



**Article ID:** hco-17297515

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**Human Relations**  
[0018-7267(200302)56:2]  
Volume 56(2): 147–166: 030889  
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SAGE Publications  
London, Thousand Oaks CA,  
New Delhi  
[www.sagepublications.com](http://www.sagepublications.com)

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# Societal and workplace responses to perinatal loss: Disenfranchised grief or healing connection

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**ABSTRACT** Perinatal loss is a life-altering event for a mother, affecting every aspect of her existence, including her work and career. Fifteen women describe how such loss affected their work and how the responses of others influenced their healing. I consider the effects on grief of silence, disenfranchisement, attachment, trauma, shame, secrecy, and the social context. I note patterns of healing: connection to the self, attachment to the dead child, and linking the self and child to the family and community. Community attachments include those made in the workplace. Relationships at work and work itself can contribute to disenfranchised grief or healing from perinatal loss.

**KEYWORDS** disenfranchised grief ■ perinatal loss ■ workplace response to grief

A late-pregnancy miscarriage, stillbirth, or death of an infant is a life-altering event for a mother. It can affect every aspect of her existence, including her work and career. My son, Matthew, died two days after his premature birth in 1969. My long process of healing motivated me to ask the research question, 'What are mothers' experiences of healing from perinatal loss?' Among the secondary questions was 'How do mothers' experiences of perinatal loss affect their work and careers?' Fourteen women

whose perinatal losses occurred between 1965 and 1999 described their experiences of grief and healing to me.

In 1970, 3,731,386 babies were born in the USA. Of every 1000, 20 infants died before they reached their first birthday; 13 died in the first week of life. In the same year, 14 of every 1014 pregnancies of 20 weeks or more ended in fetal death. In 1998, 3,941,553 babies were born in the USA. Of every 1000, more than 7 died in the first year of life, with nearly 5 dying in the first week. Almost 7 of every 1007 pregnancies of 20 weeks or more ended in miscarriage or stillbirth (National Center for Health Statistics; National Bureau of Economic Research). In 1999, an infant died every 15 minutes in the USA and three babies died each day in Michigan (Groves, 2001).

Numerical data alone cannot fully convey the serious toll that such deaths take on parents. I portray what women told me about how their perinatal losses affected them and their work lives. I consider silence and isolation, disenfranchisement, attachment, and trauma as influences on grief, as well as the importance to healing of connections to the self, the child, and the family and community.

## Silence

'How does perinatal loss affect women's work lives and relationships?' has been largely unasked in the literatures regarding grief and loss, as well as those related to organization and management. Among the unspeakable topics in career theory are 'the many complexities of reproduction and mothering: pregnancy, fertility and infertility, miscarriage, abortion, birth, breastfeeding and so on. It is the physicality, the sexuality, and the emotionality of these topics which is taboo' (Gatenby & Humphries, 1999: 290). Further, 'grief to do with experiences such as stillbirth, abortion, miscarriage, and infertility remains largely unspeakable in organisations and management education' (Gatenby & Humphries, 1999: 290).

Silence about perinatal loss was pervasive especially before 1980, when work about attachment and loss (Bowlby, 1988), death and dying (Kubler-Ross, 1983) or maternal-infant bonding (Klaus & Kennell, 1976) was not well known. Mothers' voices are often unheard in the academic literature about perinatal loss (Sullivan, 1996), although they are evident in some popular writing (e.g. Davis, 1996; Fumia, 2000; Ilse, 1990; McCracken & Semel, 1998; Mehren, 1997). Jean, one of the women that I interviewed, said that grieving mothers form a 'secret sisterhood.'

## Disenfranchised grief

Silence contributes to disenfranchised grief, 'grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported' (Doka, 1989: 4). Grief is disenfranchised when the loss, the relationship, or the person who grieves is not socially recognized (Doka, 1989).

Grief is disenfranchised in the workplace. Becker (1973, 1975) theorized that human culture and organizations are mechanisms by which we deny death and assure our immortality. Menzies (1960), in her study of hospital nursing routines, saw organization as a defense against anxiety, especially that related to death. Such unconscious processes can lead to the avoidance of bereaved persons at work, with the consequence of disenfranchised grief. Mechanistic goals and values are in conflict with the needs of the bereaved person (Stein & Winokuer, 1989). Personnel policies allow limited time off for funerals. Many managers do not understand the needs of grieving employees (Bento, 1994; Charles-Edwards, 2000; Nemec, 1997; Shellenbarger, 1999a, 1999b; Smith, 1997; Stein & Winokuer, 1989). Often, employees' bereavement is discounted in the workplace so that the relationship with the person who has died, the loss itself, and the person who is grieving are disenfranchised (Bento, 1994) or stifled (Eyetsmitan, 1998).

