

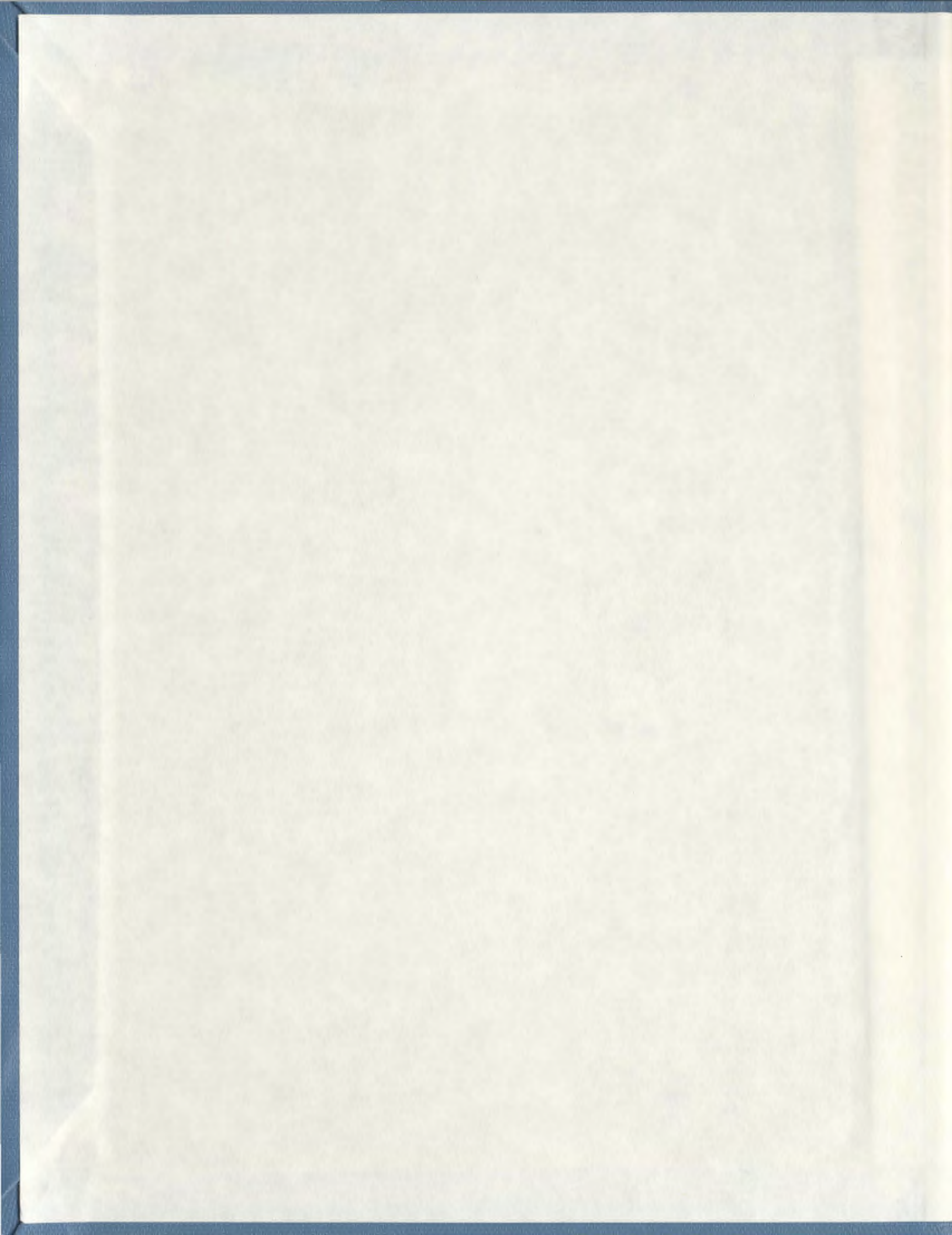
THE MEANING OF PERINATAL LOSS FOR WOMEN IN
NEWFOUNDLAND: A PHENOMENOLOGICAL STUDY

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KATHY WATKINS



**The Meaning of Perinatal Loss for Women in Newfoundland:
A Phenomenological Study**

by

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**A thesis submitted to the
School of Graduate Studies
in partial fulfillment of the
requirements for the degree of
Master of Nursing**

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DEDICATION

This thesis is lovingly dedicated to my late father, Roy Gordon Watkins, whose strong work ethic, integrity and humor have inspired and sustained me throughout life.

ABSTRACT

Pregnancy is generally a time of joyous anticipation and positive outcomes for expectant couples. However, the expected birth of a healthy baby can come to a tragic end with a sudden, unanticipated pregnancy loss. This event can be devastating for women, their partners, and their families. Although there is a large body of literature on parental responses to perinatal loss and some of the factors influencing grief intensity, very few studies have examined a woman's lived experience with perinatal loss. This phenomenological study used van Manen's method to explore the question: What is the meaning of perinatal loss for women who have experienced a miscarriage or stillbirth? From the data collected in unstructured interviews, seven themes were identified: shattering of hopes and dreams; centrality of the loss; shared grieving; identifying and accepting differing coping styles; dealing with others; dealing with the loss; living with emotional uncertainty; gentle reminders; and letting go and moving on. The essence of this experience was **searching for meaningful integration**. The findings indicate that women who have early and late perinatal losses cope with feelings of loss and grief in an individualized manner. In searching for meaning in her experience, each woman was influenced by the responses of partners, family, others in the social world, and health care providers.

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TABLE OF CONTENTS

DEDICATION.....	II
ABSTRACT.....	III
ACKNOWLEDGEMENTS.....	IV
TABLE OF CONTENTS.....	VI
CHAPTER 1.....	1
Introduction.....	1
Background and Rationale.....	3
Problem Statement.....	5
Research Question.....	6
CHAPTER 2.....	7
Literature Review.....	7
The Experience of Perinatal Loss.....	7
Parental Responses to a Perinatal Loss.....	9
Grief Intensity.....	16
Health Outcomes.....	26
Summary.....	29
Factors Influencing Parent's Experience with Perinatal Loss.....	29
Support Mechanisms.....	30
Additional Factors.....	44

Summary	48
Discussion	48
CHAPTER 3.....	51
Methodology	51
Phenomenology as a Research Methodology.....	51
Hermeneutic Phenomenology.....	54
Turning to the Phenomenon.....	54
Investigating the Experience	55
Phenomenological Reflecting.....	55
Describing the Phenomenon.....	56
Strong/Oriented Relation to the Phenomenon	57
Balancing.....	57
Methods	57
Participants.....	58
Procedure.....	59
Ethical Considerations.....	60
Data Analysis	62
Credibility of Findings.....	64
CHAPTER 4.....	66
Findings	66

Participants' Characteristics.....	66
Thematic Analysis.....	67
Shattering of Hopes and Dreams.....	68
Centrality of the Loss.....	76
Shared Grieving: Identifying and Accepting Differing Coping Styles.....	80
Dealing with Others.....	85
Dealing with the Loss.....	96
Living With Emotional Uncertainty: Gentle Reminders.....	100
Letting Go and Moving On.....	107
The Essence.....	112
CHAPTER 5.....	117
Discussion.....	117
Discussion of Themes in Relation to the Literature.....	117
Shattering of Hopes and Dreams.....	117
Centrality of the Loss.....	119
Shared Grieving: Identifying and Accepting Differing Coping Styles.....	120
Dealing with Others.....	121
Dealing with the Loss.....	124

Living with Emotional Uncertainty: Gentle Reminders	125
Letting Go and Moving On.....	126
The Essence.....	128
CHAPTER 6.....	130
Limitations, Nursing implications and Summary	130
Limitations	130
Implications	131
Nursing Practice	132
Nursing Research.....	135
Nursing Education	136
Summary	137
REFERENCES	138
APPENDICES.....	149
Appendix A: Consent Form.....	150
Appendix B: Interview Schedule	151
Appendix C: Letter of Approval from the Human Investigation Committee (HIC) Memorial University of Newfoundland.....	152
Appendix D: Letter to Perinatal Bereavement Advisory Committee, Health Care Corporation of St. John's	153

Appendix E: Letter of Support from Perinatal Bereavement Advisory

Committee, Health Care Corporation of St. John's..... 154

CHAPTER 1

Introduction

The prenatal period is generally a time of happiness, hopes and dreams, a time in which couples seem willing to accept the risks of pregnancy for a healthy baby (Costello, Gardner & Merenstein, 1993). However, the joy and excitement of a desired pregnancy can be abruptly ended. Despite the best efforts of the health care system, pregnancy related losses, more commonly known as perinatal losses, continue to occur. Perinatal loss includes miscarriage, stillbirth, neonatal death, and therapeutic abortion (Health Canada, 2000) and uniquely touches the lives of thousands of couples annually.

The statistics on perinatal losses during the childbearing years are significant. It is estimated that perinatal loss occurs in 20% of all pregnancies (Côté-Arsenault & Mahlangu, 1998). In 1997, there were 2143 stillbirths in Canada, 31 of these were in Newfoundland (Statistics Canada, 1999). There were 1358 neonatal deaths in Canada in 1997 with 22 of these in Newfoundland (Statistics Canada, 1999). In 1998, 110,223 therapeutic abortions were performed in Canada, 803 of these were in Newfoundland. In Newfoundland, 268 spontaneous abortions and 33 stillbirths were reported in 1998-1999 (Newfoundland and Labrador Centre for Health Information). Despite the prevalence of perinatal loss, couples are often unprepared for this significant life event.

Perinatal loss is one of the most difficult events a couple can encounter (Wagner, Higgins & Wallerstedt, 1997). Couples who want children do not expect pregnancy to end in death (de Montigny, Beaudet & Dumas, 1999). Instead, pregnancy is usually a journey of anticipation that leads to the birth of a healthy baby. During pregnancy many expectant parents imagine who the baby will look like and what the birth experience may entail (Brost & Kenny, 1992). However, the reality of the experience may be vastly different from what expectant parents had dreamed of or anticipated. A situational life crisis is placed upon those who experience a perinatal loss, a loss that can bring sorrow and pain to women and their families. The impact of perinatal loss is unique in that it can deprive parents of a most important part of their future, leaving a void that is felt throughout the lifespan (Weiss, Frischer & Richman, 1989). Furthermore, perinatal loss often involves a lack of tangible evidence of the life and death of a baby thus making the loss seem less significant and real to others (Costello et al., 1993; Lovell, 1983).

Nurses and other care providers plan and deliver care to women and families who have experienced perinatal loss. In order to provide effective care, nurses and others would benefit from a greater understanding of perinatal loss and its impact on women. Understanding of another's experience is vital to the development and implementation of timely and appropriate nursing strategies for addressing the unique needs of women who experience perinatal loss.

Background and Rationale

Since the early 1970's, researchers have documented how devastating a perinatal loss may be for women regardless of the gestational age of the baby (Benfield, Leib & Vollman, 1978; Tudehope, Iredell, Rodgers & Gunn, 1986). From early anecdotal accounts to more rigorous investigations, it is clear that perinatal loss can produce significant psychological trauma for women. Findings from studies focusing on the symptomatology of maternal grief following perinatal loss suggest that grief reactions are comparable to that following other losses (Benfield et al., 1978; Kennell, Slyter & Klaus, 1970; Smith & Borgers, 1988). However, perinatal loss is different because it can be characterized not only by the loss of a desired child and one's hopes and dreams, but also the loss of self-esteem, anticipated motherhood, and confidence with one's own ability to produce a healthy baby (Brown, 1993). Although the degree to which understanding perinatal loss and its impact upon those affected is improving (Hebert, 1998), further research is needed if we are to make significant inroads toward improving the health of those that have experienced a perinatal loss.

Historically, it was believed that perinatal loss was less significant than other types of losses (Wallerstedt & Higgins, 1996). The absence, in many cases, of a visible and publicly acknowledged "object" to mourn may have made the grieving process more difficult and complex. In fact, grieving the loss of a

baby that parents have not had the opportunity to get to know differentiates this loss from others (Leon, 1992). An understanding of this kind of loss needs to include a greater appreciation of the bonding that takes place with the unborn child. The reality of prenatal attachment with the baby has been well documented in the literature (Klaus & Kennell, 1982; Rubin, 1975).

A growing body of quantitative studies, spanning a couple of decades, has focused on identifying the factors that are associated with the intensity of grieving following perinatal loss (Franche & Mikail, 1999; Janssen, Cuisinier, de Graauw & Hoogduin, 1997; LaRoche et al., 1982; Lasker & Toedter, 1991; Murray & Callan, 1988; Smith & Borgers, 1988; Theut et al., 1989; Toedter, Lasker & Alhadeff, 1991; Tudehope et al., 1986; Zeanah, Dailey, Rosenblatt & Saller, 1993). Because these studies and others have used a variety of variables, methodologies and samples, inconsistent findings have resulted. It is plausible that other situational and personality factors that impede or facilitate grief remain unknown. Therefore, more qualitative studies are needed to explore the role of these and other factors in shaping the meaning of perinatal loss.

Although substantial literature now exists describing the extreme effects of perinatal loss, there is need for a greater understanding of what perinatal loss means to women who have had this experience. The development of a knowledge base grounded in women's experiences with perinatal loss is essential for the provision of quality care by health care providers. Sufficient

knowledge of this phenomenon is necessary to ensure that informed decisions are made about specific nursing interventions for different women.

Problem Statement

The researcher's interest in exploring women's experiences of perinatal loss was stimulated by years of nursing practice with this population. Further, as a co-facilitator of the Mending Hearts Support Group (Health Care Corporation of St. John's) for couples experiencing a perinatal loss, the researcher heard many stories of how perinatal loss had uniquely affected women's lives. For the most part, women came to the support group alone, men rarely attended. It was apparent that these women experienced intense grief reactions following all types of perinatal loss. Therefore, the researcher chose to investigate the lived experience of women who had both early and late perinatal losses.

The purpose of this study was to develop a deeper understanding of the phenomenon of perinatal loss and its impact on women who experience such losses. The position taken by this researcher is that, while much has been written about perinatal loss, the only real access is through some form of phenomenological inquiry. That is, a deeper understanding of perinatal loss can only be gleaned from an in-depth, thematic analysis of narrative accounts of women who have had such losses. Instead of searching for universality in predicting grief intensity and providing care following this type of loss, we should

first focus our efforts on grasping an appreciation for the intrinsic, personal side to the experience. In doing so, nurses will come to understand the lived experience of perinatal loss through an approach that is rich in detail and context.

Research Question

This study was designed to address the following research question:
What is the meaning of perinatal loss for women who have experienced a miscarriage or stillbirth?

CHAPTER 2

Literature Review

A greater understanding of how parents experience a perinatal loss is needed if health care providers are to develop appropriate and effective strategies to facilitate meaningful integration of such losses into their lives. The review of relevant literature is divided into two major sections. The first section summarizes qualitative and quantitative research findings on the overall experience of perinatal loss, the intensity of grief reactions, and consequential health outcomes. The second section highlights the key factors influencing parental experiences with perinatal loss, grief intensity, and post-loss health outcomes.

The Experience of Perinatal Loss

Perinatal loss is defined as the loss of a baby from conception to the first 28 days of life and includes miscarriage, stillbirth, and neonatal death. Although perinatal loss is a frequent and profound experience, it has often been underestimated in terms of its impact and significance (Malacrida, 1997). Only since the early 1970's have researchers documented the psychological phenomena surrounding this type of loss. While earlier studies focused almost exclusively on couples' grief experiences following a neonatal death and stillbirth,

it was not until later that miscarriage experiences became the focus of research efforts.

The theoretical perspective of earlier clinicians and researchers was that grief following perinatal loss would be less intense or qualitatively different (Zeanah, 1989). This was attributed to the belief that the developing baby could not be the object of maternal affection if the woman could only fantasize about the baby (Zeanah, 1989). However, Rubin (1975) argued that a prenatal bond between a mother and baby begins and exists during pregnancy and consists of events such as fetal movement, adjusting to the pregnancy and conceptualizing the unborn infant. Since Rubin, several authors have documented the presence of maternal prenatal attachment (Bansen & Stevens, 1992; Cecil, 1994; Klaus & Kennell, 1982; Peppers & Knapp, 1980). Wallerstedt and Higgins (1996) have even suggested that maternal prenatal attachment may occur before conception as the mother fantasizes about the mothering role.

The discussion that follows is focused on the research literature that examined parental responses to a perinatal loss, the intensity of the grief reaction, and health outcomes in the aftermath of a loss. In reviewing the literature on perinatal loss, it is apparent that the process of grieving is just as intense and long lasting as with other types of loss. It is also evident that while both parents respond in similar ways to a perinatal loss, women tend to grieve

longer than men and display more intense grief reactions which may have negative repercussions for their health and overall well-being.

Parental Responses to a Perinatal Loss

There are only a few articles identified from the literature that dealt with parents' total experiences with a perinatal loss. Two of the studies focused exclusively on women (Bansen & Stevens, 1992; Swanson-Kauffman, 1986) and three of the studies restricted their samples to male participants (Miron & Chapman, 1994; Murphy, 1998; Worth, 1997). Only one was identified that examined the experiences of both women and men (Kavanaugh, 1997).

In a study of 20 women who had miscarried prior to 16 weeks, Swanson-Kauffman (1986) applied the constant comparative method of analysis to the interview data to identify themes characterizing the miscarriage experience. Six theoretical categories emerged during data analysis: "coming to know" (i.e., balancing hope for a healthy baby against warning signs of an impending loss); "losing and gaining" (i.e., struggling to recognize what was lost and gained through miscarriage); "sharing the loss" (i.e., sharing feelings with understanding others, especially partners and women who miscarried); "going public" (i.e., telling others about the loss, and dealing with painful reminders and unhelpful comments from others); "getting through it" (i.e., struggling to have the good

times outweigh the bad); and, "trying again" (i.e., deciding to conceive again, while living with the fear of another loss).

In a phenomenology study, Bansen and Stevens (1992) explored womens' (N = 10) experiences with a miscarriage prior to 15 weeks gestation. Content analysis of the transcribed interviews identified four dominant themes: the miscarriage event, dealing with the loss, interacting with others and facing the future. The central theme, the miscarriage event, focused on participants' descriptions of physical (heavy bleeding and pain) and emotional (fear of dying) experiences, as well as denial of ominous signs indicative of loss and the delay in seeking health care. The dealing with the loss category captured the diversity of coping responses, the positive and negative aspects of grief expressions (e.g., talking, crying, anger, etc.), and the common experience of searching for a cause and the attributions of self-blame and guilt. The interacting with others theme described the discomfort/emotional pain experienced when mothers were confronted with their grief, the unhelpfulness of others (i.e., lack of acknowledgement, unhelpful comments and avoidance), and the support and reassurance received from caregivers, as well as those who had similar experiences but subsequently had a successful pregnancy. The final category, facing the future, highlighted changed perspectives on becoming pregnant and

having a baby, the increased sense of vulnerability to all types of loss, and the positives of having experienced a miscarriage (i.e., learning and growing).

Using a grounded theory design and the constant comparative method of analysis, Miron and Chapman (1994) investigated how men ($N = 8$) experienced their partner's miscarriage event. The core category defining the men's experiences was the concept of "supporting". Husbands' support for their partners occurred in four successive phases: (a) recognizing the signs, (b) confirming the news, (c) working through it, and (d) getting on with life. In the first phase, men were concerned and worried that certain physical symptoms were indicative of an impending loss. Whether men used denial tactics or sought validation of the warning signs by accessing informal and formal sources (e.g., reading materials, family members, friends, professionals, etc.), their goal was to provide their partners with support and comfort. During the second phase, the men received confirmation of an actual or impending loss, worried about their partner's physical and emotional health, and continued to be strong and supportive for their partners. Descriptions of interactions with health care providers were both positive and negative. The "working through it" phase captured men's responses to the loss (e.g., sadness, anger, disappointment, helplessness, etc.). Most of the men indicated that they were able to support their partners by not openly expressing their feelings to them and/or engaging in

a search for an explanation for the loss. Participants also acknowledged working through their grief faster than their partners. The final phase, "getting on with life" was reflective of coming to terms with the miscarriage event, living with the uncertainty of future pregnancies, and becoming vigilant during subsequent pregnancies. During the planning stages for another pregnancy, the men supported their partners by seeking information from professionals and informal sources.

