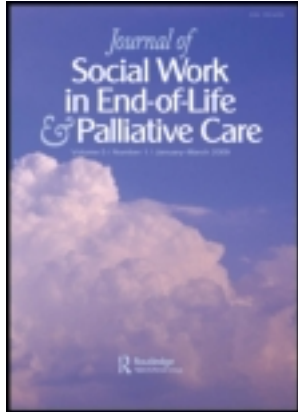


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### Stillbirth: The Mother's Experience and Implications for Improving Care

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## Stillbirth: The Mother's Experience and Implications for Improving Care

Joanne Cacciatore, LMSW, FT  
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**ABSTRACT.** More children die as a result of stillbirth than all other causes of infant deaths combined (Ananth, Shiliang, Kinzler, and Kramer, 2005; Goldenberg, Kirby, and Culhane, 2004; Froen, 2005; National Institute of Health, 2004); yet, mothers experiencing stillbirth are often left without support afterwards (Kubler-Ross, 2004; Fahey-McCarthy, 2003; Fletcher 2002; Saddler, 1987; DeFrain, 1986; Kirkley-Best & Kellner, 1982). Despite social work's growing involvement in care at the end of life, parents of stillborn children have not experienced consistent, relevant, and competent professional care in coping with the tragedy of death. Forty-seven women between the ages of 19 and 51 were recruited through nonprofit agencies that provide bereavement care to grieving families. Results of this qualitative study suggest that stillbirth is emotionally complex with long-lasting symptoms of grief and significant struggles to find meaning. The findings also support the need for perceived psychosocial and spiritual support from professional caregivers, family, and friends. The women's own experiences argue for comprehensive approaches to support the grief and loss of

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stillbirth, and for the importance of social work involvement in both immediate and longer term interventions. doi:10.1300/J457v03n03\_06 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2007 by The Haworth Press, Inc. All rights reserved.]

**KEYWORDS.** Stillbirth, social support, spiritual support, grief, pediatric death

### *INTRODUCTION AND PURPOSE*

Every day in the United States, nearly 100 babies are stillborn (Froen, 2005; Fletcher, 2002). More children die as a result of stillbirth than all other causes of infant deaths combined (Ananth, Shiliang, Kinzler, and Kramer, 2005; Goldenberg, Kirby, and Culhane, 2004; National Institute of Health, 2004; Hankins and Spong, 2001; Smith Armstrong, 2002); yet, mothers experiencing stillbirth are often left bereft of support in one of life's most unexplainable experiences (Fahey-McCarthy, 2003; Hagenow, 2003; Kissane, 2003; Fletcher 2002; Vaisanen, 1999; DeFrain, 1986; Kirkley-Best & Kellner, 1982). Despite social work's growing involvement in care at the end of life, parents of stillborn children have not experienced consistent, relevant, and competent professional care in coping with the tragedy of infant death. The shifting focus of hospital social work to discharge planning and referral services, and inadequate preparation of social workers, may contribute to this neglect. Social workers need to advocate for the importance of psychosocial and spiritual care, and the role of social work in providing this care.

This study sought to understand the experiences of women who have had a sudden intrauterine infant death, to explore what they have found helpful in the process of moving through their grief, and how the experience has transformed them. It was expected that the women's experiences may enrich our understanding of the need for more comprehensive and holistic models for support which address the bio-psycho-social-spiritual needs of women experiencing stillbirth.

### *SCOPE OF THE PROBLEM AND IMPACT*

Worldwide, there are about 4 million sudden intrauterine infant deaths every year. Historically, minority groups have been over-represented in both fetal and infant mortality rates. The rates, measured per

1,000 live births, have remained between 20 and 30 for African Americans, 30 and 35 for Native Americans, and between 10 and 15 for Caucasians (Centers for Disease Control, 2004). Despite the fact that stillbirth happens to about one in 100 pregnant women, it is a loss that has been largely overlooked and even ignored.

Stillbirth most frequently takes place in hospitals, where labor and delivery services focus on birth, and may not be well prepared to address death. Stillbirth has one common denominator absent in all other types of deaths. The sudden death occurs only in a woman's body and often is known as the "invisible death" (DeFrain, 1986). Social workers would do well to recognize that the grief experience after a child dies is debilitating. It is one of the "most painful bereavements" (Sheldon, 1998), and is among the most "intense and profound" human experiences still prevalent in Western civilization (Michon, Balkou, Hivon, & Cyr, 2003). Yet, "little is known about the experiences a family has after a child dies" (Fletcher, 2002, p. 58), especially in the case of stillbirth. In part, this is due to the change of status of the mother experiencing stillbirth: "by the time a loss has occurred, the . . . neonatal patient is no more and the woman is no longer pregnant, therefore no longer an obstetrical patient" (Layne, 2006, p. 605). Stillbirth was an under-researched, unexplored arena in medical literature until recently.