Perinatal loss is disenfranchised or not socially recognized (Nichols, 1989; Peppers, 1989). Perinatal loss can evoke guilt or even shame in the mother (Kennell & Klaus, 1976). A sense of failure frequently pervades such loss. With secrets or social sanctions, such as pregnancy outside of marriage or the termination of a pregnancy, shame, isolation, and disenfranchisement can be compounded. The mother, fearing disapproval, might hide her grief or isolate herself (Peppers, 1989). Others might withdraw support from her because they feel vulnerable, do not know what to say (Wallerstedt & Higgins, 1994), or do not approve of the situation.

Thus, the grief of a parent who has suffered perinatal loss is doubly disenfranchised at work – grief in the workplace tends to be discounted, disenfranchised, or stifled; and the loss itself is often perceived as minimal. Grief is further disenfranchised when guilt, shame, negative social sanctions, or secrets are attached to the pregnancy or loss.

## Attachment

One reason that others discount grief after perinatal loss is that they assume that the mother has not had time to develop a relationship with the child.

However, the strength of the attachment between mother and child does not depend on the age of the child. In a recent review of the literature on attachment theory and perinatal loss, Robinson et al. (1999) considered neonatal and prenatal attachment. Attachment begins long before birth, with planning the pregnancy through feeling fetal movement, birth, then seeing, touching, and caring for the baby (Bowlby, 1988; Klaus & Kennell, 1976; Robinson et al., 1999). In his study of infants in neo-natal intensive care units, W. Ernest Freud noticed mothers, 'who would become depressed, withdrawn, uncertain, and emotionally frozen when they were not allowed to hold their newborns or touch them' (Kaplan, 1995: 81). Winnicott wrote of 'primary maternal preoccupation' (1958: 301–2), the state of the mother shortly before and for a period after giving birth. If all is well, the mother is almost totally focused on the child and his or her needs. Psychologically and physically, the mother's life, during the period surrounding birth, centers on the child. Perinatal loss interrupts this natural process of attachment. The object of the mother's fixation is not present: there is no child with whom to bond, no baby to hold, nurture, and care for. Grief is 'manifested as physical pain and longing, feelings of emptiness, strange sensations and a phantom baby. . . . [The mother is] symbiotically dependent on her baby, who no longer exists as a living being. She is constantly preoccupied with the baby, the grave and death' (Väisänen, 1999).

A child's death before birth 'awakens fantasies in the potential parent of her own bodily decay and degeneration' (Kaplan, 1995: 125). When an infant dies, a mother has 'a tendency . . . to interpret her baby's death as a commentary on her caregiving capacities' (Kaplan, 1995: 125). These psychological meanings, combined with real or imagined social disapproval, contribute to disenfranchised grief. It would be difficult – even impossible – for a mother to return to 'business as usual' in her career immediately after or while experiencing such intense physical and emotional reactions to perinatal loss.

## Trauma

Trauma can accompany perinatal loss. 'Traumatic events generally involve threats to life or bodily integrity, or a close personal encounter with violence and death. They confront human beings with the extremities of helplessness and terror, and evoke the responses of catastrophe' (Herman, 1997: 33–4). Some women suffer from post-traumatic stress disorder after pregnancy loss or difficult childbirth (Ayers & Pickering, 2001; Creedy et al., 2000; Engelhard et al., 2001). Symptoms include hyperarousal and anxiety, intrusive

memories that are encoded in wordless images, and constriction or numbing (Herman, 1997). Trauma and the stress that comes from it add an additional burden to a bereaved person. To heal, Herman (1997) encouraged people to tell the stories of their trauma, whereas Levine (1997) worked with the body, sensation, and imagination.

In this article, I examine how knowledge about grief, attachment, and trauma changed over time, affected responses in healthcare organizations and the workplace, and influenced how women healed from perinatal loss.

## Methodology

I define perinatal loss as miscarriage or termination of a pregnancy in the second or third trimester, stillbirth, or the death of an infant during or shortly after birth. One mother that I interviewed, although undergoing none of these losses, experienced many years of disappointing infertility treatments and a failed adoption.

