



Evaluating a Support Group for Perinatal Loss

Marguerite A. DiMarco, MSN, RN, CPNP,

Edna M. Menke, PhD, RN, and

Tiffany McNamara, MSN, RN, CPNP

ABSTRACT

Purpose: This study attempted to determine if a support group intervention makes a difference in grief reactions of parents who have experienced a perinatal loss, and describes what parents perceived as being helpful and not helpful in handling the loss.

Design: A cross-sectional, retrospective, two-group research design was used. The independent variable was having attended or not having attended a perinatal loss support group.

Methods: A convenience sample of 121 participants ($n = 67$ in support groups; $n = 51$ not in support groups) was obtained from a mail survey to families who were on a perinatal loss support newsletter mailing list. The participants completed the Hogan Grief Reactions Checklist and a demographic questionnaire.

Results: There were no statistically significant differences in parents' grief reaction scores between the two groups, but there were some differences in grief scores by gender and ethnicity. In both groups, the parents perceived their spouse, their extended families, and their friends as "most helpful." Physicians were perceived as "least helpful."

Clinical Implications: Grief is very individual, and not all individuals may benefit from a support group. When suggesting a support group or any intervention, timing and a caring approach are essential.

Key Words: Grief; Infant mortality; Self-help groups.

Pregnancy is considered a joyous event for most families, but for some it unfortunately ends as a perinatal loss. Each year there are more than 30,000 neonatal deaths, approximately 30,000 stillborns, and at least 20% of all pregnancies result in miscarriages during the first 20 weeks of gestation (Armstrong & Hutti, 1998).

It was not until the 1970s that perinatal loss became the subject of professional research. For this reason our understanding of the known effects of perinatal loss on a family are still evolving (Reed, 1990). One of the first studies on perinatal loss examined factors that put mothers at risk for pathological grief reactions (Kennell, Slyter, & Klaus, 1970), but most subsequent research has focused on the reactions of parents to perinatal loss (Beutel, Willner, Deckhardt, Von Rad, & Weiner, 1996; Hunfeld, Wladimiroff, & Passchier, 1997; Stinson, Lasker, Lohman, & Toedter, 1992; Theut, Zaslow, Rabinovich, Bartko, & Morishisa, 1990; Vance et al., 1995; Worth, 1997). For example, we know that there seem to be differences in grief reactions between men and women, for women have been found to attach earlier and more intensely to the fetus than men and, therefore, have more intense grief reactions (Kish & Holder, 1996). This disparity of emotions can create incongruent grieving between mothers and fathers, leading to problems between the spouses. Other factors besides gender can influence grief, including the individual's socialization and emotional development, cultural and ethnic heritage, religious beliefs, and past experiences with loss (Beutel et al., 1996; Hebert, 1998; Wallerstedt & Higgins, 1996).

Several studies have focused on the most helpful caring behaviors in working with families that experience perinatal loss (Calhoun, 1994; Lemmer, 1991; Rybarik, 1996). Kavanaugh (1997) has also studied components of supportive relationships between healthcare providers and parents who experienced a perinatal loss. Most helpful behaviors were:

1. giving information straightforwardly, in understandable language that enables parents to gain a sense of control over the situation and alleviate many fears
2. providing competent care utilizing expert medical knowledge, and
3. giving special attention by expanded visitation, additional time, and making the parents a priority over other patients.

Parents might find additional support and comfort in discussing their experience with other bereaved parents.

Support by healthcare professionals is critical because the family/friend support network of these parents is unlikely to have ever experienced perinatal loss and, thus, may not understand the intensity of the parents' grief. The research affirms that these parents need others to acknowledge the baby, and they also need to be provided with education and information concerning support groups, the grieving process, gender differences in grieving, and funeral information (Calhoun, 1994; Kish & Holder, 1996). Parents might find additional support and comfort in discussing their experience with other bereaved parents in support groups where they might find an atmosphere of acceptance of their loss (Kish & Holder, 1996; Wallerstedt & Higgins, 1996). Since the early 1970s the need for parent programs for those who experienced a perinatal loss has been emphasized. However, there remains a paucity of research on the effects of such support programs. This study is an initial attempt to determine if a support group intervention makes a difference in grief reactions of parents who have experienced a perinatal loss.