Childbirth has a significant social, emotional, physiological, and political influence on the lives of many women (Smith Armstrong, 2002; Arms, 1994). An experience that traverses culture (Smith Armstrong, 2004), childbirth is recognized in the customs and rituals of both modern and pre-modern societies. In some cultures, the pregnant woman is revered. Most often, childbirth is celebrated with joy, anticipation, and high expectations (Worth, 1997). Instead, when the baby is stillborn, mothers experience death, departure, and grief (Cacciatore, 2007). Bereaved parents are known to suffer higher rates of complicated grief (Zhang et al., 2006). The vital role of social workers and other psychosocial providers with expertise in dealing with these tragic events has recently been identified (Truog et al., 2006).

### ***ROLE OF SOCIAL WORK IN HOSPITAL SETTINGS***

Immediate responses by social work and the interdisciplinary team to bereaved parents vary considerably. The advantages of full participation of hospital social work as part of the interdisciplinary team have been well documented (Kitchen & Brook, 2005; Mizrahi & Berger,

2005). Increasingly, social work's role within the hospital setting has shifted, and these changes have sometimes limited the involvement of social work to discharge planning (Mizrahi et al., 2005; Berger et al., 1996). Barriers to effective and active social work involvement have been identified, including the need for training (Reese, et.al., 2005; Papadatou, 1997) and a personal philosophy on life and death (Lattanzi-Licht, 1991). Hospitals have adopted standards of care which may include referral for psychosocial and spiritual support, and protocols for disposition of the remains. But open and honest communication, opportunities to hold and photograph the child, information, time to process the experience, and other supportive counseling interventions vary widely. Nurses, social workers, and other caregivers can buffer negative, long term effects to those who have experienced traumatic loss (Cacciatore; 2007; DeFrain et al., 1990; Malacrida, 1997; Sheldon; 1998), and they play a particularly important role when a child has died. Immediate intervention strategies in the hospital, however, may not be enough when a child has died. Thus, many professional disciplines, including social work, have relied on community-based intervention modalities (Callahan, 1995).

### ***THEORETICAL FOUNDATIONS***

Attachment theory, theories of social support, and transpersonal theory have particular relevance to the loss experienced in stillbirth. Present-day epistemology in grief, loss, and mourning "rests on foundations" constructed by British psychiatrist, John Bowlby. Bowlby's model does not suggest that attachment is contingent on age, time spent in a relationship, or interdependency. Rather, Bowlby's model recognizes the complexities, strata, and scope of attachment. Bowlby, as well as some Neo-Freudians, postulate that grief is an emotion to experience and work through rather than an emotion to circumvent. The implication is that healing from the traumatic death of a loved one requires work, time, and support from others. Bowlby's attachment model does not minimize the attachment which might be present between a mother and her stillborn child, and there is reason for social groups to provide support which extends beyond the immediate event of stillbirth (Fast, 2003).

There are many "unique factors of parental bereavement" (Rando, 1985, p. 21) and "the death of a child incites an incalculable range of responses" including somatic and psychological distress (Cacciatore,

2007). Rando's understanding of grief and loss suggests dual struggles to deny the loss, and avoidance of letting go of the loved one (Rando, 1992). Within a framework of "retreat, exclusion, and mastery" the death of a child complicates the need for support. Social, and sometimes political, support groups have emerged as creative and successful interventions "undertaken to create a community of bereavement" (Fast, 2003, p. 486). Their apparent successes are attributed to the connection between those with like, often difficult and painful, experiences (Muller & Thompson, 2003; Griefzu, 1996; Rodale & Stocker, 1994). Social workers who recognize the value of connecting vulnerable individuals with one another may make referrals to community-based support groups (Boivin, 2004; Hurdle, 2001; Anke & Fugl-Meyer, 2003) whereby the client can experience emotional support (a sense of belonging), instrumental support (a safe place for dialogue), educational support (advice and suggestions), and appraisal support (normalization and social comparison) (Cacciatore, 2007; Glanz, Rimer, and Lewis (2002). Support for bereaved parents has also been found to facilitate meaning-making (Lister, 2006). Social support and attachment, however, do not fully account for the aspects of meaning and other spiritual losses associated with stillbirth. The need to address loss more holistically suggests a need for theories which incorporate the spiritual dimension of grief.

