

## **Trauma Associated with Perinatal Events: Birth Experience, Prematurity and Childbearing Loss**

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I recently spoke at a large childbirth education conference on “Helping women make peace with their birth experiences.” The topic resonated with the audience, and many waited afterwards to share their stories with me. Later that evening, a woman approached me when I was alone. She told me that her first birth had been like a rape, and that she had never discussed her experience with anyone. It had happened more than 20 years ago.

Perinatal events can cause trauma in young adult women, and influence them for the rest of their lives. Although these events would seem to only occur when women are of “childbearing age,” traumatic perinatal experiences can impact women’s lives well into their 70s and 80s (Smart, 2003). As common as these experiences are, however, they are usually missing from a discussion of trauma in the lives of women. This chapter is an initial step in addressing that oversight.

According to the diagnostic criteria for posttraumatic stress disorder (PTSD), a traumatic experience is one that victims believe is life threatening, or could cause great bodily harm to themselves or a loved one. This applies to many perinatal events, when women sincerely believe that they or their babies might die. Even if their risk of death is not strictly true in a medical sense, women’s beliefs about impending harm can still affect them. In this chapter, I describe how perinatal events can cause trauma and leave a life-long imprint on women’s lives. The perinatal events I describe include negative birth experiences, having a premature baby, and childbearing loss (miscarriage, infertility, abortion, stillbirth and neonatal death). These are described below.

### **Negative Birth Experiences**

I first broached the subject of negative birth experiences while working on my first book. So many women had related these types of experiences to me, but negative birth experiences were not acknowledged in the research literature. One of the first women I interviewed for my book had had a cesarean section with failed epidural anesthesia. She was awake and could feel everything during the surgery, and the anesthesiologist did not believe her. She screamed throughout the procedure. Her birth was fairly recent, about a year before I interviewed her. Not surprisingly, was deeply traumatized by her experience.

The situation I've just described is, thankfully, relatively rare (although I know of several similar cases). But generally speaking, are negative birth experiences common? One national study addressed this question (Genevie & Margolies, 1987). It is an older study, but the only one of its kind. Women in this study were a nationally representative sample of 1,100 mothers, ages 18 to 80. Given the age range of the sample, a very wide range of birth experiences was covered. Still, 60% of the mothers described their births in predominantly positive terms. This group also included mothers who described their experiences in terms such as "tough, but worth it." However, 40% of mothers in this sample described their births in predominantly negative terms. More concerning, 14% described their births as "peak negative experiences"—one of the worst experiences of their lives. In the qualitative accounts, women in this study expressed deep feelings about their births. Several of these women explained that their births had been so difficult that they had elected not to have any more children.

So another question then becomes were their experiences sufficiently bad to cause psychological trauma? Two more recent studies have found that some women did indeed develop PTSD following birth. The first of these was a prospective study of 289 women who were assessed while pregnant, and when they were six weeks and six months postpartum. The authors found that at six weeks, 2.8% of women met full criteria for PTSD, and approximately half of these women still met criteria at six months (Ayers & Pickering, 2001). Women with preexisting PTSD or depression were not included in the analyses.

The second study assessed 264 women who had unassisted vaginal births at 72 hours and six weeks postpartum (Czarnocka & Slade, 2000). Three-percent of the women met full criteria for PTSD, and 24% had at least one symptom. The factors that predicted traumatic-stress symptoms included a low level of partner or staff support, and low perceived control during labor.

The percentage of women who met full criteria for PTSD may, at first, seem small. But there are some factors you should take into account when considering these results. First, the Ayers and Pickering (2001) study excluded all women who had had previous episodes of PTSD or depression—the very women most vulnerable to subsequent PTSD. If these women were included, the percentage would probably double. Second, in the weeks following the September 11, 2001 terrorist attacks on New York City, the rate of PTSD in Manhattan was 7.5%. People who suffered from previous episodes of depression and PTSD were not excluded from this analysis (Galea et al., 2003). This percentage is more than double the percentages in the previously cited birth studies. But this percentage is in reference to an event that killed thousands of their neighbors. Birth, in contrast, is supposed to be a happy event. The fact that there are *any* women who meet full criteria for PTSD, and 24% who have symptoms, should alert us that something is seriously amiss.

Findings such as these raise another important question—namely, what is it about birth that can turn it into a negative experience? Researchers have also examined this issue. For a long time, research was limited by a paradigm that designated that cesarean

births as “bad,” and vaginal births as “good.” This framework is somewhat helpful, but there are many experiences that do fit neatly into these categories (e.g., women who are traumatized by vaginal births, or women who feel positively about their cesarean births). These studies, however, were a starting place for understanding the psychological impact of negative birth experiences. Some of the more recent findings are cited below.

### **The Psychological Impact of Cesarean Births**

In a prospective study of 272 Australian women, Fisher, Astbury, and Smith (1997) assessed the psychological outcomes of three types of birth: cesarean, assisted vaginal, and unassisted vaginal. As predicted, women who had cesareans were significantly more likely to have negative moods and low self-esteem following birth. In contrast, women who had unassisted vaginal deliveries had the most positive moods. Women with assisted vaginal deliveries were somewhere between the two groups. The authors concluded that operative childbirth carries “significant psychological risks rendering those who experience these procedures vulnerable to a grief reaction or to posttraumatic distress and depression” (p. 728). They noted that the prospective design allowed them to make causal inferences, and that the reactions of the women could not be attributed to preexisting symptoms.

