Theses, Dissertations, and Projects

2014

Social work practice with individuals and families who have experienced pregnancy loss

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Social Work Practice with
Individuals and Families Who Have
Experienced Pregnancy Loss

ABSTRACT

Approximately 10 to 15 percent of known pregnancies worldwide end in miscarriage and an additional one in 160 pregnancies end in stillbirth. Because of a lack of evidence-based research to support interventions in this work, social workers have come to rely on their own practical experience. This study investigated social workers' professional practice experience in order to outline the frequency and impact of pregnancy loss and to assess the formation and maintenance of current practices for effective and efficient treatment. This study utilized in-depth, qualitative interviews to further understand how clinicians in this field define and conceptualize their work. The major findings from this set of data were in the areas of: preparatory experience, fundamental approach to patients, and the ways in which clinicians continue to educate themselves on the topic of pregnancy loss. Two important themes emerged from clinicians' experiences in perinatal social work; the first was the impact of clinicians' personal experiences with childbirth and child rearing and the second was the ways in which social workers understood their roles within interdisciplinary teams. Based on the experiences of these 11 perinatal social workers, the study showed that being effective in this work, at least initially, requires that clinician's are able to adapt prior experiences, be flexible and open about their role, and that they understand the intense, psychological impact of pregnancy loss on patients and families.

SOCIAL WORK PRACTICE WITH INDIVIDUALS AND FAMILIES

WHO HAVE EXPERIENCED PREGNANCY LOSS

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2014

ACKNOWLEDGEMENTS

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CHAPTER I

Introduction

I think that what I continue, after all these years, to be in awe of is that sense of each time, approaching a door to meet somebody for the first time and thinking 'what do I have to offer in this situation? What is it that I can do to help them through this profound situation that they may or may not have any life experience with, meaning death?' However it occurs for people, that profound respect for what people are going through and just the joy and the tragedy that pregnancy can present.

And really trying to figure out their individual story, who they are, who their families are, and how that is going to impact them getting through this experience in the most positive way to help them form the family that they are going to be as they go on.

So that's, I guess, in a nutshell what I try to do, to be a part of. And just to remember why I'm there and that this is about their experience and sometimes, we all have our piece to do. In the hospital system there are things to get done, but what is it that we can most compassionately and confidently and respectfully capture with their experience.

- Study Participant

For most families, finding out about a pregnancy is a happy time; they immediately begin to consider what life will be like with their new child. What will their new baby's name be? Will this be their first child or, perhaps, their last? Will he or she be an athlete or a musician? There is no way to know what the future will hold for this new life. For most families, it is difficult to imagine that their precious child could ever be taken away from them. However, this is the harsh reality for all too many families. Approximately 10 to 15 percent of known pregnancies worldwide end in miscarriage and one in 160 pregnancies end in stillbirth ("Pregnancy Loss: Still Birth," 2010; Mahan and Calica, 1997). It is estimated that as many as "one in four women [will] experience a pregnancy loss during [their] lifetime," (Price, 2008,

p.367). The loss of a pregnancy often occurs unexpectedly and thus creates an abrupt shift in an expected family life cycle. This can leave a family devastated and grief stricken and it is believed that conventionally held theories of grief fall short of the realities described by bereaved parents (Brownlee and Oikonen, 2004). The anguish surrounding the loss of a pregnancy has been considered by some to be a form of disenfranchised grief and can be identified as the reaction to a silent loss. In other words, pregnancy loss is so far out of cultural and social norms that it often goes unaddressed, leaving families feeling isolated, unsupported, and invalidated. There continues to be a substantial lack of research in the area of pregnancy loss and, as Sarah Kye Price (2008) suggests, "the scarcity of practice-based research reflects the degree to which issues of reproductive loss continue to fall outside the realm of current professional social work dialogue" (p. 371).

Social workers have played an integral role in the study of pregnancy loss and can continue to impact its treatment. According to the National Vital Statistics Report, which is produced under the umbrella of the Center for Disease Control and Prevention (CDC), there were approximately 3.9 million births registered in the United States in 2012 and it is believed that during that same time period an additional 2 million pregnancies were lost (Martin, Hamilton, Osterman, Curtin, & Mathews, 2013). Social workers are on the front lines in treating these losses. This study investigated social workers' professional practice experience in order to outline the frequency and impact of pregnancy loss and to assess the formation and maintenance of current practices for successful intervention with this population. An additional goal of the study was to understand how social workers' clinical practice with individuals and families who have experienced pregnancy loss might be more efficient and effective. This study utilized in-

depth, qualitative interviews to further understand how clinicians in this field define and conceptualize their work.

As far as available literature on pregnancy loss, theories perspectives outnumber empirical studies on the topic. Theories of grief and loss, death and dying, and attachment appear to be most often associated with conceptualizations of pregnancy loss work. More recently, there has been a push to further consider the impact of a person or family's network of systems as a possible source of support, or as a barrier, in the wake of a pregnancy loss. Studies, such as the one conducted by Bennett, Litz, Lee, and Maguen (2005), suggest that when attempting to understand pregnancy loss, it is imperative to consider such factors as race/ethnicity, socioeconomic status, and education. As far as social work involvement, over the past four decades, authors have continued to discuss the evolution of practices surrounding pregnancy loss and the role of the social worker as a part of a larger interdisciplinary team (Mahan & Calica, 1997; Wallbank & Robertson, 2012; Roehrs, Masterson, Alles, Witt & Rutt, 2008).

As the numbers suggest, pregnancy loss is more common than most believe. While there appears to be a descent amount of books, websites and blogs that offer support to women and families as they are beginning (or continuing) the healing process, the availability of resources for clinicians is lacking. Literature on pregnancy loss began to gain ground in 1980 when Larry Peppers and Ronald Knapp published *Motherhood and Mourning: Perinatal Death*. This book was one of the first to outline the formation of the maternal-infant bond; additionally, the authors offered an initial explanation of the unique variety of grief associated with the loss of a pregnancy. Prior to this, the understanding was that it was in the mother (and family's) best interest to remain as removed from the loss as possible; doctors and nurses were encouraged to

whisk the dead babies away while offering little to no information to the patient and/or family. Families were encouraged to "move on," or to "try again," leaving them feeling as if the pregnancy had never occurred.

Though empirical research remains difficult to find, there has been a steady flow of theoretical and practice based information since the 1970's (Brownlee & Oikonen, 2004; Gaudet, 2009; Mehran, Simbar, Shams, Ramezani-Tehrani & Nasiri, 2013; Pines, 1996; Robinson, Baker & Nackerud, 1999). The lack of empirical research on women who have experienced pregnancy loss may be due, in part, to the nature of pregnant women as a protected research population. Despite the lack of empirical research on this topic, social work clinicians have continued to more seriously consider the unique grief qualities associated with the loss of a pregnancy, as well as the psychological impact of such practices as holding, taking pictures, and receiving mementos of the baby. As a group, social workers have been attempting to contribute to increasing awareness among the general public and also among clinicians. Organizations such as the National Association of Perinatal Social Workers (NAPSW) were formed as a way for clinicians to share their experiences and to continue to learn from each other. It would seem that perinatal social workers have valuable, and perhaps, untapped knowledge and resources for conceptualizing and treating pregnancy loss.

This study explores 11 social workers' experiences working with pregnancy loss and presents the clinical practices that they believe best inform their efforts. The ways in which social workers conceptualize and treat pregnancy loss are well suited to qualitative research, which allows for a deeper exploration of the their experiences in addressing pregnancy loss. The subject of pregnancy loss seems to be a particularly difficult topic of conversation both for clinicians and patients and the variety of reactions and outcomes make it difficult to generalize. I

felt it most viable to connect with clinicians in order to discuss how best to work with women and families during this fragile time. It is possible that any social worker, regardless of facility or practice modality, might find him or herself in session with a client who discloses a pregnancy loss as a part of his or her reproductive history. Because of this, I feel that the information discussed in this study is of utmost importance to the entire field of social work. Knowing how to approach these conversations may help to ease tensions, may present the opportunity for an increased, positive therapeutic connection and could provide the space for more beneficial clinical work. By offering social work clinicians the opportunity to continue to explore and reflect on their own experiences, my hope is that they will further appreciate the positive impact of their work. Additionally, knowing that this information may be used to help individuals begin to heal from such a devastating event may provide these clinicians with some personal reprieve.

