

EFFECTS OF SUPPORT GROUPS ON POST TRAUMATIC STRESS RESPONSES IN WOMEN EXPERIENCING STILLBIRTH

JOANNE CACCIATORE, LMSW, FT
Arizona State University

ABSTRACT

This research study explores the effects of support groups on traumatic stress responses of women experiencing stillbirth. Women ($N = 47$) responded to a mixed method questionnaire. Quantitative results utilizing the Impact of Event Scale Revised demonstrate that women who attend support group, when controlling for time, had fewer post traumatic stress symptoms than did the women who did not attend support group. Qualitative results elucidate the role of support groups in managing grief, suggesting that connectivity with other like women may be a useful strategy in reducing problematic psychological outcomes.

There is nothing in human nature more resonant with charges than the flow of energy between two biologically alike bodies, one of which has lain in amniotic bliss inside the other, one of which has labored to give birth to the other . . .

Adrienne Rich, Feminist and Author

LITERATURE REVIEW

Giving birth to a dead baby is an emotional, spiritual, and physiological experience. It is, in itself, a contradictory event. How is it conceivable that a woman can give birth and death simultaneously? Beyond the apparent biological contradiction, the emotional effects of sudden intrauterine infant death, or stillbirth, are often misunderstood and rarely examined beyond the cursory rhetoric of

perinatal death (Fletcher, 2002; Goldenberg, Kirby, & Culhane, 2004; Hankins & Spong, 2001; Kirkley-Best & Kellner, 1982; Malacrida, 1997; Michon, Balkou, Hivon, & Cyr, 2003). Women may feel disenfranchised from the social groups to which they belonged prior to the baby's death, while their mourning experience is generally decried and their losses minimized (DeFrain, 1986; Fahey-McCarthy, 2003; Fletcher, 2002; Kirkley-Best & Kellner, 1982; Kübler-Ross, 2004; Lancet editorial, 1991; Sadler, 1987; Worth, 1997). This research study seeks to understand the experience of sudden intrauterine infant death and how support groups affect post traumatic stress responses.

Every day in the United States, nearly 100 babies are stillborn (Ananth, Shiliang, Kinzler, & Kramer, 2005; Fletcher, 2002; Goldenberg et al., 2004). This translates to 1 in 100 pregnancies that will end in the stillbirth of a baby. Stillbirth, or sudden intrauterine death, is the death of an unborn baby past 20 completed gestational weeks. Clinical vernacular for the stillborn infant include "fetus, fetal death, and fetal demise," after 20 completed gestational weeks and weighing more than 500 grams (Conde-Agudelo, Belizan, & Diaz-Rossello, 2000; Froen, 2005). Despite improved access to prenatal care, sophisticated medical technology, and frequent obstetrical visits during the final weeks of a pregnancy, sudden intrauterine infant death rates over the past 20 years have declined only slightly in the United States, and it is greater than 10 times more likely to occur than Sudden Infant Death Syndrome (SIDS).

Rando (1985) acknowledges the "unique factors of parental bereavement" and suggests that of all death experiences, the death of a child incites an incalculable range of emotional responses and intensified physiological distress (p. 21). Women who experience stillbirth need an abundance of unconditional, social support. One of the earliest researchers to examine stillbirth and its emotional implications was University of Nebraska professor, John DeFrain. His data indicated that more than 30% of women experiencing stillbirth reported suicidal ideation and a host of other distressing symptoms. Often, grievers' symptoms are exacerbated by a lack of responsiveness from society at large.

The lack of social support for grieving individuals is based on societal misconceptions. . . . The more sudden, unexplained, and unnatural the death, the greater the difficulty expressing support. . . . Society lacks the knowledge and skill to respond to the bereaved individual, especially after a traumatic death. . . . In the absence of some supporting social structures, it is observed that some individuals do not effectively deal with the tasks of grieving. They may experience prolonged and destructive reactions (Sprang & McNeil, 1988, p. 46).

Qualitative research conducted in Finland confirmed common themes the notion that stillbirth is a paradox, an "impossible thing," that requires crisis-therapeutic intervention. The narratives of women in the study provided evidence for a preference to connect with others who had similar experiences, such as in a support group setting (Vaisanen, 1999). The mothers' grieving processes were

paramount to the ultimate outcome of familial mourning and recovery. Researchers noted that significant post traumatic symptoms were present in all 22 cases studied.

Without adequate support, the bereaved may be at increased risk for maladaptive responses that may include chronic depression, suicidal ideation, drug or alcohol abuse, and pervasive post traumatic stress disorder (PTSD) symptomology. PTSD is associated with an impairment of social functioning, family interference, occupational instability, marital problems and divorces, and parenting complications. Psychiatric sequelae also include suicidal ideation even as long as 13-25 months later (Prigerson, Bierhals, Kasl, Reynolds, Shear, & Day, 1997) and comorbidity related to alcohol and other substance abuse is particularly widespread (Deahl & Srinivasan et al., 2001).

Research shows that support groups offer practical help to both men and women (Boivin, 2003), strategies for coping (Sadler, 1987), a reduction in psychological distress (Barr, 2004; Fukui, Kugaya, & Okamura, 2001), and, even in child survivors of suicide, diminished anxiety and depressive symptoms (Pfeffer, Jiang, Kakuma, Hwang, & Metsch, 2002). Conversely, bereaved individuals who perceive inadequate social support following the death of a loved one are at an increased risk of poor outcomes (Sheldon, 1998). Additionally, support groups can foster a sense of community for the bereaved (Fast, 2003; Neukrug, 2004) and may be particularly important to women (DeFrain, 1986; Hurdle, 2001). The apparent popularity of support groups can be attributed to common, shared, and often painful and traumatic, experiences between members (Griefzu, 1996; Muller & Thompson, 2003; Neukrug, 2004; Rodale & Stocker, 1994). In a supportive group milieu, the bereaved may experience the four types of support outlined by Glanz, Rimer, and Lewis (2002): Affiliation or emotional support (a sense of belonging), instrumental support (a safe place for dialogue), informational support (practical aid), and appraisal (normalization and social comparison). A strong sense of social support can mitigate feelings of disenfranchisement for the bereaved and increase individual perceptions of long-term happiness (Anke & Fugl-Meyer, 2003; Kish & Holder, 1996) and hope. Social support networks, identified to promote health benefits, also cushion the effects of stress, reduce mortality rates, increase the likelihood that the individual will seek help, and assist in developing personal coping abilities (Hurdle, 2001; Lensing, 2001; Neukrug, 2004).