Using an eidetic phenomenological approach, Kavanaugh (1997) conducted separate interviews (i.e., at one month post-loss and two to five weeks after the first) with eight parents (five mothers and three husbands) who had experienced the death of a newborn. The first theme, realizing that the loss is occurring, captured parents' difficulties in acknowledging that a loss was imminent despite the presence of warning signs. The second theme highlighted initial responses to the loss. While both parents reported fatigue, physical pain, and sleep deprivation, fathers experienced a loss of control and concern for their wives, whereas mothers spent more time crying and worrying about their husbands. The third theme, decision-making at the time of the loss, referred to the difficult decisions that parents had to make (e.g., autopsy, mementos, burial, holding the baby, etc.) while emotionally exhausted and not having a prior experiential base. Parents acknowledged the helpfulness of health care

providers' information, guidance, and support in facilitating their decisions. The supportive relationships theme included parents' descriptions of the importance attached to others' acceptance of their feelings and behaviours, being there for them, and sharing their experience. The giving of information, providing competent care, and giving special attention were identified as important behaviours for health care providers. The final theme, adjusting at home, was characterized by several processes (i.e., responding/relating to each other, relating to others, using coping strategies, giving meaning to the loss, and deciding about future pregnancies). While fathers were concerned about their wives, they were unable to openly discuss their feelings and tried to cope by engaging in distracting activities. In contrast mothers felt emotional emptiness and tried to cope by verbalizing about the loss.

Using a grounded theory design, Worth (1997) conducted interviews with eight Canadian men two months to five years following a stillbirth. Two simultaneous interactive processes emerged following data analysis: fathering and grieving. The fathering process was comprised of seven themes: anticipating the child (i.e., planning the pregnancy and preparing for the birth), acknowledging the child's reality (i.e., watching the birth, and seeing and holding the child), experiencing empty arms (i.e., absence of the baby), incorporating the child into the family (i.e., naming and burial rituals), struggling for recognition

(i.e., others' acknowledgment of fatherhood), accepting the reality of altered fatherhood (i.e., absence of a child to raise) and maintaining memories (i.e., ways to ensure the child is not forgotten). The grieving process interacted and overlapped with the fathering process. It consisted of the following six themes: learning about the death (i.e., feelings of shock, disbelief, and denial), acknowledging the loss (i.e., seeing and holding the child confirmed the absence of life), dealing with practicalities (i.e., feeling pressured and unprepared to make decisions about the partner's well-being and the stillborn child), communicating the loss (i.e., informing others), coming to terms with the loss (i.e., coping strategies), and moving on (i.e., living while remembering).

Murphy (1998) used a phenomenological approach to examine the lived experience of five men following an early miscarriage. Seven thematic categories were identified from the data: feelings, loss, characteristics and differences between men and women, staff actions and attitudes, what to do, coping, and time. The feeling category was the most pervasive and included early (e.g., shock, disbelief, hope, etc.) and later (e.g., anger, hurt, frustration, etc.) reactions to the loss. The loss category reflected the loss of future hope and expectations concerning fatherhood. With regard to male/female differences, participants' perceived women to have more intense feelings about miscarriage than men and believed that men should be strong in supporting their

partners. In describing negative aspects of hospitalization, most men felt that the actions and attitudes of health care providers suggested that they were unaware of the emotional impact of miscarriage. The “what to do and coping” categories reflected participants’ uncertainty in how to deal with their partners’ emotional outbursts, feelings of being alone to deal with their grief, and trying to get on with living. The final category, passage of time, differed for the men, with some seeing time as healing and for others the loss of hope for a successful pregnancy.

The literature review indicated that the commonalities and differences in how mothers and fathers respond to a perinatal loss are important factors influencing the grief intensity experienced by both parents and the ability of each to find meaningful closure within an acceptable time frame. The tentative conclusion at this point in the analysis is that the male/female grieving process is very similar but different in important ways. While mothers tend to be more open in sharing their feelings, fathers are more inclined to suffer in silence. As well, while mothers stress the importance of having supportive others around them, fathers perceive their principal role as being supportive for their wives.

Grief Intensity

Researchers have consistently documented that intense grief reactions can follow perinatal loss regardless of the stage of pregnancy. While there are variations in parental reports of grief intensity, there are more commonalities than differences. The following review of the literature presents an overview of studies dealing with maternal and paternal grief responses in the aftermath of a perinatal loss.

In the first published investigation of bereavement following perinatal loss, Kennell et al. (1970) interviewed 20 women three to 22 weeks after the death of their newborns. The dominant themes that emerged from the data included symptoms of sadness, sleep disturbances, anorexia, irritability, preoccupation with thoughts of the dead baby, and inability to resume normal activities. The interview transcripts of each participant were rated independently by two raters who assessed the intensity and duration of the six themes. Individual scores were subsequently summed to generate an overall score, which was categorized as low (0 to 14) or high (>14) mourning intensity. The findings indicated that all of the mothers displayed signs of mourning, with 50% of the sample showing high mourning reactions. Significantly, the most common symptoms expressed by women were sadness, preoccupation with the baby, insomnia, and disturbances in daily routine.

Another early study explored couples' ($N = 50$) reactions to a neonatal death (Benfield et al., 1978). During a follow-up visit to discuss autopsy results, each parent was asked to rate the intensity of seven grief symptoms (i.e., sadness, loss of appetite, inability to sleep, irritability, preoccupation with thoughts of baby, guilt, and anger) on a scale ranging from 0 to 3. Responses to the items were summed to determine an overall grief score. Parents were also asked to indicate the presence or absence of crying episodes, depression, disbelief, praying for the baby, and wanting to be left alone. Although the findings indicated that both parents experienced mild to moderate grief intensity, the mean maternal score (13.4) was significantly higher than the paternal score (9.7). Preoccupation with the baby, difficulty sleeping, and sadness were the most frequent grief symptoms reported by both parents. Guilt was also more of a problem for mothers than fathers. With regard to other factors, depression and crying were the most common reactions reported by both parents.

Peppers and Knapp (1980) studied the grief reactions of 65 women, six months to 36 years following a miscarriage, stillbirth or neonatal death. Participants were also asked to rate the six variables identified by Kennell et al., as well as additional factors identified by the authors (i.e., anger, guilt, difficulty in concentrating, failure to accept reality, lack of strength, time confusion, exhaustion, depression, and repeated dreams about the lost infant). The

findings indicated that there were no significant differences in the grief scores of those women who had experienced different types of losses. The researchers concluded that all perinatal losses have equal importance for women and often result in similar grief reactions.

In a study focusing on early pregnancy loss, Leppert and Pahlka (1984) studied the grieving characteristics of 22 women and some partners over a 15-month period following a miscarriage. Data were collected during counselling sessions and follow up telephone contact. Each participant experienced intense emotions characterized by seven stages of grief: shock, disorganization, volatile emotions, guilt, loss, relief and reestablishment. While the first three stages were intense but short-lived, the guilt stage was the longest in duration and the most difficult for couples. In fact, supportive counselling was required to help couples deal with self-blame (e.g., physical activities, sexual intercourse, illness, nutrition, etc.) and move through the other stages of grief. Another significant study finding was that men who were most distraught were the partners of those women who had experienced a miscarriage later in pregnancy.

During the mid 1980's researchers began to classify grief reactions as appropriate or inappropriate (LaRoche et al., 1984) and pathological (Tudehope et al., 1986). In a longitudinal study, LaRoche et al. (1984) investigated mothers' (N = 30) reactions to a stillbirth or neonatal death at one to two days, three

weeks and three months post-loss. The appropriateness of the grief reaction was based on the presence and severity of select factors (i.e., somatic distress, subjective distress, preoccupation with image of the baby, guilt, hostility towards others, and breakdown of normal patterns of conduct). The findings indicated that most of the women (80%) had appropriate grief reactions to the loss. At the fourth assessment, one to two years post-loss, Kennell et al.'s (1970) Mourning Scale was administered to the women. With the total mourning score hovering around 14.3, it was apparent that most of the women were still experiencing mild to moderate grief intensity. Similar to Kennell et al. and Benfield et al., the researchers found that sadness, preoccupation with the baby, and difficulty sleeping were the most frequent grief symptoms.

In a descriptive study of 67 couples following a neonatal death, Tudehope et al. (1986) recorded and graded grief reactions to the loss. Major grief symptoms were rated on a scale ranging from I (physically, psychologically and emotionally settled) to IV (serious symptoms that disturbed daily functioning). The most common grief reactions reported by mothers included sleep disturbances, depression/periods of crying, anorexia/weight loss, nervousness/anxiety, and social withdrawal. The grief symptoms reported by the fathers were different from and less frequent than mothers, with inability to work and excessive guilt, anger and hostility, and almost complete denial of death the

most common. Comparatively, Tudehope et al. found that a higher percentage of the women (31%) had pathological grief reactions than those (20%) participating in LaRoche et al.'s study.

Theut et al. (1989) examined the grief reactions of 25 pregnant women and their husbands who had experienced a miscarriage, stillbirth, or neonatal death within the previous two years. Data were collected with the Perinatal Bereavement Scale (PBS), a 26-item scale derived from interviews with women and men who had experienced perinatal loss and the work of Kennell et al. and Peppers and Knapp. Each couple completed the PBS during the eighth month of a subsequent pregnancy and six weeks post-delivery. The findings indicated that mothers grieved more than fathers, parents who experienced later losses grieved more than those who experienced early losses, and parents grieved more during a subsequent pregnancy than following the birth of a viable child. The authors argued that the shortened time frame between the loss and a subsequent successful pregnancy may explain the contrasting findings with previous research (i.e., Peppers & Knapp).

In a longitudinal study, Goldbach, Dunn, Toedter and Lasker (1991) interviewed women ($n = 138$) and their partners ($n = 56$) at six to eight weeks, 12 to 15 months, and 25 to 29 months following a perinatal loss. The Perinatal Grief Scale was used to measure grief intensity in the content domains (i.e.,

active grief, coping difficulties and despair). The findings indicated that participants who experienced a late loss evidenced significantly higher grief levels than those who experienced an early loss. As well, the women scored significantly higher than men on overall grief and each of the three sub-scales at the initial data collection period. However, by 12 to 15 months, there were more similarities than differences between the sexes, with women only differing from the men on the active grief sub-scale.

In a descriptive study, Lindberg (1992) examined the grief response of 20 mothers within one year of experiencing a mid-trimester loss (12 to 24 weeks). Participants completed the Personal Inventory Questionnaire, a researcher-developed instrument consisting of demographic and pregnancy/loss questions, and the Grief Experience Inventory (GEI). The scores from the nine clinical scales of the GEI were compared with normative scores from parents who had lost a child - the Parental Bereavement Group (PBG) ($n = 192$) - and a sample of women with variant loss types - the Female Combined Bereavement Group (FCBG) ($n = 346$). All of the participants exhibited grieving, with despair, somatization, death anxiety, loss of control, and anger/hostility evidencing greater intensity, respectively. Comparatively, the sample mean scores were significantly higher for despair, anger/hostility, social isolation, loss of control, depersonalization, somatization, and death anxiety than scores obtained from

both the PBG and FCBG. While the sample depicted significantly higher scores for guilt than the FCBG, the mean scores for rumination were significantly lower than those found in the PBG. The researchers concluded that grieving intensity after fetal loss is equal to or greater than grief intensity after the death of a child.

In a descriptive study, Hutti (1992) examined the perceptions of six couples who had experienced a miscarriage within the past 12 to 18 months. Using Dougherty's (1984) framework of cognitive representation, information was collected on participants' expectations about miscarriages versus their actual experience with this miscarriage. Because none of the study's couples had prior experiences with miscarriages, they did not have any pre-set expectations or an experiential base from which to judge their current miscarriage experience. Thus, the experiential context for interpreting the event unfolded as it occurred. The findings indicated that both the significance of the miscarriage and the intensity of grief reactions were greater for parents who perceived the pregnancy and baby as being "more real" (e.g., mother experiencing the symptoms of early pregnancy, mother and father seeing the baby on ultrasound, etc.). Husbands frequently noted that the pregnancy did not seem real to them because they could not see the physical changes of pregnancy experienced by their wives. Another significant finding was the presence of a more intense grief reaction in those parents who described a greater incongruence between the actual

miscarriage experience and their standards for a desirable experience. Finally, couples who found it difficult to make decisions and/or institute actions to reduce the discrepancy between the actual and desirable experienced more intense grief reactions than those who were able to implement proactive measures.

In a quantitative study of 57 couples who lost an infant (greater than 20 weeks gestation and less than one year of age), Lang and Gottlieb (1993) examined parental grief reactions. Data collection involved the use of the Bereavement Experience Questionnaire to assess the behavioural and emotional manifestations of grief (e.g., guilt, anger, yearning, meaninglessness, etc.) and the Modified Somatic Perception Questionnaire to assess physical components of grief (e.g., dizziness, nausea, etc.). The findings indicated that mothers rated their grief feelings higher than fathers on guilt, anger, meaninglessness, yearning, depersonalization, morbid fear, and isolation. Mothers also experienced more physical symptoms than did fathers. The researchers concluded that mothers and fathers experience the death of a baby in a different manner.

In a qualitative-quantitative study, Madden (1994) investigated the emotional reactions to miscarriage in a sample of 65 women four months following their loss. Data were collected with the Horowitz and Wilner (1980) coping strategies inventory and an interview schedule focusing on a variety of

loss-related issues (e.g., attachment to baby, whether pregnancy was planned, responsibility for the miscarriage, amount of support received, emotional impact of miscarriage, etc.). The results demonstrated that sadness, frustration, disappointment, and anger towards themselves were the most common occurring emotions at the time of the loss. Four months after the loss, mothers reported that their emotions were less intense, with feelings of hopefulness, sadness, and happiness most common.

Beutel, Willner, Deckardt, Von Rod and Weiner (1996) studied grief reactions in 56 couples shortly after miscarriage, six months and 12 months later. Participants completed the Munich Grief Scale. The findings indicated that the majority of women had higher grief scores than their partners. Specifically, men tended to score lower on sadness, fear of future loss, guilt, anger, and search for meaning in life than their partners. Although there were no qualitative gender differences in the feeling of sadness, men tended to cry less often than women and did not find it as painful to see other pregnant women. As well, the women had more dreams about the pregnancy than men. Comparatively, men reported feeling less need to talk about the miscarriage, identified fewer people to talk with other than their partners, and reported coping with the loss by immersing themselves in their work. Although grief scores fell significantly for

both the men and women at six months, gender differences persisted and were still apparent at 12 months.

Using a comparative study design, Hutti, dePacheco and Smith (1998) examined the intensity of grieving in women ($N = 186$) prior to and 12 to 18 months following the loss. The Perinatal Grief Intensity Scale, developed from findings from a previous qualitative study by Hutti (1992), was used to assess grief intensity on three factors: reality of the pregnancy and baby, congruence between the actual miscarriage experience and the standard of the desirable, and the ability to confront others. The findings indicated that most study participants experienced a moderate to intense grief response that lasted from a few days to three months. In addition, most of the women experienced the pregnancy and baby within as real, and experienced high congruence between the actual and the desirable. Furthermore, although about half of the women had difficulty confronting others immediately after the loss, this improved significantly in later weeks.

The findings suggest that most parents experience mild to moderate grief intensity, regardless of the gestational age of the fetus. This conclusion is based on empirical support derived from studies with variant research designs, samples, and data collection instruments. Furthermore, although the findings are somewhat inconsistent with regard to the degree of variability in parents'

grief intensity, most studies found support for a longer and more intense grief response from mothers versus fathers. There is also some suggestion that mothers are more likely to develop health problems if their reactions are prolonged and not dealt with in a timely and appropriate manner.

Health Outcomes

Besides the grieving process, other researchers have investigated the impact of a perinatal loss on parents' physical, emotional, and social well-being. Some studies have used health indicators as correlates or outcomes of the grieving process, while others have used them to predict grief intensity. The following review highlights those studies that focus on health indicators as correlates or outcomes.

In a study of maternal grieving following a stillbirth or neonatal death, Nicol, Tompkins, Campbell and Syme (1986) interviewed 110 mothers at six to 36 months following the loss. The General Health Inventory was used to measure the outcomes of bereavement. The majority of the women fell into either the moderate (32%) or marked (21%) health deterioration category. The most common symptoms were psychological in nature (i.e., general nervousness, insomnia, headaches, excessive fatigue, nightmares, persistent fears, depression, fearful of nervous breakdown, panic feelings, and repeated

peculiar thoughts). In addition, there was evidence of behavioural changes (i.e., diminished capacity to work and increased use of sedatives and cigarettes).

Neugebauer et al. (1992) compared the depressive symptoms of 232 women within four weeks of miscarriage (less than 28 weeks) with those of pregnant women ($N = 283$) and women who had not recently been pregnant ($N = 318$). Depressive symptoms were measured by the Center for Epidemiologic Studies Depression (CES-D) Scale, a 20-item checklist that assesses the presence and duration of symptoms in the preceding seven days. The findings indicated that although most of the women in the loss group had low depressive symptoms (i.e., a score of 30 or more on the CES - D), 36.2% were highly symptomatic for depression. Furthermore, depressive symptom levels were higher in women in the loss group than their counterparts in the pregnancy and community groups cohorts.

In a descriptive study of a cohort of women ($N = 160$) who had experienced a miscarriage within the past 13 to 16 months, Conway (1995) completed semi-structured interviews with 24 of the women. The Daily Hassles Scale, The Daily Uplifts Scale and Beck's Depression Inventory (BDI) were also administered at this time. The results indicated that most of the participants (92%) had bereavement symptoms at some point following the miscarriage, with feelings of loss, crying, anger, depression, and guilt as common reactions.

However, at the time of the interviews, the majority of participants (79%) did not exhibit symptoms of depression (i.e., scored in the low range on the BDI). As well, most (71% and 71%, respectively) had low intensity scores on the Daily Hassles Scale and fairly high gratification scores on the Daily Uplifts Scale.

Beutel et al. (1996) also investigated the health and well-being of couples ($N = 56$) over time. Participants completed standardized questionnaires for depression (von Zerssen Depression Scale), physical complaints (The Complaint List, C-L), and anxiety (State -Trait Anxiety Inventory). The findings indicated that men scored significantly lower on depression, bodily complaints, and anxiety than their partners. This was true even for those men who evidenced fairly high grief scores. The gender differences in depression persisted until six months follow-up but disappeared after 12 months.

In summary, the findings suggest that approximately 20% of women evidence severe enough grief symptoms to increase their risk for mental health problems. Comparatively, men are less prone to experience severe grief reactions and/or mental health problems. However, the research data is limited on the implications of perinatal losses for health outcomes.

Summary

The research literature on perinatal loss suggested that, despite the stage of pregnancy, many women and men experience feelings of loss, as well as mild to moderate grief reactions. While some researchers found support for gender differences in grief intensity, others have suggested that men do not experience less intense grief reactions than women but rather grieve differently from them. The findings also indicated that women, more so than men, tend to be at higher risk for health problems in the aftermath of a perinatal loss, especially if grieving is prolonged and inadequate supports are available to help them resolve their grief in a timely fashion.

Overall, studies examining the total experience of perinatal loss are limited. More recent research findings are suggesting that perinatal losses are individualized experiences influenced by a number of personal and situational factors. These factors will be addressed in greater detail in the following section.