Methods

A cross-sectional, retrospective, two-group research design was used to determine if there were differences in grief reactions between parents who attended a support group versus parents who had not. Approval from the Institutional Review Board of the University of Akron and Metrohealth Medical Center of Cleveland was sought prior to implementing this study.

Sample

A convenience sample was obtained from families who received a perinatal loss support newsletter. Any parent who had experienced a perinatal loss at a large hospital in a mid-western metropolitan area of the United States had been invited to receive a newsletter and to become members of the ongoing perinatal loss support group. Some parents receiving the newsletters had attended the perinatal support group and other parents chose not to attend the support group.

A letter was sent to all 200 families on the mailing list which described the research project and the two data collection instruments, one for mother and one for father. After the initial mailing, two additional follow-up mailings were sent to those parents who had not responded.

Marguerite A. DiMarco is a Pediatric Nurse Practitioner, Akron, OH. She can be reached clo The University of Akron, 209 Carroll Street; Akron, OH 44325-3701; e-mail: dimarco@uakron.edu

Edna M. Menke is an Associate Professor, The Ohio State University, College of Nursing, Columbus, OH.

Tiffany McNamara is a Certified Pediatric Nurse Practitioner, The University of Akron, Akron, OH.

Responses were returned from 128 individuals, representing a 32% return rate. Data from 121 participants were complete and, therefore, used for the data analysis. A sample size of 120 participants was needed based on a power analysis using a power of 0.80, alpha (0.05), medium effect size (0.25) and variables ($kx = 2$, $ky = 6$) (Cohen, 1983). The data from seven individuals (female = 6, male = 1) were not included, as they had not completed the Hogan Grief Reaction Checklist (HGRC). The final sample was 67 individuals who attended at least one support group meeting and 54 who had not attended any support group meetings.

Support Group

The independent variable for the study was having attended or not having attended the support group offered by the primary author. Support group participation was defined as attendance at a minimum of one support group meeting. The support group was cofacilitated by the primary author or nurse/patient and a chaplain, met once each month for a period of 2 hours, and was typically attended by 8 to 12 people. The topics of the meeting varied according to the needs of the parents at the meeting, but would usually include how to cope with feelings of grief, family, friends, work, and holidays. Parents socialized during the last 30 minutes and could borrow books on perinatal loss that were available at the meeting.

Instrumentation

Study participants completed a demographic questionnaire and a grief scale. The demographic questionnaire consisted of 13 fixed response and two open-ended questions. The two open-ended questions pertained to what was most helpful and what was least helpful in regard to the perinatal loss.

The HGRC was used to measure the grief reactions of the participants (Hogan, 1992). The HGRC is a 61-item, Likert type instrument comprised of six subscale scores: despair, panic behavior, personal growth, blame and anger, detachment, and disorganization. For each item, the individual chooses how well it describes one's behavior from (1) "does not describe me at all" to (5) "describes me very well." For each of the subscales, the lower the score, the less the grief reaction. The despair subscale measures separation distress characterized by hopelessness, sadness, and loneliness (range of scores: 13 to 65). The panic behavior subscale is a physiological characteristic of fear and somatic symptoms such as fatigue, headaches, stomachaches, and backaches (range of scores: 14 to 70). The personal growth subscale measures spiritual and existential awareness with items like being more compassionate, forgiving, and hopeful (range of scores: 11 to 55). The blame and anger subscale measures feelings of being bitter and hostile (range of score: 7 to 35). The detachment subscale refers to being withdrawn and avoiding others and self; the disorganization subscale pertains to trouble with concentration and remembering (range of scores for both: 8 to 40). Cronbach alpha coefficients for the factors are despair ($r =$

0.89), panic behavior ($r = 0.90$), personal growth ($r = 0.82$), blame and anger ($r = 0.79$), detachment ($r = 0.87$), and disorganization ($r = 0.84$) (Hogan; Hogan, Greenfield, & Schmidt, in press).

