Introduction

A woman who undergoes prenatal genetic testing—whether it be chorionic villi sampling, amniocentesis, ultrasound, maternal serum alpha-fetoprotein testing, or whatever the current technology serves up—experiences many physical and psychological changes during her pregnancy. Chances are high that this is a “wanted pregnancy,” but the meaning of that phrase may be clouded by issues of genetic risk or by any prior reproductive difficulties she may have had. We do not know very much about the potential or developing relationship between mother and fetus when it occurs against the backdrop of genetic risk. We as yet, for example, know little about how the experience of pregnancy is altered when the woman sees the baby on ultrasound or sees the baby’s chromosomes and learns its sex (Black, 1992; Blumberg, 1984; Fletcher, 1972).

When pregnancy loss follows genetic testing, a woman faces in rapid succession two major and contrasting life crises: pregnancy and death. The following discussion of the psychological experiences of women undergoing prenatal genetic testing thus begins with a review of the common human experiences of loss and pregnancy loss before moving on to consider the more particularized experience of pregnancy loss following prenatal genetic testing. Results from a study of pregnancy loss among
women who had undergone amniocentesis or chorionic villi sampling (CVS) will be presented to provide a detailed illustration of women’s experiences and to highlight needed directions for future research inquiries.

Loss and Bereavement

The wide variations in people’s individual responses to bereavement (Osterweis, Solomon, & Green, 1984; Wortman & Silver, 1989) suggest the need for considerable caution in developing any assessments about what are normal or usual behaviors or feelings of a person who loses a loved one. Certainly such cautions must be applied in any research efforts to assess women’s experiences after pregnancy loss. Most descriptions of the bereavement process (Osterweis et al., 1984) outline a series of general phases through which many people pass, with recognition that some people will experience relatively mild distress while others will show persistent difficulties for a prolonged period of time (Wortman & Silver, 1989). However, the lack of consensus about criteria for distinguishing normal from abnormal grief suggests that concepts about the phases of the bereavement process should be used only as a loose framework for predicting or assessing any bereaved individual’s experiences.

For the same reasons, it is difficult to define when recovery should occur or even whether the concept of recovery has meaning in this context. The quality and quantity of reactions over time seem more important than a precise endpoint in time in assessing the normality of a grief process (Osterweis et al., 1984). Concern seems appropriate when the bereaved person continues, even some months after the loss has occurred, to lack any hope for the future, or shows a worrisome intensity of anger, self-blame, or depression. Chronic grief should be suspected when there is not only sadness but also “active resistance to changing that feeling. Not only is there no movement [in that person’s life], but there also is a sense that the person will not permit any movement” (Osterweis et al., 1984, p. 54).

This is not to say that favorable resolutions of the grief process mean a return to life just as it was before the loss. “People
Testing and Pregnancy Loss

do adapt and stabilize, . . . [but] some of the pain of loss may remain for a lifetime” (Osterweis et al., 1984, p. 53). Certain events such as birthdays, anniversaries, or missed developmental milestones may be particularly powerful triggers of strong and painful emotions. However, the process of recovery would appear to be on the right course when the bereaved person seems able, despite occasional setbacks, to invest in current life, feel hopeful about the future, and experience some gratification from present activities.

Parental Bereavement

Although not all women who lose pregnancies, whether through elective termination or miscarriage, think of themselves as bereaved parents, clinical experience suggests that many women who undergo prenatal genetic testing do speak of the fetus as their baby and say they mourn the loss of that child if the pregnancy is lost. The literature on grief suggests that parents who lose a child face a particularly long and complicated bereavement course (Osterweis et al., 1984). Although they have much in common with other bereaved adults, bereaved parents also face several unique aspects in their grief (Rando, 1985). Perhaps foremost, the death of a child is “out of turn.” Deaths of infants and children are no longer common events in families and thus our life-cycle expectations suggest that parents will die before their children. Social reactions to the death of a child are also often problematic. Other parents, in particular, may attach a certain social stigma to such losses because they become anxious about their own vulnerability to a similar loss.

