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Social Work in Health Care

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title~content=t792306964>

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Online publication date: 19 February 2010

To cite this Article Cacciatore, Joanne(2010) 'The Unique Experiences of Women and Their Families After the Death of a Baby', *Social Work in Health Care*, 49: 2, 134 – 148

To link to this Article: DOI: 10.1080/00981380903158078

URL: <http://dx.doi.org/10.1080/00981380903158078>

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The Unique Experiences of Women and Their Families After the Death of a Baby

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This study sought to discover the ways in which the woman's experience of a baby's death affects her as an individual and within the family system. More specifically, this study asked: Does a woman's experience of stillbirth appear to have long-lasting effects, and what variables influence such changes? Expressed through their own narratives, it appears that a baby's death has long-lasting effects for a woman. Variables that affect her perceptual experience include social support, legitimization of her loss, opportunities for rituals, and existential emotions such as shame and guilt. Results revealed that enhanced understanding of the experience and psychosocial support may help some women and their family systems cope with the long-term effects of this loss.

KEYWORDS *stillbirth, infant death, fetal death, psychosocial intervention, maternal grief*

INTRODUCTION

The image of a woman reaching down to bring her baby onto her breast at the moment of birth is a powerful one. She birthed her baby, and every cell in her body knows and shows her strength. At the end of hours of pain and emotions felt more intensely than at any other time in life, she is exultant. To know the exhilaration, euphoria, and power that comes with the exhaustion and pain of giving birth is truly empowering. (Verhaeghe, 2003, p. 1)

Received January 8, 2009; accepted April 28, 2009.

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Pregnancy and birth are uniquely female processes that entirely change a woman's body. "Birth represents a complex and highly important series of functional changes" (Montagu, 1986, p. 57). The pregnancy and birthing process is a complex, painful, and difficult process for the female body (Bingham, 2006). "During the birth process mother and infant have a somewhat trying time. At birth each clearly requires the reassurance of the other's presence. The reassurance for the mother lies in the sight of the baby, its first cry, and in its closeness to her body" (Montagu, 1986, p. 73). Yet, the stillbirth of a baby is often an overlooked tragedy that occurs in approximately 1 in 110 births (Silver, 2007). These are mostly sudden and unexpected deaths, occurring within a woman's body and thus they are largely an invisible death (DeFrain, Martens, Stork & Stork, 1986).

LITERATURE REVIEW

An estimated 30,000 families will experience the death of a baby to stillbirth during 2009. While child deaths are often recognized as traumatic (Rando, 1985; Prigerson et al., 1997), the death of a baby to stillbirth brings unique social and psychological features (Cacciatore, 2007). These include feelings of disenfranchisement and limited social support for what may be considered by much of society as a non-event (Vaisanen, 1999; Rådestad, Steinbeck, Nordin, & Sjogren, 1996; Wheeler & Limbo, 1998; DeFrain et al., 1986). Malacrida (1999) suggested that parents' "expectations of support, based on their own valuation of the loss stood in contrast to the actual support they received from . . . immediate and extended families, the medical community, and helping professionals" after a perinatal death (p. 510). It is this incongruence between the grieving mothers' affect and the social responses she receives that result in pathological grief. The "social nonrecognition and nonsupport . . . are precisely the types of interactions that eventually will lead parents to require therapy" (Malacrida, 1999, p. 513).

Physiological Aspects of Stillbirth

The process of giving birth to a stillborn baby is physiologically identical to that of a live born baby, although giving birth to a stillborn is recognized as significantly more traumatic (Kendall-Tackett, 2004; Rådestad, Nordin, Steinbeck, & Sjogren, 1998). Maternal behaviors are not mere a product of emotion and affect. Rather, "the brain is a nexus between the input of an understanding" that the baby died and "the output of emotion, behavior, and thought" (O'Connor, 2005, p. 905). Researchers have identified an evolutionarily designed complex "set of behaviors involved in the care of the young" (Deutsch & Deutsch, 1966, p. 61). These biological