In this current study of perinatal loss the Cronbach alpha coefficients for the subscales were: despair ($r = 0.86$), panic behavior ($r = 0.88$), personal growth ($r = 0.84$), blame and anger ($r = 0.71$), detachment ($r = 0.70$), and disorganization ($r = 0.69$).

Descriptive statistics, chi-squares, t tests, and analysis of variance were used for data analysis. An alpha level of 0.05 was set a priori to ascertain significant differences. The qualitative data from the two open-ended questions were analyzed with content analysis (Weber, 1990).

Results

Table 1 presents a comparison of the characteristics for the two groups and total sample. Two demographic variables were statistically significantly different: marital status (more married participants attending the support group, $p = 0.03$), and ethnicity, with significantly more Caucasians attended the support group than other ethnic groups ($p = 0.002$), although the total sample was overwhelmingly Caucasian. There were no statistically significant differences between the two groups for age, sex, religion, having at least one living child, or type of perinatal loss. The mean age for the support group was 31.8 years, and the 32.5 years for the nonsupport group. The length of time since perinatal loss

TABLE 1. Demographic Characteristics of the Sample

Variable	Support Group ($n = 67$)		No Support Group ($n = 54$)		p value
	N	%	N	%	
Sex					
Female	49	73.1	39	72.2	ns
Male	18	26.9	15	27.8	ns
Marital Status					
Never married	6	9.0	12	22.2	0.03
Married	56	83.6	35	64.8	ns
Separated/divorced	5	7.5	5	9.3	ns
No response	0	0.0	2	3.7	ns
Ethnicity					
Caucasian-American	58	86.6	35	64.8	0.002
African-American	4	6.0	10	18.5	ns
Hispanic-American	1	1.5	4	7.4	ns
No response	4	6.0	5	9.3	ns
Religious Preference					
Catholic	37	55.2	24	44.4	ns
Protestant	25	37.3	20	37.0	ns
Other	2	3.0	3	5.6	ns
No preference	2	3.0	4	7.4	ns
No response	1	1.5	3	5.6	ns
Has a Living Child					
Yes	49	73.1	40	74.1	ns
No	18	26.9	14	25.9	ns
Miscarriage					
Yes	21	31.3	16	29.6	ns
No	46	68.7	38	70.4	ns
Ectopic Pregnancy					
Yes	1	1.5	7	13.0	ns
No	66	98.5	47	87.0	ns
Stillbirth					
Yes	32	47.8	19	35.2	ns
No	35	52.2	35	64.8	ns
Early Infant Loss					
Yes	35	52.2	25	46.3	ns
No	32	47.8	29	53.7	ns

ns = no statistically significant difference.

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for the entire sample ranged from 1 month to 13 years ($m = 2.76$ years). There was no statistically significant difference between the groups for this variable ($m = 3.10$, $SD = 2.79$). In the support group, 31 (46.3%) of the participants attended 1 to 3 support group meetings, 9 (13.4%) attended 4 to 7 meetings, 16 (23.9%) attended 8 to 12 meetings, and 10 (14.9%) had attended more than 12 meetings.

Grief Reactions

Table 2 contains the HGRC scores for the two groups. There were no statistically significant differences in subscale scores between the two groups. Overall, for both groups the mean scores were low for all six subscores. Two-way analysis of variance showed the only statistically significant differences were for the main effect of gender, with females having higher scores than the males for the subscales of despair, panic, and detachment. The only statistically significant difference for the main effect of ethnicity was the Caucasian-American participants had lower detachment subscales than the ethnic minority participants.

Parent's Perceptions of Individuals/Groups That Were Helpful

Data from the demographic questionnaire were used to describe whom the participants perceived as being helpful with their perinatal loss. For participants who had attended the support group, 35% or more of the participants perceived their spouse, extended family, close friends, and support groups as most helpful. Participants who had not attended the support group perceived their spouse, extended family, and close friends as most helpful.