A transpersonal perspective is one that can "move beyond the person, or beyond ego" (Smith, 1995, p. 403). Transpersonal approaches recognize the spiritual dimension, while rejecting the artificial divisions of the physical, psychological, social, and spiritual self, and may be necessary in order to communicate a respect for the person's values and beliefs (Cowley & Derezotes, 1994). By focusing on wholeness, healing, transformation, meaning, and hope, transpersonal approaches may offer a more holistic framework for approaching women experiencing stillbirth. "Validation experienced through support may assist bereaved mothers in reconciling spiritual beliefs and re-working relationships" (Lister, 2006, p. 6335) as well as transforming previously held beliefs (Matthews & Marwit, 2006). Transformation has been identified as a "stage" in the process of grief (Kubler Ross) and this process of transformation is often represented by a new perspective on the loss. "When change is transformational, it moves people forward on their spiritual paths" (Canda & Furman, 2000, p. 252). It is precisely this transformation that may assist mothers who experience stillbirth to redefine their distress in terms of finding meaning in the short life of their child.

### **LITERATURE REVIEW**

Mothers experiencing a stillbirth have been studied with respect to the epidemiology of stillbirth (Goldenberg et al., 2004; Froen et al., 2002; and Hankins & Spong, 2001). However, many stillbirths are unexplained. Stillbirth has been identified as a high risk indicator for psychiatric morbidity, including PTSD (Barr, 2004; Walling, 2002; Vaisanen, 1999; Radestad et.al., 1996 Fones, 1996), and the impact is long-lasting (Boyle et al., 1996; Vance et al., 1995). Yet, attempts to study intervention outcomes have produced mixed results. Certainly, sensitivity to the mother's experience is one indicator of satisfaction with hospital care (Lasker & Toedter, 1994). Nevertheless, staff are often not adequately prepared (Chan & Day, 2005). Guidelines for best practices in psychosocial care following stillbirth include seeing and holding the stillborn child, as well as other rituals (Hughes et al., 2002). There is little evidence, however, that these practices result in improved outcomes. This study fills an important gap in the literature, by focusing on women who have experienced a stillbirth. While it is clear that stillbirth places women at risk for complicated mourning, many mothers may not experience hospital based interventions specifically targeted at their needs; moreover, it is unknown whether or not these interventions, even when experienced, are helpful. The qualitative study reported here was part of a larger, mixed-methods study which explored the effects of social support on women experiencing stillbirth (Cacciatore, 2007). This study explored what bereaved mothers have found to be helpful in the process of moving through grief, and how the experience has transformed them.

### **METHOD**

Phenomenology is one method for gaining insight into the lived experience (Rose et al., 1995). Perspectives on the most sensitive life experiences may require this approach (Lee & Renzitti, 1993), in order to better understand the mothers' lived experience.

#### ***Participants***

Participants were recruited using purposive and snowball sampling. Participants were notified of the study through nonprofit agencies that provide bereavement care to grieving families. Other participants who



were recruited by snowball sampling learned about the research through others in their social network.

### ***Data Collection***

Participants were provided general instructions as well as a copy of the Informed Consent. They were instructed to respond to the self-administered questionnaire reflecting on their current feelings and emotions. Participants completed the questionnaires in their own homes and returned the questionnaires by mail to the researchers. Upon receipt, questionnaires were assigned identification numbers and stored separately from consent forms, in order to maintain the anonymity of participants.

### ***Instrument***

Two qualitative questions were asked along with an open ended narrative that allowed participants to share primary concerns or previously unexplored thoughts. Question one (Q1) inquired, "What do you feel has most helped you deal with the death of your child?" Question 2 (Q2) 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), "Please share any other information that you believe will be helpful in this research."

### ***Qualitative Data Analysis***

Qualitative data were placed in a matrix to isolate clusters of common, emergent themes in the responses provided to participants. Horizontal linkages and regularities in language were carefully analyzed. The phenomenological rubric was used to discover both the objective and subjective realities and meanings associated with the experience of the child's death. Following the process outlined by Moustakas (1994), the essential essence of what was experienced and how it was experienced was described. Bracketing was used to isolate the researcher's own experiences and reflections.



