

## Bonds of Bereavement Care and Caregiving Among SIDS Mothers

*SIDS mothers comprise and illustrate a model network of female caregiving, providing for each other on emotional, practical, cultural, cognitive, and symbolic fronts. SIDS mothers are ideal caregivers for each other because they share an intersubjective understanding of the world (a form of “maternal thinking”) that develops from their critical experience of infant loss. Caregiving itself is a healing practice that enables mothers to voice the continued love for and significance of the baby. By portraying the complex network of mutually supportive relationships that SIDS mothers have crafted and participate in, I hope not only to provide a window onto the experiences of mothers who lose infants to SIDS, but also to present an alternative, feminist model of caregiving that expands the definition of care to include the bereaved, breaks down traditional binary divisions and power imbalances between care giver and receiver, and highlights the transformative potential of interactive connections among women with shared experiences and identities. These bonds of bereavement are a rejection of western individualism and an expression of the caregiving power of human interdependency. In accordance with Ruddick (1995) and Benjamin’s (1988) emphasis on mothering as constructed and relational, SIDS mothers actively re-create their identities and process experiences through complex, ever-changing relationships not only with their own departed children but also with other mothers. By performing acts of caregiving, isolated women relate as “SIDS mothers” and survive tragedy armed with the collective strength to reject patriarchal discourses on maternity and redefine what being a mother means.*

Mothers, traditionally viewed as the ultimate caregivers in American culture, sometimes find themselves unexpectedly in a state of overwhelming grief and in dire need of care. Thousands of infants in the United States die each year of Sudden Infant Death Syndrome (SIDS) and despite decades of medical

research<sup>1</sup> and recent findings (Paterson et al., 2006; Rubens, Vohr, Tucker, O'Neil and Chung, 2007) SIDS remains the leading cause of death for babies from one week to one year of age (Keens, 2006, 2002: 22).<sup>2</sup> Social scientists have pointed to child loss as one of the most devastating events possible in human experience, with resulting grief more severe than that associated with loss of parent, sibling, or spouse (Arnold and Gemma, 1994: 1; Bernstein, Duncan, Gavin, Lindahl and Ozonoff, 1989: 227). Mothers whose infants die suddenly and unexpectedly are cast into an indescribable abyss of pain; a central part of themselves has been ripped away, their future hopes and dreams destroyed. They may continue to function as primary caregivers for their other children or face the confusion of being childless mothers, but regardless, they are traumatized and permanently altered human beings.<sup>3</sup>

Care is commonly understood as forestalling suffering and providing assistance or attending to children, seniors, the sick or disabled, and not categorically invoked on behalf of the bereaved who in the weeks or months after the funerals are expected to “get over it” and “move on.” Yet for mothers who lose infants “the pain of the loss continues to unfold as the future unfolds without the child” (Bernstein et al., 1989: 227); suffering expands and even intensifies well beyond the shock and pain experienced in the immediate aftermath of the child's death.<sup>4</sup> Struggling to cope with mental, physical and emotional anguish, bereaved mothers yearn for solace and increasingly turn to their grief-stricken counterparts to find the fundamental care they require. Bereaved mothers come together at support meetings, on-line groups, and SIDS conferences, bridging differences in age, class, religion, ethnicity, and race,<sup>5</sup> to make up a diverse community of female survivors, largely overlooked by the rest of society that fails to notice their unexpressed needs. For many bereaved mothers, the care they receive from mutually supportive relationships among SIDS mothers is a lifeline; indeed, the most significant source of care available.<sup>6</sup>

In this article, I delineate significant ways SIDS mothers support each other, and offer an analysis of why this intragroup caregiving is healing.<sup>7</sup> By portraying the complex network of mutually supportive connections that SIDS mothers have crafted and participate in, I hope not only to provide a window onto the experiences of mothers who lose infants to SIDS, but also to present an alternative, feminist model of caregiving that expands the definition of care to include the bereaved, breaks down traditional binary divisions and power imbalances between care giver and receiver, and highlights the transformative potential of interactive connections among women with shared experiences and identities. SIDS mothers create safe arenas of female space, meaningful “beloved communities” (cf. White, 2001: 1603) that profoundly serve them in their struggles to survive child loss. These bonds of bereavement are a rejection of western individualism and an expression of the caregiving power found in human interdependency. This generation of SIDS mothers, while still largely invisible to the wider society, copes with their grief more cooperatively than in the past, coming to terms with loss in part by trekking through the