CHAPTER II

Literature Review

Pregnancy loss is incredibly prevalent, occurring in approximately 10 to 15 percent of known pregnancies worldwide (Price, 2008; Robinson, Baker & Nackerud, 1999). Though this phenomenon is also known as perinatal loss or reproductive loss, this author has chosen to use *pregnancy loss* as an umbrella term throughout the remainder of this paper. For the purpose of this study, *pregnancy loss* is defined as any loss occurring during the perinatal period – conception through seven days postpartum. The types of loss included are: ectopic pregnancies (which occur when fertilized eggs attach outside of the uterus, usually on the walls of the fallopian tubes), miscarriages or spontaneous abortions (0-20 weeks gestation), intrauterine fetal demises (IUFD) or stillbirths (20-40 weeks gestation, or full term) and neonatal or infant deaths (post delivery)[1]. In an attempt to limit the scope of this research, the author has chosen to exclude pregnancy termination and elective termination due to fetal anomalies as they presents an element of choice, which is not present in other forms of loss. Additionally, the perinatal period has been limited to seven days postpartum, versus the twenty-eight days suggested by some researchers, as this author believes that the loss of an infant beyond seven days postpartum provides an opportunity for increased physical attachment and is thus beyond the scope of this research.

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[1] Definitions were adapted from the Official Journal of the American Academy of Pediatrics

Theoretical Understandings of the Prevalence and Impact of Pregnancy Loss

It is believed that prior to 1970, pregnancy loss was considered a non-event (Brownlee and Oikonen, 2004). At this time, standard practice was to remove the baby from the scene before parents had the opportunity to further attach to it. Theory held that "the less the mother knew of the baby, the less she would mourn its death," and family and friends were encouraged to remove any and all items that might remind the mother of the lost baby (Lundquist, 1998, p. 246). This was perceived to be a well-intentioned effort aimed at decreasing the psychological trauma of the event (Cacciatore, Radestad and Froen, 2008; Hughes, Turton, Hopper and Evans, 2002; Stringham, Riley and Ross, 1982). However, advances in attachment and grief theories began to suggest that this might not be the best course of treatment (Peppers and Knapp, 1980).

It is imperative for social workers to have an operational understanding of attachment and loss in the context of a pregnancy, in order to inform their practice with this population. Though mainstream theories can be adapted to help conceptualize pregnancy loss, it is important to recognize that earlier theories were, for the most part, presented to explain phenomena present in the relationships created between and among *living* children and adults (Bowlby, 1969). Additionally, these theories did not include relationships created by individuals (with their baby) during a pregnancy. The loss of a pregnancy offers an interesting juxtaposition in that rather than grieving the loss of the past, a family must grapple with the grief associated with losing a future.

Early attachment theories suggested that bonding begins at delivery and highlighted the ways in which relationships were created between parents and children following birth. This attachment is defined as a deep and enduring emotional bond that connects one person to another across time and space (Ainsworth, 1978; Bowlby, 1969). These theories were specifically

designed to explain how young children function, either adaptively or maladaptively, based on their relationship to their primary caregivers. Although attachment theories can help to inform pregnancy related work, these theories make no mention of the bonds forged between parents and their children during pregnancy, or prior to the child's birth. As it turns out, the relationship between mother and child begins long before conception.

From a young age, girls as socialized to include motherhood as part of their identity (Pines, 1996). As they become women and chose to act on this facet of their identity, they begin to imagine what life as a mother might be like; part of this fantasy includes the relationships that they will create with their future sons or daughters. In grieving the loss of an adult you might grieve the times you had together and think about what was; however, when a pregnancy is lost, so too is a part of the future, evidently this loss becomes much more difficult to mitigate (Jaffe, 2011; Price, 2008; Stringham, Riley and Ross, 1982). Additionally, for some women, their identity as a female is closely tied to their ability to birth children, thus, when a pregnancy is lost, a women might begin to challenge her self-worth, or worse, she may feel like a failure as a woman or a wife (Pines, 1996). In considering the strength of the attachment formed between mother and child prior to birth, one can begin to understand how the loss of a pregnancy could be emotionally devastating. Similarly to attachment theories, grief and loss theories were originally presented with the intent of understanding the loss of a living person or one's own death (Kubler-Ross, 1977); however, over the past few decades, these theories have been adapted to inform loss in the context of a pregnancy.

Elizabeth Kubler-Ross's *On Death and Dying* (1977) presented a revolutionary understanding of grief and loss. This stage-model suggested a series of emotions faced by individuals as they were coming to terms with their own death, or the death of a loved one.

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However, "[o]ne of the drawbacks to the stage theory model of bereavement is that people do not necessarily grieve in a set order or totally complete a stage before entering the next," (Jaffe, p. 93). Since then, this theory has been expanded on and extrapolated to include many different types of losses and, as such, can be a useful platform from which to understand the grief associated with pregnancy loss. Using Kubler-Ross's theory as a corner stone, Peppers and Knapp (1980) offered one of the first in-depth analyses of attachment, loss and grief as they pertain specifically to pregnancy.

Motherhood and Mourning: Perinatal Death offered an expansion on Klaus and Kennell's (1976) concept of Maternal-Infant Bonding. This platform suggested that the formation of a mother's attachment to her baby could be outlined in series of nine distinct stages, including: 1) planning the pregnancy, 2) confirming the pregnancy, 3) accepting the pregnancy, 4) fetal movement, 5) accepting the fetus as an individual, 6) birth, 7) seeing the baby, 8) touching the baby, and 9) giving care to the baby. It is important to highlight that five of the nine stages occur while the baby is still in utero and it is worth mentioning that stages do not have to occur in a linear fashion. In addition to further exploring the maternal-infant bond, Peppers and Knapp discuss the loneliness surrounding pregnancy loss, the possible impact on intimate and other relationships, and the responses of the medical and other communities. Peppers and Knapp's work presented a groundbreaking understanding of maternal-fetal attachment and since the publication of *Motherhood and Mourning: Perinatal Death*, research on the impact of these early bonds has continued. A study by Mehran, Simbar, Shams, and Ramezani-Tehrani (2013) on maternal-fetal attachment behaviors some three decades later concluded that "MFA (maternal-fetal attachment) [is] conceptualized by the attachment theory as an effective emotional relationship between a mother and her baby that initiates from the prenatal period

while the physical development of the fetus and transformation of a woman into a mother are occurring simultaneously," (p.185).

Whichever theory clinicians use to scaffold their work with pregnancy loss, it is imperative to consider the systems that impact the loss. These considerations are suggested and supported by a person-in-environment or ecological perspective (Bennett et. al., 2005; Price, 2008). Circumstances influencing the risks and resiliency of couples' facing pregnancy loss might include: reproductive history, parent(s) familial relationships, social acceptance (or lack there of) and provider response and/or support (Brownlee & Oikonen, 2004). It appears that most researchers have failed to incorporate these additional layers of complexity into their studies (Bennett et. al, 2005; Shreffler, Greil, & McQuillan, 2011). As Shreffler, Greil, and McQuillan (2011) state, "the context of women's pregnancy and fertility experiences as a whole and the meaning they attribute to their pregnancies are crucial in shaping the psychological response to pregnancy loss," (p. 352).

The Role of Social Work Practice in Cases of Pregnancy Loss

Although access to theory regarding the impact of pregnancy loss continues to expand, empirical and evidence-based research to support clinician's work with this population remains sparse. Brownlee and Oikonen (2004) states their views:

> The care provided after such a loss should be founded upon sound practice models that are supported by the clinical and research literature. It is observed that within the field of perinatal bereavement, shortcomings continue to exist… in the soundness of practice models (p. 518).