I interviewed 14 women in the late summer and early fall of 2000. They ranged in age from 29 to 58. Their pregnancy losses or the deaths of their children occurred between 1965 and 1999. Four of the women experienced their first perinatal loss between 1965 and 1977; seven between 1980 and 1989; and four between 1991 and 1999. Twelve participants are of European descent and three are African American. All are educated, middle-class, and currently live in the Great Lakes region of the USA.

Each woman that I interviewed is part of my personal network, either a friend or a friend of a friend. This relationship seemed necessary because of the intimate nature of the inquiry and the depth with which I wished to explore it. Before I interviewed them, I asked a colleague to interview me and I included my responses in the research. I sent a copy of the questions to each woman before our meeting. Many prepared with notes. The open-ended interviews were taped and lasted from 45 minutes to 2 hours. After each interview was transcribed, I sent a copy to the woman and asked her to read, review, and revise it, crossing out what she did not want to include in the study, adding anything she had left out earlier, and changing her and others' names if she wished. I thematically coded the responses, using a software program to create initial categories from the text then further refining the analysis. I worked with each interview at least four times.

I could not be, and was not, objective in data collection and analysis. If the mother that I was interviewing did not know me or my history well, I briefly stated at the start that my son had died more than 30 years ago and

my desire to more fully understand the process of healing was one of the reasons that I was conducting the research project. Rather than intruding on the respondents' expression, this explanation seemed to support disclosure. During the interviews, I felt close to each participant. I felt involved and connected, with my focus on each woman's story. There were tears on both of our parts at least once during each interview. My experiences of loss and healing allowed me to be open to fully hearing what were often painful narratives. While collecting and analyzing data and writing results, I worked with a psychologist and bodywork therapist and participated in a weekly writing workshop. These processes helped me to manage my feelings so that I could use myself as an instrument to receive, understand, and interpret the data fully. Although some of the women experienced their losses years ago, many had not often told their stories; their interviews had about them a raw sense, with a struggle for words and confusion about chronology that mark a tale not often told about a subject that is often unspeakable.

### Disenfranchised grief, connection, and healing

All of the women in my study experienced disenfranchised grief. Those who were socially isolated and whose grief was greatly disenfranchised experienced delayed grief, including numbness and depression. This was especially true for the four women whose perinatal losses occurred between 1965 and 1977. When the father was not present at delivery or when the mother did not mention in the interview the father's presence at delivery, the marriage did not remain intact. When social sanctions, secrecy, or shame were part of the pregnancy or loss, isolation seemed to be greater. Isolation, especially self-isolation, seemed to occur with trauma.

Every woman reported interactions in her community, including the hospital and workplace, that resulted in disenfranchised grief. People commented to them, 'You are young, you can still have another baby.' 'Your child might have been brain-damaged. It is best that he died.' 'It's all for the best.' 'This part of your life is over. Forget it.' 'You have your hands full, anyhow.' Nichols (1989: 117) reported similar remarks: 'You're lucky you never took him home.' 'You're lucky it happened now; she would have been such a burden.' 'You have your other children.' Chris described her responses when people made such statements:

Do not tell me that 'Everything's going to be okay.' 'You'll have another baby.' 'God did this for a reason.' All those statements when I was in so much pain did not help me *at all*. To hear that 'God wouldn't give

you this if you couldn't handle it' – well, why did He do it to me in the first place?

While others might intend such expressions to be comforting, parents perceive them as cruel and uncaring. 'They are clichés that write off the experience of other human beings; statements that discount grief; remarks that say "never mind"; words that sear into the heart and create chasms in relationships. They are statements of disenfranchised loss' (Nichols, 1989: 117).

Just as isolation and disenfranchisement can impede healing, the women's stories indicate that connection and support are necessary to heal. Three patterns of healing from perinatal losses emerged from the interviews, although not every mother described every pattern. All involve connections. The mother connected with her body and feelings. She bonded with her dead child, physically touching the body of the fetus or infant or contacting the spirit of her child. She identified herself and her child with the family or larger community. Such bonds were physical or symbolic and some mothers formed them many years after the loss. Because the primary focus of this article is on how healing from perinatal loss is related to organizations and work life, data most relevant to this focus are considered here.

