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# Stillbirth

### A Sociopolitical Issue

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Stillbirth occurs in approximately 1 out of 110 births in the United States, yet little is understood about this experience. Unexplained stillbirths are major contributors to the developed world's perinatal mortality, as only about half have an identifiable cause of death. Because still-births are unpredictable and thus unpreventable, given the current state of science, researchers have called for more uniform definitions, a stricter postmortem protocol, standardized data collection, and increased funding to aid in prevention. The macrosystem for stillbirths includes epidemiology and public health systems that gather statistics on the incidence of stillbirth and its known causes and state record keeping related to both birth and death. Legitimation for women who have experienced stillbirth, through legislative and terminological changes, education, and research, is overdue, despite fears that related policy will trump reproductive rights. This article explores recent policy changes promoted by grassroots organizations relating to how stillbirths are recorded.

Keywords: bereavement; fetal death; social policy; stillbirth

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)

Approximately 1 in 110 women in the United States who give birth will experience the death of a baby during or just before birth (Ananth, Liu, Kinzler, & Kramer, 2005; Centers for Disease Control and Prevention [CDC], 2003; Goldenberg, Kirby, & Culhave, 2004; Silver, 2007). Giving birth to a dead baby is one of the most profound losses that a woman can suffer and has a wide variety of emotional, cognitive, psychological, spiritual, and physiological consequences (DeFrain, Martens, Stork, & Stork, 1986; Goldenberg et al., 2004; Hankins & Spong, 2001; Kirkley-Best & Kellner, 1982; Laakso & Paunonen-Ilmonen, 2002; Samuelsson, Radestad, & Segesten, 2001). Some women feel paralyzed with overwhelming, irresolvable grief. Others feel disenfranchised from their social groups because their mourning experiences are generally devalued (Cacciatore, 2007; DeFrain et al., 1986; Fahey-McCarthy, 2003; Fletcher, 2002; Sadler, 1987; Samuelsson et al., 2001; Worth, 1997; E. Kübler-Ross, personal communication, September 4, 2004).

The macrosystem, which is the overarching sociopolitical system in a society, shapes attitudes, values, and beliefs about a social problem through legislation and policy as well as culture. This sociopolitical system, then, influences public policy administration and social service programming as well as the management of care, research, and the formation of

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agencies that are related to the social problem at other levels. One way that this process is manifested is how stillbirth is recorded in state vital records: A death certificate is issued, and each state legislates financial responsibility for the final disposition of the baby's body to the baby's family (burial or cremation). However, prior to 2001, no record of the baby's birth was issued; hence, mothers who wanted birth certificates for their stillborn babies were denied. This article examines the social movement to change laws that are related to the way that stillbirth is recorded and the gender politics that grieving mothers face in the process.

### Impact of the Macrosystem

Political systems are a major influence (together with culture, family, and other social institutions) on one's sense of self (Saleeby, 2001). In addition to this contextual understanding of identity, there are reciprocal arrangements in this person–environment paradigm. Gender is expressed politically (Burns, 2007), and the political context influences the definition of problems, policy development, and the legitimation of policy (Popple & Leighninger, 2008). From a constructionist viewpoint, gender is a property both of people and of the systems in which they reside, making the context of gender within the political environment important yet sometimes difficult to distinguish. For women, the childbirth experience and motherhood are interwoven in the fabric of gender politics. Gender politics is, therefore, at the core of issues related to stillbirth: how society defines stillbirth, the policies related to the acknowledgment of the life of the stillborn baby, and the social acceptance of these policies.