drives occur due to a synchronistic balance of the endocrine and limbic systems, anterior pituitary, sex hormones, and the hypothalamus. The same complex, biological, hormonal, and physiological changes occur without the presence of a live baby to balance the trauma with joy, or fulfill the evolutionary yearning—the maternal call—to nurture the newborn (Deutsch & Deutsch, 1966). Giving birth to a stillborn baby involves physical, emotional, and cognitive trauma. Fear and negative cognition, as well as the state of pain, both predict post-traumatic stress symptomatology (Shalev et al., 1998), eliciting a concomitant set of biological responses in areas of the brain such as the amygdala, hippocampus, and neocortex (MacLean & Delgado, 1953). These processes are likely to exacerbate the mother's risk for depression, post-traumatic stress disorder (PTSD), psychosis, and other adverse psychobiological outcomes (Gamble et al., 2005; Trulsson & Rådestad, 2004; Malacrida, 1997; Condon, 1986; Kirkley-Best & Kellner, 1982).

Social and Psychological Effects

Rådestad et al. (1996) found that three years after stillbirth, bereaved mothers were twice as likely to experience anxiety compared with mothers of live born babies. Both bereaved mothers and fathers demonstrated significantly higher levels of depression from a control group, those effects being longer lasting in mothers up to 30 months after the death (Boyle, Vance, Najman, & Thearle, 1996; Vance & Najman, 1995). Linda Layne (2003) in her book, *Motherhood Lost*, notes that stillbirth, as opposed to live birth, offers “no rites to reincorporate the woman” (p. 60). She tells of one woman in a support group who describes herself as being in limbo, questioning her motherhood, and living in a strange threshold, a place between heaven and hell, between birth and death. Shainess (1963) referred to childbirth as a “crucible tempering of the self,” recognizing that when birth goes wrong, it may not only damage the woman's sense of self but also her sense of self in relation to others.

Rubin, Malkinson, and Witztum (2003) acknowledge that some traumatic losses often go unrecognized by society. They describe this parallel feature as uniquely stressful because it “attacks the very coherence and association” of the decedent in the mind of the mourner (p. 679). In other words, the mental image of and the expectations associated with the person who died is in complete incongruence with the mourner's cognitive representation of the person and the experience (Condon, 1986). This may be particularly complicated in the case of stillbirth due to the relational interdependence between the mother and her baby. Thus, “the task of working through loss can become overwhelming, and the task of reorganization of the relationship to the deceased can depart from its natural course” (p. 681):

When my baby died it left me empty inside. Young mothers, they all think I wish to share their babies, which I surely don't. I cannot bear their energy . . . my child is in darkness . . . she cannot compete with bright eyes or dirty diapers nor can I. (van Praag, 1999, p. 54)

In addition, when a baby is stillborn—that is, when family and peer support are most imperative for a woman's psychological and physical health—the social support system of many bereaved mothers falters (Cacciatore, Schnebly, & Froen, 2009; DeFrain et al., 1986). Perhaps, the unique difficulty for women lies in the private, intimate nature of these types of losses whereby the baby is *really* known only to the mother, and often recognized and mourned solely by the parents. There are social pressures as well: Facing other people's children can leave bereaved mothers resentful (Lehman, Ellard, & Wortman, 1986), and they learn to avoid confrontation with others, including family and friends who find it "difficult to comfort a parent who is angry, resentful, and jealous" (p. 444). Moreover, while most child deaths are recognized as tragic, the emotional backlash of stillbirth is generally minimized and negated and is often treated as a *non-event* (Cacciatore, 2009a; Vaisanen, 1999; Rådestad et al., 1996; Wheeler & Limbo, 1998; DeFrain et al., 1986). Thus, grieving mothers may feel disenfranchised from the social groups to which [they] belonged prior to the baby's death (Cacciatore, 2007; Laakso & Paunonen-Ilmonen, 2002; Kavanaugh, 1997). It is an isolating, marginalizing experience for women that often affects the entire family system, including surviving and subsequent children (Cacciatore, 2007; Kirkley-Best & Kellner, 1982; Goldenberg, Kirby, & Culhave, 2004; Hankins & Spong, 2001; Laakso & Paunonen-Ilmonen, 2002; Malacrida, 1999; Michon, Balkou, Hivon, & Cyr 2003; Walling, 2002).