Parents’ potentially strongest sources of support, their spouses, are less available because each is deeply involved in his or her own grief. In reaction, feelings of anger and blame may be displaced onto the spouses because they are closest at hand. One spouse may negatively misinterpret the behavior of the other when the pace and style of their grieving differs. Sexual problems, too, may arise when one partner’s grief blocks sexual feelings, while for the other partner sexual contact is seen as healing (Osterweis et al., 1984).
Other problems common to many forms of bereavement may become particularly hard to resolve when it is a child who has died. For example, the often-found anger toward the deceased may be especially hard to acknowledge and deal with when directed at a child. Parents must also "grow up with the loss" (Rando, 1985) as they note missed birthdays and major developmental milestones, while if there are other siblings, the parents must continue to function as parents, in the very role that they are trying to grieve for and relinquish.

Perhaps not surprising in view of these stresses are findings on the critical importance of the marital relationship in recovery after a child's death. The frequently different coping styles of mothers and fathers can become an increasing source of stress, although couples also may be drawn together as they share their common loss and develop understanding and respect for the differences in their coping styles (Glicken, Harmon, Siegel, & Rudd, 1986; Helmrath & Steinitz, 1978; Jones et al., 1984; LaRoche et al., 1984; Osterweis et al., 1984; Peppers & Knapp, 1980; Rosenblatt & Burns, 1986; Videka-Sherman, 1987; Videka-Sherman & Lieberman, 1985).

Family and friends are often important sources of initial support and frequently are the only people, apart from spouses, from whom help is sought. However, even close relatives can become less available and sympathetic over time. Parents often report that others expect them to "snap out of it" or "get back to normal" when the parents still feel a need to mourn and talk about their loss (Glicken et al., 1986; Helmrath & Steinitz, 1978; Videka-Sherman, 1987).

**Pregnancy Loss**

The woman who begins a pregnancy only to lose it, whatever the reason, finds herself aboard a rollercoaster of changing emotions and coping tasks. Pregnancy itself has been described as a "critical phase" in a woman's life (Blum, 1980), precipitating one of life's normal, developmental crises (Erikson, 1950). It often is a time when a woman reconsiders her previous roles, coping strategies, and self-image (Bibring, 1959; Bibring, Dwyer, Huntington, & Valenstein, 1961; Deutsch, 1945).
Physical and emotional change occur over the course of gestation, with the conclusion of pregnancy, regardless of timing or outcome, requiring additional psychological and physiological adjustments (Blumberg, 1984).

**Miscarriage**

Unfortunately, the same tradition that viewed the mother’s bonding with the baby as developing only gradually, accelerating at the time of quickening (Bibring et al., 1961; Blumberg, 1984), influenced thinking about early miscarriage as a "nonevent" (Osterweis et al., 1984) and minimized the personal anguish generated by early pregnancy losses. In contrast, a "woman-centered view of pregnancy" (Rothman, 1989), suggests that the woman’s construction of the meaning of her pregnancy will influence profoundly her experience of its loss.

The woman who finds herself unexpectedly pregnant and does not want to be pregnant, in effect may choose not to enter into a relationship with that fetus (and, in fact, may prefer to use the term fetus rather than baby). The fact of its loss may not evoke psychological feelings of grief in that woman for that particular pregnancy. In contrast, a woman may embrace her relationship with the baby (and prefer to say baby rather than fetus) from the earliest moment she is aware of her pregnancy. Its loss, regardless of gestation, will evoke grief, the nature of which will be colored by the motivations for the pregnancy (Kessler, 1979) and the nature of the relationship that had been formed.

Miscarriage thus may call an abrupt halt to the woman’s thinking about herself as a mother and to fantasizing about her future life with a child. If siblings have been told about the new brother or sister, parents face the task of finding words to explain miscarriage, genetic defects, or pregnancy termination. Additional hardships include having to inform friends, family, and perhaps employers about the loss. Or alternatively, if the loss occurred very early in gestation, the woman and her partner may have told almost no one else about the pregnancy. In such cases, they face either a very lonely struggle with their grief or the difficult role of informing significant others about the pregnancy at the same time they tell them of its loss. The
privacy of an early pregnancy loss thus makes it more difficult for them to receive the social support that may prove helpful in facilitating their bereavement process (Vachon et al., 1982).