While all of the mothers experienced disenfranchisement as well as healing, the kinds of loss, the social context, and the work-related circumstances changed between 1965 and 1999. I summarize relevant data and include elements of the social context using three periods, 1965–1977, 1980–1989, and 1991–1999.

#### Unemployed and isolated: 1965–1977

I spoke with three women, Jean, Mary Ellen, and Cheryl, whose perinatal losses occurred before 1977. My son also died during this time. Although none worked outside the home at the time of loss, work was a later influence on their healing.

- Within one year, Jean, at age 22, gave birth prematurely twice and each time the child died from respiratory distress. Robin was born in August 1965 and Gus in May 1966. Jean had just finished college, was newly married to a graduate student, and was unemployed. Her son Ben was born 18 months later.
- In April 1971, Mary Ellen was a 22-year-old unemployed wife when she gave birth to Kirsten, a full-term baby who was diagnosed with congenital heart disease and died shortly after birth. Three years later, she had an early miscarriage before giving birth to three sons.



- In 1977, Cheryl was 27, a wife and full-time mother of a three-year-old daughter, and pregnant with twin boys. Labor was induced at the end of the fifth month of pregnancy when her uterus so filled with amniotic fluid that her life was endangered. Both twins were stillborn. Cheryl experienced emotional and physical trauma. She later gave birth to a daughter.
- When I was 23, in June 1969, my only child, Matthew, was born prematurely and died from respiratory distress. I was unmarried and living with the child's father (whom I later married), had just completed my master's degree, and was unemployed. I experienced physical and emotional trauma.

At the time of loss, all four of us were young and unemployed. None had friends with children. Most hospital personnel were indifferent or actively hostile within the context of uncaring hospital policies. As was the practice at that time, no fathers were present during delivery. Only Mary Ellen held her baby. The deaths of the children who were born alive were reported coldly with no accompanying sympathy. The pediatrician told Jean, coming out of general anesthesia and alone in her room, 'Your baby has expired,' and left. I was awakened with the same words. Only Jean and Mary Ellen buried their children.

Mary Ellen's experience of having her relationship with Kirstin discounted illustrates the widespread sense, at that time, that mothers and infants did not form attachments before or shortly after birth.

Some people said to me, 'Oh, aren't you glad it was only four days?' People said, 'It's probably better, if it was going to happen, it happened quickly,' or 'It could have been millions of surgeries.' I just always said, 'I loved her for nine months before she was born. I didn't just love her for four days!'

Many years later, two women co-workers whose adult sons had died in accidents confirmed her connection to her baby. One said, 'You had a loss as significant as I did. Don't ever underestimate what that loss was.'

Small kindnesses loomed large in the initial isolation, although they were not always easy to accept. Cheryl noted,

When I came home, I received a lot of cards and flowers, which struck me as odd. . . . I felt angry about it. I looked at flowers and cards as some kind of a celebration as opposed to a mourning. Yet, I did not know how to mourn, either. I did not know where I was. I was in a twilight zone.

Jean noticed, 'You don't know what's expected of you. . . . Nobody prepares you for your child dying. There are no role models for how to behave.' Mary Ellen said, 'I remember going through the charade of the kind of life that it was. Friends wanted to come visit and I did not want people visiting.' For three of us, a close connection with another woman who had experienced a similar loss was a saving grace. Jean and I met one another months after Matthew died and Mary Ellen's best friend's infant daughter died weeks after Kirsten.

All were emotionally numb for many years and had delayed grief. Jean, Cheryl, and I were depressed. All four marriages ended in divorce. Jean said, 'When Steve [my second husband] and I were in therapy, we talked about this . . . after that time, I do not remember thinking about them and crying. It was 20 years ago, 15 years after [they died].' Mary Ellen did not grieve until after her second marriage: 'Gary and I got married in 1988, and . . . it could have been 1990, when I met with this psychologist and she said, "You've never properly grieved for this, have you?" . . . I really do not think I did.' Cheryl felt that she stifled her grief although she has 'dealt with this . . . different times in therapy in the last couple of years.' I began to grieve when I saw a perinatal loss grief counselor 12 years after Matthew died and grieved fully in therapy in the early 1990s.

Work lives were affected by the delayed grief. Jean said, 'I have never known my choice of careers. I just had a job. I never had a career. I have no idea whether that is who I am or if it is part of having been depressed, having gone through loss.' Jean brought her experience to her work as a counselor in an abortion clinic.