journey in alliance with akin others. As John, the chaplain presiding over the services of my own daughter's funeral in 2003, stated, "God never promised you that life would be fair, but only that in your grief you would not have to walk alone." In accordance with Sara Ruddick (1995) and Jessica Benjamin's (1988) emphasis on mothering as constructed, intersubjective, and relational, SIDS mothers actively re-create their identities and process experiences of being a mother through complex, ever-changing relationships not only with their own (deceased) children but also with other mothers. By performing acts of caregiving, isolated women relate as "SIDS mothers" and survive tragedy armed with the collective strength to reject patriarchal discourses on maternity and redefine what being a mother means.

### **Empathetic care and the network of SIDS mothers**

Caregiving has become widely practiced among this generation of bereaved SIDS mothers in the US through a variety of fluid and flexible formats that include friendships, peer contacts, grief support meetings, and online communities.<sup>8</sup> Informal relations may develop from formal structures; mothers initially meet at state, national or international SIDS conferences, convened annually or biannually by private (e.g., the CJ Foundation) or government-sponsored organizations, SIDS walks and other public awareness and fundraising events, and local support meetings organized by SIDS parents. Bereaved mothers also get together as a result of federally-funded SIDS programs,<sup>9</sup> for example, in San Bernardino County in California, when there is a suspected SIDS death, the chief medical examiner or coroner notifies the public health nurse who not only arranges a home visit but also passes the information on to a "peer contact." The peer contact, a SIDS parent who has been bereaved for at least one year and ideally has undergone state training,<sup>10</sup> visits the newly bereaved SIDS mother to establish a caregiving connection.

In recent years, SIDS mothers engage in mutual caregiving widely through social networking on the web. Online groups such as <SIDS MOMS@yahoo.com> and <SIDS families@yahoo.com> have hundreds of registered members who chat and post emails daily. The web has facilitated the ability of SIDS mothers to reach out, connect across space and in greater numbers, and provide vital emotional care to each other in an unprecedented way. Cheryl explains the significance of the SIDS community to her:

I found the SIDS network on the Internet late one night when I couldn't sleep. I immediately felt a connection to others who could understand my feelings. It has since become a comfortable place where I can gather information, share ideas, and talk about my son at any time of the day (cited in Horchler and Morris, 2003: 204).

Local support groups, which started to appear in the 1980s, offer mothers the benefits of face-to-face human interaction but entail the practical and

emotional challenges of organizing and attending meetings; traveling to set locations may be difficult for women with work, family, and other responsibilities. On-line communities, however, allow women to express themselves freely at any moment of need. They enable bereaved mothers to externalize feelings and expect a response, if not immediately, then within an hour or two. Regardless of the format that brings them together, the SIDS community gives bereaved women a requisite audience when no one else wants to hear.

### **Caregiving mentors: Guiding, advising, and educating**

In conjunction with being empathetic listeners, SIDS mothers provide care for each other through the sharing of medical information, opinions, and social and emotional experiences. In the initial months after a child dies, SIDS mothers tend to dwell on the details of the events surrounding the baby's death, repeatedly replaying the minutiae in their minds. While primarily wishing they could turn back time and undo the outcome, SIDS mothers desperately search for information to make sense of the tragic event. They seek knowledge from multiple sources including autopsy reports, meetings with coroners and medical researchers, articles and printed materials, SIDS organizations, and other SIDS mothers. Mothers share information and compare notes on aspects of their experiences and situations including, interaction with medics and first-responders, idiosyncratic characteristics of their deceased babies (e.g., if they had any illness before death, the condition of the baby when found), and prior and subsequent pregnancies and miscarriages. Mothers form theories of what does or does not cause SIDS, and integrate newly gained expertise with prior frameworks of thought and belief (e.g., religious, spiritual, scientific). They inform, correct, and gently challenge misinformed positions, for example, when one mother wrote to an on-line SIDS group, "I heard that SIDS may be caused by vaccinations. Did I cause my baby's death because I brought her to the doctor for shots?" respondents provided references to assure her that her fears were fallacious.