The benefits of a support group setting, wherein members tell and retell their stories, include the process of desensitization to the trauma, as well as a "communalization" (Tedeschi & Calhoun, 1995). This connection between two or more human beings reduces feelings of disenfranchisement, isolation, and helps the mourner create and recreate meanings in their experiences. Parents of children who have experienced violent deaths report that monthly support groups are their "predominant source" of aid (Murphy et al., 1996). Research conducted by the American Mental Health Counselor's Association found that "person-centered

counseling” along with “sharing memories” about the deceased are a way for the bereaved to make meaning out of the death (Muller & Thomson, 2003).

SUMMARY

The stillbirth of a baby can be a debilitating experience for women, inciting feelings of isolation, powerlessness, and aloneness in an apparently unsympathetic world (Kübler-Ross, 2004; Lovell, 1983; Radestad et al., 1996). Child death is one of the “most painful bereavements” (Sheldon, 1998), and is the most “intense and profound” human experiences still prevalent in Western civilization (Michon et al., 2003). Yet, “little is known about the experiences a family has after a child dies” (Fletcher, 2002), especially in the case of stillbirth (Goldenberg et al., 2004; Radestad et al., 1996). Support groups may play a role in reducing the effects of trauma. Based on the previous review of the literature, this research examines the effects of support groups on post traumatic stress responses for women experiencing stillbirth.

METHODOLOGY

Participants and Procedures

This study used a cross-sectional, mixed methods approach to evaluate the effects of support groups on women experiencing stillbirth. Primary data were collected directly from respondents who were recruited using purposive sampling. Participants were notified of the study through four major nonprofit agencies over a eight week period of time: Stillbirth and Neonatal Death Society (Australia), MISS Foundation (International), and SHARE (United States). Methods for notification included newsletters and e-mail from participating groups.

Women between the ages of 19 and 51 ($n = 47$) responded to the questionnaire. There were 38 European Americans (81%), three African Americans, three Latino, two “Other,” and one Asian. Most respondents had obtained an undergraduate degree ($n = 23$, 49%), followed by high school diploma ($n = 12$, 26%), graduate ($n = 7$, 15%), and postgraduate ($n = 4$). One respondent did not answer this question. Respondents had all experienced the stillbirth of their baby at various gestational ages; however, the majority, nearly half, was at or past full term.

The nature of the death was most often sudden and unexpected ($n = 44$, 94%) and the time since death ranged from within the past year ($n = 10$, 21%), one to two years ($n = 10$, 21%), two to five years ($n = 17$, 36%), five to 10 years ($n = 7$, 15%), and greater than 10 years ($n = 3$). Most women had surviving children at home at the time of their child’s stillbirth and 62% ($n = 29$) had not had a subsequent child born after the death.

About 38% of the respondents had never used prescription medications to help them cope with their child’s death and 60% ($n = 28$) of the respondents had

used prescription antidepressants since their child's death. Of those, 40% ($n = 19$) were on prescription medications at the time they were responding to the questionnaire. More than 21% ($n = 10$) of respondents admitted to self-medication with illegal drugs or alcohol since their child's death and 45% ($n = 21$) also reported having thoughts of self-harm. Every respondent ($n = 47$) stated that the stillbirth of their child had caused significant change in their sense of identity.

Participants were provided the instrument along with the Informed Consent and were instructed to return the questionnaire to the researcher upon completion. After responding to the IES-R scale, participants were also provided a questionnaire with the following demographic questions: age, race, and education level. Other data were collected through a self-report survey provided to participants and collected over an eight-week period of time.

Instrument

The dependent variable was measured using the Impact of Event Scale-Revised (IES-R). This instrument is a self-reporting questionnaire designed to measure traumatic stress responses. It is a modified version of the Impact of Event Scale (IES). The IES, developed by Horowitz, Wilner, and Alvarez (1979), was intended to measure ongoing subjective distress related to a traumatic event. This instrument focused on two major types of responses to traumatic stressors: intrusion and avoidance. The IES is considered to be the earliest self-report measure of post traumatic stress disorder (Briere, 1997). The original IES consisted of 15 items with seven targeted items measuring intrusive symptoms such as sudden and disruptive thoughts, nightmares, and distressing emotions and imagery. Eight questions address avoidance symptoms such as constrained affect and intentional avoidance of thoughts and feelings. All 15 questions on the original instrument are closely associated with a specific stressor (Briere, 1997).

The original instrument had high reliability. Horowitz (1979) administered the IES to a group ($n = 30$) in two tests. There was an interval of one week between the dates. Outcomes demonstrated a reliability of .87 for the total stress scores: .89 for the intrusion subscale and .79 for the avoidance subscale. The IES indicated excellent internal reliability based on two sample groups and coefficients ranged from .79 to .92 for the intrusion and .90 for avoidance (Corcoran & Fischer, 1994). This instrument's predictive validity was sensitive to both changes over time and to recognizing relevant variables of traumatic events, degrees and variations in affect, and severity of symptoms by different groups (Corcoran & Fischer, 1994).