In the absence of evidence-based research, social workers have come to rely on their own practical experience along with that of their colleagues in order to inform their work with this population. Because the reactions to pregnancy loss can be so varied, the creation of a model from which to predict, and subsequently treat, outcomes is complicated (Bennett et. al., 2005).

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Additionally, at least one study (Hughes et. al., 2002) has shown that abiding strictly by a preconceived protocol can, in some cases, cause further trauma for women and families. It is the intent of this study to synthesize the available research and combine it with examples of clinician's experiences in an attempt to offer a best practices guide for working with this population.

Of the empirical research that has been conducted surrounding pregnancy loss, a majority has included samples that are small and homogeneous. Often participants are conveniently selected based on their willingness to participate in a study and their geographic proximity to the study location. When considering such factors as race, education, age, socioeconomic status and strengths of supports, time and again the samples appear to be non-representative of the population at large. Though it would be interesting to assess the differences in response to pregnancy loss across these various dimensions, unfortunately, it is not within the scope of this study.

In 2008, Bennett, Litz, Maguen and Ehrenreich conducted a part quantitative, part qualitative study in which they explored the predictors of and mental health outcomes associated with pregnancy loss. The self-selected sample was generated from patient databases of four major hospitals in the Boston area. Of the 91 participants, approximately 92% of the sample was white, 97% were married, and 51% reported having at least a graduate level degree and a minimum household income of $100,000 annually. In attempting to explore predictors and possible risk factors, it would be difficult to generalize the findings of this study based on the similarity of the sample. The study offered, however, the notion that "research on perinatal loss poses challenges to investigators, such as multiples provider and/or hospital coordination, the low base rate of such losses at any one hospital or medical setting, and sensitive data collection

with a grieving sample," (p. 505); suggestions which have been validated by many other researchers. Additionally, the results suggested that the ability to recover from the effects of a pregnancy loss functions independently of other traumatic experiences and that maladaptive coping skills and lack of support were among the most notable predictors of negative mental health outcomes. In a longitudinal, qualitative study with bereaved couples in Canada, Lang, Fleiszer, Duhamel, Sword, Gilbert, and Corsini-Munt (2011) state "the findings of this study help improve our understanding of how many textures of ambiguity, ambiguous loss, and disenfranchised grief contribute to bereaved couples' suffering and influence their mourning experience surrounding perinatal death," (p. 192). Once again, this study's sample was small (only 13 couples) and homogeneous; while results can offer insight with regard to work with this population, the findings are not representative of the population at large and cannot be generalized as such. A study by Joanne Cacciatore (2008) attempted to understand the effects of physical contact with a stillborn baby on maternal depression and anxiety. Thirty-seven organizations recruited over 2900 women to participate in the online survey. Contrary to other findings, this study found that seeing and holding the baby (after its death) are associated with fewer anxiety and depressive symptoms for mothers.

Mahan and Calica (1997) looked specifically at the unique role that social workers play within the hospital interdisciplinary team that is responsible for care of a family after a pregnancy loss has occurred. The study found that "the social worker is in a key and unique position to assist families with important tasks of grieving," (p. 144). In a quantitative study, Wallbank and Robertson (2013) attempted to assess staff distress in folks who work with loss in the professional setting. The study concluded that certain predictive factors could make staff

more vulnerable to the impact of loss, including: negative coping styles, lack of personal support, and self-doubt.

A concept that continues to resurface in research is the notion that the intensity of the grief or distress experienced by an individual or family does not have a positive correlation with gestational age of the baby at the time of the loss (Jaffe & Diamond, 2011; Shreffler, Greil, & McQuillan, 2011). Though this may have been suggested in earlier works, such as Peppers and Knapp, it has since been determined that the length of a pregnancy cannot serve as an accurate predictor of a woman or family's degree of grief (Brownlee & Oikonen, 2004; Jaffe, 2011; Shreffler, Greil, & McQuillan, 2011). This can be helpful to consider as a clinician begins to contemplate working with an individual or family.

Sarah Kye Price (2008), a leader in the field of perinatal social work, discussed key dialogues that social workers can initiate with clients in order to mitigate discomfort and avoid further emotional trauma. First, Price suggests active integration of reproductive loss into routine assessment; Price argues that by incorporating discussion of reproductive history, the clinician can normalize and legitimize the experience of the loss. Second, she suggests empowering clients to define their own words, terms and labels; by not inferring one's own values based on word choice, clinicians can give clients the space necessary to tell their stories in their own terms. To support this, clinicians should engage in active listening, while validating and normalizing client's response. Third, Price mentions, differentiating adaptive and complicated responses to reproductive loss; Price believes that social work professionals should understand that the response to a reproductive loss is expected to include a level of psychological distress, grief, and depression, as well as, situational anxiety during subsequent pregnancies. Though these are discussed as normative responses, it must be understood that they are not

mandates. Lastly, Price suggests that clinicians assist clients in facing the future; because it is impossible to forget the past, the client's challenge becomes living within a new normal, in which past experiences inform, but do not dominate, thoughts, feelings, and actions.

   In sum, perinatal loss is its own category of loss that warrants special clinical and research attention. Theories of perinatal loss and practice guides emerged from an awareness that perinatal loss was distinct from other forms of grief and child loss. Despite an abundance of theory driven literature on the topic, few empirical studies exist that explore perinatal loss and grief. Those studies that do exist have very small homogenous samples, making the experience difficult to generalize. With little evidence to support what works as a best practice for treating perinatal loss and grief, clinicians have developed their own ways of addressing this harrowing loss. Social workers, in particular, attend to parents who suffer perinatal loss. Their first hand experience with their clients' grief could provide a window into the best ways of treating perinatal loss. To address a gap in the literature, this study aimed to explore the experiences of 11 perinatal social workers and their work with perinatal loss.

CHAPTER III

Methodology

Research Purpose and Question(s)

The goal of this study is to gain a deeper understanding of social worker's clinical role when working with individuals and families who have experienced a pregnancy loss. By combining an analysis of the current literature on the prevalence and effects of pregnancy loss, an appraisal of currently utilized practices and protocols, and social workers' practical experience this study hopes to provide a foundation from which clinicians can begin (or continue) to offer the most beneficial treatment interventions to patients, while maintaining both personal and professional integrity.

Research Method and Design

This qualitative study, which sampled a group of clinical social workers, was initially targeted specifically at OB/GYN and perinatal social workers; however, because of the prevalence of the phenomenon, participation was expanded to include any and all social workers that, at some point in their career, have worked with individuals who have experienced pregnancy loss. The study utilized a smaller sample size and a qualitative design in order to gain a deeper understanding of the phenomenon. Individual, phone interviews were conducted using semi-structured questions as a guide; the researcher was open to expanding on or changing questions as necessary to accommodate each participant's unique background and practice experience. Delineations were made as to what types of pregnancy loss would be considered so

that information remained consistent and relevant; the study included discussion of miscarriage, intrauterine fetal demise, stillbirth and early neonatal death, however, the study intentionally excluded discussion of elective termination or termination due to fetal anomaly as well as later neonatal death. All data is exploratory and based on participant's personal, practical experience and thus there are no concerns about lack of validity or reliability. However, because the sample size is relatively small, it will not be possible to make generalizations based on the findings of this study alone. In order for the findings to be indicative of the population, a larger and broader sample of social workers from across the nation would be necessary; however, that was not possible within the scope of my study.

Sample

This qualitative research study includes a sample size of 11 participants and, unlike other research that has been conducted with regard to pregnancy loss, this study focuses solely on social work clinicians rather than on mothers or families. Inclusion criteria for participants required that each participant be fluent in English and have access to an hour long phone session with the interviewer. Though the researcher was located in Boston, offering phone sessions allowed the opportunity for clinicians from around the country to participate. No participants were excluded on the basis of age, gender, race/ethnicity or level of experience, however, all participants were expected to be licensed clinicians (e.g. LCSW) and currently employed full time. Additionally, participants must have current or prior professional experience working with individuals and/or families who have experienced pregnancy loss. In recruiting this sample, the hope was for the final group of participants to be representative of the larger social worker population, including varied: ages, years of experience, geographic locations, racial or ethnic backgrounds, and agency/facility settings. The study utilized a non-probability sample, since

participants were self selecting based on a willingness to disclose personal and professional information.