Factors Influencing Parent's Experience with Perinatal Loss

Because of the plausible complexity and uniqueness of perinatal loss, it seems logical that parents' experiences can be influenced by a number of factors. The research literature provides empirical evidence for the influence of several factors on how parents experience a perinatal loss. In the review that

follows consideration is given to those factors which have received the most attention in studies focusing on perinatal loss.

Support Mechanisms

The literature indicates that formal (health care providers) and informal (i.e., partner, family, friends, and others in the social world) support mechanisms play a significant role in influencing perinatal loss experiences. While informational and emotional support were expected from health care providers, study findings suggest that it is important for caregivers to acknowledge that a loss has occurred regardless of the gestational age of the fetus. With regard to informal support, study findings suggest that parents, especially mothers, placed great importance on the willingness of significant others to acknowledge that a loss had occurred and to allow them to grieve in a manner that best suits their needs.

Formal. In one of the earliest studies examining the significance of information from health care providers, Rowe et al. (1978) conducted telephone interviews with 26 mothers 10 to 22 months following a stillbirth or neonatal death to document their post-loss experiences. About one-quarter of the women were judged to have morbid grief reactions based on the interview statements. The findings also revealed that most of the women had access to various

sources of support (e.g., spouses, family, friends, religious beliefs, etc.) and conveyed an adequate understanding of the reasons for the infant's death and the risk for re-occurrence. While most of the women reported receiving information about the loss during hospitalization and/or subsequent physician contact, the majority was either dissatisfied or only partially satisfied with this information. The women who were most satisfied with information received had post-hospital contact with physicians. Similarly, Conway (1995) reported that although most women were given an explanation for the loss, only a little more than half were satisfied. Some women reported that health care providers placed little significance on the miscarriage event and did not ask most participants (79%) how they were coping with the loss.

In a randomized, control trial of 50 women who had experienced a stillbirth or neonatal death, Forrest, Standish and Baum (1982) investigated the effects of a planned support and counselling intervention versus routine hospital care on emotional well-being. Data were collection at six and 14 months post-loss with a semi-structured interview schedule and two structured scales, the General Health Questionnaire (GHQ) and Leeds scales. The findings indicated that all mothers experienced symptoms of grief (i.e., tearfulness, sadness, lethargy, insomnia, palpitations, guilt, and irritability) and searched for a cause. At six months post-loss, 50% of the women who received routine care showed

symptoms of a psychiatric disorder compared to only 12% in the support group. The women who scored high on the depression scale of the GHQ also exhibited high anxiety, somatic symptoms, and impaired social functioning. Furthermore, results from the Leeds scales indicated that 63% of the women in the routine care group exhibited pronounced symptoms of depression and anxiety, whereas only 31% of the support group evidenced such symptoms. Significant declines were observed in the general health indicators and depression and anxiety symptoms for both groups at 14 months. In fact, no statistical differences existed between the two groups at this point in time. The researchers concluded that the greatest benefit of the support group was that it shortened the duration of psychological symptoms accompanying the grieving process.

Lovell (1983) interviewed a number of health care providers and 22 mothers following a miscarriage, stillbirth, or neonatal death. With regard to health care providers' attitudes, the findings indicated that all of those interviewed considered early losses to be less significant than later ones. In addition, a perinatal loss coupled with fetal anomalies seemed to further decrease a baby's significance and identity. With regard to the mothers' experiences, the data suggested that they felt a loss of identity as a mother and patient, were quickly discharged from hospital and often denied routine nursing care. Denial of the baby's existence was expressed by the providers' words and

deeds, confirming that the bereaved mother did not belong with those who had delivered a healthy baby. Whether or not mothers saw their babies after the loss often depended on the judgement of health care providers. Most of the women (N =12) who never saw their baby regretted it, whereas those who did so reported that they were better able to accept the loss because the baby's existence had been acknowledged and made tangible by others.

Swanson-Kauffman (1986) examined the caring needs of women (N = 20) who had experienced a miscarriage. Five theoretical categories emerged following application of the constant comparative method of analysis to the interview transcripts. The "knowing" category referred to the woman's need to have others (i.e., health care providers, family, and friends) understand her perspective on the loss. The "being with" category entailed sharing the bereaved woman's pain, whereas the "doing for" category captured not only doing things for her that she would normally do for herself but also the actual doing in a thorough, expedient and expert manner. The "enabling" category placed the onus on others to be cognizant of the woman's coping resources and needs, and to provide accurate information about the loss in a timely fashion and sensitive manner. The final caring category, "maintaining belief", involved giving the woman reassurance that she will get through the loss, derive meaning from her experience, and receive support for decisions related to future child-bearing.

Murray and Callan (1988) investigated the role of various factors in the adjustment of 130 parents (91 females, 39 males) to a stillbirth or neonatal death. Data collection involved the use of a researcher-based demographic questionnaire, a rating scale to examine the level of satisfaction with events that occurred post-loss, and three structured measures to assess current levels of adjustment (i.e., global rating of well-being or happiness, Self-Esteem Scale and Health and Daily Form). The results indicated that, while parents exhibited more depression than general members of the community, they showed fewer symptoms than depressed patients. Satisfaction with support from hospital staff was the single predictor of fewer depressive symptoms. Increased satisfaction with support from health care providers also predicted higher levels of self-esteem and well-being. Overall, a consistent predictor of better adjustment was the parent's level of satisfaction with the comfort and support provided by doctors, nurses, and other health care providers. Forrest et al. (1982) reported similar findings with a program of formal support following perinatal loss shortening the duration of grief for mothers in the support group.

In a longitudinal, qualitative study of how couples explain a pregnancy loss, Dunn, Goldbach, Lasker and Toedter (1991) conducted interviews with 138 women and 56 of their partners at two months and one to two years following a miscarriage, ectopic pregnancy, stillbirth, or neonatal death. The findings

indicated that participants (72%) who had been provided with an explanation for loss were more satisfied than those who did not receive any explanation.

Lemmer (1991) used qualitative methods to examine parents' (15 women and 13 men) perceptions of caring following stillbirth, neonatal death, and infant death. Following application of descriptive and interpretative coding to the transcribed interviews, as well as intrarater and interrater reliability checks, two major categories of caring were confirmed: "taking care of" and "caring for or about". Taking care of involved providing expert care (i.e., nurses as being sensitive, attentive and advocates; and physicians as thinkers and decision-makers), as well as information (i.e., explanations of what was happening and preparing them for the loss). Providing expert care and information resembles Swanson-Kauffman's (1986) caring categories of "doing for" and "enabling". The caring for or about category involved the provision of direct emotional support (i.e., listening and verbal, sharing presence) and individualized family centered care, acting as a surrogate parent (i.e., nurturing the newborn), facilitating the creation of memories, and respecting the rights of parents. Perceptions of non-caring were described as occurring when caregivers failed to meet physical needs, provide emotional support, or recognize the unique needs of the family.

Using the findings from the qualitative component of a randomized control trial of a social support intervention program in high-risk pregnancy, Rajan (1994)

reported on how women experienced formal supports following a perinatal loss. The findings indicated that most women found health care providers to be supportive. The helpfulness of providers was described in terms of words and deeds and/or actions that conveyed sensitivity and acknowledgement of the depth of the loss. The researcher concluded that women's interactions with health care providers are remembered and can influence their success or failure in coping with a perinatal loss.

In a qualitative study of 21 women and five men, Malacrida (1997) investigated problems encountered while interacting with medical and nursing personnel during a perinatal loss (i.e., a miscarriage, stillbirth or neonatal death). The findings indicated that parents had little understanding of perinatal loss and acknowledged that it would have been helpful to be informed of such a possibility during early contacts with health care providers (tell me the truth). Parents wanted individuals to be sensitive to their needs and forthright with information prior to and during the assessment of an impending loss, while the loss was occurring, and immediately following the loss (tell me what to do). Parents also expressed the need to have an explanation for the loss, and for others to acknowledge the event's significance and exonerate them from guilt (tell me about what happened). Finally, there was strong desire by both parents to be more prepared for the profound effects of perinatal grief on their lives in the

aftermath of the loss (tell me what's next). Mothers were especially vocal about the need to be aware of possible physical and emotional adjustments. Malacrida concluded that health care providers have an important role to play in facilitating parental grief resolution.

There were a couple of other studies that examined the importance of receiving appropriate and timely support from health care providers during a perinatal loss. Kavanaugh (1997) asserted that health care providers can be very helpful in offering information, guidance and support to parents following perinatal loss. In addition, de Montigny et al. (1999) found that while some parents felt supported, others did not. Some parents also reported being given contradictory advice about subsequent pregnancies.

Informal. Several studies have examined the influence of partners, family, friends and others in the social world on grief associated with perinatal loss. Besides the importance of adequate social supports, some researchers have examined the influence of the marital relationship on grief intensity and its resolution following perinatal loss. The following review highlights some of the key findings from studies investigating the support needs of couples dealing with a perinatal loss.

Early studies measuring grief intensity found that higher maternal grief scores were associated with communication difficulties (Kennell et al., 1970;

LaRoche et al., 1984) and low intimacy (Forrest et al., 1982) with a partner. Later studies also found support for the influence of the quality of the marital relationship on the couples grieving patterns (Gilbert, 1989; Lang & Gottlieb, 1993).

In a qualitative study of 27 couples following a miscarriage, stillbirth, or neonatal death, Gilbert (1989) examined grief experiences and recovery processes six months to seven years after the most recent loss. Independent semi-structured interviews were conducted simultaneously with each partner. Two distinct factors emerged to describe couple's behaviours and attitudes toward each other: high relational conflict and low or limited relational conflict. The couples who experienced high conflict encountered differences between their own and their partner's beliefs and expectations (i.e., variations in meaning of the baby; the woman dealing with both physical and emotional stressors and husband feeling alone to deal with his emotions while cognizant of the need to support his wife; adjusting to the changes in prescribed roles and a diminished capacity to act as a supporter; and variation in coping styles). As well, couples with high conflict reported incongruent grieving or disagreements about the grieving process (i.e., expectation that a common loss would involve similar grieving; appropriate grieving behaviours; misinterpretation about the meaning of selected behaviours/approaches; disagreements about the duration, the

publicness of mourning behaviours, and the timing of a subsequent pregnancy; and, competitiveness regarding grief intensity, blame, and frustration). In contrast, couples who experienced low conflict reported open and honest communication with each other, sharing the loss, accepting differences in grieving and role flexibility, conveying sensitivity to each other's needs, and maintaining a positive view of their relationship and themselves. Although some couples faced intense marital conflict, they were able to work on stabilizing their relationship.

Lang and Gottlieb (1993) also examined the relationship between marital intimacy and parental grief reactions in a sample of 57 couples. The BEQ and the MSPQ were used to assess behavioural and emotional aspects, as well as the physical components, of grief, respectively. The Personal Assessment of Intimacy in Relationships (PAIR) assessed the perceived and expected intimacy from the relationship. The findings indicated that mothers rated emotional intimacy lower and the sexual and recreational intimacy higher than fathers. Various parental, infant, and situational factors were found to be significantly correlated with grief reactions and marital intimacy. Suddenness of the baby's death was the most common predictor of maternal grief intensity. Mothers with lower intellectual intimacy ratings (sharing thoughts and feelings) reported more

intense grief reactions. Fathers, who rated emotional, recreational, social, and sexual intimacy lower experienced more intense grief reactions.

Several studies have also identified the role played by other members of couples' support networks in buffering the impact of a perinatal loss. Overall, partners and immediate family members were reported to provide both emotional and practical support. However, there were also reports of unhelpful comments and behaviours from some members of couples' support networks.

Cecil (1994) explored the supportive role of families for women ($N = 27$) who had miscarried during the first trimester of pregnancy. Participants were interviewed immediately following the loss and again one to three times during a six-month follow-up period. All of the women acknowledged that their partners shared their grief and provided practical as well as emotional support. In addition, some perceived their partners to be more focused on their well-being than the loss, were pressured to adopt supportive roles or to be the strong one, and were ready to move on with their lives sooner (i.e., support from husbands did not last as long as needed). Besides partners, mothers were identified as an important source of support in helping participants cope with their loss. Additional sources of support included other children and sisters. In general, women tended to receive more support from their own family than from their partner's family. The support received was both practical and emotional (i.e.,

listening, sympathizing, and empathizing). A final important source of support for participants were other women who had experienced a similar loss.

Rajan (1994) also reported on how women experienced informal social supports following a perinatal loss. The data suggested that some of the women perceived their partners to experience the loss differently from them (i.e., socially conditioned to not express one's emotions or communicate feelings). What was significant was the tendency for participants to refrain from seeking emotional support from their partners in order to protect them (i.e., perceived to have inadequate coping mechanisms). When asked about desired sources of support at the time of their loss, participants identified partners, family, and friends. Significantly, many of the women stressed the importance of being given permission to grieve the loss in a supportive environment. In reality, many of the participants had to contend with unhelpful responses from others (i.e., awkwardness, lack of understanding, failure to acknowledge the loss, and/or rely on avoidance behaviours) which often compounded their feelings of isolation and abandonment. For many, the most support came from women who had experienced a similar loss. Similarly, Leppert and Pahlka (1984) found that family and friends were not always able to acknowledge the loss and were sometimes uncomfortable with their openness about grieving. As well, other researchers have documented the helpfulness of support received from other

women who have experienced a similar loss (Kavanaugh, 1997; Kimble, 1991; Tudehope et al., 1986).

Conway (1995) also examined support from partners, family, and friends following miscarriage. Study findings indicated that a significant majority (96%) received support from their partners which was considered to be helpful (87%). The majority (70%) found friends helpful with 87% describing their relationships with friends as no different or even closer. Most participants (67%) found relatives supportive with 87% reporting no change in these relationships. Support from others (e.g., acquaintances, neighbours, co-workers, etc.) was not forthcoming and 78% did not feel encouraged to talk about their loss with these people. Participants reported avoidance behaviours and a failure of others to say anything.

Beutel et al. (1996) also investigated the role of support following miscarriage. Study findings indicated that immediately following the miscarriage, 75% of the women reported that their partners were understanding and considerate, but not necessarily later on. Another 14% complained that their partners avoided talking about the loss, this increased to 29% and 27% after six and 12 months, respectively. Women with the least support had the highest depression and anxiety scores but support had no effect on the intensity of grief reactions. Many women (41%) complained about the lack of understanding of

and interest in their loss by friends and family members. The women who remained depressed six months following the loss more often reported that partners avoided talking about their loss than women who were not depressed. After 12 months, depressed women reported increased marital conflict. Nicol et al. (1986) also found that a lack of perceived support from partners and/or family was associated with pathological grief reactions in women following stillbirth or neonatal death.

In a descriptive study of 20 parents (14 mothers and 6 fathers) who had experienced an abortion, miscarriage, in-utero death less than 20 weeks, stillbirth or neonatal death, de Montigny, Beaudet and Dumas (1999) explored the impact of the loss on the family's social network. During content analysis of the data, a number of categories emerged reflecting parents' descriptions of the impact of perinatal loss. In describing relationships with extended family members, parents reported that relatives were often uncomfortable and uncertain with parental grieving, avoided talking about the loss, and made inappropriate comments. While some parents felt that relationships with others had improved, others isolated themselves to avoid painful remarks. Although colleagues and friends provided support immediately following the loss, they expected parents to resume normal activities fairly quickly. As a rule, fathers were given little support and both parents felt unable to openly express feelings

and emotional needs. Consequently, both fathers and mothers refrained from social contact with friends and many abandoned social relationships to avoid having to deal with others' uneasiness with the perinatal loss. Overall, the findings indicated that parents' social networks were significantly impacted by perinatal loss and some suffered permanent losses of relationships with friends, colleagues, or extended family members.

Additional Factors

The duration of pregnancy or gestational age has been used to classify perinatal loss as early or late. Inconsistent findings have been reported on the effects of gestational age on the grief intensity of parents. Some researchers have found that grief intensity was greater following loss of a pregnancy that reached a longer duration (Goldbach et al., 1991; Janssen et al., 1997; Lasker & Toedter, 1991; Madden, 1994; Theut et al., 1989; Toedter et al., 1988). Other researchers have found that women who have early pregnancy losses experienced grief that was just as intense as those who had later losses (Leppert & Pahlka, 1984; Neugebauer et al., 1992; Peppers & Knapp, 1980; Smith & Borgers, 1988; Zeanah et al., 1993).

Kennell et al. (1970) also examined the influence of select factors on the intensity of maternal mourning following a neonatal death. Study findings

indicated that higher mourning scores were significantly associated with previous loss, positive feelings about the pregnancy, and touching the infant before death. In contrast, other researchers have failed to find support for the effects of contact with the baby after birth (Benfield et al., 1978) and previous loss on grief intensity (Benfield et al., 1978; Janssen et al., 1996; LaRoche et al., 1984; Nicol et al., 1986; Toedter et al., 1988). However, Tudehope et al. (1986) reported that contact with the baby after birth correlated with a higher degree of attachment but not with pathological grief outcomes.

In a study of women's grief reactions following early and late pregnancy losses, Peppers and Knapp (1980) also found that participants who give birth to a subsequent child experienced a less intense reaction, whereas those with a history of pregnancy complications experienced a more intense grief reaction. Less grief intensity (Theut et al., 1989) and higher ratings of well-being (Murray & Callan, 1988) have been reported by others following the birth of a subsequent child.

In a longitudinal study, Toedter et al. (1988) investigated predictors of grief intensity in a sample of 138 women and 56 partners following early and late perinatal losses. Data were collected at six to eight weeks post-loss with semi-structured interviews and several structured scales (i.e., the Perinatal Grief Scale consisting of three subscales: Active Grief, Difficulty Coping and Despair; a 27-

item scale to assess quality of the marital relationship; an 18-item scale to measure religiosity; the Symptom Checklist - 90 to assess mental health symptoms; and overall physical health based on a five-point rating scale ranging from very poor to very good). During regression analysis, poor evaluation of overall health, longer gestational age, poor quality of marital relationship, and presence of mental health symptoms combined to explain 52.7% of the variance in grief scores. Older mothers were found to have lower grief scores, a finding supported by Zeanah et al. (1993) and Janssen et al. (1996). Other studies failed to find support for the variant effects of maternal age (Benfield et al., 1978; Hutti et al., 1998; LaRoche et al., 1984; Nicol et al., 1986; Tudehope et al., 1986) or depressive symptoms (Beutel et al., 1996; Neugebauer et al., 1992).

In a follow-up study of the same participants used by Toedter et al. (1988), Lasker and Toedter (1991) investigated predictors of chronic grief. The findings indicated that difficulty coping and despair scores at two months were the best predictors of overall grief at two years post-loss. While there were variant predictors for the different sub-scales (i.e., difficulty coping, despair, and active grief), prior mental health surfaced as the most constant predictor over time. Interestingly, those factors (i.e., length of pregnancy, marital satisfaction, gender, and presence of living children) which were significant predictors of all components of grief at two months lost their significance by two years post-loss.

Only, gender (female) and length of pregnancy (late losses) remain as significant predictors of active grief at two years.

Madden (1994) investigated the factors influencing the emotional reactions of women following a miscarriage. Intensity of emotions immediately following the loss were positively correlated with degree of attachment to the pregnancy, responsibility attributed to oneself overall, physical characteristics and personality, and wanting to talk more about the loss. Although emotional intensity was negatively correlated with overall support from others, only perceived support from the husband maintained its significance at four months after the loss. The researchers concluded that women's emotional responses to miscarriage are highly variable and diverse.

In a prospective longitudinal study of 2,140 pregnant women, Janssen et al. (1997) investigated factors predictive of grief intensity following pregnancy loss ($N = 221$). Gestational age, pre-loss neuroticism, pre-loss psychiatric symptoms, pre-loss physical health, absence of living children, previous loss, maternal age, pre-loss partner relationships, and pre-loss social support together explained 35% of the variance in grief scores between the subjects. Women with longer pregnancies, a more neurotic personality, and more psychiatric symptoms showed more intense grief reactions. Those without living children and were older also showed more intense grief.