The Family System

Parents may become anxious, fearful, overprotective (DeFrain et al., 1986), and in particular, mothers are susceptible to depression after stillbirth. Peterson (1994) found that stillbirth crosses generations and that "women can absorb during childhood the impact" of their mother's loss—the death of their sibling—and thus they are "particularly vulnerable to fear during their own pregnancy" (Verny, 2002, p. 50). Some women report significant effects decades after their own mothers' stillbirths. They experience intense emotions, such as anxiety and guilt, and an intergenerational transmission of grief, and this influenced their actual and perceived interactions with their own children (Peterson, 1994) as well as attachment. Thus, the death of a baby often affects a mother and the entire family system.

This study is an exploration of the unique experiences and struggles of women and their families after stillbirth, seeking to understand from the mother's perspective the ways in which the baby's death and the responses

of others affect her mourning process. This study sought to discover the ways in which the woman's experience of a baby's death affects her as an individual and within the family system. More specifically: Do these experiences of loss appear to have long-lasting effects and what variables influence such changes for grieving mothers?

METHODOLOGY

This study was part of a larger, mixed methods study on the efficacy of support groups as an intervention for mothers after stillbirth. The original study included both quantitative and qualitative measures in a self-administered survey. Self-identifying participants were recruited through the newsletters and e-mail lists of two nonprofit organizations that provide aid to families after stillbirth. This portion of the study focuses on data discovered through open-ended questions presented to participants to elicit narrative explanations of their phenomenological experiences. Phenomenology is one method for gaining insight into the lived experience (Rose et al., 1995). This approach is particularly beneficial when allowing the participants to construct their interpretation and understanding of a profound event. Thus, perspectives on the most sensitive life events may require this approach in order to better understand, and for the purposes of this study, best illuminate the mothers' unique experiences (Lee & Renzitti, 1993).

Data Collection

Once the study design and methodology were approved by Arizona State University's Institutional Review Board and all criteria were satisfied, primary data were collected directly from respondents who were recruited using purposive and snowball sampling. Participants were notified of the study through nonprofit agencies that provide bereavement care to grieving families. Other respondents were recruited by snowball sampling. Participants were provided general instructions and an informed consent form. They were instructed to respond to the self-administered questionnaire reflecting on their *current* feelings and emotions. Participants completed the questionnaires and returned them by mail.

Instrument

Three qualitative questions and an open-ended narrative that allowed respondents to share previously unexplored thoughts will be discussed. 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. There was also a place for an optional narrative.

Data Analysis

Data from the qualitative portions of the study were organized on note cards for data reduction and manageability. Then data were thoroughly reviewed for salient themes and recurrences (Marshall & Rossman, 2006). During this process, analytic memos were utilized to discover unique features of the data that "move the analysis from the mundane and obvious to the creative" (Marshall & Rossman, 2006, p. 161). This process aided in uncovering insights into the uniqueness of the participants' experiences of loss, increasing the coherence of the themes revealed in the data.

RESULTS

Descriptive Statistics

Women between the ages of 19 and 51 ($n = 47$) participated in this study. There were 38 European Americans, three African Americans, three Latino, two "Other," and one Asian. Most respondents had obtained an undergraduate degree ($n = 23$), followed by high school diploma ($n = 12$), graduate ($n = 7$), and postgraduate ($n = 4$). One respondent did not answer this question. Most of the respondents had experienced the stillbirth of their baby at or near full-term ($n = 34$). The nature of the death was most often sudden and unexpected ($n = 44$) and at 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 ($n = 29$) had surviving children living in the home during the time of the baby's death. More than 21% ($n = 10$) of respondents admitted to self-medication with alcohol or illegal drugs 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 changed their identity in a significant way.

Qualitative Outcomes

WHAT DO YOU FEEL HAS MOST HELPED YOU DEAL WITH THE DEATH OF YOUR CHILD?

Out of 47 participants, 37 cited social support as the most important factor in helping them deal with the baby's death. One participant noted that "other (grieving) parents who support me and have validated my grief. . . . Once I got validation from others, things starting getting better for me." Social support came from various sources including partners, support

groups, counselors or therapists, and hospital caregivers. The specific word *support* is cited in 13 of the responses, and similar words such as *validation*, *acknowledgement*, *compassion*, and *caring others*—all words that could easily relate to a supportive environment, were used 21 times in the narratives. Mothers sought acknowledgment of their grief and appreciated when others provided such validation. Yet in nearly every participant's narrative, grieving mothers expressed their disappointment with the limited social support around them. For example, one woman praised her spouse's expressions of support; yet, she experienced little support from most others in her life. These women clearly appreciated efforts by others to provide compassion and comfort, and they were also perplexed by the lack of support by so many others. Many mothers discussed an implicit invalidation of their child's life and death by others in their social support system.

