

Abortion after Prenatal Testing *



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In advanced industrial countries prenatal testing in order to detect fetal abnormalities has become routine. The amount of genetic information that has become available through such testing has expanded enormously within the past few years. There are a number of ways of carrying out these tests, yet for each of them there is a danger of inaccurate results, and for some of them there is the additional hazard of injury to the fetus. Pregnant women and their partners are often unprepared for the news that they are carrying a “defective” fetus. An abortion agreed to in haste and under coercive pressure, can have devastating consequences, not only for the parents, but for other children. Is enough being done to inform women about the implications of prenatal testing, and to provide them with alternative choices to abortion when tests prove positive?

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Selective or genetic abortions are undertaken not because the pregnancy itself is unwanted but because some fetal attribute discovered through prenatal diagnosis has made the particular fetus unwanted. According to one study, "as many as four out of every 1000 recognized pregnancies are terminated in the second trimester for fetal abnormality"¹ as discovered during prenatal diagnostic testing.

Prenatal diagnosis is increasingly seen as a routine part of prenatal care, although it seems rarely to be linked explicitly to abortion, at least in the minds of pregnant women and their partners. Yet an abortion following the detection of a fetal anomaly can be devastating for all concerned. Additionally, even the diagnostic tests carry risks to fetal well-being quite apart from abortion.

Testing for Fetal Abnormality

Over the past two decades, little emphasis has been placed on the psychological outcome for women who abort a child owing to genetic disorders following prenatal diagnosis. But one significant change in the past decade has been the growing amount of available genetic information about individual fetuses. This information increases the likelihood that a woman will opt for abortion, perhaps at a late stage in her pregnancy.

Since the early 1980s, *amniocentesis* has been used to diagnose chromosomal anomalies such as Down Syndrome or Tay-Sach's disease after the sixteenth week of pregnancy. The introduction of ultrasonography has also allowed physicians to identify the presence of neural tube defects (*spina bifida*).

In the mid 1990s, the application of the technique of *chorionic villi sampling* has led to further advances in early detection.

Through prenatal diagnosis it is now possible to detect medical conditions such as cystic fibrosis and late or adult-onset diseases such as Huntington's Chorea or multiple sclerosis. Further, it is now possible to test for what is known as "genetic susceptibility" or predisposition for conditions such as breast cancer or Alzheimer's disease.

Methods of Prenatal Diagnosis

There are four types of prenatal diagnosis commonly offered to women.

1. Ultrasonography ("ultrasound"):

Through the use of sound waves, ultrasound provides a visual picture of the developing fetus. It is a test used to detect anomalies that are physically distinctive – defects of limbs and internal defects of the abdomen, chest, and heart. Neural tube defects, such as anencephaly, can also be diagnosed quite reliably by the fourteenth to sixteenth week of pregnancy. Ultrasound may also be used to confirm the presence of more than one fetus in the womb or measure the progress of fetal growth.

2. Maternal Serum Alpha Fetoprotein Screening (MSAFP):

Raised alpha fetoprotein levels in the pregnant woman's blood may mean that the fetus has a neural tube defect. The test is usually done in the fifteenth to seventeenth week of gestation with results available up to two weeks later. Because MSAFP has a high ratio of false-positives,² the test is usually followed by an ultrasound or amniocentesis to confirm the presence of an anomaly in the fetus.

3. Amniocentesis

Amniocentesis normally involves inserting a needle into the uterus through the abdomen and withdrawing fluid. This may be a therapeutic intervention, as when a pregnant woman suffers from polyhydramnios – that is, an excess of amniotic fluid. For diagnostic purposes, however, amniotic fluid is withdrawn in order to test for the presence of chromosomal abnormalities or neural tube defects in the fetus. Amniocentesis is usually performed at sixteen to

20 weeks' gestation, with the results being available three to four weeks later. The risk of miscarriage with amniocentesis, while small (one per cent), is nevertheless real.³ As well, there is the possibility that the fetus may be hit by the needle.

4. Chorionic Villi Sampling (CVS):

In this relatively new procedure, the villi are used to provide chromosomal information about the fetus. The test can be done in the first trimester, with the results available within one or two days. However, because placental rather than fetal material is used, CVS is not as accurate as amniocentesis. Because it is performed so early, it cannot be used to detect anomalies that develop later in the pregnancy (e.g. neural tube defects). CVS carries with it a 3.2 per cent risk of miscarriage⁴ and the danger of "limb reduction" in the fetus. In one study of 394 fetuses, four genetically "normal" babies nevertheless had damage to their limbs; in another study of 289 pregnancies, five fetuses were similarly affected. These deformities were attributed to CVS.⁵ However, proponents of CVS believe that its advantage lies in the early detection of fetal anomalies which allows for the early termination of those pregnancies.