The sociopolitical and epidemiological milieus and policies affect women and their families by influencing the very context within which women experience stillbirth. Stillbirth is a relatively frequently occurring child death that has been historically marginalized by public health officials. Psychological and sociological theories have not fully discussed stillbirth as a unique experience from other losses or sufficiently explained the psychobiological effects on women within the context of social, legal, and political currents. Many factors have contributed to the inadequate inquiry into stillbirths, including poor record keeping resulting in inconsistent and unreliable data; nonstandardized state-by-state protocols (Froen, 2002); and a societal environment that restricts discussion of this topic (Goldenberg et al., 2004; Hankins & Spong, 2001; Laakso & Paunonen-Ilmonen, 2002). There is also a social discrepancy in the legitimation of grief responses after the death of a stillborn child versus the death of a live-born child (Dunkel-Scheetter & Bennett, 1990; Malacrida, 1999; Mulkay, 1993). "Such ignorance of the significance of the loss on the part of society... impedes the mother's bereavement process" (Ney, Fung, Wickett, & Beaman-Dodd, 1994, p. 1193). It exacerbates a grieving woman's sense of aloneness after stillbirth, intensifying and complicating her grief (Cacciatore, 2007; DeFrain, Martens, Stork, & Stork, 1990; Malacrida, 1999; Peppers & Knapp, 1980), and may protract her grief, causing further withdrawal from social interaction (Rando, 1993). This article explores the sociopolitical climate of stillbirth as a result of grassroots efforts by bereaved parents to change laws that are related to how babies' births and deaths are recorded.

## **Epidemiology of Stillbirth**

Every year in the United States, tens of thousands of parents experience the death of a child owing to a wide range of causes, including automobile accidents, congenital

anomalies, prematurity, injury, and disease (CDC, 2003). Yet stillbirths, which account for a significant number of infant deaths, are not included in the calculation of infant mortality (Gourbin & Masuy-Stroobant, 1995). Exclusion of these data may affect public perception of and responses toward women who experience stillbirth and the overall political milieu as it relates to stillbirth. If these data were included, calculated infant mortality rates for the United States would increase significantly, and a country's "infant mortality rate is considered a fundamental measure of a society's wellbeing" (Stein, 2004, p. A11). Underestimation of the problem, misinformation, societal devaluation and fragmentation of women's bodies, and the politics of the unborn (Layne, 2003a) may have led to relative inaction by policy makers. Certainly, "policies not only reflect values, they can also shape and enforce behavior" (Moroney & Krysik, 1998, p. 43).

Approximately 26,000 babies are stillborn every year in the United States alone (Ananth et al., 2005; Fletcher, 2002; MacDorman, Hoyert, Martin, Munson, & Hamilton, 2007). Of these stillbirths, as many as 50% are of unknown etiology (Froen et al., 2002; Goldenberg et al., 2004). Researchers believe that "data on the prevalence of stillbirth is often inaccurate" as a result of poor documentation and underreporting (Goldenberg et al., 2004, p. 79; see also Conde-Agudelo, Belizan, & Diaz-Rossello, 2000; Hankins & Spong, 2001).

Stillbirth, or sudden intrauterine death, is defined in the United States as the death of an unborn baby, clinically referred to as a fetus, after 20 completed weeks and weighing more than 500 grams or 1.10 pounds (Froen, 2002; Goldenberg, et al., 2004; Gourbin & Masuy-Stroobant, 1995). However, international definitions, as well as data collection, vary widely, and there has been much discussion since the early 20th century surrounding the classification of stillbirths (Gourbin & Masuy-Stroobant, 1995; Hankins & Spong, 2001). Despite improved access to prenatal care, sophisticated medical technology, and frequent obstetrical visits during the final weeks of a pregnancy, the rates of stillbirth have declined only slightly in the United States during the past 20 years. More babies die as a result of stillbirth than of all other causes of infant deaths combined (Conde-Agudelo et al., 2000; Smith Armstrong, 2002; Spong, 2003), and it is more than 10 times more likely to occur than sudden infant death syndrome.