Parent's Perceptions of Individuals/Groups That Were Not Helpful

For participants who had attended the support group, physicians, extended family, and nurses were perceived as least helpful. For participants who had not attended the support group, physicians and extended family were perceived as least helpful.

Interventions Perceived as Most Helpful

A question on the demographic questionnaire asked, "As you look back on the perinatal loss experience, what was the most helpful thing that someone said or did for you?"

Table 3 contains the themes that emerged from the content analysis, including crying with them, being there, listening, assigning meaning to the experience, and having pictures of the baby. The two groups did not differ in the themes; however, participants in the support group were more likely to mention specific persons who were helpful and what they had done to be helpful. These included extended family members, friends, nurses, physicians, clergy, and listening to others who had experienced a perinatal loss.

Interventions Perceived as Least Helpful

Participants were asked, "As you look back on the perinatal loss experience, what was the least helpful thing that someone said or did for you?" Several themes emerged from the content analysis (Table 3) including being told not to cry, not acknowledging the experience, making light of the experience, and being told the loss was for the best. Some participants in both groups gave specific incidents of an experience that they had while in the hospital of a someone being insensitive to their needs. For example, several of the participants described being unable to have their baby in the birth room or being placed on a general surgical floor. While most attendees at the support group described the support group as being a helpful intervention, one identified it as being the least helpful, stating that attending the support group and hearing the sad stories of others "set me back."

Clinical Implications

This was a retrospective study with a convenience sample of individuals who had many different types of perinatal losses over several years, and who chose to or not to participate in a support group. The findings cannot be generalized beyond this sample; however, despite this limitation, this study gives us a beginning look at an evaluation of a support group for parents who have experienced a perina-

TABLE 2. Comparison of the Hogan Grief Reaction Checklist Scores for Both Groups

Scale	Support Group (n = 67) M ± SD	No Support Group (n = 54) M ± SD	p value
Despair	32.18 ± 11.76	31.13 ± 9.55	ns
Panic behavior	33.31 ± 11.55	33.98 ± 10.75	ns
Personal growth	27.32 ± 9.16	29.39 ± 7.49	ns
Blame and anger	16.06 ± 5.21	16.07 ± 4.66	ns
Detachment	21.40 ± 6.00	20.00 ± 5.67	ns
Disorganization	19.22 ± 5.54	17.94 ± 5.74	ns

SD = standard deviation; ns = no statistically significant difference.

TABLE 3. Perceptions of Parents Regarding Most and Least Helpful Interventions After Perinatal Loss

Most Helpful	Least Helpful
<ul style="list-style-type: none">■ Crying with the family■ Being there (hugging, someone being present, receiving cards, and hearing from friends)■ Listening■ Assigning meaning to the experience (e.g., was God's will*, the baby is a special angel in heaven, and telling parents you are sorry about their loss)■ Having pictures of the baby	<ul style="list-style-type: none">■ Being told not to cry■ Not acknowledging the experience (friends not asking about the experience or acting as though it never happened)■ Making light of the experience (e.g., comments such as "You are young," "You can have more children," "You already have a child," "Forget about it," and "You can try again.")■ Being told the loss was for the best

*God's will was also listed as least helpful.

tal loss. While we found no statistically significant differences in grief reaction scores between those who had attended a support group and those who had not, all the parents might have received "support" in some way because they were on a mailing list for a bereavement newsletter. Whether they read the newsletter is unknown, but they had been contacted by the institution and were aware that support groups were available to them. It is possible that the individuals who chose not to attend the support group felt fully supported in their personal lives without additional help. Likewise, a formal support group may not be helpful for all people who experience perinatal loss. This question cannot truly be answered without a randomized trial, but such a trial is unlikely because most nurses would not want to randomize parents who had a perinatal loss to a "no support group" arm of a study.