Research findings have begun to confirm women's statements about the anguish of miscarriage. At least some women and their partners experience the volatile emotions and feelings of shock, disorganization, guilt, and loss similar to the bereavement reactions seen after other significant losses. One study (Neugebauer et al., 1992), for example, reports a three-fold increase in depressive symptoms in the six months following miscarriage. These findings are particularly powerful because the study was unique in drawing from a large sample of 382 miscarrying women who were interviewed at two weeks, six weeks, or six months after loss.

Factors thought to affect the heightened distress felt after pregnancy or perinatal loss include the following: loss of a wanted pregnancy; loss at a later stage of gestation; poorer overall physical health; poorer quality of marital relationship; and higher level of mental health difficulties before the loss occurred (Toedter, Lasker, & Alhadeff, 1988). Incongruent grieving among couples and stress on the marital relationship may be negative consequences of a pregnancy loss when the man's process of attachment to the child is not as developed as that of the mother's at the time of the loss (Peppers & Knapp, 1980).

**Elective Termination of Pregnancy**

At first glance, the decision to electively terminate a pregnancy might appear to have little in common with the spontaneous, uncontrollable end of a pregnancy through miscarriage. Indeed, the research literature on general, elective abortion consistently finds few significant emotional problems as a result of that procedure (Figa-Talamanca, 1981; Nadelson, 1978; Smith, 1973). However, a small percentage of women do suffer worrisome psychological reactions after elective terminations. Among those at increased risk are women with abnormal obstetrical histories, medical indications for the abortion, or negative or ambivalent attitudes toward abortion (Ashton, 1980; Figa-Talamanca, 1981). Viewed another way, the literature suggests that women who want to develop a relationship with the
baby, or whose ambivalence prevents them from blocking the
development of that relationship, are vulnerable to strong re-
actions after a termination.

Prenatal Genetic Testing and Pregnancy Loss

Research on the experience of prenatal testing (most research
on experience concerns amniocentesis) suggests that women
feel heightened anxiety before the testing, worry as they await
test results, and experience a decline in anxiety if they receive
word that no abnormality has been detected (Adler, Keyes, &
Robertson, 1991). The majority of those who already have chil-
dren will tell at least one child in the family about the testing
(Black & Furlong, 1984a, 1984b) and provide at least a partial
explanation of pregnancy loss if the pregnancy is terminated
after detection of a defect (Furlong & Black, 1984). Even very
young children and those unaware of all the facts show reac-
tions to their parents’ distress and maternal absence when a
pregnancy termination occurs after genetic testing (Furlong &
Black, 1984). Younger children may have an especially hard
time coping with complete information about the termination
(Furlong & Black, 1984).

Some limited inquiry has also been made into the developing
relationship between the mother and baby prior to amniocen-
tesis. At least some women attempt to withhold investment in
the pregnancy until test results are available (Beeson & Golbus,
1979). These are the “tentative” pregnancies (Rothman, 1986)
in which women try to delay use of maternity clothing and to
deny awareness of the baby’s movement until testing has been
completed.

However, CVS and early ultrasonography create a psycho-
logical milestone of quickening in the first trimester. Rather
than feeling the baby kick, the woman (and perhaps the father)
sees its heart beat and its limbs move. For the woman at risk for
a serious defect in the baby, the technology itself works against
any efforts she may have made to maintain an emotional dis-
tance until results are confirmed (Black, 1992; Blumberg, 1984;
Milne & Rich, 1981). She remains physiologically in the more
unsettling period of first trimester symptoms and changes,
while psychologically being propelled rapidly forward. Thus,
from the outset, we can predict that women undergoing terminations of wanted pregnancies after CVS or amniocentesis will be more likely to face a more difficult emotional course.