WHAT REGRETS, IF ANY, DO YOU HAVE RELATED TO YOUR CHILD'S DEATH?

Out of 47 respondents, 46 of them expressed regret and guilt. The participants agonized over both the decisions they made and the decisions they did not make. In codifying painful thoughts of self-blame and guilt, the words *guilt*, *kill*, *regret*, *wish*, and *should have* appear in the text more than 45 times. Mothers expressed regret over many things they believed they should have done differently, from including surviving children in rituals and engaging in more rituals for longer durations of time to unrealistic expectations that they should have had a prescient experience forewarning them of the impending death. Many mothers blamed themselves for the baby's death, citing their "body's failure" such as "I have moments when I apologize for killing our daughter even though there was nothing I could do to stop it . . ." This sense of failure meant, for some women, maternal inadequacy, and they questioned their parenting of surviving children: "How can I possibly be a good mother to my other children?"

HAVE YOU EVER HAD THOUGHTS OF SELF-HARM?

Struggling to cope was a consistent theme for all the participants. Almost one-half of the participants ($n = 21$) reported thoughts of self-harm. Most of their expressions of self-harm were during the early periods after the baby's death. Some women experienced thoughts of self-harm after several months. One mother in particular noted that her return to work, surrounded by unsympathetic others, caused her to think of ending her life. Passive thoughts of self-harm, such as not wanting to "wake up" or "praying to die" were expressed by mothers like this one who said, "A week or so after (he) died . . . I wanted to die. I never tried. I just wished I wasn't here." Some mothers expressed that having surviving children helped them to cope with their loss.

OPEN-ENDED NARRATIVE

The final question was an open-ended narrative opportunity to allow participants to explore issues related to the death of the baby that were most important to them, allowing them to construct their own stories. Three main themes emerged in the open-ended narrative:

1. There is a need for validation of the loss and subsequent bereavement:
“We refuse to forget or minimize her existence (as suggested by some family).”
2. Bereaved mothers desired both an internal and an external recognition and valuing of the baby’s identity:
“Taking pictures was so helpful for me. Having some proof that she existed.”
3. There exists an imperative for social support and compassionate interventions:
“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”
“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.”
“It’s like some people (doctors, nurses) are afraid to talk to you. . . . No one told me what to expect delivering a dead baby . . . no one told me that I should bring a camera . . . no one told me that the baby would start changing colors. . . . No one told me how hard it was going to be leaving the hospital without my baby.”
“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. 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. . . . I didn’t know there was a support group until I got home. We were told a social worker would visit us prior to discharge but one never did.”

The majority of the responses converged on many of the mothers’ concerns over the care and support from others after the death of their baby. 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. About one-half wished they would have engaged in more ritualistic contact with the baby or had “more time to make memories.”

Nearly every mother cited a need to talk about the loss, many expressed feelings of loneliness, and all of them stated a desire to connect with compassionate others. More than one-half of the mothers talked about having aching arms and other symptoms of physical distress as well as distress about parenting surviving children within the family system.

DISCUSSION

These data suggest that, when confronted with the stillbirth of a baby, women experience some struggles that are unique from other types of losses. Family members and friends may mourn the death of a stillborn baby differently, since interaction with the baby was limited; whereas, if a ten-year-old child died, an entire community—friends, neighbors, teachers—would likely share in the mourning. This is consistent with previous research that suggests that in the case of such an invisible death (DeFrain et al., 1986), the grieving mother may experience “social pressure to forget . . . with the fact that the person being remembered was known to so few” (Layne, 2003, p. 202). Another unique factor associated with stillbirth is that there are few tangible artifacts to remind her of the baby, and she may desperately cling to anything that recognizes and validates her sense of motherhood (Cacciatore, 2009a). Additionally, while somatization is common after any child’s death, the fact that the baby died *within* her body adds a layer of complication: her breasts continue to produce milk for the baby. There is often a powerful, evolutionary impetus to nurture the baby who died. The emotional state derived from maternal hormones is incongruent with her reality as she cannot physically bond with her baby. The maternal drive is a potent, biological instinct originating in the brain that, when prematurely or traumatically interrupted, sets the stage for anger, jealousy, insecurity, “disruptions in social and sexual rhythms,” severe stress, and depression. Many women feel like failures, and sometimes, even murderous (Layne, 2003). After all, “what kind of woman kills her own child while in the womb?” (Layne, 1999, p. 11).

