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Pregnancy Loss Support Groups: A Comparison of Therapeutic Factors for Men and Women

Leslie Williams Beitch

PREGNANCY LOSS SUPPORT GROUPS:

A COMPARISON OF THERAPEUTIC

FACTORS FOR MEN AND WOMEN

Leslie Williams Beitch, B.S.

An Abstract Presented to the Faculty of the Graduate School of Lindenwood College in Partial Fulfillment of the Requirements for the Degree of Master of Art.

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ABSTRACT

Parents who experience a miscarriage, stillbirth, or newborn death often find themselves feeling profound grief with limited support or understanding from the community. Support groups for this population have emerged and gained in popularity throughout the country. This research will focus on specifically on the miscarriage, stillbirth, and newborn death experience and how the support group can meet these parents needs.

Parents attending SHARE pregnancy loss support groups participated in the study. Questionnaires were given to SHARE group leaders from all regions of the United States to distribute at their meetings. Fourteen men and twenty women completed questionnaires anonymously that supplied demographic characteristics and information on their pregnancy loss history. A 17 item instrument was constructed to measure the perceived therapeutic factors of participation in the support group. The participants were then asked to choose the top three group functions and to rank them.

The support received from meeting others with similar losses, sharing stories, and the expression and acceptance of feelings were the most highly rated group functions for men and women. The educational components were least valued. A significant gender difference for preference was found for only one group function.

Women rated; Finding out that others feel as I do, "I'm not crazy" as more significant than did men.

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Dedication

To my husband and children for their great patience and support.

To all the bereaved parents, their babies, and the National SHARE organization.

TABLE OF CONTENTS

LIST OF TABLES

Chapter 1

Introduction

Perinatal death is a tragedy that occurs with greater frequency than most individuals or helping professionals are aware. This group of parents is often ignored by the therapeutic and medical community due to a lack of awareness by many professionals of the special grief issues related to this loss. The term perinatal death is used in the literature to refer to miscarriages, stillbirths, newborn death, Sudden Infant Death Syndrome and any death occurring before the first birthday. It is estimated that these factors represent over a million perinatal losses a year (Smith & Borgers, 1984) . This research will focus specifically on the miscarriage, stillbirth, and newborn death experience and how the support group can meet these parents needs.

To deal with the special grief issues of these parents support groups have developed throughout the country. Compassionate Friends is for bereaved parents who have had a child of any age die. SHARE and RESOLVE THROUGH SHARING are two groups that deal with the grief of parents experiencing miscarriage, stillbirth, or newborn death. These groups have expanded rapidly since the early 1980's due to increased awareness of the need to openly discuss grief issues for these parents.

Grief issues had not received attention as significant mental health issues until the 1960's. Elizabeth Kubler-Ross's work with the dying

received international attention and the publication of Omega: Journal of Death and Dying began. Groups for the bereaved began receiving professional attention in the mid 1970's and since the 1980's there has been an increase in the professional literature of articles focusing on these bereavement group issues (Zimpfer, 1991) . There has, however, been a lack of research focusing on the therapeutic factors of bereavement group participation for parents experiencing miscarriage, stillbirth, or newborn death. Their grief and support issues have some unique qualities. Society and the literature have particularly ignored the father, his grief issues and his needs within the grief support group. It is hoped that this research may provide useful insight into these areas.

CHAPTER II

LITERATURE REVIEW

GRIEF SUPPORT GROUPS

Groups that provide mutual help for participants are a growing phenomena in the mental health field. They are of particular significance for the bereaved because they create community, emphasize interaction and growth, and place the locus of control on the individual (Klass & Shinners, 1984-85). Groups have become the recommended treatment of choice for dealing with grief issues.

The support group is a community of people in which the open expression of grief is accepted. It is often a relief for the mourner to let down the false cheerfulness the world demands of one to share a range of feelings without fear of judgment. For many, this is their only outlet for these feelings. By recognizing that others experience similar feelings that are a part of the human condition it reduces the fear that one is abnormal or "going crazy". This connection with other bereaved people decreases feelings of isolation and helps one feel that dealing with death is a human experience shared by all (Schwab, 1986) .

Groups for the bereaved differ from traditional psychotherapy groups. They generally can be classified as either self-help groups or as support groups but even these distinctions are not always clear. In self-help groups the members assume primary responsibility for the organization, functioning, and leadership of the group (Gazda, 1989) . They emphasize

help through mutual support whether it is in a group setting or over the telephone. They do not charge for their services and are self supporting and not dependent on outside funding. Many of these self-help groups have national chapters that establish clear guidelines on the functioning of the group and the role of the professional. They may also have a national newsletter and referral network. The leader of the self-help group is generally someone who has experienced the same loss as the members and is not a professional therapist.

Support groups provide a form of self-help to the bereaved but differ in leadership. They are often organized by professionals under the auspices of an institution such as a hospital, funeral home, church or synagogue. This leader is a professional group leader who takes responsibility for the group process. The meetings may be structured with an educational component included (Schwab, 1986). The term support group will be used in this paper to refer to groups structured in the self-help and support group philosophy due to the great deal of overlap in these group functions.

Parents grieving the loss of their baby through miscarriage, stillbirth, or newborn death often find the support group particularly beneficial due to the lack of social support they may feel. In a study of twenty women who gave birth to a stillborn baby, Stringham, Riley, and Ross (1982) concluded that many of these parents are grieving in isolation and experiencing profound loneliness. They feel their grief is not sanctioned by society and often hear messages such as "You'll have another baby," or "You never held him" from well meaning family and friends. The grief support group

provides parents an opportunity to express feelings in an accepting atmosphere, to realize their grief reaction is not abnormal, to meet others resolving a similar loss, and to eventually increase their self-esteem by helping new members (Stringham, Riley, and Ross, 1982) .

From Klass' (1984-85) work with bereaved parents in Compassionate Friends, he found that affiliation has:

> a cathetic dimension that entails a sense of unity with those whose lives have also been shattered, a sense of hope at seeing that others have made it, a sense of finding an appropriate object on which to attach the energy formerly given to the child, and a sense of family in a supportive community. Second, affiliation has an experiential dimension that is an attempt to develop an existential stance in a problematic world based on shared solutions to concrete problems (p.372).