The IES-Revised, developed as an adaptation to the IES by Daniel Weiss and Charles Marmar (1997), was intended to parallel the DSM-IV criterion for post traumatic stress disorder (PTSD). This instrument taps hyperarousal, intrusion, and avoidance symptomology. This instrument has 22 items with three subscales measuring the following: seven items tapping hyperarousal with one new intrusion

item, seven of the original intrusion items, and eight avoidance items. The minimum value is zero (not at all) and the maximum value is four (extremely). Weiss and Marmar also found high levels of internal reliability in a study of four populations with intrusion alphas ranging from .87 to .92, avoidance from .84 to .86, and hyperarousal from .79 to .90. Predictive validity was determined to be good and detects a change in respondents' clinical status over time. Content validity had high approval of up to 85%. Test-Retest reliability was available for two samples in the Weiss and Marmar study. Data from sample one ($n = 429$) demonstrated the following correlation coefficients for the three subscales: intrusion = .57, avoidance = .51, and hyperarousal = .59. Sample two correlations coefficients were significantly higher: intrusion = .94, avoidance = .89, and hyperarousal = .92. The disparity is likely related to time since experience: The second sample experienced a more recent traumatic event than the first sample.

The self-report survey included questions to enrich the data, support or dispute quantitative data analysis, and offer participants an opportunity to further discuss important issues related to their experiences. Those included: When did your child die? Was it sudden or expected? What was the cause of death, if known? Do you have surviving children? Have you used prescription medication administered by a physician since your child's death? If so, are you currently taking them? Have you used illegal drugs or alcohol to cope with the death of your baby?

Open ended questions were then posed: Question one (Q1) inquired, "What do you feel has most helped you deal with the death of your child?" Question 2 (Q2) inquired, "What regrets, if any, do you have related to your child's death and the events before or after?" Question 3 (Q3) inquired if the person had experienced thoughts of self-harm, and if so, what were the circumstances. Question 4 (Q4) inquired, "Has your child's death changed you and if so in what way/ways?" There was also a place for an Optional Narrative (QOpen). This provided an additional page to collect any data the participant wanted to share in an open narrative format.

RESULTS

Quantitative Results

IES-R scores were calculated on a scale ranging from 0 to 12, with 0 representing the lowest score of avoidance, hyperarousal, or intrusion, and with 12 being the highest score. The correlations between each pair of scales and their levels of significance were calculated using the Statistical Package for the Social Sciences v12.0 (SPSS). Most respondents ($n = 29$) did attend local support groups and the mean IES-R score of this group was 3.41, on a scale of 0-12; while 36% ($n = 17$) never attended a group and they had a mean IES-R score of 7.56. Quantitative data were analyzed Independent Samples *T*-Test to determine if a relationship existed between the mean IES-R scores and involvement in a local

support group. Data indicate that there is a significant difference ($t = -7.585$, $p < .000$) in the IES-R scores between those who did and those who did not attend local support groups even when controlling for time (Table 1).

In order to consider the role of time since death and participation in support group, a regression analysis was done. Three variables were included in a regression analysis: The first variable was *time* since death. Time since death was a dichotomous variable asking participants the length of time since the child's death. These responses were categorized into: 1) death within two years and 2) death greater than two years. The second variable included in the regression equation was *participation* in support groups, and was also a dichotomous variable in which participants responded "yes" or "no" to the question regarding their attendance at a support group. These two variables were used to predict a respondent's score on the IES-R instrument. As seen in Table 2, the data demonstrate that women who participated in local support groups had lower, mean IES-R scores (Table 2). Another way to look at these data is included in Figure 1.

Qualitative

Four qualitative questions were asked along with an open ended narrative. Question one (Q1) inquired, "What do you feel has most helped you deal with the death of your child?" Question 2 (Q2) inquired, "What regrets, if any, do you have related to your child's death and the events before or after?" Question 3 (Q3)

Table 1. Relationship between Support Group Participation and Mean IES-R Scores

Support group participation	<i>N</i>	IES-R Mean	<i>SD</i>
Yes	29	3.40	2.20
No	17	7.56	1.50

Table 2. Time Since Stillbirth and Participation in Support Group Regressed

Variables	Beta	<i>t</i>	Sig.
Participation	.575	5.015	.000*
Time	.277	-.280	.019*