## A Plea for Recognition: Legislation to Recognize Stillbirth

Despite the high incidence of stillbirth, it is a tragedy that has been largely overlooked in public policy and legislation, research, and even academia. "Feminist researchers have tended to skirt the [stillbirth] issue, perhaps because of its ambiguous relation to abortion and choice" (Reinharz, 1988, quoted in Malacrida, 1999, p. 505). In addition, according to Layne (1999, p. 11), pregnant mothers are "encouraged to think of the baby...as a precious person, a valued subject," until the baby is stillborn, at which point society revokes or, at least diminishes, the value of the baby and implicitly the status of the grieving mother. In maternity care, a gendered layer is added; it manifests not just in withholding information and choices from women "for their own good" but also in assuming professional authority on all maternity matters (Walsh, 2005, p. 708).

Historically, the birth of a stillborn child has not been recorded as an event; only the death is recorded and memorialized by state governments via the issuance of a death certificate and the mandated final disposition of the body (Lovell, 1983; "When Is a Fetus a Dead Baby?" 1991). Throughout childhood and adolescence, individuals acquire material items in day-today life, objects that abet memories, which are attached to family narrations. Yet there are few tangible mementos for women whose babies are stillborn. These "emotional artifacts and durable reminders" (Layne, 2003a, p. 125) help women to actualize their losses. Lovell (1983, p. 760) found that for stillborn babies, "there was an abrupt cut off in the identity construction process" by others and that "denial of the baby's existence was expressed" both explicitly and implicitly. In a dramatic instant, there is an "unraveling of a woman's lived experience and rapid deconstruction of her motherhood" (Lovell, 1983, p. 760). Because women often experience their babies as an extension of the self, to deny the baby's worth is to refute the woman's worth. In the case of stillbirth, "the bereavement of the mother...is unique in that she is grieving the loss of a part of the self' (Theut et al., 1989, p. 637). The absence of any civil documentation implicitly asserts that the baby never existed (Lovell, 1983). It is a part of the shroud of silence surrounding death, particularly death with birth (Cacciatore & Bushfield, 2007; Kübler-Ross, 1969; Layne, 2003b). Until 2001, legislation in all 50 states required the issuance of a death certificate for the stillborn baby and mandated final-disposition responsibilities to the family. However, no state recognized the birth of a stillborn baby. Yet many women struggled to accept this policy: How can you die if you never were? Mothers who wanted birth certificates for their stillborn babies were denied the option to obtain them. The only way to change this situation this was through legislation.

The grassroots efforts of women and men who are involved in an international nonprofit organization for bereaved parents, the MISS Foundation, led to the passage of the first law to provide for birth certificates for stillborn babies. The MISS Foundation provides emotional and financial aid to families after the death of a child and spearheads various advocacy efforts. Enacted on August 9, 2001, House Bill 2416 altered the way in which stillbirths are handled and recorded in Arizona. The Arizona Revised Statutes, Section 36-329.01, entitled "Certificate of Birth Resulting in Stillbirth," or CBRS, states,

A. In addition to the requirements of section 36-329, the state registrar of vital statistics shall establish a certificate of birth resulting in stillbirth on a form approved by the state registrar for each fetal death occurring in this state after a gestational period of at least twenty completed weeks. This certificate shall be offered to the parent or parents of a stillborn child.

B. The certificate of birth resulting in stillbirth shall meet all of the format and filing requirements of section 36-322, relating to a live birth.

The law, commonly called the MISSing Angels Bill, requires that mothers of stillborn babies should be allowed to pay for and request a certificate of birth resulting in stillbirth in addition to the state-issued death certificate. With the aid of families who were affected by stillbirth, Arizona was the first of 21 states, as of summer 2007, to pass such legislation. As a press release of the MISS Foundation (2001) noted,

HB 2416 is an important step allowing grieving parents the same respect given to the woman leaving the hospital with a healthy infant in her arms....Senator Sue Gerard (R-Dist. 18), chair of the Senate Health Committee, agreed. "The passage of this bill will give much-needed respect to those who have experienced the stillbirth of a child," Gerard noted. "It may even be the first step toward increased knowledge about the causes of stillbirth. In addition, it makes Arizona the first state in what hopefully will be a national trend toward recognizing the significance of this tragedy."