Although I don't think I ever spoke to any of the women I was counseling about having lost a child, my guess is that because I had had this experience of pregnancy and loss, even though it was not voluntary, I could have some sense of connection with them, to understand the loss they would feel. I did not discount their grieving.

The other women in this group echoed such attention to the needs of others. Mary Ellen and Cheryl attended full-time to their children before completing their education and embarking on service-oriented careers.

At the time of the interview, Mary Ellen was a human resources manager. Earlier, she had elected to remain at home with her children for 12 years. She explained, 'I look at that as a career decision. I always thought, even at the wildest moments when I wanted to bang all three of their heads together, that it was my choice to be there. . . . That was my intention when I had Kirsten, to stay home full-time.'

Cheryl, too, remained at home with her daughters. She later completed

two degrees and now works as a psychologist with high-risk mothers and infants:

I work with new moms and babies. As a therapist, I can tap into more compassion when I talk to moms. [Many] moms I talk to have had miscarriages or abortions previous to their current successful pregnancy. I realize . . . the importance of having had a miscarriage or an abortion.

Soon after Matthew's death, I worked as a social worker in a psychiatric hospital. Shortly before the first anniversary of his death, I quit and was underemployed for over a year. Since then, I have often worked in nurturing roles with people who are the age that my son would be, first as a social worker with kindergartners and later with adolescents, then as a business school professor with young adults and adults.

Grief was disenfranchised and healing delayed for all four mothers who lost children between 1965 and 1977. Although careers were denied or deferred, they brought awareness of and compassion for others' needs to their work, which contributed to their well being and healing.

#### Shifting context: 1980–1989

The pattern of disenfranchised grief continued with the seven women in my study whose losses occurred between 1980 and 1989. However, their varied experiences reflect the start of a shift in social context. Four of the seven women who experienced perinatal losses between 1980 and 1989, Phyllis, Renée, Amanda, and Judith, reported that they received support and caring from hospital personnel. They held their babies' bodies and some took home pictures, footprints, or other mementos.

- Phyllis was 29 in August 1980 when her firstborn, Geoffrey Aaron, was stillborn in the eighth month of her pregnancy. She felt 'tended to' by her doctor and nurses. Her husband was present at delivery and with her held Geoffrey's body. She was moved from obstetrics to the surgical floor.
- Renée was 24 and recently married in 1982 when her son, Brandon, died *in utero* at 19 weeks. Her husband, mother, and uncle were present at delivery and they held the baby's body for several hours. Her doctors and nurses were 'patient' and 'compassionate.' She said, 'I was laboring and . . . hearing babies crying and being born. My doctor apologized, "Renée, there is no other place to deliver your baby."' She later had a miscarriage. At the time of the interview, she had six children.

- Amanda was married and the full-time mother of three young daughters when she had a first trimester miscarriage in February 1987. The following November, in month five of another pregnancy, doctors discovered fetal anomalies. Although she elected to continue the pregnancy, the fetus soon died. Amanda held her daughter Jeanette's body and was given pictures of her. Most of the hospital personnel were kind. She remained on the obstetrics floor. She later gave birth to two daughters.
- In December 1989, Judith, age 35, in her first pregnancy, had chronic hypertension, which led to toxemia. Despite medical intervention, her life was threatened. Her doctor induced labor. Her daughter, MacKenzie, was stillborn, having died before induction. Her husband was present and they held the child's body immediately after delivery. Two daughters were born later.

Three of the women, Melodie, Carol, and Rita, had less supportive or hostile hospital responses at the times of their losses.

- In January 1983, Melodie was the mother of a young son when her full-term pregnancy with twins concluded in a Caesarian birth. The first survived; the second, Ellis, died 10 to 60 minutes before delivery. She saw the surviving twin immediately; a half-hour later, after trying to resuscitate Ellis, hospital delivery room personnel presented his body to her. When she later asked to see his body, she and her husband were taken to the morgue.

The pathologist said that I should not touch the baby because the baby was not clean. The body must have been injected with something. The lips were bright red and the baby was . . . The hands and feet were bound with string. It was nude. There was a card on the baby attached with a wire to the string going around its wrist. And the card read 'Baby Boy B. [Name].' My screaming filled the room. I was just sobbing uncontrollably and very loudly. . . . It was a burned-in image. It felt to me like an inexcusable violation, that they would present my baby like a trussed-up chicken.

