that social workers in their hospital do not deal with perinatal loss and that the issue is left to the chaplains and bereavement counselors. One nurse reported that social workers only get called if there is coexisting issue such as drug abuse, violence, or substance abuse.

Research Methodology Applied to the Data Analysis

Qualitative data were collected in the forms of semi-structured phone interviews of the women, interviews and questionnaires of nurses and a social worker, and field notes. The information collected was typed into a word document to allow for coding and analyzing the themes. NVivo 11 was the software chosen to assist in organizing data for coding used to identify emerging themes from the interviews and questionnaires.

Analysis

To analyze the collected data, the constant comparative method of analysis was used. Glaser and Strauss (1967) developed the constant comparative methodology to

allow for systematic data collection and coding simultaneously (Kolb, 2012). Along with the constant comparative method, Corbin and Strauss (2008) designed a process to analyze the data which involves three levels: (a) open coding, (b) axial coding, and (c) selective coding (Kolb, 2012). Using these three phases helped obtain a complete picture of the collected data (Kolb, 2012).

Coding

Open Coding

According to Corbin and Strauss (2008), the first phase of coding takes place when data collected from multiple data tools are compared, like interviews and questionnaires and continually looks to find answers to information that was not understood prior to the research (Kolb, 2012). During the open coding phase, different codes were assigned to the raw data. By using the constant comparative method to review all information, interview transcripts, field notes, and questionnaires it helped to develop a systematic process to understand what has been discovered from the analysis (Kolb, 2012). As each transcribed interview was reviewed, it was compared with the next interview, until all interviews had been compared to each other. During each comparison, assigned codes to words or phrases that described the same experience were analyzed. Some of the words or phrases that were assigned the same code were, needing more time with baby, wanted more photographs, and unable to change baby or bathe baby. All of these phrases were given the code of regret. This type of process was then extended throughout all interviews and questionnaires.

Axial Coding

After completing the open coding phase, the process then proceeded to the axial coding phase. Codes were compared and analyzed to develop sub-categories from the themes that emerged from the raw data. Theoretical saturation was reached since no new data emerged upon the completion of subsequent interviews. After the point of saturation, there was a better understanding to the areas of concern from both the women, the nurses and social workers. Within this phase, codes were reviewed that had been given to the words and phrases to find similarities between them. At that time, sub-categories began to be developed due to similarities. Specific elements, such as disappointment with mementos, unable to bathe baby, no memory box, lack of photographs, began to shift toward sub-category (see Table 3 and Table 4). Using NVivo 11's coding and data functions, assisted in developing overarching categories. This was completed by uploading each transcribed interview and field notes into NVivo 11. The NVivo 11 software assisted with organizing initial codes, sub-categories, and categories. Different color codes were assigned to the above areas, which organized information for further analyzing. Using data search queries along with the color codes, the process was more organized and increased efficiency.

Table 3

Coding-Women Interviews

	Women Interview		
Themes	Categories	Sub-Categories	Initial Code
Practices that Work	Lack of memories	Regrets	lack if photographs
			needing more time with baby
			no family pictures
Practices Needing Change			Not told we could take pictures
			Wish mother could bathe baby
	Negative Experiences	negative actions	lack of communication
			Disappointment
			poor communication
			poor attention to mother's physical needs
			neg. bedside manners
			healthcare staff speaking too clinically
			dry personalities
			too many doctors
			medically focused
			no follow up
			didn't feel supported
			not seeing chaplain
			not seeing social workers/social services
			not empathic
			shut off emotionally-staff
			not sympathetic
			giving false hope
			more resources
			Miscommunication
			Disconnect
			placement of mother
			didn't give lots of information on support groups
	Acknowledgement of Loss	Not Validated	poor attention to mother's emotional needs
			not validated
			felt alone
			not being recognized as a parent
			final arrangement
			Didn't help contacting funeral homes
	positive experiences	positive support	showed compassion
			felt supported
			received mementos
			nurses/staff being present-crying hold hands
			gave resources

Table 3 Continued

Themes	Categories	Sub-Categories	Initial Code
			encouragement
	Suggestions for the future	peer support	peer support
			bereavement doula
			need to offered more support
			patient advocate
			point person
			reduce stigma of perinatal loss
			support father's too

Table 4

Coding-Nurses/Social Workers Interviews

Themes	Categories	Sub-Categories	Initial Code
	Compassionate Care	Emotional support	standardize protocol
			willingness to go the extra mile
			nurturing environment
			delivering service in a compassionate manner
			being empathetic/showing sympathy
			unlimited time with baby
			Mementos
			encouragement
			giving resources
			following up with care
			personal connection
			providing emotional, spiritual support
	Staff training	Trainings	more training to staff
			sensitivity training to staff
			offer palliative care
			having social workers involved-have clinical expertise
			providing how to engage with a bereaved parent
			how to discuss death
			how to approach women with empathy
			team approach
			learning how to discuss what to expect
	Staff support	mindfulness to staff	resources for their mental health
			supporting staff
			giving staff time to reflect with other staff
	Field notes acknowledgement of loss	regrets	emotional about not getting pictures
			wanting more time with baby
			Alone
			Frustration
			not getting mementos
			wasn't treated with respect as a parent

Table 4 Continued

Themes	Categories	Sub-Categories	Initial Code
			giving false hope afraid to talk to them feel "different"-had a stigma against her disrespected-healthcare word choices negative "you can try again" or "it was for the best"

Selective Coding

The third phase of Corbin and Strauss's (2008) method is selective coding, the process of identifying and finding core categories (Kolb, 2012). Within this phase, the categories are redefined, to develop similarities and relationships between them to help guide the coding process (See Table 3 and Table 4). Themes that have emerged thus become the findings of the research. After this phase was completed, the themes that emerged from the women's interviews and questionnaires were practices that work and practices needing change. During the coding of the open-ended questionnaires completed by nurses and social worker, trainings and support emerged as the principal areas of growth that nurses and social workers wanted.