Parents Unprepared for Diagnosis

There appears to be dissonance between the practitioner's understanding of the purpose of prenatal diagnosis and the pregnant woman's perception of the procedure. While the practitioner may offer or even insist on the diagnostic tests as a way of preventing the birth of a "defective" child, pregnant women seek them out for reassurance that their babies are well and healthy.⁶ For many expectant couples, the link between testing and abortion, at least initially, does not exist.⁷ This may be in part because genetic counselors do not make this link explicit to their clients. In her study of the effects of prenatal diagnosis on the dynamics of pregnancy, Barbara Katz Rothman found that, while genetic counselors might presume that selective abortion would follow the detection of an anomaly, rarely did they offer any information about actual abortion procedures. Indeed, some did not even include a discussion of abortion in the first counseling

session.⁸ Even when birth defects and abortions are explicitly discussed, couples seem to “deny this possibility, and when faced with the reality, react as though they were hearing for the first time that birth defects can occur.”⁹ The pregnant woman and her partner simply do not link this outcome to prenatal diagnosis.

Quick Decision

Despite the shock and grief they may experience upon hearing the news of a fetal anomaly, the pregnant woman and her partner are usually urged to make the decision to terminate quickly.¹⁰ Behind this urgency is the physician’s desire to avoid complications of “late” terminations of pregnancy. Because of the delays involved in amniocentesis, abortions may occur in the second and even third trimesters of pregnancy. In health care settings, the issue of such late abortions has raised ethical and legal questions.¹¹ In one early study, most of the terminations occurred within 72 hours of the woman receiving the news of the abnormality.¹² This hardly allows enough time for the couple to become informed about parenting children born with that anomaly and thus consider carrying through with the pregnancy.

Methods of Termination

The method of termination chosen will depend on the stage of pregnancy. CVS, with its results available in the first trimester, may be followed by dilation and curettage, the type of abortion normally done at an early stage of pregnancy.¹³ Later terminations following amniocentesis may be carried out by dilation and evacuation or by the instillation of urea or saline into the uterus, to kill the fetus and initiate labor.¹⁴ While D&E may be relatively fast and physically painless for the pregnant woman, the destruction of the fetus makes post-mortem examination almost impossible. Similarly, instillation procedures that kill the fetus make fetal tissue unsuitable for later examination.¹⁵ This type of abortion may take up to 40 hours.¹⁶ More commonly, women undergoing late termination of pregnancy have labor induced through the use of prostaglandins.¹⁷ It is a procedure that has the advantage of delivering the fetus intact, therefore making the baby suitable for post-mortem examination.

Unless urea is injected into the womb prior to delivery, the procedure carries the possibility of delivering the baby alive, normally not a desired outcome.¹⁸ The labor itself can be lengthy and intense¹⁹ but because of a desire not to interfere with the labour, analgesics are usually not administered.²⁰ According to one study, “virtually all of the women experienced the termination procedure as one where they felt sick, painful, or frightened.”²¹

Sequelae of Genetic Termination of Pregnancy

While couples may not be completely aware of the physical aspects of genetic abortions, they usually know even less about the accompanying and subsequent psychological and emotional distress of the procedure.²² In interviews conducted by White-Van Mourik and colleagues and by Zeanah and colleagues *all of the study subjects* found the pregnancy termination to be a traumatic experience.²³ Rayburn and Laferla support the finding, observing that, “Terminating a pregnancy because of a major fetal malformation is often a shattering experience, and time for adjustment may be prolonged.”²⁴ This is true for both “early” as well and “late” genetic abortions.²⁵ Indeed, there may be instances in which an early abortion may present more difficulties than a later abortion. One study subject reported this to be so because “there was no fetus to see and hold” after an early termination.²⁶ Boss speculates that “it is possible that the ‘privacy’ of first trimester prenatal diagnosis and selective [genetic] abortion may actually increase the unresolved ‘disenfranchised’ grief since so few people know about the person’s loss.”²⁷