Summary

It is apparent from the review of studies in this section that mothers' and fathers' response to a perinatal loss is influenced by a number of factors. As noted by Hutti (1992), the intensity of grieving may be related to individual perceptions of the loss event and influenced by a combination of perceptual, individual, demographic and life experience factors. Lang and Gottlieb (1993) also concluded that different factors interact to predict maternal and paternal grief reactions. It is also acknowledged that cultural factors may influence the nature and intensity of the grief response. However, this aspect was not addressed in the research literature. However, the one constant factor that emerged as a significant force for helping couples deal with their grief following a perinatal loss was the presence of supportive significant others, as well as health care providers.

Discussion

The literature reviewed for the current study indicated that parents grieve following a perinatal loss regardless of the duration of the pregnancy. Although conflicting findings were observed in terms of the intensity of the grief reaction, as well as its duration and impact on overall health, some of these variations

could be attributed, in part, to the use of small convenience samples, failure to include both early and late pregnancy losses, use of different instruments to measure grief and health outcomes, data collection at variable time periods following the loss, use of diverse qualitative and quantitative research methodologies, among others.

There were also a number of factors identified as influencing the intensity of grief reactions and long-term health outcomes, especially for mothers. Despite the variations across decades and studies, there were definite consistencies with regard to the influence of gender on the nature and intensity of the grieving response. While all of the studies reviewed indicated that many men grieve following perinatal loss, most of them found that men reported less symptoms or grieved less intensely than women. While most studies have shown commonalities in the grieving response (e.g., sadness, preoccupation with the baby, sleep disturbances, anorexia, anger, etc.) of men and women, others have suggested differences (e.g., guilt, inappropriate grief reactions, etc.). In particular, men tended to be less expressive than their partners about the loss, coped by immersing themselves in their work, and grieved for shorter periods of time than their spouses/partners.

The presence of supportive others was perceived by both parents as an important facilitator of successful coping with their loss. The most frequently

identified sources of support were spouses/partners, family, friends, and health care providers, respectively. While many reported receiving emotional and tangible support from these sources, there were also reports of inadequate or unhelpful support. Importantly, several studies revealed that men not only felt obligated to fulfill the role of comforter but also were often expected to assume this role. In fact, a few studies found that men often neglected their own needs in an effort to be strong and supportive for their partners, and felt alone in coping with their loss. An additional source of support outside of the couple's support network were other parents who had experienced a loss. These individuals were perceived as being the most helpful contacts following the loss. It seems that having a similar loss established a common bond that facilitated a level of sharing and understanding that was not possible to forge with someone who did not have this life experience.

CHAPTER 3

Methodology

This chapter presents an overview of the research methods used during data collection and analysis. The first section discusses phenomenology as a research method. The second section presents a summary of the phenomenological method used in the current study, hermeneutic phenomenology, and the rationale for choosing this type of approach. The remaining section describes how the phenomenological approach was used to explore how women experience a perinatal loss.

Phenomenology as a Research Methodology

Phenomenology can be described as a philosophy, an approach, and a research method (Oiler, 1982; Omery, 1983). As a research methodology, its purpose is to uncover and describe the meaning of lived experiences. The goal of phenomenology is to provide a "description of the experiential meanings we live as we live them" (van Manen, 1990, p. 11).

Phenomenology is a method of direct inquiry that is holistic in nature. The researcher probes deeply into the essence of selected phenomenon to interpret and understand rather than explain (Bergum, 1989; Ray, 1994). From a nursing perspective the lived experience of a patient's existence is unique and

subjectively perceived. According to Morse (1992) phenomenology seeks to discover this uniqueness of living.

Phenomenological research involves a number of key concepts and principles. One core concept is that of the lived world, the world described by Husserl as the world of lived experience (Cohen & Omery, 1994). If the aim of phenomenology is to explicate the essence of everyday experience, then it is necessary that research begin in the lived world. A person's experiences are shaped by a world that influences how everyday situations are perceived. Therefore, exploring personal perspectives on selected phenomena is essential in capturing reflective descriptions of human experiences.

Another core concept is that of intentionality of consciousness or awareness (Cohen & Omery, 1994; Streubert & Carpenter, 1995). van Manen (1990) described "intentionality" as the way a person connects to the world. The basic structure of consciousness is intentional; consciousness is in the world and is always intentional (Streubert & Carpenter, 1995). Although persons are not aware of their intentional relation to the world, consciousness or awareness is the only access individuals have to the world. Thus, as human beings reflect on their experiences, intentionality becomes available and consciousness is revealed.

An increased awareness of the researcher's consciousness is significant in phenomenological research (Beck, 1994) as perception or original awareness is what gives one access to experience in the world (Munhall & Boyd, 1993). The process of recovering this original awareness, known as reduction, is a third concept critical to phenomenology. Reduction involves a concentration on the phenomenon, becoming absorbed in it while setting aside subjective feelings, previous experiences, theories, and scientific concepts. It is achieved by rigorous reflection on the taken-for-granted aspects of life (Cohen & Omery, 1994) and leads back to the source of meaning of the experience. This process is referred to as bracketing (Beck, 1994; Oiler, 1982; Streubert & Carpenter, 1995).

Bracketing can be viewed as the main methodological technique used to accomplish phenomenological reduction. Bracketing, freeing oneself from bias in reflecting back on the experience, is necessary so that the researcher can focus full attention on the phenomenon as it appears. It involves accurately portraying the lived experience as it is described by the participant (Beck, 1994). van Manen (1990) suggests that trying to forget, deny, or ignore what is already known is challenging.

Hermeneutic Phenomenology

This study used van Manen's (1990) hermeneutic phenomenology method to capture the lived experience of women who have encountered perinatal loss. van Manen presented a hermeneutic-phenomenologic approach, grounded in Dutch and German philosophic traditions, which emphasizes the interrelationship between phenomenology, hermeneutics (concerned with the interpretation of experience), and semiotics (the study of texts or signs) (Ray, 1994). van Manen (1990) describes phenomenological research as consisting of six methodological themes: turning to a phenomenon of interest, investigating the experience as it is lived, reflecting on essential themes of the phenomenon, describing the phenomenon through the art of writing and rewriting, maintaining a strong and oriented relation to the phenomenon, and balancing the research context by considering parts and whole.

Turning to the Phenomenon

Phenomenology starts with the researcher choosing a phenomenon of interest and committing to an aspect of human existence. van Manen (1990) describes this as turning to the nature of human experience as it is lived. This approach allows the researcher to focus on the whole as opposed to the parts. The researcher must be committed to investigating the chosen phenomenon so

that the lived experience can be explored and understood. The research question guides the inquiry and the explication of understandings, assumptions, and presuppositions (van Manen, 1990).

Investigating the Experience

Once the researcher has identified a phenomenon of interest, he/she then turns to investigating the phenomenon as it is experienced. In this step the researcher aims to strongly connect with the original experience and to set aside the “taken for granted” and “the given”. The researcher investigated the lived world of perinatal loss through: (a) experience acquired through personal clinical practice in women’s health and perinatal loss support groups; (b) experiential descriptions capturing the lived experience of 10 women who had experienced perinatal loss (i.e., two in a pilot study and eight in the current study); (c) reflective accounts of experiencing perinatal loss in journals; and (d) a review of other phenomenological studies to provide greater insight into how lived experiences may be investigated and interpreted.

Phenomenological Reflecting

Phenomenological reflecting involves reflecting on the essential themes while trying to identify essential meaning. This activity requires the researcher to

reflect on the descriptions given by the participants by reading and rereading the text as the tapes played. By using the selective highlighting approach as described by van Manen (1990), the researcher identified common themes. The analysis was focused on “recovering a theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work” (van Manen, 1990, p. 78). These themes gave shape to and described the content of the experience of perinatal loss.

Describing the Phenomenon

Once essential themes have been identified, the researcher must describe the phenomenon through the art of writing and rewriting. van Manen (1990) suggests that phenomenological research “describes the original of which the description is only an example” (p. 182). Describing the phenomenon involves exploring the meaning as it unfolds for the participants, allowing the researcher to capture the essence of the experience in writing.

The description of the phenomenon of perinatal loss was expressed through writing and rewriting of the text. Writing assisted the researcher to explicate a more indepth analysis of the perinatal loss experience. Furthermore, it enabled the researcher to see the phenomenon as a lived experience.

Strong/Oriented Relation to the Phenomenon

This activity requires that the researcher maintain a strong and oriented relation to the phenomenon. The researcher remained strongly focused on the original question and continually asked what something was really like. The researcher resisted settling for preconceived ideas and opinions and became engrossed with accessing the lived experience of perinatal loss.

Balancing

The researcher must balance the phenomenological themes to make up the whole. The themes may be conceptualized as the parts that make up the whole. Each theme is interconnected and dependent on the other. In writing and rewriting the text, one can lose sight of the main goal, which is to capture the essence (whole). Therefore, the researcher must step back and look at the total design of the text, to weigh the significance of the parts against the overall textual structure.

Methods

The phenomenological research approach outlined by van Manen (1990) was used to guide this investigation into women's experiences with perinatal loss. With this mode of inquiry, the researcher is viewed as a scholar of human

science research and the phenomenological method as “scholarship” (p. 29). This section will present a detailed description of the methods used for this particular study.

Participants

The participants in this study were women who had experienced a perinatal loss and were a part of the Perinatal Bereavement Program, Grace Hospital Site, Health Care Corporation of St. John's. For the most part, women registered with the Perinatal Bereavement Program had either experienced a miscarriage or stillbirth. Women who experienced neonatal deaths were excluded from this study because most of these women were not involved with the Perinatal Bereavement Program as their infants usually died in another institution. Therefore, it would have been difficult to recruit these participants (i.e., involvement of other institutions and health care personnel). Furthermore, they would not have had the support of a perinatal bereavement counsellor. Study participants met the following inclusion criteria: (a) experienced a perinatal loss within the last eight to twelve months, (b) mentally competent – able to understand the purpose and objectives of the study, and provide written, informed consent, (c) 19 years of age and older, (d) English-speaking, and (e) living within a 100 km radius of St. John's. Exclusion criteria included women

who had history of psychiatric illness (e.g., severe grief reaction, depression, etc.).

A phenomenological study lends itself to fewer participants, as the interview technique used yields large amounts of narrative data for analysis (Munhall & Boyd, 1993). Although small sample sizes are normally adequate, participants were enrolled into the study until no new descriptions and/or themes emerged from the data. Eight participants were recruited for this study.

Procedure

A nurse, who was a member of the Perinatal Bereavement Advisory Committee, agreed to act as an intermediary in contacting potential participants who met the inclusion criteria. None of the potential participants contacted refused to be interviewed. All study participants chose to be interviewed in their homes. A detailed overview of the study was presented, and informed, witnessed consent was obtained prior to the first interview (see Appendix A).

The first interview of each participant was audiotaped and lasted between 50 to 100 minutes. Participants were asked to describe their experiences with perinatal loss. Open-ended questions were used to prompt or clarify statements (see Appendix B). However, the researcher's questions and the flow of the interviews were largely directed by the participant's responses.

During a second interview, four to six weeks after the first, participants were asked to confirm an interpretative summary derived from the text of the first interview.

Ethical Considerations

Prior to commencing this study, permission was sought and granted by the Human Investigation Committee (HIC), Memorial University of Newfoundland (see Appendix C). A letter of support for the study was also received from the Chairperson of the Perinatal Bereavement Advisory Committee, Health Care Corporation of St. John's (see Appendix D and E). The intermediary contacted all potential participants via telephone. At this time, the nurse ascertained the potential participant's interest in being involved in the study and permission for the researcher to contact them was obtained. Names and telephone numbers were subsequently released to the researcher. During the initial telephone contact, the researcher outlined the purpose of the study, possible risks and benefits, and the voluntary nature of participation. Upon receiving verbal agreement, an interview time and setting were arranged.

Prior to commencing initial interviews, all women signed a written consent. The consent was thoroughly reviewed and an opportunity was provided for the woman to clarify issues and voice concerns. Participants were provided with a

copy of the consent, including the researcher's name and phone number.

Participants were informed that they could withdraw from the study at any time and refuse to respond to any questions posed by the researcher that they would prefer not to answer.

The researcher took all reasonable precautions to protect the anonymity of participants and confidentiality of information. All taped and transcribed data identified the participants by a code rather than names. Direct quotes were used to support emerging themes but the use of interview numbers and omission of identifying markers (i.e., physicians, nurses, and health care facilities) ensured confidentiality. Audiotapes were erased following a review of transcripts for accuracy. Interview transcripts and consent forms were kept in a locked filing cabinet only accessible to the researcher and thesis supervisor.

Participants were informed that there were no expected risks from participating in this study. However, it was stressed that certain interview questions could potentially elicit uncomfortable memories therefore participants were reminded that they could stop the interview at any time. Particular attention was given to participants' verbal and non-verbal responses during the interviews. Although some of the participants became emotional during the interview, all commented on how therapeutic it was to talk about their experiences with perinatal loss.

As well, the researcher had 12 years experience in the area of women's health and perinatal loss. The researcher had also been a co-facilitator of the Mending Hearts Support Group, a group specifically for couples who had experienced perinatal loss. Furthermore, all participants in this study were registered with the Perinatal Bereavement Program and had a perinatal bereavement counsellor assigned to them. Based on this background, it was anticipated that risks to participants would be minimal. In addition, the emotional status of each participant was assessed before terminating each interview. All were encouraged to contact the researcher if any concerns or questions surfaced.

Data Analysis

Immediately following the interview each participant's taped interview was coded and transcribed verbatim. Each transcript was read and reread, often while simultaneously listening to the corresponding audiotape. This ensured that tapes had been transcribed accurately, but also allowed the researcher to grasp what was being "said" and acquire a deeper meaning of each participant's lived experience.

The researcher also made a conscious effort to bracket any thoughts, feelings, preconceptions, and beliefs about the phenomenon under study. As well, the researcher made all possible efforts to become aware of her biases and

engage in critical reflection on the data. The selective or highlighting approach as outlined by van Manen (1990) was used to uncover thematic aspects of the phenomenon under study. Through reading and rereading the text, the researcher searched for phrases or statements that seemed particularly essential or meaningful in explaining the phenomenon of perinatal loss. The researcher then examined each of these highlighted phrases or statements and attempted to capture the meaning conveyed, while conscious of the need avoid imposing conceptual abstractions or generalizations on the data. The next step involved comparing and contrasting the themes emerging from each interview, to allow commonalities and differences to become apparent. Finally, the researcher identified overall themes which best described the women's experiences with perinatal loss.

Once essential themes were identified, the researcher began the process of writing. Each section on the themes was written and rewritten allowing the researcher to grasp a better understanding of the text. Eventually, the researcher felt that she had captured, as adequately as possible, the significance between parts (themes) and the whole (relationship among themes), thus providing insight to women's experiences with perinatal loss.

Credibility of Findings

Credibility, in qualitative research, measures how well and true the descriptions of the phenomenon are (Beck, 1994; Sandelowski, 1986). As well, qualitative research should not be evaluated against the same criteria of reliability and validity as is used for quantitative research. Qualitative research should be evaluated by examination of the credibility, fittingness, auditability, and confirmability of findings (Sandelowski, 1986).

A qualitative research study is credible when people having the experience being investigated immediately recognize as their own (Oiler, 1982; van Manen, 1990). To ensure credibility (truth-value) and auditability (consistency) member checks have been suggested (Hoffart, 1991). Two researchers experienced in qualitative analysis (i.e., thesis supervisor and committee member) read the transcripts and conducted a thematic analysis of the text. Discussions confirmed and refined the themes, and helped clarify the meanings emerging from the text.

Fittingness was addressed by seeking participants who were able to clearly articulate their experiences. The participants were good informants who provided rich data to facilitate insight into the lived experience of perinatal loss. Fittingness was also ensured by providing thick, rich slices of data, such as

numerous direct quotes from participants, in the discussion of the findings (Krefting, 1991).

Confirmability (neutrality) was achieved by ensuring that fittingness, credibility, auditability, and bracketing were established. Through bracketing, the researcher attempted to ensure that researcher bias did not influence the results of the investigation. Credibility, fittingness, and auditability were enhanced by having participants confirm their summaries, through member checks, and by having articulate participants.

CHAPTER 4

Findings

What is it like to experience a perinatal loss? This question is explored from the perspective of eight women who have experienced perinatal loss. The presentation of findings is divided into three sections. The first section presents a brief description of the participants' characteristics. The second section describes the themes that emerged from the phenomenological analysis of the text. The third section explores the essence of the experience, that is, the unique element that made the experience what it was.

Participants' Characteristics

The women who agreed to participate in this study had experienced a perinatal loss eight to twelve months prior to the first interview. The eight women ranged in age from 21 to 35. Just as their age varied, so did the timing and type of perinatal loss for each participant. Three of the women experienced losses late in pregnancy (over 20 weeks gestation) while the remaining five suffered early losses (before 20 weeks gestation). A couple of participants had experienced a previous early pregnancy loss.

All of the participants were married and lived with their husbands. Most of the women had one or two children living at home, ranging in ages from 6 weeks

to 10 years. One of the three women without children was pregnant at the time of the first interview. The educational level of the participants varied from completion of high school to post-secondary education. These women also worked at a variety of occupations, including the service sector, education, secretarial, and health care provider positions. Only one participant was not employed outside of the home.

All but one of the participants in this study were contacted by a perinatal bereavement counsellor one to two times following the loss. Only one of the women availed of the support group services provided locally. Issues surrounding perinatal loss and the intensity and duration of grief reactions were fairly similar regardless of the woman's age, early or lateness of the perinatal loss, or presence or absence of children at home.

Thematic Analysis

The following thematic analysis provides a detailed discussion on the themes identified from the interview transcripts of eight women who had experienced perinatal loss. Although presented separately to highlight different aspects of the lived experience, the themes are interrelated and interdependent with each other. The themes identified were: shattering of hopes and dreams, centrality of the loss, shared grieving: identifying and accepting differing coping

styles, dealing with others, dealing with the loss, living with emotional uncertainty: gentle reminders, and letting go and moving on.

Shattering of Hopes and Dreams

The theme shattering of hopes and dreams emerged as participants reflected upon the sudden onset of their perinatal loss. Webster's (1988) dictionary defines shattering as "causing deterioration or breakdown". Synonyms include breaking, devastating, and destroying. As used in the present context, perinatal loss shattered participant's hopes and dreams for the anticipated child.

Each woman related a detailed story of the events surrounding the pregnancy and subsequent loss, which was sudden and unexpected. Feelings of shock and disbelief were echoed by all participants as initial responses to the loss. This was true regardless of the presence or absence of warning signs that something might be wrong with the pregnancy. One participant summarized her initial reactions thus: "I can't deal with this right now, this is not happening, this is sort of like an out of body experience, you know, they're telling me the baby is not alive but I don't really believe it".

It was apparent from participants' stories that none anticipated anything other than a positive pregnancy outcome. Although pregnancy loss is a common event, it seems that these women never considered the possibility that this could

happen to them. Having a previous normal pregnancy and healthy baby made the loss in a subsequent pregnancy seem even more remote for some of the women. This sentiment is captured in the following statement: "It couldn't happen to me, I had a perfect pregnancy before, what's to go wrong? God woke me up, didn't he? Somebody did". A second woman made reference to the fact that the absence of warning signs enhanced the shock and disbelief that followed: "It was unexpected, I felt fine, had no inkling whatsoever". Comments made by others who experienced a loss early in the second trimester indicated they did not anticipate a loss at this stage in the pregnancy: "I thought when I made it that far, I was going to be fine"; "You have this false security. You're finished the first trimester and don't worry about it anymore".