These same authors also conducted a study with women admitted to a private mother-baby unit for psychiatric care (Fisher, Feekery, Amir, & Sneddon, 2002; Fisher, Feekery, & Rowe-Murray, 2002). Thirty-six percent of mothers were disappointed with their births, but the percentage varied by type of birth (66% for cesarean birth, 45% for assisted vaginal, and 20% for unassisted vaginal).

Durik and colleagues (Durik, Hyde, & Clark, 2000) had contrasting findings. They compared women who had vaginal deliveries, women who had planned cesareans, and women who had unplanned cesareans. They assessed women at one, four and 12 months postpartum. As predicted, women with unplanned cesareans described their deliveries more negatively than women in the other two groups. But they were not more likely to be depressed or have low self-esteem during the first year postpartum.

Another large study (N=1,596) of planned cesareans vs. vaginal deliveries for breech birth had similar findings to those of Durik et al. The authors found similar rates of postpartum depression in both groups—approximately 10% (Hannah et al., 2002). Breastfeeding rates were high in both groups and not significantly different. Also, 78% of women found it “easy” or “very easy” to care for their infants, and approximately 82% of the total sample found adjusting to motherhood “easy” or “very easy.” These findings on postpartum depression, breastfeeding and women’s transition to motherhood are unusually good, and strongly suggest that these women had an exceptional amount of support postpartum, perhaps because of participating in the study.

In summary, the results of the above-cited studies indicate that cesarean births can cause negative reactions for women who experience them. Women who received ample support following their cesareans, however, were significantly less likely to have

negative reactions than those with no support. These variations in responses indicate that it is not the procedure of cesarean delivery *per se* that causes negative reactions. Women are less likely to have negative reactions to cesarean deliveries if they are provided with support, reassurance, and are involved in decisions about their care.

## **Subjective Variables**

So if objective factors, such as type of delivery, do not consistently predict a negative reaction, what does? I've found that women's subjective experiences of their births are often far better predictors. Three subjective variables have emerged from the literature so far: a woman's sense of control, how supportive she perceives the environment to be, and her prior vulnerabilities. These are described below.

### **Sense of Control**

Women's subjective sense of control is one of the most consistent predictors of positive feelings after birth. But it can be difficult for a woman to achieve a sense of control in a hospital setting. Hospital environments have many aspects and procedures that can disempower patients in general (American Medical Association, 1995; Rothman, 1982; Wertz & Wertz, 1989). Patients are stripped of their clothing and surrounded by strangers. Other people control their most basic functions including eating, drinking, and going to the bathroom. Men and women often have little say about what happens to them, and medical decisions may be made without their input. This is especially likely when there is a medical emergency. And this lack of control can lead to a negative reaction to birth.

The importance of sense of control was recently demonstrated in the large clinical trial of planned cesarean vs. vaginal deliveries for breech presentation described earlier. Sense of control predicted what women in both groups liked about their deliveries. Women in the planned-cesarean birth group liked being able to schedule their deliveries, that their pain was well controlled, and that they felt reassured about the health of their babies. Women in the planned-vaginal group liked being able to actively participate in their births, that their births were natural, and that recovery from childbirth was not difficult. Women in both groups felt reassured about their own health (Hannah et al., 2002).

Personal control also varied by type of delivery in a prospective study from Australia (Fisher et al., 1997). Fifty-six percent of women who had unassisted vaginal deliveries felt that they had personal control over their deliveries compared with 19% of the women who had cesarean births. For women in the cesarean group, it did not matter whether their births were emergency vs. planned cesareans; neither group felt that they had control.

Simkin (1991), in her longitudinal study of women's reaction to birth, noted that being "in control" included two specific elements. The first was "self-control"; it included women's feelings that they conducted themselves with discipline and dignity.

The second aspect was feeling that they had control over what was happening to them. Some of the women in the study were still quite angry and disappointed by what doctors and nurses did to them, even after 20 years had elapsed. Indeed, Simkin noted: “the way a woman is treated by the professionals on whom she depends may largely determine how she feels about the experience for the rest of her life” (p. 210). Which brings us to our next variable.

### **Supportive Environment**

Another subjective variable is a mother’s perceived level of care. When women perceived a lack of care, especially during labor and delivery, they were more likely to have a negative reaction. In a study of 790 women at eight to nine months postpartum, Astbury and colleagues (Astbury, Brown, Lumley, & Small, 1994) found that women were more likely to be depressed if their caregivers were unkind, they had unwanted people present during birth, were dissatisfied with their care during pregnancy, or felt that the doctors or nurses did not do enough to control their pain during labor.

A more recent study (Rowe-Murray & Fisher, 2001) found that lack of support during labor increased the risk for depression postpartum. The authors compared the experiences of 203 women after their first births. They found three variables related to postpartum depression at eight months: a perceived lack of support during labor and birth, a high-degree of postpartum pain, and a less-than-optimal first contact with their babies. These variables accounted for 35% of the variance in depression.