Presentation of the Data and Results of the Analysis

Results from Women Participants

The goal of this study is to have hospital staff understand the expectations of women when experiencing a perinatal loss. Women continue to want and need acknowledgement of the loss in a meaningful way. Three women in this study went to a routine prenatal check-up when no fetal movement or no heartbeat was detected. One

mother described the experience as follows: "I was at a routine prenatal appointment, and the doctor could not find the heartbeat, and my blood pressure was through the roof, so I was asked to drive myself to the hospital facility. I got there, and it was confirmed on an ultrasound that her heart wasn't beating." This is just one example of how perinatal loss is not being acknowledged by healthcare professionals. Making a woman drive herself to the hospital is not showing acknowledgement that what she is going through is a valid loss. This mother and all mothers deserve respect and the upmost care when dealing with a perinatal loss.

Four women experienced an early perinatal loss as well as cramping or bleeding and ultimately miscarried. The following is a sufficiently typical description of the experience:

> [I] went to the ER experiencing preterm labor throughout the day, went to the ER going through the miscarriage and felt terrible at that time, but they didn't have any beds yet, so I had to wait in the waiting room until a bed was ready. While in the waiting room, I felt like I was going to throw up, so I went to the bathroom and that is when I lost him.

Experiencing this type of treatment is again showing that healthcare professionals are not acknowledging this mother's fear of losing the baby. Allowing her to lose the baby in the ER restroom is unacceptable and protocols need to be reexamined. Since healthcare professionals are unable to tangibly hold the baby or visually see the baby, it seems as though it does not count or mean as much, so less care is being given.

One woman was given the news that her baby had trisomy and would not live much after birth, the mother reported that: "Right before the 35 weeks I went in for an

ultrasound stat, and at that appointment they found out she had trisomy 13 and she wasn't going to be viable." This was the first time that her doctor told her that her baby had trisomy 13 and would not live. There were other opportunities for the doctor to discuss this with the mother, but waited until 35 weeks. Having earlier notice of the baby's condition could have prepared her to deal with the loss better. Unfortunately, in this case the doctor did not seem to understand that the longer a woman carries a baby, the more attached she is. Having more open communication in this situation would have benefited the mother and prepared her for the baby having trisomy 13.

Themes

Practices that Work and Practices that Need Changed

Negative Experiences and Positive Experiences

During the course of this study, many women suggested that there needs to be more intimate forms of caring actions from the nurses and social workers. Many women expressed that there was a lack of empathy presented by professionals. Women want to feel that their care is exceptional and they are not alone. By compassionate care these women referred to bedside manner of those attending them, the presence of nurses and social workers during the loss, and showing sympathetic actions, like crying with them, holding their hands and using kind words.

Throughout the interviews with the women, many of them discussed the bedside manners of healthcare professionals. Their experience varied from distinctly positive to distinctly negative. One mother reported, "I was not thrilled of how my OBGYN handled it; I felt like he/she was looking at it as a very perfunctory, this is what happens, this is part of trying to get pregnant and part of the process." Another woman had a similar

experience with her OBGYN:

> I was really disappointed, especially with my primary OBGYN (I had been her GYN patient for over 10 years). Her words of comfort were: "I am sorry, this really sucks," and she stood beside me for about 3 minutes. Her bedside manner was underwhelming to say the least.

Another respondent had even less sympathetic attendants, both in her physician and her nurse:

> My OBGYN, I feel like she had kind of like a dry personality. She didn't do anything bad; I just felt like it was kinda dry, um, not sympathetic or empathic really. One nurse, because I had to stay there for a few days because I had a C-section, so my first nurse I had that night was very subpar. She did not even say "sorry for your loss"; umm, she seemed like she didn't want me to have visitors, just didn't say "sorry for your loss"; she was very dry and just more focused on what she had to do".

Other women reported that they experienced a lack of empathy and sympathy, due to the way the nurse or doctor presented him or herself. A woman noted, "the midwife that I had to deal with was not helpful; her demeanor was not very gentle or comforting, and so I would say that any conversations were not very helpful." These women experienced nurses and healthcare workers who did not provide the care these women needed. This study shows that it is vital in caring for women to provide care that meets the needs of women.

On the other hand, some women, based on their responses, had a more caring and sympathetic environment. One participant reported, "it sounds awful, but we were

catered to" while a second woman added, "nurses and doctors were there with me crying, with me, holding my hand, so that was crucial – that expedited my healing process." A nurse who participated in the study said, "we listen, advise, cry with, and support the parents in any way we can." Many women stated that they found comfort in knowing that the nurses and other staff were grieving with them and understood the magnitude of the loss.

One woman who described a positive experience reported:

> There was one particular nurse that was amazing, not that they all weren't really good, but this was just one nurse that particularly stuck out. She was very empathetic and not afraid to acknowledge and validate my child through her name, acknowledging she was beautiful, all of those things are so important!

This particular example illustrates how important it is for nurses to validate women experiencing perinatal loss as mothers.

Women stated that one of the difficult parts of losing a child was the lack of recognition given to them as mothers. Having hospital nurses and social workers who are sympathetic would allow women to feel valued as mothers and provide healing. One mother agreed that being validated as a mother would always be an area that is a struggle for mothers after they leave the hospital:

> 'The one thing that is hard is not being recognized as some kind of parent, some kind of mother, because I don't have the pictures that people want to see. I have pictures of my daughter; those are the ones that you can't just whip them out and people say, 'oh she is cute. It comes with a heavy weight.'

Having nurses and social workers validate and legitimize the death of their child will help

women recognize themselves as mothers.

When women do not receive such compassionate care, their road to psychological and physical recovery can be more difficult. One nurse claimed, "the most helpful tools and support that we [nurses] supply is our compassion and out knowledge." Having nurses and social workers provide gentle care that includes empathetic words, sympathetic actions, active listening, and overall compassionate care will lead to more meaningful interactions, thus improving the satisfaction and potentially even the health condition of the women.