It is possible that some individuals might perceive support groups as helpful while others do not and, therefore, chose whether or not to attend. Qualitative data analyzed here showed that the support group was helpful for those who attended; however, the support group did not change the quantitative grief reactions. This could have been the case for many reasons. The cross-sectional design used meant that the grief scales were completed one time only by the participants, despite the differing amounts of time that had elapsed since their loss, and despite how many sessions of the support group they attended. Additional research needs to be done with parents shortly after experiencing the loss, with repeated measures of grief obtained over a period of time.

Parents obviously grieve, regardless of attendance at a support group. Perhaps the support group attendance does not lessen or alter the grief reactions, but merely helps the participants to cope more effectively. In that case, a grief scale may not be the most appropriate instrument to use. It is possible that a coping scale would have found differences between the groups. These scenarios could be answered if additional larger studies were launched to measure the effect of a support group intervention on social support, coping responses, and grief reactions. The instrument used in this study to measure grief—the HGRC—is a relatively new instrument and has not been used for perinatal loss previously. Other studies using it have focused on samples

who had experienced the death of a child, spouse, or significant other; were survivors of suicide; or were parents of murdered children (Hogan et al., in press; Gamino, Sewell, & Easterling, 2000). This could have had an impact on the lack of difference in scores as well.

In general, healthcare providers were not chosen as the most helpful individuals to these parents. While there were reports of kindness from nurses ("the nurse gave me a warm blanket, comforted me, and said she was sorry," "a nurse read a poem and hugged me," "a nurse seemed to share our loss," "a nurse talked to me and helped a lot," "a nurse cried with me and told me my daughter was beautiful," "a nurse told us it wasn't our fault," and



Suggested Clinical Implications

- Listen and be there to support the parents during the perinatal loss experience
- Assess individual parent's needs and try to meet those needs
- Say very little, but express empathy through touch and expression of nonverbal emotions (e.g., crying with the family)
- Assign meaning to the experience, giving pictures and footprints of the baby to the family
- Assess the needs of the other children, and provide anticipatory guidance
- Provide adequate time for the parents to discuss their loss
- Remember that gender often affects the manner of grieving
- Remembering the deceased child will be meaningful to the family; provide follow-up calls at key points in the grieving process (e.g., anniversaries, holidays)
- Make referrals to support groups and mental health practitioners as needed

While there were reports of kindness from nurses, nurses in these situations still have much to learn about how to have the most positive impact during such a stressful time. Our best teachers about this are the parents who have experienced loss.

“a nurse let us spend time with our baby and took pictures”), nurses in these situations still have much to learn about how to have the most positive impact during such a stressful time. Our best teachers about this are the parents who have experienced loss. Many of the parents in this study stated that it was the people who listened and were “with them” who helped the most. The nurse can easily fill this role. Some suggestions for empathetic caring based on this study are listed on the previous page. [In addition, McCown (1988) advises scheduling follow-up visits approximately 1 year after the death to review the grief process and to make referrals to support groups and to mental health practitioners as needed.

While not studied in this research, the other children in the families might require assistance as well because they have been shown by others to often exhibit behaviors and emotions related to the loss including separation anxiety, grief, mourning abandonment, and guilt (Calandra, 1993). Parents may be unable to support their children due to their own grief, thus, nurses could suggest ways that the other children can be helped through support groups, information giving, and occasionally, short-term therapy. Pediatric nurses could consider coping with grief a part of a child's general growth and development (Calandra, 1993).

Nurses have the opportunity and responsibility to assist in the grieving process. While the question of the benefit of support groups for people who have experienced perinatal loss has not yet been answered, this study can be used to help nurses better understand the most supportive actions they can take to help grieving parents and to develop additional research to answer the question. Until additional research definitively answers these questions, that is the best we can do for our patients. ❖

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ONLINE



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On Health: Miscarriage Resources www.onhealthnetworkcompany.com

National Perinatal Association www.nationalperinatal.org/Index.html

March of Dimes www.modimes.org

ToleNet Services (Provides memory boxes painted by volunteer artists for families suffering perinatal loss) www.groups.yahoo.com/group/memoryboxes/ or send e-mail to: mgemmil@netadventure.com