## *FINDINGS*

### *Demographics*

Women between the ages of 19 and 51 ( $n = 47$ ) responded to the questionnaire. There were 38 European Americans, three African Americans, three Latino, two 'Other,' and one Asian. Most participants held an undergraduate degree ( $n = 23$ ), followed by high school diploma ( $n = 12$ ), graduate ( $n = 7$ ), and postgraduate ( $n = 4$ ). One participant did not answer this question. All experienced the stillbirth of their baby at various gestational ages (Table 1).

The nature of the death was most often sudden and unexpected ( $n = 44$ ). The time since death ranged from within the past year ( $n = 10$ ), one to two years ( $n = 10$ ), two to five years ( $n = 17$ ), five to 10 years ( $n = 7$ ), and greater than 10 years ( $n = 3$ ). Most women had other surviving children. A higher level of diversity was apparent in demographics relating to religious faith and spirituality, although some who responded "None Specified" may have considered themselves to be spiritual. Participants were Christian ( $n = 24$ ), Catholic ( $n = 9$ ), None Specified ( $n = 9$ ), Buddhist ( $n = 3$ ), Jewish ( $n = 1$ ), Atheist ( $n = 1$ ). More than one-half (53.2%) of the participants claimed membership to a specific church, temple, or synagogue.

*Q 1: 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 and talking with other bereaved parents were the most helpful in dealing with the death of their child. This help came through a sense of belonging and affiliation, reversal of isolation, and through validation of the mother's experience. This sense of connection and support was experienced as a bittersweet oasis, within a world which frequently dismissed, ignored, or minimized the painful loss of stillbirth.

*Q1 Theme1: Support and talking perceived as helpful validation of the mother's experience*

Mothers reported that the experience of talking about their loss, hearing from others experiencing similar losses, and meeting others who shared the grief experience as helpful. It appears that this sense of vali-

TABLE 1. Gestational Age of Child at the Time of Death

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	20-32 weeks	13	27.7	27.7	27.7
	33-36 weeks	12	25.5	25.5	53.2
	37 or more weeks	22	46.8	46.8	100.0
	Total	47	100.0	100.0	

dation, coming from others who have experienced stillbirth cannot be replaced by other types of support. “Meeting those who had actually survived the death of their child,” and “other grieving parents . . . have validated my grief.”

*Q.1 Theme 2: Support as reversal of isolation, providing comfort, connection, and a frame of reference*

Mothers expressed that this type of support and acknowledgment provided a frame of reference within which mothers experiencing stillbirth could begin to normalize their feelings. For example, “. . . having people acknowledge (her) life and death and her impact on my family, helped me to know that I’m not crazy.”

Mothers were particularly helped by feeling that they were not alone in their grief, and that someone else could understand the experience. One mother noted, “I was so grateful to have a place to turn where people experienced the same nightmare and knew what I was going through...Others just can’t relate to what has happened.” The examples of others who had survived the experience provided hope, a place to validate the child’s life, and a sense that survival was possible. “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!” Mothers also noted the courage others demonstrated, serving as a beacon to carry on the journey of grief. “Without the courageous parents I’ve met through support groups, in person and online, I do not think I’d be here today.”

*Q2: Has your child’s death changed you and if so, in what ways?*

This question addressed transformations, which can take a long time after the child’s death. All 47 respondents noted that their child’s death

had evoked some type of change. Many had epiphanies about the fragility of life. Some discovered inner strength and some reported they have become activists for related causes. Many, particularly those further along in the grief, expressed frustration with others for the perceived lack of validation and acknowledgement of their child's life. Those who reported involvement in helping others through various parental or advocacy organizations generally stated a positive change of direction, focusing on a new sense of compassion for others. Again, this change, while perceived as mostly positive, came with a price that no one wished to pay. The integration of the death and loss into the mother's continuing life represents a profound struggle, and also a transformation. The element of time is significant; some participants had taken many years to come to a sense of meaning or purpose.