* $p < .05$
 $R^2 .423$

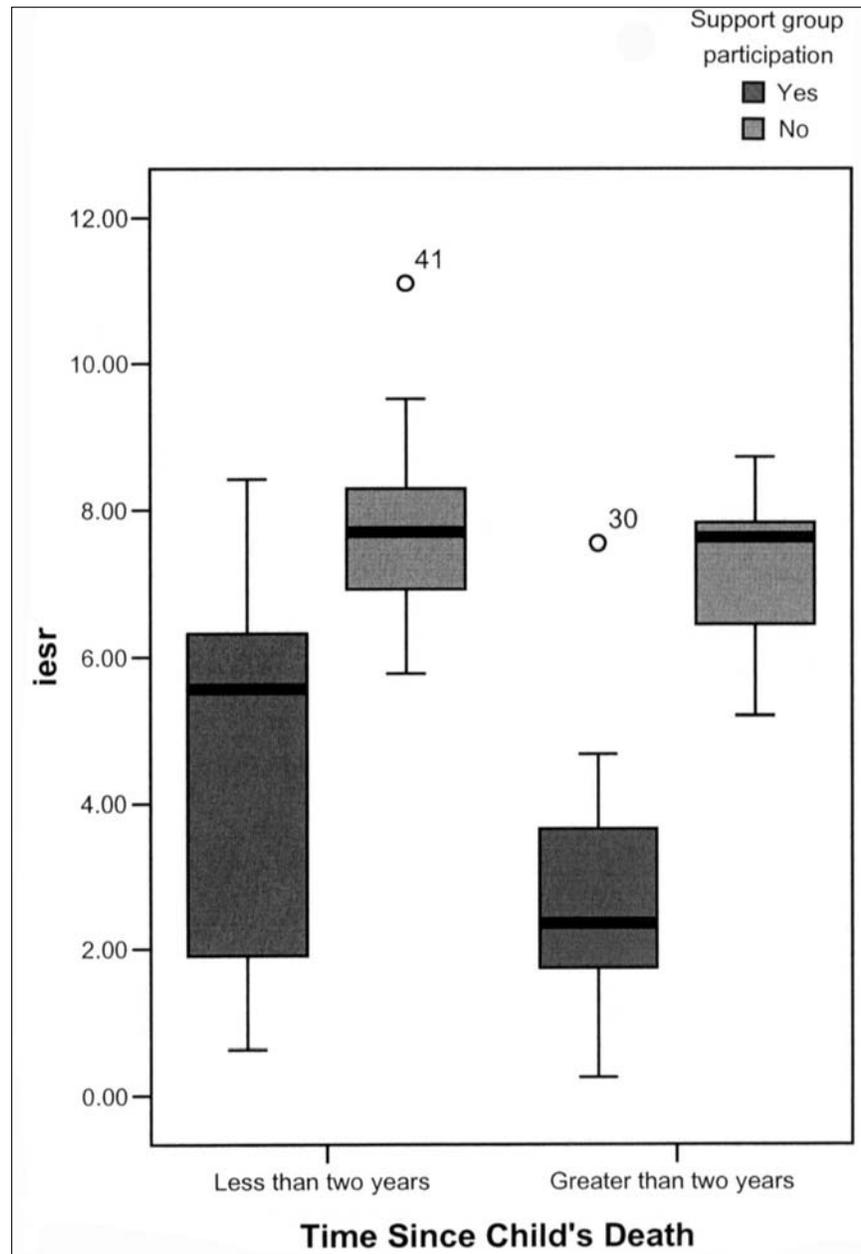


Figure 1. Relationship between support group participation and mean IES-R scores over time.

inquired if the person had experienced thoughts of self-harm, and if so, what were the circumstances. Question 4 (Q4) inquired, “Has your child’s death changed you and if so in what way/ways?” There was also a place for an Optional Narrative (QOpen).

Q1: What do you feel has most helped you deal with the death of your child?

Out of 47 responses, four of whom chose not to respond, 39 reported that support groups, or talking with other bereaved parents, was the most helpful in dealing with the death of their child/children.

. . . support groups and meetings and listening to others in the same situation . . . and meeting those who had actually *survived* the death of their child.

Attending support group and therapy were the best things I could have done for myself.

Being able to share my inner most feelings with other parents outside of my family was different but very healing.

Talking, talking, talking, and more talking about it all!

(Our support group)—the sense of belonging somewhere and that you are not alone.

. . . It was incredibly helpful that other women were out there who had experienced what I had . . .

Q2: What regrets, if any, do you have related to your child’s death and the events before or after?

The second qualitative question (Q2) addressed any specific regrets the woman has related to the death of their child, either before, during, or after the child’s death. Out of all 47 respondents, only one mother reported, “I don’t have any regrets.” For most participants, this induced agonizing, yet honest, answers. These responses often focused on tangible, irreversible decisions, having to do with ritualization and the creation of memories with their child. The mothers, for example, wanted more photos or more time. They wished that they had held their child if they had chosen not to- or they wanted to hold their child longer.

Other concerns included intrapsychic and, sometimes, irresolvable decisions related to the death such as what a mother believed she “could’ve, would’ve, or should’ve” done to evoke a different outcome and to ostensibly prevent the infant’s stillbirth. Some focused on the perceived failures of their bodies.

Both centerpieces elucidated the emotionally diverse dimensions of the experience of stillbirth with emergent themes of guilt, shame, and feelings of failure and responsibility on the part of caregivers or the mothers themselves:

I regret everything I ever said or did that may have had a negative impact on my pregnancy. Guilt, guilt, guilt. I regret not holding (her) more. . . . I regret not letting (siblings) see their little sister. I regret not having an open casket. I wish I would have known I could hold her at the funeral home. I just wish I would have had more time with her . . .

I have moments when I apologize for killing our daughter even though there was nothing I could do to stop it . . .

My biggest regret I have is not wanting to hold my daughter. I was in denial and didn't want to believe that she was dead.

I regret that I was sedated during labour . . . that I trusted the doctors and not my instinct.

Not taking pictures of us holding her and not being a better advocate for my need to deliver prior to her death (we called and visited the hospital several times but were always sent home).

I wish I had taken more pictures—footprints and handprints—those things. I wish I would have had the courage to ask to be alone with my son. Just for a few moments.

I have many regrets. I regret not knowing he was in danger and not getting to the hospital fast enough. I regret not holding him longer and taking more pictures. I regret not unwrapping him from his blanket and looking at his naked body. I regret having so much pain medicine during labor. I regret not making the funeral director let us see him one more time. I regret not seeing his eyes.

Q3: Have you ever had thoughts of self harm and if so, when?

There were 21 participants, nearly one-half of the respondents, who answered “yes” to this question. They wrote about their thoughts of self-harm at some point since the death of their child. Some women who responded qualified their response by stating that they would not actualize the thoughts:

After my baby died, there were times I did not want to live. I wanted to be with her. I would envision driving off a cliff or wrecking my car . . .

. . . There have been times I wished I would die so I could be with him.

For months after (she) died...The pain was so great, I prayed to die.

I felt the desire to harm myself about six weeks after I delivered. I did not want to face going back to work. It would make it real with I continued with my life. It was easier to avoid everyone at home.

I have thought of wanting to die or seeing it as too painful to go on- but have not thought that I would take my own life.

Right after I was discharged from the hospital because I blamed myself for my baby's death.