Upon reflection, some of the women described how they intuitively knew that something was wrong but tried to ignore the warning signs of an impending loss. It was as though they were aware that things were not normal with this pregnancy but were denying that anything would happen to them. One woman described how she felt decreased fetal movement but convinced herself not to focus on it hoping that this feeling would pass: "Throughout the day I noticed I didn't feel much movement. . . I thought no I'm not going to think no more about that, don't dwell on anything, maybe things will be okay". Another woman spoke about how she tried to alleviate her concerns by rationalizing the observed

spotting: "It happens all the time, a lot of people spot and go on, nothing to be concerned about". Other participants also described how they tried to de-emphasize or deny the importance of warning signs:

I recall now that day, I wasn't feeling the best, but I just passed it off as being pregnant, just one of those days. It was really warm all day and I just contributed it to the weather and I was having lower back pain.

I've always had a bit of spotting, for the first month. I always had spotting on the first two that I had, but then it continued, so I knew in a way there was something wrong. But I left it alone.

For many, evidence of an impending loss began to mount even though some still had hope for a healthy pregnancy outcome. For most, there was a relatively short timeframe between awareness that something was wrong and the actual loss. Without exception, concerns about the pregnancy eventually led participants to their family physician or the emergency department. Many participants vividly described how they came to know that their baby had died and how they initially responded to the actual loss:

I went in to use the washroom and I felt the membranes starting to bulge down so I went to the hospital. They [*doctors*] told me everything was going to be fine. . . I knew there was no hope. I was going to lose the baby. . . Hard labour started coming on and I had her [*baby*] through normal labour. . . The hardest thing that I ever had to go through, definitely.

I woke up on Saturday morning and there was more blood and I felt something had disconnected up here. I could feel then it was something wrong. I made an appointment with the doctor. . . They [*doctor*] couldn't get a heartbeat. . . there was no heartbeat. . . When she [*doctor*] brought

me in to the ultrasound, the baby wasn't moving. She told us "You can see as well as I can, there's no movement there. I think that maybe there's no heartbeat" . . . I got right upset of course.

Another participant compared the current loss to a previous miscarriage and described how the signs of an impending loss were less evident this time:

I was almost 10 weeks when I had a little bit of bleeding and wasn't going to go to the hospital because I felt fine, no cramping, not like I had the first time. I went in just to be checked. . . . I went in and had the ultrasound done and went back to emerg [*emergency department*] and waited for the doctor to call me in. When I went in they told me there was no growth since six weeks. We [*participant and husband*] were both devastated, devastated, that's the only word I can say. . . .cause it was unexpected. I felt fine, had no inkling whatsoever.

Another woman indicated that when her membranes ruptured at 14 weeks she didn't know she was going to miscarry: "I had no idea I was going to miscarry after the doctors saying don't be so foolish and everyone trying to be so positive for me". However, after visiting the emergency room, her loss was confirmed by ultrasound. Upon seeing the ultrasound and realizing her baby had died she described her feelings as follows: "I found that very difficult because there was the baby and there was no heartbeat. They [*doctor*] told me I'm sorry but your baby has died. That was really, really hard" [*crying*].

Some participants had more time between having the loss confirmed and the actual loss event. One woman described how she was sent home after being told her baby had died and asked to return to hospital the next day for

labour induction. She spoke of how she wanted her husband and daughter to sleep with her. Her thoughts are best reflected in this passage:

I want the four of us to sleep together for the last time. I was lying in her [daughter] double bed and I was next to the wall and I was just like, I'm just going to lie here lifeless. I just have no strength. I just can't do anything. People can't expect me to do anything. I can't do anything. How am I going to live through the next few days? This can't be happening to me.

Amidst the shock and disbelief felt immediately after the loss, many questioned why this had happened to them. This line of questioning led some of the participants to search their lifestyles and activities for a causal basis for the loss. Self-blame emerged as the main culprit. One woman described how she questioned the impact of her smoking habit, constant lifting of her two-year-old son, and other stressors in her life on the untimely termination of her pregnancy.

I guess I was worried about what we were going to do. I think it had a lot to do with that. I was home by myself with a two-year-old child. A year and a half raising him basically by myself and I did too much and I think that's half the reason.

Other participants echoed similar sentiments: "We were out last night dancing. . . . I think I did feel a little bit of maybe it was something I did"; "The second time when we miscarried we were having intercourse. . . .In my mind, I know, but in my heart I don't, you always question". Because the cause of the loss remained unknown for many participants, they may always question whether or not their actions somehow precipitated the loss. For some, feelings of guilt and self-

blame may persist for an extended period of time. One woman verbalized how she should have known that something was wrong and was going to be “much more careful” with subsequent pregnancies.

The loss also precipitated feelings of anger for more than half of the women. One woman described how she was angry because she had to go through labour and delivery to give birth to her stillborn baby: “I was almost a bit resentful that I had to do the labour. . . .Can’t they understand that I’ve already gone through enough? The baby just died and now they are expecting me to have labour pains”. Others extended their anger towards those who have unwanted pregnancies.

We planned this child. . .and then people who don’t want children, who are just practising unsafe sex and end up getting pregnant and having abortions and getting pregnant again and deciding to have this one, that makes me very angry.

That first day that I went back to work there was a girl. . .whose now turned sixteen who has a child of her own. . .and I can remember being really angry. . . .Very angry that she had this child. . .and I could give it such a much nicer home.

Anger was also precipitated by responses from others that were perceived as conveying insensitivity to the loss. One participant described her feelings thus: “They [*family members*] were laughing and joking and I was lying in bed going how can they be doing these regular things? Don’t they know about my experience”? Another woman conveyed similar feelings:

I want you to understand that I lost something very dear and precious to me. . . .I don't think it's fair that the rest of you can go on home with your children and go out for dinner and do whatever it is that you do when I'm sitting here.

Most of the participants responded to the loss with feelings that are characteristic of grieving. While some described the devastation that was felt, others verbalized being numb and having no feelings at all. While all of these feelings are part of the normal grieving process, each woman's experience was unique and individualized. A couple of women described their feelings as follows:

I guess I went through the whole grieving process. Now I've never lost anyone really close to me to compare it to the death of a family member or anything, but I know I went through the crying, to listening to really sad music to wanting to talk about it, to denial to back to crying again.

Something being taken away from me that I didn't think I'd ever have. I think that just kept coming back, I never thought I was going to have it, I was okay with not having it. I was given it and it was taken away from me.

For one woman, the intensity of the grieving process had severe repercussions for her emotional well-being. She experienced feelings of failure as a woman and diminished self-worth in response to her loss: "I feel like some failure. . . .I'm probably not as important in life as *[those with children]*. I'm just here existing". It was also apparent that the reduced possibility of future pregnancies intensified her feelings of depression and low self-esteem. For her, coming to terms with not having children is a struggle that continues today:

I feel worthless even today. . . .I've said to [*husband*] several times, I feel that if you don't have children people don't look at you the same. They treat you like you're insignificant and maybe that's not true, I'm just trying, like I want you to see through my eyes, how I'm seeing.

Within the narratives study participants made reference to the loss of a baby that had been hoped for and desired. One of the participants spoke of the hopes and dreams that she and her husband had for their unborn child and how the sudden loss had destroyed those plans: "You know we had hopes and dreams for this baby but that was destroyed". Another conveyed a similar sentiment: "I knew how bad it was to lose something I never felt, never seen, only dreamed about". Other women who experienced an unexpected pregnancy after years of trying to conceive were faced with diminished hope and confidence of ever having a child. One woman commented thus: "For me it took so long to get pregnant and I wondered if it would ever happen again, or wondered what was wrong with me". A second woman described having similar feelings.

It was really disheartening and of course we had tried so long that I thought that this was the miracle child that never was to be. . . .That was a fluke of nature and it was taken from me. Now how do I get over it. It would have been better if I had never been pregnant.

Because of their experiences participants realized that pregnancy can be suddenly shattered by events beyond their control. The anticipated birth of a healthy baby can be abruptly destroyed without warning. This loss was an

awareness-raising event that made the participants feel vulnerable to loss and unanticipated life events.

Centrality of the Loss

Descriptions of thought patterns immediately following the loss reflected a dwelling upon the circumstances of the loss event. The loss experience became central in the thoughts of participants as they focused on the events that happened before, during, and immediately following the loss. Webster's (1988) defines centrality as "the quality or state of being central." The synonyms for central (e.g., focal, main, principal, key, etc.), when applied to a person experiencing a perinatal loss, conjures up an image of someone who consistently focuses or dwells on the loss experience.

During the initial stages, the loss of the baby took priority over participants' physical condition and symptoms. Despite being acutely ill with septicemia, one woman could only focus on the loss of the baby that she so desperately wanted. Her words conveyed a lack of concern about her personal health: "No, I didn't care, like I felt, I didn't care about me. I felt, well, who cares now if I live or die because I went through all this and I lost what was so important to me".

In addition to having the loss experience central in their own thoughts, some women felt that it should be a focus for others as well. In the period immediately following the perinatal loss, these women felt that their routines of daily living had been abruptly ended. Many of them found it difficult to accept that others around them could go on with their lives. The following comments illustrate this point:

I was looking out the window and watching the cars go along the Harbour Arterial. . . I was inside the hospital experiencing the most tragic thing of our life and people still going to work, everybody still had their routine.

How can you all go back to doing what you normally do, wait now, wait now, I wanted to be the centre of the attention. . .my loss, it should have been the centre, everyone should focus on that. How can you go to dinner tonight with your husband. . .don't you remember I had a miscarriage. . . I don't think the rest of the world should go on".

With time, the centrality of the loss for these women was reflected in their need to tell and retell others about the experience of losing the baby. Many of the participants described how they felt the need to talk about their experience repeatedly and to tell and retell their stories, especially to supportive others. The following comments made by a couple of women convey this message: "I told my story right down to the minute details. Seventeen thousand million times, anybody who'd listen, why sit down, I got a story to tell you", "That's all I wanted to do, if anyone would listen, I'd tell them. And mostly it would be people who had miscarried themselves". The telling and retelling of the events surrounding

the loss helped facilitate acknowledgement and validation of the loss and, most importantly, helped these women deal with their grief. One woman described how important it was for her to talk about her experience. She made the following comments: "I still wanted to validate the fact that we did have a baby and to dignify that fact; "I always felt that I wanted to talk about it and when I wanted to talk I would talk to anybody who was willing to listen".

Study participants indicated that all pregnancy losses are worthy of recognition regardless of the timing of the loss. For some women, not having had a baby to hold and grieve over led them to feel that others would perceive their loss as less significant than other forms of death. This seemed to be particularly true for those who had experienced a miscarriage. One woman verbalized that if others cannot see evidence of a pregnancy it might not be acknowledged: "No matter if it's one week or 10 weeks or 12 weeks you're still pregnant and it still deserves an acknowledgement". Another woman who experienced a miscarriage described how she felt about seeing her baby after the loss:

It would have been unbelievable cause it took me so long to get pregnant. I never did feel the baby, although I did see the baby on ultrasound. I never did feel the baby kick and for some to say that you lost your baby, it was almost like I was never pregnant.

Recognition of the loss was important for another woman who had experienced a miscarriage. She did not want to face the silence often associated with a childbearing loss and wanted others to be willing and unafraid to talk to her. She indicated that saying "I don't know what to say" was more therapeutic than not confronting the loss at all.

All of the study participants indicated that it was important to have their feelings acknowledged or confirmed by others. What was perceived as being especially helpful was to receive acknowledgement or confirmation from other women who had experienced a perinatal loss. Knowing that others had endured a similar loss and survived provided these women with a glimmer of hope and reinforced the fact that they could get through this difficult time. One woman described her feelings thus: "So I did find that helpful, knowing that other people do have the loss and that other people have come through the loss". Another woman, who had experienced two miscarriages and was facing the possibility that she may never have a successful pregnancy, longed to talk with someone living under similar circumstances. The following passage captures how receiving reassurance from someone who had the same experience was perceived to be vital to her well-being:

People don't understand. . . I wish that I could meet somebody who went through the same thing. . . I'd like for somebody to be able to say I've

gone through this and I'm never going to have any children and I feel like you too. Somebody could tell me it's going to be okay.

For most of the women, the loss event was dwelled upon and talked about for some time. Talking about their experiences enabled the participants to focus on the loss and validate their feelings to others. Many women also felt the need to have their loss recognized and acknowledged by others. For most, sharing with others who had experienced a perinatal loss provided hope and support to the newly bereaved mother.

Shared Grieving: Identifying and Accepting Differing Coping Styles

Each woman's experience was woven within the context of others' reactions to the events surrounding the loss, especially those of her husband. Even though the women and their husbands experienced a joint loss and shared grieving, the narratives clearly documented differing coping styles between them. Another striking finding from the current study was the number of women who experienced differences in relation to the patterns and timing of grief expression by themselves and their partners.

Study participants were clearly aware of how their husbands' coping styles may or may not have differed from their own (i.e., less emotional, expressive verbalizing). Some of the women identified gender as being a

possible reason for observed differences. It was as though the women were aware of societal expectations in relation to grief responses of men and women. One woman described her husband as “a typical male who didn’t show any emotions”. A second woman spoke about how she responded differently than her husband to their loss: “I mean [*husband*] and I experienced the same thing but in two totally different ways”. She elaborated further on their different coping styles: “I’m going to talk about it, I’m going to write it out and he wasn’t going to do any of those things. But it was more of how a woman would deal with things, how a man would deal with things”. Similar sentiments were echoed by other women: “My husband, he was devastated and men handle things differently. He cried at the time and then after that he didn’t talk about it much”; “We’re different in that respect because I need to talk about things. I need to get it out in the open and he [*husband*] keeps everything inside”.

Some of the women described how their husbands were ready to return to work before them which further reinforced their belief that men cope with grief differently. One woman felt angry and isolated because she perceived that her husband worked through his grief in a shorter period of time:

I remember being downstairs and [*husband*] would be working on his computer and I’m thinking how can he be getting on with his life. . . .How can he deal with work? We just went through the most tragic thing of our life. I can’t deal with work.

Conversely, another woman seemed more accepting of her husband's return to work and attributed it to male and female differences: "He [*husband*] lost a lot of weight. Now I probably did too. He went back to work, I didn't. He handled things differently".

Without exception, all of the women wanted their husbands to be there for them. While some of the women seemed to accept the differences in coping styles, it became a source of frustration for others. One of the women viewed her husband as being cold and distant, while he saw her as being overly emotional. She believed that different ways of dealing with loss led to stressful confrontations which had negative repercussions for the quality of their relationship.

I did ask him [*husband*] several times to go to a marriage counsellor and he wouldn't come. He feels that he doesn't need to go tell somebody his problems or talk about our marriage. We're different in that respect because I need to get it out in the open and he keeps everything inside. I guess he feels that I should be more like him, be able to keep everything inside and handle it and I feel he should be more like me.

Another woman talked about how her husband wanted the grieving process to end and regain some semblance of normalcy in their lives. She reported him as saying: "Let's bring some normal life back here. We can't be grieving about this. Let's not talk about it too much more. We talked about that once before".

Although aware that this was how her husband was coping, she felt isolated in

her grief because of the pressing need to share her feelings openly with him: "[*Husband*] would be on the computer and I'd be lying on the couch. I'd be writing everything down and tears would be streaming down my face. . . .I'd just feel alone. I'd feel isolated".

Besides not feeling totally supported in how they wanted to deal with the loss, some of the women voiced feeling frustrated and concerned because they neither really knew how their husbands were handling the situation nor how to help them. One woman noted that she did not know how her husband felt about the loss because he had not been open with her and was not as comfortable sharing his feelings with family or friends as she was: "I don't know exactly how [*husband*] feels. . . .Because I get to speak everything out. . .but no one asks him how he feels. . .he's going to say it's okay anyhow". Feeling somewhat inadequate in helping him deal with his loss, she hoped that he could find someone with whom he felt comfortable enough to express his feelings.

Recognizing that their husbands differed with regard to sharing of feelings, other women described how they hid their "true" feelings and pretended to be strong for them. One woman described how she created an emotional front (i.e., in control of her feelings and the situation) for her husband's benefit: "I can handle it, don't worry, I'll take care of it, I'll call my family doctor. I'll notify people, I'm fine, my husband was not fine".

Those couples who were able to give support to their partner and receive it when needed seemed to have coped in a more positive way. The women spoke about differences in the timing of grief responses for themselves and their partners, noting that there were times when one would grieve and the other would remain strong. One woman elaborated upon how her and her husband took turns being supportive for each other:

When we first lost her, he was devastated. He found it really hard and I was the strong one when I was in the hospital and when I came home I was the strong one. As soon as he got laid off work, the tables were turned, it was my turn to grieve and he had to be the strong one for me and that's the way we did it.

A second woman also described how her and her husband rotated between supportive roles:

Every time the phone rang or we told people, if it was on his side [*of the family*], I would be the strong person. . . .It would be reversed, like if I was talking to [*my sister*]. . .he took over and was the strong one at that point.

It was as though these women expected that they had to be strong when the other wasn't and vice versa.

For all of the women, their experience entailed a joint loss that was shared with their husbands. For many participants, the loss resulted in the identification and, for the most part, acceptance of responses and coping styles that were different from their own. Given this, it was as though the women expected their husbands to share their grief and respond to the loss in a similar manner. Even

though the women were aware of how their husbands coped with life events, most wanted to be able to express openly to their husbands. The participants also wanted their husbands to express openly to them. However, the women did not force their husbands to continue talking about the loss when they indicated wanting to talk less about it. While some women seemed accepting of the differences in coping, it became a source of concern and frustration for others.

Dealing with Others

Besides their husbands' differing coping styles, participants often experienced differing coping styles when encountering others within their social worlds. While some similarities were found between participants' accounts of their reactions to the loss and those of family, friends, acquaintances, and health care providers, there were also many differences. Dealing with others following the loss seemed to be influenced by a number of factors including perception of the loss, coping style of the bereaved woman, closeness of relationships with others, responses from significant others and health care providers, and others' experiences with similar losses.

All of the women in this study felt the need to deal with their feelings and share their experiences in an individualized, unique manner. One approach that was useful was emotional distancing from or avoidance of family members or

others in their social networks immediately following the loss. The following quotes from different participants illustrate how some of the women felt that they could not talk to or face anyone:

I . . . couldn't talk to anybody at all on the phone, the phone would ring and I would panic.

I didn't really want to let my mind do any more thinking and I didn't want to talk to anybody about it.

I thought, I can't face all these people, I just got to stay in the bedroom. . . I'm not going to leave this house. . . I'm not going to go anywhere.

One woman described how she initially distanced herself from the loss and others around her by focusing on other things. She also spoke about trying to deny the reality of the situation by not talking about her loss with the nurse who was caring for her: "I'm talking to her about going to Texas. . . I'm talking about everything except what I should be talking about". Two other women also described how they thought about ways to avoid the reality of the situation:

I felt as long as I stayed in the hospital it wasn't real, but I felt once they let me go home, it meant it was going to be real, you know the baby was gone.

It was like the hospital was really secure. I don't want to leave the security of the hospital and have to go home and face my inlaws and parents and answer questions and talk.

Participants indicated that they avoided others initially because they expected painful questions. One woman described how she was fearful of

interacting with others who might ask her about her loss: "I don't want to see anybody, I don't want to see people. Where's your belly? Where's your baby? I didn't know how I was going to deal with those questions". Other participants described wanting to distance themselves from those individuals who did not know how to deal with the grief and suffering of another. One woman summarized her feelings in the following manner: "I wasn't quite ready for the different things that different people say that don't understand or the people that don't know what to say". Other women also echoed similar sentiments: "They didn't know what to say to me. They didn't know what to say, other than I'm sorry"; "It was like people didn't know what to say so they had to say something and then I was just tired of listening to the same things being said". Rather than continue to deal with uncomfortable situations which made interactions strained for all involved, many of these women, when possible, tried to avoid any kind of social encounters. A couple of the women described how they reacted in anger to others' attempts to get them out socially:

Let's go to the mall. And I thought, I'm not going to the mall, there could be people there that I know, I'd have to keep my head down. I don't want to see anybody. I don't want to see people.