Recruitment of the sample was gained through a combination of strategies, including: convenience sampling, which incorporates participants who are easily accessible to the researcher and are willing to participate; snowball sampling, where the researcher would ask colleagues to refer willing participants; quota sampling to ensure that participants represent varied practice settings and demographics; and judgment or deviant sampling to ensure that the sample is not misrepresentative or too homogeneous.

During initial analysis of available data and literature collection, the researcher learned of, and subsequently reached out to, the National Association of Perinatal Social Workers (NAPSW). According to their website, "NAPSW began in 1974 as an informal organization of social workers employed in various perinatal settings. These professionals recognized the need for a formal mechanism for support and ongoing communication regarding the unique circumstances and needs of perinatal social workers," (www.NAPSW.org). A preliminary email describing the premise of the study was sent to the association's president followed by a blurb explaining the inclusion and exclusion criteria for participants; this blurb included the researchers contact information. This blurb was electronically distributed to the entire NAPSW list serve of approximately 215 members.

In thinking about how this study can be relevant to the field of social work at large, it was important to keep in mind the aspects outlined in the National Association of Social Workers established Code of Ethics, including: commitment to clients, cultural competence, self-determination, and privacy and confidentiality. To ensure participants confidentiality, all data was coded using a standard practice, additionally, all identifying information was modified or

excluded. In the final presentation, data will be discussed in the aggregate and participants will be referred to by assigned participation number only.

Ethical Issues/ Bias, Diversity, Omissions

Working with individuals who have experienced perinatal loss provides many ethical considerations. Given that pregnant women are a protected population and the notion that any potential sample would be in the process of grieving, access to a random sample is virtually impossible. It is for this reason that the researcher elected to conduct research using clinicians as the sample as opposed to women and families. Prior to conducting the interviews, regrettably, little consideration was given to the possibility that some of my participants may have themselves experienced a pregnancy loss. Once this was learned, the researcher was sure to offer active and empathetic listening and to ensure that participants were comfortable disclosing such personal information. The author was open to exploring possibilities for continued discussion and processing with participants, if they felt the need to do so.

While conducting the study, the researcher will be sure to pay careful attention to the diversity of the sample; it was important to the validity of the study that participants represent a varied sample of the population – including various ages, races, ethnicities, cultures, etc. Without this, the findings might be swayed in a way that does not accurately depict the population at large. Lastly, the researcher will consider how her position as a young, inexperienced, childless, white woman, with a lack of personal and professional knowledge on the subject may, at times, be questioned or challenged. Also, participation in this research could be emotionally difficult for the researcher; it is important to be aware of and to maintain personal and professional boundaries and to manage any arising countertransferencial issues.

Data Collection Methods

As previously mentioned, this study utilized a qualitative method. Upon confirmation of interest in participation, perspective participants were sent a packet containing the informed consent, authorization to be audio taped, and a demographic info sheet; all materials were reviewed and approved by the Human Subjects Review Board from the researcher's academic institution. The demographic sheet asked each participant to identify the following: age, location, level of certification, number of years in practice, practice setting and race/ethnicity. Once all original documents were signed and received by the researcher, interviews were scheduled; initially either in-person or phone interviews were offered, however, most individuals elected phone interviews based on convenience. In an effort to maintain privacy and confidentiality, the researcher conducted all interviews in a quiet, private space. All participants were reminded that their information would be kept confidential and that any identifiers would be changed or omitted during the transcription phase to ensure anonymity.

Interviews were conducted using a semi-structured approach and each lasted between 45 minutes and one hour. While the interview questions provided a sense of structure and organization, the researcher remained open to any unexpected turns that the interview might take. Each interview began with the researcher's introduction and a brief explanation of her interest in the subject matter. From here, questions led into participants' experiences.

Data Analysis

A preliminary run of demographic descriptive statistics provides some basic information about how the sample looked as a whole, including participant's average age and average years of experience. This information will allow the researcher to draw inferences suggesting how these variables might affect the types of answers offered. Since this study utilized qualitative

methods the research data cannot be synthesized directly into numeric statistics. Instead, all interviews were transcribed and coded based on conceptual trends that were observed throughout the data. Initially, content analysis or open coding was used, subsequently moving into identification of themes and drawing connections between those themes. In addition to watching for trends as the interviews progressed, transcribing and coding the data allowed the researcher to measure frequency and intensity of topics which presents the opportunity to draw additional inferences about what topics seem to be of most or least concern to participants.

CHAPTER IV

Findings

The goal of this study was to interview social work clinicians in order to gain a deeper understanding of their clinical role when working with individuals and families who have experienced pregnancy loss. The hope was to uncover a foundation from which clinicians can begin (or continue) to offer the most beneficial interventions while maintaining both professional and personal integrity. An initial analysis of the data focused on the answers to eight original questions posed by the researcher; these questions served as the basis for the semi-structured nature of the study. The major findings from this set of data were in the areas of preparatory experience, fundamental approach to patients, and the ways in which clinicians continue to educate themselves on the topic of pregnancy loss. Two important themes emerged from clinicians' experiences in perinatal social work; the first was the impact of childbirth and child rearing and the second was the ways in which social workers understood their roles within interdisciplinary teams.

Social workers living in California, Massachusetts, New York, Rhode Island, Virginia, Washington, and Washington D.C. compromised this sample. There were no exclusions based on gender, age, or race/ ethnicity, however, it turned out that all participants were women, all but one were over the age of 45 (average age was 53) and nine of the eleven participants identified themselves as Caucasian, one as Portuguese and one as Mixed. As far as experience, three participants listed 30+ years in the field and all together this group of women averaged

approximately 23 years of experience each. Most of the participants (ten of the eleven) had

experience working in hospital settings; of those ten, eight had only ever worked in a hospital

while the other two had additional experience in both private practice and community agency

settings. One participant worked exclusively in private practice and had most of her experience

in pregnancy loss support group settings.

Preparatory Experiences

Though many of their responsibilities and expectations overlapped, each of the social

workers that I interviewed identified and described her position in a different way; some were

Neonatal Intensive Care Unit (NICU) Social Workers, while others were Perinatal Social

Workers; some worked only in Postpartum or High Risk Units and one worked exclusively in

outpatient group settings with couples. Regardless of how they identified their position, or how

each found her way to pregnancy loss work, most of the participants had no prior experience

with loss as it relates specifically to pregnancy and, surprisingly, some had no idea that

pregnancy loss would be a part of their job description. As one participant explained,

> From the beginning I never thought that there would be an element of loss that I would be
> working with, so that was surprising... When I arrived here, I realized that I was going to
> start dealing with losses, anything from a young miscarriage to an IUFD or even a
> neonatal loss. I don't know if I was resistant, I think I was a little worried because I didn't
> have much training in that.

Another participant stated that she did not "remember being told," that pregnancy loss work

would be a part of her job description; she continued to say, "it wasn't a secret, but it was a

surprise." Conversely, some participants felt drawn to working specifically with pregnancy loss.

When asked if she knew that pregnancy loss work would be a part of her job expectations, one

participant stated

> Yeah. I was drawn to that, I was excited about it, but I was also very anxious. I think I
> felt overwhelmed by the affect that I anticipated, I felt in awe of what that kind of grief
> might be like and anxious about to what extent I might be helpful versus to what extent I

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might be found inadequate and awkward and not helpful and someone people would be angry with or that.

Having found their way into the work, either intentionally or accidentally, it them became necessary to become informed about the population at hand.

In response to questions about their first experiences with pregnancy loss and how they learned about working with the population, three areas became apparent: preparation though education, preparation through personal experience and preparation through prior professional experience. Nine of the eleven participants interviewed identified specific educational, personal or professional experiences - most unrelated to pregnancy loss- that provided them with a foundation from which they could begin work with women and families who have experienced pregnancy loss.