Researchers offer various explanations for this phenomenon. In almost all cases, pregnancies terminated for genetic anomalies were pregnancies in which maternal attachment had begun,²⁸ even as women may have hoped to avoid such attachment.²⁹ Many of the women choosing or urged to undergo prenatal diagnosis were older and, as some authors speculate, the pregnancy may have been seen to be one of a declining number of opportunities to have a child.³⁰ As well, unlike a miscarriage, a genetic termination occurs because the woman chooses or consents to it. According to Kolker and Burke, “genetic abortions are especially poignant

because the parents take an active part in the baby's death."³¹ Blumberg and colleagues speculate that "Perhaps the role of decision making and the responsibility associated with selective abortion explains [sic] the more serious depression following [the abortion]."³² Whatever the reason, as Boss observes, "Prospective parents are rarely prepared...for the extent of the psychological trauma experienced after a selective [genetic] abortion."³³ According to Brown, after having a genetic abortion, "It took several weeks to recover physically; emotional scars are raw two years later."³⁴

Grief, Guilt, Depression

The extent and intensity of grief can be a surprise to many couples.³⁵ Iles and Gath found that nearly one half of the women in their study had symptoms of grief six months after the abortion and almost one third continued to grieve thirteen months after the termination.³⁶ Seller and colleagues discovered that "the loss of a fetus can cause intense grief reactions, often commensurate with those experienced over the loss of a spouse, parent, or a child."³⁷ Zeanah and colleagues found that neither the method of termination nor the type of anomaly seems to have affected the intensity of grief, and Kolker and Burke found that women grieved abortions following both CVS and amniocentesis.³⁸ White-Van Mourik and colleagues observed that, with abortions following ultrasound and maternal serum alpha fetoprotein testing, there was "more confusion, numbness and subsequently more prolonged grief reactions...." They suggest that, with these "relatively non-invasive procedures...less thought is usually given by the women to preparation for an abnormal finding."³⁹

Following genetic termination of pregnancy, women endure the normal but difficult symptoms of grief, such as psychosomatic disturbances, guilt and anger, as well as the symptoms characteristic of an abruptly ended pregnancy in which the fetus dies – distress upon seeing pregnant women or newborn babies, continuing to feel pregnant, and experiencing more pronounced stress around the due date and anniversaries.⁴⁰ Recovery can take a very long time⁴¹ and, because of the nature of genetic abortions, the grief may be accompanied or complicated by other factors.

Guilt and shame are often experienced after a genetic abortion. In one study, this was the case for one-third of subjects.⁴² In another, researchers found that, more than a year after the abortion, 31 per cent of the women who had terminated their pregnancies for fetal indications continued to feel guilt and anger.⁴³

Following a genetic abortion, the guilt and shame may be two-pronged. On the one hand there is a sense of failure elicited by the fact of the fetal anomaly. Parents may feel that they are to blame for their child's imperfection.⁴⁴ Sixty-one per cent of woman and thirty-two percent of men felt this way in one study.⁴⁵ In another study, 43 per cent of the women suffered from this sense of guilt.⁴⁶

On the other hand, there is the guilt generated by having made the decision to terminate the pregnancy.⁴⁷ In one study, "forty per cent of the women and nine per cent of the men" felt this way.⁴⁸ One researcher found that many women are reluctant to admit that they have had a genetic abortion and will tell relatives and friends that they had suffered a miscarriage instead.⁴⁹

A very common form of psychological disturbance following a genetic abortion is depression.⁵⁰ Taking into account some study subjects' strong denial of feelings, Blumberg and colleagues speculate that "the actual incidence of depression following selective abortion may be as high as 92 per cent among women and as high as 82 per cent among the men studied."⁵¹ In another study, researchers found that, six months after the abortion, almost half of the study subjects suffered from depression and anxiety and that ten of 48 women were receiving psychiatric treatment.⁵² The researchers concluded that it was not the case that women were simply relieved not to be giving birth to or raising a child with an anomaly.⁵³ According to Donnai and colleagues, "women undergoing termination of a planned or wanted pregnancy after prenatal diagnosis constitute a high risk group, vulnerable to depression and social disruption."⁵⁴

Grief, Whether Pregnancy Had Been Planned or Unplanned

The assumption of many researchers is that genetic abortions are the terminations of planned or “wanted” pregnancies.⁵⁵ In this respect, researchers contend that genetic abortions differ from elective terminations of pregnancy.⁵⁶ Further, the assumption of many researchers is that the grief and depression that often follow genetic abortions occur precisely because the pregnancy was planned and “wanted”.⁵⁷ In many cases, maternal attachment may even have begun.⁵⁸ Thus researchers have compared genetic abortions to miscarriages and stillbirths insofar as they evoke grief and depression arising from the loss of an anticipated and hoped-for baby.⁵⁹