At times I wished for death.

Approximately two weeks after (her) death. That's when I started psychotherapy.

I cut myself a lot the first year after her death. I went into an outpatient psych program for a week around her six month "angel-versary." When I have a hard time dealing, I cut. I also have been suicidal mostly on birthdays and holidays.

Q4: Has your child's death changed you and if so, in what ways?

This question addressed transformations since the death of the child. All 47 respondents noted that their child's death had evoked some type of intrapersonal shift in beliefs, values, and attitudes. Some discovered inner strength and some reported they have become activists for related causes. More than one-half the participants ($n = 26$), particularly those further along in grief, expressed frustration with others for a perceived lack of acknowledgment of their child's life, making support groups one of the few 'safe places' to talk about their grief. Those who reported involvement in helping others through various parental or advocacy organizations generally stated a positive change of direction:

It has made me more compassionate toward others and made me want to help others going through the same pain . . .

Her death has opened me up . . . in ways I never dreamed possible. Although I'd give up all the growth in a second to have her back, her death has propelled me toward being more compassionate, helping others, and she has changed the way I view the world.

I am now part of a "club" that I never knew about or wanted to know about. . . . There is a physical pain in my heart and nothing can repair it. My body aches to hold and know who my son would have been . . . my soul will never be the same.

The pain . . . is still so often painful that it takes my breath away. I suspect the loss has made me particularly protective of my daughter and has probably caused me to not consider having any other children. While I have come to love and understand boys, I am often struck by how my heart aches when I interact with them.

I'm more compassionate, giving. I cherish everyday . . . the everyday things mean so much more to me.

I'm not the person that I used to be. I don't smile the same or laugh the way I used to. I find it hard to get interested in much besides my grief over him. . . .

In a way, though, I feel I've changed for the better. He has made me appreciate how very fragile life is and not to take anything for granted. He made me a mom and made me realize how very much I want to be me . . . he is my hero.

I'm completely changed. I feel like I've got a missing child out there who isn't "recognized" by the world because he died before delivery. I hate the question "Is this your first (child)?" I cry more easily when I hear about something happening to another woman's child. Maybe I'm more sensitive hopefully more compassionate, hopefully more grateful for what I have because it can all be taken in a split second. My loss is part of me, of who I am, and makes up my life story.

I am more patient, compassionate, and able to help others. (His) short life changed me forever.

Accepting and facing my daughter's death has enabled me to find myself in the process. I spent so many years trying to find that "something" that would give me peace. I have my husband and son but still needed to find myself. To find my own purpose in life. My daughter's life was short but I thank her for giving me true purpose to help others.

. . . In some ways, I feel broken and helpless and in other ways I feel so much stronger than I've ever felt. I value friendship so much—true friendship. My son's death has brought me some of the most beautiful and loving women I have ever met.

QOpen: Please share any other information you believe will be helpful in this research.

This narrative opportunity was open ended so that participants could explore the most important issues that needed reiteration or that were not covered in the research. Again, the responses here illuminated the power of supportive environments. Some respondents openly discussed their feelings of disenfranchisement and social isolation, while others expressed concern regarding the care provided to them during their child's death and others praised caring professionals:

Time, love, faith, support, prayers, and going to support group meetings, proved to be a great help. . . . At the support group, everyone can cry together and comfort each other share pictures- that is priceless!

I never imagined I would be standing today (after 5-1/2 years) as a strong, healthy mother of a child who died. . . . Through our stories, our children live and we heal.

Holding (her) and taking pictures was so helpful for me. Having some proof that she existed.

I just wish that support groups weren't the only place where I feel comfortable talking about my son. . . . I wish someone would have encouraged me to spend more time with him, hold him more, and take lots of photos.

Stillbirth is so often misunderstood that we have a fear of talking about it. . . . The support groups offered at the time were lacking and I am making one available now by facilitating.

I have found support from other mothers and therapy to be so important. This kind of loss/grief is not understood or even much acknowledged in our society. It has been two years and most friends and co-workers never even mention or forget entirely about my son. I think about him constantly. He is and will always be the center of my being.

There are so many African American families in denial about infant and child death because they refuse to trust the traditional thinking regarding therapy and support groups. . . . I believe our society is still faced with racial problems even though we try to deny that culture and class difference don't exist in the medical field. Mistrust still exists because of past history. There have been so many racial barriers broken but mental healthcare and support groups are still considered taboo among our culture. I still struggle and feel isolated by my own culture but I also know the life changing advantage of therapy and support groups." "(His) death has by far been the most devastating, life-changing event in my life.

The months after were filled with therapy and medication for post-traumatic stress disorder, anxious days and panicked nights. I am no longer whole. A part of me is gone forever-literally. Like a limb torn from a body . . .

I cannot express how important it is for moms who go through a stillbirth to be given information immediately after it happens in order to help her (and husband) cope . . . being a physician myself, I asked to speak to a social worker on call . . . she was less than helpful. . . . I was not sent home with a single number I could call or any type of literature on bereavement. I've since then read about bereavement packets being available from MISS Foundation and March of Dimes that are wonderful...but that would have been much more helpful in the immediate days and weeks after my son's death.

I have found support from other mothers and therapy to be so important. This kind of loss/grief is not understood or even much acknowledged in our society. It has been two years and most friends and co-workers never even mention or forget entirely about my son. I think about him constantly. He is and will always be the center of my being.

DISCUSSION

Women who participated in support groups after the death of their child to stillbirth experienced significantly fewer traumatic stress symptoms than women

in this study who did not attend support groups. The amount of time since the death was not isolated as a significant factor in reducing the IES-R scores. Those who were not involved in a support group had very little improvement, despite the time since the stillbirth, in their mean IES-R scores. This finding suggests that support groups provide, not only benefits during the acute crisis, but more importantly, some long term benefit to women years after the stillbirth of their child.