### **Prior Characteristics of the Mother**

The mother’s previous experiences may also influence how she felt about her birth. In a study from Finland (Saisto, Salmela-Aro, Nurmi, & Halmesmaki, 2001), the authors found that pain in labor and emergency cesarean sections were the strongest predictors of disappointment with delivery. Depression during pregnancy also made a difference; women who had been depressed during their pregnancies were significantly more likely to be disappointed with their deliveries, and to become depressed after they had their babies.

In summary, these studies demonstrate that women who had poorly controlled pain in labor or during delivery, felt out of control during their births, felt that the hospital was a hostile or unsupportive environment, or who had pre-existing depression were more likely to perceive their births negatively (Reynolds, 1997). In the next section are two of birth stories from a woman named Kathy. Each birth was difficult, but for very different reasons. These stories are described below.

### **Two Difficult Births: Kathy’s Story**

When Peter was born, the birth itself was pain free. He was small, especially his head and shoulders, and it truly didn’t hurt at all. I kept insisting I wasn’t really in labor up until two minutes before he was born, when the doctor told me to lay down, shut up and push! But afterwards, he was born at 9:30, they

told us he had Down syndrome at noon, and by 4 p.m., I was hemorrhaging so badly that I came within two minutes of death. I had to have an emergency D & C with no anesthesia (talk about PAIN!!) and a big blood transfusion.

That night, they told us Peter needed immediate surgery and had to go to a hospital in another city. A very traumatic day, to say the least. And then they sent me home the next day with no mention at all that I might want to talk to somebody about any of this—the Down syndrome, the near-death experience, nothing. I can still call up those memories with crystal clarity. And whenever we hear about another couple, I have to re-process those feelings. Interestingly, most of them relate to the hemorrhaging and D & C, not to the Down syndrome “news.” They’re all tied up together. Maybe it’s good to remind myself, every so often, of how precious life is.

My third birth was excruciatingly painful—the baby was 9 lbs 3 ounces, with severe shoulder dystocia—his head was delivered 20 minutes before his shoulders. I had some Stadol in the IV line right before transition, but that’s all the pain relief I had. I thought I was going to die, and lost all perspective on the fact that I was having a baby. I just tried to live through each contraction. Of course, I was flat on my back, with my feet up in stirrups, and watching the fetal monitor as I charted each contraction—I think those things should be outlawed! I know now that if I had been squatting, or on my hands and knees, I probably could have gotten him out much easier. I’m the one who has the giant shoulders and incredibly long arms, so I can’t blame anyone else on my two babies with broad shoulders (Miranda, the first, also took several extra pushes to get her shoulders out, but she was “only” 8 lbs 1 ounce).

That night, after Alex was born (at 9 in the morning), I could not sleep at all because every time I tried to go to sleep, my brain would start re-running the tape of labor, and I would feel the pain and the fright and the fears of dying all over again. I stayed up all that night and the next day, and didn’t sleep until I was home in my own bed.

In Kathy’s stories, we see some classic symptoms of a posttraumatic stress response: fear of dying, sleeplessness, and re-experiencing of her birth, both immediately afterwards, and when someone had a similar experience. There was also a lack of control, and the perception that the hospital was not a supportive place. She did eventually come to a place of peace over her experiences, but the memories of those two episodes have remained vivid.

## **Summary**

A negative birth experience can exert an influence for years afterwards. Immediately afterwards, women may feel grateful to have simply survived. It is often later, when they can allow themselves to feel the anger, guilt or sadness that accompanies their experiences that they appraise these experiences negatively. Unfortunately, this

delayed reaction means that care providers are often completely unaware of the impact their actions have on their patients. Women rarely feel empowered enough to go back later and tell their care providers how they really felt.

The good news is that recovery is possible, and women can gain some closure on their experiences. But first, women must allow themselves to be angry or upset. Then they must be given the opportunity to voice their concerns. Only then, can they put these experiences behind them.

In the next section, I describe an experience with many similarities to a negative birth experience—giving birth to a premature baby. Women who have premature babies have often had difficult births. Their reactions are compounded because their babies are medically fragile.

### **Premature Delivery**

My first child was premature. He was born at 35 weeks with severe Hyaline Membrane Disease....He was in the hospital for five months; in the NICU for four months and in intermediate care for one month....The depression started around the time he was three or four weeks old....Up until that time, everything had been so urgent. He had had a couple of arrests. It was overwhelming. Suddenly my son was doing better. Why was I feeling so bad? I had difficulties going to sleep. I was up several times during the night. It was difficult to wake up in the morning. I didn't want to do anything during the day except sleep and call the NICU to check in. I started not to eat well. I felt an impending sense of doom.

Premature birth can also be a source of trauma for women. Every year in the U.S., more than 400,000 premature babies are born. A premature baby born in the U.S. has a high chance of survival. However, babies born very early, or very small, are still at risk for a number of serious complications including brain hemorrhages, chronic lung disease, respiratory distress, blindness or visual impairment, cerebral palsy, and language delays (American Association for Premature Infants, 2000). These serious problems can cause mothers a great deal of worry. Mothers may carry these fears long after their children have recovered. Linda, whose son was born at 27 weeks and weighed two pounds, describes these feelings.