*Q2 Theme 1: Life is forever changed: view of self and others*

The experience of a child's death marked a transition in how mothers viewed themselves and others. "My child's death has changed me to be a more sensitive person to other's feelings. Her death has made me realize not to take things for granted such as my living children." Noting that this change, even when positive, was not welcomed due to its cost, mothers identified a movement toward sensitivity to others, and compassion for the needs of others. ". . . 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." This change, as well as the loss, is described as permanent, and transformational. ". . . My loss is part of me, of who I am, and makes up my life story." Another mother indicated, "I am touched forever. The void will always be there." The change was also marked by a turning point, an outward view of self which begins to focus on the needs of others. "I feel so much more deeply for people who have lost a child at any age. I am not naive and innocent about life and I have learned what grace from God is—truly. I appreciate life more and the fragility of pregnancy that I never knew existed.

*Q3: 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. Three themes were identified: profound

loss, what professionals should know and do, and transformation over time, with spiritual dimensions of meaning and purpose. Again, the responses here overwhelmingly converged on many of the mothers' concerns over societal legitimization of their child. This theme was woven throughout the voices of many women in this research. Respondents openly discussed their feelings of disenfranchisement and social isolation. Some expressed concern regarding the ethic of compassionate care provided to them during their child's death and others praised caring professionals. Many were now able to recognize what was needed or what would have been helpful, and how others were ineffective in meeting the need. Mothers emphatically communicated the depth of their losses, and the longing for "what would have been helpful." The transformations described suggest the spiritual focus on meaning making and transcendence, which signals a transformation of the grief to a sense of purpose and "giving back." However, for some respondents, the challenge to faith which is presented by grief has yet to be resolved.

### Q 3: Theme 1: *Expressions of profound loss*

Despite the transformation that stillbirth brings, and the ability of mothers, over time, to find meaning, it does not diminish the sense of loss. "(His) death has by far been the most devastating, life-changing event in my life." This experience of loss is profound, and continues as a painful reminder of what is missing. This loss may be expressed differently, but commonly with deep physical sensations. One mother wrote, "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. . ."

Another expressed, "There were moments when I could have shriveled up in bed forever." The physical pain can also begin to manifest as a spiritual pain.

"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."

This multidimensional loss has a way of separating the mother from others. “I’m not sure of ‘faith’ in any traditional sense nor do I believe in heaven or angels . . . sometimes, I felt like an outsider in a place where I’d hoped to be understood . . .”

Q 3: Theme 2: *What professionals should know and do (and what they did not do):*

### ***Need for Information and Guidance***

In looking back, participants were able to identify a number of “missed opportunities” in the hospital, when staff might have offered additional help, through information and process. “I wish the nurses could have guided us more in our final hours with our son. I didn’t think to bathe or dress him or have our pictures taken holding him. I wish someone would have suggested it.” In retrospect, mothers can identify needless struggles that might be prevented by proactive involvement of hospital personnel, particularly social workers.

“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 . . .”

Some seemingly small gestures are appreciated and remembered as significant. “Our nurses called our child by her name which helped our feelings to know that she was not being treated as another statistic.”

### ***Need for Timely Intervention***

It is also noteworthy that there is a critical window for intervention. Leaving the hospital without the anticipated child may make mothers even more sensitive to the timely intervention of social work. “Hospitals should have caring, competent social workers . . . the social worker we saw didn’t see us until ten minutes before discharge . . . No one was there to help us make major decisions or even lend guidance . . .” Another mother indicated, “We were told a social worker would visit us prior to discharge but one never did.”

### ***Need for Follow Up and Personalized Care***

Mothers identified a need for follow-up during the immediate post-stillbirth experience. This follow-up should be from someone experienced in this particular kind of loss. “There is a strong need to find a therapist that has experienced the loss . . . I’ve yet to find one that has experienced the death of a child . . . the most hurtful thing was never getting a call from our Drs. to see how we were doing.” The absence of contact is often interpreted as a lack of concern or care, and increases the feelings of isolation and loss.

“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.”

Mothers are otherwise left on their own. Mothers who have experienced timely support and concern, as well as follow up, remember this reaching out for a very long time.

“I also would have liked to receive follow-ups in the months after my loss to see how I was coping emotionally. I also wish that infant loss support members could have come to the hospital to lend support and guidance . . .” “My doctor called and checked on us after we were home which showed us that he cared . . .”

Q3: Theme 3: *Transformation takes time; “giving back” as a milestone for healing*

It may take months, or even years, but mothers who experience stillbirth do identify change over time. “As time passes, I feel I am beginning to see the more positive ways in which I can take action and reach out to other bereaved parents.” It may be surprising that this grief trajectory is lengthy. “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.”