SIDS mothers discuss common struggles and guide each other through "tried but not true" routes to "recovery." During the months after a SIDS loss mothers frequently turn to doctors for help, either on their own volition or due to the persuasions of family and friends. Medical doctors and psychiatrists prescribe anti-depressants for SIDS mothers to alleviate the immediate symptoms of distress. Medication is widely taken among SIDS mothers during the first year of grief; however, with hindsight and through discussion many SIDS mothers come to regard pills as a limited means of coping with their grief, often just a "temporary numbing device." One SIDS mother recounted her story to other SIDS mothers:

*I tried a variety of drugs in the year after losing my baby. Even then I knew that these pills couldn't help me, but I was just going along with what the doctor recommended. I remember being dumbfounded when he*

*looked me squarely in the eye and asked, "Is the medication helping?" How could I possibly answer his question? By what measure did I have to say if the pills were or were not "helping?" What would "helping" look like, I wondered? My world was crushed. I felt sadder inside than I could ever possibly express. My heart was ripped out and my daughter was dead. It seemed so trivializing to ask if the medication was helping. It was a bizarre, unanswerable question, and one that made me feel even more alone and unable to communicate with anyone other than SIDS mothers. (Parent support meeting, March 4, 2006)*

On social fronts, SIDS mothers help each other grapple with unwittingly hurtful remarks made by others that deny the magnitude of their pain and the significance of the child such as, "It's good that she was only a baby," "Thank God it wasn't Brian; it would have been worse if it had been your older child," and "At least you have your other children." SIDS mothers regularly encounter challenging social situations that they may be unprepared for initially, for example, when acquaintances commonly inquire: "Do you have any children?", "How many children do you have?", or "How old are your kids?" Bereaved mothers talk about such paralyzing moments along with their feelings and responses. Some mothers do not disclose the existence of their SIDS child, either not wanting to create discomfort for the other party or simply not wishing to discuss the child's death. These parents, however, may subsequently feel guilty for not acknowledging their beloved child. Other SIDS mothers always include their SIDS child in the count, determined to recognize them, affirm their existence, and even raise public awareness on SIDS. Many SIDS mothers vacillate in these contexts. Rina stated that in the initial years after her son's death, she would always acknowledge him, regardless of the situation or her relationship with the inquirer. In latter years, however, she kept her son's existence more private "to protect his memory" and make herself less vulnerable, should the listener's response be insensitive.

By discussing information and sharing their social experiences, qualified mothers advise and assist each other on countless SIDS-related matters including: how to pay for funeral and cemetery expenses; whether or not to take anti-depressants and the effects of such drugs; how to face societal insensitivities and ignorance on SIDS death and grief; how to set up a memorial web site for the baby; and how to respond to issues with grieving SIDS siblings (e.g., "My other son is flunking out of school and having so many problems. I know it is related to his brother's death." "My daughter said she wants us to die and go to heaven to be with her sister").

### **The sociocultural context: Overcoming maternal (self) blame**

SIDS mothers correct others' notions of maternal blame, even as they struggle to overcome their own feelings of guilt and self-blame. Finding themselves on uncharted ground in the period after the loss, bereaved moth-

ers may not recognize their own needs or the validity in seeking care. Even worse, they may internalize patriarchal notions of idealized “motherhood” that expect them to be omnipotent protectors, fully responsible for the care and well being of their children—the maternal experience is never divorced from the sociocultural context. Although mothers may indeed be supremely self-sacrificing (expressing that they would “switch places if they could”), the ideology that avers mothers as always capable of protecting their young has insidious effects when the baby dies and the mother is left feeling helpless, confused, and responsible. Her inability to raise healthy children may translate into a sense of personal failure and confirm her own lack of value and self worth. SIDS mothers badger themselves with an endless (and contradictory) series of “if onlys” (“If only I had checked in on him,” “woken up sooner,” “kept him in bed with me,” “hadn’t kept her in bed with me,” “taken her to the doctor,” “had not had her vaccinated,” etc.). They may even resist the idea that their babies died of SIDS, choosing instead to implicate themselves. Melissa stated:

*It wasn't SIDS that killed her. It was my fault. That is what I told the police and the coroner and anyone around me. They were trying to find some medical explanation for her death. But I knew that if I had only taken care of her better, if I had only checked in on her sooner, she never would have died.*

Guilt and self-blame at some level are nearly universal sentiments of mothers who suffer child loss (Kübler-Ross, 1983: 32) and these emotions can be especially strong for parents who do not have any warning prior to their child’s death; they may regret certain thoughts or actions, or may not have had the opportunity to focus their attention fully on the child. Mothers who feel responsible for their child’s death deepen their wounds and may deem themselves fundamentally undeserving of care. Mandy, who turned to drugs and alcohol after her son died, explained:

*I did not want to take care of myself. If I couldn't feed my baby, I didn't want to eat. If my baby could not breathe and live, I had no desire to breathe and live myself. I did not deserve to, for I had not protected my baby.*

In a culture that promotes unrealistic maternal expectations and idealized mother images, SIDS mothers are not the only ones holding them accountable for the failure of their children to thrive. Maternal suffering is compounded by people in the family or community who likewise hold the mother responsible. First responders (i.e., police, fire-fighters, EMT, medical examiners) routinely proceed from the assumption that they are investigating a homicide or case of neglect. Societal blame may be overt. Raphael, an elderly man, admitted to me that he had always blamed his daughter-in-law for the death of his grandson

and had not spoken to her for ten years. The autopsy report listed SIDS as the cause of death, but he held to the popular misconception that SIDS is a form of accidental suffocation. Jocinda, a SIDS mother, recalled the added pain her estranged boyfriend caused her when their son, Lucas, died:

*Salvador (the father of the baby) blamed me for Lucas' death. He told all the doctors and staff at the hospital that I killed him. He had never heard of SIDS and was certain that I had done something to cause Lucas' death. He told people that I must have dropped or intentionally killed our son to cause him (Salvador) pain.*

In the years after Lucas' death, Salvador continued to blame Jocinda for their son's death despite the SIDS determination.

The presumption of maternal culpability may be unstated in some cases but still clearly present. A SIDS mother named Sarah relayed how Madison, a friend of her oldest daughter, used to stay over at her house frequently. After Sarah lost her baby to SIDS, Madison's mother made excuses for why her daughter could not come over and spend the night. To Sarah the insinuation that she was an unfit mother, somehow responsible for her child's death, was clear. Sarah commented, "People are ignorant but it hurts all the same. To your face they are nice but they think such terrible things. Everyone needs an explanation for the unexpected shock when a seemingly healthy baby suddenly dies." Westernized culture considers the death of seemingly healthy infants to be "unnatural," making mothers the obvious scapegoats. For SIDS mothers too, the internalization of responsibility may be more palatable than the alternative—a chaotic world where rules are inverted, order is threatened, children die before their parents, mothers cannot protect, and the basic systems by which we function are no longer controllable, predictable, or stable.

Destructive self-recriminations, however, are challenged and checked by other bereaved mothers who assure and remind each other that SIDS is real, even if not medically solved, and that to date there is no known way to prevent SIDS. The struggle of SIDS mothers is still in its infancy, however, with women striving to accept themselves as "good" mothers and human beings, but most not yet willing to challenge misconceptions openly and risk society's wrath; it is simply too painful. The silent anguish of bereaved mothers remains to be understood, addressed, and even noticed in the public eye.

### **"Am I bad? Am I going insane?": Validation among SIDS mothers**

As a marginalized group so far deviated from the "good" mother standard, SIDS mothers ban together to grapple with questions of identity (e.g., Am I a "bad" person? Am I still a mother?) as a first step in the challenge of convincing themselves that they are indeed still "good" mothers. In a society that casts them as suspect, SIDS mothers need to create safe arenas in which they can share taboo thoughts and experiences that cause them to



question themselves and feel immoral, abnormal, and even “crazy.” Bereaved mothers may, for example, experience resentment toward pregnant friends, children, family members, and strangers. They may not desire to partake in celebratory social gatherings even years after their child’s death. SIDS mothers may do or think things that seem illogical or extreme to the non-SIDS community; for example, mothers may continue to save and cherish all baby-related items for many years, including soiled diapers, dirty clothes, broken toys, and possibly any item touched by the baby. Anne confessed how hurt she was when her sister cleaned out the baby’s room in an attempt to be helpful; she could not tell her sister how much that “trash” meant to her. Maureen continued to cycle baby clothes and blankets through the laundry long after her daughter was gone. Cherisse had her daughter cremated but continued to take the boxed ashes everywhere she went, buckled up carefully in the car seat. When she revealed this practice to other SIDS mothers they laughed, compared “crazy” behaviours, and made jokes about it, but no one was critical.