A few participants identified educationally based experiences they felt that either informed them about or lead them directly to pregnancy loss work. One participant discussed her experience working with pregnancy loss during social work school; she recalls

> My first introduction to perinatal loss was when I did my social work field internship. I remember going to the morgue with my supervisor to get a baby to take back up for the mother to see again… I remember warming up the baby to make it a more natural experience for the mum, while trying to prepare the parents ahead of time for what to expect when we opened the blanket so they wouldn't be shocked at some of the changes in the body since they last saw it.

As she reflected on her experience, she expressed a sense of honor and pride at having had the opportunity to participate in such meaningful work as an intern. When discussing her perceived lack of pregnancy loss experience, another participant reflected on her social work education as a preparatory experience by noting that "as social workers we are trained to get into the swamp and it would be hard to say 'no thanks' and to just sit on the sidelines… Diving right in has been really helpful for me." One participant shared that she took a break from social work to further her education; she earned her Masters in Theological Studies and attended seminary. She

explained that the lessons she learned from that experience helped to inform the work that she does professionally with loss patients. She went on to say "even if the conversation is not about anything religious, it adds another layer… it's present in my heart and it's present in my head." In addition to this participant, a few other women discussed how trainings in other modalities and or other fields helped to inform their work with pregnancy loss.

On a more personal level, and quite remarkably, a few participants identified their own reproductive struggles as important preparatory experiences, which allowed them to more closely join with the patients and families that they serve. Not long into my very first interview, the participant shared that she herself had suffered a pregnancy loss. She discussed how this experience motivated her to pursue pregnancy loss as a career and allowed her to more closely connect with individuals and families who might find themselves in a similar situation. After disclosing a history of infertility problems, another participant recalled, "even though, on a professional level I could be very compassionate towards people having losses, my initial feelings were towards people who were going through infertility and how hard it was for them to get pregnant in the first place." She went on to explain, "a lot of people who are involved in this work professionally are people who have, themselves, experienced some kind of pregnancy loss." This was an interesting phenomenon and one that had not been considered prior to initiating the study. Yet another participant disclosed that she and her partner had attempted to conceive a number of times via artificial insemination and that ultimately she was unable to bare children. She explained that the grief and loss associated with her personal infertility struggles allows her to join with the women and families that she works with professionally.

Also on a personal level, but separate from reproductive issues, seven participants identified a personal relationship with, or understanding of, death and dying as a fundamental

factor in how they inform and make meaning of their work. One participant encapsulated this

view as she stated,

> When you have your own safety with it [death], if you feel okay about it and you present that way, it can make things go a lot smoother. So if it's something, as a provider, that you are uncomfortable with, maybe you should do some work with a coworker or a supervisor, or your own therapist. To see if you could get to a place that you'd be more at ease with it, because I think that patients pick up on that.

Another participant explained that she was fortunate enough to have "good quality, open

communication" about death and dying with both her father, who was an Episcopal priest, and

her grandmother when she was in the process of passing on. She explained that she understood

these very difficult conversations to be emotional training for what would come later in her

professional career.

Many participants discussed employment or professional based preparatory experiences,

though most were not specific to pregnancy loss. One participant explained that because of her

professional experience working with HIV/AIDS patients in a medical setting, many people

assumed that she knew how to work with patients who were dealing with death and dying or

loss. As she reports, the two kinds of loss (pregnancy loss vs. loss due to HIV/AIDS) "feel very

different and intense for different reasons." Another explained how her experience working at a

women's college providing pregnancy options counseling helped to prepare her, though

unbeknownst to her at that time, for her work with pregnancy loss. Both of these women

explained that despite the fact that their previous employment was not directly related to

pregnancy loss, the lessons that they learned from the work became applicable later. In addition

to the skills that they brought with them to new positions, one participant noted the physical

reserves that she carried with her from one place to the next: "when I came here, I brought with

me what I had saved from other places that I had worked and just Xeroxed them all to use and to

make my own… We kind of pooled our resources together here."

Fundamental Social Work Skills

In analyzing the results from questions involving "do's and don'ts" or "best practices," it was interesting, though not surprising, to find out that many of the participants identified fundamental social work skills as the most necessary tools for success in this very difficult work. From such primary notions as active, empathetic listening to more complicated ideas surrounding management of personal emotional experiences while remaining physically and mentally present in the room with a patient or family. As one participant so eloquently stated, "... basically, being respectful, listening to people, seeing where they are, that sort of thing, is what has been most helpful to me." Another participant discussed the importance of understanding one's countertrasnference when she said,

> One thing that I've learned over time is that you have to monitor yourself so that it doesn't become about your loss… you have to be careful that this is not about you; making sure that if you share something that it's because it's going to help the family or the patient. It cannot be about you.

One long-time OB/GYN social worker highlighted a few separate skills that she felt were necessary at various stages of any given session. She discussed the impact of positive termination with patients at the end of their hospital stay

> Every ending, whether conscious or unconscious, for that family is another good-bye; it's another loss. Even saying good-bye at the end, you just have to be so mindful of it and how to get yourself gracefully out of the room and let people sure them up to leave the hospital… It's a really important step.

She also highlighted the intricate ways that defenses play into the work with this population

> What's very interesting to me is that lots of times, women and/or couples who are having a pregnancy loss - and this doesn't happen every time, but certainly it has happened enough times that I note it- they will say, 'I think it might be easier to have a pregnancy loss than to actually see your baby because then you would get attached and it would be even harder.' And, conversely, what do parents in the NICU say? 'I'm so glad I had the opportunity, that I had these hours or days with my baby and I can't imagine what it would be like to lose a pregnancy and never have had this opportunity.' So aren't defenses fascinating and wonderful?

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Self-preservation was another important skill for one participant; she explained that

> Allowing myself to feel what was going on, not necessarily at the time, but allowing myself to cry when I needed and having a good support group… realizing that being there and being a calm, gentle presence for them and compassionate, and being able to recognize that that's all they needed right then, I didn't need to do anything else.

She highlights the importance of being present with the patients during this terrible time and also the importance of good self-care. Other participants referenced self-care as a way in which they remain grounded in the work. One woman stated that

> Taking care of myself has been so important… At the beginning it was really coming home; my kids were young and that was healing for me. To be able to say 'I'm okay, my kids are okay.' And I have gotten really good at leaving the stuff in the office. There are some stories that stay with you and I talk to colleagues about those when I need to... And, just to be honest, at the end of my groups, if it's a difficult session, I have chocolate in my office and I will take a piece of chocolate and sit quietly and breathe and it helps. It definitely helps. And then once I'm home, I just really leave stuff in the office and I've gotten very good at that.

Similarly, another participant talked about using her coworkers as a support system, reporting that they "could call each other up and say 'hey, I need to talk about this,' or 'can you give me some feedback on that?'

Many participants identified the necessity to meet patients and families wherever they are emotionally situated, emphasizing the need to move forward at a pace that feels comfortable for the family. The following quote from one participant summarizes this stance:

> The way that we approach these patients and families speaks to our understanding of grief and about that journey… Sometimes people are not ready, they can't do it. It's not that they don't want to, but they just can't. It's too hard, they are not at that place, and you can't tell them, nobody can tell you when you will be at that place. It could be a month from now, 6 months from now, a year from now… It is just a journey that goes the way it goes and there is no way to predict it, you have to just allow it to unfold however it is going to unfold… You want to allow the journey to go the way that it wants to go… You need to make room for that and just be available for it.

Normalizing and validating were also identified as critical skills. One participant mentioned differential use of self as an important way of connecting and working with families during this delicate time.