Q3: Theme 4: *Finding meaning and purpose, renewed sense of self*

The renewal and transformation of the profound loss of stillbirth comes slowly. When this meaning is accompanied by a sense of purpose, mothers acknowledge that the child they have lost was uniquely valuable.

“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.”

This transformative aspect of loss depends on the compassionate support of others. “But (they) helped nourish me, to continue to see myself as someone’s mommy, to do meaningful work in the world, not for ‘gains’ but as my child’s legacy.” It is through this compassionate support that mothers make sense of the loss. “And I believe in human kindness and goodness even more after the outpouring of love we received from the moment we found out her heart was not beating . . . I’m learning to trust at a different level.”

### DISCUSSION

Mothers experiencing stillbirth reflect a sense of profound loss that is long-lasting. This does not always meet with supportive responses within the usual settings. Hospitals, where most births and stillbirths take place, have often neglected to attend to the special needs of mothers experiencing stillbirth. Moreover, the short-term hospital stay would suggest that other community-based interventions may be needed. A shift to incorporate transpersonal approaches may offer better models of responses to mothers experiencing stillbirth. The shift might also begin with subtle changes to deconstruct the way that stillbirth is perceived and allow women who have undergone stillbirth to construct their own realities about their losses. In open ended responses, the women participating in this study referred to the stillborn child as her child. Acknowledging and reflecting this language used to talk about stillbirth may be significant in addressing the disenfranchisement



of mothers experiencing stillbirth. The prevailing culture, medical or non-medical, often uses the terms “reproductive loss,” “fetal demise,” or “adverse outcome of pregnancy” when discussing sudden intrauterine infant death. Mothers indicated that this serves to de-personalize and minimize the loss of their child.

. . . The language chosen to describe social issues is very powerful. Historically, euphemisms are used to “clean up the mess” of social problems. Yet, if we do not call it what it is, such as in the case of stillbirth, frankly, the birth of a dead baby, society will never pause to pay attention and the ‘cause’ will take longer to establish firm roots . . . . (By using) the phrase “pregnancy loss” to talk about the death of a child to stillbirth, there is an inference that a child, in fact, did not die. Rather that “merely” a pregnancy was “lost.” For many women, the phrase decries and derogates their very personal tragedies. (MISS Foundation, 2005, p. 1)

Further, mothers experiencing a loss through stillbirth are vulnerable. Expectations have been thwarted, and the experience, to many, is traumatizing. The long lasting impacts of the experience suggest the need for longer trajectories of recovery and reintegration of the loss.

### ***Limitations***

This study was part of a larger study on the effects of social support on traumatic stress and grief responses in women experiencing stillbirth. Purposive sampling was used, targeting women who were accessing support for bereavement, and data collected in a self-administered survey. This may clearly have limited participation of mothers who did not experience any distress related to stillbirth. The study also relied on memory recall of the participants. Limitations also include social desirability bias. Despite the limitations, the findings suggest that psychosocial and often spiritual support may be necessary for women experiencing stillbirth, and that caring social workers and other professionals should recognize and respond to this need.

## ***IMPLICATIONS FOR SOCIAL WORK***

### ***1. Need for Emotional Support: “Linkages and Nourishing Relationships”***

“Other (grieving) parents who support me and have validated my grief . . . Once I got validation from others, things starting getting better for me.”

Grief can be a lonely and self-indulgent experience for many individuals. 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 may ameliorate the sense of aloneness and encourage intimacy in relationships, interdependence, and reciprocity, helping to alleviate traumatic stressors associated with the child’s death. Hospital social workers play a key role in linking mothers to on-going support and services beyond the hospital experience.

### ***2. Need for Instrumental Support: Reciprocal Healing and Transcending***

“Reaching out to others in my son’s memory.”

“Tangible aid is one of the fundamental functions of a support group” (Cacciatore, 2007, p. 85). Support group leaders should provide not only emotional, but practical aid and resources to grieving families. Many groups are deeply embedded in their communities, and frequently network with professional caregivers and the faith based community, providing referrals for counseling and other services. The development of those relationships encourages mutual referrals, and more people learn about the group. The result is that the group may experience faster growth, and seasoned members can then reach out to many others who are more recently bereaved. Some of those relationships that begin in the support group setting appear to carry benefits beyond the monthly sessions, and relationships between members often become mutually compassionate and beneficial. “These concrete interactions facilitate healing and help to create important subcultures of women who transcend their previous place in the world,” find a higher purpose in their losses, and discover that they are making a difference in the lives of others (Cacciatore, 2007, p. 85). Hospital social workers are in a key position to be the first responders to the need for instrumental support, through provision of information, presence, and taking time to help the mothers process the experience.