Acknowledgement of Loss

When women are faced with perinatal loss, their healthcare providers need to make sure they have the resources and support they need for the healing process. The support given to women in this study ranged from excellent to less than desirable. Three out of nine women (33%) reported that nurses were excellent and supportive of their decisions while the other six (66%) felt alone and had no guidance.

> One mother said, "I was left completely unsupported" while another participant stated, "a family who has lost a baby or child should not have to ask for support information; it should be provided to them with a discussion between a hospital professional, so the family understands and know they can come back with more questions."

Making sure that women are provided sufficient information makes women feel that they are being supported and that their wellbeing matters.

The data collected in interviews show that all the women were offered chaplain services and one was offered services of a social worker. However, the chaplain services

were generally mentioned to the women as soon as the loss was delivered to the parents, not once they had some time to get used to this difficult news: "We were never seen by social services, and I was only offered pastoral care once, within the first hour of digesting the news." Women reported that at the moment they did not want to talk to anyone and wanted to grieve the loss, but they wished that later in their stay they would be offered that support again.

Another area where mothers felt that they did not receive sufficient support was making final arrangements for their child. Most participants believed that the hospitals at which they delivered did not support them or communicate with them about final arrangements. Women reported that they were dissatisfied with the lack of information provided about final arrangements for their child. Six out of the nine women participants (66%) did not receive any information about how to handle final arrangements. One women was offered shared burial, but did not want that, and no other options were offered to her, so a family member needed to reach out to funeral homes. Another participant said, "They [hospital] didn't help with the funeral arrangements… I asked her [the nurse], can you give me names of some funeral homes' and she gave me some." Another woman stated, "Well, actually, the hospital didn't do that [help make final arrangements]. We talked to a local minister here, and he kind of directed us to where to start."

Findings throughout this study have shown that supporting women at all stages of perinatal loss is essential in the grieving process. Making final arrangements is a difficult task for a grieving mother: "You don't know that you are going to have to be making funeral arrangements for your child." Making final arrangements is a very stressful time;

however, extra support in making final arrangements by having nurses or social workers to take the extra time and go over the different type's of burials or cremations would be valuable. If nurses or social workers could help the women understand the information, it would show support and help guide them to make important decisions.

Supporting women is an important aspect of the nurses and social workers' job in the hospital setting. The women face many difficult decisions, and it is crucial that support be given to each women on an individual basis. Professionals need to remember that if they do not fully explain information or discuss different options, women feel unsupported and may have feelings of regret, which can lead to a more difficult grieving process. Showing sensitive care, respect, and support will help women have a better experience.

Suggestions for the Future

A number of women stated that having someone who has also gone through a perinatal loss be there to support and give guidance to them would be much more helpful than having a chaplain come in and not understand what they are going through. More than half the women identified with the feelings of being alone and wanting the support of another mother who had experienced a perinatal loss. One woman stated,

> I am a huge advocate of these hospitals to hire Bereavement Doulas: a non-medical lay person who can advocate for the family and assist in "walking this journey" with them to validate their situation, their grief, and coordinate services on their behalf… I did not realize the strength of needing another person who has experienced a loss until about four months after our experience.

Women reported that chaplain services had only been offered once or twice

during the hospital stay; however, only one mother reported being called by a social worker 3-4 weeks after the loss occurred. Having the support of social workers can help reduce stress, lessen fears or worries, as well as provide resources to, and support the grieving mother (Cacciatore, 2009). Unfortunately, many hospitals do not employ social workers who are experienced in clinical interventions and rely on nurses to drive the bereavement care.

Having additional support from a woman who has experienced perinatal loss was an important desire expressed by several participants:

> It would be nice to see if they actually had a person or a point person that could actually come and talk to us about [loss and making memories]. I didn't even know there was a way to know, when you have a loss, to have a memory box or to be able to get access to your child's remains, or just to be able to do some of those things that might help the grieving process. So having a social worker or someone who could be above and beyond medical aspects for the rest of those pieces, to sit down and talk to you about the groups and tell you what they are not just hand you a flyer.

Another respondent agreed with the importance of having other women who experienced this type of loss to provide support, so that the grieving mother is not alone.

> I was there by myself; there was not anybody. I wish they would have something in place that they could have someone with you… I have often thought if there was a network of people who would be able to come at a moment's notice just to come [to the hospital] or have a nurse or social worker say: "if you want someone we can call someone" yeah, they will be a stranger, but they have gone through

> this and they will be able to hold your hand, and be able to talk to you, and answer questions the best they can.

Overall, there was a general consensus that having a nurse, social worker, or chaplain who has not experienced a perinatal loss did not provide the support that most women were looking for after experiencing such loss. In addition, women felt those who did not experience a loss did not understand the depth of what the women was experiencing.

Lack of Memories

During the interviews, a reoccurring theme was the hospital workers' lack of communication in regards to giving mothers the opportunities to bathe, dress, hold, or take personal photographs of their baby. This type of communication is very important in making memories. In one hospital, a nurse reported, "the mementos we supply give a sense of the respect and value of every human life, no matter at what gestation stage the loss occurs. This child has LIVED, and the families had plans and dreams for this child."

Unfortunately, some nurses and healthcare staff do not communicate to the parents what opportunities they have to make memories. One woman mentioned that she was disappointed in the fact that she missed out on having items touch her baby's skin because she was not told she could dress her in the clothes she picked out.

> I wish that the nurse would have told us that we could bathe her and change her like I wish she would have offered that to us or told us we could do that. We were not resistant at all to anything that they were saying about holding her or seeing her or taking pictures, so I really wish that she has said that.

Another mother stated in the interview, "I mean I didn't even know we could dress him

in different clothes." Clear communication between the women and the nurses is important for the women, so they can leave the hospital without regrets.

Having regrets after leaving the hospital can possibly extend the grieving process. A women was saddened by the fact that she was given no memory box or anything to remember the baby: "no they didn't [give memory box] I think because I miscarried naturally. They didn't offer me a whole lot of anything in that way." In a study by Burden et al. (2016) it was also reported that a majority of parents express regrets about not holding their baby, not spending enough time, or providers not providing women with accurate information. Making sure that nurses and social workers are able to provide accurate information and provide ways to make meaningful memories allows parents time to grieve the loss.