When my son was about 16 months old, I began to have anxiety attacks. I don't think I ever dealt with all of the pain and heartache of the NICU.... No matter how old or big our babies get, they will always be preemies to us (Kendall-Tackett, 2001, p. 172).

A preterm birth is one that occurs before 37 weeks of gestation. Although these babies have a high chance of survival, prematurity is the second leading cause of infant death in the United States. A problem related to premature birth is low birth weight (LBW), or a baby that weighs less than five pounds (<2500 grams). Babies at highest risk are those who are classified as “very low birth weight,” or less than 3 ½ pounds (<1500 grams). Approximately 7% of babies are of low birth weight, and approximately 1.5%

are very low birth weight. The highest mortality rates occur in babies born at the lowest weights or youngest gestational ages.

Premature delivery has been characterized as an “ambiguous loss,” in that parents often feel the contradictory emotions of joy at the babies’ birth, and grief over their fragile state. In a qualitative study of family members who experienced a premature delivery, the subjects experienced a range of reactions. They mourned the loss of a full-term pregnancy, and feared for the baby’s life and health. They also sometimes had difficulty communicating their grief to others because the baby was still alive (Golish & Powell, 2003).

Some risk factors of premature birth have been identified. In a sample of low-income, African American women, maternal depression during pregnancy was associated with spontaneous preterm birth, and was an independent risk factor for prematurity (Orr, James, & Blackmore Prince, 2002). In a study of more than 100,000 women in Bavaria, Martius and colleagues (Martius, Steck, Oehler, & Wulf, 1998) found that preterm birth was associated with premature rupture of the membranes, treatment for infertility, previous induced abortion, a maternal age of greater than 35 or less than 18, cervical dilatation, history of stillbirth or previous preterm birth, malpresentation, preeclampsia (hypertension during pregnancy), uterine bleeding, preterm labor, or chorioamnionitis (infection of the amniotic fluid). The authors concluded that these risk factors fell into approximately four categories: obstetrical history, genital infections, preeclampsia, and maternal age.

Not surprisingly, degree of infant illness is related to how well mothers coped. Blumberg (1980) examined the direct relationship between neonatal illness and maternal depression. She found that neonatal risk was significantly causally related to depression: the sicker the baby, the more likely the mother was to be depressed. Mothers with babies who were most at-risk had higher levels of anxiety and more negative perceptions of their newborns than mothers whose babies were not at risk. This finding was true regardless of ethnicity or socioeconomic status of the mothers, indicating that the effects of neonatal risk were independent of other characteristics within the sample.

In another study, mothers with sick, very low birth weight babies showed high levels of distress postpartum, and this influenced their interactions with their babies one year later. At one year, the mothers of babies at highest risk were less responsive, and the babies showed less cognitive growth. The authors recommended interventions for maternal distress as a way to help both mother and baby (Singer, Fulton, Daviller, Koshy, Salvator, & Baley, 2003).

A study of 67 mothers of medically fragile infants found that mothers can experience both distress and personal growth through the process of caring for their infants (Miles, Holditch-Davis, Burchinal, & Nelson, 1999). Measured at six months postpartum, these mothers were at risk for depression. However, by 16 months, some were reporting positive growth. Distress was influenced by a stressful and non-

supportive hospital environment, and the mothers' worry about their infants' health. Interestingly, maternal growth was influenced by these same characteristics.

### **Intervention with Mothers of Premature Infants**

As noted previously, support can help mothers cope. In a recent study (Preyde & Ardal, 2003), mothers of babies who were very preterm (less than 30 weeks) were randomly assigned to either a parent "buddy" who had had a previous preterm infant, or a control group. After four weeks, mothers in the peer-support group reported less stress than mothers in the control group. By 16 weeks, mothers in the peer-support group were less anxious and depressed, and reported greater levels of social support than mothers in the control group.

Another popular intervention for prematurity is Kangaroo Care, where mothers or fathers have extensive skin-to-skin contact with their babies by "wearing" them in slings that are under their clothes. This technique has proven highly effective in helping both mothers and babies. In a recent study (Feldman, Eidelman, Sirota, & Weller, 2002), mothers and fathers who participated in Kangaroo Care had more positive interactions with their babies, were less depressed, and were less likely to perceive their babies as abnormal compared to mothers and fathers whose babies received standard incubator care. The babies also fare better with Kangaroo Care. As newborns, their respirations are consistently better, they gain more weight, and are able to leave the hospital sooner than their counterparts who receive standard care (Anderson, 1991; Dombrowski, Anderson, Santori, & Burkhammer, 2001). At six months of age, the babies in the Kangaroo-Care group also had higher scores on the Bayley Mental Development Index (Feldman et al., 2002).

Much of the above discussion assumes that the babies survived. In some sad cases, they do not. These babies may have died shortly after birth. Or they may have lingered for several weeks or months in the hospital before finally succumbing. In either case, the loss of one or multiple babies can influence women last for the rest of their lives.