When I miscarried that time, mom wanted me to go to a barbecue that night when I got home. I said Mom, how could you think? Mom, why did you do that? What was your purpose? I felt it was just cold. . . .She was just trying to get my mind off it and trying to get me out to socialize and do

whatever, but to me it was too fast, it was too soon. When you're depressed you can't do that.

Other participants indicated that they avoided people because they felt unprepared to deal with "unhelpful comments" and/or statements that conveyed a lack of understanding about the depth of their loss. Some of the women described feeling resentful when encountering individuals who felt compelled to say something even if it wasn't helpful. The following quotations capture what participants meant by unhelpful comments:

This was meant to be and that kind of thing. I felt like saying I've heard everything, you don't need to say anything for your peace of mind. It was like people didn't know what to say, so they had to say something.

One of the things that really bothered me was people saying, "Oh you're only young you can have another one". That was one thing that really bothered me, I didn't want to hear that.

Oh, don't worry. I know such and such and she miscarried and she has two healthy children now.

You'll get pregnant again or don't worry about it, or time's a great healer, or it doesn't matter.

It seems that comments from others did not always satisfy a participant's need for support and understanding. It is interesting to note that most of the responses perceived as unhelpful came from those who had never experienced a perinatal loss. Although aware that most people meant well, these women felt that it was sometimes better not to say anything at all.

While on one level the women tried to distance themselves from others, they also expected them to reach out and confront their grief. When others failed to acknowledge their loss, the bereaved women blamed them for not being there. One woman commented thus: "I just kind of shut myself off from everybody and somehow I used to blame them for not, well, I was the one probably shutting people out but I kind of blamed them for not being there for me". As her comments indicate, she was cognizant of pushing people away who tried to reach out to her but also expected them to be strong enough to break the barrier and acknowledge her grief. Because these women were uncertain about what they wanted from others, feelings of ambivalence and discord left them searching for a balance between what was expected and what was actually received from others. These feelings are conveyed in the following passage: "It's just a mixture of things, you don't know how you're feeling. You get these little cards and all of a sudden you cry. . . . You just don't know what you want from people".

It seems that emotional distancing was also a common strategy used by others with participants. Many women felt avoided by others who were not comfortable in discussing the loss experience. This was frustrating for the bereaved woman who needed to express her feelings. Some women described how helpful and supportive family members were, while others reported that

family members did not want to talk about the loss. Half of the women discussed how their husband's families were unable to express their feelings about the loss. One woman described her family's reaction in the following manner: "I have a sister-in-law who I was always close to and she never talked about it. I felt hurt. She did say to me one time that sometimes people don't say anything because they don't know what to say". Another woman reflected on the reaction of her husband's family thus: "They [*husband's family*] were good through it all. They're not really a family big on emotion. I don't know how they dealt with it. I have no idea".

For the most part, the participants simply wanted to have their loss acknowledged by others. Instead, several women felt that their experience went unrecognized by those around them. Those women who had experienced a perinatal loss were perceived as supportive and understanding. Many of the participants found that sharing with these individuals was positive and helpful. It was as though their common experiences created a bond that transcended the grief and enabled the other to presence themselves with the bereaved women. These feelings are captured in the following statements:

There was one person. . .she had had a stillbirth many years ago. . . .She didn't have to say a whole lot, it was almost a look, it was a presence, it was like, I do understand and I knew that she understands. . .I know you really do understand. . . .It helps to know that you can talk to someone else who has gone through this.

When you know that someone has had a difficult time getting pregnant or has had a miscarriage before, it's like there is a certain bond there with that person.

When you talk about it, they're [*others who had loss*] happy to talk back to you. I think they understand it because they've been through it. They have to feel something if they've been through it.

It was apparent that these women found it less difficult to express their feelings to those who had experienced a similar loss because they felt understood and cared for by those individuals.

Many of the women reported that those who had experienced a similar loss were often the first ones to visit and offer support. Some women seemed to feel that to completely understand another person's experience one must have experienced the same thing. One participant described what she meant by this in the following manner: "I didn't understand what [*friend*] went through until I went through it. I was sitting in that bed in that position realizing that it must have been hard for her but I never realized that until my baby died". Another woman commented on how supportive individuals were who had similar experiences but who they were not close to prior to their loss: "There was one person who I'm not particularly close with, a co-worker, she called about ten days after and she had had a stillbirth many years ago and she didn't have to

say a whole lot". She elaborated further on the helpfulness of others who had experienced similar losses:

One had a stillbirth, numerous, numerous had miscarriages and they came forward. I had calls upon calls. I had visitors, people who would leave cards in the mailbox with a little note. I had a miscarriage, I understand. Call me if you need me, those kind of things.

It was their common experiences which facilitated a closeness where each felt free to share their thoughts and feelings. This common experience also resulted in the participants being able to be supportive and understanding to others who experience similar losses. This was seen as a positive outcome of the loss as participants now felt prepared to offer comfort and strength to those who are bereaved. These feelings were reflected in the following comments:

I learned alot from my own experience. I will call, I will approach these people and you can take cues from them. You'll know they want to talk and if they don't you pull back and you can try again in a few days or whatever.

I'd help anybody. I know what it's like to go through it and there's a girl [at] work now, I think she went through two miscarriages. She finally got pregnant, I mean I always go in to see her and talk to her and see how she's doing. . . .That's the one good thing about going through it, you can help other people. If they need it, you're there. You know what they went through.

I guess, if anything, my experience helped my cousin who went through a miscarriage in December, as far as being able to share with her.

For the most part, interactions with health care providers during the loss experience were described as supportive and comforting. Nurses were

perceived as “being there” for the bereaved woman and her family. Several participants commented on the helpfulness of the care providers:

They [*health care providers*] were always there no matter what time of day or night, they were there for you and whatever, you know, to talk or just sit there and just, they were there.

We had a really caring, kind nurse. . .she was like fantastic. . . .She'd be crying with us.

I think they [*health care providers*] were all very helpful from the moment the casualty officer came out and told me.

Another woman who did not receive expected follow-up telephone support from a perinatal bereavement counsellor was not distressed by this because she had adequate social support. Two others described negative experiences associated with the emergency department. For one woman who was heavily bleeding, having to wait in an emergency room waiting area was frightening and traumatic.

They [*hospital personnel*] said to come down right away and so I came down but I had to wait in the waiting area for three hours. . . .I know they were busy at the hospital but this was really traumatic for me.

While nurses were perceived as caring, some women reported non-supportive actions and responses from other health care providers. Participants commented thus:

To be quite honest with you I didn't find her [*social worker*] helpful. Now I don't know if it was my frame of mind at the time. I don't think it was because [*husband*] said he found her more of a bother. . . .I didn't feel it was genuine. I felt like okay, I have a job to do and now I'm going to do it.

She [*nurse*] was really helpful. The doctors weren't. They were not, whatsoever, helpful. They just came in and did their job and went on again. They, I don't know, they don't look at you as a person. You're just a patient not a person. That's the way I felt but the nurses were really helpful.

Overall, most participants expected that health care providers would be comforting and supportive. This is significant given the fact that health care providers, especially nurses, are in a unique position to provide support, information, and reassurance.

Several participants also commented on the limited support by health care providers given to the fathers. These women perceived that the focus of reassurance was on the bereaved mother not the father. The participants described situations in which the father's feelings and needs were not explored or addressed. This aspect is conveyed in the following passages:

I felt like there was no support for him. That everyone was coming to see me. I was the one that lost the baby but it was his baby too.

We forget about him, I think because he did not go through the physical act of having a D & C done, but it was his loss as well and sometimes we concentrate on the female aspect of the couple rather than the male.

Like I think everything is so generated to the mother, nothing is generated to the husband at all, like very seldom someone asks him a question, are you all right or how do you feel about this.

Despite recognizing the father's need for support, two of the participants reported that they were unable to offer that much needed support to their

husbands. One woman verbalized how she could not deal with her husband's emotional response immediately following the loss. Amidst the devastation and shock of miscarrying, she felt unable to cope with his feelings in addition to her own. Although aware of his need for comforting, she felt the need to deal with her own feelings first.

My husband was really, really upset and we went straight to my doctor's office. I didn't know what else to do because I could not cope with him. I had to sort this out, my own feelings out myself. I could not baby him at this point. I could not explain it to him. . . .I could not comfort him. I couldn't, I knew that he needed something and I didn't know how to give it to him because I couldn't get over this myself.

Another participant who was also concerned about her husband's lack of support felt unable to deal with his reaction to the loss. She perceived that he would be more expressive with someone other than her and, up to this point, had not had the opportunity to fully express his feelings about the loss. Her account of her husband's feelings are best captured in this statement: "I don't know exactly how *[husband]* feels, I know a little bit about it, but not much, because I get to speak everything out, but he's not, no one asks him how he feels".

Following the loss, many participants used emotional distancing in interactions with others. While some participants tried to deny the reality of the situation, others intentionally avoided anticipated painful questions or comments. Despite this, some women expected others to reach out and acknowledge their

grief. When this did not happen, some felt frustration and uncertainty in relation to what they wanted from others. Accounts of interactions with others indicated that many family members and friends were uncomfortable in confronting the loss. Without exception, the women in this study had their losses acknowledged and were comforted more by those who had experienced a similar loss. Further, being able to offer comfort and support to others experiencing a perinatal loss was seen a positive outcome of a tragic experience. Interactions with health care providers, for the most part, were positive and supportive. However, several participants commented on the lack of support for fathers.

Dealing with the Loss

Throughout the interviews each participant described coping mechanisms that were used in dealing with the loss over time. The women worked through their grief by doing such things as crying, talking, writing, listening to sad music, reflecting on mementos of the baby, spending time with young children, and reading about pregnancy loss. For one participant, writing letters to her stillborn son helped her deal with her grief. She commented thus:

That was one thing that I found really helpful for me was to be able to write things down and to say, I miss you [*baby*]. I can't hold you in my arms right now and I want to be able to hold you right now. I feel so alone and I'm upset and nobody is knowing how I'm feeling right now. That helped me a tremendous amount.

Another participant described how spending time with other children helped her deal with the loss. Her feelings were reflected in the following statements:

You have to learn to cope with it. All the love I got for children I'll give it to other children I see around. I always got the neighbour's child. She's always over plus my sister just had a little baby, that helped. Going in and watching her born the baby was good.

In addition to spending time with other children, some participants perceived that having other children of their own made dealing with the loss easier. Focusing on other children was seen as positive and helpful.

Participants reflected on the significance of having another child at home: "I think the biggest help was having *[son]*, having him here. That was the biggest thing knowing, I did, we did have *[son]*"; "I still have a life here with *[daughter]*, that was easier for us, knowing that we had *[daughter]* to be here, to be strong for her. I had to make life normal for her".

Several participants commented on the importance of having mementos of the baby. Reflecting on these helped the women deal with their loss and grief. The significance of mementos were conveyed in the following statements: "I found that things were really good at the hospital, I mean even pictures, I got the pictures of the baby and stuff like that and the blanket that she was in and everything"; "Even when I went through my stages of crying, I'd go up and get my little box with all my things and look through it. For me, that was everything".

One woman described how she initially did not want to have pictures of her stillborn son. She felt that she did not want to have reminders of the baby that had died. She described how she reacted to a nurse informing her that her baby would be photographed:

I thought, Oh God, how mortifying. . .please don't take pictures. . .we're going to have a package ready for you to take home and all I kept thinking is oh my God I can't have nothing to remind me of this baby. I don't want anything, but then when it finally happened and we left the hospital, I wouldn't have left without it. . . .When we left the following day, it was extremely important for me and the picture was very important to have.

She commented further on how she felt about the picture of the baby when she was at home:

I don't know if I want to go in and look at the pictures of the baby but I know in time when I feel that I can I will do that. It was a lot of apprehension to have that picture and that I looked at it once and then said, "I'm going to put it away and I'm not going to look at it again". I knew that [*husband*] was going back constantly looking at the picture and I thought I can't do that. I'm not ready. . .when I actually looked at it I felt okay. That was a little baby true to life. That was our baby.

Several participants spoke of the importance of seeing the baby after the loss. One woman who had experienced an early pregnancy loss perceived that seeing the baby validated the pregnancy and baby. She described how she felt at the time:

They [*nurses*] cleaned the baby up and they brought it to me. They took little footprints and measured it and put a little hat on it and everything that I needed. If not, it would have just been something that happened and it would have been unbelievable cause it took me so long to get pregnant. .

. .Yes, brought closure cause I always would have wondered what the baby looked like. Was it a boy? Was it a girl?

Another participant echoed a similar sentiment in relation to her relatives seeing and holding the baby. She commented: "I'm glad they [*relatives*] got the chance to see her, even though she wasn't alive when they held her. I'm glad they got the chance to see her". Conversely, another woman described how she was initially unsure if she wanted to hold the baby despite being encouraged to do so. Her feelings were best reflected in this passage:

I don't know what I wanted to do but I was glad that he [*husband*] was so sure of everything that he wanted to do. That gave me the strength to hold him [*baby*] and to love him. . .that was really something I needed to do.

Hope of having a successful pregnancy in the future was reported by some as a means of dealing with their immediate loss. Focusing on having a subsequent pregnancy and healthy baby was seen as a way of facilitating the grieving process. Participants commented:

If I had been told that I could never have any more [*children*] I don't know how I would deal with it. I think I would be really, really devastated. But knowing that I'm just hanging on to some hope, that's what's getting me through.

I'm going to be able to get through this. This feels really, really hopeful that tomorrow is going to bring me something better. Something is going to happen, and the reassurance for me was I'm going to have another baby. That's all I kept believing in.

Another participant who did not expect to get pregnant again noted the significance of hope as well. She became tearful when she spoke of the difficulties she had experienced in trying to conceive. She commented that having hope for a future pregnancy would have enabled her to cope more effectively with the current loss: "If I could say well, I'm going to get pregnant again now, it's only a matter of time. That would have helped ease the pain". Not having a child or hope for a future child made the participant feel that she was different from others who have perinatal losses. Her experience was seen as "more traumatic" and, in addition to coping with the pregnancy losses, she was trying to accept that she will never have any children.

The women in this study were able to deal with their loss in an individualized manner using various coping mechanisms. While some participants found similar things helpful, others described ways of dealing with loss that were unique to them. Writing, focusing on other children, seeing the baby, reflecting on mementos, and having hope enabled the participants to confront and deal with perinatal loss.

Living With Emotional Uncertainty: Gentle Reminders

Perinatal loss challenges one's resources and coping mechanisms and forces individuals to view life with new perspectives and uncertainties.

Throughout the interviews participants made reference to the theme of living with emotional uncertainty. Uncertainty is defined as the state of being uncertain or doubtful. Synonyms include doubt, concern, and distrust. When applied to those who have experienced a perinatal loss, grieving women face many uncertainties in relation to their coping abilities, grief resolution, and future life experiences.

Many of the participants were uncertain as to whether they were strong enough to endure the loss. The women's descriptions echoed a struggle to control emotional upheavals with the passage of time. One woman stated:

It's always going to be there. It gets a little bit easier after awhile, knowing that you have to deal with it but, I don't know. I guess when you first lose the child you have more bad days than good, but now it's the opposite. So yes, it does get easier but when you have a bad day it don't feel any easier.

Forced to deal with the emotional pain of the loss, many of the women felt uncertain about whether they would ever completely be able to resolve their grief. Participants verbalized uncertainty about how they would respond when confronting situations which precipitated emotional outbursts. Comments made by one participant illustrate how emotionally labile she felt:

I ran into a girl Christmas and she went through the same thing. I was fine when I met her, when I left the store I screeched until I got home.

When she walked in the door I was fine, like it's emotions that you got no control over and you don't know if they're going to come out or you're just

going to be okay. . .it hits you at certain moments and there are moments when you're okay with it.

Another participant described having similar feelings:

I cannot handle it but at other times, I deal with it. . . .Some days I can get through it and I'm fine. I don't even think about the baby but then there's other days I get up and as soon as I get up I know it's going to be a bad day because she's [*baby*] just on my mind constantly all day.

These encounters served as reminders of the loss thus "bringing it all back" validating the fact that grief is a process with "good and bad days". Two of the participants described their emotions as a "roller coaster". One of them conveyed her feelings in the following manner: "I'd be fine for one minute and then all of a sudden a couple of hours later I would cry and cry and cry". Coping with grief became part of everyday living in the aftermath of perinatal loss. The following passage illustrates this point: "It is definitely the same pain. . . .You know you have to cope with it. You have no other choice. It's not going to go away so you might as well make the best of it".

Not knowing when emotional upheavals would occur generated feelings of uncertainty. For the most part, the women expected and accepted this. A couple of participants commented on how they came to accept the unexpected: "I'm not going to get depressed over this. . .I'm going to have some good days and I'm going to have bad days"; "I don't know how to explain it emotionally. I

think it's something that I'm going to have to live with. At times it just hits you. I'm just going to have to learn to live with it".

Although not unexpected, another woman described how certain dates reminded her of the loss, in particular her due date, Christmas, and the anniversary date of her loss. Good Friday was also significant to this woman because, prior to the loss, she participated in supportive demonstrations against abortions on this day. She commented thus: "It was Good Friday that this flood of memories came back and this feeling of loss, this empty feeling". On these dates the participant reported thinking about her baby and the significance of specific events and occasions. Even though these meaningful dates can be anticipated, confrontations with grief can still occur.

Besides certain dates, various other situations, serving as painful reminders of the loss, forced participants to confront their feelings of grief. The participants' accounts of these reminders illustrate this point:

Christmas morning seeing *[son]* open all his gifts and knowing his little sister should have been there. . .and then going out shopping for toys. Seeing little girls' dresses and little girls everything and nothing for a little boy. . . Well, the worst, oh God, the day. . . I got. . . in the mail. . . a little spoon from Gerber. . . that was just when I was supposed to have her *[baby]*. . . Brought it all back nice and fresh.

I tell you what bothers me even today is just seeing commercials on TV like advertising pregnancy tests and just when I see babies on TV and people saying this is the best thing that ever happened to me when they have a baby.

I came home that day and there was no belly and I was having milk and I don't have a baby. All these reminders that are constant reminders or immediate reminders that I lost a baby, really cruel reminders.

Seeing others pregnant and with babies served as reminders of the loss as well. While many found it difficult to see others pregnant, responses to these situations were individualized. One participant commented thus: "Seeing other people pregnant, especially my friends, even now that bothers me". Another woman described how she forced herself to be around co-workers who were pregnant even though it bothered her.

I pushed myself to make me feel their stomachs, feel their baby's kicks and do it all. I did not want to walk into a room and people say here she comes, don't talk about her baby or don't talk that she's pregnant. I wanted things to be open so I tried not to be upset about things, but I know inside it bothered me.

Conversely, another participant described how she did not want to go to work and see her co-workers pregnant. She felt a mixture of bitterness and guilt towards others who were pregnant. Her account of how she felt was best reflected in this passage:

I didn't want to go to work but I had to. I kind of shut myself. . .off. I did become very bitter and I felt guilty because I felt like I'm supposed to be happy for these people but really I'm not.

For the most part, the participants seemed to be coping with the uncertainty associated with grieving. Most seemed to acknowledge that grieving

is a process that requires time and acceptance. Living with grief and its unpredictable nature seemed to be woven into the participants' daily life experiences. Even though one can anticipate and prepare for difficult situations, feelings of grief can surface at any time. This is captured in the following statement: "When somebody brings it up to me when I'm not expecting it, that is when it hits you, when you're least expecting it and somebody says something".