In DeFrain's (1991) research with families experiencing perinatal death he identifies reaching out for help as one of the most important variables in grief resolution. He views the grief support group as a powerful tool, particularly if it has leadership from both a bereaved parent and a professional family therapist.

MISCARRIAGE

Miscarriage, or the medical term *spontaneous abortion* , refers to the termination of a pregnancy by natural causes before twenty weeks of pregnancy. It is difficult to obtain accurate statistics on the incidence of miscarriage because states do not require these records to be kept and most miscarriages occur during the first three months of pregnancy, sometimes before a pregnancy is confirmed by medical exam. It is estimated that 20% to 30% of all confirmed pregnancies end in miscarriage. In addition, the incidence of miscarriage is increased following infertility. Sometimes the miscarriage is related to the conditions that originally caused the infertility (Isle & Burns, 1985) .

The emotions that accompany miscarriage can range from severe grief to disappointment. Research conducted by Limbo and Wheeler (1986) found that 75 % of the women experiencing a miscarriage grieved while the other 25 % considered it just another life experience. There are many factors that contribute to how the loss is experienced. Some of these are whether the pregnancy was desired, whether there are other children, the length of time it took to conceive, and whether there have been previous pregnancy losses (Friedman & Goldstein, 1992) .

A common reaction to miscarriage is a continual questioning of how it may have happened and resulting feelings of guilt and blame. The woman may scrutinize everything she may have done that could have contributed to the miscarriage. Ambivalence about pregnancy is very common and if

miscarriage occurs there is often a strong feeling of guilt for having these ambivalent feelings (Borg & Lasker, 1988) .

Husbands may become the target for the wife's anger and blame. She often perceives that he does not have the same feelings of attachment and sadness that she has. Generally, the husband feels powerless and his need to be supportive and strong is misunderstood by the woman as not caring (Worden, 1991). The husband may focus on the next pregnancy and push to conceive again as soon as possible as a way to deal with his helplessness. The wife may need a period of rest and grieving and may not find the husband's view to be helpful (Worden).

Parents who experience the miscarriage as a terrible event and have deep feelings of grief are often hurt by family and friends who give them messages that they should not be feeling so sad (Limbo & Wheeler, 1986). These parents often appreciate the validation of their feelings that they receive from the support group members.

STILLBIRTH

A stillbirth is the death of a baby between the twentieth week of pregnancy and birth. Most often the pregnancy is normal until it is noticed that there are no fetal movements, bleeding occurs, or labor starts. There is one stillbirth for every eighty live births in the United States (Friedman & Grandstein, 1992) .

"A stillborn baby is born into an atmosphere of silence and is mourned by parents who often find that the silence continues long after the birth itself" (Stringham, Riley, Ross 1982, p. 322) . The parents often feel intense grief but find that few people are able to share this with them. When the death is acknowledged it is often not with the same respect as other deaths. Since others cannot see the attachment between parent and child before birth the parent's grief is often viewed as abnormal (Kirkley Best & Kellner, 1982) .

The emotions of anger and guilt are normal components of grieving but are particularly pronounced for parents of stillbirths. The guilt can be overwhelming as the mother scrutinizes every aspect of her pregnancy looking for causes of the stillbirth. The anger and guilt lead to a search for blame. The mother may blame herself, may blame God, the doctor, or blame her husband. This anger and blame are often intensified by the fact that in most stillbirths (70%) there is no cause of death identified (Kirkley Best & Kellner, 1982) .

Hospital protocol for handling stillbirths has changed dramatically over the past twenty years. Previously, mothers had been anesthetized and not given the opportunity to see or hold their baby. There is now almost universal agreement that parents need to see and hold their baby to realize the death has occurred, to be parents for a moment, and to say hello and good-bye (Kirkley Best & Van Devere, 1986) . In addition, they are frequently given pictures, a memory book, a lock of hair, and a blanket. The parents are offered emotional support from the nurses, hospital

chaplain, and social worker and more frequently support groups are available.

NEWBORN DEATH

The infant that lives hours, days, or months but dies in the hospital creates a special set of experiences for the parents that complicates grieving. The parents must deal with medical technology, possibly the transfer of the baby to another medical center, and the possibility of making difficult decisions about continued medical care. Their emotions may range between hope and despair as they deal with the realities of their infant's problems. The birth often leaves the parents feeling exhausted with little energy to deal with the difficulties to come.

Infant death is most commonly caused by prematurity, brain damage due to the lack of oxygen before or during birth, and congenital abnormalities (Borg & Lasker, 1988). Prematurity and low birth weight remain the leading causes of infant death. Although there have been great strides in medical techniques for premature neonates their inability to retain heat and their underdeveloped lungs continue to complicate attempts to save them (Borg & Lasker).

Parents have a need to be with their baby, but this may be difficult due to the intensive care that many of these babies require. Touching and holding of the baby is very important for the parents to establish a bond.

They need to feel like a family, to "parent" their baby regardless of the seriousness of the condition (Limbo & Wheeler, 1986).

If the baby is transferred to another medical facility it further complicates the difficulties in providing for these parenting needs. Some of these births are medical emergencies that necessitate that the mother receive extensive medical care in a different facility than the infant. In this situation, the father often feels pulled between his wife and his baby as he tries to take care of both. The mother aches to see and hold her baby and may not be able to do so before the death.

Parents may be faced with difficult decisions about stopping heroic medical procedures for a very ill infant. They often must deal with a variety of medical specialists, tests, and procedures that leave them feeling overwhelmed and confused. After the infant's death the parents may question their decision and wonder what life would have been if they had made another choice (Borg & Lasker, 1988). For some, this questioning becomes unrelenting guilt that complicates grief resolution

Borg and Lasker (1988) report that all the parents they interviewed talked of their depression and preoccupation with the events around their infant's birth and death.