Bereaved mothers consider this recognition vital, contending that there are tangible psychological benefits to the issuance of the new certificate recognizing the birth.

This bill was important to me for many reasons, not the least of which is that this legislation recognizes a traditionally illegitimate loss and grief for me and for thousands of women. It acknowledges a very significant event—birth. (MISS Foundation, 2001)

#### The Political Divide

Yet how to do language when the representation constraints are of such particular rigor? How to bear witness to the suffering of body and mind where the economy of representation always threatens to reinscribe that suffering in unwanted terms? How to do language about the death of another, the one event for which we cannot really have a language? (Murphy, 2004, p. 149)

Following Arizona's passage of the CBRS legislation, a few other states quickly followed suit. Yet from the beginning, concerns of reproductive rights groups threatened to halt the bill. They were apprehensive, claiming that the bill was a slippery slope toward the erosion of women's right to choose. Indeed, the slippery-slope argument has been invoked in the political theater for provocative social issues from abortion and stem cell research to euthanasia and end-of-life issues (van der Burg, 1991). Often reform movements with the most favorable arguments—those that make the most sense—are met with objections of the slippery slope (van der Burg, 1991). Legal scholars have stated that there are ways to avoid the feared slippery slope. One such way is to avoid vagueness in the language. Another concern, though unvoiced by the opposition, may have been the *empirical* slippery slope or a "general shift in the ethos of a society" (van der Burg, 1991, p. 51) and a type of psychological precedence. Rather than invoke the slippery-slope argument, van der Burg suggested that both sides should "analyze and discuss the more fundamental questions that are hidden;...this will probably be more effective in preventing the developments that are feared than the rhetorical and emotional" argument of the slippery slope (p. 65).

Although legislation is a reflection of popular morality, there is room for mutual understanding and accommodation on both sides of an issue. Thus, statutes often reflect moderate positions that represent "compromises between opposing groups" (van der Burg, 1991, p. 49). For example, concerns were raised about the cost of the certificate. This issue was easily addressed by attaching a nominal fee to the document, commensurate with a Certificate of Live Birth. Concerns were also expressed about potential identity theft and fraud. In states where this was a concern, language was inserted to add the line, "This is not proof of a live birth." Yet in at least three states, the opposition was able to quash the legislation, and the controversy made headline news in both New Mexico and California.

New Mexico Governor Bill Richardson vetoed the stillbirth-certificate bill in March 2007 after it passed unanimously in the New Mexico legislature, surprising legislators and bereaved mothers who supported it. The media suggested that Richardson's actions were politically motivated, driven by his presidential campaign advisers who warned him that supporting the legislation might alienate women's rights groups (Gardner, 2007; Lewin, 2007; "Richardson Must Apologize for Insensitivity to Parents," 2007). Indeed, the issue of reproductive rights occurs in a political milieu in which "amid all the shouting, it is hard for adversaries to hear one another" (Sagan, 1997, p. 197). It is an issue that divides families and friends, that couples avoid discussing, and "politicians check the latest polls to discover the dictates of their consciences" (Sagan, 1997, p. 197).

It would take two attempts to get the bill through California's legislature. The first, in 2003, failed to move beyond the first committee hearing. The second attempt, in 2007, encountered equally vociferous opposition from the National Organization for Women, Planned Parenthood Federation of America, the American Civil Liberties Union, the National Abortion Rights Action League, the American College of Obstetrics and Gynecology, and the California Medical Association (California State Senator A. Maldonado, personal communication, July 15, 2007). Lobbyists for these groups invoked the slippery-slope argument, suggesting that this bill might interfere with a woman's right to choose an abortion in the future.