Decision-making after a defect is detected can itself be a major source of stress and anguish for women and their partners (Blumberg, 1984; Rothman, 1986). Although on one level women choose the testing with full knowledge that they might face the need to decide about continuing the pregnancy, on another level they often remain optimistic about beating the odds, however high they may be, and coming out on the winning side of the technology.

The prognostic implications of the specific defect that is found can also have a significant impact on decision-making (Blumberg, 1984). For example, although the woman may have come for testing because of concern about higher risks for Down syndrome, the test might reveal a clinically ambiguous abnormality. Chromosomal mosaicisms (where only a portion of cells show chromosome abnormalities), new (de novo) chromosome rearrangements, or unclear details on the ultrasound picture are some of the findings with uncertain clinical significance. Other specific disorders, such as those involving the sex chromosomes, may be identified. Such disorders may carry some, but by no means certain, risks for lowered intelligence, learning problems, or behavioral difficulties.

A number of authors have described the anguish of terminating a pregnancy in the second trimester, after amniocentesis (Ashery, 1977; Blumberg, Golbus, & Hanson, 1975; Donnai, Charles, & Harris, 1981; Fletcher, 1972; Furlong & Black, 1984; Jones et al., 1984). Parents often report mild to moderate depression for at least the first few months after the losses, with mothers, more often than fathers, reporting that they find it difficult to feel that the incident is behind them (Jones et al., 1984). Since, in previous years, these later terminations involved a procedure all too similar to labor and delivery, the particular stresses surrounding these termination procedures has been a major focus of concern and some medical centers have made efforts to develop protocols for the sensitive handling of such terminations (Magyari, Wedehase, Ifft, & Callahan, 1987).

The increased use of dilation and evacuation techniques
(D&E) for later terminations avoids such concerns because the termination is done under general anesthesia. However, some professionals have pointed out that the process of delivering the baby and the option to see and perhaps hold it carry the psychological value of confirming the loss and thereby facilitating grieving (Magyari et al., 1987).

Pregnancy Loss after CVS or Amniocentesis: A Closer Look

The literature discussed above provides a framework for considering a research project conducted by the author on pregnancy loss among women who had undergone CVS or amniocentesis. Findings from prior research on pregnancy loss and prenatal testing has been limited by very small sample sizes and retrospective reporting. The project presented here is unique in its access to a large, national sample and in its access to women in the months immediately following their pregnancy losses. Review of the findings presented herein also highlights both the value and the limitations of using structured, quantitative research methodologies of large samples to learn about women's experiences.

Subjects were obtained from the women enrolled in the National Institute of Child Health and Human Development's collaborative chorionic villus sampling and amniocentesis study (Rhoads et al., 1989), and were those who experienced pregnancy losses as a result of either elective terminations after abnormal test results or spontaneous abortions. The overall participation rate was 60.5%. The 121 women in the pregnancy loss study were mainly white (94%), married (91%), well educated (63% had completed college or a more advanced level of education), and affluent (74% had family incomes of $40,000 or more). (Additional details about recruitment procedures and demographic characteristics of the sample are provided in Black [1989].) It is important to note that the lack of diversity in the sample mirrored a similar deficiency in the larger collaborative study and many previous research projects. Women of color and from lower socioeconomic groups generally did not have equal access to CVS at the time of the project (the mid-1980s), and the general lack of equal access to genetic services continues.
to be a significant problem (Paul & Kavanaugh, 1990). The importance of future research studies involving diverse populations is discussed later in this chapter.

Subjects participated in semi-structured telephone interviews and completed mailed questionnaires at approximately one to two months after the pregnancy loss and then again at approximately six months after the loss. Each participant completed by mail the Profile of Mood States (POMS) (McNair, Lorr, & Droppelman, 1971), which provided an assessment of their general level of mood disturbance after the losses. They also completed by mail the Dyadic Adjustment Scale (DAS) (Spanier, 1976), which asks questions about the general functioning of their major relationship (usually marriage for the women in this study). Interviews were tape recorded with the consent of the participant. (More complete details about instrumentation and findings are available in Black [1989, 1991, 1992].)