> One mother said: It takes a long time before these feelings are no longer a part of every day or even every hour. I always picture in my mind that tiny baby, crying in the nursery, fighting to live. But I can

> think of her now without so much pain and feel glad that she was part of our family at least for a little while (p. 85).

Multiple births increase the chances of premature delivery. When one twin dies and the other lives the parents experience conflicting feelings of grief and joy. "Love and grief; reminders of life and death occur simultaneously every day, almost every minute (Limbo & Wheeler 1986, p.58). Parents find themselves torn between these conflicting emotions. Friends and family often do not understand these varied feelings. They may ignore the baby that died and respond in hurtful ways with advise such as "You're lucky you have one" (Limbo & Wheeler 1986, p. 59). Many of these parents find understanding in the pregnancy loss support group and through a national multiple birth loss support network.

GENDER DIFFERENCES IN GRIEF

A miscarriage, stillbirth, or newborn death creates strain in the marriage as nonparallel grief patterns often occur between husband and wife. This often creates a breakdown in communications. The mother has a "biologic-tactile experience of the baby" while the father's attachment is primarily cognitive. This creates a different experience with the pregnancy loss for each parent (Kirkley Best & Van Devere, 1986) . In research conducted by Theut, Pedersen, Zaslow, Cain, Rabinovich, and Morihisa

(1989) on parental bereavement, they found that in perinatal loss mothers grieved more than fathers. They looked at psychodynamic literature on attachment formation during pregnancy for understanding of differences in male and female experiences. The mother's experience is that of the baby being part of her body and part of herself. At birth, she incorporates the baby more into her mental representation. The father's experience with the baby is always more of the mental self. They conclude that due to these differing experiences of attachment the resulting bereavement is different (Theut et al, 1989).

Although the grief experience for men and women may not be precisely the same, most fathers have deep sadness and often do not receive the emotional support from others that their wife may receive. Rather, they are often asked "how is your wife doing?" (Lister & Lovell, 1991) . Often a man must return to the public eye very soon, he typically has the responsibility of contacting family and friends, making funeral arrangements, and returning to work before dealing with his own feelings of grief. He may immerse himself into his work as a way of coping. His lack of open mourning is misunderstood as a lack of feelings or indifference (Scully, 1985).

Starting in childhood boys are given messages that it is a sign of weakness to express sadness and that real men do not cry. When faced with a tragic loss as an adult, the man "finds himself stuck in his cocoon of loneliness, pain, and sadness" (Scully 1985, p.99) . Society expects the man to assume the role in the family of protector and provider. He experiences

conflict between the tendency to grieve according to his traditional role as family protector versus responding to his own emotional experience (Tedeschi & Hamilton, 1991).

Men often focus on dealing with problems. When he is unable to take care of the situation, to protect his child and make his wife feel better, he is often left feeling out of control. Due to his role as protector, he may need to put his own feelings of grief on hold to support his wife and children in their process (Schatz, 1984). It may be difficult for the man to watch his wife grieve so deeply. He may fear that he is losing her emotionally and that she may never get better. He may feel like a failure because he is not handling this situation, he is unable to keep her from these states of despair.

Research on the effects of gestational age and gender on grief after pregnancy loss concluded that the gender differences in the grief response were initially different with mothers showing a greater bond to the unborn child than fathers. This lead to greater grief at the time of loss. However, after one to two years the reported grief scale scores converged with both parents showing similar levels of overall grief, difficulty coping, and despair (Goldbach, K., Dunn, D., Toedter, L., & Lasker, J., 1991). Women continued to show significantly more active grieving in this follow up period than did men. Researchers believed that grieving was more socially sanctioned for women. They concluded that women may cope better if able to express their grief, while men may not be as comfortable doing so and may need to develop more internalized coping methods (Golbach, et al).

In a longitudinal study by Bohannon (1990) on the grief responses of spouses following the death of a child, their research indicated differences in grieving intensity that was gender related. The husbands experienced lower levels of grief but higher levels of denial than did the wives. The fathers reported fewer types of emotional support and more isolation as time progressed. The study did not find any increase in divorce over time as a result of the child's death.

DeFrain, Martens, Stork, and Stork (1990-91) researched the psychological effects of a stillbirth on surviving family members. Their study concluded that men and women often appear to respond differently to the death of a baby but underneath their responses are very similar. Both husbands and wives took on the average of three years to regain their perceived level of personal happiness that they felt before the baby's death. Women had seriously considered suicide 28% of the time and men had 17% of the time during the period following the stillbirth. The researchers did not find a significant increase in divorce as a result of the stillbirth. The spouses seriously considering divorce were 9% of the mothers and 7% of the fathers. Those actually divorcing as a result of the baby's death were 1.5% of the mothers and 3% of the fathers.

In a study conducted by Feeley and Gottlieb (1988) on coping strategies for men and women following infant death, they found three significant differences out of fourteen total coping strategies. Mothers and fathers differed in their seeking social support, preoccupation, and escape avoidance. Mothers utilized all of these coping methods more than

fathers. Mothers were more likely to want to talk about the baby's death as a way of coping and sought social support more than fathers did. Freeley & Gottlieb noted that the parents who had similar coping styles and open communication were able to adapt better. Tedeshi and Hamilton (1991) reported that in their years of experience with grief support groups they have never been contacted by a man seeking help for himself. Rather they seek help for their spouse.

When a man attends a pregnancy loss support group it may be a threatening experience for him. It is difficult for a man to acknowledge his own dependency needs and seek assistance for himself. It is common for a man to come to the group for the stated purpose of supporting his wife. Thus, most grief support groups consist of eighty percent women (Wolfelt, 1990) .

The structure of the grief support group may inadvertently discourage male participation. The group norms of self-disclosure, emotional expression, and acknowledgment of an extended grieving process threaten the man's tendency to suppress these experiences (Tedeschi & Hamilton, 1991) . If a man cries at a support group meeting he may be so embarrassed that he does not return. Thus, many men are viewed by group leaders as poor group members due to their tendency to "disclose little, intellectualize, distract the group from emotionally laden material, and interrupt communication with jokes, pronouncements, and other attempts to lighten the atmosphere or play the role of caretaker rather than person in need" (Tedeschi & Hamilton 1991, p.27) .