In the first several years and periodically thereafter, SIDS mothers may find themselves distracted, not fully present in their immediate environment. Mothers report driving past their freeway exit and not realizing it until they are miles down the road. Inattentiveness can affect the mother’s relationships: Tracy’s son often complained to her that she was not listening to him. Clare’s husband grew impatient with what he took to be her extreme absentmindedness. Countless daily experiences may trigger daydreaming about the baby, crying, or a reliving of tragic events; indeed, any sight, smell, noise, or thought may lead to bittersweet memories. “Whenever I hear a siren,” Arielle explained, “my heart aches and I have to fight back tears.” Maura sympathized, “It took years before I could walk down the baby aisle in the supermarket, and when commercials for baby products came on television, it was like a knife going through my heart.” For Susan it was the smell of the orange blossoms each spring. While SIDS mothers strive to function according to social norms and their own standards of acceptability, they share their struggles with other SIDS mothers and learn that these are “normal.”

Some SIDS mothers ponder spiritual or religious questions concerning their child that they do not dare to voice to non-SIDS others around them. They may wonder what their child will look like in heaven (“Will she still be a baby or will she be grown up when I see her?”) or worry if their baby will still remember them. SIDS mothers may believe that their babies communicate with them through various forms of nature. Lucille believed that the yellow butterfly that flew by her at the cemetery was a manifestation of her daughter. Laura told me that she hears birds singing every morning at dawn and believes these to be SIDS babies playing in heaven. Ellie explained her belief that the new life she became pregnant with was the reincarnated spirit of her recently deceased SIDS child. SIDS mothers often reflect back to the child’s expressions and actions shortly before death and with hindsight



believe these to have been communicative signals foretelling of their impending departure.

While not all SIDS mothers hold to these particular beliefs, engage in these precise actions, or have these exact experiences, many have variations on them, listen with interest and respect, and validate the feelings behind the beliefs and practices, all of which serve to reassure the mother that she is “normal” and “good.” SIDS friendships, support groups, and on-line communities allow women to live openly as extremely bereaved mothers. Even if the rest of the world does not comprehend this side of the woman, she is strengthened by the existence of and affirmation from the SIDS community.

### **Symbolic care: The cycle of hope and meaning**

The newly bereaved mother yearns to connect with another who knows and understands her pain; she feels that only someone who has been in her place can comprehend the depths of her anguish. Laurie recalled her initial days of grief:

*When Haley died, I was moving in and out of consciousness. I screamed and cried uncontrollably for days. My parents came over, as did friends and relatives. But I couldn't hear what they were saying to me; I don't remember how they interacted with me. Lisa, who I didn't know at the time, called me the day after my baby died and told me she had also lost her child to SIDS many years before. She was my saviour. All I wanted was to look into her eyes and connect with someone who knew what I was going through. I didn't want, no, I couldn't talk to anyone else.*

Susan, another SIDS mother, stated, “I felt alone in the world, except for other SIDS mothers.” Margaret Pike and Sara Rich Wheeler write about this connection among SIDS mothers: “For many people, it is a tremendous comfort just to learn that they are not alone in the experience of loss and bereavement, that others have journeyed down the rocky road of grief and are making it...” (cited in Horchler and Morris, 2003: 206). Carla wrote, “The voice of another SIDS mother was a lifeline. It didn't lessen the pain any, but it showed me that people do get through it and that they even reach the point where they can support other parents” (cited in Horchler and Morris, 2003: 210). Seasoned in their grief, veteran mothers serve as survival guides and living proof that others too will somehow endure what feels like a fatal blow. “I remember meeting Melissa (a SIDS mother bereaved for three years) just after my daughter died,” Sarah recalled,

*...and asking her, “does it get better?” She said, “yes.” And although I couldn't imagine how I might feel in a few years, it was just a relief to see that she was okay. I asked her if the weight pressing on my chest would ever lift and she told me, “after a year or two that physical pain stops.” And it did.*

Some bereaved mothers are inspiring role models, organizing fundraisers and SIDS walks, setting up memorials, and holding support meetings. But activist or not, the veteran SIDS mother is a symbol of hope for the future of the newly bereaved. With time, the provision of care may become more balanced and mutual, as the once newly bereaved mother moves into a caregiver role herself.