Some mothers spoke of their family systems and their surviving children, questioning their roles of motherhood. Indeed, children within the family system are affected by the death of a baby, and their emotional needs may go unmet due to the many demands of grief on the parents. Mothers, often primary caregivers of surviving children, may be unable to provide the emotional and physical sustenance demanded of them. While maternal depression can lead to problems for children, including disorganized attachment (Leckman & Kuint, 1999; Hughes, Turton, Hopper, & McCauley, 2001), it is also important to distinguish normal grief responses, which often persist well beyond the expectations of society, and chronic depressive disorders. There is much conflict in the literature about attachment

disorders after perinatal loss with some studies suggesting that subsequent pregnancies after stillbirth result in psychopathological maternal attachment and others suggesting no such connection (Smith Armstrong, 2002; Hughes et al., 2001). For many families, although not all, the time comes when they consider another child after their baby's death. Unquestionably, fear plays a role in the decision for another baby (DeFraim et al., 1986). As in any circumstance involving trauma, when the traumatized person returns to the place or state in which the original trauma occurred, there is likely to be some degree of physical, emotional, and psychological distress, and sometimes, grief can be complicated. According to Worden (1991), complicated grief reactions include: (1) chronic grief that is excessive in duration; (2) delayed grief that has been inhibited by suppression; (3) exaggerated grief that is exacerbated by multiple factors (i.e., social stigma or traumatic nature); and (4) masked grief that results in inorganic physical illness or triggers maladaptive behaviors. The highest risk to the individual is when all four criteria overlap. That is, grief becomes protracted, the grieving mother has historically repressed her emotions and has no safe place to express her grief, her loss was socially stigmatized (such as stillbirth), and she manifests her grief through bodily ailments or self-harming behaviors such as cutting, eating disorders, or engaging in risky behaviors. Other concerns include a persistence of acute grief symptoms, severe depressive symptoms, substance abuse, suicidal ideation, dependency on prescription medication, and avoidance.

Implications for Culturally Competent Practice

Bereaved mothers, often overwhelmed by the traumatic nature of stillbirth, often take their cues about how to interact with their dead baby from caregivers. Usually, "women [submit] almost unquestioningly to the expectations of the staff" (Lovell, 1983, p. 759). For this reason, caregivers should be careful not to impose their own values and beliefs; rather, gently guide the woman to making the most appropriate choices for her very personal experience (Walling, 2002).

Research suggests some commonalities among grieving mothers, such as disconnectedness from friends and family, struggles with one's faith, isolation, and guilt. "Grief is a hardwired feature of human biology . . . biologically determined" and mourning is socially influenced and culturally determined (Eberle, 2005, p. 542). Shaking the mother's belief in the order of the world, stillbirth can incite a sense of total helplessness for women of all backgrounds. Healing begins when these effects are reversed, sometimes over months, often over many years. Families need to be able to trust that their caregivers will be compassionate and respectful.

Social workers in hospital settings are in a unique position to aid women experiencing the death of a baby. Kavanaugh (1997) suggests that

parents experiencing a newborn's death need supportive staff to "be there for the parent . . . giving special attention" (p. 49). In a population-based study of 636 postpartum women, of whom 314 had a stillbirth and 322 had a live birth, Rådestad et al. (1998) found that "delivery was judged as physically and psychologically insufferably" more difficult when the baby was stillborn (p. 113). In the case of stillbirth, the hospital stay was also shorter, and mothers were less satisfied with the care they received. Thus, an expedited hospital discharge may replace "the provision of emotional support" from medical staff (p. 115). Interdisciplinary bereavement teams addressing perinatal death at hospitals ameliorate somatic distress and relieve hostility in grieving mothers. The benefits of these interactions are particularly discernible in cases where women reported low social support from family and friends (Benfield, Leib, & Vollman, 1978; Lake, Johnson, Murphy, & Knuppel, 1987).