Proponents of the bill countered, during bicameral hearings, that California currently issues death certificates for all stillborn babies, which, by definition in the current statute, excludes abortions, specifying that a baby must be stillborn to qualify for the certificate (personal communication, A. Maldonado, July 15, 2007). They argued that California currently issues a Certificate of Live Birth for babies who are born alive, implying there are birth outcomes other than "live" and that this request for a new document that accurately records the outcome as a stillbirth represented a complementary measure. They also noted that California requires families to pay for the final disposition of stillborn babies. Finally, they pointed to the current statute that requires the issuance of a Certificate of Live Birth for infants who are born even prior to 20 weeks gestation, well before gestational viability, if they exhibit any sign of life including taking a breath or having a single heartbeat (personal communication, A. Maldonado, July 15, 2007). Yet many stillbirths occur at, or even past, full-term to viable babies. The bill was signed into law by Governor Arnold Schwarzenegger in October 2007.

According to Layne (2003a), feminist discourse has either ignored stillbirth or the issue is regarded as an anathema. Layne called for changes to this thinking and asserted that feminists are "abandoning their sisters in hours of need," thus contributing "to the shame and isolation that attends" stillbirth. And in so doing they have "surrendered the discourse...to antichoice activists" (Layne, 2003a, p. 239). Yet despite the macrosystem's opposition to stillbirth legislation, many individual feminist thinkers spoke out publicly in support of efforts to get it passed. Miriam Eldridge, former president of the New York Chapter of the National Organization for Women, said the following in *Salon.com*:

To establish at the outset my bona fides for commenting on this matter, I am a mother of three (grown) children and never experienced either a stillbirth or an abortion. I am also a committed pro-choicer, and in fact was President of the Westchester County (NY) chapter of NOW back in 1973 or thereabouts. Yet when I first read of this controversy in the *San Francisco Chronicle*, my sympathies immediately went to the mother of the stillborn (even though I don't regard myself as ideally [excessively?]) maternal. I was surprised to learn that the objection was coming from the pro-choice side, and wonder if my pro-choice sisters might not be a bit too rigid in this case. I can understand why the mother of a stillborn infant, who was able to see and hold the dead baby, might wish for a more dignified memorial than a death certificate. The birth certificate would acknowledge that she had indeed carried the fetus, with everything that that entails, and had intended for it to be born alive. Since some states do issue birth certificates under such circumstances (a fact of which I was unaware), a precedent has been established, and I think my home state of California should follow suit. (Eldridge, 2007)

According to Sharon Kaplan (2003, quoted in MISS Foundation, 2007), former chief executive officer of Planned Parenthood of Delaware, "If this certificate helps ease their pain, then we support it. It does not seem to me to be an anti-choice agenda."

These views more accurately reflect feminist ethics that seek to incorporate the voices of women as a means of constructing their realities. Under this paradigm, what women want—their personal choices—should greatly influence policy making regarding reproductive

issues (Petchesky, 1980). Yet strong sociopolitical forces are sending messages to women who have experienced stillbirth. These messages crystallize the stark discrepancy between what the bereaved mother feels and the degree of grief response that is proscribed or legitimated by others. The result for some women has been public censure and even reprimands of expressions of their angst and despair after stillbirth. Subtle affirmations of unworthiness plague bereaved mothers: "Your baby never existed; thus there is no birth certificate or justification for one"; "Your baby doesn't matter, so the baby is not counted in infant mortality rates"; "We don't care about you or your baby, so we're not going to devote resources to research stillbirth or to support grieving mothers." The messages can also be highly conflicted: "You must bury your dead baby, and we'll issue you a death certificate, but you cannot request a birth certificate." These intimations are often incongruent with a grieving mother's profoundly painful reality.

Women's participation in political decision making has been studied from a variety of viewpoints (Burns, Schlozman, & Verba, 1997, 2001), identifying the importance of power (or its lack) as well as visibility. What issue could be more closely identified with invisibility and powerlessness? The stillbirth experience is made invisible through key social and political messages. From a radical feminist perspective, the structural inequalities that are created by these messages are carried out through public policies that have a significant impact on women's private lives. Women may combat these inequalities by expanding the boundaries of feminism and enacting social change (Saulnier, 1996). As key stakeholders and beneficiaries (or subjects) of policy and politics, women who have experienced stillbirth have added their voices to the framing of solutions as well as to the politics of enactment for gender equity. According to Kirsten Pert (personal communication, July 15, 2007), a bereaved mother and California team leader for this grassroots movement, grieving mothers now want the "dignity of a birth certificate," and their efforts have led to a now-recognized sociopolitical movement by women and for women to engage in the political process.