Another area of making memories that women felt needs to be improved is having nurses, social workers, or chaplains explain the importance of taking photographs of their child[ren] and especially taking a family photograph. As one respondent explained, "I regret when we lost Danny we didn't take any of our own photographs." Another participant expressed the same regret:

> We took a handful of photos with our cameras but didn't have the forethought to take one of all three of us together or one of me holding her, and we were too hindered from our grief… no one from the hospital offered to take photos.

Finally, another woman described the following experience:

> They did take pictures but the pictures were done like how the regular babies were taken. We asked to call a photographer; they claim they tried, but every time we would ask them I feel like that was kind of brushed off or we would have called.

Several of the women reported that they were given hats, blankets, locks of hair, footprints, handprints, teddy bears, books, moldings of the babies' hands and feet, crocheted outfits, angel gowns, memory boxes, and pictures. One respondent stated, "They cared for my deceased baby, our daughter with the upmost respect." Most of the hospital nurses who answered questionnaires reported that women receive tangible items to help them cope with the loss. One nurse explained that a basket is given to the women with different items such as mugs, a clay heart, herbal wraps, a journal, a baby book, an angel statue, a candle, a stuffed bear, and educational books. Also this particular hospital gives the siblings a stuffed animal to help with their healing process too.

Understanding why communication is important is a key factor in showing effective support. Having meaningful conversations between the nurses, social workers, and women experiencing loss is a strategy to improve the overall experience. Communicating with women continues to be important in the healing process as well as it can reduce the anxiety of women, which provides a better experience.

Data from this study support the notion that communication is essential in identifying what women need and want when experiencing a perinatal loss. These findings coincide with the conclusions of Peters, Lisy, Riitano, Jordan and Aromataris (2016) systematic review research; these scholars noted that signs of sympathy are appreciated, and parents value professionals who communicate with them in a genuine manner. Professionals need to validate, sympathize with, and communicate feelings to women to appropriately support them throughout the perinatal loss.

Results from Nurses and Social Worker Participants

Staff Training and Staff Support

The data gathered from nurses and social workers showed that most of the participating hospitals are working towards having a comprehensive bereavement program. Two nurses stated their hospitals use Gundersen Health System's "resolve through sharing" bereavement services (RTS) to educate and provide ongoing training to staff. Resolve through sharing is a standardized bereavement program that many hospitals implement. RTS is an evidence-based approach to bereavement care which helps professionals gain a better understanding and awareness that can be applied when directly working with patients (Gundersen Health System, 2016).

One participating nurse pointed out that, along with using RTS, her hospital provides trainings that include having parents who have lost a child share with staff both the good and bad experiences that they went through to understand the perspective of the parent. Having trainings in-house and made more available to professionals working with perinatal loss will not only increase the parents' confidence in the professionals, but also the professional would have more confidence and feel more comfortable in dealing with such trauma. Allowing hospitals to be creative such as bringing in parents who are willing to express their concerns and experiences will allow professionals to get a glimpse into how their behaviors affect the patients.

On the other hand, hospitals seem to vary in how much training they provide to the staff. Some hospitals give in-house sensitivity trainings to know what to say or how to treat grieving parents while other hospitals offer minimal training to hospital staff, which was disappointing to some of the nurses and social workers interviewed.

Providing staff with opportunities to enhance the understanding of perinatal loss continues to be something both nurses and women want, so that the care provided is excellent and meaningful. Offering RTS can be a mode for formal training to better support perinatal losses and to help nurses and social workers to feel more capable of providing bereavement services.

Many of the women who participated in the study felt that more training needed to be provided to medical staff. Having medical staff learn to be empathetic, have sympathy, and show compassion was a major theme throughout the interviews. One woman stated, "I think that where the disconnect is, is with the doctors themselves that maybe there needs to be some training in the terms of how to be clear but also gentle with women in my situation." Another mother mentioned, "I think they should continue to fund training for them [nurses] and allow their bereavement program to grow. This will only help them when encountering another woman like me." When working with a sensitive population, it is important to make sure that professionals understand how their behaviors affect the grieving process.

According to Evans (2012), nurses can only provide proper care when they are supported with constant education. Allowing nurses and social workers to continue to have training is necessary for nurses and social workers to be comfortable enough to care for women experiencing perinatal loss (Evans, 2012). Offering education to all the staff involved with perinatal loss would be beneficial to the hospital and provide women with better care.

A mother reported in her interview,

"I kind of wish the OBGYN office staff could get better training on how to actually communicate with someone that is more supportive, supposed to just treating it as perfunctory. It may be every day for them, but it's not every day for the person it is happening too."

As hospitals continue to work together with hospital nurses, social workers, chaplains and women experiencing perinatal loss, better care for women can be provided. Breaking the silence and talking about perinatal loss will empower women and begin the conversation on how hospitals can better support these women.

Compassionate Care

Making sure women have a supportive and compassionate team within the hospital setting is helpful in their grieving process. Having inadequate support can lead to women having regrets and extending the grieving process. The current study showed that when nurses and social workers do not provide adequate support, the women end up having a negative experience in an already difficult situation.

Two of the nurses who participated in the research study reported that their hospital is able to support women by providing them the resources that they need such as mementos, follow up meetings or calls to parents, information on joining the Walk to Remember, support groups, shared burials, chaplain services and tangible items for the mother. Other nurses and social workers from hospitals provided conflicting reports on the training and preparation the staff receive; while one nurse claimed, "we have improved our bereavement program in the past year," another reported, "I do not feel that we have good training or support for are staff." Having support for both the women experiencing the loss and the staff providing care for them is equally important.

Furthermore, support provided by nurses, social workers, or other hospital professionals needs to be consistent across all departments. In this study, nurses and social workers reported that several hospitals felt that improving trainings offered to staff will ultimately empower staff and increase their skills to care for women that experience perinatal loss. Having trainings will increase the support provided by nurses and/or social workers.