- Carol was in her late thirties, the mother of a toddler, when she had three miscarriages between 1984 and 1986, two in the first trimester and one at 16 weeks. She was taken to the hospital when she miscarried at home at 16 weeks. 'They just removed something from us,' she

reported. She and her husband did not know the gender of the fetus, did not see the body, and had no burial or memorial service – it was a ‘disappearance.’ They later had another daughter and a son.

- In 1989, Rita was 30, married and the mother of three children under five when she miscarried in week 13 of her pregnancy. Her doctor was supportive when he met her at the emergency room but little attention was paid to her or her family’s need to grieve. Eleven years after her loss, during a high-risk pregnancy, she finally expressed her grief when a friend confronted her about the lack of joy in her life. She had two more children after her miscarriage. Rita reported numbing, depression, and delayed grief.

Melodie’s marriage ended in divorce and, at the time of the interviews, Amanda and her husband were separated. In the interviews, neither mentioned whether her husband was present at delivery.

The different experiences among this group of women indicate that changes in hospital policies and practices were not universally applied. Carol and Judith worked to bring about further social change. Carol and her husband made suggestions to the hospital about policy changes that would support grieving parents. They also addressed the lack of a mourning ritual for miscarriages in their church and petitioned the diocese to develop one. Judith worked with her physician to educate medical students about toxemia in pregnancy.

Only Carol joined a grief support group. Phyllis and her husband attended one meeting but did not find it helpful. Her husband, family members, and women from her church who had suffered perinatal losses supported Renée in her grief. She, in turn, supported Rita and Amanda. Judith, Melodie, and Phyllis all consulted with psychotherapists.

Phyllis, Renée, Judith, Melodie, and Carol worked outside the home around the time of their losses and Amanda and Rita were stay-at-home mothers. Renée, Amanda, and Rita are friends and members of the same church. After Brandon’s death and a later miscarriage, Renée decided that when she had children, she would be a full-time mother: ‘This season of life – child-rearing – is short.’ All three of them now home-school their children with the support of their church community; Renée and Rita also have the support of their husbands in this work.

Phyllis, a social worker, quit her job when she became pregnant and was unable to work for a time after her son was stillborn, although colleagues were encouraging and supportive.

I had left my job. . . . I was resentful about not having a job to go back to and fill my time. I did get a job. . . . I was at that job a month, in a girl’s residential center. I was in no position to work. Girls would come

in; some of them had been abandoned. The facility had its own difficulties. I left that position. . . . I ended up working for four months at McDonald's, which fit the bill. 'All I have to do is serve hamburgers and not think about people's emotions. I can take care of my own.'

Melodie was an assistant professor. A short-term effect on her career was a shift in her emotionality, which affected work relationships. She recounted an incident when her secretary failed to contact a student:

The real terrible moment for me happened when I had come down with strep throat and was not able to attend a class that I was teaching at the university. . . . One of the class members drove a long distance, well over an hour to get there. That student was not reached, although the secretary attempted to make that contact. She drove all the way over to the class. I remember calling up the secretary and viciously attacking her in a way that was totally out of my character, for failing to contact the student. I could not sleep that night. The whole thing was out of proportion and it seemed like I could not right it. My irrationality and my pain were spilling over even into my professional life. The next morning, I called this therapist on campus and asked him if he knew anything about perinatal loss, because I recognized what I had done to her, to that secretary, was irrational and wrong.

When she applied for tenure, she asked that the death of her son be considered and was told 'that my private life should be kept out of the matter.' She later became an editor and writing teacher.

Carol was an educator and social worker at the time of her losses and now works with high-risk mothers and infants.

I am a social worker in the parent/infant program at the development center, mostly dealing with moms who have babies. We are working with moms to help [them to] be the best moms possible. . . . I am with . . . parents whose children were born prematurely or have a developmental delay. . . . I bring a whole new awareness to things [since I] have been through certain experiences.

Judith continued to work as a social worker after her loss but her focus shifted from her career to her family after her daughters were born. Herman (1997) and Levine (1997) stressed the importance of telling one's story and gaining social – even political – support in healing from trauma. Only Judith asked for and received such support at work immediately after her daughter was stillborn.

I needed to tell my story . . . for at least five months, pretty repetitively and pretty intensely. . . . I worked in a community of such great people that were so generous with listening to me. I think that was the biggest thing – the support I got from my co-workers. . . . I felt more accepted in the place where I work.