Helping with practical issues and working in a step-by-step fashion with patients and families in the wake of a loss was referenced as a basic yet effective tool. A few participants offered examples of how this step-by-step approach involves an intentional combination of clinical social work knowledge and practical, logistical skills. One participant shared that

> Being with someone when they have gone through something as difficult as losing a baby, just your presence is something that they appreciate. Just being there to listen and answer questions that they may have; a lot of people are worried about the practical things. Like what do I do next? How do I have my baby buried? All these sorts of things. And then talking to people about what may happen next, suggestions about how to go forward... We also might show the baby, if the patient wants to see the baby again. Go to the morgue and get the baby, get the baby dressed, bring the baby up to the floor, for the patient or the patient's family some times to see.

Two clinician characteristics that surfaced often were the notions of flexibility and open mindedness, both with yourself as a clinician and with your expectations of patients. As one participant explained, "this work is not, and cannot be, one size fits all." One participant expanded on this notion, stating that

> Sometimes somebody gives you a list and says 'okay, make sure you get this and this,' and then after a while you realize that some of those things don't apply to every family. It's about going in and really looking at the situation and being open minded about the situation. I mean, yes, you have some things in the back of your head that need to get done, like when the family needs to bury their child because that's the law, so you want to be able to provide them the right information and the right resources in that way, but there's still other things that are very flexible as to how it happens.

In the same vein another participant expressed that

> There is a way in which, because we're working with people, you're always learning something new. And so I say to stay open. Stay open to really listening to another person's experience because it always invites and you will learn new things.

She went on to explain that for the patients at her facility "everything is so individualized...

There is a protocol, but it comes with a lot of flexibility."

Continuing Education

The following response echoed many participants' experiences with regard to how they

continue to learn about working with pregnancy loss

> The people that we are most informed by are the families. I mean when I think of what
> I've learned along the way, and what I've said to other people coming in, new to the field,
> it's like listening to the families, that's how I've learned. I mean, of course, I read and I
> found articles and research and books and read, but really what informed me is listening
> intently and being with families. And being present with them and being a container for
> all kinds of reactions, whether its anger or fear, sadness, regrets, whatever that is and
> learning how to handle that.

One participant spoke of patient led, peer support groups for which she served as a

consultant. She credited her greatest learning opportunities to her participation in these groups.

A few participants identified the lack of evidence-based or other empirical research as an

obstacle for continued learning; as one stated

> [This] is a crucial field that has such a paucity of training and information… As much as
> I've done in this field, you think you're making progress and then you end up back at
> square one… Information doesn't seem to get passed along to the next generation.

Other sources of education and training that were noted included reading and book knowledge,

using supervisors and coworkers as resources, relying on the knowledge base of the person you

replaced, conferences and networking, and workshops and trainings (either specifically on

pregnancy loss, or more often, on another topic which was then adapted by the participant to help

in work with pregnancy loss). One participant spoke of a realization that she had made

throughout her work with this population

> One of the things that's changed my practice lately is realizing that not only are you
> dealing with grieving people, but you're dealing with traumatized people ...It helps me
> now to look at people through the lens of trauma to really help them understand
> flashbacks, which happen, they definitely happen. Also, to understand that somebody can
> be a bit too physically traumatized to be able to use a group, and perhaps screening first

to assess whether or not this is the right time for them. There may be other work that they need to do first. That is something that I have learned along the way that has been very helpful.

She went on to discuss a training that she had attended which she felt would help her to more accurately treat with traumatized population. She reported that she

> Completed a yearlong course on sensory motor psychotherapy for treating trauma, which is pretty fascinating. I am very trauma informed and whenever there is anything on pregnancy loss I'm there. It's not like I really learn anything new, but it's just sharing and supporting each other.

As stated earlier in reference to the participant who attended seminary, it seems that these alternate forms of trainings allow perinatal social workers to provide more holistic treatment when working with individuals and families who have experienced pregnancy loss. Another participant, when discussing her preparation for the job and continuing education, reported that she

> Learned by having some mentors, a pediatric social worker who was my mentor and a great supervisor and director at that point and several other social workers in the department including the women who I replaced who was able to spend some time with me and orient me before she left… But otherwise, a lot of the learning was on my own, reading, going to workshops, mostly reading.

Other participants found communities within their facilities that were supportive of their professional clinical development. One participant mentioned a designated bereavement committee and another mentioned a pregnancy loss task force, both of which seemed to be their respective institution's attempt to continue to consider ways to make the process smoother and more beneficial for patients and families, while continuing to educate and inform providers. Interestingly, both participants explained that the groups were comprised of members from different sections of the care team (doctors, nurses, social workers, chaplains). Along with these, many participants mentioned debriefings after particularly difficult cases, which they felt allowed space for both professional and personal processing.

Impact of Clinicians' Personal Experiences of Child Birth and Child Rearing

In addition to the subjects that resulted from responses to the original set of questions, some interesting themes began to emerge in talking with the first few participants, which I then continued to inquire about in subsequent interviews. One of those themes was participant's understanding of how having their own children impacted them professionally. Earlier, I mentioned a few participants who referenced their own reproductive difficulties as preparation for the work; however, actually having children while doing pregnancy loss work seems to have had a substantial impact on many of the participants. As one participant poignantly reported

> I do think as a social worker it matured me, in a way. Maybe some people can do that without having kids, but for me, it gave me a different perspective, having my own kids gave me a different perspective. And you appreciate things, when we lose a baby on the unity, we appreciate our own families and our own kids and go home and say you're here and I love you. I came in very immature and naive, and I don't know everything, but I've come along way.

Another participant disclosed that after failing to conceive through IVF, her and her partner decided to adopt. She recalled that this experience allowed her to "really connect with the patients who have had a recent loss," because she knows how strong her connection with her own child is.

While some participants' emphasized the ways in which childbirth and loss influenced their clinical understanding of perinatal loss, others pointed to the ways in which their clinical work affected their world view and their view of pregnancy. One participant described having conversations with her partner about what they would do if their baby was born at or around viability (24 or 25 weeks), conversations she felt she would not have had if she wasn't involved in this type of work. Another participant described what she called a loss of *naïveté* that happens for women in the profession, explaining that you can't help but be aware of the terrible things that could happen during a pregnancy. Yet another participant explained that

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I think that for me, working here has helped me to see that pregnancy is not quite as benign as perhaps I thought about it previously… It kind of skews your perception of pregnancy and what it can mean and some of the outcomes, including loss. You get a sort of hyper vigilance about it… It sort of colors how I see things and how I think about things. It definitely changes things.

When discussing becoming a mother, one participant recalled

When my daughter was born, she aspirated and she had to be in the special care nursery, and I really learned from being a new mom that, it certainly made me a lot, it humbled me a lot and made me a lot more understanding of that. The incredible vigilance and anxiety and momma bear instincts and that sense of vulnerability. You've never been as vulnerable as when you've got this separate part of yourself out there.

Having children while working with pregnancy loss seemed to be an important and impactful parallel process for many of the participants that I interviewed.

The Role of Perinatal Social Workers within Interdisciplinary Teams

Also interesting, was how participants defined their roles within their respective interdisciplinary teams. Though I had not initially included the question, it seemed to become important to ask about how participants experienced their role as a social worker within their respective institutions. In some instances, it seemed as though social work was brought onto a case at the very first sign of trouble, where as in other cases it might be further down the road before social work is involved. One participant, who worked at a military hospital, postulated that "the active duty military doctors wanted and valued social work input… I think social work has been used really differently in the military, so they value the clinical work that we can do, such as with veterans with PTSD." Another referred to her role as a "liaison between the family and the doctor… the nurses take care of the medical stuff and we would take care of the feelings stuff." One participant referred to her role as a sort of "guest services representative for the families." Many participants described what appears to be a very collaborative relationship with doctors, nurses and other staff. As one participant stated

One of the things that makes the work really gratifying for me is that so much work has been done here, so that all different members of the interdisciplinary team, whether its doctors, nurses, photographers, whoever, I think we all tend to convey sympathy or empathy and acceptance and acknowledgement that this is a great loss.