Supporting women at all levels of the hospital stay is crucial to healing. Making sure that women have information and supportive professionals can ease the anxiety and stress of the loss that was experienced. One nurse explained that to support women, "[they] attempt to have continuity of care by the same nurse." Another nurse also emphasize the significance of the nursing personnel: "the most important tool is the nurse and personal connection, being there with the patient not leaving her alone. Mothers will remember the person caring for them." Support can be offered in many different ways: socially, spiritually, physically and emotionally. Having nurses and social workers trained in how to care for bereaved women will support the women in the grieving process, by allowing women to have trust in their nurses and social workers' ability to care for them.

Results from Field Notes

Self-Reflection

When engaging with the women participants I was able to develop insight into each woman's experience, and realize how different each experience was even though each had the same result. During two of the nine interviews I had strong feelings about how unfair the experience was for these mothers. I was not prepared to become

emotionally involved with the interviews. With that said, I enjoyed being able to talk with each women, nurse and the social worker during the study.

When interviewing the nurses I was very pleased to hear that they are aware of the obstacles surrounding how care is given to women experiencing perinatal loss. When speaking to the social worker that participated in the study, I was very upset that social workers were not more involved with bereaved parents. I did notice that this social worker was also disappointed with the care that was given to women experiencing perinatal loss.

Overall the research that was collected was very meaningful. I was honored that women opened up to tell their stories and felt a level of trust. The nurses and the social worker were very candid and able to share what is currently working and want needs to be improved in caring of women before, during and after their loss. After reviewing the field notes I was able to begin pulling important information, like the passion of the nurses and the social worker and also the pain that each women went through during their journey. From the information collected through the field notes, acknowledging the loss and how healthcare professionals interacted with them were two very important areas that need to be addressed when developing new protocols and procedures.

Acknowledgement of Loss

After reviewing the interviews, field notes were analyzed as another source of data. Within the field notes it was observed that women became emotional when discussing not getting pictures of their baby, or a family picture. This was a source of regret and frustration for many of the mothers. In the tone of their voice and the language

in how they spoke it is reasonable to assume that this is an area that needs improvement in the hospital setting.

Women also expressed that not getting mementos was not acceptable. When healthcare professionals do not make time for the mother to make memories they are not acknowledging that this loss was valid and had an impact on the woman's life. The last area that was discussed was women felt that they were not treated as a parent. Women who had no other children expressed that they wished they were respected as a parent and given the opportunity to grieve as a parent, not just a loss that has little meaning because it was not tangible.

Healthcare Interactions

Another area that emerged from the field notes was healthcare interactions with women before, during and after the perinatal loss. Women expressed that they were given false hope that everything would be okay. Women wanted healthcare professionals to be honest with them in a caring and compassionate way. Lying to them did not make them feel supported or that the healthcare professionals acknowledged the loss. During the loss it was noted that nurses and doctors did not always present themselves in a respectful manner, due to the choice of words that were used while caring for the women. Lastly, after the perinatal loss women heard comments like, “you can try again”, or “it was for the best” which left the women feeling misunderstood.

Having positive interactions is very important in caring for women going through such a tragic event. Being sensitive and not being afraid to talk to the women grieving is essential to showing compassionate care. Allowing the women to express themselves and having the healthcare professionals show empathy is helpful in having more

meaningful interactions. Continuing to research and understand the areas that need improvement will be monumental in how hospitals deliver care to women experiencing perinatal loss.

Summary

This research allowed women to express how they were supported in the hospital setting. Nurses and social workers were also included within this study to evaluate the current programs within their hospitals and to see whether what they are providing is meeting the needs of women. All the interviewees emphasized that women want to have healthcare professionals show compassion and empathy.

By investigating and researching perinatal loss, we can understand how hospitals can better support and guide women experiencing a perinatal loss. The data collected from interviews and questionnaires demonstrate that more support should be given in the hospital setting to women experiencing perinatal loss. Chapter 5 contains a discussion of the results as well as the response to the overarching research questions.

CHAPTER 5. RESULTS, CONCLUSIONS, AND RECOMMENDATIONS

Introduction

An appreciative inquiry action research was conducted to examine what women experiencing perinatal loss need to feel supported, emotionally, physically, socially, and spiritually within a hospital setting and how such support may influence these women. The goal of this study was to provide knowledge to hospital administrators on what women want from healthcare professionals in order to feel supported when experiencing a perinatal loss. The final chapter will include a summary and discussion of the results, conclusions, limitations, and further recommendations for research and interventions.

Summary of the Results

The data collected from the current study supported previous literature on perinatal loss. All nine participants who experienced perinatal loss had feelings of sadness, regrets, loneliness, and frustration, which was also the same feelings of other women in previous literature. Each participant described her perinatal loss differently; however, on the whole, their perceptions lead them to an understanding of where the needs are when caring for women experiencing perinatal loss in a hospital setting.

Hospital professionals providing individual care and acknowledging the loss will create compassionate care and positive experiences, so the woman can grieve the child who was taken away too soon. In the context of such a situation, the actions and behavior of nurses, social workers, and all of those who work with perinatal loss may contribute to the healing process. Providing acknowledgement to the loss can show women that they are not alone, that nurses and other hospital staff are invested in the care

they provide and have genuine sympathy for these women.

To support a grieving woman, a nurse or social worker can use different strategies, such as encouraging the woman to hold, take pictures of, bathe the baby, and change the baby's clothes. These memories will be long-lasting and maximize the women's experience. Women need to have a positive experience interacting with nurses and social workers, so that when they reminisce about their baby and being at the hospital, positive thoughts flood their minds instead of regrets and anger. Helping women make decisions that are not easy, such as final arrangements, is another way to show support. Lastly, nurses and social workers can verbally provide information to women on what support groups are available and how they would be beneficial, so that women understand the value they can receive from attending support groups.