For veteran SIDS mothers, caregiving itself is a deeply meaningful “performative act” (Butler, 1993: 30) of maternity. SIDS mothers state that “helping other SIDS mothers is healing,” “a means of honoring one’s baby,” and “a channel for one’s pain.” SIDS mothers continue to support each other actively years after their child’s death “not because they are depressed or obsessed” Debbie, a SIDS mother/author, wrote, “but because it still matters, their child is still dead and another family is entering down the same horrible path.” She reacted strongly to her friend’s remark “Oh ... You’re still doing that?” about her long-term care work, explaining, “Others who have not lost a child do not realize that the mothering and the love and the corresponding grief and sadness never stop.... It all goes on and it all continues to matter to the mother, even if the rest of the world has moved on and forgotten” (Horchler and Morris, 2003: 208). SIDS mothers who reach out to others in the SIDS community relive their maternal love and heartache in the process, but with the passage of time, do so from a position of strength, control, and with the positive feelings that come from helping their “soulmates.” SIDS mothers note that their volunteer work within the SIDS community (as this care work is often conceived) establishes the child’s impact on world—despite a short physical existence, the child’s life mattered; it inspired the mother to reach out to others. The care work also helps the bereaved woman to reestablish her place as a “mother” (i.e., SIDS mother). Caregiving thus keeps the mother and child alive by preserving the baby’s memory and allowing the mother to commune with the baby’s spirit by connecting her story to that of her child (cf. Elbert, 2002).

## Conclusion

In this article, I call attention to intragroup caregiving, which although acknowledged in the form of self-help groups, has not been cast as primary. As a non-judgmental community of empathetic equals, bereaved women come together as “SIDS mothers” to comprise and illustrate a model network of female caregiving, providing for each other on emotional, practical, cultural, cognitive, and symbolic fronts. Caregiving relationships that enable SIDS mothers to express love for and voice their baby’s continued presence are healing. While professionals, other family members, and friends may expect or hope the mother will “get better” (“My therapist told me I will get to a place where my daughter’s death is no longer painful to me. I knew then that she couldn’t help me”), SIDS mothers know intuitively and by experience that “getting over it” is impossible and even undesirable—losing the pain is often equated with

letting go of the child and no longer caring. Rather than ignoring, downplaying, or denying the hurt, SIDS mothers help each other to acknowledge, process, and live with their reality.

SIDS mothers are ideal caregivers for each other precisely because they share an intersubjective understanding of the world (a form of “maternal thinking”) that develops from their critical experience of infant loss. Identifying as a “SIDS mother” entails a transformative process whereby a woman comes to think and function within a SIDS paradigm, that is, from a comprehensive perspective on life wherein maternal love coupled with the devastation of sudden and unexpected death of the beloved become touchstones for the daily aspects, thoughts, and actions of life. One SIDS mother captures this fundamental outlook:

*As I go through the experiences of life, I now view everything through a certain lens—that of a SIDS survivor. When friends, colleagues, acquaintances complain about problems they are having in their lives, I often think, “If only they knew what a real problem was!” And when I am stressed or having a hard time about anything, I remember my daughter and tell myself, “You can get through this; you have lived through much worse.”*

For SIDS mothers, the deceased child is never far from consciousness. “There is nothing that I do in my life that doesn’t in some way relate or connect to my experience of loss and my identity as a SIDS mother. What I do is often directly out of love and honoring my child,” Maura stated. Arielle concurred, “The baby is always in your heart and mind.”