The sequelae following genetic terminations of pregnancy may not be so easily explained, however. Research indicates, first, that not every pregnancy terminated because of fetal indications is a “wanted” or planned pregnancy. In the study by Iles and Gath, 23 per cent of pregnancies aborted for genetic reasons were unplanned as were 27 per cent of the pregnancies in the White-Van Mourik study. As well, two per cent of women remained “ambiguous” about their pregnancies in the latter study.⁶⁰

Second, and more importantly, research indicates that grief and depression are not confined to the termination of planned and “wanted” pregnancies.⁶¹ The “ambiguous” subjects of the White-Van Mourik study “felt very guilty about the intervention two years after the event.”⁶² Reardon’s study shows a clear link between depression and the abortion of “unintended” pregnancies.⁶³ Similarly, work by Brown links grieving and elective abortions, not normally considered to be terminations of “wanted” pregnancies.⁶⁴

While grief and depression often follow genetic terminations of pregnancy, it is a mistake to attribute this reaction solely and simply to the “wantedness” of the pregnancy.

Living Children

The decision to abort for genetic reasons can have a negative impact on living children. Although it is not often considered a factor in the initial decision-making process, the

abortion of a sibling can have emotional consequences for children in a family. Children are affected by the anxiety of parents over the abortion and react to the absence of the baby (whose presence they will have been aware of from the third or fourth month of pregnancy).

Furlong and Black studied the impact of genetic abortion on families and found that even very young children react to their parents' distress and may have difficulty understanding and coping with the outcome. They show that young children are unable to deal with the complexity of the decision.⁶⁵ In the presence of prenatal life, young children do not separate the concept of "fetus" from the concept of "baby". The conceptual difference between the two is a medical and social construct of adults and is not easily understood by children whose approach to the world is concrete.

The couples who participated in the Furlong and Black research adopted one of three approaches in explaining the abortion to their children. The first was a partial explanation that avoided discussing the role of their own choice. The children who received such an explanation expressed sadness, disappointment, and guilt and one child wrote an essay on the event as the worst thing that had ever happened to him. Parents of very young children chose to give no explanation and yet observed behavioral changes such as motor regression in their children. Those parents who chose the third option – to give a complete explanation – did not find that it solved the problem. Rather, they reported marked and disturbing reactions. Garton reports that "Abortion can produce a deep, subtle (and often permanent) fracture of the trusting relationship that once existed between a child and parent."⁶⁶ Looking at this problem from a psychodynamic perspective, Ney and Peeters have identified a number of "*post-abortion survivor syndromes*". They conclude that: "There are terrible conflicts that arise from these situations, and these have an impact on the individual and society."⁶⁷

Public Opinion versus Medical Opinion

At present, in the general population, there appears to be a gap between acceptance of testing for disorders and acceptance of abortion of the affected fetus. When a similar group of Canadian adolescents was presented with already com-

pleted prenatal test results, the researchers Curtis and Standing found that “females are consistently more opposed to abortion than are males and both sexes show a considerable opposition to abortion in absolute terms”.⁶⁸ But Drake, Reid and Marteau note that “Health professionals hold more positive attitudes towards termination of pregnancy for a fetal abnormality than do lay groups.”⁶⁹ Under the present circumstances, this could lead to “stimulating a demand for services” rather than responding to a perceived need.

Prenatal diagnosis, already accepted as part of obstetrical care, is expanding to include many conditions, disorders, and personality traits. With these new opportunities for aborting affected pregnancies come issues about informed consent and possible social coercion to abort.

As noted, health professionals are more in favor of abortion for genetic reasons than the general public. If women choose to abort as a result of medical pressure then the decision will be conflicted and a violation of their personal autonomy. Indeed, Feitshans raises issues of autonomy and informed consent and also asks: “Does genetic testing of a foetus empower women or pose an unanticipated threat to autonomy? To address these issues there is a need to articulate a feminist perspective on genetic testing and possibly to legislate protection for women’s rights during prenatal care.”⁷⁰ Furthermore there is a negative presumption in the medical milieu regarding children with these conditions. There is an imbalance of information, with little provided that is favorable to children with special needs.