Stillbirth is a life-changing, traumatic experience for many women. Reconciliation evolves slowly and painfully for many women as they find their way through, not only early grief, but also, the many other elements associated with traumatic events. This research was intended to explore the effects of support groups on post traumatic stress responses. The findings in this study suggest that support groups may moderate post traumatic stress responses after stillbirth. Women often have a desire to reach out for nurturance from others, from resources outside the self and beyond their core systems. This study captures the acute intensity, trauma, and interminable aspects of mourning after a stillbirth. Those early years are often the most challenging for many bereaved women. However, the challenge does not end there. Well beyond the first years after having a stillborn baby, women may continue to be overwhelmed as they struggle for equilibrium, to regain a sense of control and normalcy, and to discover meaning in their very personal tragedies.

Based on both the quantitative and qualitative responses, the difference between groups in the IES-R scores does not appear to symbolize recovery as a result of time passing since the death. Rather, it embodies the idea that somehow, bereaved mothers who are well-connected to others sharing their experiences are able to develop skills they need to better cope with traumatic stressors. This difference between IES-R scores, in addition to the lower subscale mean scores in the categories of intrusion, hyperarousal, and avoidance, and the qualitative data all represent a symbiotic relationship between the scope and breadth of traumatic stress responses and involvement in a support group.

Several respondents involved in a support group longer than two years had assumed a leadership position, now helping newly bereaved parents. Overwhelmingly, these respondents' narratives focused on feelings of empowerment, renaissance, and epiphany. They talked more about involvement and social change, focusing on making a "difference" for others and doing things in "honor of" the deceased child.

A SOCIAL MICROCOSM: QUALITATIVE CONCLUSIONS ABOUT SUPPORT GROUPS

The role of the support group is multi-faceted: Support groups are created to fulfill needs not currently being addressed by other systems. The recent popularization of the self-help movement in contemporary culture may have had its genesis in individuals who were disappointed by the lack of support, resources,

and widespread misinformation about a particular social issue. Why do support groups benefit bereaved mothers in such a profound way?

Establishment of Linkages and Nourishing Relationships

Some respondents in the research discussed difficulties with friends and family because they felt burdened by their unrealistic expectations of recovery. As a result of this, some seemed to experience a gradual withdrawal of their nuclear support system and kinship during the readjustment period. Some relationships suffer irreparable damage and others are irreversibly severed. Yet, remaining connected with others can be a crucial aspect of healing. The disappointment and bewilderment at the lack of information and responsiveness from others seem to incite bereaved mothers to seek out a sense of communion with others. Support groups connect women to other women in mutually nurturing relationships.

In the majority of instances, even the most self-reliant individual, endowed with boundless intellectual, psychological, and social resources suffers immense, and sometimes unmanageable, feelings of loss upon the death of a child. Support groups seem to ameliorate the sense of “aloneness” and foster intimate human relationships, interdependence, and reciprocity, helping to alleviate traumatic stressors associated with the child’s death.

Parental bereavement support groups may cushion the effects of traumatic stress responses and provide a safety net for women. This safety net is discussed as one of the themes which emerged in the qualitative section of this research. Namely, the superseding thesis was that individuals feel safe at support group, surrounded by others who understand their experiences. Women felt they were at a protected place, unencumbered to realize an emotionally intense experience, free of judgment, demands to move on, and social proscriptions.

Reciprocal Compassion and Transcending Their Place in the World

More than half the women in this research discussed compassion toward others, and becoming more involved in helping others, as important to them after their child’s death. Tangible aid is one of the fundamental functions of a support group. Five of the respondents were actually support group facilitators. Often, peer leaders provide one-on-one support, books, brochures, videos, art, and music resources to grieving families. Some parental support groups network with mental health professionals and thanatologists, specializing in death and loss issues. These concrete interactions facilitate healing and may help to create important subcultures of women, men, and families who are able to excel beyond their previous place in the world, returning to a higher level of social, emotional, and psychological state of functioning. Often, volunteers touched by personal

experiences of trauma or loss discover altruism as an important strategy to abate negative, long-term outcomes.

Establishment of New Cognitive Functions and Coping Skills

The purposes and benefits of support group clearly extend beyond just emotional support. Participants reported the benefits of targeted topics such as: medical conditions, clinical questions, and information and resource sharing. They reported both giving and receiving helpful advice and being able to network with others. A common thread woven throughout nearly every respondent's qualitative responses was the immense burden of guilt. While support group did not seem to help parents to relinquish those emotions, just the knowledge that others struggled with similar feelings seemingly eased the burden.

Some respondents discussed a type of consciousness-raising that addressed pervasive social problems and policy/legislative issues relating to the manner of their child's death. For example, one mother began volunteering to speak to medical professionals about the experience of stillbirth. Another joined forces to lobby for issuance by the state of a certificate of birth. For individuals who benefit from highly-task centered strategies, support group provided a place to marshal support for an issue or cause. Refocusing psychic energy into specific objectives seemed to help respondents find new ways to cope.

Many of the respondents who were longer than two years into their grief journey expressed some degree of metamorphic transformation. For these participants, support groups provided, not only comfort in the acute phases of bereavement, but also, a place to make a difference, for mobilization, during the later phases of the mourning process. Several respondents in the research currently played a key role in helping others through outreach; a role which they found to be serendipitously gratifying and that, instead of encouraging a cessation of bonds with the deceased child, cultivated ongoing bonds and empowerment through remembrance and ritualization. All of them cautiously discussed the profound ways that their lives had changed and they expressed significant spiritual and personal growth because of their experiences. Most noted that they would give all their learning and growth back to be able to parent their deceased child.