### ***3. Need for Transpersonal Approaches When Experiencing Stillbirth***

“I didn’t understand . . . why me?”

“Every night I pray for those who are in mourning over the loss of a child.”

Spirituality was a strong theme for many participants. A few mothers sought support from multiple systems, one of which included faith based counseling and support groups. The grief of these mothers had a vicissitudinous quality, as they volleyed between acceptance and rejection of their babies’ death. For participants in this study faith was a source of both comfort and strength. Others further down the grief road cited a semblance of control through altruism: they discussed helping newly bereaved parents navigate and prepare for obstacles along the journey. Altruism was a common marker for the majority of mothers, and it signaled a transition of grief to a place in which they were able to discover purpose and meaning in their very personal losses. Social workers are increasingly involved in spiritual assessment, and have new tools to assist them in developing spiritual competency (Hodge, 2006; Hodge & Bushfield, 2006), and in fostering hope and meaning-making (Bushfield, 2003). Involving spiritual caregivers, and working to remove barriers to collaboration, may be important (Furman & Bushfield, 2000). Recognizing that the loss of stillbirth may prompt a spiritual crisis, it may be necessary for social workers to develop an awareness of the difference between “spiritual emergence and spiritual emergency” (Canda & Furman, 2000), which is sometimes precipitated by loss.

### **CONCLUSIONS**

This study explored the experiences of bereaved mothers after stillbirth. The death of a child at any age and from any cause is an irretrievably life-changing experience. Time was an element in this process, and women whose experience was many years ago still voiced issues related to their loss. Reconciling the loss may take many years for some women “as they find their way” through the effects of traumatic grief (Cacciatore, 2007). While historically, the emotional effects of stillbirth and perinatal death have been minimized, politicized, and perhaps, stigmatized, the results of this study support the notion that stillbirth is as emotionally complex and traumatic as deaths that occur in later childhood.

These findings demonstrate the need for psychosocial support from professional care-givers. Social support and psychosocial intervention strategies may play a promising and fundamental role in helping to ame-

liorate the most severe responses and reestablish a sense of equilibrium. They may enable women to engage with other women who relate to the phenomenological crisis of a stillbirth (Hagenow, 2003). A strong sense of social support and coherence help mitigate feelings of disenfranchisement and increase individual perceptions of long-term happiness (Anke & Fugl-Meyer, 2003) 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 help people cope (Cacciatore, 2007, p. 73; Hurdle, 2001). Support networks are particularly important to women (Hurdle, 2001; DeFrain, 1986).

During the hospital stay, uncaring and dismissive responses may have a long lasting impact, while supportive responses are beneficial. However, compassionate care by hospital staff and traditional mental health services alone may not be enough. On-going support and connection with others who have experienced similar deaths fosters a sense of belonging and connection and is helpful to mothers as they mourn their babies. "More training, education, and research is necessary for social workers . . . to fully understand the unique dimensions of this type of tragedy" (Cacciatore, 2007, p. 88). Social workers, in addressing this often unmet need, will find opportunities for advocacy within both the medical environment in which stillbirth usually takes place, and also within the larger political environment, both of which may not support the full recognition of and attention to stillbirth and the benefit of social work's holistic responses to mothers experiencing stillbirth.

In support of more holistic approaches, women often have a desire to reach out for nurturance from others, from resources outside the self and beyond their core systems during both the acute and chronic crisis. This aspect of healing and transformation suggests a need for more transpersonal approaches. The effects of having a stillborn infant are perduring; some women "struggle for equilibrium, to regain a sense of control and normalcy, and to discover meaning in their very personal tragedies" for years after their baby's death (Cacciatore, 2007, p. 85). The opportunity to make sense of the loss, find ways to help others, and honor the life of their stillborn children seems to provide help and a sense of purpose. Inclusion of holistic approaches to support and integrate the experience of stillbirth in women's lives may be required. Social workers need adequate preparation to provide effective interventions at the time of loss, and across the lifespan of grief, and may need to address systemic barriers which prevent their full participation in multi-disciplinary interventions at the time of stillbirth, and be-

yond the hospital experience. Future research which addresses the needs of parents experiencing stillbirth, as well as their responses and outcomes to specific social work interventions, may provide additional insight into the need for policies which support more holistic interventions.

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