On one level, this project sought to confirm the already available evidence that pregnancy losses of prenatal diagnosis patients often precipitate a grief process. The literature on parental and other forms of bereavement suggested there would be considerable variation in the women's grief levels, although generally a greater degree of distress at the first interview, with perhaps some easing by the six month contact. It also was hypothesized that more difficult grief reactions would be found among the women who had losses later in their pregnancies; had a greater number of prior miscarriages; had previously had a pregnancy in which the baby carried a serious defect; had some known genetic risks; were older; had used professional mental health services before the loss; and who perceived less emotional support from their partner, family, friends, and significant others.

Confirmation of these hypotheses would indicate that prenatal diagnosis patients who lose their pregnancies have much in common with others who lose children or loved ones. However, perhaps more important than confirming such likely similarities was learning more about what is unique in the bereavement experiences of women undergoing new forms of prenatal diagnostic technologies. Since an explicit aim of the project was
to provide information to guide the development of services for this population, the study sought to determine both the minimum level of supportive follow-up indicated for all prenatal diagnosis patients who lose pregnancies as well as variables for assessment to guide identification and treatment of women who could profit from more specialized assistance.

The pregnancy loss group's average mood level (POMS) at the first interview was poorer than that of the control group of pregnant prenatal diagnosis patients but showed significant improvement at the second interview (Black, 1989). Sixty-eight percent of the women said they were able to resume normal work and social activities by the end of the first month after the loss, with 80% reporting normal levels of activities at six months (Black, 1989). The majority said they received understanding and positive support from husbands, partners, and significant others, and average scores on the Dyadic Adjustment Scale were well within range reported by the scale's author for married couples (Black, 1989; Spanier, 1976).

These positive general findings for the majority, while encouraging, nonetheless should not divert attention from the greater difficulties experienced by minorities of the women or from the internal anguish some felt even as they functioned quite well in their daily lives. Indeed, the mood scores on the POMS showed very large standard deviations (Black, 1989), thus showing much more severe distress among some of the women. Similarly, in the ratings of social and work functioning, close to one-third of the women reported reduced functioning at the one month assessment and 21% still noted some decrement at six months (Black, 1989). Comparisons of the women's reports of support from partners and significant others revealed small, yet statistically significant declines in perceived support (Black, 1989, 1991).

A few key factors were found to be associated with the women's reported mood levels at the second interview (Black, 1989). Total POMS scores at one to two months after the loss (Time #1) and six months after the loss (Time #2) were strongly correlated \((r = 0.59)\). Measures of post-loss social support most consistently showed associations with mood. Women who re-
ported greater mood disturbance at Time #2 more often had sought some type of mental health services after the loss, described less support from and congruence with their partners at either Time #1 or #2 and reported less support from family and friends at either Time #1 or #2. The only pregnancy-related variable that emerged with a significant correlation was length of gestation, with women who had later losses reporting poorer mood at both Time #1 \( (r = 0.20) \) and #2 \( (r = 0.17) \).

Examination of the women’s responses to two specific sections of the interview provides additional information on their experiences. First, a series of questions asked about the understanding and support the woman felt she was getting from her male partner (usually husband). (See Black [1991] for detailed discussion of the couples material.) As noted earlier, women did perceive a small, but statistically significant decline in partner support between the first and second interviews. Ratings of the overall impact of the loss on their relationships showed considerable variation at both interviews, with increased negativity at the second interview. Women reporting that they felt closer to their partner after the loss declined from 62% to 51%. Those reporting that they felt pulled more apart from their partner increased from 7% to 14%.

Later in this chapter I will consider the implications of those findings for development of minimum standards for psychosocial services for prenatal diagnosis patients who lose pregnancies. However, these general recommendations must be developed in the context of a more detailed look at the experiences behind the numbers. Themes identified in the women’s open-ended comments about two aspects of their experiences will be presented: 1) the experience of pregnancy loss in the context of their relationships with husbands or male partners (Black, 1991); and 2) the experiences they described when asked how it had been to see the fetus on ultrasound (Black, 1992).