Informed Consent

Generally speaking, practitioners must have the patient’s consent before undertaking any treatment. To make an informed choice, the patient must have the pertinent information, including the benefits and risks of the treatment, explained in a way that can be understood by her; she must be deemed competent to make this particular decision; and the choice must be voluntary. Given current practices, there is some question as to whether the criteria for informed choice are met when women choose genetic abortions.

a) Information:

As Kolker and Burke note, "To make a truly informed decision, clients need to be aware not only of the risk of miscarriage entailed in the two procedures [CVS and amniocentesis] but also of the consequences of the abortion experience. Yet counselors rarely discuss this prior to the test and the diagnosis."⁷¹ While genetic counselors may simply assume that clients come to the initial sessions with ready knowledge, Kolker and Burke point out that ignorance may in fact underlie clients' tendency to ask few questions about genetic terminations of pregnancy. Because clients do not make a ready link between prenatal diagnosis and abortion, because they have little or no knowledge of the procedures or of the aftermath, they do not know what they should be asking. This ignorance is an obstacle to informed choice.⁷² As Brown points out, learning that there is a fetal anomaly is not the only information that is needed. "We had only one isolated piece of information, not a whole crystal ball. How were we to know what would be best?"⁷³ Additionally, there appears to be little or no positive information given about the choice of parenting a child with a given condition.

b) Competence:

A further obstacle to informed choice is the state in which parents find themselves upon learning of the fetal anomaly. Most are in shock initially and, as Brown writes, "a person reeling from shock, numbed by a sudden catastrophe, cannot think."⁷⁴ Nevertheless, patients are urged to make the decision quickly, often before they have completely recovered from the shock. In a study undertaken by White-Van Mourik, 21 per cent of the study participants agreed to an abortion even as they had uncertainty about the decision because they were experiencing numbness and shock. In their cases, "the decision was made about an event which felt unreal."⁷⁵

c) Voluntariness:

Genetic abortions involve two separate but related choices: prenatal testing and abortion. A study presented at the American Society of Human Genetics in 1997 found that 36 per cent of obstetricians did not mention to their patients that

prenatal testing is voluntary. The National Institutes for Health (NIH) note: “Care should be taken to ensure that the decision to have testing is completely voluntary.”⁷⁶

Despite current emphasis on the principle of respect for patient autonomy and the practice of informed consent, studies suggest that, for many women, there was not always a sense of having had a choice in the matter. Jones and colleagues found that, for 93 per cent of the women studied, the genetic termination of pregnancy was something that simply had to be done.⁷⁷ The pressure to abort can be subtle. Even as genetic counselors consciously attempt to be non-directive in their sessions, many nevertheless believe in the efficacy of genetic terminations of pregnancy.⁷⁸ More overtly, some physicians will insist that their patients agree not to continue the pregnancy in which a fetal defect has been found before undertaking the amniocentesis.⁷⁹ Coercion is not only an obstacle to informed choice but is a contributing factor in post-abortion distress. (See also Chapters 11 and 15.)

Conclusion

Prenatal testing is expanding rapidly, as ever more genetic markers are discovered and women are urged to undergo these tests. It seems that there can be enormous pressures applied to mothers to go through with terminations if an anomaly is found.⁸⁰ Couples are not prepared for the depression and guilt that frequently ensue. Nor are they usually informed about the help that is available for raising children with special needs. For an informed choice to be truly available pregnant women and their partners need to be told about the possible impact of abortion on them and their other children, and they also need to have information about the care of children with special needs.

Key Points Chapter 12

- Prenatal diagnosis is increasingly seen as a routine part of prenatal care, yet in the minds of pregnant women and their partners it is rarely linked explicitly to abortion.
- The growing amount of available genetic information about individual fetuses over the past decade has increased the likelihood that a woman will opt for abortion, perhaps at a late stage in her pregnancy.
- When testing reveals a fetal anomaly the pregnant woman and her partner are usually urged to make the decision to terminate quickly.
- Terminating a pregnancy because of a major fetal malformation is often a shattering experience for women. The grief, guilt, and depression experienced after a genetic abortion can come as a complete surprise to many couples.
- These negative experiences occur whether the pregnancy has been planned or unplanned.
- The decision to abort for genetic reasons can also have a negative impact on living children.
- Positive information needs to be given about the choice of parenting a child with special needs resulting from physical or mental handicaps.

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Notes

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- 38 Zeanah 1993. See n. 23, pp. 273-4;
Kolker and Burke 1993. See 8, p. 523.
- 39 White-Van Mourik 1992. See n. 23, p. 72.
- 40 Iles and Gath 1993. See n. 30, see Table 3, p. 410.
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- 43 Iles and Gath 1993. See n. 30, p. 411.
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- 46 Jones et al. 1984. See n. 9, p. 254.
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