Feelings of uncertainty and fear also surfaced when participants commented on future pregnancies and losses: "It makes me a little more neurotic the second time around with your pregnancy"; "The only thing that's changed is that through this pregnancy we've been very cautious, very scared". One participant spoke of her desire to get pregnant shortly after the loss even though she experienced fear of another loss. She felt that if she didn't get pregnant right away she might lose her courage to do so in the future. Her feelings were conveyed in this statement:

If I didn't get pregnant right away I'm going to lose my courage to get pregnant again. This *[loss]* could happen again. I kept saying to *[husband]* we have to try again. I know he was frightened to death but if we didn't get pregnant right away, I'm not sure that we would have. If we had waited I think the fear would have been too great. . . .I was feeling a little anxious about getting pregnant.

Another woman, who wanted to get pregnant again, echoed similar feelings:

"We're really reluctant. I'm really afraid. I've been putting things off. . . .Fear of

another loss". Yet another, who was pregnant at the time of the interview, verbalized how previous losses brought uncertainty to her current pregnancy:

We couldn't enjoy things. We couldn't go to Sears and look at cribs and cradles and high chairs and dream about names and things like that. It's only now that we are and we're still very, very cautious about things, even with baby names.

For another woman who was pregnant, uncertainty and fear of another loss influenced her daily routines and activities. She reported a significant change in lifestyle in response to first trimester bleeding in a subsequent pregnancy. She took precautions that were perceived as safe behaviours that could positively influence the outcome of her pregnancy: "I gave up smoking, that's one precaution I took. I don't lift [son]. I gave up working in this pregnancy. I gave up everything. I don't do anything and for nine months I'm not going to do anything".

The emotional uncertainty associated with loss and grief was evident in the participants' accounts of their lived experience with perinatal loss. At times, participants were confronted with grief unexpectedly while at other times, encounters with grief could be anticipated. Uncertainty surfaced as participants were reminded of their experience and the unpredictable nature of loss and grief. Uncertainty and fear were also evident when participants spoke about subsequent pregnancies and potential losses.

Letting Go and Moving On

For the most part, the participants in this study eventually “let go” of their central focus on the loss experience and “moved on” to a place where other aspects of their lives became central and dominant. That is, with time, the women were able to integrate the loss into their everyday lives and regain a sense of normalcy.

Without exception, women’s thoughts about their grief resolution were often woven into their comments. Even though most were coping well with grief, many reported that the loss experience would never be completely forgotten. Participants commented: “I don’t think I’ll ever forget it”; It’s always going to be there”. For one woman, not forgetting about the loss was perceived as positive and something that she never wanted to do. When others would ask her why she kept a picture of the baby on her dresser and question why she didn’t put it away and forget about it, she would respond:

No, I don’t want to, I never want to forget it *[loss]*. I always want to remember it and I want to remember how I felt. Those constant reminders are good for me.

Given that each woman differed with regards to the length of time since the loss, most seemed to be at different points of grief resolution. While some participants felt that they had worked through the grief, others had not reached

this point. Thoughts about “letting go” and “moving on” were captured in these passages:

I've worked through it, I have, I've worked through it. . . .It's just something you have to work through yourself. . . .I guess knowing that you have someone who's supporting you too, your husband, but time I think and working through it myself has been what's got me through.

I think I'm through it as much as I'm going to get through it and. . .there's no way of ever getting through it and getting over it. It will always be there and hopefully by talking about it, it's going to help other people. But you'll never get through it, never. No matter, like 50 years down the road, the hurt will be the same.

I could be wrong, it may be easier I don't know. The pain could be easier but I think the memories will always be there.

I have worked through some things and brought some resolution and some closure. But it will never leave you girl, never leave you. There will be certain reminders. . .it will bring you back to that same day.

She [*baby*] was a part of my life and always will be a part of my life and I will always remember it was a child that I never saw. We did conceive, so I do think about it, I do, I still mourn it. . . .You know it will always be there. It is easier with time, but it will always be there.

One participant, who experienced two early pregnancy losses and continues to struggle with infertility, indicated that she has much further to go in resolving her losses. Although she perceives that she has made significant progress in her grieving, she has not been able to accept her loss and face a future without children. Accepting the reality of not being able to conceive again and “letting go” of her previous losses has been challenging. Her continued

struggle and a life without children have led her to question the meaning and purpose of her life: "It's a terrible way to live to feel like this all the time. It's like you don't have an interest in anything. You don't really care, like what's the purpose"? Until she is able to find meaning in her experiences, accepting the reality of her situation and moving on with life may be difficult.

In moving on with their lives, women's perspectives of pregnancy, life events, relationships, and loss appear to have been significantly changed by their encounters with perinatal loss. A theme underlying these changed perspectives is "not taking anything for granted". Some felt that they had taken their pregnancy and the ability to have children for granted. Participants stated:

Oh, I don't take things for granted anymore. I really don't. I mean, I thought that I'd have a child no problem, like everybody. You look at everybody, the people that you'd least think would have a child are having them left, right, and center and here you are. I never, ever thought I'd have a problem having a baby.

I always felt, like every little girl, you grow up to get married and have children. I thought that's the way my life would be. I just thought when you wanted to get pregnant you got pregnant.

I took it for granted. I know I did. I'll never take anything for granted anymore and it's unfortunate that this had to happen to me. . .an awful lot of people take being able to have children safely for granted.

Other participants echoed this shift in perspectives as well. One woman spoke of how the loss had changed her perspective on relationships with her daughter and others. She described herself as having a "true different appreciation" for

her daughter since the loss. She commented thus: "This is bringing us all closer together and deepening relationships overall. Not just *[husband]* and I but with *[husband]*, *[daughter]*, and I and everybody and even Mom".

Other participants also felt that the loss experience had impacted relationships with their husbands. Several women perceived that the loss facilitated a closer marital relationship: "We're really close, we've gotten really close, it's unbelievable that the past two, three years probably the closest we've been"; "Our relationship is after getting better"; "We came out much stronger for it". One participant elaborated on the possible impact of perinatal loss on a marital relationship:

I can see how it can make or break a couple. If nothing else it pulled us closer together. . . .I think that if you were unsteady before this happened, I can see that definitely splintering a relationship. I can see this festering into something very major, but we didn't.

One participant described how the loss negatively affected the relationship with her husband. Differences in communication patterns following the loss led to many confrontations and a near breakdown of their relationship: "Like we came to almost splitting up, it got so bad". However, at the present time, this woman reports that their relationship has improved. Both the participant and her husband were aware of the significance of the problem and sought appropriate counselling.

A changed sense of appreciation for what one already has was evident in the comments of some of the women. One participant described how the loss made her realize that you have to make the best of what you have in life.

It [*loss*] makes you appreciate what you have a lot more. . . you got to appreciate what you got and say I'm lucky to have this and make the best of what I got. If you didn't go through it you take a lot of things for granted.

Another woman echoed a similar sentiment in relation to the important things in life:

Life is just too important to be rushed in and out. You really got to take time to care about people and be with people and tell them how much you love them. That's all the things that really helped me deal with it.

Furthermore, the loss experience appears to have left many of the participants with an increased sense of vulnerability, not only in terms of pregnancy losses but to other losses as well. For one woman, the experience triggered recognition of the ups and downs of life as well as an opportunity for learning and growth.

I think it's good for people to go through something like that because then you learn that life is not always smooth sailing, like everything was supposed to go smooth. I mean there's things that go bad and it's not the material things that should be important to you.

For the most part, the women in this study have "let go" of focusing on the loss and regained a sense of normalcy in their lives. Even though the perinatal loss will never be forgotten, most participants seem to be working through their

grief in a positive manner. The women have acknowledged the pain of grief and accepted that memories of the loss will always be there.

The Essence

Through formal, unstructured interviews, participants reflected upon and described their lived experiences with perinatal loss. The themes that emerged from the data presented by participants were: shattering of hopes and dreams, centrality of the loss, shared grieving: identifying and accepting differing coping styles, dealing with others, dealing with the loss, living with emotional uncertainty: gentle reminders, and letting go and moving on. Having identified the various themes that emerged from the data, the researcher turned to the question: What was the one unifying feature of this particular experience? The researcher identified the essence of this experience as searching for meaningful integration.

Each woman anticipated a positive pregnancy outcome and birth of a healthy baby. Even the women who were surprised by the pregnancy welcomed the idea of giving birth. In particular, those who had difficulty conceiving responded to the event with joy and confidence in being able to get pregnant. The prenatal period was filled with hopes and dreams for the anticipated baby. Further, the happiness associated with the expected birth of a baby was shared

with partners, family, friends, and others in the social world. However, because of its suddenness and poignancy, perinatal loss resulted in a shattering of hopes and dreams for a baby that would never be. Feelings of grief emerged as women responded to the loss with shock, denial, disbelief, anger, and self-blame. The sudden encounter with loss and grief forced women to commence their search with integrating perinatal loss into their daily and future lives.

In the aftermath of perinatal loss the women focused on the loss in search of meaning and a deeper understanding. Dwelling on the experience led the women to search for a cause and question why the loss had happened to them. For many, this led to the emergence of self-blame and guilt. As well, a central focus on the loss resulted in the need to tell and retell their stories of perinatal loss. Telling others about their experiences enabled the women to validate their loss and deal with being suspended between expectant motherhood and the emotional instability of grief.

Given that perinatal loss was shared with husbands, the women's search for meaning was intricately woven within shared grieving and coping. While the women acknowledged the presence of their husband's grieving, living with perinatal loss forced them to identify and accept that men can deal with grief differently. For the most part, the women were accepting of these differences. However, their husbands' less expressive grieving style was distressing and

isolating for some women. Those couples that were able to share feelings of grief, peaceful moments, and emotional turmoil coped with their loss more positively.

In the daily struggle to find meaning in perinatal loss, the women developed an acute awareness of the response to loss from those around them. Those that displayed coping styles different from the women's were immediately recognized and remembered. All indications of support and acknowledgement from others were welcomed and cherished and in turn, helped the women cope with loss and grief. Conversely, failing to acknowledge the loss was a source of anxiety and frustration. Messages from others, perceived as unhelpful, were a particular source of distress for some women as it indicated a failure in recognizing the grief that can follow perinatal loss. Such messages did little to acknowledge the real pain of the loss and the meaning of the experience.

In coming to terms with sudden loss, the women were able to find coping mechanisms that facilitated grief resolution. While some worked through the grief similarly, others displayed unique coping styles. Memories of seeing the baby and having tangible mementos brought comfort and guided the women in their continual search for stability in a world shaken by loss and grief. Some focused on other children at home while others clung to the hope of having a

successful future pregnancy. These diverse ways of coping reflected individuality in confronting a loss that was devastating and shattering.

Recognizing that feelings of grief do not simply cease, day to day living brought uncertainty and a struggle to control emotional upheavals. When consumed by grief, the women were uncertain as to whether they would be able to endure the loss and regain a semblance of normalcy in their lives. The women reflected on numerous reminders of the loss that would often bring on waves of emotion. While these reminders were difficult at times, they also offered reassurance that the loss would never be forgotten. A consensus that memories of the loss would always be there was not distressing. In fact, many women intentionally created memories and adapted well to living in a world impacted by perinatal loss. For one, accepting the reality of the loss led to diminished self-worth and feelings of failure as a woman.

In integrating perinatal loss into their daily lives, women looked to the future with a degree of uncertainty and changed perspectives. Those that did become pregnant lived with uncertainty and fear that the pregnancy would end in a shattering of hopes and dreams again. In letting go and moving on, the women identified how the experience of perinatal loss had resulted in creating new perspectives on life and loss. Dealing with the loss forced the women to view life events differently and "not to take anything for granted". For most, there

was an awareness the experience presented an opportunity for learning and as well, an ability to help others who are also touched by perinatal loss.

Women who encounter perinatal loss are often faced with a sudden, unexpected loss that is painful and shattering. The loss symbolizes an abrupt end to hopes and dreams for an anticipated baby and forces them to find meaning in their experiences. The loss, which often results in grief, is coped with in the context of relationships with others. Those women who accept and receive unconditional recognition of their grief deal with the loss more positively thus enabling them to find meaning and move on to other aspects of their lives. Everyday living following loss brings emotional upheaval, uncertainties, and challenges for the women and others in their lived worlds. For the participants in this study, all of whom had experienced a perinatal loss, searching for meaningful integration was the single common thread that made this experience what it was.

CHAPTER 5

Discussion

This chapter discusses study findings in relation to the literature on the experience of perinatal loss. As would be expected in a phenomenological approach to research, the participants' experiences of perinatal loss were influenced by other aspects of their lived world.

Discussion of Themes in Relation to the Literature

While this study's findings provide new insights into the experience of perinatal loss, certain components of the themes augment clinical and research findings presented in the literature. In the text that follows, each theme and the essence will be discussed separately.

Shattering of Hopes and Dreams

This theme described how the loss had shattered the participant's hopes and dreams for the anticipated child. A number of authors have documented the loss of hopes and dreams that parents feel when they experience a perinatal loss (Brown, 1993; Conway, 1995; Hutti, 1992; Kirkley-Best & Killner, 1982; Robertson & Kavanaugh, 1998). The unexpected nature of the loss contributed to the sudden shattering of a life that would never be.

Despite the gestational age of the baby, all of the participants in this study experienced feelings of grief following their loss. Similar findings have been reported by other researchers (Kennell et al., 1970; Leppert & Pahlka, 1984; Neugebauer et al., 1992; Peppers & Knapp, 1980; Smith & Borgers, 1988). Hutti (1992) noted that while most women grieve following perinatal loss, some do not. In the current study, participants experienced feelings of denial, shock, disbelief, anger, and self-blame.

Several participants in this study denied warning signs of an impending loss and failed to seek health care promptly. Bansen and Stevens (1992) noted this response under the "miscarriage event" category in which women denied the meaning of their symptoms and subsequently delayed seeking health care. Similar findings of denial or failure to acknowledge the imminency of the loss were reported by Kavanaugh (1997).

Searching for a cause of the loss led to feelings of self-blame for many participants. Several participants questioned whether specific activities (e.g., smoking, lifting of another child, sexual intercourse, dancing, etc.) had precipitated the loss. Attributing perinatal loss to various individual and lifestyle factors has been reported by others (Bansen & Stevens, 1992; Dunn et al., 1991; Gilbert, 1989; Leppert & Pahlka, 1984; Malacrida, 1997).

Only one participant experienced feelings of failure as a woman, depression and diminished self-esteem. Feelings of depression (Beutel et al., 1996; Conway, 1995; LaRoche et al., 1984; Murray & Callan, 1988; Neugebauer et al., 1992; Nicol et al., 1986; Zeanah et al., 1993), failure as a woman (Herz, 1984; Kowalski, 1980) and diminished self-esteem (Brost & Kenney, 1992; Brown, 1993; Herz, 1984; Murray & Callan, 1988; Rajan, 1994) have been reported in the literature.

Centrality of the Loss

This theme captured the ways that participants responded immediately following the loss and their perceptions of how others should respond. Participants dwelled upon the circumstances of the loss and wanted their loss to be a focus for others as well. The women felt the need to tell and retell their stories. Talking about their experience validated the loss and helped them deal with their grief. The need to talk about perinatal loss has been supported by others (Stierman, 1987; Wallerstedt & Higgins, 1996).

Recognition of the loss was important to the participants in this study. The importance of recognition following perinatal loss has been documented in the literature (Swanson, 1991; Swanson-Kauffman, 1986). For those who had experienced a miscarriage, acknowledgment of their loss by others was

perceived as less likely. Not being able to see the physical changes associated with pregnancy may lead to a lack of recognition and acknowledgment. Frost and Condon (1996) suggested that miscarriage may be considered a non-event because the baby is not viewed as a real person.

Shared Grieving: Identifying and Accepting Differing Coping Styles

Perinatal loss was an experience shared by participants and their husbands. This theme reflected participants' accounts of shared loss and grief in the context of their marital relationship. Following the loss, participants identified ways in which they and their husbands were coping with and expressing grief differently. Participants' perceptions that "men handle grief differently" (e.g., less expressive, return to work earlier, etc.) is supported in the literature. Peppers and Knapp (1980) first documented "incongruent grieving" between men and women. In comparison to women, men are reported to grieve less intensely (Benfield et al., 1978; Beutel et al., 1996; Cecil, 1994; Goldbach et al., 1991; Hughes & Page-Lieberman, 1989; Lang & Gottlieb, 1993; Miron & Chapman, 1994; Murphy, 1998; Smith & Borgers, 1988; Theut et al., 1989) and for a shorter period of time (Cecil, 1994; Hughes & Page-Lieberman, 1989; Miron & Chapman, 1994; Murphy, 1998). Further, men are less expressive about the loss (Beutel et al., 1996; Benfield et al., 1978; Cecil, 1994; Feeley & Gottlieb,

1989; Gilbert, 1989; Hughes & Page-Lieberman, 1989; Kavanaugh, 1997; Rajan, 1994) and immerse themselves in their work (Beutel et al., 1996; Forrest et al., 1982) more so than their partners.

Most participants were accepting of their husband's differing coping styles, a finding supported by Gilbert (1989). However, this was distressing for two participants in the current study. Feelings of isolation emerged when women were unable to openly express to their husbands and receive support that was needed. Cecil (1994) and Rajan (1994) reported similar findings. Cecil (1994) reported that support from partners ended before women were ready to manage without it.

Dealing with Others

This theme captured participants' accounts of interactions with family, friends, others in their social world, and health care providers. Many participants distanced themselves from others immediately following the loss. While some tried to deny the reality of the loss event, other participants withdrew from their social world to avoid painful questions or comments from others. Refraining from contact to avoid painful remarks or others' uneasiness with perinatal loss was reported by de Montigny et al. (1999).

Similarly, the majority of participants perceived that others avoided them when they were not comfortable in confronting the loss. At times, this led to feelings of isolation and frustration. It seems that, even though some participants were deliberately avoiding others, they did not want others to avoid them. The women wanted others to recognize and acknowledge their loss and grief. Feelings of avoidance and abandonment have been reported by other researchers who investigated parents' experiences with perinatal loss (Bansen & Stevens, 1992; Cecil, 1994; de Montigny et al., 1999; Herz, 1984; Leppert & Pahlka, 1984; Lovell, 1983; Rajan, 1994; Stierman, 1987).

Having to endure and deal with unhelpful remarks from others was a finding in this study that has been consistently documented in the literature (Bansen & Stevens, 1992; de Montigny et al., 1999; Kavanaugh, 1997; Smith & Borgers, 1988; Stierman, 1987; Swanson-Kauffman, 1986). Comments that failed to recognize the significance of the loss or reflected a lack of understanding were distressing for participants. Conversely, participants reported that other people did not know what to say to them. While some would avoid participants and say nothing at all, others would simply say, "I'm sorry". Failing to say anything is supported by the findings of Rajan (1994) and Cecil (1994) who found that others did not know what to say to bereaved parents.

One participant in Rajan's study reported that saying "I'm sorry" was better than silence and avoidance.

Being able to share feelings with others who had a similar loss was highlighted in this study. Other women who had experienced a perinatal loss were perceived as being able to understand participants' experiences. Similar findings have been reported by other researchers (Cecil, 1994; Kavanaugh, 1997; Rajan, 1994; Tudehope et al., 1986). In turn, because of the experience of perinatal loss, participants in the current study reported being able to assist others who experience loss. This was perceived as a positive outcome of a tragic experience.

Interactions with health care providers, for the most part, were supportive and comforting. Nurses were perceived as "being there" and helpful to women and their families. Swanson-Kauffman (1986) identified the importance of "being with" as part of her Caring Theory. Supportive interactions with health care providers have been reported by others (Bansen & Stevens, 1992; de Montigny et al., 1999; Forrest et al., 1982; Hutti et al., 1998; Kavanaugh, 1997; Lemmer, 1991; Madden, 1994; Malacrida, 1997; Rajan, 1994; Swanson-Kauffman, 1986). However, unhelpful interactions with health care providers are reported in the literature (Benfield et al., 1978; de Montigny et al., 1999; Forrest et al., 1982; Kavanaugh, 1997; Lemmer, 1991; Lovell, 1983; Malacrida, 1997; Rajan, 1994)

and in the present study. Murray and Callan (1988) reported that a consistent predictor of better adjustment following perinatal loss is the parent's level of satisfaction with support and comfort received from health care providers.