**Physical Experience**

The physical experience of the pregnancy and loss marked a central difference between the men and women. All the women, regardless of type of loss, experienced at least some pain, encounters with medical personnel, and a period of physical re-
covery. The men, even if very involved, were described as bystanders.

**Degree and Duration of Distress**

Many of the women felt they experienced greater distress after the loss than did the men. Particularly striking were reports of divergence in partners' feelings over time, as the men seemed more quickly to put the loss behind them. All too often the women also felt their partners did not share their resurgence of painful feelings at the due date, when the baby would have been born.

**Expression of Feelings**

The women often said their partners did not discuss their reactions to the loss. Even, in some instances, when the man seemed to be grieving intensely, the women seemed to prefer a verbally or physically more expressive coping style than did their male partners. However, women often noted that they limited their own expression of grief to private times. An apparently normal round of work and social activities might exist alongside long and tearful evenings.

**Sexuality**

The majority said they experienced no change or perhaps enhancement of their sexual relationships. However, sex for some became associated with pain and loss, making it hard to feel sexual. Sexual strains also arose over conflicting priorities about whether to try to have another baby as well as different views about their likelihood of success. Some women who were trying to achieve another pregnancy also reported that they lost the pleasure of having spontaneous sexual encounters motivated solely for pleasure.

**Couples' Coping Patterns**

The interaction of each woman's personal experience of the loss interacted with her partner's experience to yield what I have called a conjoint coping pattern. Any evaluation of these coping patterns of course must be made very tentatively, but for the
sake of discussion, I have characterized them as “satisfactory” or “problematic.”

Satisfactory patterns included:

1. mutual agreement to limit discussion of feelings
2. mutual acceptance of differences in coping styles
3. mutual sharing of feelings about the loss, sometimes leading to a general increase in communication about a range of feelings and concerns

Problematic patterns included:

1. woman perceives that the burden is on her to initiate any discussion of the loss
2. woman does not act on her desire to express feelings, citing need to protect partner from painful feelings
3. woman does not act on her desire to express feelings, citing potential or actual lack of responsiveness from partner
4. woman precipitates a “fight” in order to evoke response from partner

A second section of the interview concerned the experience of undergoing ultrasound. Although there was no significant statistical association between frequency of ultrasound and mood scores, 60% said that seeing the ultrasound image had made them feel closer to the fetus. Forty-four percent responded affirmatively when asked if seeing the fetus had made coping with the loss more difficult. Only 9% felt it had made coping any easier.

Again, qualitative analyses provide a look at the experiences behind the numbers. A number of major themes were identified.

The Reality of Seeing

For many, seeing the fetus on the ultrasound screen marked a “moment of acceptance that you were indeed pregnant.” Intellectualization gave way at that moment of recognition. “It
made it more than a concept; it made it what appeared to be a living thing.” For some who had tried to distance themselves from the pregnancy because of the genetic risk, the ultrasound tended to reduce that distance: “all the precautions my husband and I had taken to protect our feelings just went right out the window.”

Additional Anguish

One woman said the ultrasound was the worst part of the testing. Another vividly described “flashing” on the ultrasound image as she thought through her plans to terminate the pregnancy. Others said it had heightened their general grief over the loss. Some wished they had not seen the fetus and suggested women be given the option not to see the ultrasound. Another spoke of not seeing the image as inconceivable, despite the distress it caused her. She could not imagine not watching along with the professionals who were seeing her “child.”