### **Childbearing Loss**

In a moment's time, our world shatters like fine china. And the darkness comes. For some, it was a phone call from the doctor. Still others were all alone. Perhaps you found your precious baby lifeless in the crib, a heartbeat suddenly stopped. Or maybe, like me, it was in a cold, dark room that you felt life slip away as you watched a black, silent ultrasound. Our stories are all different, but our pain is the same (DeYmaz, 1996, p. 1)

Childbearing loss is another common, and unacknowledged, source of trauma in the lives of women. Women of all nationalities and income levels have suffered from childbearing losses. And childbearing loss can strike a woman more than once. For example, treatment for infertility may have finally resulted in a pregnancy, which ended

in miscarriage. Women may have one baby die, only to miscarry on a subsequent pregnancy. Or they may be unable to get pregnant again. The pain from each of these experiences is real, and can persist for years.

In this section, I describe some of the more common types of childbearing loss including miscarriage, infertility, abortion, stillbirth, and neonatal death. Although the focus of this chapter is pregnancy and infant loss, much of what I share in this section can apply to the death of an older child as well.

## **Miscarriage**

Miscarriage is the most common, and least acknowledged, form of infant loss. Each year, 600,000 to 800,000 women miscarry in the United States (Diamond, 1996). And these numbers probably underestimate the true incidence. Women vary in the amount of grief they feel following a miscarriage. Some women seem to take miscarriage in stride, and are ready to “try again” in relatively short order. Other women feel a deep sense of loss after a miscarriage, as several recent studies have documented. For example, in a cohort study of 229 women who miscarried and 230 women from the community, women who had miscarried had a relative risk of 5.2 for minor depression in the six months after a miscarriage. Risk did not vary by length of gestation or women’s attitude toward their pregnancies (Klier, Geller, & Neugebauer, 2000).

The psychological and emotional impact of miscarriage is compounded for women who have had more than one. Each subsequent pregnancy is filled with fear, as women wonder whether this one will last. Diamond (1996) describes her experience of multiple miscarriages this way.

The mourning process became shorter after each miscarriage, because I was resigned to failure and did not actually think each pregnancy was real....After each miscarriage, I went about business as usual. No one else could possibly feel as badly as I did, and besides, I had a sense of terrible shame and failure (p.67).

Miscarriage might also occur in the midst of treatment for infertility (see below). After months of hormone treatments, invasive exams, daily temperature charts, and one or more sessions of *in vitro* fertilization, women can still miscarry. With each miscarriage, the odds of having a baby are reduced. Women often feel an overwhelming sense of hopelessness. Getting and staying pregnant can become the driving force of their lives.

A qualitative study of eight women found that women who had this experience. They reported feeling like they were going back to “square one.” They had an inner struggle between hope and hopelessness for their future fertility. They also reported feeling like they were running out of time, were angry and frustrated with others, felt alone and numb with their grief, guilty, and frustrated with others’ lack of understanding of what they were going through. These women grieved intensely and felt profoundly alone. Some of the women reported that they were hospitalized for their miscarriages on

postpartum units, and that this experience was unbearable for them (Freda, Devine, & Semelsberger, 2003).

The physical aspects of miscarriage can also be traumatic. A woman's first hint that she was about to miscarry may have been a small amount of blood. She may have frantically called her doctor's office, only to be told there was little that she can do. Or rather than a little blood, there may have been a lot. Gushing blood and passing large clots are frightening to most people. In the case of miscarriage, bleeding is the harbinger of impending pregnancy loss.

Many women I've interviewed described the aftermath of miscarriage to be one of the most traumatic parts. It may have occurred at home or on a gurney in the Emergency Room. Hospital staff may have treated the woman in a callous or cavalier way (Ujda & Bendiksen, 2000). Women may have found out that their babies were gone by looking at a black ultrasound screen. And they may have had to undergo a surgical procedure, such as a D & C, to make sure that there were no remnants of their pregnancies left behind. These procedures can be frightening and painful, and their invasive nature can reinforce feelings of powerlessness (Ujda & Bendiksen, 2000).

To complicate matters further, when women miscarry, there are few outlets for them to acknowledge their grief. There is no funeral, few condolences, and little compassion. Women often mourn these losses alone, not realizing that many other women around them have probably had similar experiences (Panuthos & Romeo, 1984).

In a study of 174 women whose pregnancies had ended before 20 weeks gestation, those most at risk for depression were those women who attributed high personal significance to the miscarriage (e.g., felt like failures because of it), who lacked social support, had lower incomes, and did not conceive or give birth after their loss (Swanson, 2000). Partners of women who miscarry are also at risk for depression, but were less likely to receive support from others in a prospective study of women and their partners (Conway & Russell, 2000).

## **Infertility**

Related to the discussion of miscarriage, is another form of childbearing loss: infertility. Infertility is also relatively common. More than six million women in the U.S. (approximately 10% of women ages 15 to 44) reported impaired fecundity--difficulty in conceiving or carrying a child to term (Fidler & Bernstein, 1999). Miscarriage and infertility are intimately related. Indeed, some healthcare providers won't even start a work-up for infertility until a woman has had her second or third miscarriage (Ujda & Bendiksen, 2000).