Establishment of New Norms and Meaning Making

Respondents discussed how helpful interacting with other parents was in honoring, recognizing, and destigmatizing their current emotional state. Cognitive modeling, that is, how theorists explain aspects of thought processes accomplished by a set of primitive processes (Lewis, 1999), normalizes responses particularly for the newly bereaved, and is an important function of the

support group. Cognitive modeling can be useful in a support group setting where women who are well-established in the group have an opportunity to mentor newly bereaved mothers.

Spirituality emerged as a theme in those respondents who reported a religious or faith based affiliation. Several participants connected with support through several systems including community and faith groups. Vacillating between acquiescence to “destiny” and languishing objections to their child’s absence, these participants said that their strong faith, along with support group involvement, was a source of strength, buttressing the plea for a synchronization of multiple systems.

Powerlessness is a tragic consequence of loss. Rituals are a way to participate in the early and ongoing stages of grieving, and often, support groups facilitate culturally competent ritualization. This process reduces the sense of victimization and empowers the griever to help themselves. Rituals are traditional, formal, or ceremonial acts or procedures that remove us from the everyday world to the world of spirit and emotion, from the ordinary to the sacred. Mastery and control of the process of grieving seemed to emerge as positive outcomes of support group participation. Respondents discussed having their own clandestine subculture with its own social system, words, language, and rituals.

Respondents reported that their feelings and beliefs were often valued and validated in the safe realm of the group. Others further down the grief road cited a semblance of control through altruism: They discussed helping the newer parents navigate and prepare for obstacles along the journey. Altruism within the group also helped foster a sense of triumph over tragedy, although, as one respondent mentioned, a bereaved parent would sacrifice anything just to have their child back and not belong to “this very sad club.”

LIMITATIONS

This was a preliminary study on the effects of support group involvement and perceived psychosocial support on traumatic stress and grief responses in women experiencing stillbirth. Among the limitations of the study is the low sample size ($n = 47$) which impinges on the generalizability. Purposive sampling was used to recruit some respondents and a random sample was not employed. Because information was collected in a self-administered survey, it may be prone to some inaccuracies with human subjects, depending on willingness to disclose, recall limitations, and social desirability bias. Finally, the only way to properly address the role of support groups is with a concisely designed, controlled study. This would be a tenuous undertaking and one with concerns related to ethics. Despite the limitations, the data appear to demonstrate the efficacy of support group involvement and psychosocial support for women and families experiencing sudden intrauterine infant death.

CONCLUSION

Support groups can be an effective strategy, combined with therapeutic interventions, for practitioners working with bereaved mothers after a stillbirth. The group setting may confer benefits including: unsilencing a story a woman wants to tell; desensitizing the teller to the trauma; connecting bereaved mothers with a common community thus reducing feelings of isolation; providing a place for the story to change form as the teller focuses on different details with each retelling; cultivating nurturing relationships and empowering women through remembrance and ritualization; through the narrative and information sharing processes, helping the teller gain a sense of control during early grief; providing a place for reciprocal compassion, where bereaved women can reach out as mentors to other newly bereaved women; normalizing of emotions and experiences; and providing a place to explore creative ways to cope with the loss through cognitive modeling.

The death of a baby used to be the tragic family secret that so few dared to openly discuss, shaming women into dark closets to mourn their losses with the same silence in which their dead child was born. Women are no longer finding themselves alone, navigating “an unanticipated journey with outdated maps that no longer accurately represent the sociocultural geography” of their grief (Layne, 2003, p. 236). Further, more training, education, and research is necessary for social scientists, caregivers, and clinicians to fully understand the unique dimensions of this type of tragedy.

REFERENCES

- Ananth, C., Shiliang, L., Kinzler, W. L., & Kramer, M. S. (2005). Stillbirths in the United States, 1981-2000: An age, period, and cohort analysis. *American Journal of Public Health, 95*(12), pp. 2213-2217.
- Anke, A., & Fugl-Meyer, A. (2003). Life satisfaction several years after severe multiple trauma: A retrospective investigation. *Clinical Rehabilitation, 17*, pp. 431-442.
- Barr, P. (2004). Guilt, shame, and grief following perinatal bereavement: Synopsis of an empirical study. *Psychology and Psychotherapy, 77*, pp. 493-510.
- Bird, J., & Cohen-Cole, S. A. (1990). The three-function model of the medical interview: An educational device. *Advances in Psychosomatic Medicine, 20*, pp. 65-88.
- Boivin, C. (2003). Men and women in infertile unions benefit from psychosocial intervention. *Social Science Medicine, 57*(12), pp. 2225-2341.
- Briere, J. (1997). *Psychological assessment of adult posttraumatic states*. Washington: American Psychological Association.
- Cacciatore, J. (2001). *The power of compassion: A new attitude in healthcare*. Arizona: MISS Foundation Publishing.
- Conde-Agudelo, A., Belizan, J. M., & Diaz-Rossello, J. L. (2000). Epidemiology of fetal death in Latin America. *Acta Obstetrics and Gynecology, 79*, pp. 371-378.
- Corcoran, K., & Fischer, J. (1994). *Measures for clinical practice: A Sourcebook* (3rd ed., Vol. 2). New York: The Free Press.