Open communication between hospital staff and the mother is an essential expectation of women going through a perinatal loss. Open communication should help the women understand what is happening, and nurses and social workers should treat them with respect and empathy. These findings support the study of Simwaka, de Kok, and Chilemba (2014) who discovered that some of the most important actions provided by a nurse are reflected listening, using empathy, and communication skills. The findings are also consistent with the study by Sereshti et al. (2016), which showed that most participants were dissatisfied with healthcare professionals' communication. Healthcare professionals showing feelings of caring is important to how women perceive their experience in the hospital.

Discussion of the Results

This research study was guided by the following overarching research question:

What are the needs of women who experience perinatal loss, and are those needs being met within a hospital setting?

The three research sub-questions included the following:

1. What are the physical, emotional, spiritual, and social needs of women who have experienced a perinatal loss?
2. What do women find helpful in coping with perinatal loss when in a hospital setting?
3. What are examples of compassionate care as revealed by women who have experienced perinatal loss?

After completing the coding and analyzing the data, the overarching themes that emerged were practices that work and practices needing change. Throughout the interviews, women indicated a greater need for nurses and social workers to show acknowledgement of the loss and deliver a positive experience to the women. Women want to feel validated as mothers and to receive physical, emotional, spiritual and social support. Acknowledging the loss can be showed by empathy, support, and being sympathetic to the women are imperative in helping women manage their feelings about the loss. Findings from the data helped answer the research questions outlined below.

Question 1: What are the physical, emotional, spiritual, and social needs of women who have experienced a perinatal loss?

The collected data suggest that most women do not feel that hospitals are able to meet the needs of physical, emotional, spiritual, and social support. Participants reported that nurses, doctors, and other healthcare professionals were able to meet their physical needs but had trouble meeting emotional needs. Meeting women's emotional needs

would require some more training among nurses and doctors.

Women also stated that nurses were not all able to use empathetic words or communicate effectively with them. Women had mentioned that many healthcare professionals did not even acknowledge their loss and did not say, "I am sorry for your loss." This lack of care made women frustrated and dissatisfied with the care they were receiving.

In most cases, women were offered some type of spiritual support; however, it was not always given at the correct time, according to the women. Women needed time to process the loss before having their spiritual needs met or having others come into the room to provide support. In the current study, women expressed a wish to be given the choice later in their stay of having pastors, spiritual advisors, chaplains, or other clergy members to meet with them after the family was notified and the women began to grasp the magnitude of the loss.

Lastly, women were split on the topic of social support. About half of them said they were offered to attend support groups while the other half claimed it was not even mentioned during the women's stay at the hospital. In most cases, women claimed that nurses or social workers did not explain the purpose and value of support groups, making most women uncertain of what the groups entail. As a result, they were reluctant to attend. Women in this study had an impression that family and friends were more supportive than the nurses and other healthcare professionals. Receiving the support of nurses and social workers can help women feel more socially supported in the hospital setting.

Question 2: What do women find to be helpful in coping with perinatal loss when in a hospital setting?

According to the study's results, women felt that having nurses and social workers being present with them, crying with them, holding their hands, and showing genuine empathy were helpful in their coping process in the hospital setting. Women also found that it was easier to cope with the loss when nurses and social workers validated the loss and treated women as mothers. When healthcare professionals expressed their acknowledgement of the difficulties of perinatal loss, women also found that helpful.

Question 3: What are examples of compassionate care as revealed by women who have experienced perinatal loss?

Based on the findings, women experienced compassionate care when nurses and social workers were sympathetic, had empathy, communicated, and listened to their needs. As stated before, the actions of being present with women before, during, and after the perinatal loss were perceived by women as showing compassionate care. Elements of compassionate care included allowing the women to cry and express their fears, worries, and disappointments. When nurses or social workers permitted women to grieve the loss of their child while being available to listen and show sympathy by crying with them was very meaningful to women and led to compassionate care.

Relationship to Previous Research

During this study, two principal themes emerged from the data collected: practices that work and practices needing change. All of the categories identified, which

led to the themes, coincided with those revealed by previous research. The theme of practices that work show that creating positive experiences and having healthcare professionals have positive attitudes play a great role in the women's experience, according to the current study. Peters et al. (2016) concurred that providing meaningful care for women contributes to a positive experience. These findings were also consistent with the study conducted by Kelley and Trinidad (2012) where women stated that they received the most meaningful support from nurses and physicians who took time to sit with them and be present with them.

The second theme that emerged was practices needing change, such as how healthcare professionals acknowledge the loss and how memories are made with the baby and mother. A review of the literature suggested that women experiencing a perinatal loss were not satisfied with the care provided by nurses. Erlandsson, Lindgren, Malm, Davidson-Bremborg and Radestand (2011) reported that women felt neglected by hospital staff when they did not get the care they needed. Nordlund et al. (2012) noted that women felt that professionals did not listen and lacked empathy while caring for them. In the current study, women had expressed the same concerns. Women claimed that they felt alone when nurses and social workers did not engage in conversation or validate their loss at least in a verbal manner, such as stating, "I am sorry for your loss" or "This is a difficult thing to go through, I am sorry." Having these meaningful conversations helps validate and acknowledge that what the woman is going through is not easy.

Women expressed concerns about feeling unsupported in making decisions, final arrangements, what to do after they left the hospital, and getting resources and guidance

from nurses. Previous research suggested that nurses play a significant role in helping women get professional support (Moore et al., 2011). In this study, some women reported that they felt unsupported by nurses and lacked the resources to guide them throughout their journey. Many women in their interviews mentioned feeling lonely in their grief.

Determining the type of support that needs to be given depends on the woman and how information is delivered. Support and empathy can help women who have high distress levels (Moore et al., 2011). Delivering support can come in many forms, such as guiding women through final arrangements, giving resources to the women, or just being present. These findings agree with those of Malm, Radestad, Erlandsson, and Lindgren (2011) who reported that a lack of information given to mothers led to them feeling unsupported. In the current study, many felt that little guidance and support were given in making final arrangements and that they were alone in this daunting task. Women need to be supported throughout all stages of their loss, so that they can make important decisions and not have regrets later in their healing process.