Benefits of Confronting Reality

How could something be so emotionally painful and yet carry some benefits? The women’s responses suggested that they were struggling with this paradox. For some, the benefit seemed to derive from the pregnancy having been made more real. For example, one woman who miscarried saw the fetal heartbeat at an initial ultrasound (when CVS was postponed) and then no heartbeat two weeks later. She compared her experience to a previous miscarriage when she had had so many doubts about what had happened. Here the “concrete” evidence made it easier to cope with the loss. Some women seemed almost grateful that they had been forced to confront the realities of their pregnancies:

I think it’s important to see it . . . to confront it. . . . I would have been better off if I had really let myself think about it more. . . . I was trying to sort of come in through the back door, saying if I didn’t think about it then the loss wouldn’t be as bad as if I had thought about [it]. . . . I’m glad I saw it and I think women should see it so they know that there was a reason for all the things they were going through.
Discussion

Interpreting the findings of my own research and that of others sometimes yields one of those situations where people differ on whether the glass is half full or half empty. A positive reading is that most women who undergo prenatal genetic testing, even those who terminate their pregnancies after a fetal defect is found, cope well with the experience. Grief reactions after pregnancy losses, while painful, usually seem to follow an expected course of gradual improvement without professional intervention. Extensive counseling or therapy does not seem to be needed or wanted by most women (Black, 1989).

On the other hand, a second look at the data brings into view not only that minority who experience greater coping difficulties but also the difficult decisions and painful feelings faced by those who carry on with their usual, everyday routines. Prenatal genetic testing is a major psychological and social event for women—even more so if the testing reveals a serious defect in the baby. The accumulated evidence confirms that these new technologies have changed the experience of pregnancy as well as the experience of pregnancy loss. As the women attest, major changes and even painful experiences are not necessarily evaluated negatively. For example, some women I spoke with said that seeing the ultrasound image intensified their grief, but they recognized the healing power of confronting their loss without avoidance. Unfortunately, others seemed more shaken by their experiences and less able to see positive aspects of their encounters with genetic testing.

There is enough information on women's experiences to support development of minimum service standards for women who lose pregnancies after prenatal genetic testing. The overwhelming majority of women interviewed for my study wanted at least some follow-up. For most, this meant a follow-up telephone call and referral, as needed, to appropriate support groups and mental health professionals knowledgeable about pregnancy loss, genetic disorders, and prenatal technologies. A minimum service standard for prenatal genetic testing programs (Black, 1989) should include: 1) at least one follow-up telephone call to all prenatal diagnosis patients who lose preg-
nancies; 2) assessment of psychosocial distress and need for additional services by inquiry about the woman’s mood, recent use of mental health services, satisfaction with emotional support she is receiving from her partner and significant others, and interest in referrals to support groups or professional counselors; and 3) preventive intervention by providing information about the considerable variation and sometimes persistence of grief reactions, possible differences between partners in reactions to the loss, and likelihood of decline in support from others that will feel premature to the woman.

Clinical priorities for mental health professionals who provide therapeutic services to couples should include helping them: 1) to identify the unique personal meanings of the loss for each of them, their perceptions of its reproductive implications, and their preferred coping styles; 2) to openly discuss any differences that may emerge; 3) to negotiate a mutually acceptable balance between expression and containment of feelings; and 4) to negotiate a mutually acceptable decision about whether to attempt a future pregnancy.

Future research on the psychosocial experience of reproductive genetic testing and pregnancy loss has many exciting directions to pursue. Some research questions follow directly from my own and other previous studies. For example, fathers’ reactions throughout testing and after pregnancy loss need to be studied carefully, not only for the men’s own sake but also because of their interactive impact on the women. Similarly, a family-focused research agenda should investigate the impact of prenatal genetic testing on the parents’ other children and on communication between family members. Service research also is needed that examines the impact of various models of supportive contact for prenatal diagnosis patients before and after detection of a serious defect in the fetus (Elder & Laurence, 1991). If there is increased access to reproductive genetic technology for women of color and economic disadvantage, certainly we must ask again many of the questions addressed in previous studies that have been done largely with white, highly educated, and relatively affluent women.

It also is important to recognize that there is a limit to what we can learn from giving large numbers of patients standardized
instruments and structured questionnaires. Nomothetic, quantitative research provides information that is very helpful in setting service priorities and identifying at-risk populations (for example, knowing that the majority of prenatal diagnosis patients who lose pregnancies do not need extensive counseling, but that services should be organized to make more intensive services available for the minority who need it). The clinician, however, seeks information to guide interventions with individuals. Having used nomothetic data to identify that a patient is at increased risk for coping difficulties, the clinician seeks to "beat the odds" by way of skillful intervention" (Roberts, 1989, p. 67). Idiographic, qualitative techniques are more likely to prove helpful in guiding clinical practice.