- Deahl, M., Srinivasan, M., Jones, N., Neblett, C., & Jolly, A. (2001). Evaluating psychological debriefing: Are we measuring the right outcome? *Journal of Traumatic Stress, 14*(3), 527-529.
- DeFrain, J. (1986). *Stillborn: The invisible death*. Massachusetts: Rowman & Littlefield.
- Fahey-McCarthy, E. (2003). Exploring theories of grief: Personal reflection. *British Medical Journal, 11*(10), 595-603.
- Fast, J. (2003). After Columbine: How people mourn sudden death. *Social Work, 8*(4), pp. 484-488.
- Fletcher, P. N. (2002). Experiences in family bereavement. *Family and Community Health, 25*(1), p. 57.
- Froen, F. J. (2005). Personal communication.
- Fukui, S., Kugaya, A., & Okamura, H. (2001). A psychosocial group intervention reduced psychological distress and enhanced coping in primary breast cancer. *Evidence Based Mental Health, 4*(1), p. 15.
- Glanz, K., Rimer, B. K., & Lewis, F. M. (2002). *Health behavior and health education: Theory, research and practice* (pp. 190-198). San Francisco: Wiley & Sons.
- Goldenberg, R. L., Kirby, R., & Culhane, J. F. (2004). Stillbirth: A review. *The Journal of Maternal-Fetal and Neonatal Medicine, 16*, pp. 79-95.
- Griefzu, S. (1996). Grieving families need your help. *RN, 58*(9), p. 22.
- Hankins, G., & Spong, C. (2001). Stillbirth: The overlooked obstetrical tragedy. *Contemporary Obstetrics and Gynecology, 46*(2), pp. 13-18.
- Horowitz, M., Wilner, M., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine, 41*, 209-218.
- Hurdle D. (2001). Social support: A critical factor in women's health and health promotion. *Health and Social Work, 26*(2), pp. 72-79. National Association of Social Workers.
- Kirkley-Best, E., & Kellner, K. R. (1982). The forgotten grief: A review of the psychology of stillbirth. *American Journal of Orthopsychiatry, 52*(3), pp. 420-429.
- Kish, C., & Holder, L. (1996). Helping say goodbye: Merging clinical scholarship with community service. *Holistic Nursing Practice, 10*(3), pp. 74-82.
- Kübler-Ross, E. (2004). Personal communication.
- The Lancet*. (1991). When is a fetus a dead baby? Editorial. *The Lancet, 337*(8740), p. 526.
- Layne, L. L. (2003). Unhappy endings: A feminist reappraisal of the women's health movement from the vantage of pregnancy loss. *Social Science & Medicine, 56*(9), 1881-1891.
- Lensing, V. (2001). Grief support: The role of funeral service. *Journal of Loss and Trauma, 6*, pp. 45-63.
- Lewis, R. L. (1999). Cognitive modeling, symbolic. In R. Wilson & F. Keil (Eds), *The MIT encyclopedia of cognitive sciences*. Massachusetts: MIT Press.
- Lovell, A. (1983). Some questions of identity: Stillbirth and perinatal loss. *Social Science Medicine, 17*(11), pp. 755-761.
- Malacrida, C. A. (1997). Perinatal death: Helping parents find their way. *Journal of Family Nursing, 3*, pp. 130-148.
- Michon, B., Balkou, S., Hivon, R., & Cyr, C. (2003). Death of a child: Parental perception of grief intensity. *End of Life and Bereavement Care, 8*(6), pp. 363-366.
- Muller, E., & Thomson, C. (2003). The experience of grief after bereavement. *Journal of Mental Health Counseling, 25*(3), p. 183.

- Murphy, S. A., Baugher, R., Lohan, J., Scheidman, J., Heerwagen, J., & Johnson, L. C. (1996). Parents' evaluation of a preventive intervention following the sudden, violent deaths of their children. *Death Studies, 20*, 453-468.
- Neukrug, E. (2004). *Theory, practice, and trends in human services*. Pacific Grove, CA: Brooks/Cole-Thompson Learning.
- Pfeffer, C., Jiang, H., Kakuma, T., Hwang, J., & Metsch, M. (2002). Group intervention for children bereaved by the suicide of a relative. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*, pp. 505-509.
- Prigerson, H. G., Bierhals, A. J., Kasl, S. V., Reynolds, C. F., Shear, M. K., & Day, N. (1997). Traumatic grief as a risk factor for mental health and physical morbidity. *The American Journal of Psychiatry, 154*, pp. 616-623.
- Radestad, I., Steineck, G., Nordin, C., & Sjogren, B. (1996). Psychological complications after stillbirth: Population-based study. *British Medical Journal, 312*(7045), p. 1505.
- Rando, T. A. (1985). Bereaved parents: Particular difficulties, unique factors, and treatment issues. *Social Work, 30*(1), 19-23.
- Rodale, A., & Stocker, S. (1994). Beyond grief: A guide to reconciling life after loss. *Prevention, 46*(8), p. 88.
- Sadler, M. (1987). When your patient's baby dies before birth. *RN, 50*, pp. 28-31.
- Sheldon, F. (1998). Bereavement. *British Medical Journal, 316*(7129), pp. 456-459.
- Smith, A. D. (2002). Emotional distress and prenatal attachment in pregnancy after perinatal loss. *Journal of Nursing Scholarship, 34*(4), pp. 339-345.
- Sprang, G., & McNeil, J. (1998). Post-homicide reactions: Grief, mourning, and post traumatic stress. *Omega Journal of Death and Dying, 37*, pp. 41-58.
- Tedeschi, R., & Calhoun, L. (1995). *Trauma and transformation: Growing in the aftermath of suffering*. Thousand Oaks: Sage Publications.
- Tedeschi, R., & Calhoun, L. (2004). Posttraumatic growth: A new perspective on psychotraumatology. *Psychiatric Times, 26*, p. 4.
- Vaisanen, L. (1999). *Family grief and recovery process when a baby dies*. Doctoral dissertation. University of Oulu, Department of Psychiatry.
- Weiss, D., & Marmar, C. (1997). The Impact of Event Scale-Revised. In J. Wilson & T. Keane (Eds.), *Assessing psychological trauma and PTSD*. New York: Guilford.
- Worth, N. J. (1997). Becoming a father to a stillborn child. *Clinical Nursing Research, 6*(1).

Direct reprint requests to:

Joanne Cacciatore
 Arizona State University
 West CHS
 Dept of Social Work
 P.O. Box 37100
 Phoenix, AZ 85069-7100
 e-mail: joanne.cacciatore@asu.edu