Communication has been a topic of research as an area of growth for many hospitals. Peters et al. (2016) reported that healthcare professionals communicating to parents should strive for an empathetic manner to reduce the latter's stress and anxiety. In the current study, women felt that communication was lacking as they were not allowed the means to make more memories of the lost child. Women who had more empathetic nurses and social workers had a much better experience and felt more supported. Communication for nurses and other healthcare professionals continues to be vital in caring for women experiencing a perinatal loss.

In the Kerslake and Parkinson (2012) study, one mother reported that no one had told her she could hold her baby. A similar concern emerged in the current study in some of the interviews. Women felt that they did not receive clear information about what women were able to do with their babies and what was not allowed. Women who have never experienced such loss are going through great emotional pain; for that reason, the simplest things such as holding their baby might not be at the forefront of their minds, and they need reminders and encouragement from nurses and social workers.

The participants in the study included both women experiencing perinatal loss and healthcare professionals as well. In their interviews, women, nurses, and social workers alike expressed the need for more staff training. The lack of appropriate training has been acknowledged in research for almost eight years. McCreight (2008) stated that researchers need to reexamine the training of medical personnel in emotional and caring aspects. In the current study, only one out of the four nurses felt that they were exceeding expectations in caring for women's emotional needs. O'Connell, Meaney, and O'Donoghue (2016) received similar results, suggesting that appropriately trained and educated nurses or social workers would help the mother in the grieving process. Evans (2012) highlighted the importance of the nurses' role when caring for women experiencing a loss. Developing trainings and educational seminars for healthcare professionals working with perinatal loss would be important, so that women are treated with the upmost respect and dignity.

Many studies in the literature review suggested a need for formal education and training to those caring for women experiencing perinatal loss. Gergett and Gillen (2014) identified that a lack of such training and knowledge negatively affects the care given. It

is important to train healthcare professionals on how to respond and support women at any stage of loss (Peters et al., 2016). Until nurses, social workers, and other healthcare professionals are trained and educated in how to deal with perinatal loss, women are likely to be continually dissatisfied with their experience within the hospital setting before, during, and after a perinatal loss.

Discussion of the Conclusions

The results of the study suggest that women need an all-encompassing support group while at the hospital that would provide them with acknowledgement of the loss. The study also revealed the importance of giving women the opportunity to grieve their loss, while helping them create memories, such as taking pictures of, holding, bathing, and changing their baby. Understanding the grief that women experience and developing interventions and protocols to support these women experiencing a loss will ultimately reduce the level of anxiety and help their grieving process.

The interviews revealed there were specific factors based on how the women evaluated the care they received. Much of the information points to the crucial importance of support within the hospital setting for the women's experience. Most women desire open communication between all those involved in her care. The terms "sympathetic" and "empathic" were mentioned throughout most interviews. In a study by Sereshti et al. (2016), poor communication by the treatment team was shown to worsen the mothers' problems and increase their distress. The participants in Sereshti et al. (2016) study expected better emotional support from medical professionals. This lack of empathy and communication also frequently came up in this study: women expressed their desire for improvements in this area in their current hospitals. Women felt that

participating in the study was their way of helping develop awareness and provide feedback on the specific issues hospitals need to address to better support women experiencing a perinatal loss.

Limitations

There were several limitations of this study, the required methodology being one of them. It limits how the study was designed and how information was disseminated to hospital administrators. Participants within this study only included women who experienced a loss within the first 40 weeks of gestation and did not include those with ectopic pregnancies or losses that occurred within the first month of life. In addition, participants had difficulties in obtaining information due to the sensitivity of the topic of perinatal loss. Furthermore, selection criteria required the removal of participants if they became pregnant. This occurred with two women.

Reaching out to nurses and social workers ended up being a challenge. Most hospitals did not have social workers involved in the bereavement process for women experiencing perinatal loss, so finding social workers to participate was difficult. Several hospitals needed to be contacted until just one social worker was able to participate. Lastly, having only nine participants did not allow generalizable findings. Having a larger population with both targeted populations (a) women and (b) nurses and social workers might have yielded different responses. Unfortunately finding participants was difficult.

Recommendations for Future Research

There continues to be a need for future research on how to incorporate interdisciplinary teams within the hospital setting. Using social workers in alleviating

mothers' grief could help hospitals improve patient satisfaction. Social workers can play an integral role in the grieving process of women experiencing a perinatal loss. They are equipped with some tools and education to evaluate the psychological impact of the loss and help advocate for these women. Using an interdisciplinary team for such patients will also allow hospital personnel to use different perspectives of their disciplines to provide additional support, advocacy, and care to help ensure women are receiving the best care.

Many of the women in the study expressed a need and desire to have someone who has experienced a perinatal loss guide them through their journey. Women believed that those with such an experience could make sure that pictures are taken, information is given, and ultimately show they are not alone in this journey. Participants also echoed throughout the interviews that having a non-medical laywoman who has experienced perinatal loss and can advocate for them and help them walk through this journey is important. Having this type of person can help the women with the grieving process while in the hospital. Women felt that having a non-medical layperson would allow them to discuss and answer questions that a person who has not be adequately trained, educated or experienced perinatal loss might not be able to answer. Furthermore, this person could provide emotional support while the nurses are focusing on the medical treatment of these women.

Another area that is underutilized is an organization that was mentioned prior in this dissertation is the National Association of Perinatal Social Workers (NAPSW). The NAPSW has been advocating for more social workers to become involved in the treatment and care of women experiencing perinatal loss. Within the hospital setting, it

seems there are social workers with the knowledge and resources that are going unused, according to the participants in the study.