The experiences of the mothers who had losses between 1980 and 1989 reflect a changing social context. Hospital policies and practices began to show increasing knowledge about attachment and loss. For Judith, who worked in a mental health agency, supportive practices spread to the workplace, as well. These changes seemed to sustain healing. Women in this group, as in the earlier one, responded in their long-term work with compassion, caring, and hope to the needs of others, especially children and mothers.

#### Support for healing from trauma: 1991–1999

Four women in this study, Andrea, Marcy, Chris, and Shelley, experienced infertility or perinatal loss or both after 1991.

- When she was 40, after years of failed fertility treatments, Andrea and her husband arranged a private adoption in 1991 and were present at the child's birth. Although he never lived with them, they were close for the first weeks of his life. Before the adoption was finalized, the child's father decided that he would not relinquish his parental rights. The demise of this relationship was devastating. They later adopted two sons.
- Marcy, about to begin treatment for infertility, conceived at age 40. She and her husband were shattered when Andrew was stillborn at 37 weeks in 1992. She had two miscarriages before giving birth to a son several years later.
- In 1993, Chris discovered in the nineteenth week of pregnancy that her child Angela could not live because her heart was not developing. With the advice of doctors, she and her husband made the difficult decision to induce labor in week 20. They later had four miscarriages and now have three pre-school children.
- Shelley also underwent treatment for infertility. When she was 27, she had a miscarriage. A year later, she and her husband discovered in week 20 of her second pregnancy that Shelley's life was in danger and the fetus was nonviable. They, too, made the difficult decision to induce labor and end the pregnancy. She later had another miscarriage before giving birth to a healthy child.

All four women were proactive in healing from their losses and all had some support. Husbands were present and active at delivery. Chris, Marcy, and Shelley held their children's bodies at the hospital. All sought the help of a psychotherapist soon after the loss. Chris and Marcy were active in perinatal loss support groups and, as part of her participation, Marcy spoke with doctors, nurses, and pastoral counselors about the needs of grieving parents. Andrea and her husband led an infertility support group.

Even with some social support, Chris and Marcy did not return to their jobs. Chris said:

I had a stressful job at the time. . . . I could not face going to work. I took six weeks off . . . then I asked the doctor to extend it to ten weeks because I could not face anybody. I had a hard time with crying, letting my emotions out, because I was so angry and so empty. I decided that I could not go back to work after ten weeks. . . . I felt so vulnerable and naked or exposed. I could not tolerate even the thought of . . . people just looking at me . . . and not going, 'Oh, I'm so sorry.' I ended up quitting my job.

She and her husband decided that she would remain at home and she is now a full-time mother.

Marcy reported:

I never went back to my job. I had been there seven years. . . . It was such a devastating loss, that to go back to work and just to get back into the same routine was impossible. I stayed home for a couple months and that was not working very well, because I was always very angry and very, very sad. So I signed up for a temporary agency and I worked temporary jobs, clerical jobs.

She later earned her degree. 'I wasn't sure I could achieve having a live child . . . but I knew I could get my degree.' She now works in an obstetrician's office.

Andrea and Shelley continued their work, Andrea as a psychologist and Shelley as a teacher. Both of them reported supportive colleagues. Andrea was part of the same professional group as Judith and Phyllis. She was also 'in a training group at that time. . . . The people in the training group were very supportive.' She now counsels people experiencing infertility.

When I counsel infertility patients, they relate well to me and I relate well to them. My experience of going through infertility and sharing



that experience with clients who are going through it, gives them hope, even though I did not have a baby myself, because they see that we have come to some kind of resolution.

Shelley's loss and grief affected her work, although co-workers were caring:

My work went crazy; I mean, they absolutely – all these women who are wonderful and are mothers, and care about me and like me – I got over 50 pounds of chocolate, a gazillion cards. I mean gazillions of love poured in and I pretty much put my hands up to it . . . I felt ashamed . . . like if someone looked at me, they would be able to tell . . . I felt like a freak . . . like there was something really wrong with me. I needed to cover that up. I could not be that open and that vulnerable. . . . I am a teacher. Three years in a row, I have lost babies. . . . For three years in a row I have been recovering physically and emotionally from losing the pregnancies and not been quite myself at the end of the year. The school year that I taught after the big loss, I was not quite . . . all there. I did not do anybody a disservice, or teach incredibly poorly, but I was not my best.