### Conclusion

This woman-centered social problem seems to lack a place in the politically controversial world of choice. In an argument that he purported to be both pro-choice and pro-life, scientist Carl Sagan (1997) stated that, with the exception of imminent danger to a mother's life, "prohibitions on abortion in the last trimester... [strike] a fair balance between the conflicting claims of freedom and life" (p. 214). After a detailed exploration of fetal development based on biology, he argued, "It's hard to maintain that a transformation to full personhood happens abruptly at the moment of birth" (p. 198). Indeed, "discourses are largely framed by the debates raging in the context of pro-life or pro-choice camps" (Jutel, 2006, p. 426) because both extremes entangle bereaved mothers in their impassioned political debate about the status of the unborn and legal definitions of personhood. Perhaps it is time for the feminist agenda to legitimate the stillbirth issue through legislative and terminological changes as well as education and research. Perhaps there is a more compassionate woman-centered sociopolitical approach to the stillbirth of a baby that recognizes the reproductive needs and choices of all women. Moderation and compromise may be the key.

Stillbirth contradicts "two fundamental premises of the women's health discourse of pregnancy and birth—that women can control their reproduction and that birth is a...joyful experience" (Layne, 2003a, p. 241). Feminism has long celebrated childbirth as a "way to affirm our uniqueness and power as a gender" (Berg, 1995, p. 85). Thus, feminist thinking

has a relative stake in unraveling the sophistry of the controversy regarding stillbirth. As with the battle about birth certificates for the stillborn, "discourses are largely framed by the debates raging in the context of pro-life or pro-choice camps" (Jutel, 2006, p. 426), and both extremes entangle bereaved mothers in their impassioned political combat over the status of the unborn and legal definitions of personhood. Yet for the mother of a loved and wanted stillborn baby, "denying fetal personhood simultaneously denies maternity by creating the childless mother" (Jutel, 2006, p. 432).

Despite radical feminism's framing of the structural inequalities in reproductive politics, stillbirth remains excluded from gender-based structures that support choice. Perhaps postmodern feminism offers an epistemology to move from an "either/or" to a "both/and" conceptual frame with respect to stillbirth. In this respect, stillbirth need not be seen as opposition to reproductive choice or a slippery slope with respect to when life begins. Rather, stillbirth is uniquely experienced by each woman, and an inclusive understanding of her reality is necessary. Legal scholar Leslie Bender (1988) stated that the feminist movement can enact a tort system that is caring, compassionate, and responsive, focusing on women's individual needs rather than on the political agenda of the macrosystem, even when that system purports to protect women's choices. Creating political and social structures that both respect and include these women's needs and validate their experiences can reduce their suffering. As an issue of social justice, researchers and practitioners should turn their attention to this issue and contribute to the scholarly literature that incorporates stillbirth as a woman's issue, support clinical research on maternal health and the prevention of stillbirth, support compassionate legislation and policies that represent the needs of all women, and advocate for responsive sociopolitical systems that recognize the complex needs of vulnerable groups.

Truly, stillbirth belongs in the pantheon of issues that need to be championed by feminist thinkers. It is the ultimate woman's issue. This social movement appears to be much like a reclamation, for many women, of the solely feminine experience of childbirth and motherhood as "women [find] their power over mourning language" policy, and ritualization even when it is...pathologized, marginalized, and otherwise restricted" (Kanter, 2002, p. 7). The time has come to give these women—these mothers—back their voices and, "in so doing, to end the silence" (Cacciatore, 2007, p. 91).

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