Mothers in this study expressed concern about social support from others. The impact of stillbirth on parents may be underestimated, not only by family and friends, but also by mental health and physical health professionals. Some view it as a *reproductive loss* and not the death of a child—they may feel that since the parents did not experience the child outside the mother's body, there was minimal attachment or love. Interestingly, even church doctrine can marginalize these women by refusing baptism when requested by a grieving mother:

Baptism is the only ritual in the Christian tradition signifying that, above all, the person belongs to God . . . when parents request baptism for the dead newborn, they are requesting an acknowledgement of the presence of God in the midst of their profound loss. They are requesting recognition of the specialness and personhood, the hopes and dreams embodied in their child. If a pastoral caregiver were to deny the parental request to baptize a stillborn infant, it may be tantamount to a denial of the life and significance of their child. (Gamble & Holz, 1995, p. 350)

Yet, grieving mothers often hear that their baby cannot be baptized. Instead, some clergy offer a blessing or memorial tribute (Gamble & Holz, 1995).

Mothers also hear messages that may not be helpful from within their very own social circles (Cacciatore, 2009a). These intimations often imply value based on the *age commensurate grief* myth: the older the child, the more intense the mourning. It is not uncommon for grieving mothers to hear platitudes such as: "You're young, you can have more" or "At least it wasn't one of your older children who died" or even "At least you didn't have to bring the baby home and then have it die" (DeFrain et al., 1986; 1990). These invalidating assertions may exacerbate the sense of disconnectedness from others and cause her to feel alone. "Loneliness is a state of being unconnected, to be out of touch with others, of wanting to be with

somebody who isn't there, of having no one . . . to affirm one's essential humanity" (Montagu, 1986, p. 266). This lonely state may lead her to distrust herself and her feelings—or perhaps to distrust others and to recoil from social environments where there is the potential for such verbal assaults. Therefore, hospital staff, friends, family, and clinicians require education about the experience of stillbirth to better provide culturally sensitive and compassionate care to bereaved mothers. This means working toward an aware, but not presumptive, respect-based intervention that includes exploring options with the family, being certain not to impose external values or beliefs about a baby's death (Cacciatore, 2009b).

Limitations

Among the limitations of the study is the low sample size of the original mixed methods study ($n = 47$), which impinges on the generalizability. Purposive sampling was used to recruit some respondents and, thus, 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. Despite the limitations, this is an important exploration that can be used to incite important discussions among health care social workers. Social workers, in confronting the real experiences and, thus, the unmet needs and concerns of this population, may uncover opportunities to improve psychosocial care in hospital and clinical settings.

CONCLUSIONS

Enhanced understanding of the experience and better psychosocial support may help some women and their family systems cope with the long-term effects of this loss. Variables that affect her perceptual experience include social support, legitimization of her sense of loss, opportunities for rituals, the family system such as whether or not there are surviving children, and existential emotions such as shame and guilt. Bereaved mothers and their families need unconditional support beginning from their hospital caregivers, and then from community organizations, and when appropriate, faith-based institutions. Psychosocial support may help them cope with the death of a baby. Certainly, the effects of this type of tragedy appear to be timeless in nature, a lifelong experience of grieving and re-grieving, understanding and re-understanding, as new associated meanings of the baby's death emerge and evolve.

As awareness increases regarding the many types of loss found in society, "there is a pressing need for research that really describes the particular and unique responses to different types of losses; compares reactions outcomes, and problems associated with these losses; assess possible interventions;

and describe the critical variables affecting each loss" (Doka, 2002, p. 19). Future research in this area could focus on the broader, idiographic context of child death in society. It would be interesting to examine the differences in benefits, if any, between mothers' and fathers' reactions to the death of a baby. Also, a strengths-based theoretical study could be undertaken to evaluate resiliency, temperament, and proclivities to altruism, exploring how individuals and families find meaning and renewed purposefulness after such a uniquely tragic, and largely unrecognized, loss.