Medical technology and the social context changed the experiences of loss for women in this period. Two were in their forties. Three endured treatment for infertility. All had multiple losses. All expressed a conscious intention to heal and received support from hospital personnel and others. All were professionally employed at the time of loss. Andrea and Shelley reported supportive work environments. Chris and Marcy did not return to work. Even with enlightened medical practices, trauma and loss devastated these women so that their work was affected. All now work in roles in which they care for and nurture others.

## Conclusions and implications

The social context in which perinatal losses occurred affected mothers' experiences of grief and healing. From 1965 to 1977, grief was disenfranchised at least in part because people were not conscious of the effects of perinatal loss. Studies about grief, attachment, and trauma were either not completed or not widely known. Connecting sufficiently with their bodies and feelings, their dead children, and the community were largely impossible tasks at the time of the losses. As society's knowledge about relevant issues

grew, the women made more such connections, years later, with the help of psychotherapists.

The healthcare environment began to shift by 1980. Partly in response to new knowledge about grief and maternal–infant bonding, as well as pressure from the feminist and home birthing movements, many hospitals in the USA began to change birthing practices to include fathers and other family members at delivery. When a child was stillborn or died soon after birth, some parents were encouraged to look at, touch, and hold the baby's body. Grief support groups began to spring up. Mothers were encouraged to bond with and let go of the desired as well as actual child; their grief was validated; and they associated with others who expressed support.

Changes in medical technology altered the experiences of mothers with perinatal losses between 1991 and 1999. Treatment for infertility was common. Prenatal diagnostic techniques were improved. Knowledge about attachment, loss, trauma, and healing was sophisticated and widely dispersed. These mothers consciously intended to heal. They were supported to connect with their bodies and feelings, their children's bodies or spirits, and the family and community.

Just as no one brings a child into being alone and, in the words of African American folk wisdom, 'it takes a village' to successfully rear a child to adulthood, no one heals alone from the death of a child. To heal from perinatal loss, a mother connects with her body and feelings; connects with her child physically or symbolically; and connects her child and herself with the social environment. The workplace is becoming an important part of women's community life. Some of these connections can and should be made through work. For example, conducting this research project and receiving personal and institutional support from colleagues to do so has contributed to my own healing.

The literature indicates that both grief in the workplace and perinatal loss are disenfranchised. My interview data support these findings. However, I found a second pattern of responses: three women reported that their colleagues and co-workers supported them as they grieved. Judith and Andrea worked with mental health professionals who were educated about grief and for whom the expression of emotion was valued. Shelley worked as a teacher with a close-knit faculty of women.

While co-workers in other settings might be less knowledgeable about or less comfortable with grief, emotions, and childbirth, they can learn from the supportive colleagues of these three women. They can acknowledge the loss appropriately by saying simply, 'I am sorry for your loss.' They can send cards and flowers, as they might if someone's parent or partner died. They can act as witnesses, listening to the mother's story of what happened or

looking at pictures and other remembrances. These seem like simple gestures, yet they are important and meaningful ways to acknowledge grief.

Some employees might feel uncomfortable or awkward giving even these signs of support. Managers can initiate supportive policies, educate employees about how to respond to others, and act as role models. For example, one assistant plant manager for an automobile manufacturer, the mother of two young children, offered to support a colleague whose child was stillborn in week 37 of pregnancy by meeting her at the door when she returned to work, to walk through the plant with her as she let people know that the expected baby had died (A. Bartos, personal communication, March 2002). Just as changes in hospitals' policies and practices related to perinatal losses influenced the expression of grief, organizations can change policies and practices to help managers and employees transcend denial and defense and consciously support bereaved co-workers.

Perinatal loss is searing and can erode a parent's self-confidence and sense of competence. Managers and co-workers can affirm a loss and support healing. Engaging in meaningful work after recovering from the immediate shock can be restorative to a grieving mother. For the women in this study, work was a means through which they connected their dead children and themselves to a larger community. Such work is a way to regain a sense of hope, reclaim one's life, and redeem the future.

## Acknowledgements

I am grateful to the following people for their help with this research: Gary Giamartino and the College of Business Administration, University of Detroit Mercy, for support through a Summer Research Grant (2000) and research leave (Fall 2000); Ken Bartos, Constance Savage and Jane Hazen for their feedback on earlier versions of this article; and *Human Relations* Associate Editor Barbara Townley and three anonymous reviewers for their encouragement and insightful comments.

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