In conclusion, it is apparent from the literature that the pregnancy loss support group has norms for participation that more closely match the mother's needs than those of the father. Men and women share many of the same feelings of grief but society's expectations often interfere with the expression of that grief.

PURPOSE OF THE STUDY

The purpose of this study is to focus on the miscarriage, stillbirth, and newborn death experience and how the support group can meet these parents needs. Of particular interest are any gender differences in these responses. A comparison of male and female responses will be made. It is hoped that the results will provide group leaders with information that will enable them to better meet the needs of both the mothers and fathers.

This study is set up to answer the following questions: (a) what do group members find most/least helpful about group participation? (b) Are there any gender related differences in the rating of support group functions?

CHAPTER III

METHOD

Subjects

The parents who participated in the research had experienced a miscarriage, stillbirth, or newborn death and had attended a SHARE support group. SHARE is an international organization offering support groups and information about perinatal death.

The 34 participants included 20 women and 14 men. The age range was 24-57 years with a mean of 36 years old and a mode of 34. The majority of the participants were married, 18 women (90%) and 14 (100%) men were married while 2 women (10%) were single. There were 17 Caucasian women (85%), 2 African American women (10%), and 1 Asian woman (5%). The male group consisted of 13 Caucasian (93%) and 1 African American participants (7%). The completed educational levels of both men and women ranged from a high school diploma to a J. D. Law Degree, the mode was a four year college degree. Refer to Table 1 for a description of the sample.

The types of pregnancy loss for the 34 participants were: 10 miscarriages (29%), 10 stillbirths (29%), and 6 newborn deaths (18%). There were 8 participants who experienced two types of loss, 3 (9%) experienced a miscarriage and newborn death, 4 (12%) experienced a miscarriage and stillbirth, and 1 (3%) experienced a stillbirth and newborn death. Of the 10 participants who had a miscarriage, 7 (70%) had more than one miscarriage ranging from 2 to 15 losses.

Almost half of the participants, 16 (48.5%), attended their first support group meeting within one month of their loss. Within 2-4 months after a loss, 8 (24.2%) first attended, 5-7 months after a loss 3 (9.1%) first attended, and after more than 8 months of a loss, 6 (18.2%) first attended. The length of attendance in a support group for participants was: 8 (24.2%) attended 0-5 months, 9 (27.3%) attended 6-12 months, 2 (6.1%) attended 13-24 months, and 14 (42.4%) attended more than two years. One participant did not respond to Question 9 or 10 regarding time after loss and length of participation. Refer to Table 2 for a summary of pregnancy loss data.

The majority of the respondents resided in St. Louis, Missouri (21). The remaining resided in the following states: Georgia (1), Florida (1), Oklahoma (4), New York (2), Arizona (2), Illinois (1), Colorado (1), Kansas (1).

The parents were volunteers who agreed to participate in the study after the pregnancy loss support group leader explained the stated purpose (to explore therapeutic values of group participation) and the procedure of completing the four page questionnaire. This researcher passed out questionnaires to the group in which she was a co-leader. All subjects were treated in accordance with the ethical standards of Research with Human Participants. The participants were assured of anonymity by the exclusion of identifying demographic information or identification of group affiliation.

Table 1

Description of Sample

n = 34

	n	%
Males	14	41%
Females	20	59%
Age		
20-25	2	5.9%
26-30	6	17.6%
31-35	10	29.4%
36-40	8	23.6%
41-45	5	14.7%
46 & Over	3	8.8%
Ethnic/Race		
African-American	3	8.8%
American-Indian	0	0%
Asian	1	3%
Caucasian	30	88.2%
Hispanic	0	0%
Education		
8-12 years (no degree)	0	0%
High-school Grad	7	20.6%
2 year college/trade school	8	23.5%
4 year college graduate	13	38.3%
RN/BSN Degree	3	8.8%
Masters/Doctoral Degree/JD	3	8.8%

Table 2

Pregnancy Loss Data

n = 34

	n	%
Miscarriage	10	29%
Stillbirth	10	29%
Newborn Death	6	18%
Miscarriage & Newborn Death	3	9%
Miscarriage & Stillbirth	4	12%
Stillbirth & Newborn Death	1	3%
Time After Loss Attending a Group		
0-1 Months	16	48.5%
2-4 Months	8	24.2%
5-7 Months	3	9.1%
More Than 8 Months	6	18.2%
(one response missing)		
Length of Attendance in a Group		
0-5 Months	8	24.2%
6-12 Months	9	27.3%
13-24 Months	2	6.1%
More Than 2 Years	14	42.4%
(one response missing)		

INSTRUMENT

There was no adequate instrument available to measure the variables under consideration. A 14 item questionnaire was constructed by this researcher to supply information about the parents demographic characteristics and information pertaining to their pregnancy loss. A 17 item instrument was developed to measure the importance of functions of a support group (see Appendix A) . These items were selected based on the literature (De Frain 1991), the personal experience of this researcher, and the recommendations of other support group leaders. These items were rated by participants on a five point Likert-type scale ranging from not significant to very significant. The participant was then asked to choose the three most significant group functions and to rank them first, second, and third.

PROCEDURE

The Director of the National Share Office headquartered in St. Louis reviewed the research proposal and questionnaire to approve the participation of Share group members in the study. This researcher passed out 10 questionnaires to the support group she co-leads at Christian Hospital in St. Louis. The National Share office distributed 10 questionnaires after a support group meeting at St. Josephs Hospital in St. Louis. The third Share support group in St. Louis held at St. Mary's Hospital distributed 8 surveys following a meeting. To gain nationwide representation 50 surveys were distributed to support group leaders from

New York, Oklahoma, Arizona, Illinois, South Dakota, and Kansas at a national Share conference held in St. Louis. The leaders were asked to distribute these in their groups for completion. Finally, six additional surveys were mailed, one each to group leaders in Colorado, Florida, Georgia, Maine, Pennsylvania, and California. Confidentiality was assured by omitting identifying information from the questionnaires and by having the participants complete the study at home and return it in the provided self addressed stamped envelope. There were a total of 84 surveys distributed and 34 questionnaires returned, which represented a 40% return rate.