In the study of women encountering the new genetic reproductive technologies, this translates into intensive qualitative studies that ask epistemological questions about the meaning of those experiences for women. For example, in my research I found no statistical difference in mood levels between women who miscarried rather than terminated their pregnancies. Future research with larger samples might or might not confirm this finding. However, a general mood score will never tell us anything about the different meanings these two experiences carry for women or their male partners. It is not enough just to ask whether one type of loss evokes more or less distress than another.

Recent work by a number of feminist scholars may prove useful in providing frameworks for looking at prenatal diagnosis patients in new ways. While a comprehensive review of feminist writing on women and reproductive issues is beyond the scope of this paper, three examples should suffice to illustrate the potential contributions of this literature.

Rothman (1989), in her discussion of pregnancy as a physical and social relationship, suggests that a women may choose not to enter into the social part of the relationship. Because of this element of choice, "some abortions are easy, avoiding motherhood, while some are hard, ending motherhood" (p. 107). How does this concept of choosing to enter into a maternal relationship apply to women undergoing prenatal testing? We know these are mostly wanted pregnancies and that ultrasound may
have heightened the reality of the fetus as baby. Yet many women choose to end the relationship through abortion when a serious defect is found. Is this avoiding or ending motherhood? What factors enter into the woman’s choice to enter that relationship? For example, what are the woman’s experiences and knowledge about physical and mental disabilities and available services (Ashe, 1989)?

Philosopher Sara Ruddick (1989) has observed that three demands constitute maternal work and shape what she calls “maternal thinking.” They are the demands for preservation, growth, and social acceptability; “to be a mother is to be committed to meeting these demands by works of preservative love, nurturance, and training” (p. 17). Ruddick talks of woman’s labor to protect and sustain her baby, and later, her child. Yet Ruddick introduces a perplexing notion for those involved with reproductive genetic technologies when she asserts that a “mother takes care of her fetus by taking care of herself” (p. 50, Ruddick’s italics). We need to know about women’s thinking as they contemplate prenatal genetic testing and ending a pregnancy when a serious defect is identified. Who are they protecting? Can Ruddick’s ideas about maternal demands and thinking help us formulate new ways to learn from the women undergoing prenatal testing? Can the woman, early into her first pregnancy, be thought of as a mother? How is prenatal testing different when the woman is already a mother to children?

A third example of how feminist scholarship can contribute new research perspectives comes from the work of scholars such as Gilligan (1982) and Belenky, Clinchy, Goldberger, and Tarule (1986). They ask questions about how women develop ways of knowing and about the perspectives from which women draw conclusions about morality, truth, knowledge, and authority. Researchers in reproductive genetics might ask: How does the woman undergoing CVS evaluate whether she is doing the right or the wrong thing? How does the woman’s resolution of this question influence her psychosocial reaction to genetic testing or pregnancy termination? The learning styles of some women may emphasize the place of “received knowledge,” that is, listening to the voices of others while placing little value on their own voices. In contrast, other women grow
into an awareness of the constructed nature of knowledge and of their central role in interpreting and evaluating all evidence (Belenky et al., 1986). How do these different ways of knowing shape women's responses to genetic reproductive technology? For example, consider the woman who is accustomed to following the advice of experts and lacks confidence in her ability to make her own decisions. How does she feel as she confronts the option of terminating her pregnancy when professionals and perhaps also husband and friends say they cannot tell her what she should do.

Additional work is needed to determine which, if any, of these possible lines of inquiry will bear fruit. However, more important than any specific research question is the importance of ongoing inquiry into the meanings of genetic reproductive technologies for women. Psychosocial responses occur in context, and the context of genetic technologies is changing constantly as new technical options appear and as the very idea of genetic testing becomes woven into our social thread.

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BIBLIOGRAPHY


Testing and Pregnancy Loss