Where some participants describe a collaborative effort, others describe how some nurses, particularly those in the NICU, can sometimes be less inclined to involve social work. As one participant explained, "they [the NICU staff] are supposed to contact the social worker if they are aware of a child about to die or that has died... The culture, or environment in the NICU sometimes seems like they have it under control so to speak, and don't necessarily want to reach out." Though there are differing experiences as far as dependence on social work, a good number of participants- when asked to define their role as a social worker- explained that they serve as a support person for members of their various hospital teams. One participant described the relationships amongst the staff at her institution

There is a lot of informal support. Going back after the baby has died and the family is gone. Going back and checking on the nurse, to say 'how are you doing? Are you okay? You haven't really had much time to talk or process this,' and a lot of nurses come from this mindset that you don't talk about your feelings or emotions, you just don't do that. But I have found that the younger nurses did talk about, or even got some relief by saying 'yeah, thank you so much for checking, I'm good and thank you for your support.' So giving that support back seemed to help them... I've had nurses and interestingly it's usually older nurses, who just want to talk privately. Whether it was about the loss of a child or a baby on the unit, or I had one nurse who would come ask me questions about her grandson who was living in her home and just kind of the dysfunction happening with her son and her grandson and that seemed to happen more as the rapport built. They realized what social work resources can actually provide, then they were seeking it for other reasons.

One participant stated that the social workers at her hospital "have really worked hard to establish [themselves] as integrated members of an interdisciplinary team and the identified people that you can go to say 'hey, can we talk about this?'" A third participant reflected on her role within the team

The team recognizes the role of the social worker… The other thing is certainly I've had the opportunity to be available and supportive to other members of the interdisciplinary

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team; be it doctors or nurses, to be present with them, listening to their own thoughts and feelings about what has just happened… Being available to staff, being able to lend a shoulder to them, lend a listening ear, or just offer some words of encouragement… I see that as a piece of my role as a social worker.

Additionally, this participant discussed how she sees her role

To figure out what our role would be, not just for the family, but also for our staff, just supporting the family and being that in between person. Some babies' die right away and some died later, after being with us for weeks or for months. So our role was a little bit different with each of them... And we were such team, you know the team of social workers but also in the unit, that I wasn't doing it by myself, I was never by myself. So if I had questions, or there was something different in the process, I always had somebody that I could go to. And I think over time you just get the experience of doing it and you know what to look for and how to be supportive and when to step in and when to step back and just let it happen.

It's impossible to assess and understand every facet of this work, however, these 11 participants offered valuable information about the skills and experiences that impact their success in this work. They referenced their past experiences (personal, professional and educational) and the shared creative ways in which they continue to educate themselves on the topic. These women have become subject matter experts can continue to provide invaluable knowledge to future generations of perinatal social workers. While it is imperative to categorize the findings, it is equally important to synthesize and discuss what these finding suggest about the field at large.

CHAPTER V

Discussion

This past year, my MSW field placement landed me in the Social Work Department at a major medical center in Boston, MA, specifically working in OB/GYN. I was initially introduced to the notion of pregnancy loss about a year prior while listening to a social work pod cast; what peaked my interest then, only continued to develop as I became increasingly familiar with both pregnancy and pregnancy loss. I could never have imagined how prevalent pregnancy loss would be and how difficult it would be to learn to do the work. It's tough to imagine that pregnancy and loss could even belong in the same sentence. When I learned that almost a quarter of all women will experience some form of pregnancy loss during their lifetime, it became evident to me that this topic is not discussed enough, clinically or medically. I believe that learning about loss and how to work with this population is a skill set that will benefit any social worker in the field.

Initially, when I set out to explore how social workers practice with this population, my goal was to compile a set of "best practices" or a "how to" guide for working with individuals and families who have experienced pregnancy loss. I imagined that I would learn about practical information, such as: what resources should be offered to a family following a loss? Is it beneficial to see or hold the baby? Should families be encouraged to take pictures? What should be included in a memory box? I wanted to create a central hub that perinatal social workers could consult in order to better educate themselves on how best to do the work with this

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population. I hoped to combine research and practical, lived experience in order to present a comprehensive database from which clinicians could draw materials and information. As I reflect on the process of my study and what I learned, it has become clear to me that my initial goal was, perhaps, a bit lofty.

We can still learn a great deal from the experiences of these 11 perinatal social workers. I have learned that being effective in this work, at least initially, requires that clinician's be able to adapt prior experiences, be flexible and open about their role, and that they understand the intense, psychological impact of pregnancy loss on patients and families. Skills for success in this field cannot be read in a textbook, or taught in a class. The women interviewed in this study became subject matter experts because of their repeated experiences with family after family.

It was interesting to me how many of the participants seemed to fall into the work as a matter of happenstance. Without much personal experience with pregnancy loss, they either learned from the person that they replaced, or they had to rely on other skills and trainings to get by until they felt confident in their own practice-based methods. In a way that people can be taught such therapeutic modalities as Cognitive Behavioral Therapy (CBT) or Dialectical Behavior Therapy (DBT), there seem to be no such training program offered for pregnancy loss; one cannot become officially licensed or certified in social work with pregnancy loss, in fact, there is not much training available that is specific to pregnancy loss.

Research on the subject of pregnancy loss is lacking and though I do not know exactly why this is, I speculate that it has to do with the fact that pregnant women are a protected population and that the loss of a baby is such a delicate and emotionally complex experience. The literature that is available seems to be heavily weighted towards theoretical perspectives. I believe, as some of these theories and articles suggest, that the attachment between a mother and

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her child can start many years before a woman finds out that she is pregnant. Upon confirmation of a pregnancy, regardless of whether that pregnancy was intentional or not, a family begins to imagine what life will look like once its newest member arrives. One of the caveats of theories of pregnancy and attachment is how to begin to explain, or quantify, the attachment created between a human being and something that is not yet a part of his or her tangible reality, something that the five human senses cannot physically confirm.

I believe that Peppers and Knapp's (1980) work on the maternal-infant bond was instrumental in extending the discussion of pregnancy loss. This theory, combined with adaptations of grief and loss and attachment theories, allowed social workers to gain a deeper understanding of the psychological impact of pregnancy loss. Though there are a few empirical studies that focus on this subject matter it is often the case that samples are small and homogenous, which means that results cannot be generalized or used to create standardized models. Additionally, there have been few (if any) studies that consider racial and/or socioeconomic factors as either risks or protective factors for individuals or families who have experienced pregnancy loss. I expected- and this was confirmed by my participants- that empirical research did not serve as a major resource for learning about social work with pregnancy loss. It was, as I suggested, more often the case that learning came from personal, practical experience or information that was handed down from one worker to the next. As a society that continues to place more and more value on short-term, evidence-based practice, the lack of research on this phenomenon is disappointing. While access to subjective or anecdotal experience is plentiful, empirical based research is sparse, and clinicians are left to their own devices as far as being professionally prepared.

Another take away is the reframe that these participants offered of the acuteness of pregnancy loss. I had not initially considered pregnancy loss to be a crisis event; however, as I continued to discuss the subject with participants, it became clear to me that work with this population is probably most closely associated with crisis management. Because these losses often happen suddenly and unexpectedly, there is not much time for families to prepare. Patients find themselves at an emotional loss and without psychological blue prints of what recovery should look like. In many cases, their defenses fail and their ability to comprehend the reality surrounding them becomes challenged. Work with these folks is less about effective interventions and more about managing the here an now. Social workers attempt to help individuals and families accept what has happened and begin to prepare for what may lie ahead. By coupling this notion of pregnancy loss work as crisis management with an understanding that this is a traumatized population we can begin to gain a deeper understanding of, and appreciation for, the intense psychological impact faced by these individuals and families.

Limitations

As I began to consider the methodology for this project, I wondered which research method would allow me to best capture clinician's lived experience. Ultimately, I elected to conduct a qualitative project so that I could offer participants both time and space to share their personal stories. One limitation of the study design is that I did not standardize my own interview process. I did not stick to the original list of questions in as uniform way as I should have in order to produce the most compelling collection of data. Though this modified format allowed me to gain a wealth of additional information, I compromised the validity of my initial questions by not conducting standardized interviews.