CHAPTER IV

RESULTS

The responses contained on the 34 returned questionnaires are summarized by descriptive statistics for the demographic information, summarized in Tables 1, 2, 3, and 4 and are discussed in the method section. A chi-square analyses was used to evaluate any gender differences in the responses on the 17 item instrument which measured the level of significance of support group functions. The null hypotheses states that there is no difference between male and female responses for each group function.

The results for the 17 item group functions survey are presented in Table 4 for each function (A.-Q.) with the number of responses reported for each rating (1-5 Likert scale) along with the percentage of men or women this represents. The table also reports the number of respondents, and percent this represents, who ranked the function as first, second, or third. The chi-square result for each group function is also included in the table. Two of the male respondents failed to complete the group functions survey therefore there are a total of 32 responses for this section.

An analyses of the chi-square results for the 17 group functions showed a significant difference for only one function, P. Finding out that others feel as I do, "I'm not crazy". The null hypotheses was rejected and the conclusion was made that there was a significant gender difference for this function P. Women rated this more than moderately significant or very

significant 95% of the time compared to the men's response of 66.6% at these levels, χ^2 (df=1, n= 32) yield $\chi^2 = 4.53$, p< alpha .05. See Table 3 for the crosstabulation table.

Table 3

P. Finding out that others feel as I do, " I'm not crazy."

Count Expected value Residual	Male	Female	Row Total
1 - 3	4 1.87 2.13	1 3.12 -2.12	5 15.6%
4 - 5	8 10.1 -2.1	19 16.9 2.1	27 84.4%
Column Total	12 37.5%	20 62.5%	32 100%

1 df α.05 Critical Value 3.84

Ho = There is no relationship between gender and scores on group function P.

$\chi 2 = 4.53$

Reject Ho and state there is a gender difference

n = 32; two subjects did not respond to this portion

Table 4 -- Support Group Functions Survey Response

1 - not significant
2 - slightly significant
3 - moderately significant
4 - more than moderately significant
5 - very significant

A. Meeting others with similar losses and hearing their stories.

$\chi 2 = 1.75$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	None	None	1	1	10		2	2	1
%	None	None	8.3%	8.3%	83.4%		16%	16%	8%
Women	None	None	None	4	16		6	4	3
%	None	None	None	20%	80%		30%	20%	15%

n = 32 Two male responses are missing.

B. A place to share the full range of my feelings.

$\chi 2 = 1.278$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	1	2	3	6		1	2	1
%	none	8.3%	16.7%	25%	50%		8%	16%	8%
Women	none	none	2	2	16		2	5	1
%	none	none	10%	10%	80%		10%	25%	5%

n = 32 Two male responses are missing.

C. Learning about the grief process.

$\chi 2$ = .141	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	1	3	3	5		1	none	none
%	none	8.3%	25%	25%	41.7%		8.3%	none	none
Women	none	1	7	5	7		none	none	none
%	none	5%	35%	25%	35%		none	none	none

n = 32 Two male responses are missing.

D. Obtaining information about perinatal death.

$\chi 2$ = .037	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	1	7	2	2		none	none	none
%	none	8.3%	58.3%	16.7%	16.7%		none	none	none
Women	2	5	7	4	2		none	none	none
%	10%	25%	35%	20%	10%		none	none	none

n = 32 Two male responses are missing.

E. Gaining hope through the example of others.

$\chi 2$ = .141	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	1	3	2	6		none	1	none
%	none	8.3%	25%	16.7%	50%		none	8.3%	none
Women	none	3	5	3	9		none	1	1
%	none	15%	25%	15%	45%		none	5%	5%

n = 32 Two male responses are missing.

F. Helping other bereaved parents.

$\chi 2$ = .98	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	none	1	3	8		2	1	1
%	none	none	8.3%	25%	66.7%		16.7%	8.3%	8.3%
Women	none	none	4	3	13		1	none	6
%	none	none	20%	15%	65%		5%	none	30%

n = 32 Two male responses are missing.

G. Developing new friendships.

$\chi 2 = .19$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	1	1	3	4	3		none	none	none
%	8.3%	8.3%	25%	33.4%	25%		none	none	none
Women	1	3	6	6	4		none	none	none
%	5%	15%	30%	30%	20%		none	none	none

n = 32 Two male responses are missing.

H. Hearing Speakers.

$\chi 2 = .123$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	1	4	4	3	none		none	none	none
%	8.3%	33.3%	33.3%	25%	none		none	none	none
Women	5	4	7	3	1		none	none	none
%	25%	20%	35%	15%	5%		none	none	none

n = 32 Two male responses are missing.

I. A place to tell my story.

$\chi 2$ = .258	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	1	3	4	4		1	1	1
%	none	8.3%	25%	33.3%	33.3%		8.3%	8.3%	8.3%
Women	2	none	3	5	9		2	none	none
%	10%	none	15%	25%	45%		10%	none	none

n = 32 Two male responses are missing.

J. Support through a subsequent pregnancy or adoption.

$\chi 2$ = .075	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	3	1	2	2	4		none	1	2
%	25%	8.3%	16.7%	16.7%	33.3%		none	8.3%	16.7%
Women	5	1	5	4	5		none	none	1
%	25%	5%	25%	33.3%	25%		none	none	8.3%

n = 32 Two male responses are missing.

K. Group acceptance of my feelings without judgement.

$\chi 2 = 1.24$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	none	2	6	4		none	1	1
%	none	none	16.7%	50%	33.3%		none	8.3%	8.3%
Women	none	none	1	2	17		2	2	4
%	none	none	5%	10%	85%		10%	10%	20%

Two male responses are missing.

L. Understanding differences in male and female grief.

$\chi 2 = 2.176$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	none	1	6	5		1	2	2
%	none	none	8.3%	50%	41.7%		8.3%	16.7%	16.7%
Women	1	none	6	2	11		none	none	1
%	5%	none	30%	10%	55%		none	none	5%

n = 32 Two male responses are missing.