For women experiencing it, infertility taps into women's deepest feelings of who they are, and what they want out of life. Fidler and Bernstein (1999) consider the emotional impact of infertility to be comparable to that of cancer or heart disease. Testing and treatment for infertility can become all consuming. The testing is invasive,

expensive and often painful. It lays bare the most intimate details of women's lives. Sex loses its spontaneity and becomes mechanical. Women may wonder why they are unable to get pregnant when women who do not want children seem to get pregnant with ease. In a study of 19 women in treatment for infertility, the women described infertility as an interruption of life plans. They also described their feelings of guilt, inadequacy and failure (Ulrich & Weatherall, 2000).

There are also sex differences in response to infertility. In one study, men and women had higher rates of depression and anxiety at baseline, and at the six-month follow-up than men. Women also had lower life satisfaction, higher levels of concerns about sexuality, more self-blame and avoidance of friends, and lower self-esteem than their male partners. The degree of distress for male and females did not change over time. But only a relatively small percentage of patients had clinically significant distress at the various assessment points (Anderson, Sharpe, Rattray, & Irvine, 2003).

It's also important to recognize that not all treatment for infertility ends with the birth of a baby. Indeed, approximately half of couples in treatment for infertility never give birth (Bergart, 2000). Couples may endure years of testing, treatment and miscarriages before coming to the conclusion that they are unable to have a biological child. This can also be experienced as a significant loss. In a longitudinal, qualitative study of 10 women who had had unsuccessful infertility treatment, women described how infertility had created a developmental crisis for them. It had an impact on their relationships, and sense of meaning. These women also described how treatment had often been delivered in an impersonal and dehumanizing way (Bergart, 2000).

Even when mothers go on to adopt, they may feel marginalized by other mothers who do have biological children. Although adoptive mothers cannot tell birth stories, their path to motherhood is no less heroic. However, some report that even after adopting a baby, the sting of infertility may linger for years (Smith, Surrey, & Watkins, 1998).

## **Abortion**

According to recent estimates, there are approximately 26 million legal abortions performed each year worldwide (Speckland & Mufel, 2003). Although it is a relatively common experience, it is arguably the most politically divisive issue of our time. The volatile nature of the topic has influenced how abortion has been studied. Some researchers are anxious to show that it *never* causes harm to women because they fear limitation on women's reproductive rights. Others feel that it *always or usually* causes harm because they want it to stop. The reality, as is often the case, is somewhere in between.

In their comprehensive review of the literature, Adler and colleagues (Adler, David, Major, Roth, Russo, & Wyatt, 1992) summarized what was known about the emotional impact of abortion. They stated that earlier studies had used a psychoanalytic framework to describe psychopathological responses to abortion. More current models used a stress-and-coping model, in that unwanted pregnancy and abortion were seen as

potential life stressors that could have positive or negative consequences. Abortion may reduce the stress associated with an unwanted pregnancy, or it could become a stressful event in and of itself. Several characteristics influenced women's reaction to abortion: their feelings about the morality of abortion, support the women received from their partners or others, and the experience they had in receiving the abortion.

Based on their review, Adler et al. (1992) concluded that first-trimester abortion does not create psychological harm for most women, with a small number of women reporting severe reactions to the procedure. Severe reactions were more likely for women who were ambivalent about their decision, who had lack of partner and/or parental support, who blamed themselves for the pregnancy, and who were less sure of their decision-making and coping abilities. However, they noted that women's responses are complex, and they may have both positive and negative feelings.

A more recent review (Adler, Ozer, & Tschann, 2003) on abortion in adolescents had similar findings. Adler et al. (2003) noted that rates of depression and PTSD for women who have abortions are low. This was true even when considering whether teens would be more vulnerable to these negative effects than adult women. Adler (2000) notes, however, that there are some methodological issues in studying the question of the emotional impact of abortion. One specific issue is that it is almost impossible to prove the null hypothesis because there is no way to randomly assign women to abortion and non-abortion groups. Therefore, we can never know what the women's experience would have been like if they hadn't had an abortion.

Along these same lines, in a review of literature conducted after 1990, Bradshaw and Slade (2003) concluded that after women discovered that they were pregnant, but before their abortions, 40% to 45% experienced significant levels of anxiety, and 20% had significant levels of depression. Women's levels of distress dropped after their abortions, but 30% still had emotional difficulties one month later. Abortion did not affect their self-esteem, but it did have a negative impact on quality of relationships and sexual functioning for about 20% of women (Bradshaw & Slade, 2003).

Even with these generally positive findings, another study had more negative results. In a sample from the former Soviet Republic of Belarus, Speckhard and Mufel (2003) found that a surprising 82% of women had symptoms of PTSD. This was despite the fact that abortion was used as a primary method of birth control in their country, and was therefore a common experience. The authors also found that other emotional and psychiatric symptoms were present in these women including grief, guilt, dissociation, depression, anxiety and psychosomatic responses.