REFERENCES

- Benfield, D.G., Leib, S., & Vollman, J. (1978). Grief response of parents to neonatal death and parent participation in deciding care. *Pediatrics*, *62*(2), 171–177.
- Bingham, R. (2006). Annotated bibliography of NINR findings on women's health in pregnancy and childbirth. *Journal of Obstetric, Gynecologic, Neonatal Nursing*, *35*(3), 403–407.
- Boyle, F.M., Vance, J.C., Najman, J.M., & Thearle, M.J. (1996). The mental health impact of stillbirth, neonatal death or SIDS: Prevalence and patterns of distress among mothers. *Social Science & Medicine*, *43*(8), 1273–1282.
- Cacciatore, J. (2007). Effects of support groups on post traumatic stress responses in women experiencing stillbirth. *Omega: Journal of Death and Dying*, *55*(1), 71–91.
- Cacciatore, J. (2009a). The silent birth: A commentary. *Social Work*, *54*(1), 91–94.
- Cacciatore, J. (2009b). Appropriate bereavement practice after the death of a Native American child. *Families in Society*, *90*(1), 46–50.
- Cacciatore, J., Schnebly, S., & Froen, F. (2009). The effects of social support on maternal anxiety and depression after the death of a child. *Health and Social Care in the Community*, *17*(2), 167–176.
- Condon, J. T. (1986). Management of established pathological grief reaction. *American Journal of Psychiatry*, *143*, 987–992.
- DeFrain, J., Martens, L., Stork, J., & Stork, W. (1986). *Stillborn: The Invisible Death*. Lexington, MA: Lexington Books/D. C. Heath.
- DeFrain, J., Martens, L., Stork, J., & Stork, W. (1990). The psychological effects of a stillbirth on surviving family members. *Omega: Journal of Death and Dying*, *22*(2), 83–110.
- Deutsch, J.A., & Deutsch, D. (1966). *Physiological Psychology*. Homewood, IL: The Dorsey Press.
- Doka, K. (2002). In N.B. Webb, *Helping Bereaved Children: A Handbook for Practitioners*, xxii. New York: The Guilford Press.
- Eberle, S. (2005). Memory and mourning: An exhibit history. *Death Studies*, *29*(6), 535–557.
- Gamble, E., & Holz, W.L. (1995). A rite for the stillborn. *Word & World*, *15*(3), 349–353.
- Gamble, J., Creed, D., Moyle, W., Webster, J., McAllister, M., & Dickson, P. (2005). Effectiveness of a counseling intervention after a traumatic childbirth: A randomized controlled trial. *Birth*, *32*(1), 11–19.

- Goldenberg, R.L., Kirby, R., & Culhave, J.F. (2004). Stillbirth: A review. *The Journal of Maternal-Fetal and Neonatal Medicine*, 16, 79–95.
- Hankins, D.V., & Spong, C.Y. (2001). Stillbirth: The overlooked obstetric tragedy. *Contemporary OB/GYN*, 46(12), 13–28.
- Hughes, P., Turton, P., Hopper, E., & McCauley, G.A. (2001). Disorganized attachment behavior among infants born subsequent to stillbirth. *Journal of Child Psychiatry*, 42(6), 791–801.
- Kavanaugh, K. (1997). Parents' experience surrounding the death of a newborn whose birth is at the margin of viability. *Journal of Obstetric, Gynecologic, and Neonatal Nursing* (January/February), 43–51.
- Kendall-Tackett, K.A. (2004). *Trauma Associated with Perinatal Events: Birth Experience, Prematurity, and Childbearing Loss: The Handbook of Women, Stress, and Trauma*. New York: Taylor & Francis.
- Kirkley-Best, E., & Kellner, K.R. (1982). The forgotten grief: A review of the psychology of stillbirth. *American Journal of Orthopsychiatry*, 52(3), 420–429.
- Laakso, H., & Paunonen-Ilmonen, M. (2002). Mothers' experience of social support following the death of a child. *Journal of Clinical Nursing*, 11(2), 176–185.
- Lake, M., Johnson, T., Murphy, J., & Knuppel, R. (1987). Evaluation of a perinatal grief support team. *American Journal of Obstetrics and Gynecology*, 157(5), 1203–1206.
- Layne, L.L. (1999). *Transformative motherhood*. New York: New York University Press.
- Layne, L.L. (2003). *Motherhood Lost: A Feminist Account of Pregnancy Loss in America*. London: Routledge.
- Lee, R.M., & Renzitti, C.M. (1993). *Researching Sensitive Topics*. Newbury Park, CA: Sage.
- Lehman, D., Ellard, J., & Wortman, C. (1986). Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *Journal of Consulting and Clinical Psychology*, 54(4), 438–446.
- Leckman, J.F., & Kuint, J. (1999). The nature of the mother's tie to her infant: Maternal bonding under conditions of proximity. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 40(6), 929–939.
- Lovell, A. (1983). Some questions of identity: Late miscarriage, stillbirth, and perinatal loss. *Social Science and Medicine*, 17(11), 755–761.
- MacLean, P.D., & Delgado, J. (1953). Electrical and chemical stimulation of fronto-temporal portion of limbic systems in the waking animal. *Neurophysiology*, 5(1), 91–100.
- Malacrida, C.A. (1997). Perinatal death: Helping parents find their way. *Journal of Family Nursing*, 3, 130–148.
- Malacrida, C.A. (1999). Complicated mourning: The social economy of perinatal death. *Qualitative Health Research*, 9(4), 504–519.
- Marshall, C., & Rossman, G. (2006). *Designing Qualitative Research*. Thousand Oaks, CA: Sage Publications.
- 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), 363–366.
- Montagu, A. (1986). *Touching: The Human Significance of the Skin* (3rd ed.). New York: Harper & Row.