M. A place to remember my baby.

$\chi 2 = 1.47$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	1	1	2	4	4		3	1	none
%	8.3%	8.3%	16.7%	33.3%	33.3%		25%	8.3%	none
Women	none	none	3	4	13		5	1	1
%	none	none	15%	20%	65%		25%	5%	5%

n = 32 Two male responses are missing.

N. Help with practical solutions to problems.

$\chi 2 = .0097$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	4	4	3	1		none	none	none
%	none	33.3%	33.3%	25%	8.3%		none	none	none
Women	2	3	8	5	2		none	1	none
%	10%	15%	40%	20%	10%		none	5%	none

n = 32 Two male responses are missing.

O. Support through holidays, birthdays, anniversaries.

$\chi 2 = .234$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	1	2	3	2	4		none	none	none
%	8.3%	16.7%	25%	16.7%	33.3%		none	none	none
Women	1	3	4	5	7		none	none	none
%	5%	15%	20%	25%	35%		none	none	none

n = 32 Two male responses are missing.

P. Finding out that others feel as I do, "I'm not crazy."

$\chi 2 = 4.53$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	1	3	3	5		1	none	3
%	none	8.3%	25%	25%	41.6%		8.3%	none	25%
Women	none	none	1	4	15		2	6	1
%	none	none	5%	20%	75%		10%	30%	5%

n = 32 Two male responses are missing.

Q. Understanding the reactions of my friends and family.

$\chi 2 = .207$	1	2	3	4	5	Rank:	1st	2nd	3rd
Men	none	2	5	3	2		none	none	none
%	none	16.7%	41.6%	25%	16.7%		none	none	none
Women	3	1	6	4	6		none	none	none
%	15%	5%	30%	20%	30%		none	none	none

n = 32 Two male responses are missing.

The second and third pages of the survey included four questions which requested a written response. A summary of the responses to these questions follows.

Why did you first come to the support group?

The responses to this question centered on the need for emotional support that was lacking in the individual's life. Typical responses were:

(Woman) I felt the need to be with people who had been through what I had been through. I felt so alone, so isolated. I felt no one understood. Being able to talk with others who understand has been instrumental in my healing.

(Man) We had experienced a few miscarriages and it was both physically and emotionally draining us. Our friends and my parents were of no help at all. We felt as if we had no support at all except each other.

(Woman) I needed to be around understanding people. I needed to be around people that could understand "why after four weeks I hadn't got over it" (that was what my boss and a co-worker told me).

(Man) My wife and I were getting no help or support from others. We had no where else to go.

(Woman) To share our immense pain, to continue her memory, to validate our feelings of grief, be reassured that our confusion and shock was "normal", to be with others who knew what we were going through.

(Man) Needed to find others who had similar experiences to verify we were not going insane.

Do you attend with your spouse or significant other?

76.5% reported YES 23.5% reported NO

!00% of men attend with spouse 60% of women attend with spouse

Many of the responses centered on the differences in why men and women attend the support group. Typical responses were:

(Man) I first went in support of my wife.

(Woman) He always said it was because of me he attended but he always remembered the day of the meeting and seemed anxious to attend.

(Woman) He stayed home with our son. His grief was not as deep as mine.

(Woman) I have found it's true that men and women grieve differently.

(Man) I attended with her for both of our well being.

(Woman) It's our time with our daughter.

(Man) Husbands and wives experience loss differently and a SHARE meeting may be the only place where they can talk with others who feel like they do- highly recommend both spouses attend.

(Woman) My husband attended most every meeting that I attended. Even after he felt he no longer "needed" the group, he continued to attend to support me and help others.

What do you appreciate most about the support group experience?

Most of the responses reflected on the help received from the sharing of thoughts and feelings with others who understood. Typical responses were:

(Woman) The freedom to verbalize my very confusing and changing feelings about the death of my daughter and having the reassurance that how I'm feeling is "normal".

(Man) Being able to share your thoughts and feelings with others who understand your situation.

(Woman) They listen!

(Man) Suggestions given by others who have been there. Suggestions about Christmas, birthdays etc., and the chance to help other parents later.

(Woman) The support and understanding of others in the group. The knowing that they truly have experienced your grief.

(Man) Having a set time each month to "spend with our son". And seeing others progress through their grief.

(Woman) I appreciate being able to share all my feelings. Some you cannot say out loud every day. I know that no body will hold my feelings against me. Miscarriages are taken seriously where as in the every day world I do not feel they are.

(Man) Realizing there were other people whom had our same grief.

(Woman) To have others acknowledge the loss of my son and to acknowledge my pain and grief even though I didn't bring him home.

(Man) The realization that others had experienced similar tragedies and had lived.

(Man) Being able to relate to others who have had losses. Allows there to be a setting for the discussion and release of pain that our society doesn't offer any support for.

What do you dislike about the support group experience?

Many of these responses centered on the frequency of the meetings, a lack of men, group dynamics, and suggestions to leaders. Typical responses were:

(Man) Not enough men attend.

(Woman) They only meet once a month.

(Man) Sometimes the group is slow to warm up to outsiders. It seems like the group should designate one or 2 people to be welcomers. Possibly pull them aside before the meeting starts and talk with them briefly, then come back and introduce the person. Maybe the group could come up with some pamphlets to hand out at that time, and make sure that before the person leaves that the person has someones telephone number for contact purposes.

(Woman).....the meetings are not frequent enough (once a month) and the participants change each time so it's difficult to form a bond with others when the group changes so often.

(Man) When people monopolize the meetings and won't let others talk. The body language some people exhibit towards others.

(Woman) I dislike the uncomfortable feeling at the very beginning of the meeting when we're waiting for an "official" start to each meeting. I feel there could be more home follow-up with phone calls or a note from the leader when someone has had a particularly emotional meeting or if it's known that a significant date is coming soon.

(Man) Dislike the fact that the support group is needed in the first place because of society's inability to understand people in the grieving process.

(Man) Sometimes the groups are too large.