Another limit that I faced arose during the participant recruitment phase of the study. When I initially reached out for participants, I was surprised to hear back from the National Association of Perinatal Social Workers (NAPSW) so quickly; I was also surprised that they were so willing to disseminate the information about my study. Unfortunately, I did not pay much attention to the make up of the organization. Though I knew that the association consisted of about 215 members from across the country, I did not seek specific information about members' ages, races or years of experience. I believe that if I had paid attention to these factors, I might have ended up with a more diversity sample. Additionally, when outlining my methodology, I had planned to engage in both quota and deviant sampling to ensure that my participant pool remained representative of the population at large. However, because of time and access constraints, this form of sample management did not occur, which resulted in yet another homogeneous sample.

I believe that one of the greatest pitfalls of this study is that I did not properly consider the fact that some of my participants may have, at some stage in their life, been patients themselves. It does not appear that any participant suffered any psychological damage as a result of their participation in this study; however, I believe that I could have been more sympathetic to participants who found themselves in this position. Another possible snare was the fact that, in preparing for this study, I assumed that I would be working with social workers in a medical setting; I did not consider that respondents might work with this population in a different capacity, such as couples group work in a private practice setting.

For me, it is imperative to acknowledge my sociocultural and educational/professional location with respect to the participants that I interviewed. My position as an inexperienced, single, white, childless, clinician is something that I felt impacted my participants. There were a

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few individuals who asked me about my relationship status, about whether or not I had children, and about how or why I was interested in this work. Though I never felt as though the participants didn't take me seriously, I did feel, at times, that my lack of personal and professional experience afforded me less credibility.

Future Research

While this study offers an important framework for practice-based work, it is important that research on this topic continues. Though it may be difficult to facilitate randomized control studies on this topic, studies such as these might offer a more complete picture of the types of individuals and families that experience these losses and the most effective tools for treating them. Additionally, it would be beneficial to compile a database of resources and information where social workers could come together an create a shared knowledge on the subject matter to better inform their practices. Theories on pregnancy loss began to gain ground in the mid to late 1970's, because of this, it is safe to say that we are still in the early stages of knowledge building. I believe that as advocates for our clients and their experiences, it is imperative that social workers continue to engage in conversations and research on pregnancy loss so that we can better understand how to be effective in our work with this population.

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Appendix A

HSR Approval Letter

SMITH COLLEGE

School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950   F (413) 585-7994

February 4, 2014

Sandra Stokes

Dear Sandra,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Stefanie Speanburg, Research Advisor

Participant Informed Consent Form

Consent to Participate in a Research Study
Smith College School for Social Work ● Northampton, MA
....
Title of Study: Social Work with Individuals who have Experienced Pregnancy Loss
Investigator(s): Sandra Stokes, Smith College School for Social Work, (XXX) XXX-XXXX
....

Introduction
- You are being asked to participate in a research study to further understand how social workers define and conceptualize their work with individuals who have experienced pregnancy loss.
- You were selected as a possible participant because you met the following criteria: licensed full/part time social worker and experience working with women/families that have experienced pregnancy loss.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study
- The purpose of the study is to explore social worker's clinical practice with individuals or families who have experienced pregnancy loss in order to provide a possible "best practices" model for continued work with this population.
- This study is being conducted as a research requirement for my master's in social work degree.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures
- If you agree to be in this study, you will be asked to do the following: Participate in one (either) in person or telephone interview, which will last no longer than one hour.

Risks/Discomforts of Being in this Study
- The study has the following risks: This interview could be triggering for you is you have personally experienced the loss of a pregnancy. Please be advised that the interview will be focused on the topic of pregnancy loss in the professional, clinical setting, and that you have the right to terminate the interview at any point and for any reason.

Benefits of Being in the Study
- The benefits of participation include: allowing you a space to explore some of your own processes surrounding your work with this population. Additionally, you can take comfort in knowing that the information may be used to help other individuals work through the unfortunate event of pregnancy loss.
- The benefits to social work/society are: Offering an introductory understanding of a difficult topic experienced by so many individuals and allowing clinicians in all areas of social work to have some history and insight into this condition and how best to provide the most effective clinical experience for this population.

Confidentiality
- Your participation will be kept confidential. In order to ensure that participant's information will be kept confidential, any and all identifiers will be changed during the transcription phase to assure

anonymity. To increase confidentiality, each participant will be assigned a code name by which they will be referred to in all subsequent materials. In the final presentation, all data will be delivered in aggregate with no individual identifiers used. In *addition, t*he records of this study will be kept strictly confidential. The interviewer is the only individual who will have access to the audio recordings from which she will create written transcriptions using the participant's coded identity. Upon transcription, all audio filed will be permanently destroyed. Transcribed interviews will be retained as a part of the final presentation.

- All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period. We will not include any information in any report we may publish that would make it possible to identify you.

Payments/gift
- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw
- The decision to participate in this study is entirely up to you. You may refuse to take part in the study *at any time* without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely up to the point noted below. If you choose to withdraw, I will not use any of your information collected for this study. You must notify me of your decision to withdraw by email or phone by March 31st, 2014. After that date, your information will be part of the thesis, dissertation or final report.

Right to Ask Questions and Report Concerns
- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Sandra Stokes at XXXXXXXXX@smith.edu or by telephone at (XXX) XXX-XXXX. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent
- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep.

……………………………………………………………………………..

Name of Participant (print): _____

Signature of Participant: _____   Date: _____

Signature of Researcher(s): _____   Date: _____

Are you a licensed OB/GYN or Perinatal Social Worker?

Do you currently (or have you ever) worked with women or families who have experienced pregnancy loss?

I am working on a research study that focuses on pregnancy loss and I would love for you to participate in an informational, in-person or phone interview with me. I am curious about how this work has progressed for you over time, how you define your role as a social worker in this work, and how you stay grounded in this work.

If you are interested in participating, or would like more information, please contact:

Sandra Stokes

Appendix D

Potential Participant Response Email

Good Afternoon,

Thank you so much for taking the time to respond to my request for participants. I am relatively new to this field and I have been fortunate enough to find a great deal of passion in learning about and attempting to understand pregnancy loss and its impacts.

I plan to start conducting interviews the week of Monday, February 24th, 2014. You will notice that I have included below a copy of my availability for you to consider. I'd love it if you could give me an idea of your schedule so that I can better understand what times might work best for us to connect. I plan to conduct interviews over the phone and hope for them to last no more than one hour. Please note that if you do choose to participate, I would need an address or fax number so that I can send you a copy of the Informed Consent and Authorization to be Audio Taped; both are requirements for participation and require wet signatures.

The following is my availability; it is much the same every week, unless I am asked to stay late at work.

Monday: Free All Day
Tuesday: 7:00pm – 10:00pm
Wednesday: 7:00pm – 10:00pm
Thursday: 7:00pm – 10:00pm
Friday: 7:00pm – 10:00pm
Saturday: Free All Day
Sunday: Free All Day

Again, I am so grateful that you took the time to respond and I look forward to speaking with you further.

Sincerely,

Sandra Stokes

MSW Candidate

Smith College School for Social Work

<u>Demographic Information</u>

Age: _____

Geographic Location: _____

Level of Certification (State): _____

Years of Experience: _____

Practice Setting(s)

☐ **Hospital**   ☐ **Private Practice** ☐ **Community Agency** ☐ **Other**

Ethnic/ Racial Background: _____

Appendix F

Interview Questions

Initial Questions:

1) How common is pregnancy loss in your work?

2) How did you learn about how to work with this population?

3) Can you tell me about your first experience with pregnancy loss? Was there a protocol in place?

4) What would you consider "do's and don'ts" for working with this population?

5) Based on your experience, what would you say the best practices are or should be?

6) How has your approach to this work changed over time?

7) Where do you go for resources or assistance in your work?

8) How do you stay grounded in this work?

Additional Questions:

9) How do you see the role of a social worker in this role?

10) How has your own experience of having or raising children impacted the work that you do professionally with pregnancy loss?