In sum, SIDS mothers exemplify the poststructuralist truth that maternal subjectivities are diverse, multifaceted, and shifting (Jeremiah, 2006: 22). Through interactive, mutual caregiving, mothers process aspects of their tragedy, repeatedly, in an ongoing manner, and with the knowledge that they are not alone in their pain. As bereaved women become enmeshed in informal relationships and networks of mutual caregiving, they emerge from isolation and grab hold of their new identity as a “SIDS mother.” Ultimately, this process and newly incorporated persona/perspective are healing, not because they expunge the anguish of loss, but because they provide bereaved mothers with (1) a cognitive framework to make sense of their situation and thereby (re)gain a measure of “normalcy” in life, (2) a collaborative means to understand and process the overwhelming, catastrophic experience and, (3) a categorical and meaningful way to belong to the world of mothers and continue on as a loving mother. Thus, despite the fact that the SIDS community is “the club no one would ever wish to join,” through practices of mutual caregiving, SIDS mothers create a model of feminist care that facilitates their own transformation over time from devastated human beings to survivors.

<sup>1</sup>For a detailed discussion of the scientific research and theories on SIDS, see Byard and Krous (2001).

<sup>2</sup>SIDS is a diagnosis of exclusion that is officially recognized as a cause of death for infants primarily in the U.S., Western Europe, Australia, Canada, Japan, and Israel. Although sudden infant death occurs everywhere, these unexplained fatalities are not always recognized or designated as “SIDS.”

<sup>3</sup>Fathers (and other family members) certainly endure the pain of SIDS loss too, but for the arguments of this paper, I focus specifically on mothers who make up the overwhelming majority of active caregivers within the SIDS parent community. See Horchler and Morris (2003: 89-107) and Davis (1996: 111-123) for discussions of SIDS and fathers’ grief, and Hendrick (1999: 33-43) for a discussion of maternal grief and its gender-specific implications.

<sup>4</sup>See Klass, Silverman and Nickman (1996) for a review of misguided psychoanalytical approaches to grief after the death of a child.

<sup>5</sup>The SIDS rate is twice as high among Native Americans, and three times as high for African Americans as compared to Caucasian populations in American society. Researchers have not determined the biological or cultural causes of these variances.

<sup>6</sup>Mothers also turn to family, friends, work, counsellors, religion, rituals, spirituality, nurses, doctors, anti-depressants, illegal drugs, alcohol, as well as other avenues to cope. A comprehensive and comparative analysis of individual and cultural coping strategies is beyond the scope of this paper.

<sup>7</sup>This study is based primarily on the experiences of SIDS mothers in Southern California connected to the Guild for Infant Survival, Riverside and San Bernardino Counties, of which I have served as President for the past three years. My daughter, Micaela, died of SIDS on August 27, 2003. The work is also supported by the hundreds of SIDS mothers I have met in California at local SIDS organizations, peer support, and state meetings, and internationally, through personal fieldwork in Israel (2005), on-line (US, Canada, Europe, and Australia), and at SIDS conferences in Canada (2004) and Japan (2006). Unless published elsewhere, names in this paper have been changed and quoted comments are intentionally referenced vaguely so as to protect the identity of those involved. Contributors, however, were consenting informants.

<sup>8</sup>Although I view mutual care networks as an essential form of healing for this community, my intention is not to homogenize SIDS mothers or depict intra-group care as a panacea, implying that all mothers who lose infants to SIDS develop an identity as a “SIDS mother” and engage in mutually supportive relationships. In addition, if a woman becomes alienated from SIDS mothers who initially provided her comfort and community, she may experience a heightened sense of isolation. As Sarah commented: “At our last meeting I realized that everyone else was Christian. When they started talking about seeing their babies in heaven, I felt awkward. They each said how happy they felt because of the fact that they would someday hold their babies again. I realized at that moment that I was not like my SIDS sisters, and then I felt *really* alone.”

<sup>9</sup>Federally-funded SIDS programs were established in the late 1970’s when,

at the time, there existed only a few voluntary groups including the SIDS Foundation and the Guild for Infant Survival. During the past few decades, bereaved families receive nurse-counseling services in most US counties (see Horschler and Morris, 2003: 214-216).

<sup>10</sup>Unfortunately, due to funding cuts, states no longer provide peer contact training programs (as of 2006), and public health nurses often do not coordinate with existing peer contacts. When the system is dysfunctional or nonexistent, SIDS parents may remain isolated or find each other through other avenues.

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