CHAPTER V

DISCUSSION

The study has examined data gathered from men and women who have experienced a perinatal death and who attend a support group. The purpose of the study was to focus specifically on the miscarriage, stillbirth, and newborn death experience and how the support group can meet these parents needs.

Women generally make up the majority of the group membership. It was theorized by this researcher that perhaps the support group was not meeting the needs of men and that men had different preferences for what was helpful in the group setting. However, this was not the result. When a chi-square analysis was done for the responses on each of the seventeen group functions there was only one group function that showed a significant gender difference; P. Finding out that others feel as I do, "I'm not crazy" (χ^2 =4.53). The ratings for all other group functions ranged from a very low (χ^2=.0097) for; N. Help with practical solutions to problems to (χ^2=2.176) for L. Understanding differences in male and female grief. Generally, there was very little difference in the ratings by the men and women.

There were four group functions that had an educational/ informational focus: C. Learning about the grief process; D. Obtaining information about perinatal death; H. Hearing speakers; N. Help with practical solutions to problems. These received the lowest number of very

significant ratings and were rarely chosen as ranking in the top three. Both men and women consistently rated these functions as having lower significance.

Of particular interest to group leaders is the response to hearing speakers which was surprisingly low. Women rated this not/slightly significant 45% of the time and men 41.6% of the time and no one ranked it in the top three. This was the lowest rating of all 17 group functions. This result suggests that there should not be an over reliance on speakers for group meeting time.

In a qualitative analysis on reactions to perinatal loss, Covington and Theut (1993) point out the need for grieving parents to receive both verbal and written information about the grieving process and perinatal death. The newly bereaved have difficulty retaining information and may need to have the same information communicated several times. The respondents to this survey did not rate this to be a primary function of the support group. Perhaps this need for information can be provided as an adjunct service by having a lending library within the group which provides articles, books, and resources on grief and perinatal loss.

Both men and women chose group function, A. Meeting others with similar losses and hearing their stories as the most important group function. All of the women respondents (20) rated this as more than moderately significant or very significant. At these levels, all but one man (11) agreed. This group function was chosen most frequently by women (65%) as ranking in the top three and it tied as top for men (44%) with L.

Understanding differences in male and female grief. Function E. Gaining hope through the example of others is related but was not as highly rated. It was ranked in the top three by only three respondents and 66.7% of men and 60% of women rated it as more than moderately to very significant. DeFrain (1991) reflects on the shared experience of grief with others who have had a similar loss as one of the most helpful aspects of support group experience.

> In support group discussions, however, people tend to find out soon that they are among friends: the group members have all felt guilt, fear, hysteria, anger, jealousy, depression.....the full range of emotions. This knowledge that 'we are all in the same boat' is very comforting to members and gives them the strength to carry on (p. 227).

The high male response to these group functions that relate to social support is contrary to the literature (Feeley & Gottlieb, 1988) that reports men as less likely than women to seek social support and more likely to handle their grief alone. It is possible that the men in the study appreciated the social support they received from the group once they became involved but would not have sought this help on their own. All of the men

attended the group with their spouse and many of the men responded that they initially attended the group to support their wife.

Many of the friendships formed in the group extend outside the meetings and help members cope between the monthly meetings. This group function; G. Developing new friendships was considered more than moderately/very significant for 50% of the women and 58.4% of the men. Group leaders can indirectly facilitate this by distributing a phone list of members names and numbers, by having a designated member call and check up on newcomers, and by occasionally planning outside social activities involving members and their families.

There were three group functions that focused on the expression and acceptance of feelings: B. A place to share the full range of my feelings; K. Group acceptance of my feelings without judgement; P. Finding out that others feel as I do, "I'm not crazy." These functions were rated very highly by both men and women and ranked in the top three consistently. Function B. was rated as more than moderately to very significant by 90% of the women and 75% of the men. It was ranked in the top three by 40% of the women and 32% of the men. Function K. was very highly rated at these levels, 95% for women and 83.3% for men. Women ranked it in the top three 40% of the time and men 16.6% of the time.

Group function P. Finding out that others feel as I do, "I'm not crazy" was the only item showing a significant difference in male and female responses, $\chi^2(1, N= 32) = 4.53$, $p< .05$. Women rated this as more than moderately to very significant 95% of the time compared to men's rating of 66.6%. Both men and women recognized this as one of the top three group functions at a rate of 45% for women and 33.3% for men. In a study by Defrain, Martens, Stork, & Stork (1990-91) they report that irrational thoughts and feelings of momentary "craziness" are common among bereaved parents. Mothers (65%) reported irrational thoughts at a higher rate than fathers (51%). This gender difference in the experience of irrational thoughts supports the findings of this research that shows women as rating support for these "crazy" thoughts and feelings as more significant. It is a common occurrence in the support group for a member to share "crazy" feelings and receive a response from others that says "yes, I was like that" which is therapeutic for both members (Klass & Shinners, 1982-83).

An important function of the support group is a place where parents can tell their stories over and over without anyone asking them why they are not over their grief yet (DeFrain, Martens, Stork, & Stork, 1990-91). Talking about their baby by name and reviewing the events of the birth and death help parents realize the loss and sort out what occurred (Condon, 1986). The respondents to this survey agree as shown in their responses to two of the survey functions that are related: M. A place to remember my

baby, and I. A place to tell my story. Function A. Meeting others with similar losses and hearing their stories which was the function most highly rated, overlaps. Men and women both ranked M. A place to remember my baby as the first most important group function 25% of the time. It was more than moderately to very significant to 66.6% of the men and 85% of the women. I. A place to tell my story was not ranked as highly but was rated more than moderately significant to very significant by 66.6% of men and 70% of the women.

One component of emotional healing within the group is when the helpee becomes the helper. The respondents to this survey agreed with this as shown in their response to; F. Helping other bereaved parents. This was rated as more than moderately to very significant by 91.7% of the men and 80% of the women. It was chosen as one of the three most important group functions by 33.3% of the men and 35% of the women. There was no significant gender difference in this response. It is important for the group leader to recognize this group function and to respectfully allow this process to unfold. Klass and Shinners (1982-83) warn professional group leaders to not be overly directive. The group should belong to the members with the professional providing the basic structure and organizational support.