Another study of American women (ages 24 to 45 years) found a connection between abortion and substance abuse. In their sample, women who aborted a first pregnancy were four to five times more likely to report substance abuse than women who carried their pregnancies to term, or who miscarried (Reardon & Ney, 2000). However, some of this effect could be due to the relatively high percentage of women seeking abortions who have a history of violence (Allanson & Astbury, 2001). In a study of

women seeking early abortions in Australia, women with insecure adult attachments were more likely to report high levels of violence, pregnancy, abortion, and emotional problems. Women with secure adult attachments were lower in all these indices (Allanson & Astbury, 2001).

In summary, the results of these studies indicate that many women function well after an abortion, and that their level of emotional distress is likely to decrease-- particularly if they were highly anxious and depressed beforehand. However, for some, the experience can increase the risk of depression, anxiety and posttraumatic stress. Regardless of your stand on this issue, it is important to acknowledge the experiences of all women.

### **Stillbirth/Neonatal Death**

Death of a baby at or near term is another form of childbearing loss. Stillbirth occurs in approximately 1 in 80 births, or more than 195,000 deaths per year. It has a variety of causes. Stillbirth could be due to an accident during labor, such as a prolapsed cord, placenta previa, a uterine rupture, or medical negligence. It could be due to an infection, such as Group B Streptococcus, toxemia in the mother, or physical trauma caused by a car accident or physical assault.

In some cases of stillbirth, the baby dies before labor begins. Mothers may have felt no movement, have started to bleed or had sudden searing pains. Or there may have been no warning at all. Some women learned of their babies' death during a routine examination, when the doctor or midwife could not find a heartbeat.

Sometimes women find themselves in the nightmarish scenario of knowing that their babies are dead, but having to continue to be pregnant for days or even weeks, awaiting labor. Unbelievably, they still need to go through labor knowing that their babies will not be alive at the end. Since the baby has already died, the hospital staff usually gives women strong pain medication for labor. But this often exacerbates the surreal feeling of the experience, making it seem like it is happening to someone else.

After a stillbirth, women's bodies may act like they have given birth to a living baby. Their breasts fill with milk, and they have many of the other physical signs of recent birth. Some mothers have described this experience as their whole bodies "weeping" for their lost children (Panuthos & Romeo, 1984).

Not surprisingly, prior infant loss can increase the risk of depression and PTSD. Janssen and colleagues (Janssen, Cuisiner, Hoogduin, & deGraauw, 1996) compared 227 women whose babies had died with 213 who gave birth to live babies. Women whose babies had died had greater depression, anxiety and somatization six months later than women who had given birth to live babies. One year after their experiences, these women were less depressed and had fewer trauma symptoms than they had at six months. However, the authors noted that stillbirth is a stressful life event that can precipitate a marked decline in a women's mental state for several months afterwards.

A prior stillbirth can also influence how women experience a subsequent pregnancy. Hughes, Turton and Evans (1999) compared women who had had a previous stillbirth with a group of matched controls. Not surprisingly, women who had a stillbirth were more depressed and anxious in the third trimesters of their subsequent pregnancies, and had higher levels of postpartum depression. The results were strongest for women who were most recently bereaved. In the year following delivery, depression was twice as likely for the bereaved vs. comparison women.

Men and women also have different ways of coping with the loss of a newborn. A phenomenological study compared mothers and fathers whose premature, very low birth weight babies had died. At the time of the loss, fathers indicated that they felt out of control, and they also expressed a concern for the mother. They coped by keeping busy. Women indicated they were experiencing intense feelings of loss. They coped by talking to others. They also had more difficulty than the fathers in making sense of the loss and in social situations, such as being around babies. The men and women in the study indicated that males' traditional roles were interfering with their response to their loss (Kavanaugh, 1997).

Death of a baby at term, or shortly after birth, can be highly traumatic. But death can also occur after a baby is safely delivered and appears to be healthy. In the final section, I describe another traumatic form of infant loss—Sudden Infant Death Syndrome.

### **Sudden Infant Death Syndrome (SIDS)**

Sudden Infant Death Syndrome (SIDS) is the unexplained death of a baby less than one year of age that remains unexplained even after an autopsy, examination of the death scene, and a review of the case history. SIDS is so terrifying because it strikes otherwise healthy infants. Approximately 90% of SIDS deaths occur by six months of age. SIDS affects approximately 1 in 700 babies born in the U.S., but the rate is lower in other countries (Sears, 1995). According to the Centers for Disease Control (CDC, 1999), SIDS is the third most common form of death for babies in the U.S.

While researchers have been able to identify some risk factors for SIDS, its cause remains a mystery. Babies exposed to cigarette smoke, who were born prematurely, who sleep on their stomachs, and who were formula fed are at highest risk (CDC, 1999). However, there are many babies who have all these risk factors who do not succumb to SIDS. Conversely, there are babies who have none of these risk factors who do.

In a 30-month prospective study of couples following stillbirth, neonatal death or SIDS, at each assessment period, couples that had lost a baby reported significantly more distress of one or both partners than couples that had not experienced loss. Interestingly, mothers' distress declined over time, while the distress of fathers rose during the study period. Couples who were most distressed at two months reported more marital dissatisfaction at 30 months (Vance, Boyle, Najman, & Thearle, 2002). In another longitudinal study, mothers who had higher educational attainment and more friends

showed better adjustment to their infants' deaths. Mothers who coped by seeking social support had less distress at 15 months post-loss (Murray & Terry, 1999).