Another consistent finding in this study was the women's perceived lack of support for their husbands. The participants felt as if they were the focus of caregiving efforts and support. Often, the men's feelings of loss and grief were not acknowledged. A lack of recognition and support for fathers has been reported by de Montigny et al. (1999), Hughes & Page-Lieberman (1989), and Murphy (1998).

Dealing with the Loss

Within this theme, the participants reflected on coping mechanisms that helped them deal with their loss. For the most part, each woman was able to find meaningful ways that facilitated daily living with grief (e.g., crying, talking about loss, reading about perinatal loss, writing to baby, listening to sad music, spending time with other children, etc.). Bansen and Stevens (1992) reported similar findings with the women in their study processing their grief through crying, talking, spending time with young children, and reading about pregnancy loss. In dealing with the loss, this study's findings support the importance of having personal mementos of the baby. Numerous other authors noted the

significance of mementos following perinatal loss (Brown, 1993; Costello et al., 1993; Davis, Stewart & Harmon, 1988; Kavanaugh, 1997; Lemmer, 1991; Robinson, Baker & Nackerud, 1997; Stierman, 1987). Lemmer (1991) suggested that nurses provide mementos that will facilitate the creation of memories.

Hope for a successful future pregnancy also played a role in enabling participants to cope. While some participants embraced hope for a future pregnancy, one participant felt that she would have coped more effectively if she had hope for conceiving again. Swanson-Kauffman (1986) noted the significance of “maintaining belief” for enhancing women’s ability to get through the loss and ultimately have a successful pregnancy.

Living with Emotional Uncertainty: Gentle Reminders

This theme captures women's day to day living with the emotional uncertainty of loss and grief. Some participants were uncertain as to whether they were strong enough to endure the loss and resolve their grief. Bansen and Stevens (1992) noted a similar finding, with women questioning whether they would ever recover completely. Swanson-Kauffman's (1986) “getting through it” also has comparable issues of emotional uncertainty following loss.

Participants' comments reflected difficulty with situations, events and dates that served as reminders of the loss and forced them to confront grief. Not knowing when encounters with grief would occur or how they would react led to uncertainty as well. Similarly, Bansen and Stevens (1992) report that women in their study told stories of how they were forced to deal with painful situations and feelings while encountering pregnant women, mothers with children, or maternity clothing stores.

When participants considered another pregnancy, uncertainty and fear emerged and persisted throughout a subsequent pregnancy. Fear of another loss brought uncertainty and diminished joy to a new pregnancy. The impact of a previous loss on a subsequent pregnancy has been supported in other studies, especially regarding heightened anxiety and uncertainty (Bansen & Stevens, 1992; Côté-Arsenault & Mahlangu, 1999; Cuisinier, Janssen, de Graauw, Bakker & Hoogduin, 1996; Franche & Mikail, 1999; Hutti et al., 1998; Theut et al., 1989).

Letting Go and Moving On

This theme captured women's reflections of moving on with life while adjusting to living with loss and grief. The women reflected on changes brought about by perinatal loss. Participants felt that their loss experience would never be forgotten and would always be there. Never forgetting the loss was perceived

as positive and comforting. Similar findings have been reported in the literature (Hebert, 1998; Peppers & Knapp, 1980). Peppers and Knapp (1980) and Bansen and Stevens (1992) findings indicated that women may never completely resolve their grief following perinatal loss.

Several participants commented that the loss had changed their perspectives on life, relationships, and future pregnancies. Bansen and Stevens (1992) documented that perinatal loss alters women's perspectives. These researchers found that following miscarriage women reported an increased sense of vulnerability, awareness of their own mortality, recognition of possible future pregnancy losses, and enhanced appreciation for life. In the current study, women recognized the difficult experiences that life can bring and an increased sense of appreciation for what one already has. The experience also made participants feel vulnerable to future losses.

As described by many women in this study, experiencing perinatal loss facilitated a closer marital relationship. Other researchers (Forrest et al., 1982; Gilbert, 1989; Hughes & Page-Lieberman, 1989) have documented this finding. Gilbert (1989) noted that the majority of couples perceived perinatal loss as having a positive effect on their marriage. Couples discovered that they could survive a tragic event and, in many cases, become closer. In the current study, only one participant felt that the loss had negatively impacted her marital

relationship, a finding also supported by Gilbert (1989) and Hughes and Page-Lieberman (1989). Similarly, three couples in Forrest et al's. (1982) study separated following perinatal loss.

The Essence

The essence of this experience was identified as searching for meaningful integration. The theme of searching for meaning is supported in the literature on the experience of perinatal loss (Brost & Kenney, 1992; Dunn et al., 1991; Kavanaugh, 1997; Swanson-Kauffman, 1986). Swanson-Kauffman noted that when loss and grief occurs, individuals may find that what previously had meaning for them may suddenly be rendered useless. Further, following human loss there is a tendency to find and maintain a structure of meaning in life that makes sense to the individual. In the "knowing" category of Swanson-Kauffman's study, reference is made to the importance of understanding an event in terms of its meaningfulness for the other.

Kavanaugh's (1997) study finding that parents need to "assign meaning to a loss" is supported by the essence. According to Kavanaugh, part of "making the adjustment at home" was being able to assign meaning to the loss. Searching for meaningful integration would necessitate those individuals to assign meaning to their life experiences.

Brost and Kenney (1992) suggested that the goal of health care professionals, in providing care to parents during a subsequent pregnancy following loss, is to assist them to integrate a previous loss into their lives. However, Swanson-Kauffman (1986) suggested that, in maintaining belief, the goal is not to give meaning to another's life but to enable another to choose a path in life that is filled with meaning.

CHAPTER 6

Limitations, Nursing Implications and Summary

The issues around providing support to women and families who experience perinatal loss have received increasing attention by care providers over the years. Providing support necessitates an approach that considers the diversity and individuality of women's experiences. This chapter begins by outlining the limitations of the current study. This is followed by a discussion on the implications for nurses in practice, research and education, and concludes with a brief summary of the study.

Limitations

Although it is not the intent of phenomenology to generalize results to the larger population, it must be noted that participants in this study did not represent all the attributes of women experiencing perinatal loss. Perinatal loss can happen during any pregnancy and is not limited to specific groups of childbearing women. The experience of perinatal loss from the perspective of adolescents, single women, women with psychiatric illness, and women who have had losses from a multiple gestation pregnancy were not included in this study. The experience of women of other cultural backgrounds, in particular

aboriginal women, was not represented. It is possible that these women would express the lived experience of perinatal loss differently.

In phenomenological research, the notion of credibility of the findings is enhanced by the selection of participants. Participants must be able to clearly articulate their lived experiences in order to provide rich data. Consequently, study participants tend to be the most articulate, accessible or high status members of their group – a problem which Sandelowski (1986) refers to as “elite bias” (p. 32). Because study participants were fairly well educated and involved in a Perinatal Bereavement Program, they were possibly more articulate and reflective than women with less education or not involved in a program of support.

Implications

The findings of this study have provided insight into the lived experience of perinatal loss and highlighted the role of care providers in supporting women in their search for meaningful integration of their loss experience. A significant implication for all care providers is the need to be aware that the context of the lived world is of primary importance in understanding another's experience. In this study, mothers' stories of loss were used to uncover and articulate meanings or “essences” of their experience.

Nursing Practice

This study has highlighted the significance of discovering meaning in mothers' experience of perinatal loss and a greater depth of understanding. Nurses must assess a woman's response to perinatal loss because, while some women may grieve intensely, others may not exhibit a grief reaction (Brown, 1993). Assessing a woman's perception of the event could enable nurses to respond to her individual needs (Cote-Arsenault & Mahlangu, 1999; Hutti, 1992; Wheeler, 1994) in a caring and meaningful way. Prior to perinatal loss, women of childbearing age may have minimal experience with loss and grief. Therefore, nurses can play a significant role in assisting women to cope with grief effectively, a role that is clearly supported in the literature. Given that some women may be unable to assert themselves in the aftermath of perinatal loss, nurses may need to serve as advocates in providing information and support.

This study has revealed the significance of "being there" with women and families who experience loss and grief. Nurses should presence themselves emotionally with bereaved women in facilitating open expressions of grief. Acknowledging the loss event validates a woman's grief and affirms that her experience is worthy of recognition (Costello, Gardner & Merenstein, 1993). In recognizing the loss event, participants identified mementos as valuable and

helpful. Tangible memories can validate a baby's existence (Robinson, Baker & Nackerud, 1998) and be a source of comfort and support. Nurses can identify and offer mementos that provide women with cherished memories and the affirmation of their baby's existence and death (Costello, Gardner & Merenstein, 1993; Davis, Stewart & Harmon, 1988; Lemmer, 1991). Nurses can also facilitate grieving by supporting women in creating memories that have unique meaning and significance for them.

Nurses also need to be cognizant that women and men may respond to grief differently. Helping each partner to identify and understand differences in grief expression is an important aspect of care (Beutel et al., 1996).

Furthermore, care providers can support bereaved women and their partners by helping them cope with their individual grief responses, as well as those of their partner (Lang & Gottlieb, 1993). While open communication between partners should be fostered and supported, nurses should encourage partners to be accepting of any differences in grieving responses (e.g., less expressive of feelings, different coping styles, etc.).

Many women in the current study perceived that health care providers did not support their husbands. Including fathers in all aspects of support, information sharing, and decision making is of crucial importance. Recognizing that perinatal loss is an experience shared by both partners can facilitate shared

grieving and coping. The literature identifies that men often feel obligated to be the woman's supporter following perinatal loss. While this may be a significant role for men, they too need to have their loss and grief acknowledged and supported.

Health care providers need to be aware of how others may respond to women who experience perinatal loss. The current study and the literature identified responses from others that were considered unhelpful and unsupportive. Increasing women's awareness that others may make trite comments or avoid acknowledgement of the loss may assist women in coping with the words and actions of others. Care providers must ensure that they do not trivialize or avoid women's experiences with perinatal loss.

This study has shown the importance of looking beyond the first impressions and taking the time to gain understanding of the client's lived world. Asking about the lived world of perinatal loss and listening to each woman's experiences can reveal much about the challenges faced. Clients would benefit from being given the time to facilitate this type of caring interaction. This in turn may uncover issues that could be mutually addressed by the nurse and client, or alternatively, a supportive relationship may help the woman find meaning in her experiences.

Nursing Research

Based on the present investigation, a number of suggestions can be made for future research in the area of perinatal loss. To begin with, additional qualitative investigations into the lived experience of perinatal loss, using participants from various cultural and socio-economic groups are needed to determine if others express similar lived experiences. Also, the lived experience of loss from the perspective of adolescents, single women, and women who have experienced loss from a multiple gestation pregnancy need to be investigated qualitatively. In addition, replication of this study, or a study of this population using a grounded theory or another qualitative approach would augment the present study's findings.

Qualitative studies are needed on the impact of a subsequent pregnancy following perinatal loss. Research is needed to explore ways in which care providers can support women throughout a pregnancy following loss. Research is also needed to identify the most effective role for nurses in facilitating positive outcomes. The concept of "being there" surfaced as an important aspect of providing care following perinatal loss. Given that the literature supports the role of health care providers in assisting grieving couples, research focusing on the care providers' attitudes and perceptions of perinatal loss is necessary. Very few studies have included health care providers in their samples.

Nursing Education

Nursing educators have the responsibility to educate their students about the significance of perinatal loss. Developers of maternal-child courses in basic nursing degree programs should ensure content is included to address the physical and psychological impacts of perinatal loss. Nursing education curricula should be reflective of the supportive, facilitative, and informative roles that nurses can fulfill in caring for clients who have experienced perinatal loss. Nursing students need to be taught nursing actions that are evidence based and attentive to women's individuality and diversity.

Students must develop sound assessment and listening skills in connecting with clients. Educators should also stress the importance of the therapeutic use of self in a caring relationship with clients in facilitating the grieving and healing process. In doing so, nursing students need to understand and be comfortable with their own perceptions of death and grief. Students should also be aware of the role of partners, family, friends, and caregivers in the successful integration of perinatal loss into women's lives.

Continuing education instructors and professional practice coordinators in women's health courses should ensure periodic seminars focusing on research based nursing interventions for perinatal loss. As research reveals new insights

into this phenomenon, these insights need to be communicated to practitioners in that area. This information is also important for practitioners working in emergency departments, as this area is often the point of entry to the health care system when a sudden, unanticipated pregnancy complication occurs.

Summary

This phenomenological study on the lived experience of perinatal loss used van Manen's (1990) method to explore the question: What is the meaning of perinatal loss for women who have experienced a miscarriage or stillbirth? From the data collected in an unstructured interview with eight participants, seven themes were identified as: shattering of hopes and dreams; centrality of the loss; shared grieving: identifying and accepting differing coping styles; dealing with others; dealing with the loss; living with emotional uncertainty: gentle reminders; and letting go and moving on. From the themes, the essence of the lived world of women experiencing perinatal loss was seen as **searching for meaningful integration**.

The findings were discussed in light of the current body of knowledge on the experience of perinatal loss. Implications for nursing practice, research and education were presented, as well as the limitations of the study.

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Appendices

Appendix A: Consent Form

School of Nursing, Memorial University of Newfoundland
St. John's, Newfoundland

CONSENT TO PARTICIPATE IN NURSING RESEARCH

TITLE: The Meaning of Perinatal Loss for Women in Newfoundland: A Phenomenological Study

INVESTIGATOR: Kathy E. Parrell, R.N.,B.N. 745-1231

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or withdraw from the study at any time.

Confidentiality of information concerning subjects will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Purpose of the Study: The purpose of the study is to grasp a deeper understanding of the meaning of perinatal loss. This information may help caregivers provide more appropriate care to women experiencing perinatal losses.

Description of Procedures: You are being asked to participate in two interviews which will be conducted at a time and setting of your choosing. Interviews will be audiotaped (with your permission). During the first interview you will be asked to reflect upon your experience with a perinatal loss and share any thoughts, feelings or ideas that you recall about this event. The researcher may inquire further about the sequence of events occurring prior to the loss, your reactions to the loss, and what you found most and least helpful. During the second interview you will be asked to read a written summary of the major themes to confirm that this description adequately reflects your experience.

Duration of Participation: Each interview will last approximately 60 to 90 minutes. Both interviews should be completed within a two to three month period.

Foreseeable Risks, Discomforts or Inconveniences: There are no expected risks from participating in this study. It is possible that certain interview questions may elicit uncomfortable memories. You may refuse to answer any questions which make you **feel uncomfortable (e.g., disturbing memories or events)**, and ask to terminate the interview at any time. The investigator will refer you back to your assigned **perinatal bereavement counsellor** if she determines that you could benefit from additional counselling services. All information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the principal investigator. Your name will not appear on the audiotape or written copy.

Benefits: You will have the opportunity to express feelings and emotions with an interested listener. Although you may not benefit directly from this study, your participation may help provide nurses and other health care professionals with knowledge necessary to care for others who experience a perinatal loss.

Other Information: Findings of this study will be available to you and health care professionals upon request. Findings may be published, but you will not be identified. The investigator will be available during the study at all times should you have any problems or questions about the study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I, _____, the undersigned, agree to my participation in the research study described.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

(Signature of Participant)

(Date)

(Signature of Witness)

(Date)

I, _____, the undersigned, agree to be audiotaped during each interview.

(Signature of Participant)

(Date)

(Signature of Witness)

(Date)

To be signed by investigator:

To the best of my ability I have fully explained to the subject the nature of this research study. I have invited questions and provided answers. I believe that the subject fully understands the implications and voluntary nature of the study.

(Signature of Investigator)

(Date)

Phone Number

Appendix B: Interview Schedule

Interview Schedule

Participants will be introduced to the interview with the following dialogue:

I am interested in your experiences in coping with a perinatal loss. You can share any thoughts, feelings, and ideas you have regarding your experience. I would like for you to take some time to reflect upon your experience and tell me in your own words what the loss means to you. You are free to talk about whatever comes to mind.

Examples of Probes / Questions to Facilitate the Interview

1. Could you tell me about your perinatal loss and the circumstances surrounding the loss?
2. Thinking back to when you experienced the loss, could you identify what was most difficult for you at that time?
3. What did you find most helpful in coping with the loss? (Specific areas to probe, if not mentioned: reactions from immediate social support system; how were they supportive).
4. What did you find least helpful?
5. In terms of health care providers, what did you find most and least helpful in coping with the loss?
6. Did you find it difficult to talk to others about the loss (e.g., partner/spouse, friends, family, etc.)?
7. In terms of your relationship with your spouse/partner, have you noticed any changes since the loss? If so, could you talk a little about these changes (e.g., improvements / difficulties, etc.)?
8. Reflecting on how you feel today, is it still difficult for you to talk about the loss or do you feel that you have worked through it?
9. Are there any other thoughts or comments that you would like to share with me about your experience of perinatal loss?

**Appendix C: Letter of Approval from the Human Investigation Committee
(HIC) Memorial University of Newfoundland**



Memorial

University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

12 June 1996

Reference #96.83

Ms. Kathy Parrell
4 Conran Street
St. John's, NF
A1E 5G8

Dear Ms. Parrell:

This will acknowledge receipt of your correspondence dated June 10, 1996, wherein you clarify issues and provide a revised consent form for the research application entitled "The Meaning of Perinatal Loss for Women in Newfoundland: A Phenomenological Study".

I have reviewed the information provided and examined the revised consent form and am recommending full approval of the application. This decision will be ratified by the full Human Investigation Committee at a meeting scheduled for June 20, 1996.

We take this opportunity to wish you every success with your research study.

Sincerely yours,

H.B. Youngusband, Ph.D.
Chairman
Human Investigation Committee

cc Dr. K.M.W. Keough, Vice-President, Research
Dr. Eric Parsons, Vice-President, Medical Services, HCC
Dr. C. Way, Supervisor

**Appendix D: Letter to Perinatal Bereavement Advisory Committee,
Health Care Corporation of St. John's**

4 Conran Street
St. John's, NF
A1E 5G8

May 6, 1996

Mrs. Roma Quinton
Chairperson, Perinatal Bereavement Advisory Committee
Grace Hospital Site, Health Care Corporation of St. John's
241 LeMarchant Road
St. John's, NF
A1E 1P9

Dear Mrs. Quinton:

I am a registered nurse who is a candidate for the Master's Degree in Nursing. I am conducting research for my thesis on the experiences of women who have had perinatal losses. I have enclosed a brief summary of this study for your information.

I am seeking permission for a member of the Perinatal Bereavement Advisory Committee to make initial contact with women who have experienced a perinatal loss during the past eight to twelve months. If the woman agrees, I will contact her by telephone to obtain a verbal consent to participate in the study and arrange a date and time for an interview. Written consent will be obtained at the time of the interview.

I would be happy to meet with you to discuss this further. Thank you for your consideration of this request.

Sincerely,

Kathy E. Parrell, R.N., B.N.

**Appendix E: Letter of Support from Perinatal Bereavement Advisory
Committee, Health Care Corporation of St. John's**

Grace General Hospital
241 LeMarchant Road
St. John's, NF
A1E 1P9

Mrs. K. Parrell
4 Conran Street
St. John's, NF
A1E 5G8

Dear Mrs. Parrell:

Your letter of request and summary of the proposed study have been reviewed by committee members. The committee agrees to facilitate research in this area by making initial contact with potential participants for the proposed study.

Sincerely,

Roma Quinton