Function L. Understanding differences in male and female grief was viewed more often by men to be important; 91.7% of men felt it was more than moderately to very significant compared to 65% of the women. This was not a statistically significant chi-square difference however. This was

also ranked in the top three by 41.7% of the men compared to only 5% of the women. It appears that men find this issue to be more relevant than do women (although not statistically significant). The reported high interest by men indicates that it would be helpful for the support group to regularly address this issue through open discussion, speakers, and occasional separate men's groups.

Responses to function J. Support through a subsequent pregnancy or adoption and function O. Support through holidays, birthdays, and anniversaries were not particularly high and fairly well spread out over the significance levels. Function O. received no ranking in the top three and J. was ranked by 3 men and 1 woman as most important.

It is a common theme in the support group for members to express their feelings that friends, family, co-workers do not understand their grief. Function Q. Understanding the reactions of my friends and family dealt with this issue. It was not highly rated, women rated it as more then moderately to very significant 50% of the time and men 41.7% of the time. No one ranked it in the top three.

The results of this survey have implications for the organization and focus of the grief support group for perinatal loss. It is indicated that both men and women highly value the emotional and social support received from meeting others with similar losses, the sharing of stories, the non judgmental acceptance of feelings, and eventually extending themselves to help the newly bereaved. There were much fewer differences in male and female responses than expected which indicates that their needs within the

group are similar. Both men and women placed much less value on educational components, perhaps the group can provide information as a supplemental service but not have it as the primary focus of the meetings.

Limitations of the Study

The generalizability of the study is limited by the predominance of a Midwest population, 62% are residents of St. Louis. The sample is 88% Caucasian with only 12% minority representation. Unfortunately, many of the support groups do not have racial or ethnic diversity so this representation is difficult to obtain. It is possible that the preferences for therapeutic group functions could vary in other regions or within other racial/ethnic groups. It is also regrettable that more women (20) participated than did men (14). This researcher had more difficulty finding interested male participants due to the predominance of women in most groups and the lower survey return rate for men.

The subjects were a sample of convenience who were selected based on their participation in a grief support group and their interest in volunteering. They may not adequately represent all grieving parents, most likely only those who choose to attend a support group. It would be expected that those who do attend a group have higher social support needs than those who do not attend.

The results obtained from the use of the chi-square analyses must be viewed with suspicion because of the questionable validity of this test for the following reasons: the sample size was not large enough to produce a sufficient number in each cell; to deal with this problem, the cells were collapsed from a 2x5 to a 2x2 which grouped the responses more than initially intended; even so, there were more than 20% of the cells containing expected frequencies of less than 5.

Suggestions for Further Research

Further research in the area of perinatal loss support could focus on the differences in grief resolution for those who participate in a formal support group versus those who do not. Are these groups facilitating grief resolution or are they prolonging it? Are parents who choose to participate in a support group different than those who do not? Cross cultural issues and group involvement is an area that could be explored further due to the under representation of minority group members in most support groups.

A positive trend is the expansion of the number of grief support groups for all types of loss throughout the world. It indicates an increasing awareness within society of the need to express grief and receive community support during this process.

Appendix A

The Survey

Dear Parent,

My name is Leslie Beitch and I am a graduate student in psychology at Lindenwood College in St. Louis. I am also a SHARE support group leader with Christian Hospital. As part of my graduate requirements I am doing research on the healing factors of support group participation.

The enclosed survey asks for information related to your experiences with a pregnancy loss support group. Your responses will remain anonymous and confidential. I would like to extend to you my heartfelt sympathy for your loss. I hope that the results of this study can be of assistance to future bereaved parents. Thank you for your help in this project.

QUESTIONNAIRE

1. What is your present age?

_____

2. In what city and state do you live?

_____

3. Are you male or female?

_____

4. What is your highest year of education completed or highest degree held?

_____

5. Please circle your racial/ethnic group:

Caucasian	African American	Asian American
Hispanic	Native American	Other

If other, please specify_____

6. What is your present marital status?

_____

7. What type of Perinatal Death did you experience? Please circle.
   A. Miscarriage (death of the fetus prior to the twentieth week of pregnancy)
   B. Stillbirth (death of the infant anytime between the twentieth week of pregnancy and birth)
   C Newborn death (death of the infant before leaving the hospital)

8. When did the perinatal death occur? Please give complete date, including year. If more than one, please give all dates and types of death.

_____

_____

_____

_____

9. How soon after your loss did you attend a pregnancy loss support group?

0-1 mo. 2- 4 mo. 5- 7 mo. more than 8 months

10. How long have you attended a pregnancy loss support group?

0 - 5 mo. 6-12 mo. 13-24 mo. more than 2 years

11. Why did you first come? _____

_____

_____

_____

_____

12. Do you attend with your spouse or significant other? yes no

Comments _____

_____

_____

_____

_____

13. What do you appreciate most about the support group experience?

14. What do you dislike about the support group experience?

The following items are functions of a support group for pregnancy loss. Please rate each according to the personal significance to you.

1 - not significant
2 - slightly significant
3 - moderately significant
4 - more than moderately significant
5 - very significant

_____ A. Meeting others with similar losses and hearing their stories

_____ B. A place to share the full range of my feelings

_____ C. Learning about the grief process

_____ D. Obtaining information about perinatal death

_____ E. Gaining hope through the example of others

_____ F. Helping other bereaved parents

_____ G. Developing new friendships

_____ H. Hearing speakers

_____ I. A place to tell my story

_____ J. Support through a subsequent pregnancy or adoption

_____ K. Group acceptance of my feelings without judgement

_____ L. Understanding differences in male and female grief

_____ M. A place to remember my baby

_____ N. Help with practical solutions to problems

_____ O. Support through holidays, birthdays, anniversaries

_____ P. Finding out that others feel as I do, "I'm not crazy".

_____ Q. Understanding the reactions of my friends and family

Please place the letter of the above items in their order of importance.

_____ 1 st _____ 2 nd _____ 3 rd

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