Additional qualitative and quantitative research on implementing interdisciplinary teams would be beneficial to see how collaborating with different disciplines would assist in improving best practice care. Having social workers as part of an interdisciplinary team could provide therapeutic interventions, ease patient anxiety, and allow hospitals to assess women psychologically prior to leaving the hospital. The extent of the overall support provided in hospitals should be supported by research. Due to the complexity of perinatal loss, it seems obvious that professionals with different perspectives, such as nurses, doctors, chaplains, and social workers should work together to develop policies and protocols to provide the best patient experience.

A specific recommendation of this study is to improve protocols and implement interdisciplinary teams to provide the most efficient care to women suffering a perinatal loss. Having hospitals reevaluate current protocols for perinatal loss can provide a more systematic approach. Using the theoretical framework the diffusion of innovation would help create the needed change in hospitals. Using diffusion of innovation, nurses and social workers can pave the way for a much-needed overhaul of hospital protocol and how hospitals use social workers in caring for women experiencing a perinatal loss. Team members who are invested in changing policies can develop clear policies on bereavement management. Ultimately, such policies would be available to assist nurses and other hospital staff in helping women to make plans and decisions about their child (Evans, 2012).

Conclusion

Perinatal loss is a devastating experience (Sereshti et al., 2016), but, unfortunately, it is more common than one may imagine. This research study offered new insight into the problem and helped gain a new perspective of what women need and want when they are experiencing a perinatal loss. Improving how healthcare professionals acknowledge the loss, and allow for women to make memories for bereaved mothers will positively affect overall patient satisfaction.

This research will provide groundwork on developing interdisciplinary teams, developing and implementing protocols, and training staff in providing specialized care to bereaved women. It is hoped that the findings of this study will help guide hospital administrators to develop better care and standardize procedures. Continuing to research perinatal loss both through qualitative and quantitative methods will pave the way for higher standards of care.

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APPENDIX A. STATEMENT OF ORIGINAL WORK
Academic Honesty Policy

Capella University's Academic Honesty Policy (3.01.01) holds learners accountable for the integrity of work they submit, which includes but is not limited to discussion postings, assignments, comprehensive exams, and the dissertation or capstone project.

Established in the Policy are the expectations for original work, rationale for the policy, definition of terms that pertain to academic honesty and original work, and disciplinary consequences of academic dishonesty. Also stated in the Policy is the expectation that learners will follow APA rules for citing another person's ideas or works.

The following standards for original work and definition of *plagiarism* are discussed in the Policy:

> Learners are expected to be the sole authors of their work and to acknowledge the authorship of others' work through proper citation and reference. Use of another person's ideas, including another learner's, without proper reference or citation constitutes plagiarism and academic dishonesty and is prohibited conduct. (p. 1)
>
> Plagiarism is one example of academic dishonesty. Plagiarism is presenting someone else's ideas or work as your own. Plagiarism also includes copying verbatim or rephrasing ideas without properly acknowledging the source by author, date, and publication medium. (p. 2)

Capella University's Research Misconduct Policy (3.03.06) holds learners accountable for research integrity. What constitutes research misconduct is discussed in the Policy:

> Research misconduct includes but is not limited to falsification, fabrication, plagiarism, misappropriation, or other practices that seriously deviate from those that are commonly accepted within the academic community for proposing, conducting, or reviewing research, or in reporting research results. (p. 1)

Learners failing to abide by these policies are subject to consequences, including but not limited to dismissal or revocation of the degree.

Statement of Original Work

I have read, understood, and abided by Capella University's Academic Honesty Policy (3.01.01) and Research Misconduct Policy (3.03.06), including the Policy Statements, Rationale, and Definitions.

I attest that this dissertation or capstone project is my own work. Where I have used the ideas or words of others, I have paraphrased, summarized, or used direct quotes following the guidelines set forth in the APA *Publication Manual*.

Type	
Learner name and date	Kimberly Glatfelter, MSW 8/29/16
Mentor name	Dr. Ruth Ahlman, School of Public Service Leadership

APPENDIX B. INTERVIEW QUESTIONS FOR WOMEN

Opening statement

Let me first tell you how very sorry I am for your loss and how much I appreciate your willingness to talk with me today. If at any point you feel as though you do not want to talk anymore, please let me know and we will stop.

Questions

1. Can you tell me how old you are?
2. How old were you when the loss occurred?
3. Where did you deliver?
4. How far along were you when you experienced the loss?
5. Could you tell me about how you were supported during your hospital stay?
6. What types of support did you receive after your loss? (PROBES: Did someone take pictures of your baby? Did you hold your baby? Did you get a memory box? Did someone come to talk with you specifically about your loss? How did it feel to talk to someone about your loss?)
7. Which types of support were least useful?
8. What seemed to help you the most?
9. How did the staff support your physical, emotional, spiritual, and social needs?
10. If you could address a group of hospital administrators, what would you tell them is needed to be done by the hospital to best support women who are trying to cope with their loss?
11. Did you attend support groups after your loss? Did you find this helpful? In what way?
12. Did you receive adequate support in making final arrangements for your baby?
13. What would you say to another woman who has just experienced perinatal loss?
14. Is there anything else you would like to tell me about how the nurses, physicians, chaplain, social worker, etc. could have better supported you during the loss?
15. How did it feel to talk to me about your loss? Do you feel you need to talk to someone else?

Debriefing

Each interview will close with a debriefing question, such as "What was it like for you to talk with me about your loss?" and "How are you feeling now?" (Kavanaugh & Hershberger, 2005). After the interview is concluded, I will state: "I am very thankful for your time and the information that you shared with me about your loss. If you think this interview has brought up feelings that need to be discussed, please call for information on seeing a nurse, doctor, or therapist. Again, I am grateful for your time."

APPENDIX C. HEALTH PROFESSIONALS QUESTIONNAIRE

1. What are the supports offered to women who experience a perinatal loss at your hospital?

2. In what ways do you believe hospital staff can support women physically, emotionally, spiritually, and socially?

3. What types of trainings are offered to staff to help increase their knowledge on how to care for women experiencing perinatal loss?

4. Are there protocols within the hospital when a women has experienced a perinatal loss? If so, what are they?

5. What is the most helpful tool or support provided by the hospital staff?