- Oikonen, J., & Brownlee, K. (2002). Family therapy following perinatal bereavement. *Family Therapy, 29*(3), 125–140.
- Peterson, G. (1994). Chains of grief: The impact of prenatal loss on subsequent pregnancy. *Pre Perinatal Psychology, 9*(2), 49–158.
- 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*, 616–623.
- Rådestad, I., Nordin, C., Steineck, G., & Sjogren, B. (1998). A comparison of women's memories of care during pregnancy, labour and delivery after stillbirth or live birth. *Midwifery, 14*(2), 111–117.
- Rådestad, I., Steineck, G., Nordin, C., & Sjogren, B. (1996). Psychological complications after stillbirth—Influence of memories and immediate management: Population based study. *British Medical Journal, 312*(7045), 1505–1508.
- Rando, T.A. (1985). Bereaved parents: Particular difficulties, unique factors, and treatment issues. *National Association of Social Workers, January/February*, 19–23.
- Rose, P., Beeby, J., & Parker, D. (1995). Academic rigour in the lived experience of researchers using phenomenological methods in nursing research. *Journal of Advanced Nursing, 21*(6), 1123–1130.
- Rubin, S.S., Malkinson, R., & Witztum, E. (2003). Trauma and bereavement: Conceptual and clinical issues revolving around relationships. *Death Studies, 27*(8), 667–690.
- Shainess, J. (1963). The structure of mothering encounters. *Journal of Nervous and Mental Disease, 136*, 146–161.
- Shalev, A.Y., Freedman, S., Peri, T., Brandes, D., Sahar, T., Scott, O.P., & Pitman, R. (1998). Prospective study of posttraumatic stress disorder and depression following trauma. *American Journal of Psychiatry, 155*, 630–637.
- Silver, R. (2007). Fetal death. *Obstetrics and Gynecology, 109*(1), 153–165.
- Smith Armstrong, D. (2002). Emotional distress and prenatal attachment in pregnancy after perinatal loss. *Journal of Nursing Scholarship, 34*(4), 339–345.
- Trulsson, O., & Rådestad, I. (2004). The silent child: Mothers' experiences before, during, and after stillbirth. *Birth: Issues in Perinatal Care, 31*(3), 189–195.
- Vaisanen, L. (1999). *Family Grief and Recovery Process When a Baby Dies*. Unpublished paper. University of Oulu: Department of Psychiatry.
- Vance, J.C. & Najman, J.M. (1995). Psychological changes in parents eight months after the loss of an infant from stillbirth. *Pediatrics, 96*(5), 933.
- van Praag, J. (1999). *Creative Acts of Healing*. Seattle, WA: Paseo Press.
- Verhaeghe, J. (2003). The empowerment of birth. *New Life Journal, December*. Retrieved May 14, 2007 from <http://www.thefreelibrary.com/New+Life+Journal/2003/December/1-p569>
- Verny, T. (2002). *Tomorrow's Baby: The Art and Science of Parenting from Conception through Infancy*. New York: Simon and Schuster.
- Walling, A.D. (2002). Should mothers see their infants after stillbirth? *American Family Physician, 66*(10), 1956–1958.
- Wheeler, S., & Limbo, R. (1998). *When a Baby Dies: A Handbook for Healing and Helping*. La Crosse, WI: Bereavement Services.
- Worden, J.W. (1991). *Grief Counseling and Therapy*. London: Springer.