Mothers whose babies die of SIDS are usually overwhelmed by the suddenness of the loss. Babies have died on the day that they had a well-baby check. They have died at their mothers' breasts, or while sleeping next to their mothers. In this next section, I share the story of one mother whose babies died of SIDS.

### **Jonathan's Song: One Mother's Story of SIDS**

For Joan, December 8 started like any day. But the events of that day forever changed her life. Joan went to check on her baby after his nap and discovered that he was not breathing. Her neighbor made a frantic 911 call, and the baby was rushed to the hospital. An hour later, the doctor came out to tell Joan and her husband Henk that their son Jonathan had died. He was three months old.

All I could think of was that I needed to be with Jonathan. I said: "I want to see him. I've got to be with him." The nurse said "Of course, of course." And they brought us into the room where my little baby lay, wrapped in a white sheet on the gurney.

When I reached the stretcher on which he lay, I pulled the white sheet open, exposing his pale little body. As I sobbed, "Oh, Jonathan, Jonathan, I loved you. I loved you so much." I caressed his naked body with my hand, touching every part, trying to etch into my mind what I soon would no longer be able to see. I looked up at Henk and he was weeping, tears streaming down his face, his head tipped back in disbelief. The nurses scurried to get chairs for both of us. I think they were afraid that one of us would faint. I covered Jonathan back up and picked him up to hold him. As I held him, I stroked his coppery brown hair. I told the nurse that his hair had just started to grow in. Her eyes were red as she wept with us in our grief.

I turned to Henk and said, "What can we do? I can't just walk away and leave him here." The nurses assured us that we could stay as long as we wanted to, and just hold him and be with him. I pulled his little hand out from underneath the sheet and held his fingers and stroked them. I touched his toes and his feet. I looked and looked at his face and hair.

Henk took Jonathan out of my arms and I didn't know what he was going to do. I was afraid that he was taking him away from me. But he just wanted to pray. He committed our son back into the Lord's hands and thanked Him for the time we were able to have with Jonathan. Then he gave him back to me to hold. Before that, I was afraid to let go of Jonathan. After that prayer, I felt that it was time to leave him and go home. The nurse came in and I handed Jonathan to her. I kissed the top of his head, touched him one last time, and stepped out into the corridor.

Everything after that is after. This is about Jonathan, and our story goes on. We said good-bye to him the best way we could and then tried to pick up the pieces. The great pain and emptiness are still quite real, but not as present every day. He was Jonathan—“God’s precious gift” as his name means—and as we put on his tombstone. Children are precious. People are precious. Each day is precious. That is what I learned from my son’s short life and his death. We miss him so much. That will never fade. I know he is with my Father in heaven and that helps, but there are times when I just want to hold him one more time, nurse him one more time, touch him, hear him just one last time.

But every time I feel that loss, that great void, I also feel grateful for the time we were able to have with one very special little boy, who gave us great joy for an incredibly short time and who we will never forget. No bitter grief could ever poison that, the wonderful sweet time we had with our son Jonathan.

## **Conclusion**

The birth of a baby is generally a positive event. A new life is beginning. A family is formed. Children become siblings. We now also know that substantial portions of women are traumatized by perinatal events. Events that take place during the perinatal period can stay with women for the rest of their lives. While some of what happens cannot be avoided, much of it can be, and healthcare providers can do a better job of caring for childbearing women. There have been two hopeful signs: changes in the treatment of premature babies, and how providers handle neonatal death. These are described below.

The treatment of premature babies has undergone a dramatic change. In the bad old days, parents were routinely excluded from the NICU<sup>1</sup>. They often had little contact with their hospitalized babies, and often felt that only “experts” could provide care for them. Research over the past 20 years has demonstrated that keeping parents and babies apart is bad for both. Slowly, but surely, hospital protocols changed. Parents are no longer excluded from caring for their premature babies, and are now encouraged to be involved. This can increase mothers’ feelings of confidence, and minimize their feelings of helplessness.

Hospitals are also better than they used to be in handling stillbirth and neonatal death. Women are allowed to see and hold their babies, whereas before medical staff often whisked them away before mothers could see them. Not being able to see their babies can prolong women’s grief. Even something as simple as putting a discreet sign on the door (such as a falling leaf) to let hospital staff know that there has been a death can keep women from hearing cheery “congratulations” when they are desperately sad.

Many of the changes in hospital protocols originated with women who experienced poor treatment, and were determined to improve the situation for others. They lobbied for, and got, changes made to the system. It shows what can be done.

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<sup>1</sup> Neonatal Intensive Care Unit

But there is still much work to do. As I described earlier, women who have been traumatized often do not tell their providers about how their experiences impacted them. Providers remain blithely unaware of the havoc they have created. But we know, and we can make their voices heard. We can insist that healthcare providers not silence women, but learn from them about how to do things better. We can also offer women the hope that they can recover from traumatic perinatal events. Women no longer need to suffer in silence. And that is good news indeed.

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